

**Provider Forum:**

**Vaccination in Individuals  
with Intellectual and  
Developmental Disabilities**



21 September 2023





# Welcome!

**Namino Glantz, PhD**

Manager, Health Linkages

Children & Family Resource Services

# Dynamic

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- Hybrid: in person and via Zoom
- Recorded and will be available online
- Hold questions until after the panelists present
- Disclaimer:

This presentation is for educational purposes only. Opinions or points of view expressed in this presentation represent the view of the presenter, and do not necessarily represent the official position or policies of the presenter's employer or organization. Nothing in this presentation constitutes medical advice. The images in this presentation were either provided by the presenters with prior consent from the individuals (or their parents/guardians) featured or publicly available from the websites listed in the Resources section.

# Objectives

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Before, during, and after vaccination - including COVID and flu - among individuals with intellectual and developmental disabilities (IDD), we will:

- Understand parent/caregiver concerns
- View data
- Share strategies and resources
- Ask and respond to questions

# Agenda

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Introduction

Panelist experience and expertise

- Gina Stabile, Manager, Alpha Family Resource Center
- Dr. Ivan Alvarez, School psychologist, Santa Barbara County Education Office
- Dr. Jenna Holmen, Pediatric infectious disease specialist, Cottage Health
- Dr. Jerold Black, Pediatrician serving children and adolescents, Sansum Clinic

Resources

Q & A

# Vaccines, A Parent Perspective

**Gina Stabile**

Parent of an individual with IDD and  
Manager of the Alpha Family Resource Center



# Why a parent/caregiver perspective?

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\*\*Disclaimer: This information is not representative of all families of individuals with IDD.\*\*

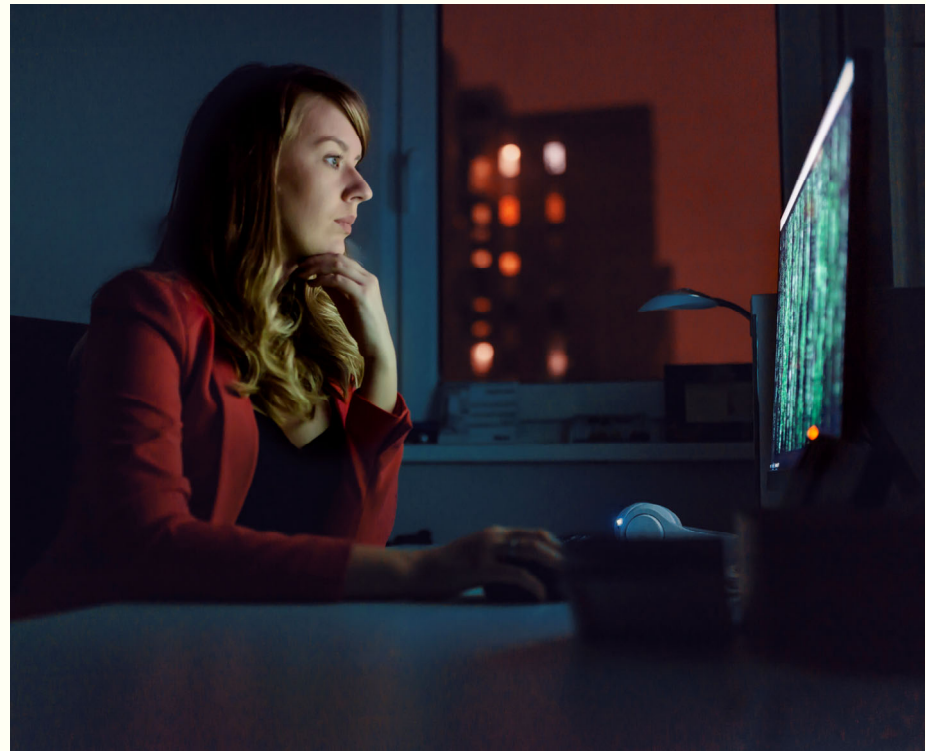
- At the end of the day, parents are making the medical decisions for their child.
- Typically, parents are the caregivers for the adult with IDD and take them to appointments.
- Vaccines no longer end at childhood; adults get vaccines annually, sometimes multiple times a year.
- We rely on medical professionals to:
  - Give us sound medical advice and answer our questions
  - Clearly explain possible side effects
  - Discuss need for vaccines, including for COVID and flu shots
  - Be able to discuss fears
    - “Vaccines will give my child \_\_\_\_\_”
    - “What if I refuse?”
    - “Do you know how the vaccine affects individuals with \_\_\_\_\_?”



