

Experiences of Ableism in Pediatric Healthcare

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abstract

BACKGROUND: There is growing evidence of ableism in pediatric health care, but our limited understanding of the experiences of ableism inhibits further evaluation and intervention. The study objective was to describe community perspectives of the experiences of ableism in pediatric health care for children with disabilities.

METHODS: Participants completed a group concept mapping study using web-based software to input experiences of ableism in health care. Following a formal statement reduction, participants sorted unique experiences into conceptual clusters. Data were mapped to generate a similarity matrix. A multidimensional scaling algorithm generated a point map, and a hierarchical cluster analysis grouped statements into clusters. Focus groups validated and labeled clusters.

RESULTS: Participants (n = 132) generated 658 statements about ableism experiences. After reduction, 145 experiences were categorized in 11 conceptually distinct clusters: 1) substandard care including withholding care, 2) dehumanizing language and behaviors, 3) negative assumptions, 4) inflexible organizational policies and practices, 5) inaccessible built environment and lack of accommodations, 6) lack of access to resources, 7) unfair standards and normalized inequity in health systems, 8) dismissal of the lived experience and caregiver expertise, 9) intersectional identities and judgements of worthiness to receive care, 10) restrictions driven by insurance coverage and policy, and 11) complexity in community and health services navigation.

CONCLUSIONS: Wide-ranging experiences of ableism occur in pediatric health care interactions. The lived experiences of ableism identified in this study provide insight for future research in pediatric health care.



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WHAT IS KNOWN? Families of children with disabilities have reported disability-based discrimination in pediatric healthcare. This discrimination may have negative impacts on health, well-being, and access to care.

WHAT THIS ADDS? This study identified 145 distinct experiences of ableism in healthcare defined by 11 conceptual clusters: substandard care, dehumanizing behaviors, assumptions, dismissal of lived experience, judgements of worthiness, inflexible policies, inaccessible environments, biased standards, limited access, insurance gaps, and navigation barriers.

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INTRODUCTION

Children with disabilities are a growing population in the US, representing approximately 1 out of every 6 children.^{1,2} Children with disabilities can face discrimination in the health care system because of their disabilities.^{3,4} Limited prior research has shown that disability-based discrimination, or ableism, can manifest in pediatric health care as substandard care, negative and dehumanizing comments, and limited access to services driven by lack of knowledge, assumptions of disability, and clinician apathy.^{4–6}

Despite growing attention on ableism in pediatric health care, the broader nature of how ableism is experienced in health care by children with disabilities and their families is poorly understood. This gap in knowledge limits clinicians, researchers, health policy experts, and administrators from adequately assessing and addressing common ableism experiences to improve health outcomes. Therefore, we sought to describe the lived experiences of ableism in pediatric health care through a national group concept mapping (GCM) study.

METHODS

Overview

GCM is a structured form of community-engaged mixed methods research designed to leverage lived-experience expertise in the assessment of a topic.^{7,8} This methodology engages participants during every step and elevates participant voices to define the dimensions of a topic; in our study, the experience of ableism in pediatric health care. This study used the web-based GroupWisdom⁹ software to conduct data collection and analysis. All study materials were available in both English and Spanish. The research team also engaged an advisory committee (AC), composed of 5 national leaders in childhood disability (Supplemental Table 1), in the study design, recruitment, and methods. This study was approved by the University of Utah Institutional Review Board (00178638).

Prompt Development

In GCM, prompts are created to operationalize the concept of interest and orient participant responses to the study goal. A focus prompt for this study was iteratively developed by the research team, which includes 3 lived experience partners (LEP) (DO, MW, DG) and the study AC. The prompt was then tested with 12 parents of children with disability and further refined for clarity and content. The final prompt stated: “Sometimes children and youth with disabilities have difficulty getting the health care they need. They might be treated differently or unfairly by the health-care system or people in healthcare settings. They may receive less attention or poor care compared to children without disabilities. One of the ways this occurs is...” Health care was defined in the text instructions as

“Healthcare refers to all the people, organizations, and services in the US that are intended to maintain or improve health. It includes interactions in numerous settings including the doctor’s office, dentist’s office, hospitals, clinics, emergency departments, intensive care units, physical and occupational therapy, and mental health appointments. It also includes health insurance, medical equipment, and home healthcare needs.” Of note, schools were not explicitly mentioned in this definition as their institutional and legal framework differs from other health care services.

