

Improving access to routine medical procedures during COVID: Addressing fear, phobia and trauma

*The Arc of New Jersey's
31st Annual Conference
on Medical Care for Persons with
Intellectual and Developmental Disabilities
June 10, 2021*

Wendy Aita, PhD

Assistant Professor

Co-director and Behavioral Health Lead

RISN Center

Rowan School of Osteopathic Medicine

Rowan Integrated Special Needs (RISN) Center



Provides South Jersey with its first special needs primary care facility with embedded behavioral health focused on care-coordination of integral services for the special needs population

Our Population Includes:

- Patients with chronic conditions originating in childhood
- Patients diagnosed with Autism
- Patients that have an intellectual disability
- Some may not use words to communicate
- Some may have challenging behaviors
- Some may have sensory challenges, fears, or trauma that make it hard to access routine medical procedures

Michele Pich, MA, MS

Assistant Director, Shreiber Family Pet Therapy Program

Adjunct Professor, Law & Justice Studies

Research Associate to the Dean, College of Humanities
& Social Sciences

Rowan University



Provides animal-assisted therapy (AAT) and other animal-assisted interventions (AAI) through interaction with certified therapy animals and their AAT providers during visits with Rowan University's diverse student body, faculty, staff, and surrounding community, to decrease stress and anxiety, and increase quality of life to recipients.

Disclosure

The authors of this presentation have no actual or perceived conflicts of interest to report in relation to this presentation, and are receiving no financial compensation for this presentation.

Objectives

As a result of this lecture, the participant will be able to:

1. Identify barriers to routine medical procedures for individuals with IDD
2. Understand impact of anxiety, fear, and previous medical trauma as barriers to healthcare access
3. Learn assessment and procedural skills to decrease fear and anxiety for vaccinations and blood draws

Intellectual Disability

Intellectual disability (ID) is characterized by significant limitations in intellectual functioning and adaptive behavior which originates before age of 18. Intellectual functioning impacts areas such as learning, reasoning, and problem-solving. Adaptive behavior is the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives.

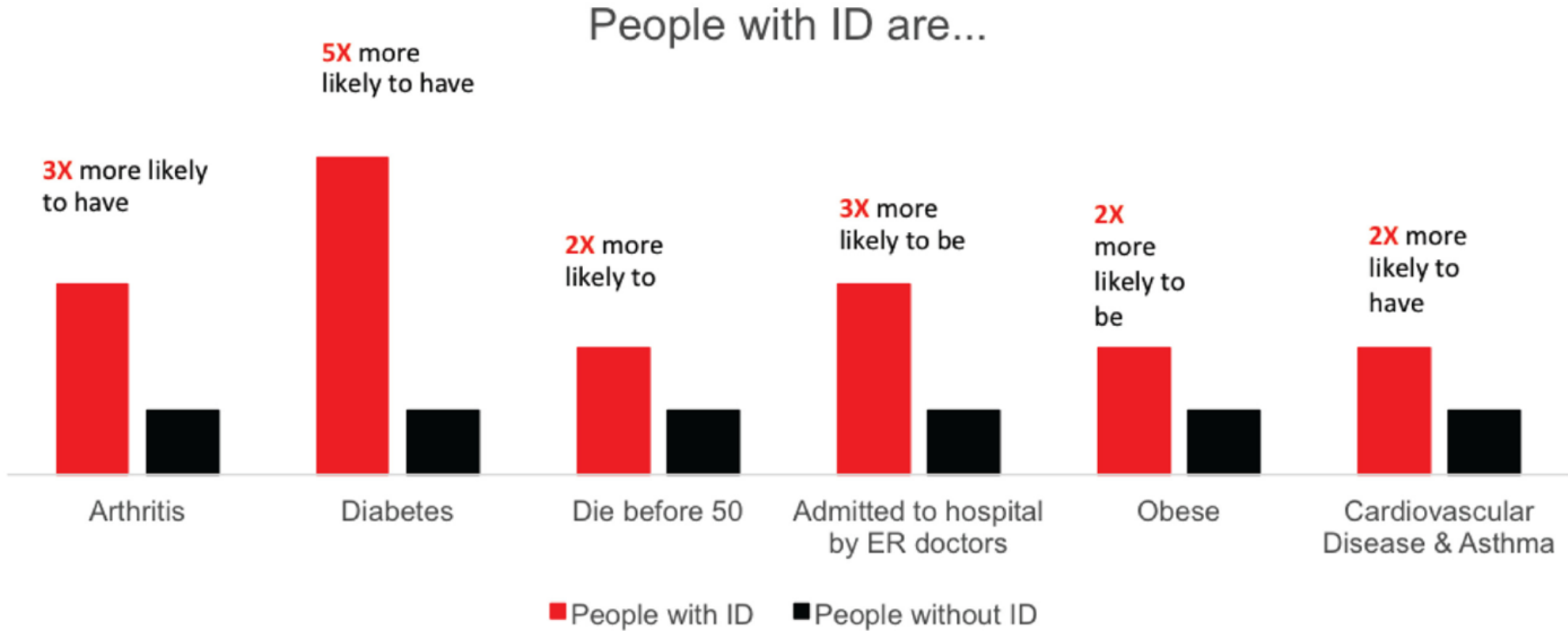
American Association on Intellectual and Developmental Disabilities (AAIDD)

Health Disparities

- Preventable health inequities or avoidable differences in healthcare between different groups of people
- Experienced by vulnerable populations as a result of poorer access to quality healthcare services
- People with ID experience dramatically higher rates of preventable health issues than peers without ID
 - 4x higher preventable mortality rates
 - higher rates chronic conditions
 - 3X higher rates of hospitalization
 - difficulty accessing care