# The battle of science versus social media “experts”

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- Parents/caregivers are surrounded by input and advice when they turn to social media forums.
- Much advice is purely opinions, not backed by science or studies.
- Example: COVID vaccines
- Fear factor and what parents hear on social media forums
- How do we reassure parents who insist that vaccines will harm their child?





# Stress and "Shot Day" for parents of a child with IDD

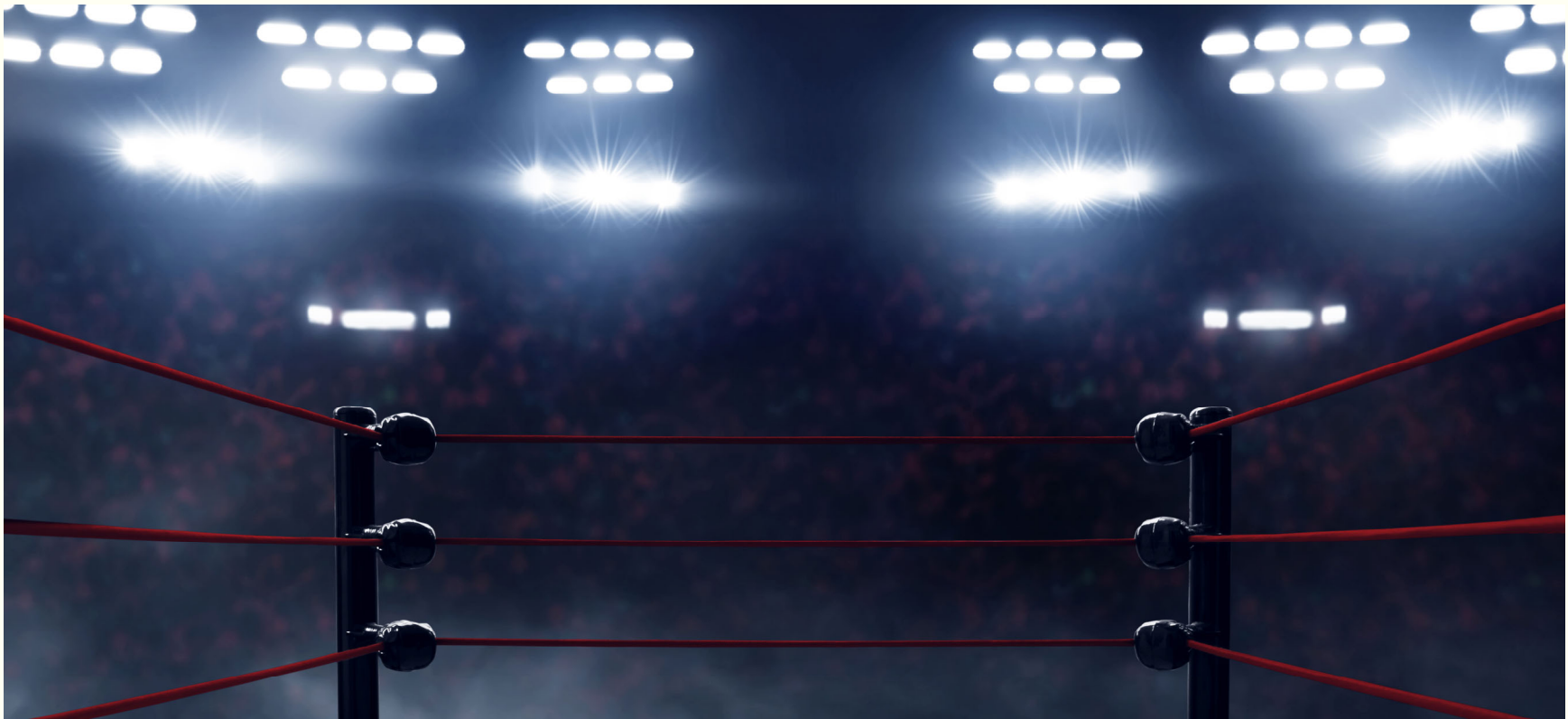
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- Emotionally prepare for the visit
  - Caregiver trauma
  - Child stress and refusal
  - Incentives, they are a real thing
- Share information with providers before the visit
  - What to Know About Me form (available from Health Linkages and Alpha FRC)
- What if the child/individual fears the person in the white coat? Or the office is sensory over-load? Or the wait is too long?
- Are there cultural beliefs to consider? Do you have an interpreter to explain things to families?
- Prepare for the vaccine
  - Did the provider explain the vaccine?
  - Can this happen beforehand, not in front of the child/individual?

