



PATH (Promoting  
Accessibility To Healthcare)

## PATH: Improving Participation in Healthcare for Neurodiverse Individuals

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- I have no financial relationship with any manufacturer of any commercial product and/or provider of commercial services discussed in this CME activity
- I do not intend to discuss an unapproved/investigative use of a commercial product or device in our presentation
- I affirm that our presentation complies with U.S. Government Health Insurance Portability and Accountability Act of 1996 (HIPAA) privacy and security standards

# Unmet Healthcare Needs

Unmet health care needs



Worse health outcomes as adult

- **Autistic individuals have 4x higher rate of unmet health care needs**
- **Individuals with ASD and ID have even higher unmet health care needs and poorer-quality care**

1. Karpur, *et al.* Health Disparities among Children with Autism Spectrum Disorders: Analysis of the National Survey of Children's Health 2016. *J Autism Dev Disord* (2019).

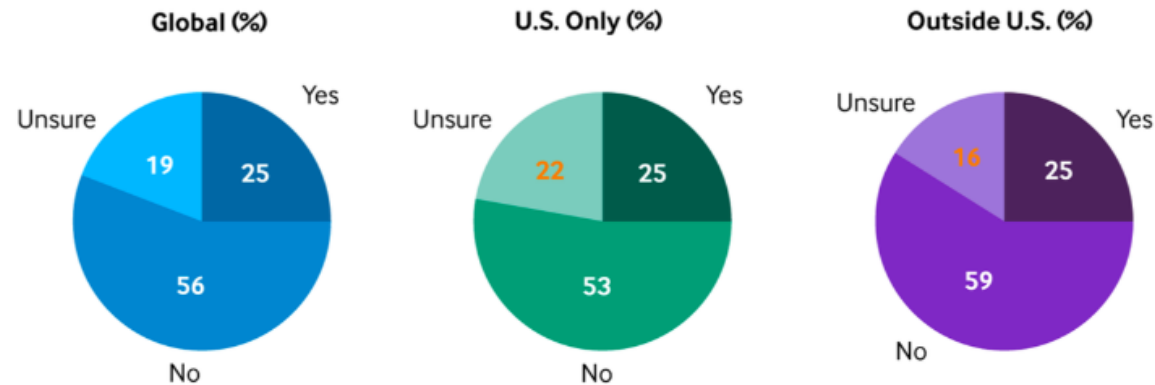
2. Forde, *et al.* Health Status of Adults with Autism Spectrum Disorder. *Rev J Autism Dev Disord* (2021).

3. Menezes M, *et al.*, Unmet health care needs and health care quality in youth with autism spectrum disorder with and without intellectual disability. *Autism*. 2021

# Training deficits-Global, U.S. and local issue

- Health care costs are more than 4 times higher for neurodiverse patients (Matin et al. 2022)
- Little training is provided for working with patients with IDD or other neurodiverse conditions.

Does your organization provide training about how to work with patients with intellectual and developmental disabilities?



Statistically significant differences are noted in orange

Base: Global – 779; U.S. only – 421; Outside U.S. – 358 (may not total 100 due to rounding)

NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

# Providers Comfort Caring for Neurodiverse Adults

The New York Times

## These Doctors Admit They Don't Want Patients With Disabilities

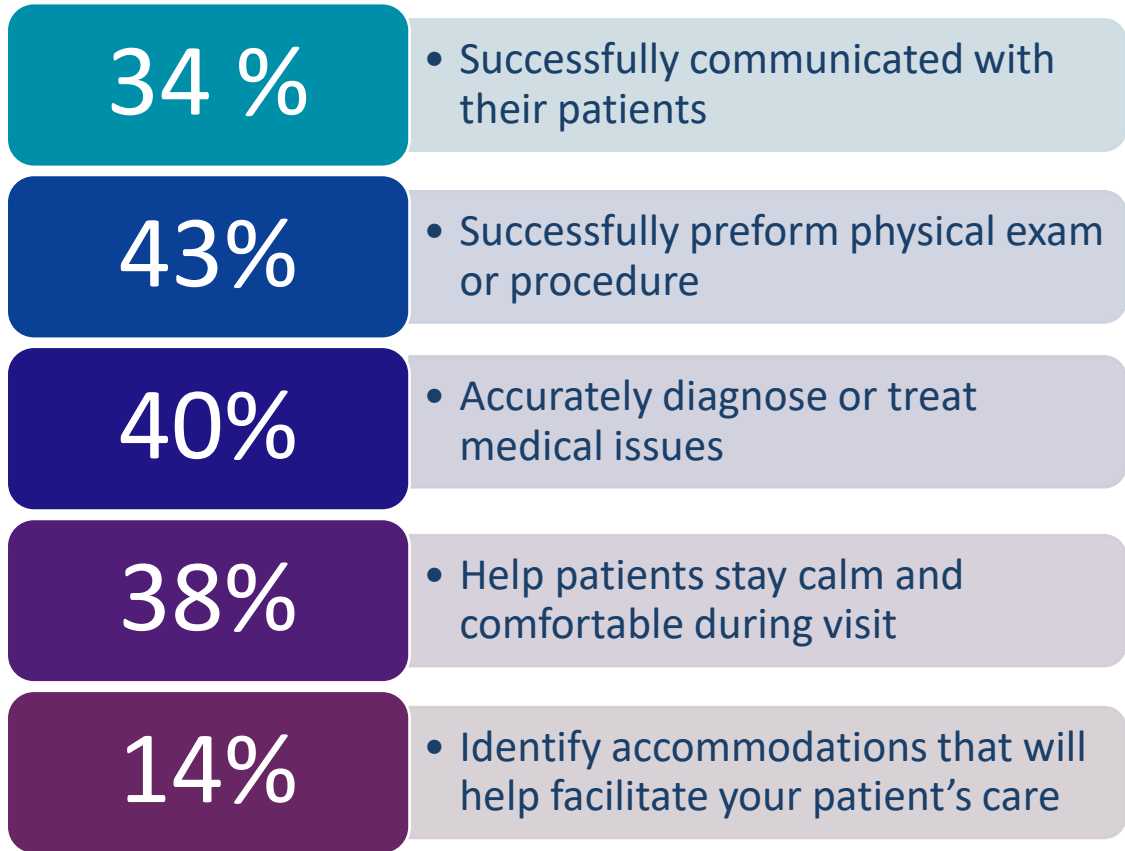
When granted anonymity in focus groups, physicians let their guards down and shared opinions consistent with experiences of many people with disabilities.