Participants

Participants were recruited to join the study between September 2024 and November 2024. Potential participants were eligible for the study if they were older than 18 years old, spoke English or Spanish, and had knowledge of or lived expertise with childhood disability, defined as: a family member of children with disabilities, young adults with childhood-onset disability, clinicians providing health care to children with disabilities, disability justice advocates, or health systems administrators. Potential participants were referred by the AC and study team and via snowball sampling, where individuals who participated in the study referred others with knowledge of childhood disability. To ensure data security and prevent fraudulent entries, only referred participants could access the study site. Enrolled participant characteristics were reviewed periodically throughout the study, and recruitment efforts were focused on ensuring a diverse sample of participants. Referred participants received an email invitation and an optional brief instructional webinar. Participants received an informed consent document, and consent was affirmed by continued participation in the study. Participants then completed a demographic survey to characterize the study sample. Participants continued to be enrolled in the study while new experiences were generated. When saturation occurred (no new experiences were added by new statements for 50 statements), recruitment for the study was discontinued. Participants were compensated for their participation in this study.

GCM Phases

Phase 1: Statement Generation

The first phase of GCM involved brainstorming responses to address the focus prompt. Participants individually entered as many experiences into the software as they believed directly answered the prompt. All entered experience statements were immediately available for other participants to view to allow for group thought and further statement generation.

Next, 2 reviewers inductively coded all statements to describe the general content of each statement to help identify redundancy of experiences. For example, a code of “parking” applied to statements describing inaccessible

parking at healthcare centers. An initial codebook was developed based on the first 200 statements. Further codes were developed iteratively by the reviewers who met intermittently to discuss and resolve discrepancies by consensus. Statements were then reviewed by the research team to identify duplicate experiences and to select the statement that most clearly represented the experience. Language from the original statements by participants was maintained verbatim apart from minor spelling and grammar edits to enhance clarity.

Phase 2: Sorting and Rating

During the next phase of the study, participants were invited to return to participate in sorting and rating experiences.

Sorting. Participants independently sorted experiences they perceived as being similar into clusters by moving virtual flashcards with an individual experience into virtual piles in the software. Participants could make as many virtual piles as they felt necessary to separate the experiences into distinct clusters. Participants were advised not to sort experiences into “miscellaneous” or “other” piles and to use as many piles as they felt necessary. Definitions for complex topics or acronyms were provided (Supplemental Table 2). Participant sorting data were evaluated for inclusion in the analysis. Exclusion criteria for sorting data included data with “other” or “miscellaneous” groups, no clustered groups (ie, sorted into 145 groups) or too few clustered groups (ie, sorted into 1 group).

Rating. Next, participants rated each experience on a Likert scale for 2 independent questions. The first question was “How difficult does this experience make it for children with disabilities to access healthcare?” with 1 = not difficult, 2 = a little difficult, 3 = difficult, and 4 = very difficult. The second question was “How likely is this experience to physically or emotionally harm a child and/or their caregiver?” with 1 = very unlikely, 2 = unlikely, 3 = likely, 4 = very likely.

Phase 3: Data Analysis

All experiences were sorted into a similarity matrix, which determines the frequency with which individual experiences were sorted together by the participants. Then multidimensional scaling generated a 2-dimensional point map of experiences frequently sorted together. Next, a hierarchical cluster analysis was performed using Ward’s Method¹⁰ to create clusters of experiences that mapped closest together. The software generated cluster map options ranging from 4 to 15 clusters. Bridging values (range 0–1), a summary statistic of conceptual cohesion, were assigned to clusters. Lower bridging values suggest conceptual distinctness, while higher bridging values indicate clusters are less distinct and act as a “bridge” between concepts.^{11–13} The

research team reviewed each cluster map option, evaluating the visual map representation and conceptual distinctiveness across clusters to identify the optimal cluster map.^{12,14,15}