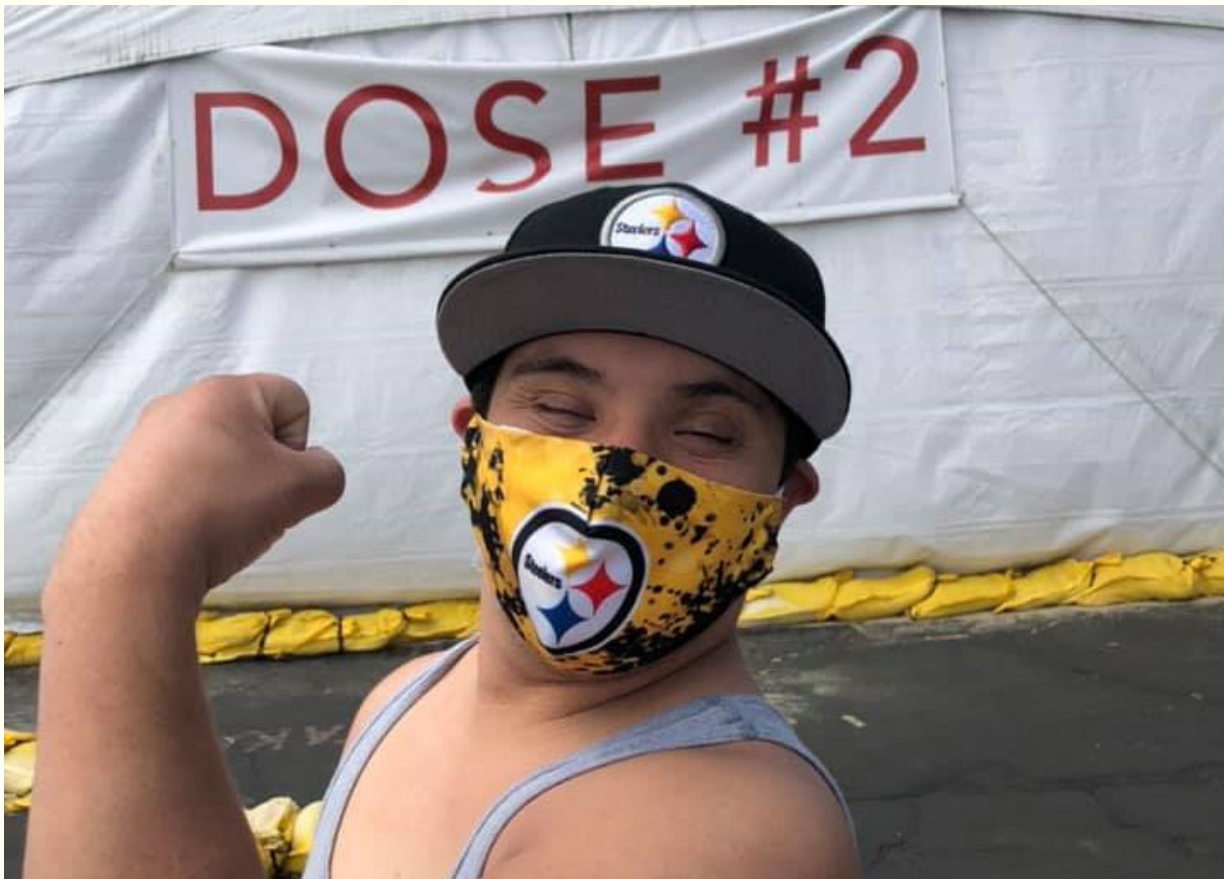
**"Vaccine day is like a WWE title match for me"** Gina Stabile