Give this article 1.2K



Lisa Tezzoni, a professor of medicine at Harvard, wanted to understand why people with disabilities kept reporting receiving substandard care. "I thought I needed to start talking to doctors," she said. M. Scott Brauer for The New York Times

By Gina Kolata



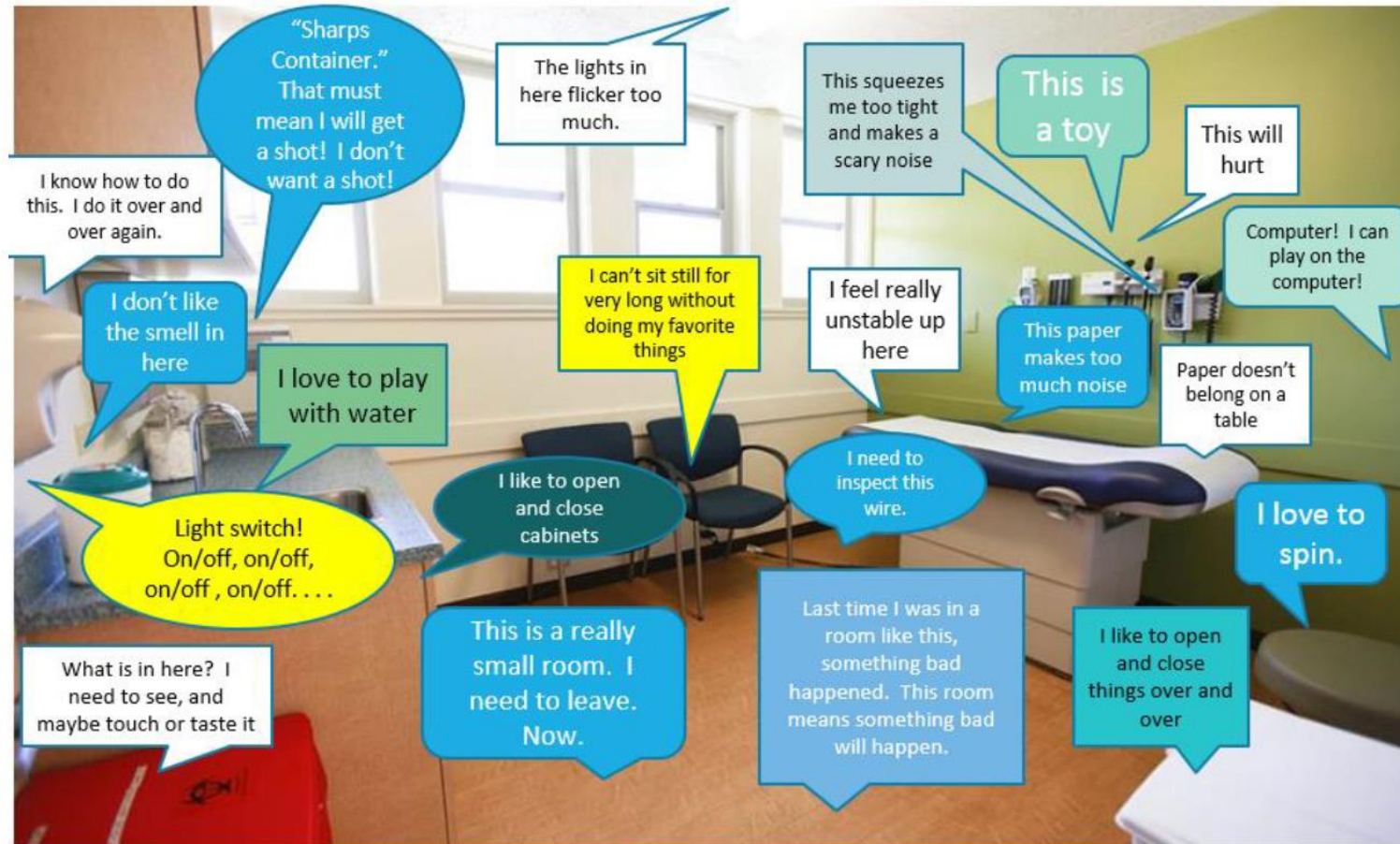
Nicolaidis C, Schnider G, Lee J, Raymaker DM, Kapp SK, Croen LA, Urbanowicz A, Maslak J. Development and psychometric testing of the AASPIRE Adult Autism Healthcare Provider Self-Efficacy Scale. Autism. 2021 Apr;25(3):767-773. doi: 10.1177/1362361320949734. Epub 2020 Aug 28. PMID: 32859135; PMCID: PMC8204689.