Phase 4: Impact of Statements

Participant rating data from Phase 2 was evaluated using layered cluster maps and a “go-zone” plot. In layered cluster maps, the final concept map is combined with the mean participant ratings on the impact of experiences on health care access or the likelihood of the experience causing physical and emotional harm to children with disabilities and their families. Mean comparison is the conventional approach in GCM to support cluster analyses.^{16–18} In layered maps, clusters with experiences with a higher mean rating, implying more negative perceived impact on access or health, are represented by more layers in the map. In the “go-zone” representation, individual experiences are represented by plotting the mean rating for the impact on access against the mean rating for impact on physical and emotional health of the child and family. This results in a scatterplot of experiences represented across 4 quadrants, with the right upper quadrant depicting the “go-zone.” Experiences in the “go-zone” are reported to have the highest perceived negative impact on both access to care for children with disabilities and the overall physical and emotional health of children with disabilities and their families.

Phase 5: Data Interpretation

Focus groups were convened to validate the final clusters and understand participant perspectives on cluster labels. Two focus groups included family members of children with disabilities, and one focus group included young adults with childhood-onset disabilities. Demographics of focus group participants are shown in Supplemental Table 3. The focus groups were led by a LEP via video conferencing with closed captioning and live transcription and lasted between 90 and 120 minutes. During focus groups, participants evaluated experiences in each cluster, discussed their relationship, and contextualized the results. Following completion, transcripts were transcribed verbatim and reviewed by the research team. Consensus cluster labels were created reflecting the focus group transcripts and experiences in the final clusters. Next, experiences within clusters were reviewed, and <5% (n = 4) were moved to a more representative cluster based on map location, bridging value, and focus group feedback.^{8,11,16}

RESULTS

One hundred thirty-two participants completed the initial brainstorming activity (215 referrals, 63% response rate). Of the 132 brainstorming participants, 61 participants completed the sorting activity, and 58 completed the rating activities. Participants in the study reflected a diversity of

TABLE 1. Participant Characteristics	
Characteristic	N = 132 N (%)
When you think and talk about childhood disability, what is your primary role?	
Family member of a child with disability	76 (50.3)
Adult with childhood-onset disability	35 (23.2)
Clinical provider for children with disability	29 (19.2)
Non-clinical role in healthcare	4 (2.7)
Justice or legal system advocate for people with disability	3 (2.0)
Health system or health policy administrator	1 (0.7)
What is your age in years?	
18–25	4 (3.0)
26–35	30 (22.7)
36–50	70 (53.0)
51–65	23 (17.4)
>66	5 (3.8)
Which best identifies your race and ethnicity?	
American Indian or Alaskan Native	2 (1.4)
Asian	4 (2.8)
Black or African American	16 (11.4)
Native Hawaiian or Other Pacific Islander	1 (0.7)
White	98 (69.5)
Hispanic or Latino	17 (12.1)
Other	3 (2.1)
What best describes your gender?	
Female/woman	105 (79.6)
Male/man	24 (18.2)
Nonbinary	3 (2.3)
What is your preferred language of communication?	
English	126 (95.5)
Spanish	4 (3.0)
American Sign Language	1 (0.8)
Over the past year, have any of these things been true for you or your household?	
Was not able to pay the water, heat, gas, electric, or other utility bill because there was not enough money	15 (8.0)
Was not able to pay the rent or mortgage on time because there was not enough money	12 (6.4)
Was worried that I would not have enough food to feed myself or my family	20 (10.7)
Received or was qualified for government assistance programs such as Section 8 housing, SSI, SNAP benefits, TANF, or EITC	30 (16.0)
Considered myself to be poor or low income	27 (14.4)
I do not know if any of these things have been true for me or my household	5 (2.7)
None of these things have been true for me over the past year	78 (41.7)
(Continued on next column)	

TABLE 1. Participant Characteristics (Continued)	
Characteristic	N = 132 N (%)
Are any of the following things true for you or your household?	
I live in a rural or remote area	22 6 (16.7)
I am an immigrant to the United States	6 (4.5)
One or more members in our household identifies as queer, lesbian, gay, trans, bisexual, intersex, or asexual	18 (13.6)
Abbreviations: EITC, Earned Income Tax Credit; SNAP, Supplemental Nutrition Assistance Program; SSI, Supplemental Security Income; TANF, Temporary Assistance for Needy Families.	

experiences with childhood disability, self-reported race and ethnicity, age, gender, socioeconomic status (Table 1), and geographic location (Supplemental Figure 1).

