

# Valuing the Vulnerable: Prioritizing the Patient Perspective

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# Valuing the Vulnerable: Prioritizing the Patient Perspective

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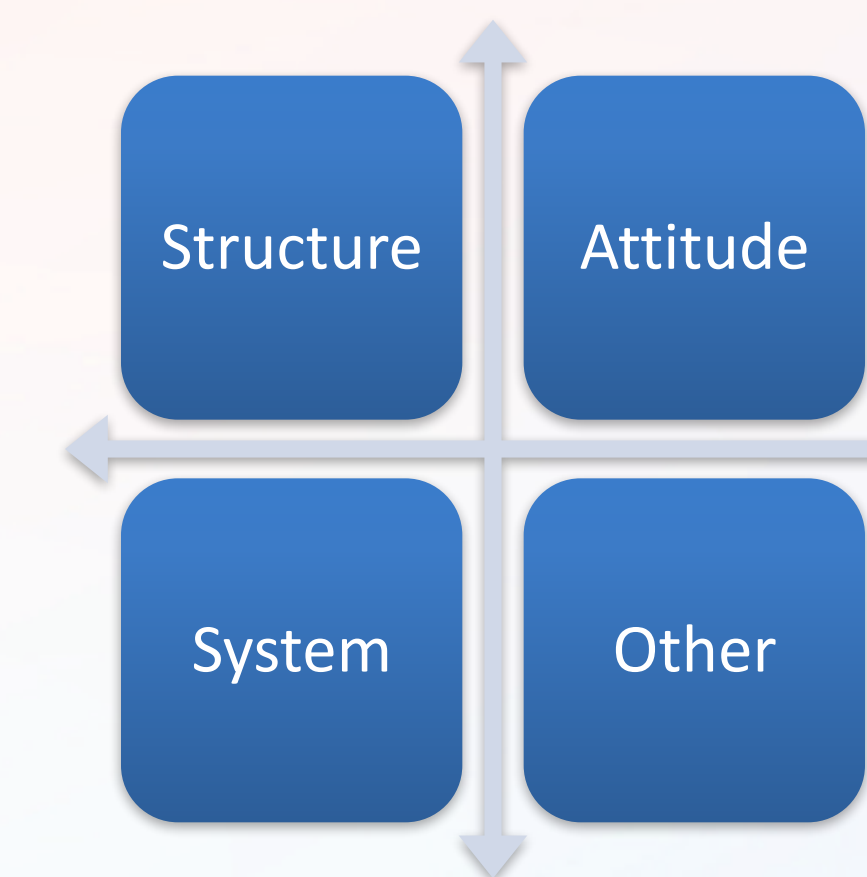
## Background

- Patients with disabilities are often underserved due to discomfort of the provider(s).<sup>1,2</sup>
- Purpose: Identify gaps in the care of patients with disabilities
- **Intellectual and Developmental disabilities (IDD)** include but are not limited to Autism, Cerebral Palsy, Downs Syndrome, Spina Bifida, and other impairments of mobility, speech, hearing, and vision.
- **Medical Home Project (MHP):** A team of professionals, patients, and family members from advocacy organizations in the Lehigh Valley, focused on the care of individuals with IDD.
- In January, MHP member with Spinal Muscular Atrophy, late Rebecca Dubin, received inadequate care. This accentuated the continuing need of change and advocacy for care that is accessible, respectful, equitable, and of high quality for patients with disabilities.<sup>1,2</sup>
- Rebecca expressed the state of her care several days before she passed away: **“Many times, staff would come into my room and not even announce themselves, and start doing a breathing treatment or something else in the room.....I would like to know when something is being done to me. There is a need for training, staff should announce themselves and ask how and if someone would like something done.”**

## Methods

- Outpatient (all of LVPG) and inpatient (Cedar Crest and Muhlenberg) feedback surveys (February to April 2019) were accessed through Press Ganey portal.
- Master list of key words pertaining to individuals with disabilities was used to draw comments.
- Positive and negative comments were categorized into structure/attitude/system-related, or other groups.

accessibility (10) advocate (6) alzheimer (2)  
amputation (2) amputee (1) and (1) asperger (2) assistance (12)  
autism (7) autistic (2) bathroom (6) behavioral (1)  
dementia (10) disability (5) disabled (1)  
friendly (1) idd (1) impaired (1) impairment (8)  
intellectual (2) parking (7) respect (12)  
sensitive (10) sensory (1) spectrum (2) staff (15)  
stroke (6) support (2) wait (2) walker (2)  
wheelchair (38)