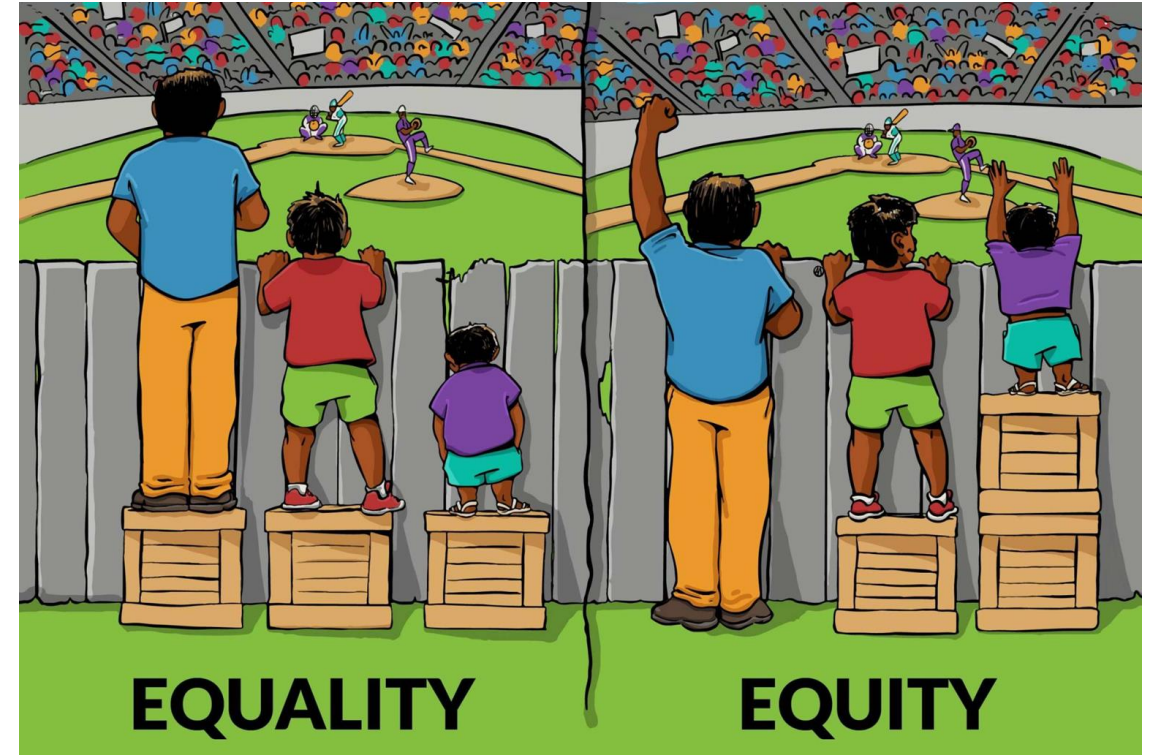
Health Disparities



Inclusive Health

- Address barriers impacting participation in mainstream healthcare
- Build sustainable inclusive policies
- Result in improved health outcomes for people with ID

Everyone should not have the same resources, but instead have the necessary resources to achieve optimal health outcomes.



Barriers

- **Physical** (building/equipment) - structural components that block mobility



Barriers

- Physical (building/equipment)
- **Policy** - the lack of enforcement of existing laws regarding access to health, access to comprehensive insurance

Barriers

- Physical (building/equipment)
- Policy
- **Attitudinal** - misconceptions, stereotyping, prejudice

Barriers

- Physical (building/equipment)
- Policy
- Attitudinal
- **Communication** - hearing or visual impairments, not using assistive devices, technical language

Barriers

- Physical (building/equipment)
- Policy
- Attitudinal
- Communication
- **Social** - employment, education, income, exposure to violence

Barriers

- Physical (building/equipment)
- Policy
- Attitudinal
- Communication
- Social
- **Inadequate Provider Knowledge**

Source: CDC <https://www.cdc.gov/ncbddd/disabilityandhealth/disability-barriers.html>

Barriers

- Physical (building/equipment)
- Policy
- Attitudinal
- Communication
- Social
- Inadequate Provider Knowledge
- **Emotional**
- **Behavioral**

Noncompliance basic healthcare

- Literature review shows compliance problems during relatively common medical procedures (1/3 of patients)
 - physical exams
 - dental procedures
 - pill swallowing
 - blood tests
 - EEG evaluations
 - ECG/EKG
 - With COVID - masks
- Related to fear and anxiety

Noncompliance basic healthcare

- Literature review shows compliance problems during relatively common medical procedures (1/3 of patients)
 - **dental procedures**
 - **blood tests/needles** (only 27% cooperative)

Gillis, et al. (2009)

Poor Cooperativity

- Severe intellectual disability
- Previous unpleasant healthcare experience
- Poor preparation for visit or procedure
- Combative demeanor
- Negative parental influence via anxiety

Source: Adler, et al (2018); Nelson, et al (2015, 2017)

Non-compliance with needles

- **Needle phobia** (Trypanophobia) is an extreme fear of medical procedures involving injections or hypodermic needles (3.5 to 10% of population)
- **Fear of needles** much higher than diagnosable phobia (24% parents and 63% children). Needle fears are a barrier to immunization.
- Approximately one-half of children with ASD meet criteria for at least one anxiety disorder. Of all types of anxiety disorders, specific phobia is the most common, with prevalence estimates ranging from 31% to 64%

Source: Nir, et al (2003); Taddio, et al (2012); Mayes, et al (2013)

Needle Fear

- Associated with
 - hypoxemia
 - tachycardia
 - vasovagal reactions
 - change in hormone levels
 - higher levels of perceived pain
 - avoidance of procedures requiring needles
 - Anxiety, sensory integration difficulty and previous trauma are common barriers



Source: Ballard (2019)

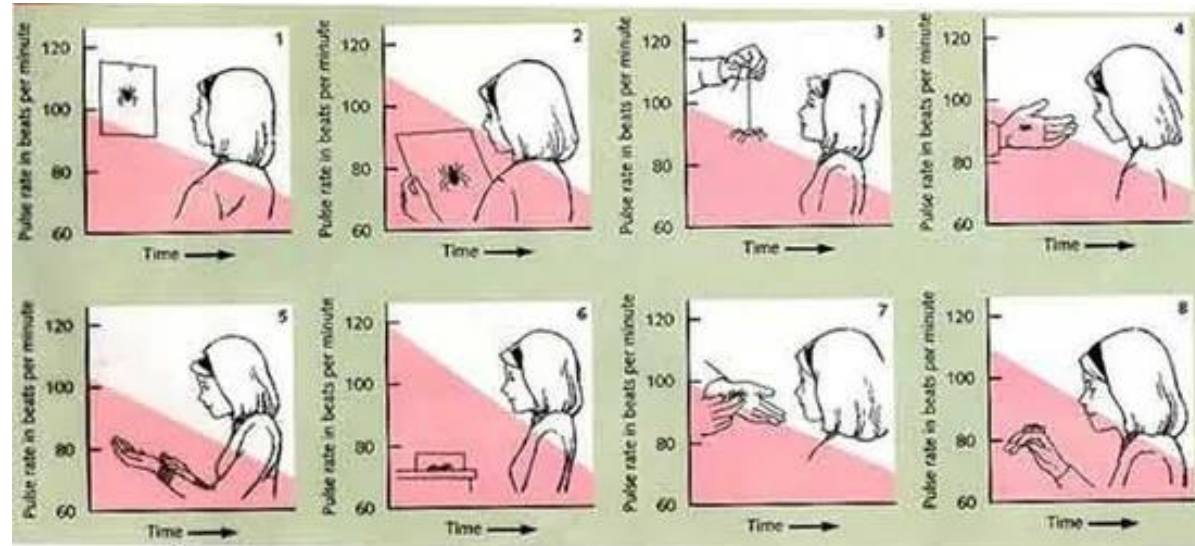
Fear Response

- For individuals with ID, fear response may look like
 - Non-compliance
 - Aggression
 - Withdrawal/escape/shut down
 - Meltdown
- Remember - behavior is communication and coping