# Who is impacted by limited neurodiversity training?



- 8-year-old with medical history of Juvenile Idiopathic Arthritis, Autism Spectrum Disorder, Intellectual Disability, minimally verbal, significant aggression and self-injurious behaviors during medical visits
- Needs frequent eye exams, imaging and blood draws Nearly all studies have required restraint or sedation at UCD and UCSF due to identified gaps in training, equipment, and support for lab draws in patients with disabilities
- **This is medical trauma**
- Many recommended studies not obtained or obtained late

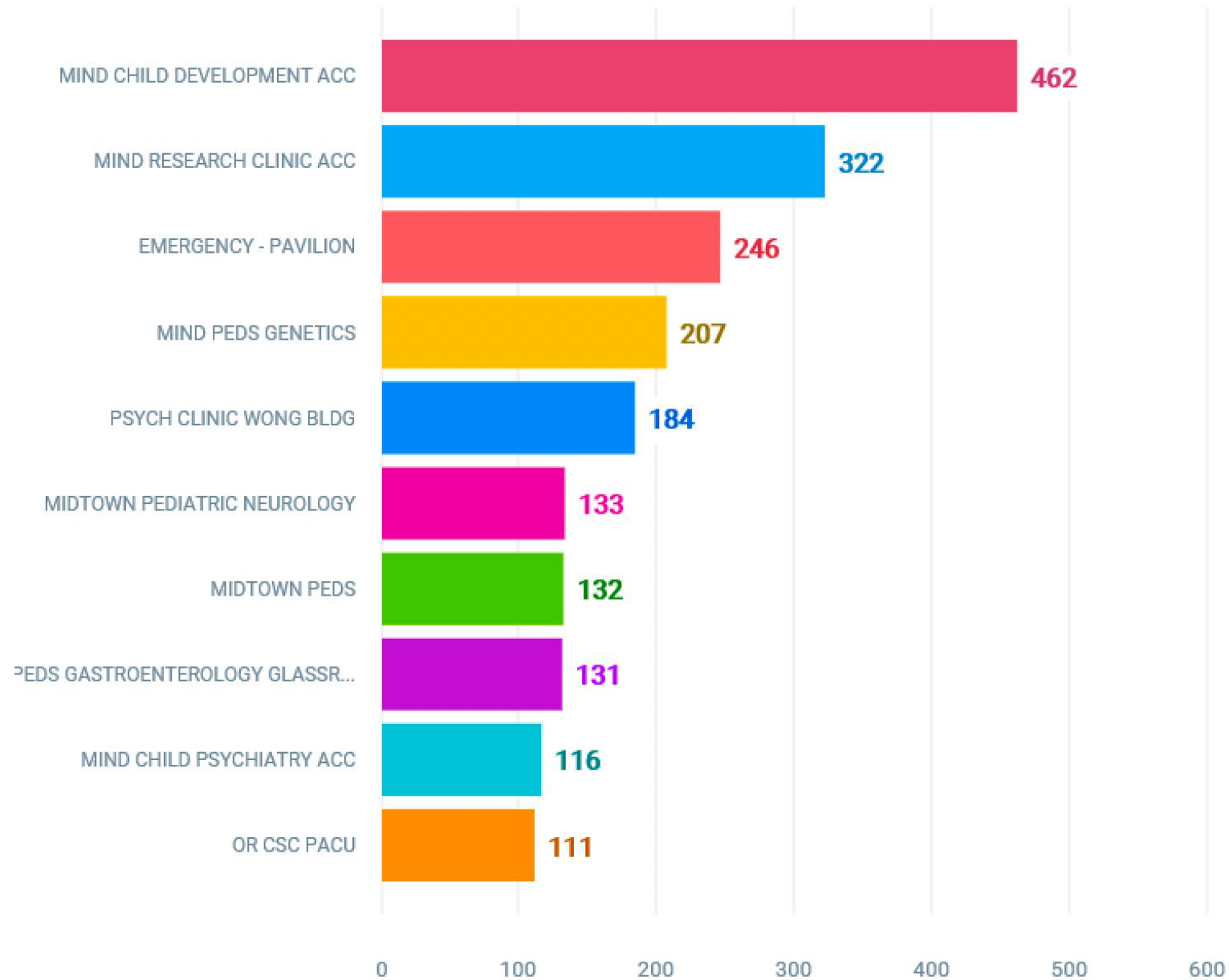
# How Neurodiverse Patients Experience a Medical Environment



# Top 10 Departments ASD Patients Seen



Between 1/1/2021 and 12/31/2021





# Why did the PATH Program Begin?

- Greater recognition of neurodiversity and evidence that appropriate, patient-centered interventions can decrease medical trauma and improve participation in healthcare
- Better understanding of impact of repeated medical trauma
- Neurodiverse individuals have **higher health care utilization**, but **experience more unmet health care needs**
- Limited training about neurodiversity for many healthcare providers



# A PATH to Positive Medical Outcomes

for neurodivergent patients



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1 Neurodivergent patients often need more frequent medical care



2 Communication and sensory differences can increase anxiety when accessing medical care



3 Healthcare staff may lack training in evidence-based strategies



3 Providers build awareness of neurodiversity and evidence-based strategies through training



4 Increased anxiety or medical trauma may occur



4 Patients have positive medical experiences

Negative medical experiences can lead to avoidance of care and unmet medical needs





5 Positive experiences help neurodivergent patients become active participants in their healthcare

Scan for more resources and information on The PATH Program



# Individuated Pre-Screening & Intake Process

- Caregivers of neurodiverse patients call and book vaccine clinic appointments
- 24-48 hours prior to the appointment, vaccine clinic staff complete a 10–15-minute intake phone call learn about the patient’s preferences, likes, dislikes, sensory needs
- Provide caregivers educational materials and social story that provides visual explanation of visit
- Develop coping plans with caregivers prior to patient arrival-ideally 2-3 days before a visit

