

Teaching Healthcare Professionals Ways to Increase the Comfort of Patients with Developmental Disabilities

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Funding Disclaimer



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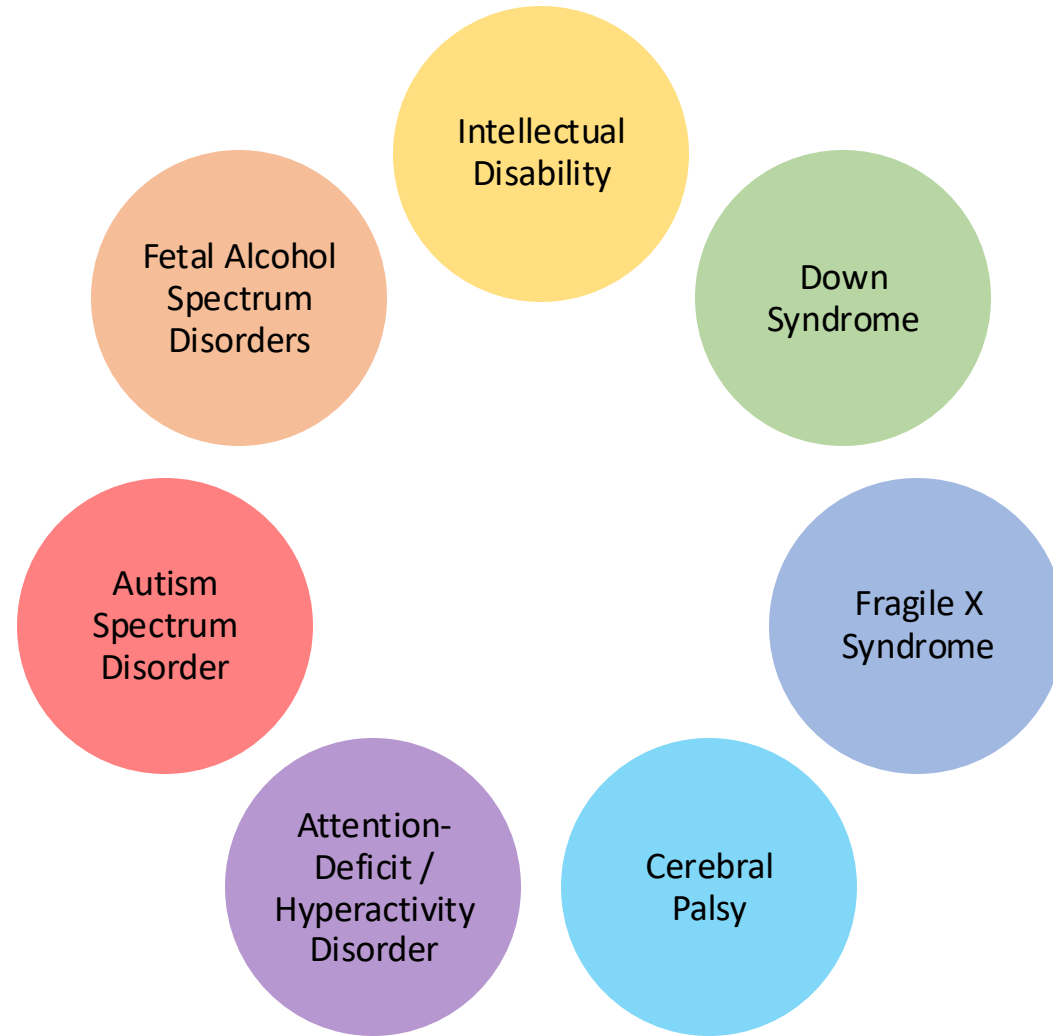
Learning Objectives

Describe health care experiences of people diagnosed with Developmental Disabilities (DD)

Discuss research to improve health outcomes for people with DD

Describe our training to teach healthcare professionals to use behavioral interventions to increase the comfort of patients with DD during physical examinations

Developmental Disabilities



People with DD Experience Health Disparities

Increased risk of:

Obesity

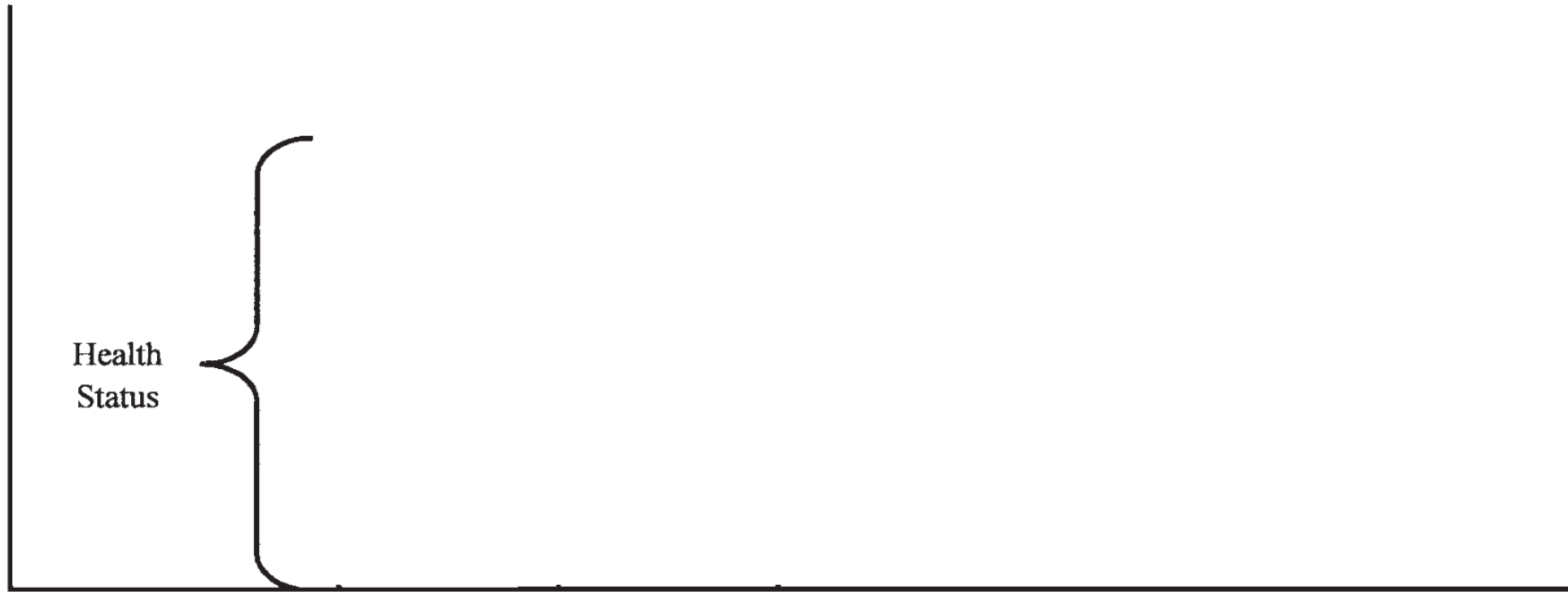
Diabetes

Hypertension


Cardiovascular
disease

Cancer

WHY do People with DD Experience Health Disparities?



WHY do People with DD Experience Health Disparities?



Genetics Biology that contributes to the disability also contributes to poor health


Social Circumstances Low socio-economic status

Environment Conditions

Health Promotion

Medical Care Access

WHY do People with DD Experience Health Disparities?



Genetics Biology that contributes to the disability also contributes to poor health

Social Circumstances Low socio-economic status, inadequate caregiver attention to medical needs

Environment Conditions Exposure to environmental toxins

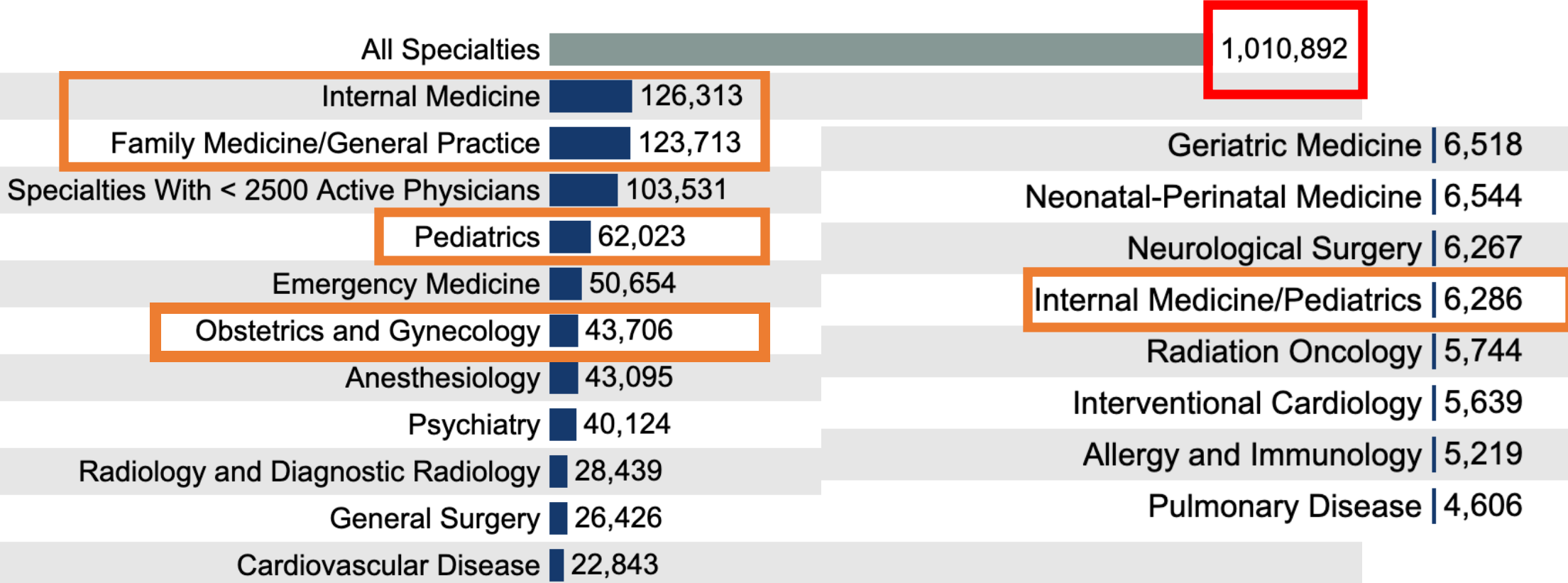
Health Promotion Inadequate knowledge of behaviors to promote health