## Conclusions

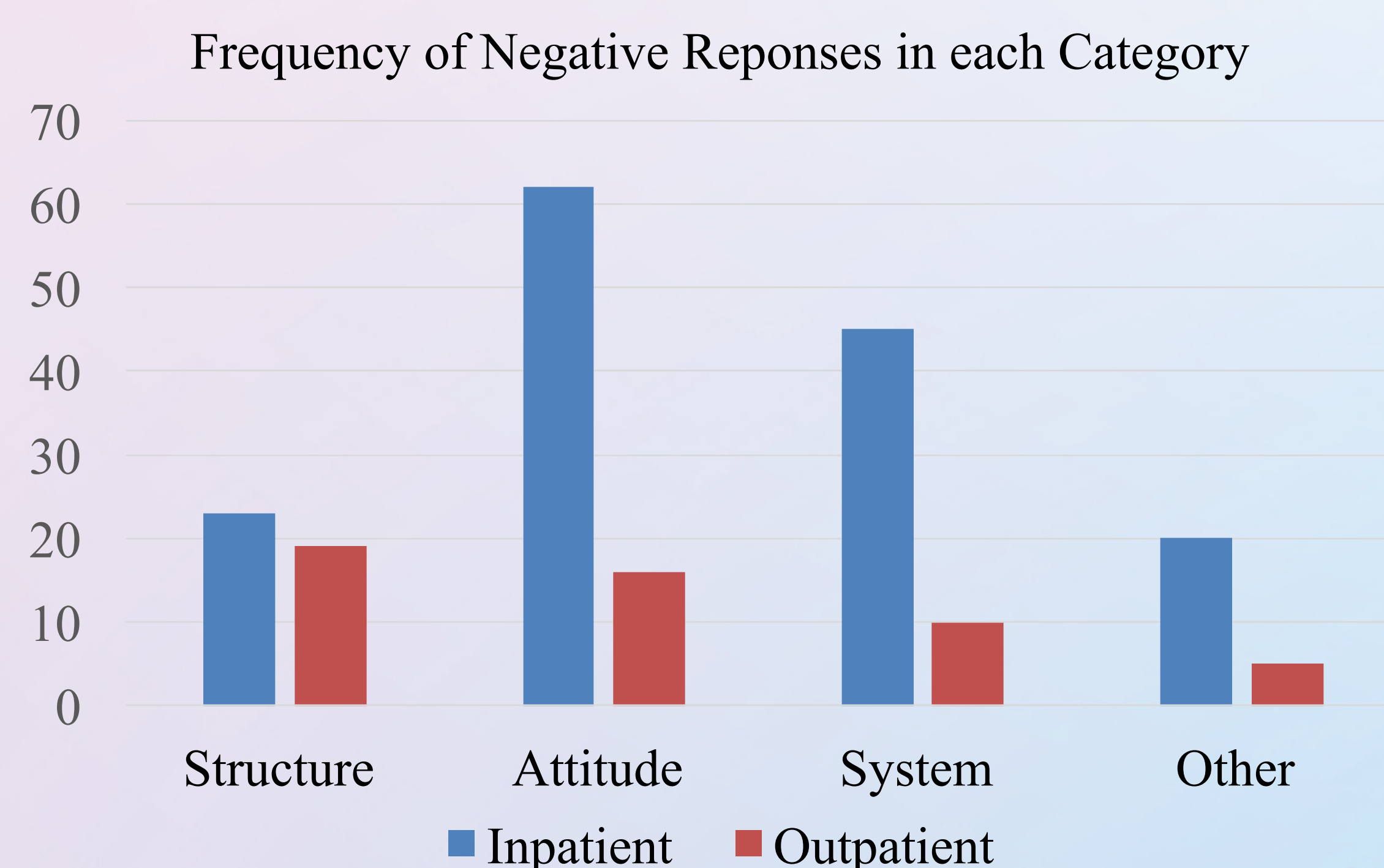
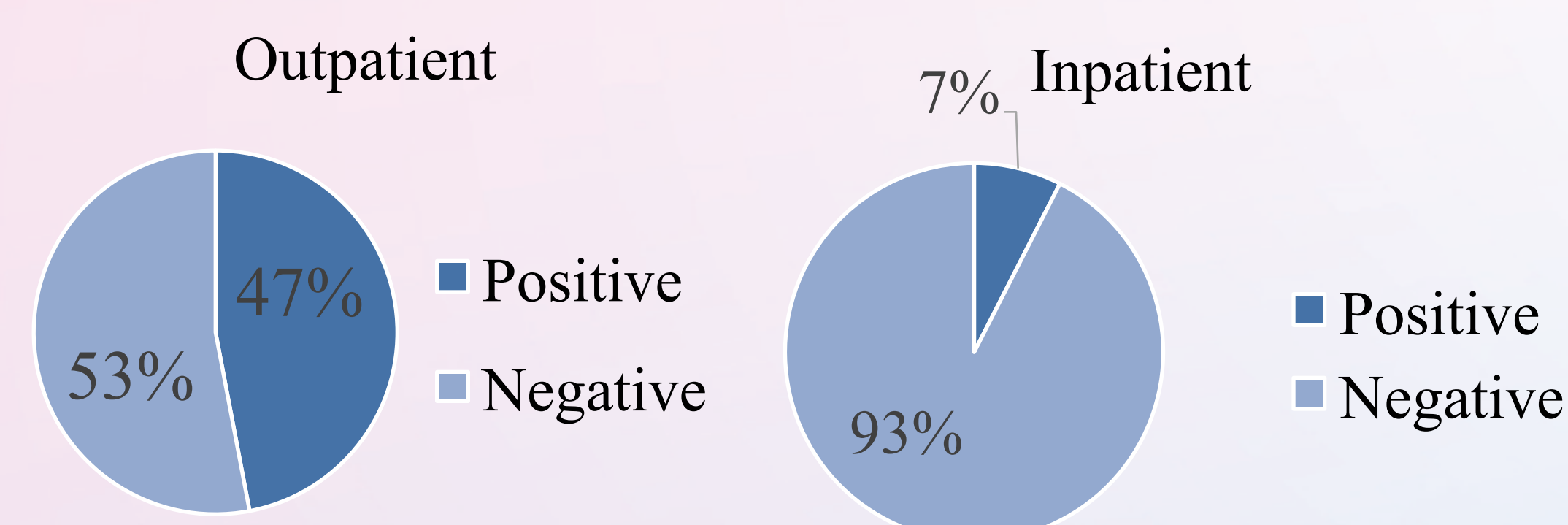
- Improvement is needed in the care of patients with disabilities
- There is more room for change and improvement in inpatient than outpatient
- Outpatient had the most structural deficits while inpatient had the most attitudinal deficits
- Overall, although barriers may exist and not all of them can be eliminated at once, many can be overcome simply through attitudinal change.
- By employing a foundation of compassion, empathy, and respect, one can be equipped to provide care for any patient.