 
<b>VACCINE CLINIC</b> <b><u>Patient Information Sheet</u></b>
Patient (First/Last): _____ Date of visit: _____ Date of Birth: _____ Phone Number: _____ Email: _____ Family Member/ Caregiver Accompanying Visit: _____ Is the family member also receiving the vaccine? Yes <input type="radio"/> /No <input type="radio"/>
How has the patient responded to receiving a prior vaccination/blood draw? Was it a <i>positive</i> @..... or <i>negative</i> @..... experience? Please describe:  Do they do better to know more information/ or less?
What are the patient’s verbal abilities? Nonverbal <input type="radio"/> , Single words only <input type="radio"/> , Speaking in short sentences/phrases <input type="radio"/> , Fluent Is English the primary language? Yes <input type="radio"/> / No <input type="radio"/>
Does the patient have any sensory issues (i.e., sensitivity to touch, sound, or light)? Yes <input type="radio"/> /No <input type="radio"/> If yes, in which situation? What triggers a possible sensory overload?
Is the patient aggressive to self or others? Yes <input type="radio"/> / No <input type="radio"/> If yes, please clarify: biting <input type="radio"/> , pinching <input type="radio"/> , hitting <input type="radio"/> , spitting <input type="radio"/> other, please specify; .....
What provokes these behaviors? How can we help them calm down? Is there anything that the patient does NOT like? (i.e., a child that does not like anyone using their name)
Does the patient have any special interests? What are their top 3 favorite things?
Any additional information you’d like to share about this patient?  Completed by: _____

# Dissemination of a COVID-19 Vaccination Social Story



# Success Rate of Vaccination

Since the opening in May 2021 vaccinated:  
Over 400 neurodiverse individuals

**Current rate of successful vaccination  
for 2023-24 clinic was 100%**

About 1/3 of patients travelled  
>50 miles for vaccination

Many patients, up to age 73, had never had  
a procedure without sedation or restraint



# PATH Program Goals



1. Decrease medical trauma and provide safe, supportive, individualized care for neurodiverse individuals
2. Improve provider and staff knowledge and confidence and competence related to caring for neurodiverse individuals
3. Improve Physical Spaces, Protocols and Training
4. Create a Community Advisory Board that provides guidance and assists with oversight

# PATH Phase 1: January – December 2023 Plans

Create PATH  
Steering  
Committee

Engage steering  
committee via  
monthly program  
development  
meetings

Implement NDD  
Trainings for  
UCDH  
Phlebotomy

Implement NDD  
Care Plans in new  
EPIC Smartform  
for all sites

Pilot best  
practices in high  
utilization site

- 2-year Children’s Miracle Network grant funded project (\$349k) aimed at improving healthcare experiences for neurodiverse children and their families.
- Initial pilot sites: Children’s Surgery Center and Glassrock Lab

# PATH Phase 2: January – December 2024 Plans

Expand Adoption of Best Practices Throughout Hospital  
(ER, Inpatient Wards PICU)

Develop novel interventions, support research

Broad Dissemination of Findings and Programmatic Solutions



# PATH Program "PATH Advisory Committee" (PAC)

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Advisory Committee formed with members that include caregivers, parents and neurodivergent youth and adults

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Multiple participants had experienced prior medical trauma and the challenges commonly faced by families and neurodiverse individuals during ER visits, hospitalizations, surgeries and routine care like labs, vaccinations, radiology studies

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A couple of committee members are parents and healthcare providers

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Monthly meetings ensure that individuals with lived experience provide leadership, guidance and oversight

# EPIC Smartform



Hyperspace - appbl - CHILDRENS SURGERY CNTR - GINGER ROUNDS

Remind Me Apts DAR - Dept Apts View Schedules In Basket Chart Telephone Call Refill Patient Station Snapboard Mark Patients For Merge Service Task Seamless

Sretest, Maria

MS

Maria Sretest  
Female, 7yr, 6/8/2016  
MRN: 9303625  
Phone: 777-888-9456  
Level of Care: None  
Service: None  
LoS: 1  
Code: Not on file  
ACP Docs: None on file

Search

No Acknowledgment

Allergies: Not on File

Transplants: None  
Pumps/Implants: None  
Care Team: No PCP

BP: —  
Ht: —  
Wt: —  
BMI: —

SELECTED VISIT  
None  
Referral: None

Previous Eye Exams: No prior dilated visits  
PCP: None

Snapshot Summary Chart Review Demographics Notes PATH Child Life and Creative Art... Telephone Call

PATH - 6/28/2023 visit with Rounds, Ginger, Child Life Specialist for Telephone

PATH

Promoting Accessibility to Healthcare for Neurodiverse Patients

Patient would benefit from PATH  Yes  No

Name of Reviewer Stevie Everdyke

Initiated/Reviewed Date 6/9/2023

Communication Preferences

PATH to understanding how you communicate best with us:  Non verbal  1-2 word responses  Full sentences  Communication device  Short phrases  Sign language  Gestures/points  Other

Other: Explain communication specifics

Behavioral Support Needs

PATH to understanding behavior when you are upset:  Cries/screams  Runs/elopes  Self injurious  Injure to others  Kicks/pushes to get away  Throws things  Hitting/biting self  Hitting/biting others  Other  Harms self

Other: Explain behavior

PATH to understanding what makes you upset so we can avoid it, if possible:  Loud noises  Touch  Sitting still for too long/waiting  Bright lights  Being held down  Sensitivity to smells  Excessive number of staff  Other

Other: Explain upsetting triggers

PATH to understanding what motivates you:  High/low fives  Tickle  Snacks  Stickers  Videos  Verbal praise  Other

Other: Explain other rewards Like goldfish

PATH to understanding what helps your caregiver or support person:  Communication/knowing what is going on or happening  Being patient  Being able to hold/comfort  Explaining procedure to support person prior to performing on you  Other

Other: Explain

Calming Methods and Comfort

PATH to understanding what  Videos  Favorite character  Being held/hugs  Music  Comfort item

+ ADD ORDER + ADD DX (0)



# In Person Trainings: September 2023

- UCDH Phlebotomists completed surveys before and after the two in-person training sessions
- Survey questions included:
  - Content assessment
  - Change in knowledge
  - Change in confidence



# In Person Trainings: September 2023

- 10 Phlebotomists completed training
  - Two in-person training sessions; each session was two hours in length
  - Asynchronous viewing of training videos
- Training topics:
  - Introduction to Neurodiversity and the PATH Program
  - Sensory and Environmental Considerations
  - Preventative Support Strategies: Visual Supports & Social Narratives
  - Comfort Positioning

## Comfort positions



### ◀ Chest-to-chest

- Best for small children who need distraction and prefer not to watch procedure.
- Allow the child to straddle parent or staff and have a secure "hug."