Medical Care Access Inadequate quality of health care

Reasons People with DD Experience Lower Quality Health Care

Inadequate quality of health care

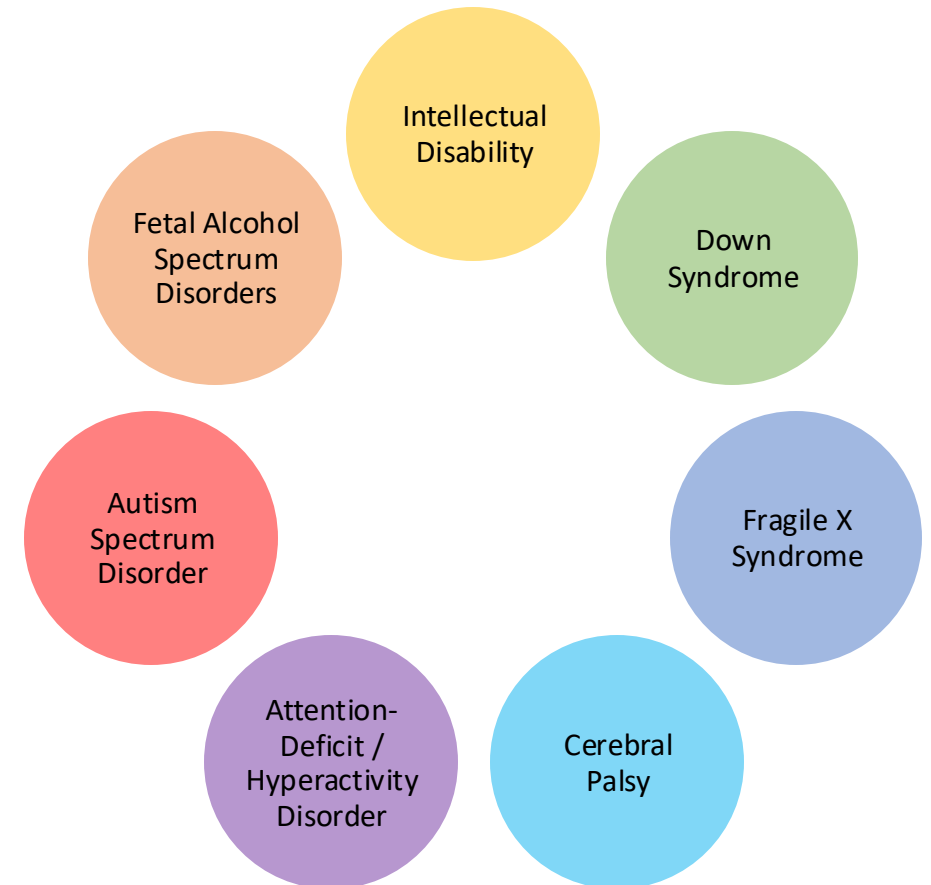
There are not very many physicians available to provide health care.



Developmental Disabilities are Prevalent

8.56% of children in US in 2021

6 million children



Reasons People with DD Experience Lower Quality Health Care

Training to accommodate people with DD appears to be uncommon

Healthcare professionals feel limited in their ability to medically care for patients with DD

This makes them feel unqualified or even UNWILLING to medically care for patients with DD



Reasons People with DD Experience Lower Quality Health Care

Training to accommodate people with DD appears to be uncommon

Healthcare students and professionals have been calling for more training to prepare them to medically care for patients with DD



Reasons People with DD Experience Lower Quality Health Care

Training to accommodate people with DD appears to be uncommon

Lee et al. (2023) studied the prevalence of training to medically care for people with disabilities

- Surveyed all 196 US medical schools
- Only 14 schools responded that they provided DD-centered training



Reasons People with DD Experience Lower Quality Health Care

Training to accommodate people with DD appears to be uncommon

Only ~16% of participants in our research reported having previous training to accommodate patients with DD



Problem

Many People with DD Experience Health Disparities...

...in part, due to Inadequate Quality of Health Care...

...which likely occurs because Training to Medically Care for
Patients with DD is Uncommon / Incomplete

Question

If a Patient has Trouble Completing a Med Exam,

What are Healthcare Professionals Trained to Do?