Participants generated 658 statements, which were narrowed into 145 unique experiences by the research team. Experiences were then sorted by participants independently into clusters, which varied in size from 3 clusters to 28 clusters. Participant data with 1 cluster ($n = 1$) and 145 clusters ($n = 1$) were excluded from analysis. Sorting resulted in a point map with a stress rating of 0.22, showing appropriate reliability and interpretability of the mapping.¹⁹ From the point map, a range of cluster map solutions combining all participant data were generated, and the cluster map determined to best represent the data had 11 non-overlapping clusters (Supplemental Figure 2).

The final cluster labels (Figure 1), definitions, bridging values and example experiences are shown in Table 2. Cluster 1 (substandard care including withholding care) included experiences where standard medical care, including medical equipment or surgical care, was not offered because of the child's disability. Cluster 2 (dehumanizing language and behaviors) included disrespectful, insulting, or stereotyping statements made to the family or child. One focus group participant described this cluster, "Dehumanization—where the statements seem to show that the patients are at this point no longer seen as people but just as subjects. When they view them as just subjects, there is no need for compassion, no need for empathy." Cluster 3 (negative assumptions) included experiences involving assumptions of a child's ability and negative assumptions of quality of life because of a child's disability. Cluster 4 (inflexible organizational policies and practices) was described by a focus group participant as "Clinic or hospital policy-wise—someone makes decisions who aren't thinking about children with disabilities and how they fit into those decisions. They are just making decisions that are not fully thought through. Not making equitable decisions and instead just trying to go off of the majority of patients."

Cluster 5 (inaccessible built environment and lack of accommodations) included experiences of inaccessible or

TABLE 2. Cluster Labels, Bridging Values, Descriptions and Example Statements			
Cluster Label	Bridging Value	Cluster Description	Example Statement
1. Substandard care including withholding care	0.31	Experiences where standard medical care, including diagnostic evaluations, medical treatments, and life-supporting therapies, are not offered or are withheld due to a child's disabilities	When treatment is not offered because "We don't do that for children like him." For example, a CPAP machine needed so our child could breathe while sleeping.
2. Dehumanizing language and behaviors	0.07	Experiences involving statements or actions that disregard a child's dignity and humanity because of their disabilities	A nurse told us that she didn't understand special needs parents who just don't know when to let go of their child.
3. Negative assumptions	0.07	Experiences involving beliefs or ideas about children with disabilities and their lives that are based on stereotypes or bias	In my experience, many providers make a large general assumption about physical differences. For instance, providers think using a wheelchair is a hardship and have an automatic negative association.
4. Inflexible organizational policies and practices	0.24	Experiences that occur because of the rules, regulations, and practices of an organization that disadvantage children with disabilities	Lack of flexibility in scheduling and late arrival policies that do not consider transition issues, unforeseen events, physical issues, toileting needs, impaired mobility, complexity, and transportation issues.
5. Inaccessible built environment and lack of accommodations	0.35	Experiences involving the physical structures and spaces of healthcare centers and the absence of necessary supports to meet the needs of children with disabilities	Inadequate disability access in every hospital I've been seen in as a patient or worked at as a physician, including a new rehabilitation hospital. When I pointed out access concerns, it was clear that minimum ADA standards were the goal.
6. Limited access to resources and services	0.24	Experiences involving the inability to obtain necessary healthcare services or equipment for children with disabilities because of lack of available support	Lack of access to providers, treatments, or therapies due to fewer providers that take Medicaid.
7. Unfair standards and normalized inequity in health systems	0.33	Experiences related to the expectations, norms, and culture of an institution that create unequal burden for children with disabilities and their families	When the families of complex patients are expected to do all of the nursing care while inpatient.
8. Dismissal of the lived experience and caregiver expertise	0.34	Experiences that occur when the concerns and knowledge of a child with disabilities or their families are minimized, devalued, or ignored despite their expertise about their life and health	Parents are ignored or not acknowledged for their expertise in the child's care. Doctors talk to me like I'm new to the diagnosis after 18 y parenting and learning about her syndrome. I'm overlooked because I am a mom and not the professional.
9. Intersectional identities and judgements of worthiness	0.73	Experiences related to devaluing children with disabilities that are heightened in children who identify as members of other marginalized communities	Children with disabilities must look as "white and middle class" as possible to get adequate care.
10. Restrictions driven by insurance coverage and policy	0.10	Experiences occurring because of inadequate insurance benefit packages for children with disabilities and specifications of coverage limits, covered services, cost sharing, and exclusions	Insurance denials of more expensive therapies—patients are forced to try less effective means of health management first before insurance will approve best evidence-based practices.
11. Complexity in community and health services navigation	0.44	Experiences related to fragmentation of care, excess administrative burden, lack of care coordination and limited communication between services within and across organizations	Not enough time, reimbursement, support, or coordination to address a child's needs in most primary care settings.
Abbreviations: ADA, Americans with Disabilities Act; CPAP, continuous positive airway pressure.			