## Recommendations

- Findings be brought to the attention of LVPG and LVH leadership to work toward equitable health care for patients with disabilities.
- After leadership is made aware, training and education regarding this population should be implemented throughout the Network.
- Reinstating and expanding the **Patients with Disabilities as Teachers (P-DAT)** program where patients share their own stories and experiences with medical students, residents, and staff.
- Clinical/Non-Clinical departments can partner with MHP to receive the guidance and resources to care for this population.
- More follow-up with patients who had poor experiences
- Work toward changing the philosophy of patient care systemically

## Results

94 outpatient and 200 inpatient survey comments



Structure	Attitude	System	Other
<ul style="list-style-type: none"> <li>• NO RAMP. I was confined to a wheelchair and had appointment pre-admission, and after more than an hour I called a private transport because LVHN has no shuttle with wheelchair accessibility. It's a hospital with sick people &amp; no ramp? Right your wrong!</li> <li>• The worst building to get into with a wheelchair, no handicap access.</li> <li>• The thing I would change about the hospital rooms is to add bidet attachments to the toilets. It is easier for people with impairments as it does not require bending or twisting which I couldn't do.</li> </ul>	<ul style="list-style-type: none"> <li>• Not Autism-friendly, ignored my child like they were not even there. Need to do training on manners.</li> <li>• I can't walk and use a wheelchair and was asked to stand and walk into a room by a doctor who said I was dramatic to my wife.</li> <li>• My mom with Dementia was neglected. She sat in her own urine and excrement and went without her medications and food the entire time.</li> <li>• No one was concerned and then made excuses when I asked why she was not getting proper care.</li> <li>• The attending nurse refused to help me order or check on me, I am legally blind so I cannot do things by myself.</li> </ul>	<ul style="list-style-type: none"> <li>• Surveys need to be more accessible to blind people</li> <li>• Waited 1 hour for a wheelchair. My wife finally got me (through an aide) and she wheeled me to the door. Something should be done.</li> <li>• I use a cane to walk, I pressed the call button which did not work and nobody ever came when I pressed the bed alarm.</li> <li>• Staff did not check on or communicate with me or my elderly blind roommate. If I didn't call someone, my roommate probably would not have gotten fed.</li> <li>• I was not assisted during the discharge process. I was immobile and left with running water, beeping alarms, and had to dress myself. I was never assisted into the parking lot or offered a wheelchair or help.</li> </ul>	<ul style="list-style-type: none"> <li>• Fell using walker in the halls, no staff member was present nor helped me.</li> <li>• Visited husband with dementia and found him naked; No curtain pulled.</li> <li>• Wheelchair was slammed into door causing my operated leg to slam into the wall.</li> <li>• The technicians had no idea how to take X-rays or perform a CT scan with my physical limitations and immobility.</li> <li>• Residents need a ton of schooling on special needs children and parents.</li> </ul>

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