RESTRAINT

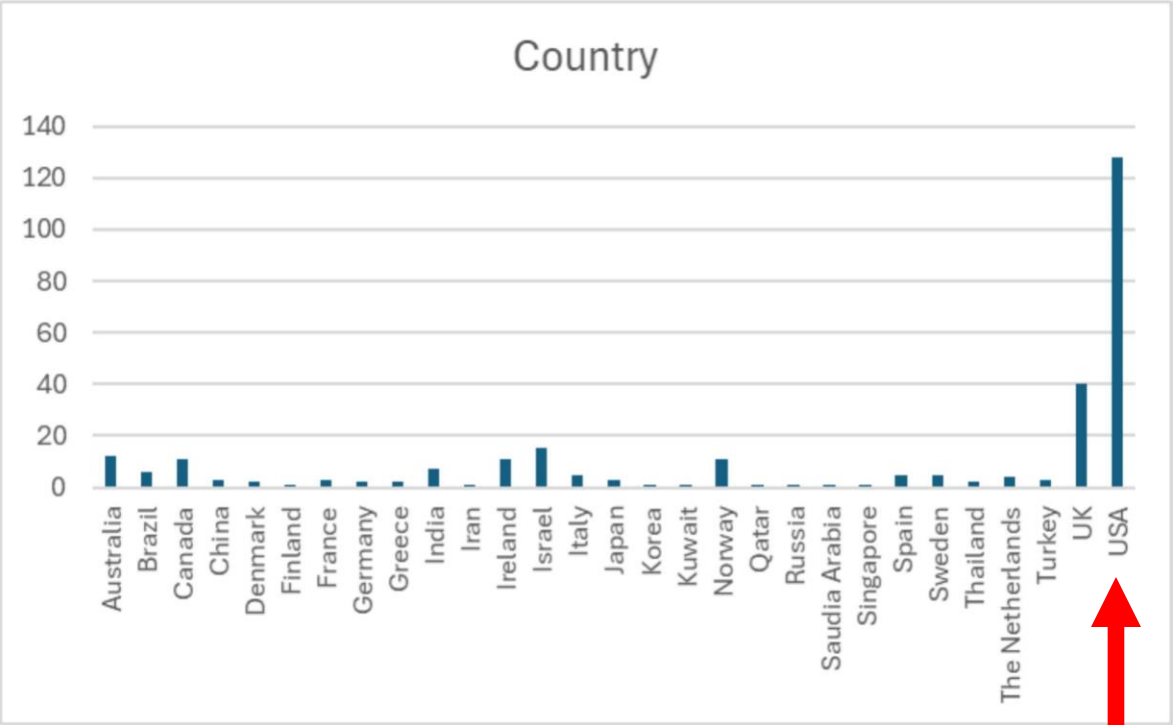
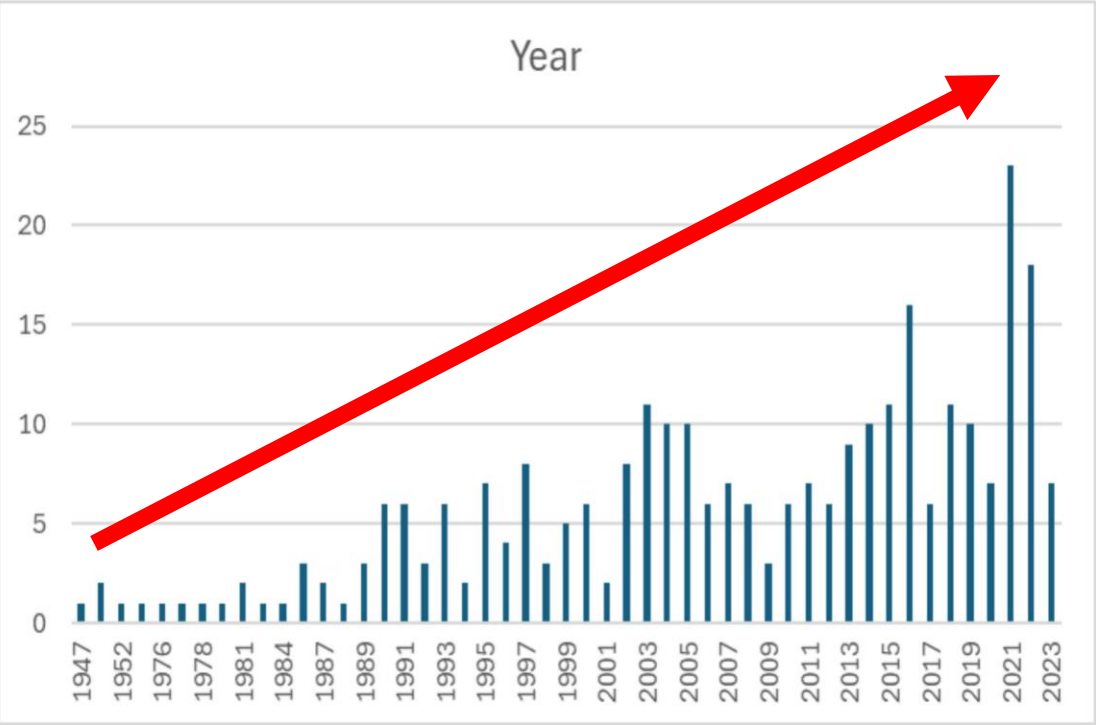
The use and prevention of procedural restraint in children – A scoping review

[Marthe Karolina Østberg](#)  ^{a,b}  · [Peter Forde Hougaard](#) ^{a,b}  · [Nina Margrethe Kynø](#) ^{b,c}  · [Edel Jannecke Svendsen](#) ^{b,d} 

Table 1
Eligibility criteria using the PCC framework (JBI).

Inclusion criteria	
Population	Children (1–18 years)
Concept	Restraint during medical procedures Restraint during anesthesia induction Restraint during mild sedation
Context	Hospitals Medical clinics Dental clinics

Identified 288 Studies



Field

Dentistry	113
Healthcare personnel	2
Medicine	65
Nursing	69
Psychology	26
Radiology	8
Other	5

Definition: “[Procedures that]...contained an element of force to ensure the immobilization of the child”

“For disruptive behavior...” (n = 17 studies)

“For the anxious and stressed child...” (n = 45)

“To safely perform the procedure and not cause harm...” (n = 48)

Restraint was Used...

Passively, using devices

Actively, with help from a caregiver or assistant

Pharmacologically, via sedation

“...[Authors] did not identify any studies
in which the main aim was to show
prevention or reduction of restraint...”

“Children with autism...had a challenging time complying with [medical] procedures...[and] seemed to be more often restrained due to procedural fear and/or inability to rationalize events.”

Holding and restraining children for clinical procedures within an acute care setting: an ethical consideration of the evidence

Lucy Bray,^{a,b} Jill Snodin^c and Bernie Carter^{b,d}

^aEvidence-based Practice Research Centre, Edge Hill University, Ormskirk, UK, ^bChildren's Nursing Research Unit, Alder Hey Children's NHS Foundation Trust, Liverpool, UK, ^cFaculty of Health and Social Care, Edge Hill University, Ormskirk, UK, ^dUniversity of Central Lancashire, Preston, UK

“The high incidence of holding
suggests that this is a routine
element of practice [for healthcare
professionals]...”

“...holding a child is judged as a ‘reasonable harm’
to... [complete] a clinical procedure or [prevent]
treatment interference.”

“Only one paper...consulted directly with children [about their experience with restraint]...

[Children in] Snyder (2004) reported that [restraint] caused anger, resistance and discomfort.”