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## Max and Mom, our story

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**Contact me**

[gstable@alphasb.org](mailto:gstable@alphasb.org)

[www.alphasb.org](http://www.alphasb.org)



# Vaccination Resources for People with Disabilities

**Dr. Ivan Alvarez, EdD, MA, LEP**  
**Bilingual School Psychologist**  
**Santa Barbara County Education Office**

# My background

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- Bilingual School Psychologist since '12
- Licensed Educational Psychologist since '14
- Worked with SBCEO since '14
- Subject Matter Expert for Board of Beh. Sciences '14
- Experience working with K-12 since '12
- Experience working with PS families since '14
- Doctoral Dissertation from Mizzou in '22



## Concerns from families with whom I meet

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- Vaccines may cause autism or other developmental delays.
- Vaccines may infect their child with the disease that we are trying to prevent.
- Vaccines may cause a child with a disability to get more ill or worsen their condition.
- Vaccines are only needed when outbreaks of a disease occur in a community.

## **Additional concerns and beliefs expressed by families**

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- Vaccines are not recommended when their child is immunocompromised or has significant disabilities.
- Schools and pediatricians “push” them to get vaccinated.
- Vaccines are not well researched or tested.
- Vaccines have significantly more risks than benefits.
- Vaccines are not necessary when most children at their school are already vaccinated.



# Supporting parents

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- Dispel the myths that vaccines cause medical conditions or disease. Instead, emphasis that vaccines are preventative in nature.
- Discuss the benefits of vaccines, including how they can help children with disabilities and immunocompromised systems.
- Encourage parents to ask question regarding anything that they have heard or read about vaccines to ensure that they are clear about their impact.

# Contact me

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Dr. Ivan Alvarez, EdD, MA, LEP

Santa Barbara County Education Office

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# Vaccine-Preventable Illness in Children with Disabilities

Dr. Jenna Holmen, MD, MPH  
Pediatric Infectious Disease Specialist  
Cottage Health



# Background data

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- 1 in 6 U.S. children ages 3 through 17 years has one or more developmental disability
- Data from WHO suggests 15% of the world's population has some impairment in function, 2-4% having significant difficulties with ADLs
- Individuals with disabilities have inequities in (as articulated by UNICEF):
  - Access to immunization
  - Access to health services
  - Exclusion from health-care initiatives
  - Lack of understanding of the safety of immunization

<https://www.cdc.gov/ncbddd/humandevlopment/covid-19-vaccination-for-youth.html>

O'Neill J et al. Human Vaccines and Immunotherapeutics. 2020;16(1):7-15.