### ▲ Side sitting

- Best for older children who may want to watch while feeling secure.
- Use when child can't straddle parent or staff.



### ▶ Swaddle

- Best for young infants.
- When possible, have the caregiver hold the infant.



### ◀ Side hug

- Best for when a child needs to remain lying down.
- Parent may lay in bed next to patient.



### ▲ Back-to-chest

- Best for older children who want independence, but need to be held.
- Secure both arms for procedures like a port access or NG tube placement.



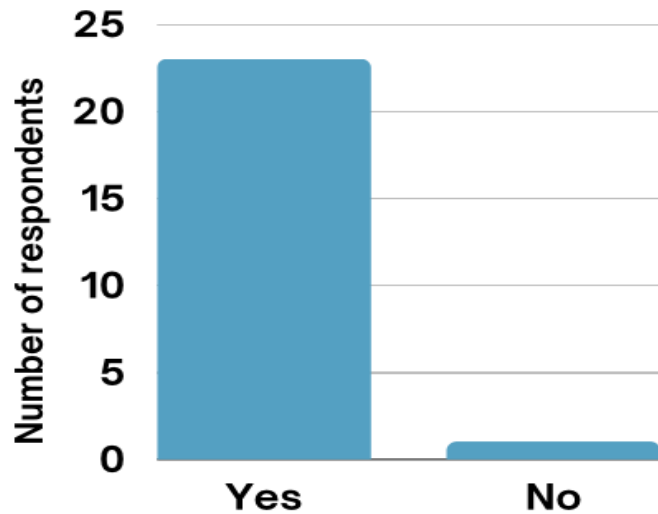
### ▶ Full body hug

- Best for when a child has needs that require extra support.
- Use when a child's lower and upper body need help staying secure.

**ASK A CHILD LIFE SPECIALIST OR NURSE**  
which position might be right for your child.

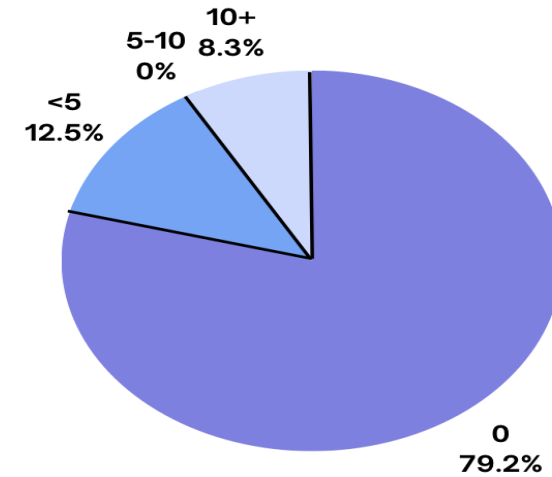
# UCDH Phlebotomy Pre-Training Survey Results

- 24 UCDH Phlebotomists were surveyed
- 96% of respondents cared for patients with NDDs



Total surveyed UCDH Phlebotomists who care for patients with NDDs

- Only 2 of 24 respondents had received 5 or more hours of training related to NDD

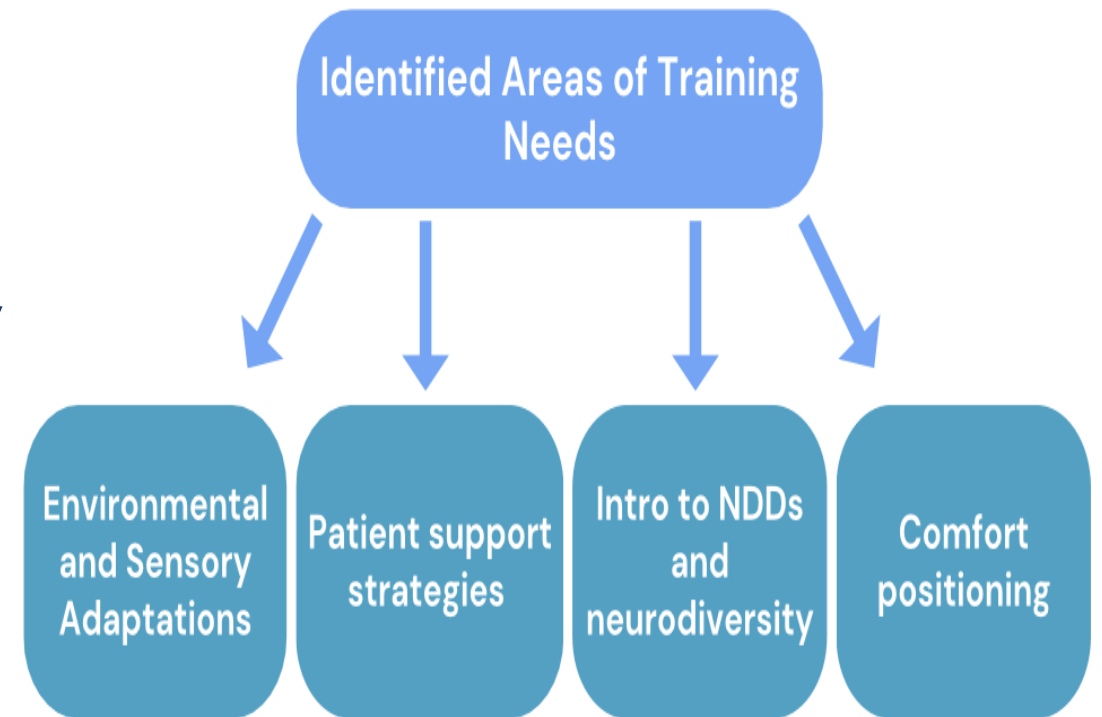


Total hours of neurodiversity training reported by phlebotomists in the last five years

- 75% stated that they were interested in receiving additional training about caring for patients with NDDs

# UCDH Phlebotomy Pre-Training Survey Results

- Phlebotomists listed lack of familiarity with neurodivergent children, environmental challenges, and time pressures in the work setting as the most significant barriers to caring for patients with NDDs



# NEW PATH Glassrock Blood Draw Clinic

## October 2023: First Clinics Begin!

- Offering appointments weekly on every Thursday from 12:30-3:30pm in 30-minute blocks
- 7 appointments per day
- NEW dedicated CCLS Danielle Giovannetti available in the clinic to provide procedural distraction, education, and support
- Patient Navigator support provided to all families to assist with scheduling appointments

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Every Thursday Afternoon  
12:30 p.m. – 3:30 p.m.  
Appointments will be  
scheduled every 30 minutes.