Restraint Summary

Healthcare professionals are trained to use restraint

Restraint considered a “reasonable harm”

Few researchers are studying alternatives to restraint

Restraint may cause children to become angry, resistant, and uncomfortable

Expanded Problem

Many People with DD Experience Health Disparities...

...in part, due to Inadequate Quality of Health Care...

...which likely occurs because Training to Medically Care for Patients with DD is Uncommon / Incomplete

...and healthcare professionals use Restraint, which seems to upset patients, and could Cause them to Avoid Health Care...

...which could Increase Health Disparities

How Are we Trying to Help?

Project Goals

Teach Healthcare Professionals New Ways to Increase Comfort of Patients with DD

Ensure the Training is Effective and then
Make Training Easy for Others to Use

Expand Training for Healthcare Professionals

Survey Patients BEFORE THE VISIT To Discover Their Abilities And Preferences

New Patient Information Form

Thank you for completing this form. For the patient's first visit, **please bring the items you list in questions 6 and 7.** The doctor will collect these items from you at the beginning of the visit and use them to increase the patient's comfort and encourage their participation.

Patient Name: _____ Date: _____

1. How does the patient communicate with others?

<input type="checkbox"/> Does not communicate	<input type="checkbox"/> Gestures	<input type="checkbox"/> Sign language
<input type="checkbox"/> Picture exchange	<input type="checkbox"/> Voice output device	<input type="checkbox"/> Word approximations
<input type="checkbox"/> Single words	<input type="checkbox"/> 2-3-word sentences	<input type="checkbox"/> Full sentences

2. Can they indicate "yes" to respond to a question? ☐ Yes ☐ No
How do they indicate? _____

3. Can they indicate "no" to respond to a question? ☐ Yes ☐ No
How do they indicate? _____

4. Can they indicate their preference when asked "do you want a break?" ☐ Yes ☐ No
How do they indicate? _____

5. Please list their preferred conversation topics: _____

6. Please list and bring one or two items that could distract them during a doctor's visit:

7. Please list and bring one item that they like very much (e.g., a favorite food, electronic item or toy) that could encourage their participation during a doctor's visit:

8. Are there any exam procedures that they may be anxious or fearful of? ☐ Yes ☐ No

What procedures? _____

How can you tell when they are anxious or fearful? _____

9. Please describe any sounds, lights, or other things that they are sensitive to:

10. Will they go into the doctor's exam room? ☐ Yes ☐ No

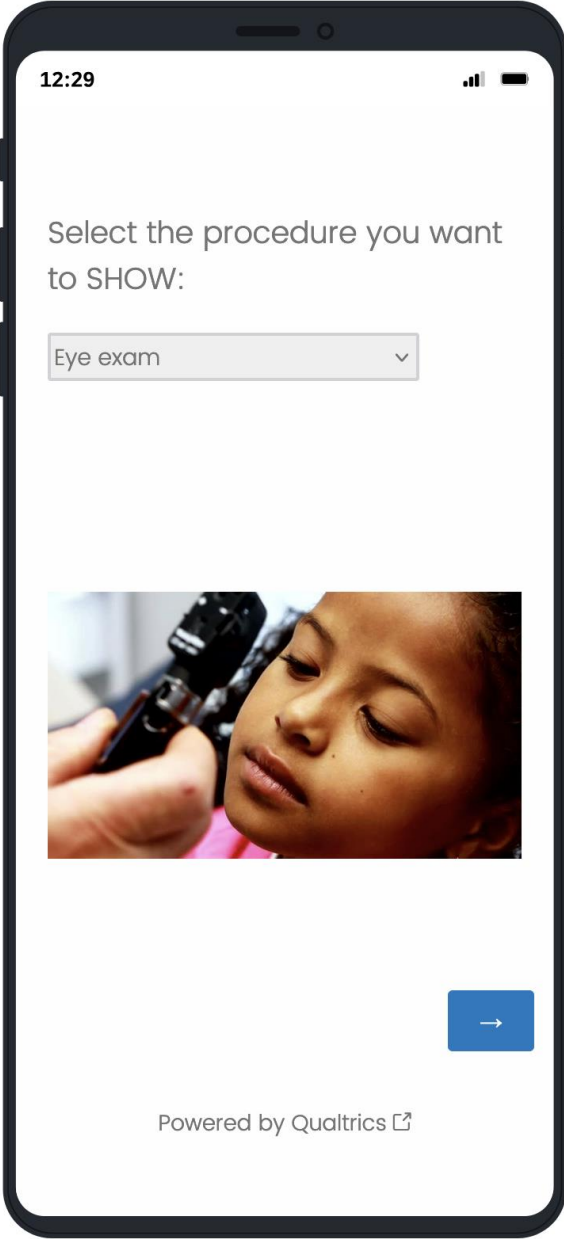
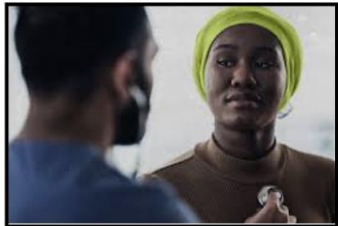
Expand Training for Healthcare Professionals