unaccommodating structures such as parking lots, doors, check-in kiosks, or waiting rooms. Cluster 6 (limited access to resources and services) was described by a focus group participant as involving "the access to care, access to providers, access to space, and then this is access just to what the system recommends, right? Or what people actually recommend you do and can you actually get that or not?" Cluster 7 (unfair standards and normalized inequity)

involved the culture and unwritten rules of organizations that perpetuate inequitable care and different standards for children with disability. Specific experiences highlighted differences in discharge criteria for children with complex needs and routine screening tools that are insensitive to disability.

Cluster 8 (dismissal of the lived experience and caregiver expertise) included experiences where a caregiver or child's

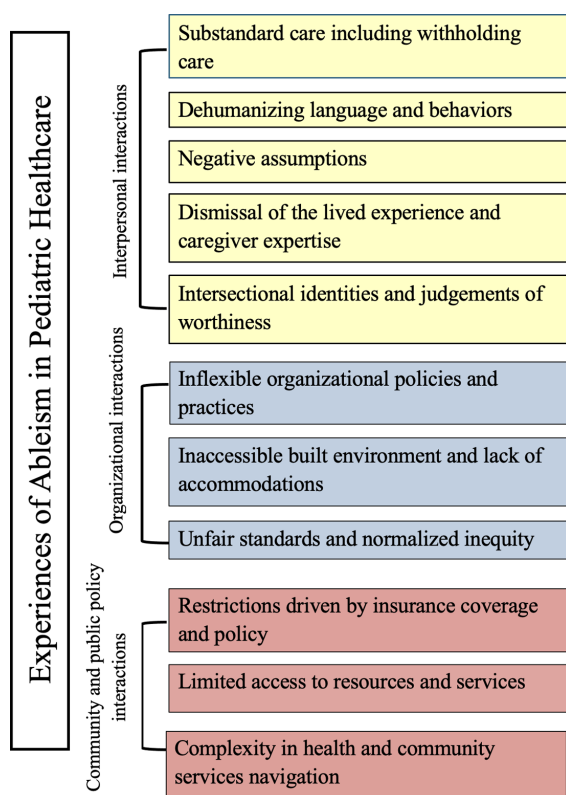


FIGURE 1.
Clusters of ableism in pediatric health care.

perspective was not considered despite their knowledge and experience with their health. Cluster 9 (intersectional identities and judgements of worthiness) experiences involved assessments of children with disabilities and the compounding discrimination that occurs with intersectional identities. This cluster had a high bridge value, indicating experiences within this cluster were less conceptually distinct to participants and may thematically span across clusters. Cluster 10 (restrictions in care because of inadequate insurance coverage and policies) experiences were summarized by one participant in the focus group as “families are feeling like insurance is setting them up to fail or the lack of coverage from insurance and that it is really negatively impacting the health of kiddos and the well-being of families.” Cluster 11 (complexity in community and health services navigation) experiences related to fragmentation of care and siloed health services. One focus group participant summarized, “It’s all the ways that we’ve fallen through the system. The system is not designed for children like ours.”