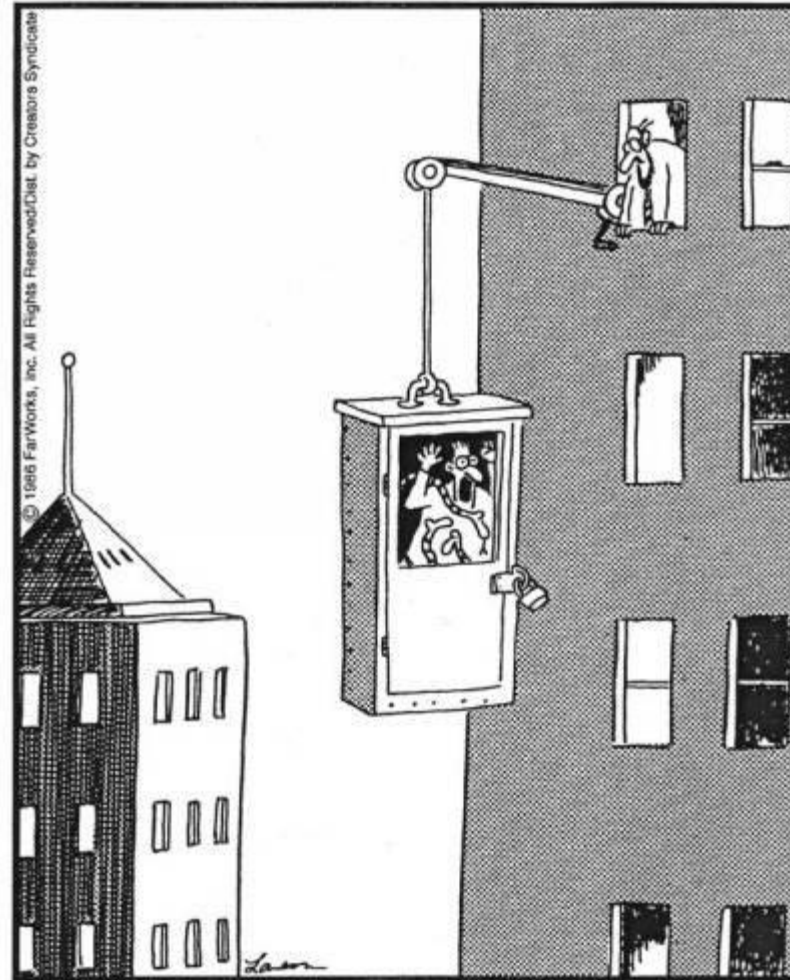
What is Desensitization

- Graduated exposure (hierarchy) combined with relaxation
- For people with ID, may be done verbally or
- Observation based on behavior and avoidance



Target is Gradual Exposure

THE FAR SIDE® BY GARY LARSON



Professor Gallagher and his controversial technique of simultaneously confronting the fear of heights, snakes, and the dark.

Goal: Reduce Medical Trauma

- Proper use of desensitization
- Reducing Anxiety
- Preparedness
- Sedation



Medical Trauma

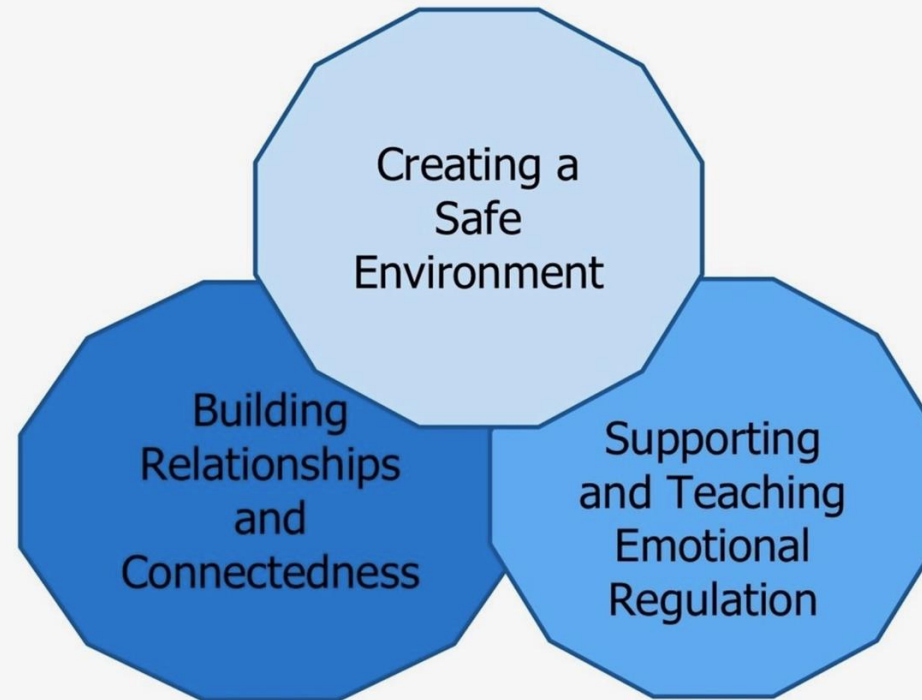
- a set of psychological and physiological responses to pain, injury, serious illness, medical procedures and frightening treatment experiences
- [Resource for Medical Professionals on Medical Trauma](#)