Use Visual Supports To Help Patients Understand What Procedure Is Happening Next



Expand Training for Healthcare Professionals

Use Visual Supports To Help Patients Understand What Procedure Is Happening



Expand Training for Healthcare Professionals

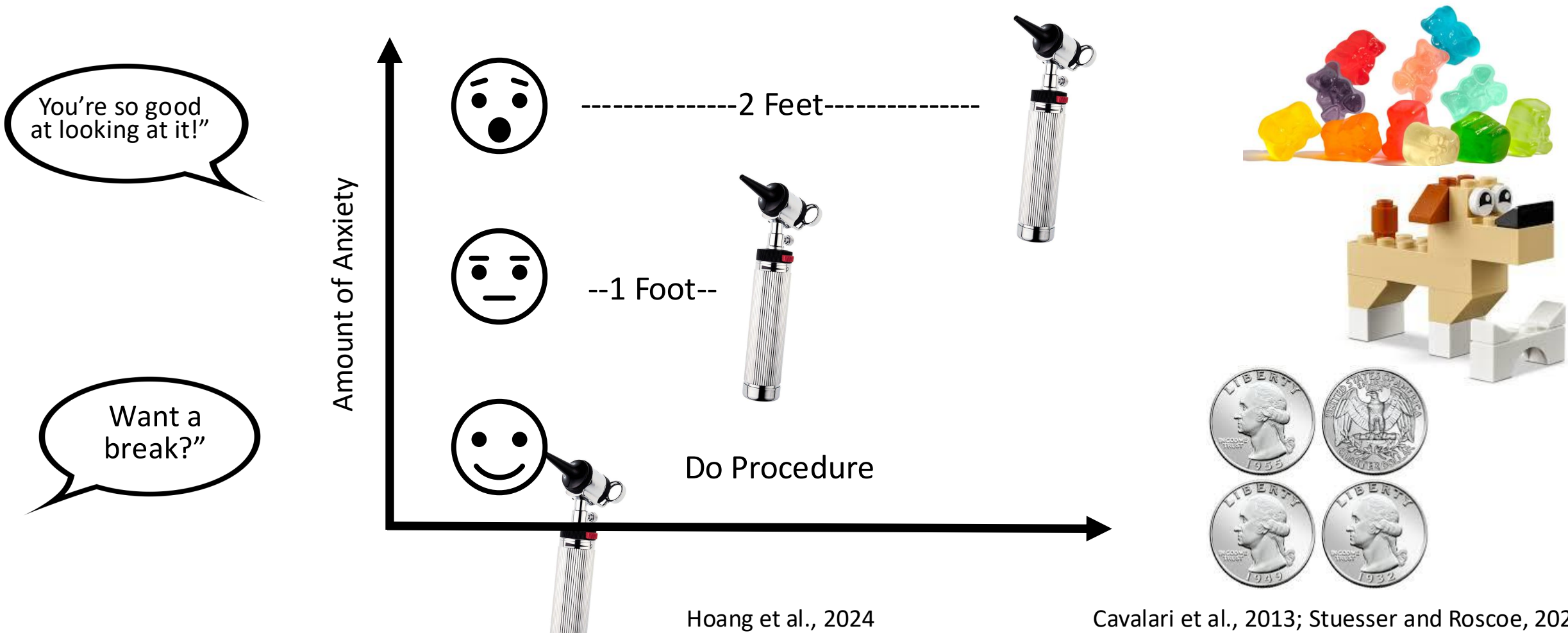
Offer Patients Brief Breaks

“We’re done with that. Want a break?”



Expand Training for Healthcare Professionals

Gradually Expose Patients To Procedures They Dislike And Offer Nice Things If They Choose To Continue



Expand Training for Healthcare Professionals

We Give Healthcare Professionals A Tool To Help Them Remember What They Learned

Behavior Analysis for Inclusive Physical Exams

1

Funding Disclaimer:



Download Materials
or Contact Us:



HOW TO PRACTICE After the Training



Physical Examiners: Use this Booklet to Help You



Patients: Choose "ACT AS PATIENT" on Training Site



Evaluators: Choose "EVALUATE" on Training Site

Training Site:



Start of Exam

2

Greet
Patient

Introduce
Yourself

Explain
Purpose

Give
Distractor

Build Rapport
During Real Visits



Expand Training for Healthcare Professionals

We Give Healthcare Professionals A Tool To Help Them Remember What They Learned

Before Each Procedure... ³

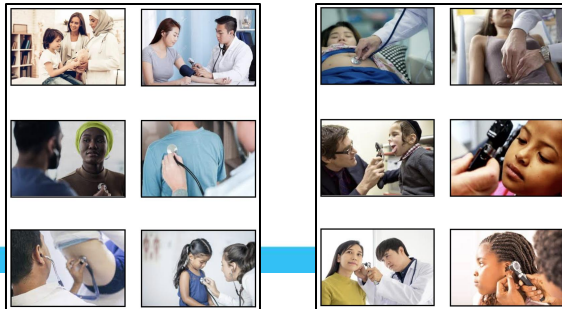
Tell what
you will do



Show what
you will do
using visual



Do
Procedure



If Patient Cooperates ⁴⁻⁵

After
Procedure:



Praise or
Thanks



Offer Break

You're a pro
at that!

Want a
break?"

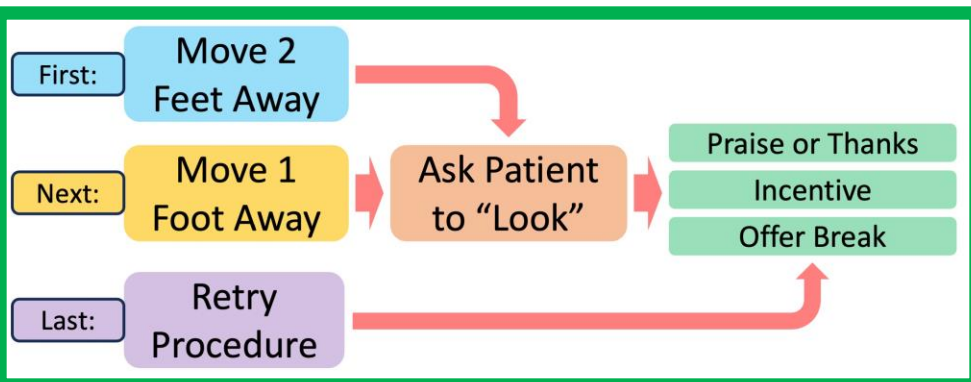
Expand Training for Healthcare Professionals

We Give Healthcare Professionals A Tool To Help Them Remember What They Learned

If Patient Doesn't Cooperate... 4-5

Break Down the Procedure: Ask patient to “look” at the medical instrument or visual support from 2 feet away, then from 1 foot away, then retry procedure. *Remember to give praise, incentive, and offer a break after each step.*

Move on if they are uncooperative during any step.



