

# Bias in health care: Study highlights discrimination toward children with disabilities

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Children with disabilities, and their families, may face discrimination in the hospitals and clinics they visit for their health care, according to a new study led by researchers at University of Utah Health. These attitudes may lead to substandard medical treatment, which could

contribute to poor health outcomes, say the study's authors.

"They mistreated her and treated her like a robot. Every single time a nurse walked in the room, they treated her like she was not even there," said one mother who was interviewed about her child's health care encounters.

The findings, published in the journal *Pediatrics*, are based on 30 in-depth interviews with family caregivers living in 15 states in the U.S. The children they looked after had medically complex conditions, with most needing health care more than 20 times each year. While the study did not measure how common it is for clinicians to show bias against children with disability, it exposes a serious problem that needs to be addressed, says lead author Stefanie Ames, M.D., a critical care physician at U of U Health.

"Our goal was to validate families' experiences and bring awareness to the issue," Ames says. She and the study's senior author, Nancy Murphy, M.D., are faculty in the Department of Pediatrics at the Spencer Fox Eccles School of Medicine at the University of Utah. "Recognizing the problem is the first step."

Analysis of interviews with caregivers identified six recurring reasons for—and consequences of—health care provider bias against children with disability and complex medical conditions.

Family caregivers perceived that the main drivers of discrimination were:

- A lack of knowledge of how to care for children with complex medical needs
- A lack of interest in providing health care or medical interventions based on a perception that the child may not be

worthy of care

- Negative assumptions based on the child's disability and quality of life

The interviews revealed that family caregivers felt that [discrimination](#) resulted in:

- Limited accommodations, for example for wheelchairs, making it difficult for children and their families to access health care
- Clinicians not providing the same health care and medical treatments to children with disabilities as they would for those without [disabilities](#)
- Clinicians dehumanizing children with disability and treating them differently than they would typically developing children

According to family caregivers, at times these attitudes impacted [patient care](#). One said that a doctor recommended against treating her daughter's cancer despite there being a high chance of success that the treatment would work. Another parent indicated that health care providers did not give her child adequate pain relievers before carrying out an uncomfortable medical procedure.

"My perception is that [clinicians] wanted to take care of the patients that didn't have a severe, special need... They just seemed like they didn't even care to treat [my daughter]," said one child's mother.

Ames and Murphy say the experiences of these families reveal an urgent need for additional medical training in caring for people with disability. The research team will be carrying out additional studies to determine how common these attitudes are nationally and whether they ultimately impact the health of [children](#) with complex medical needs.

"I believe that all healthcare providers choose this line of work because

of the common goal of helping those in need," Murphy says. "Yet when providers lack the knowledge, experience or resources to render care, we tend to shy away from situations. This tends to happen without our awareness, and this research brings this issue into clear view."

**More information:** Stefanie G. Ames et al, Perceived Disability-Based Discrimination in Health Care for Children With Medical Complexity, *Pediatrics* (2023). [DOI: 10.1542/peds.2022-060975](https://doi.org/10.1542/peds.2022-060975)

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