Source: NCTSN

Trauma Informed Care

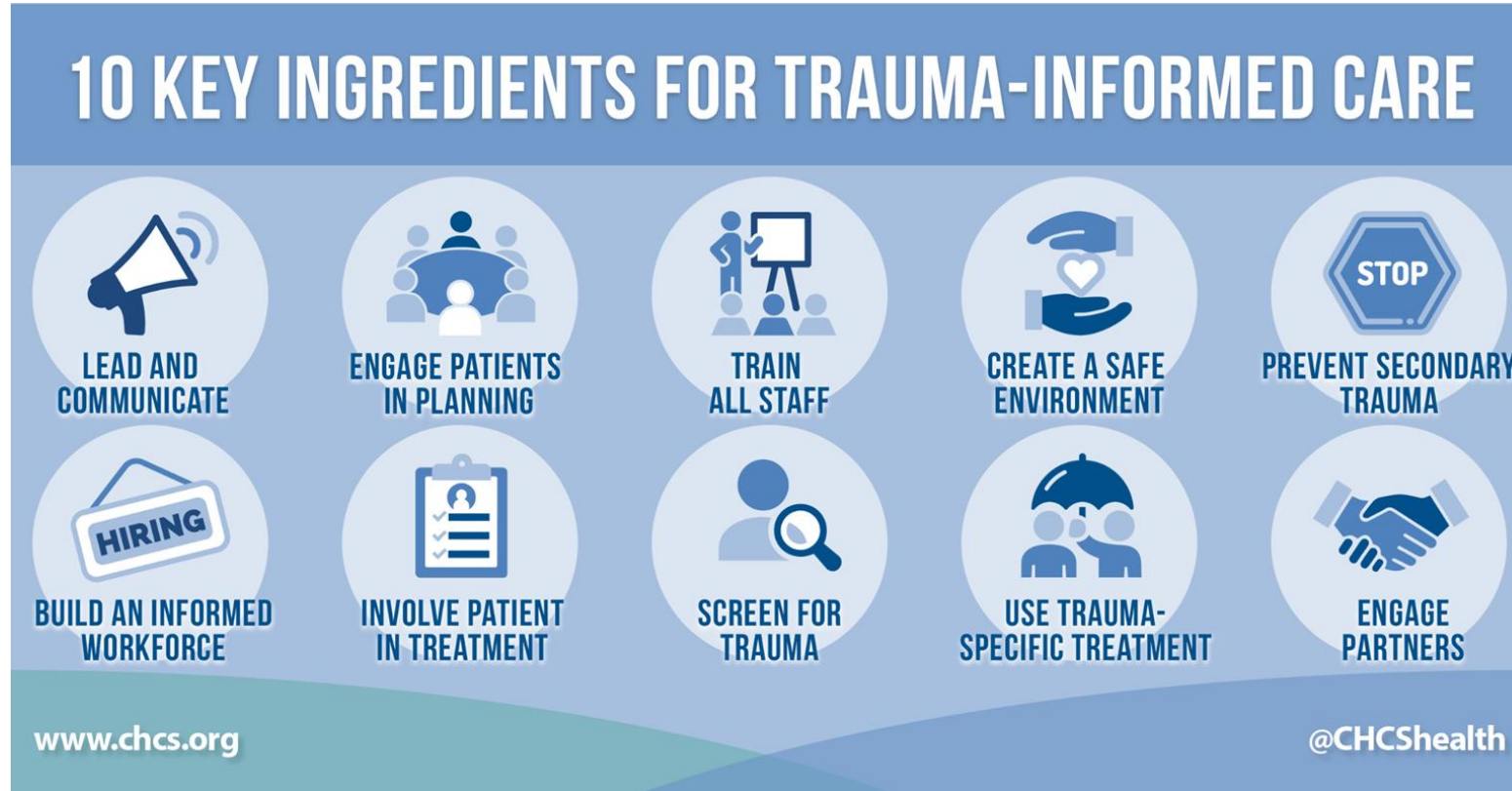
Components of Trauma-Informed Care



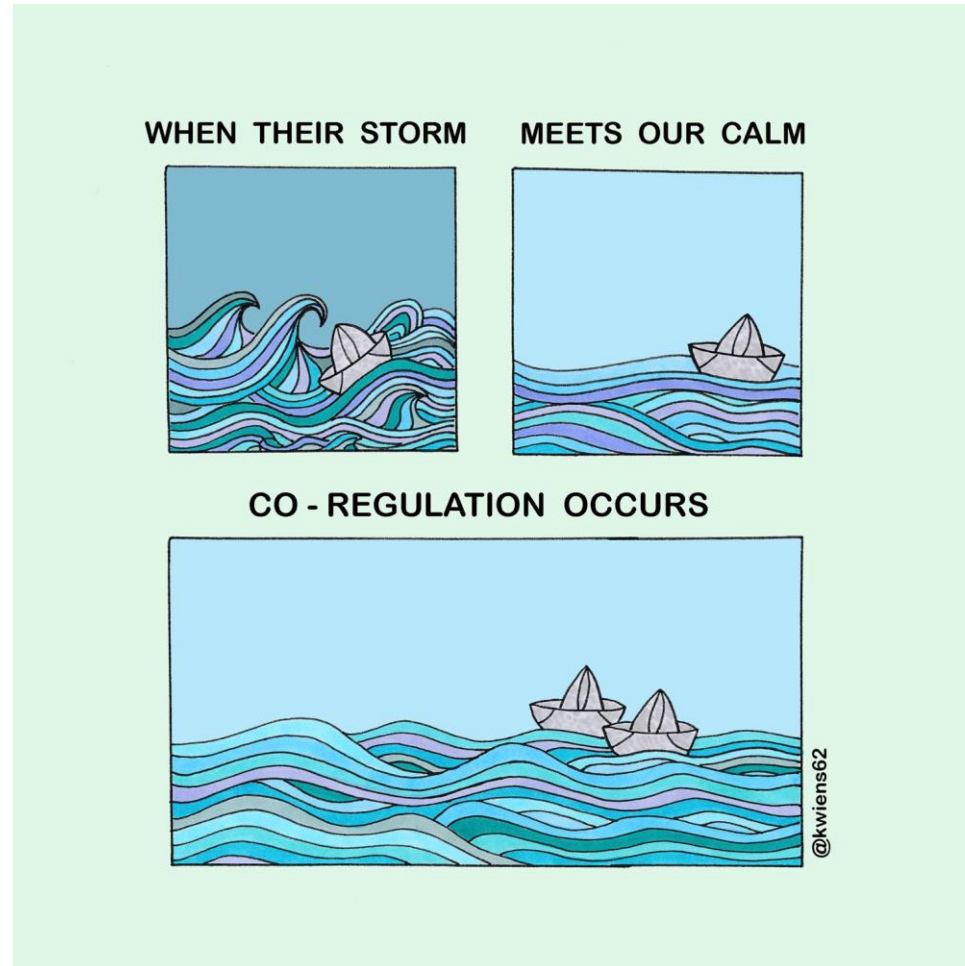
Source: Substance Abuse and Mental Health Services Administration, 2014