End of Exam 6

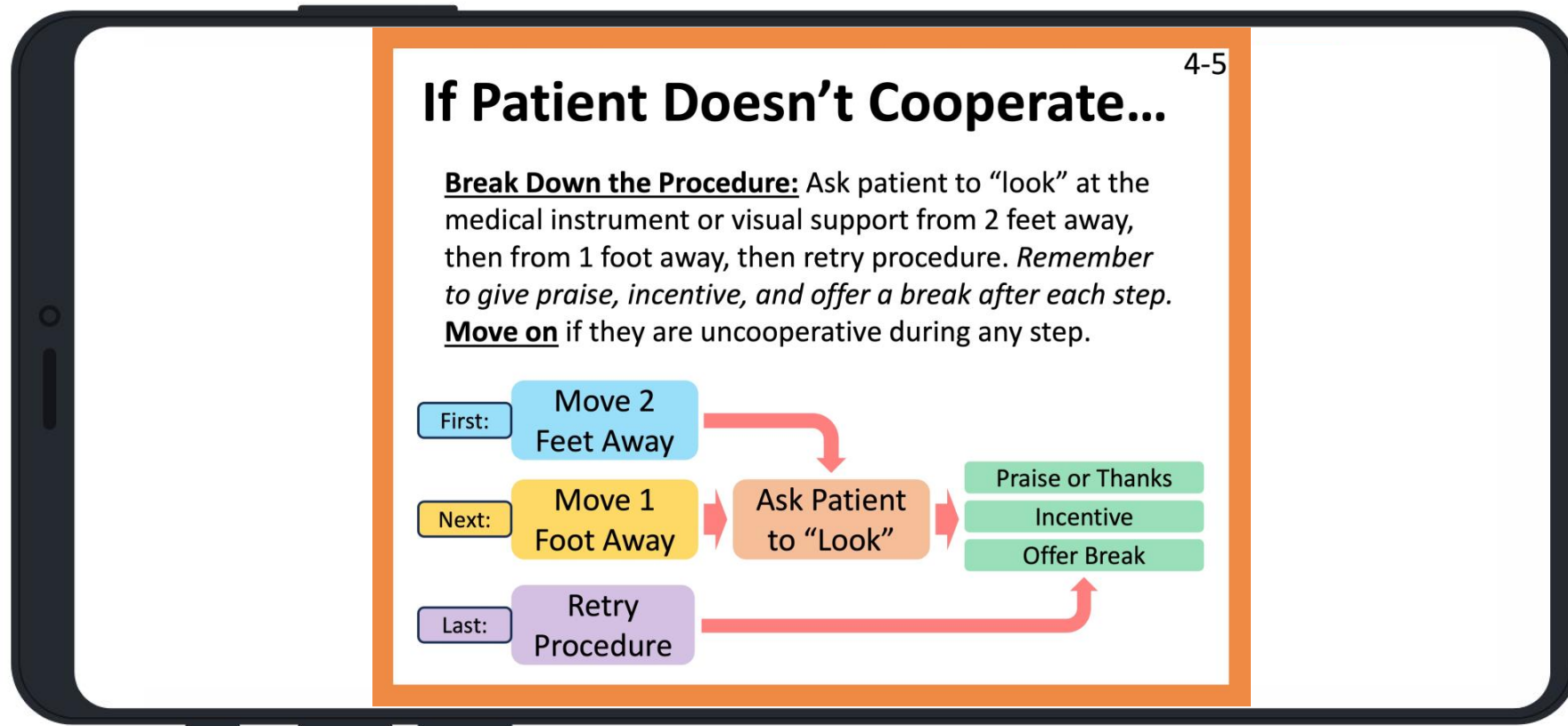
Thank Patient

Give More Incentives

Say Goodbye

Expand Training for Healthcare Professionals

We Give Healthcare Professionals A Tool To Help Them Remember What They Learned



Training Results

97.4% of participants expressed increased **Confidence to Help Patients with DD**

94% demonstrated that they could effectively **Use the Skills They Learned**

Other Interesting Training Features

Takes about **1 hour**

(important because med students and physicians are busy)

Participants **watch a video** and then **practice the skills with each other**

(there is no “teacher”)

Other Interesting Training Features

Lots of positive feedback

It was a great and helpful introduction to working with people with disabilities! I learned a lot and overall found it very useful!

Great tips for tell-see-do and breaking down procedures.

Very informative session!

I really enjoyed the interactive portion before and after the learning so I could use what I learned in real time.

I loved the exercise and appreciated the feedback. The booklet and video were very informative!

This experience was great! It was very accessible! It was helpful to practice! Great structure!

The presentation of the material and quality of the visual supports (video and booklet) were excellent. The positive nature of the real-time feedback was very appreciated.

The live role playing really helped hammer in some of the teachings from the video.

Other Interesting Training Features

Lots of positive feedback

The booklet was a great resource and helped guide me through the exam when I needed it.

I honestly loved this training. It was relatively easy to learn and incorporate, and can have a great impact on caring for individuals with ID. I could even teach this to others.