Next, the clusters were compared by mean ratings for the impact of experiences on health care access and on physical and emotional health in layered cluster maps and a “go-zone” scatter plot. Figure 2 shows 2 layered cluster maps. The clusters with the highest perceived mean impact on

access to health care were limited access to resources and services (cluster 6, mean rating of 3.27–3.32/4) and restrictions driven by inadequate insurance policy (cluster 10, mean rating of 3.27–3.32/4). The clusters with the highest perceived impact on physical and emotional health of children with disabilities and their families were substandard care (cluster 1, mean rating 3.47–3.55/4) and dehumanizing experiences (cluster 2, mean rating 3.47–3.55/4). In addition to the layered cluster maps, a “go-zone” scatter plot revealed multiple experiences to have both a perceived high impact on health care access and child and family emotional and physical health (Figure 3).

DISCUSSION

Children with disabilities and their families report many ableist challenges in the health care system. The 11 clusters of experiences of ableism in pediatric health care highlight the many ways discrimination is perceived by families and children with disabilities. Ableism experiences can occur during provider-patient interactions as substandard clinical decisions, including decisions to withhold care, dehumanizing language, assumptions about disability, and dismissal of the lived experience. Other experiences involve interactions with organizations and inflexible policies, inaccessible built environments, and a culture of normalized inequity within organizations. Community-based factors and public policies contribute to challenges with inadequate insurance coverage limiting access, complexity in community and health services navigation, and limited access to necessary resources that disproportionately impact children with disabilities.

The results of this study provide guidance for future research, advocacy, and health systems improvement. Each cluster offers a launch point for deeper investigation, including examining root causes, exploring prevalence, and determining impact on health outcomes. Furthermore, the experiences identified in this study define the conceptual constructs to guide future measurement of ableism. For example, each experience can inform the item content in future patient-reported survey measures. Novel measures of experiences are needed to determine the occurrence of ableism in health care and identify populations at highest risk for exposure to ableist experiences for future interventions. In addition, measurement of ableism within health systems could identify experiences occurring locally as targets for intervention. Interventions within health systems likely must consider the expansive nature of ableism to improve patient experiences. For example, organizational efforts to address interpersonal discrimination through workforce anti-ableism or communication training could be enhanced by synchronized assessment and modification of organizational policies and structures that inherently disadvantage children with disabilities.²⁰