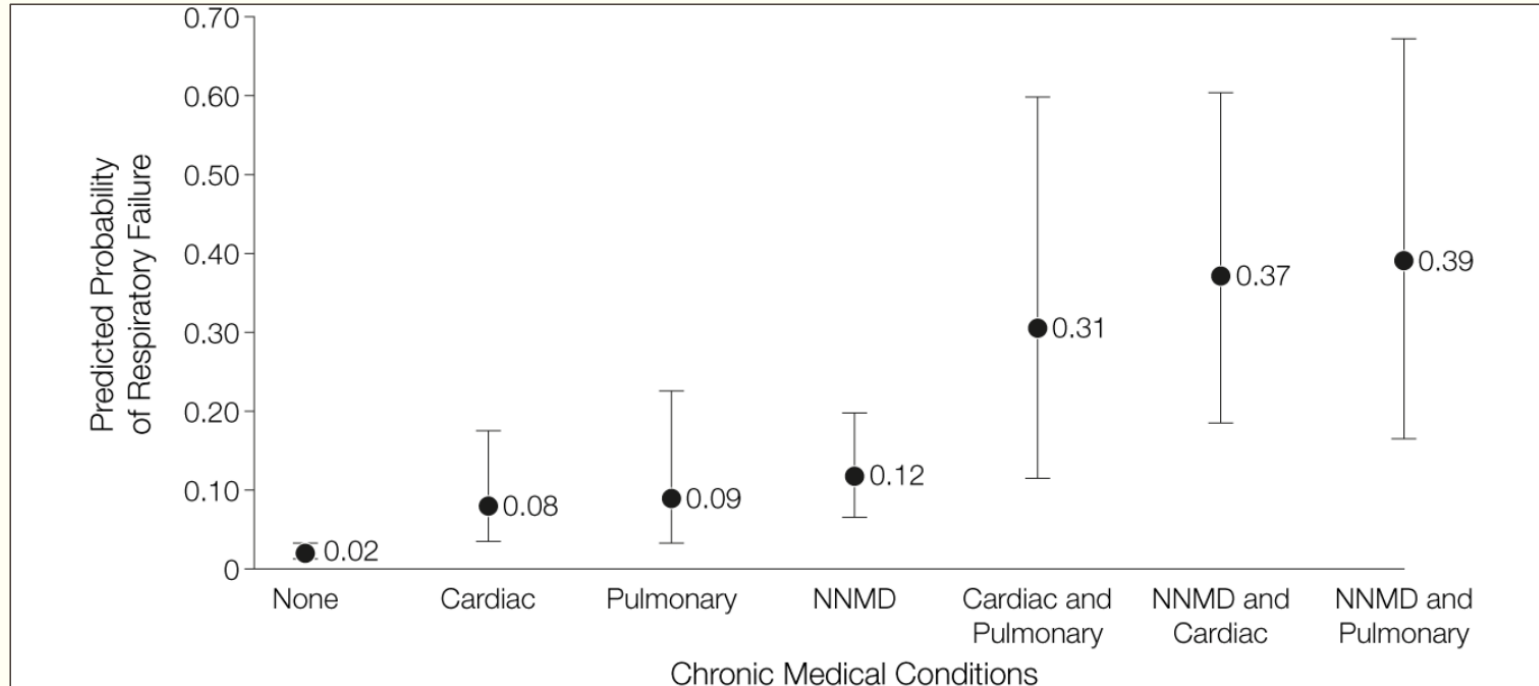
# Factors that may increase risk of severe disease from vaccine-preventable illness in persons with disabilities

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- Potential high-risk close contact with caregivers
- Limited mobility to avoid close contact
- Difficulty wearing a mask
- May have limited understanding of recommendations
- People who are deaf or blind may struggle to find information in accessible formats
- May live in group homes or long-term care facilities with higher risk of illness spread
- More likely to have associated comorbidities
- Children with neurologic/neurodevelopmental disorders can have high/low tone, poor motor control, impaired pulmonary function

# Higher risk in children with neuromuscular disease

Figure. Predicted Probability of Respiratory Failure in Children With Chronic Medical Conditions Hospitalized with Influenza Infection



## Children with disabilities have worse outcomes compared to children without disabilities from vaccine-preventable diseases

- In a 2003 H3N2 flu outbreak in Melbourne:
  - 7/26 children admitted to a rehab hospital tested positive for influenza, 6/7 required ventilatory support.
  - 13/68 admissions to a general medical ward tested positive for influenza, 2/15 required ventilatory support.
- 64% of pediatric deaths (146/227) occurring during the 2009 H1N1 outbreak to children with an underlying condition had a neurologic disorder.
  - Cerebral palsy and intellectual disability were more common.