Very solid structure to the training, interactive activities, booklets for the participants, and chances to learn. Felt comfortable the whole way through and feel much more confident. Highly recommend the training to others.

I really liked the role playing.

I liked learning different methods to have patients be cooperative and engaged.

I really appreciated the hands on learning it gave an opportunity to practice with a low amount of pressure.

It was fun and learned lots! Thank you!"

I really enjoyed this and I hope that in the future providers of patients with IDD do give out a survey that identifies the patient's method of communication and their likes/dislikes, as this method is very helpful.

Is the Training Effective?

YES! – at least, right after we train people

But, **TRUE EFFECTIVENESS** occurs when a participant can
remember the skills over time, AND
use the skills with real patients

We are currently studying how often these things happen

Making the Training Easy to Use

There is no “teacher”

The training video first teaches participants ways to increase patient comfort

Then video teaches participants how to practice the “ways” with each other

Then participants form small groups facilitate practice with each other

The video and the participants are the teachers

Making the Training Easy to Use

Training Modalities:

We designed this training to be easy to implement and highly scalable. Consider the following modalities and expand each to learn more.

I am an individual who wants this training in-person, with practice.



I am an individual who wants this training via video-conferencing, with practice.



I am an individual who wants this training, but I do not want to practice.



I would like UHCL staff to train my group of three or more people.



I, myself, would like to train my group of three or more people.



Making the Training Easy to Use

I am an individual who wants this training, but I do not want to practice.



View the Training without Practicing

- If you do not wish to practice using the behavioral interventions, follow the steps below to view the training and complete a brief knowledge evaluation.
 - This training takes approximately 30 minutes to complete.
 - Please follow the video instructions to complete the pre- and post-training surveys of confidence and knowledge. These surveys provide valuable data that we use to improve the training.
 - [Click here](#) to view the training.



How Can YOU Use This Information?

If you are a Healthcare Professional...

DO OUR FREE TRAINING!



How Can YOU Use This Information?

If you're an **Allied Healthcare Professional**...

Understand the interventions

Tell healthcare professionals about interventions and, perhaps, help them use them

Tell healthcare professionals and caregivers about our FREE training



How Can YOU Use This Information?

If you're a Caregiver of a Person with DD, or a Self-Advocate...

You are in a **perfect** position to help

Some of the interventions **rely on you** (distraction item and incentives)

You **know the patient** and can **directly advise the healthcare professional** to use the interventions



How Can YOU Use This Information?

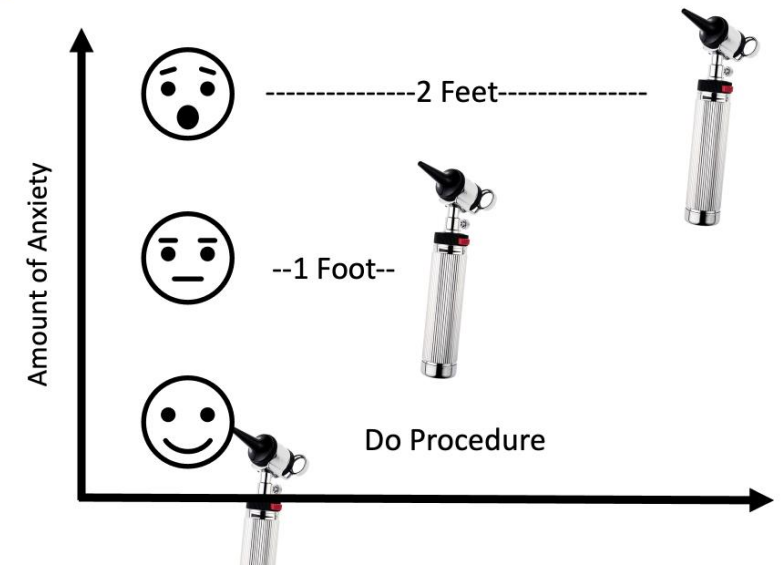
If you're a **Caregiver of a Person with DD**, or a **Self-Advocate**...

Bring distraction and incentive items to medical visits and tell healthcare pro when and how to use them



Ask healthcare professional to **offer frequent breaks**

Watch training to **learn how to use gradual exposure** so you can tell and show healthcare professional how





How Can YOU Use This Information?

If you're a Caregiver of a Person with DD, or a Self-Advocate...

If needed, **print a copy of the visual support** and let your healthcare pro have it so they can use tell-show-do

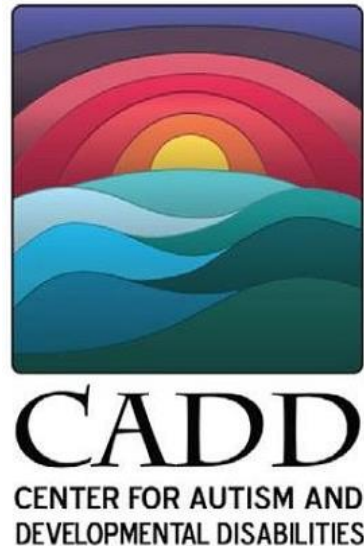


If the healthcare professional is willing to do the things you showed them, and if the interventions help them do their job better, **please link them to our training**

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Thank you!



Instructions to do the training, contact info, materials
<https://www.uhcl.edu/autism-center/baipe>

1. What has your experience been with healthcare providers?
2. What tools have you found that work for your child in a healthcare situation?
3. What have you experienced that you would like to see changed?
4. What, if anything, would you like to share with your healthcare provider after today's presentation?
5. What would you like to change, if anything, about the way you prepare yourself to take your child to an appointment?
6. What would you like to change, if anything, about the way you prepare your child to take them to an appointment?