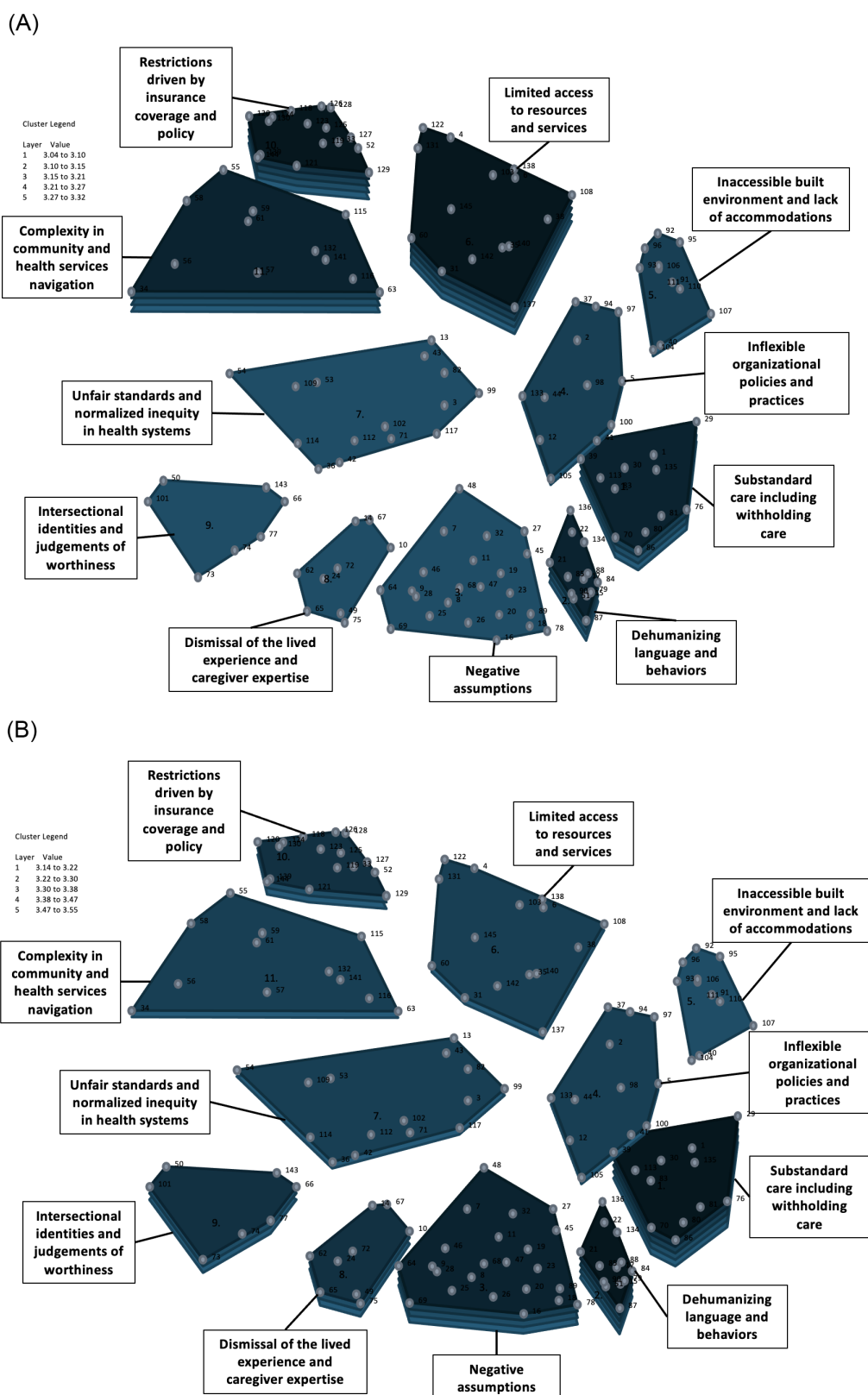


FIGURE 2.

Layered cluster maps of ableism in health care. A) Final cluster map of 11 domains of ableism experiences layered with the impact on access to healthcare for children with disability, and B) final cluster map of 11 domains of ableism experiences layered with the impact on the physical and emotional health of children with disability and their family.