Steps to schedule an  
appointment at the PATH  
Glassrock clinic:

**Step 1:** To make an  
appointment please call  
**916-734-7373** and select  
option 1 for Pathology Client  
Services. Appointments can  
be scheduled Monday-Friday  
from 8:00 a.m.-5:00 p.m.

**Step 2:** After the appointment  
has been scheduled, a UCDH  
Certified Child Life Specialist  
will reach out prior to the  
appointment date to help  
prepare for the visit and talk  
through supports.

**\*\*Appointments can only  
be scheduled with a lab test  
order. Please note: some  
specialized lab tests may  
require pre-approval from  
insurance before an  
appointment may be  
scheduled.\*\***

**Location:**

Glassrock Lab  
2521 Stockton  
Blvd.  
Ste. 2300  
Sacramento, 95817



**UC Davis Health and The PATH Program are now offering a dedicated blood draw clinic every Thursday afternoon for all children with autism and other neurodevelopmental disabilities.**

Who can get a blood draw at PATH Glassrock?

Children up to age 17 (18 if still in high school) with autism and other neurodevelopmental disabilities (ADHD, Down Syndrome, Fragile X, intellectual disability) who require additional support for blood draws. We can also see children awaiting medical diagnosis/assessments and those who benefit from additional support for medical anxiety.

What is the PATH Program?

The PATH Program (Promoting Accessibility To Healthcare) is a 2-year Children's Miracle Network funded project aimed at improving healthcare experiences for neurodivergent patients and their families.

What support will this clinic provide for my family?

Trained phlebotomy staff and a certified child life specialist will utilize sensory adaptations, visual supports, comfort positioning and other procedural supports take the experience as comfortable as possible.

**Please email any appointment related scheduling questions/concerns to: Katharine Harlan Owens, PATH Patient Navigator, at [HS-PATH@ucdavis.edu](mailto:HS-PATH@ucdavis.edu) or call 916-734-4152 for more information.**

<https://health.ucdavis.edu/mindinstitute/clinic/path-glassrock-clinic.html>

# Glassrock Lab: Environmental Changes

- Remodeling treatment room to make it a child friendly, quieter, less “medical” space
- Appropriate chairs to support comfort holds and flexible seating
- Visual supports- iPads, visual distractors
- PATH form in EMR-likes, dislikes, triggers, communication style
- Prep books, visual checklists, “First>Then” supports