Source: NCTSN

Trauma Informed Care



Trauma Informed Care



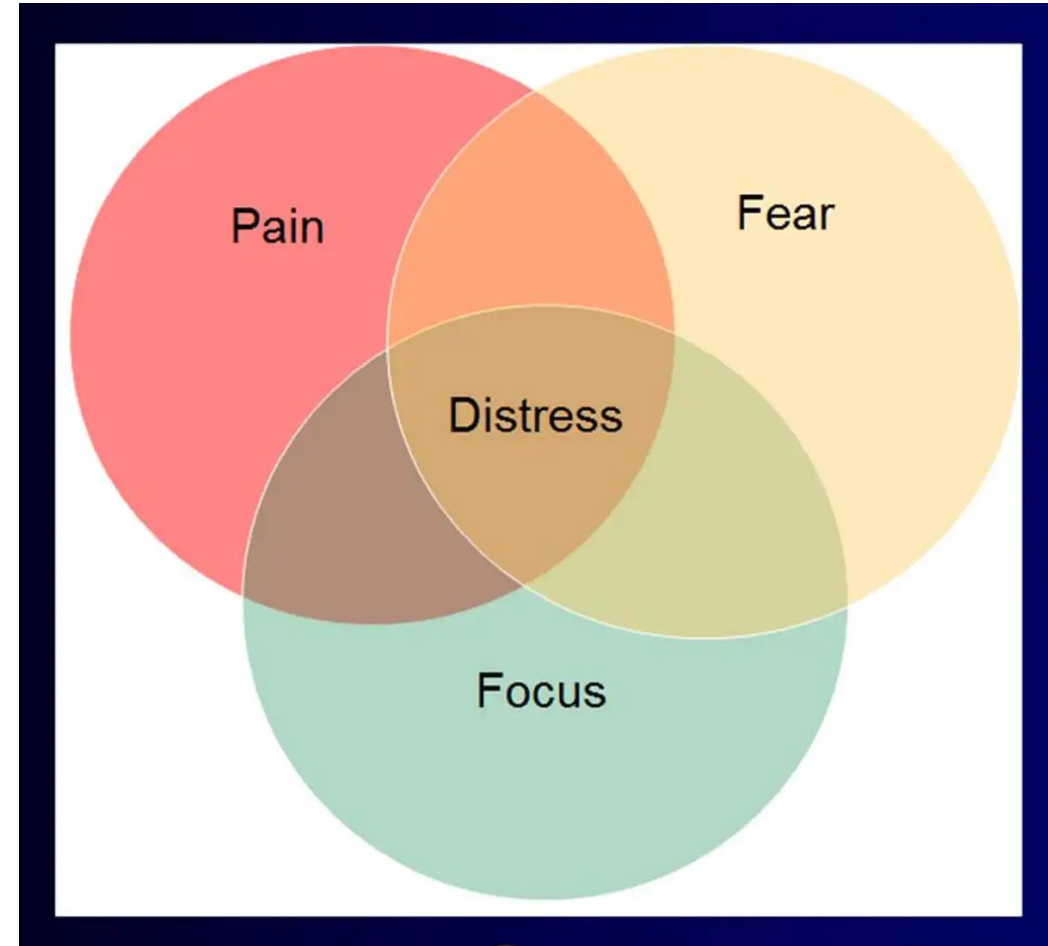
Assessment – Initial Visit

- Ask about previous experiences
 - How long ago
 - Where
 - Trauma involved (restraint/high emotions/pain)
 - Reaction
- What triggers anxiety or stress
- Coping strategies
 - identify a patient's strengths, communication, and comfort
- Make a plan

Three Prong Approach for Injections

Address

- Fear/Anxiety
- Pain
- Focus



Follow up Visits

- Preparation

Follow up Visits

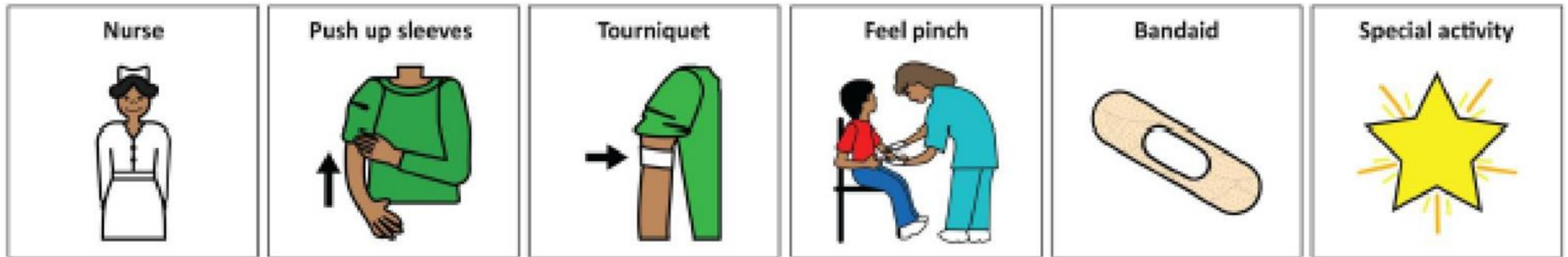
- **Preparation**
 - Social Stories
 - Kits
 - Visit (in person or virtual)
 - Virtual reality/photoshoot

Helping Patients Understand

- Social stories, PECS (Picture Exchange Systems), and Videos help explain vaccine or blood draw process in patient accessible language
- –[Getting Tested for Covid-19](#)
- –[Vaccine social story](#)
- –[COVID Vaccine \(PECS\)](#)
- –[COVID Vaccine 2](#)
- [Megaside Prep Video](#) ***

Helping Patients Understand

- Lab/blood draw resources
 - [I'm Going to have a Blood Draw Video](#)
 - [Autism Speaks Parent Toolkit for Blood Draws](#)
 - Visual Schedule (Autism Speaks)



Coping with Sensory Issues

- Some patients have difficulty with
 - Waiting
 - Noise
 - Lights
 - Cold
- Options include curbside vaccination
- In home vaccination
- Sensory room

Follow up Visits

- Preparation
- **Modeling**
 - Demonstrate on a family member
 - Practice on others
 - Therapy animals/stuffed animals



Follow up Visits

- Preparation
- Modeling
- **Control**
 - Offer choices
 - Start/stop signals
 - Bring comforting objects/people
 - Care plan individualized



Follow up Visits

- Preparation
- Modeling
- Control
- **Anxiety management**

Anxiety presents itself in many different ways...