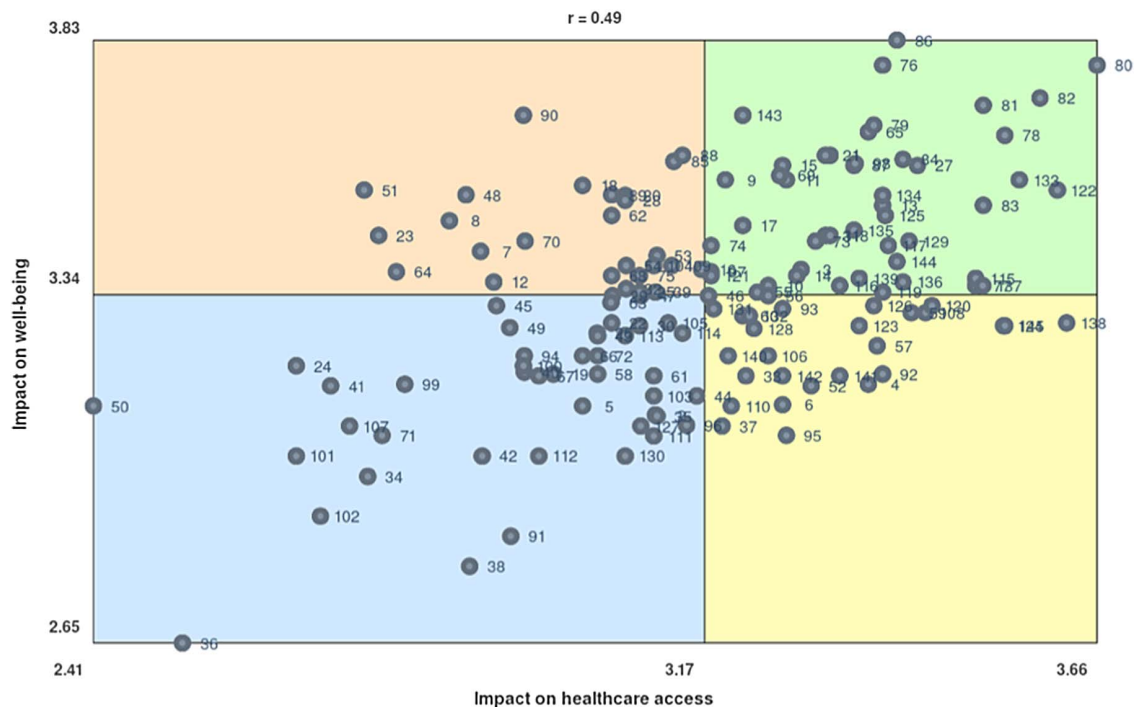


FIGURE 3.

“Go-zone” representing harmful experiences of pediatric ableism in health care.

Go-zone plot representing individual experiences of ableism in healthcare and their impact on access to healthcare and the physical and emotional health of children with disability and their families. The experiences with the highest ratings of impact on well-being and impact on healthcare access are shown in the right upper quadrant. The 5 highest rated experiences are: Care and work up was refused in the emergency room because our son was “already past his life expectancy.” (statement 80); One hospital stood in the way of transferring to another hospital for months and treatment was no longer possible leading to death (statement 82); My child has survived multiple attempts at purposeful eugenics by “medical professionals” who truly believe disabled children are not worthy of living and should be removed from the population by “natural selection.” (statement 78); When treatment is not offered because “We don’t do that for children like him,” for example, a continuous positive airway pressure machine needed so our child could breathe while sleeping or a surgery (Ventricular Septal Defect heart repair) that is considered essential for health (statement 81); the attending doctor asked us when we were going to stop treatment—he asked what they should do if they have other people who need our room. (statement 86).

This study also identifies priorities for future evaluation based on lived experience ratings. Substandard care, including withholding care and dehumanizing behaviors, was perceived by participants to negatively impact the physical and emotional health of children and families as well as access to care. Substandard care can lead to poor health outcomes due to clinical decisions influenced by personal bias and missed diagnoses caused by diagnostic overshadowing. In addition, these experiences can cause chronic and toxic stress, which is associated with poor physical and mental health.^{4,21–24} Discriminatory interactions can also influence trust, leading to alterations of health-seeking behavior and forgone care, which can have deleterious effects on health.^{25–27} Therefore, these experiences represent critical areas for future intervention, which may include addressing provider bias and lack of knowledge, increasing lived experience partnership in care through family-centered care, and mitigating value imposition in decision-making.^{28–30}

There are several limitations of our study. First, the purpose of this study is to describe ableism experiences from

the lived experience perspective. The further evaluation of causal factors, structural influences, clinical context, and prevalence of reported experiences is outside the scope of the study methods. Future research should include a deeper evaluation of the drivers and facilitators of each experience to inform intervention and facilitate necessary change. Next, the definition of health care in this study did not explicitly include school and therefore may not represent health care experiences that occur in this setting. Another limitation involves the recruitment methods, which required a direct referral and access to internet software to participate, which may lead to selection bias. In addition, the study was only offered in English or Spanish, and participants with limited or no English proficiency are not well represented in our study. Future studies should focus on the experiences of ableism and intersectionality occurring in non-English-speaking families. Furthermore, it is challenging to separate intersectional identities and experiences in health care. Ableism can compound other discrimination, impacting the experiences in health care

systems for individuals from all marginalized communities.³¹ Future efforts to design health systems interventions should consider other forms of oppression that often occur simultaneously.

CONCLUSIONS

Children with disabilities encounter ableism in the health care system with experiences represented by 11 clusters. This study identifies experiences of ableism from the perspective of participants in the study and highlights constructs for measure development and future research to improve health care experiences for children with disabilities and their families.

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ABBREVIATIONS

AC: advisory committee
GCM: group concept mapping
LEP: lived experience partner

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