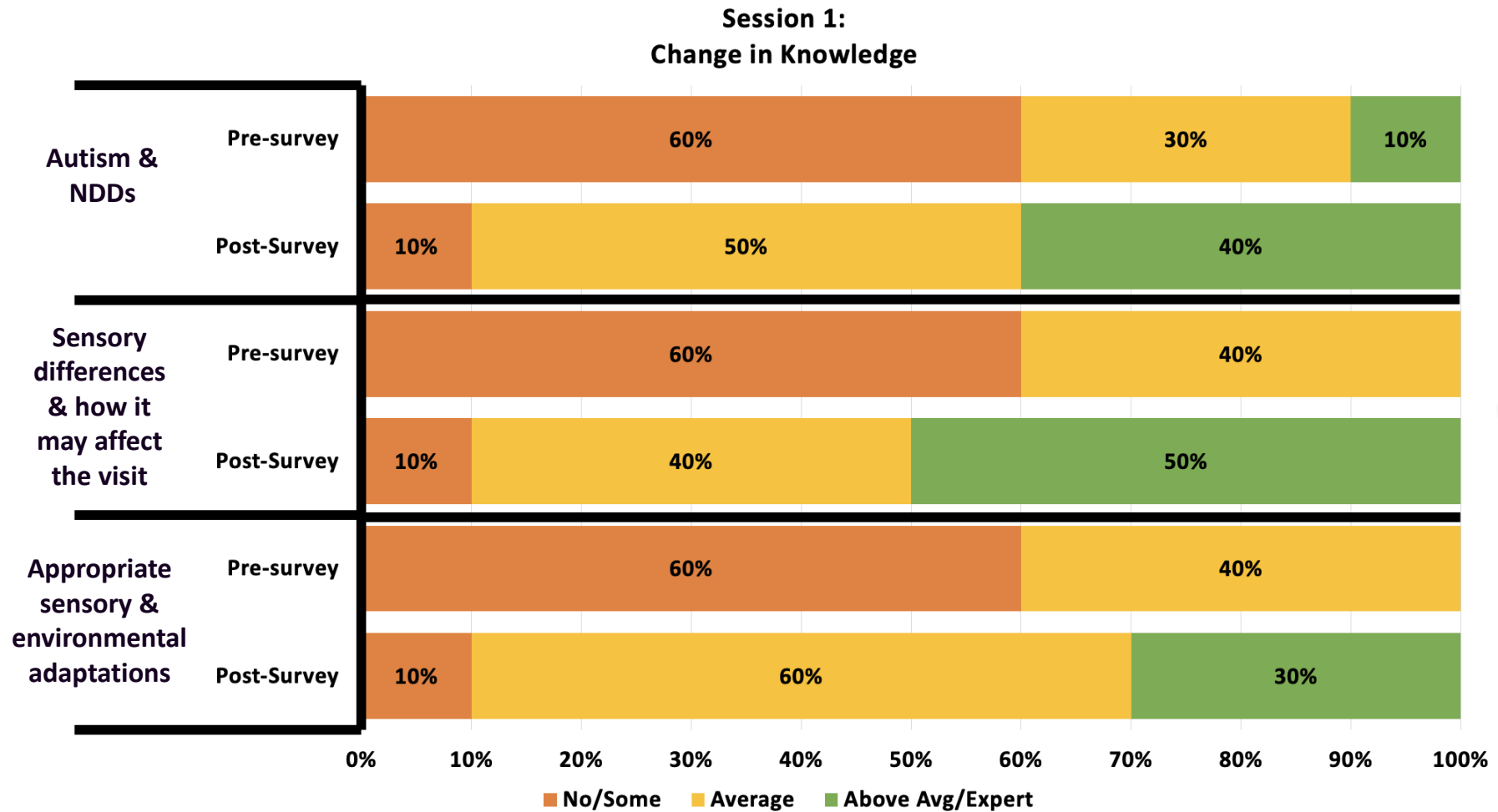
# Environmental Adaptations



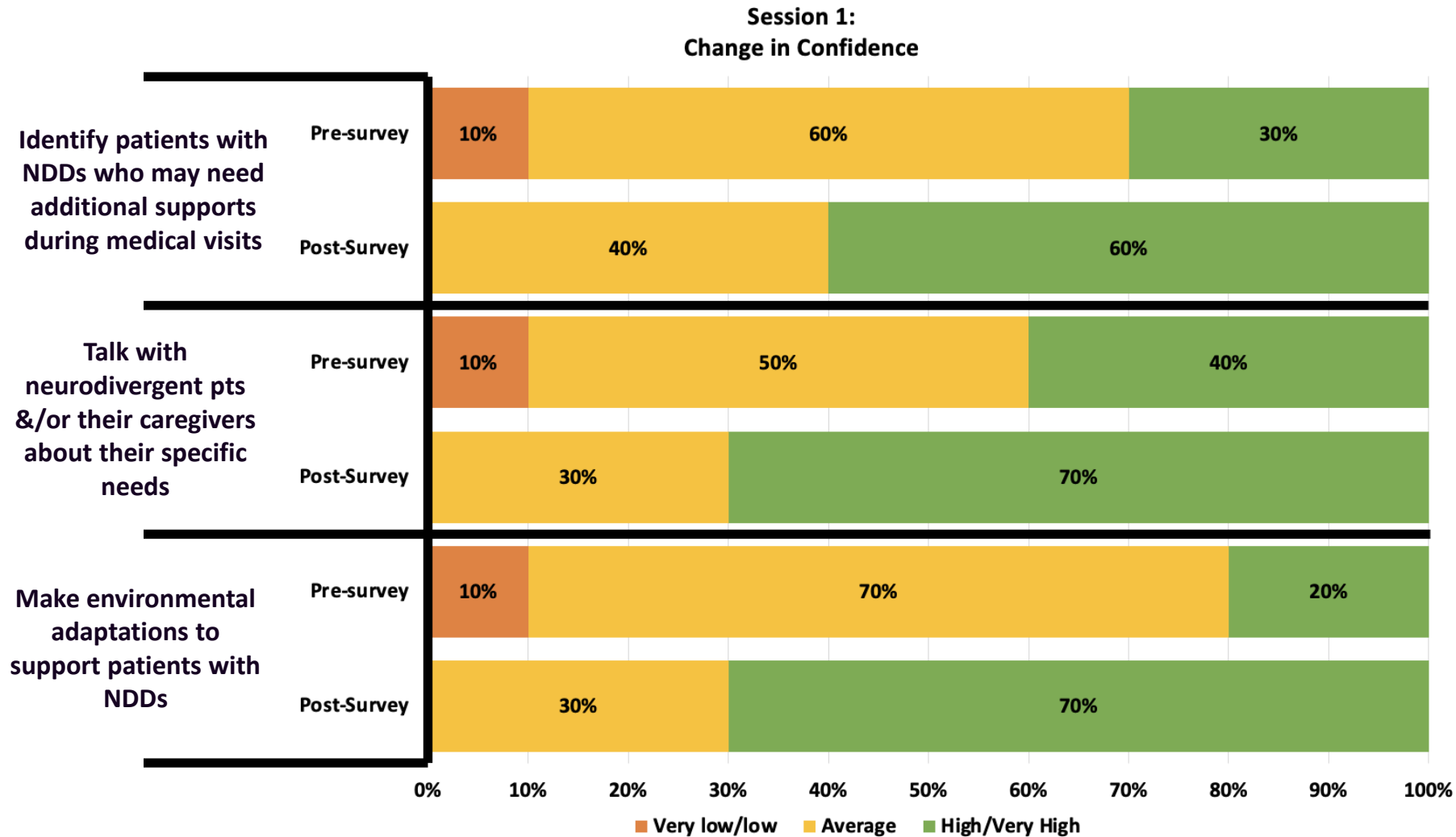
# Environmental Adaptations



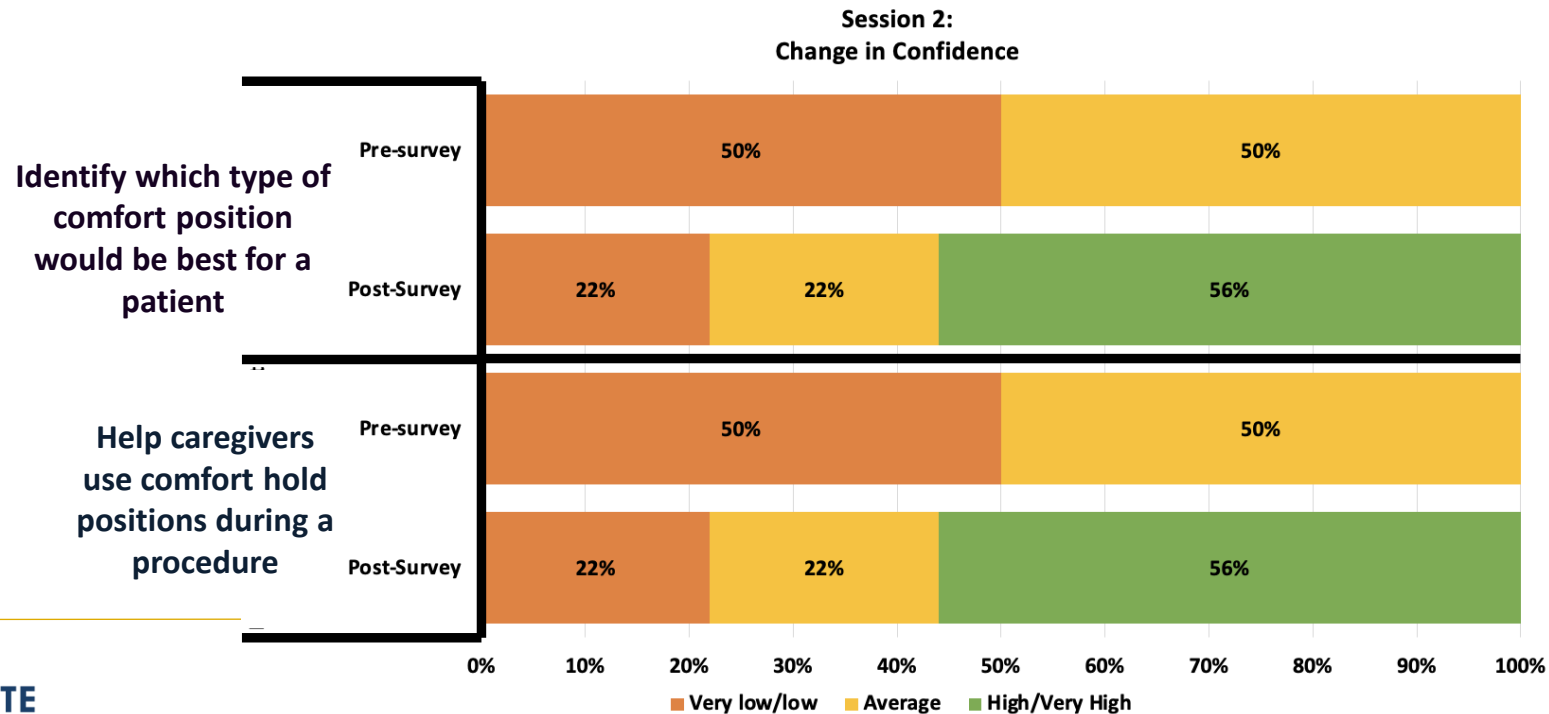
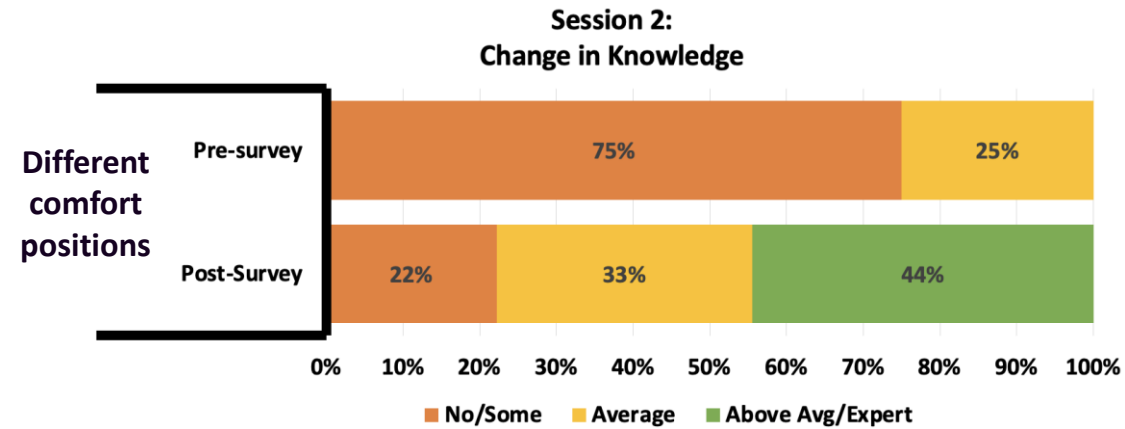
# UCDH Phlebotomy Training Pre/Post Survey Results



# UCDH Phlebotomy Training Pre/Post Survey Results



# UCDH Phlebotomy Training Pre/Post Survey Results



# PATH Vaccination Clinic at the MIND Institute

- September 2023-January 2024 the UC Davis MIND Institute offered a new seasonal clinic for both COVID-19 vaccines and flu vaccines
- We ran 8 clinics
- Our youngest patient was 2 years old and our oldest was 75 years old.
- We administered 91 total doses of COVID-19 & Flu vaccinations
- We vaccinated 33 males and 25 females at a **100% SUCCESS RATE!!**



Child Life Specialist Erin Roseborough, left, offers a sensory item to a patient at the PATH vaccine clinic in preparation for the child's vaccination.

# Children's Surgery Center: Environmental Changes & Adaptations

- Environmental improvements
  - "Yacker Tracker" decibel meter
  - Identifying private sensory friendly rooms
- Staff surveys
- Performance metrics
- Unit and service-specific training templates



# Children's Surgery Center: What's next?

- “Just in Time” Videos
- PATH Pavers Champion Training Program
- Environmental modifications to spaces on CSC floor





# About the PATH Program



# Thank you & Feedback