www.thepathway2success.com

The desire to control people and events



Difficulty getting to sleep



Feeling agitated or angry



Defiance and other challenging behaviors



Having high expectations for self, including school work & sports



Avoiding activities or events (including school)

Pain like stomachaches and headaches



Struggling to pay attention and focus



Intolerance of uncertainty



Crying and difficulty managing emotions



Over-planning for situations and events



Feeling worried about situations or events

www.thepathway2success.com

Clipart by Kate Hadfield & Sarah Pecorino

Reducing Fear/Anxiety Strategies

- Anticipatory anxiety (worrying)
 - Know what to expect (social stories/explain what you are doing)
 - Have a plan
- Breathing/relaxation (tension increases pain/anxiety)
 - Smell roses, blow out candles (or bubbles)
 - Release tongue from roof of mouth to relax jaw
 - Muscle relaxation: make sure shoulders are relaxed
- Pet Therapy / Animal-Assisted Interventions (AAI's)

Overview of Pet Therapy: Animal-Assisted Interventions (AAI's)

- Animal-Assisted Therapy (AAT)
- Animal-Assisted Activity (AAA)
- Animal-Assisted Education (AAE)

(IAHAIO, 2018)

- Standalone vs Adjunct to other medical/psychological interventions



Benefits of of Pet Therapy / AAI's

- **AAI for those w/ Intellectual Disability**: “Overall there was a positive improvement reported from studies for all psychosocial outcomes (with some cognitive, behavioural, social, emotional components reaching statistical significance $p < 0.01$).” (Maber-Aleksandrowicz, 2016)
- Presence of a friendly dog ↓ behavioral signs of distress & lower BP/HR during simulated routine physical exams compared to children without dog present (Friedman, E., 2019; Nagengast et al., 1997)
- ↓ Anxiety, depression, stress, HR, BP, cortisol (Crossman et al., 2013)
- ↑ Calmness, feeling supported, therapeutic alliance, self-regulation, response to social feedback, working memory/cognition (Limond et al., 2007; Shuck et al., 2019)

Follow up Visits

- Preparation
- Modeling
- Control
- Anxiety management
- **Pain Control**

Pain Relief



Lidocaine patch
Vapocoolant
ShotBlocker



Pain Relief

- Based on gate-control theory
 - vibration is thought to block the afferent pain-receptive fibers
 - cold application blocks the pain transmission signal
- Meta-analysis
 - decreased perceived pain (56% to 88%)
 - decreased procedural anxiety



Ballard, A., Khadra, C., Adler, S., Trottier, E., & Le May, S. (2019)

How to Use Buzzy Bee

- Attach frozen wings and turn on vibration. Place Buzzy directly on the site of the injection for 30-60 seconds, then move up (with power switch up/farthest away from site) and hold secure while administering shot.
- [Video](#)

Follow up Visits

- Preparation
- Modeling
- Control
- Anxiety management
- Pain Control
- **Distraction**

Focus/Distraction

- **Active** vs passive
 - Blowing (bubbles/pinwheel)
 - Cards
 - Counting/I-Spy
 - Massage other arm
 - Sing/listen to music
 - Tell a story
 - Pet Therapy



Focus/Distraction: Pet Therapy/AAT

- **Incorporate into treatment plan**
 - **Assess interest/potential benefit**
 - **When?**
 - **Before:** motivation, therapeutic alliance
 - **During:** distraction, de-escalation
 - **After medical intervention/assessment:** reward, formation of positive association

2019)



(Iedeschi et al.,

Interacting w/animals > observing animals > pictures of animals

Follow up Visits

- Preparation
- Modeling
- Control
- Anxiety management
- Pain Control
- Distraction
- **Sedation**

Follow up Visits

- Preparation
- Modeling
- Control
- Anxiety management
- Pain Control
- Distraction
- Sedation
- **Reward and Praise**



© CanStockPhoto.com - csp51629370

Sample Plan

A care plan will have been already completed in an earlier meeting between patient, caregivers and behavioral health clinicians to address fear, pain, sensory or behavioral difficulties.

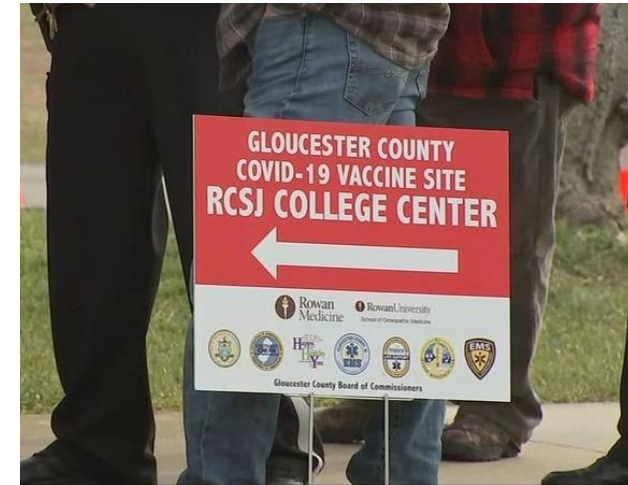
RISN CENTER VACCINE CARE PLAN

Patent's Full Name	Date of Birth
Support Person's Name	Telephone No. ()
Allergies	
WHAT MAKES GETTING A VACCINE DIFFICULT FOR ME:	
Fear of Needles: _____ Pain: _____ Fainting: _____ Previous Trauma: _____ Sensory Difficulty: _____ Behaviors: _____	
WHAT USUALLY HELPS COMFORT ME?	
1. _____ 2. _____ 3. _____	
ACTION PLAN FOR COVID VACCINATION	
SEDATION (dosage) o _____	
PAIN MANAGEMENT o Ethyl Chloride o Buzzy Bee o other _____	
DISTRACTION o Comfort Person o Cards o Count o Look	
SENSORY/BEHAVIORS o Curbside o Quiet Room o Headphones o Weighted blanket	
Notes for Next Time:	

Vaccine Clinics:

- RowanSOM in Stratford
- Megasite in Gloucester County

An innovative partnership providing stress-reduced, special needs COVID-19 vaccine clinics to those who need them most



Sensory Rooms



During the Procedure

- Comfortable position - relaxed
- May need a support person to sit with them
- Review Care Plan
 - Pain Relief
 - Anxiety Management
 - Distraction

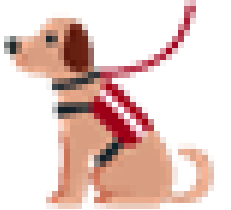


Pet Therapy: vaccine-site specific

- **Goals:**
 - Anxiety Management
 - Distraction (from pain, fear, stress)
 - Reward (positive experience for shot 1 makes shot 2 easier)
- **Site 1:** therapy dogs available before & after, not during vaccine
- **Site 2:** therapy dogs available before, during, & after vaccine
- Therapy dogs at vaccination site for 3 distinct cohorts (2 at one site & 1 at another) for both shot 1 & shot 2



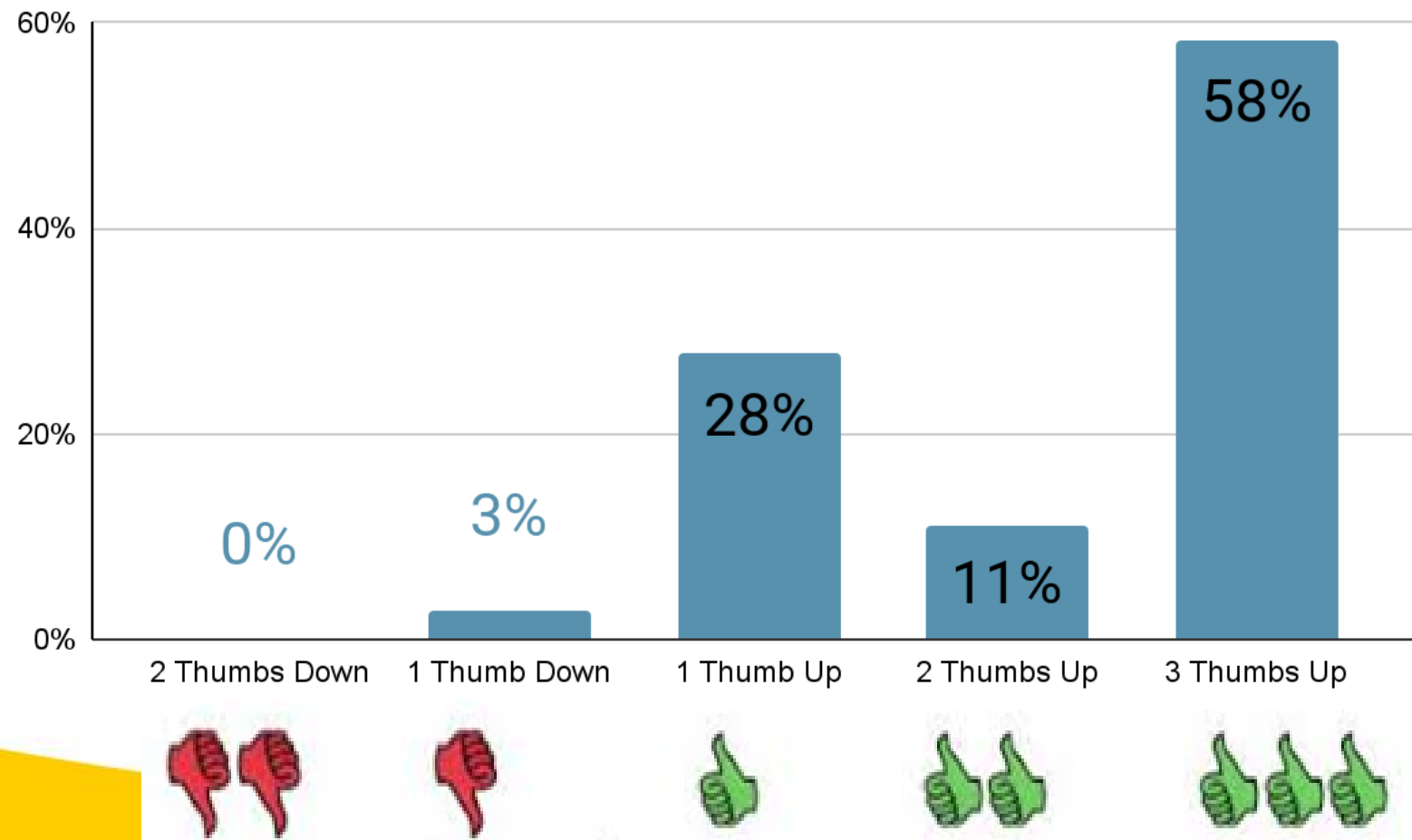
Pet Therapy at special needs COVID-19 Vaccine Clinic: satisfaction data [quantitative] (n=36)



Site 1:

Therapy dogs available
BEFORE
vaccine only
for some
recipients

I think Pet Therapy (interacting with a dog) can be helpful when receiving a vaccine

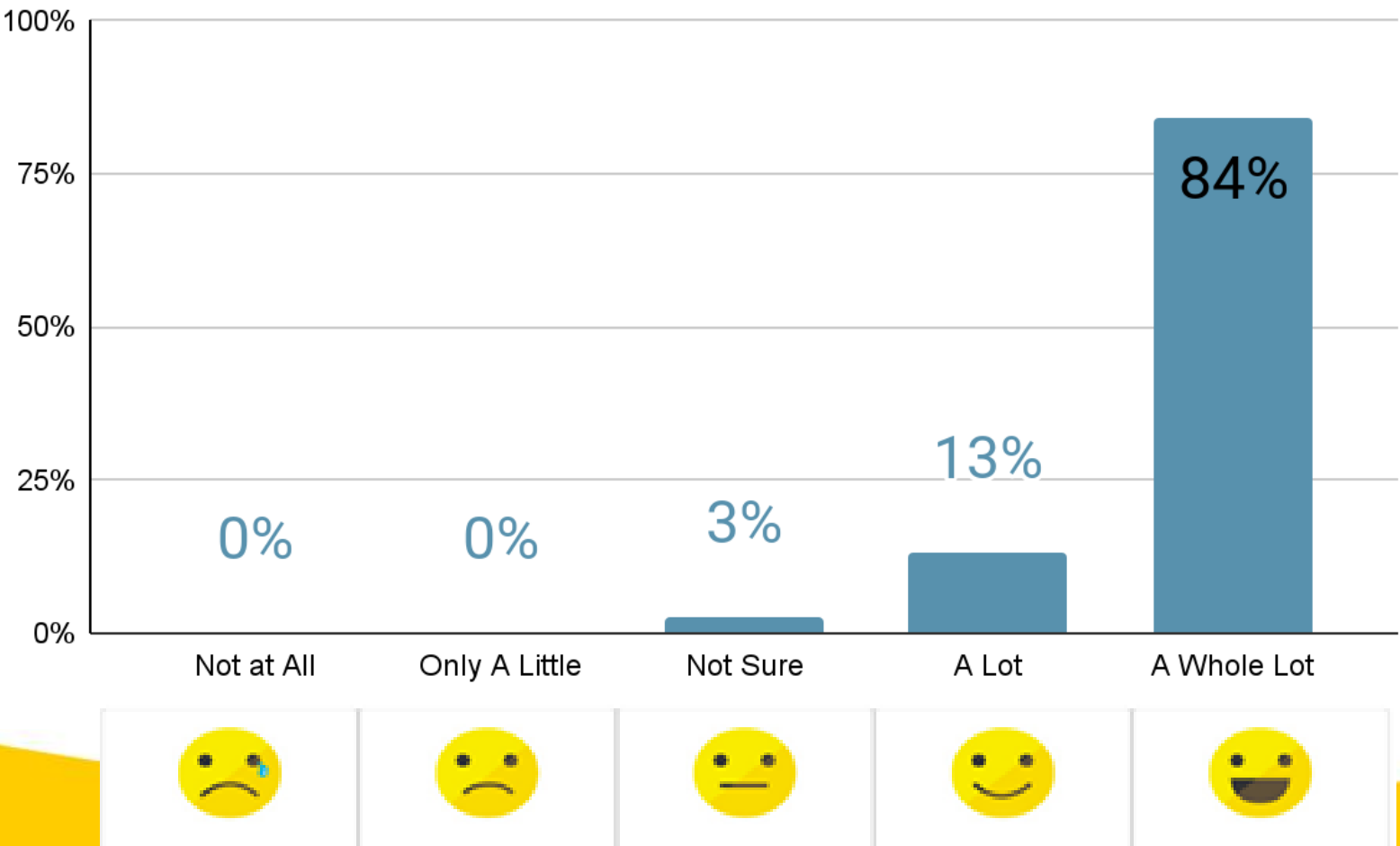


Pet Therapy at special needs COVID-19 Vaccine Clinic: satisfaction data [quantitative] (n=38)



Site 2:
Therapy dogs
available
BEFORE,
DURING, &
AFTER
vaccine for all
recipients

I think Pet Therapy (interacting with a dog) can be helpful when receiving a vaccine



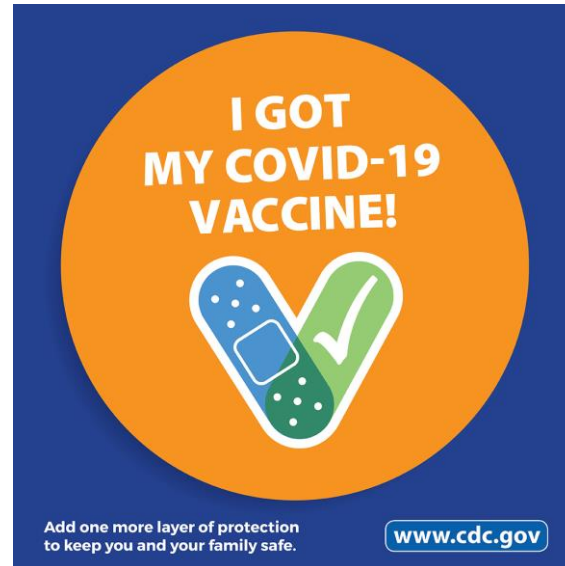
Pet Therapy at special needs COVID-19 Vaccine Clinic: satisfaction data (quantitative)

- “Animal-Assisted therapy is a wonderful way to alleviate stress”
- "A dog was great! It calmed me down. I was very nervous."
- "All vaccine facilities should have therapy dogs"
- "Loved petting the sweet pupper!!"
- “Therapy dogs are a great idea”
- “Feeling calm now thanks to [therapy dog’s name]”
- "Awesome idea with the therapy dogs!"
- "I immediately brightened up seeing the dog!"
- "Great idea having the dog visit!"



After getting vaccine/lab draw

- Praise
- Sticker
- [After getting the vaccine social story](#)
- Adapt the plan: What worked/didn't work



Example: [Video Clip](#)

Example

Non-verbal 18 yr old male

Example

Hello! It was very nice to meet your family today. Although Jimmy struggled today, I think we can help feel better prepared and less anxious for the next appointment. I can tell he has a loving and committed family to help him, which is the really the foundation for success.

Here are some suggestions:

- Reach out to his physician about a sedative to be taken about 30 mins prior to the appointment to help decrease his anxiety
- Over the next 3 weeks, at times when he is calm, practice having him show his shoulder and counting to 10 while holding your hands several times a day with a reward at the end.
- Once his is comfortable counting and showing his shoulder, add in rubbing a wet cloth (simulating alcohol wipe) until he is able to tolerate without flinching. Once he is ok with that, try 5 secs of wiping and 5 of gently squeezing/applying pressure.
- When you come next time, have him wear a sleeveless shirt/tank top. Bring his favorite music to play.
- We are working on having more of a sensory friendly room available for the injection to bypass the vaccination room.
- Here are some social stories you can also review with him: <https://aidinpa.org/resource/covid-19-vaccine-social-stories/>
- <https://rwjms.rutgers.edu/boggscenter/publications/documents/GettingACovid19VaccineSocialStoryIDD-F.pdf>

Example

Hi Wendy,

I wanted to let you know that Jimmy successfully got his second shot yesterday at the Rowan site! He was a little more anxious this time, but the workers were kind and steady and got us in and out quickly.

Thanks for telling us to request the quiet room. As soon as I said that at the screening tent outside, a worker insisted on escorting us in directly to the room without waiting or stopping at any other stations. This was so helpful for us, especially since Jimmy was more anxious than last time. The nurse who administered the shot was friendly and moved quickly to get us out of there as fast as possible. I can't tell you how grateful and relieved we all feel for Jimmy to have completed this process!

After a year of thinking about how hard it can be for people to get past differences and work together, we were so moved to see the vast array of people at the site working together to get this done. We will never forget your patience and kindness in particular! If you or your center has a need, fundraiser or cause to which we may donate or help, please let us know! We would love to make some show of the incredible gratitude we feel for your efforts for Jimmy and for all of the families you serve.

More virtual hugs,
Jimmy's Mom

ECG



Blood Pressure



Dental Procedures



Thank you! Questions?

Wendy Aita, PhD

RISN Center
Rowan University
Aita@rowan.edu



Michele Pich, MA, MS

Shreiber Family Pet Therapy
Program
Rowan University
Pich@rowan.edu

<https://centers.rowanmedicine.com/risn/index.html>

<https://sites.rowan.edu/wellness/pettherapy/index.html>