# Physician recognition of high-risk condition

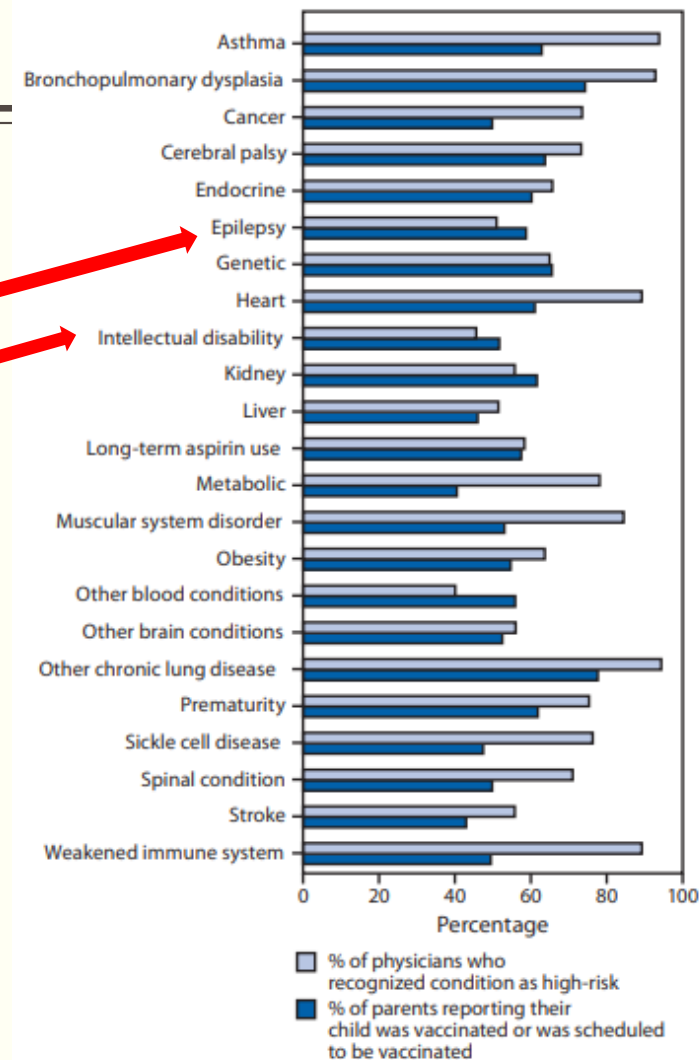
National survey of parents with children with neurologic and neurodevelopmental conditions

- Flu vaccination rates among children with:
  - epilepsy 59%
  - intellectual disability 52%
- Physician recognition of high-risk conditions among children with:
  - epilepsy 52%
  - intellectual disability 46%

On subgroup analysis of pediatricians, neurologist, geneticists, developmental pediatricians, and physiatrists, intellectual disability was still not recognized as a high-risk condition

MMWR. 2013;62(36):744-746.

FIGURE. Influenza vaccination coverage among children at high risk for complications of influenza and physician recognition of high-risk conditions — United States, 2010–11 influenza season



# Contact me

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Dr. Jenna Holmen  
Cottage Health  
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[j3holmen@sbch.org](mailto:j3holmen@sbch.org)



# Real Life Management of Vaccinations in Children and Youth with IDD

Dr. Jerold Black, MD

Sansum Clinic Pediatrics

Father of special needs twins



## Before the visit

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- Time!!!
- How to inspire confidence? Patients vs caregivers
- Kiddos with IDD/special needs and vaccines
  - Reactions
  - Need
  - Do your research



# During the visit

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- Flexible vaccine schedule
- Empathy/compassion
  - What about the anxious parent/anxious patient?
- Fear and the relationship with the provider
- Alternate visits - car, nursing visit, outside visits
- PHRASING



## After the visit

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- Side effects, course
- Follow up/scheduling boosters/contacting families

# Strategies for scenarios pediatricians face daily

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Scenarios we face every day:

- Social Media
- “Uncle Bert/Aunt Betty/My neighbor said...”

Strategies:

- Use clear, honest language, especially about COVID.
- Admit our shortcomings, be compassionate to family wanting what is BEST for their child.
- Families of children with IDD/special needs face more medical challenges and know more.
- Have some resources:
  - [healthychildren.org](http://healthychildren.org) (AAP website for families)
  - Vaccine Education Center at Children’s Hospital of Philadelphia



# Contact me

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Dr. Jerold Black, MD  
Sansum Clinic Pediatrics  
51 Hitchcock Way, Santa Barbara CA 93105  
[jblack@sansumclinic.org](mailto:jblack@sansumclinic.org)



# Resources

- Panelists and colleagues
- Partner organizations
- Tools
- Websites



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# Provider: What to know about me

## Provider: What You Need to Know About Me

This is what you need to know about me to be successful with my healthcare and vaccine administration. I may have a family member or caregiver with me for support during my appointment.

My name: \_\_\_\_\_

### Appointment

I typically respond to a medical exam with  Full or partial cooperation  Fear  Aggression

Other (describe) \_\_\_\_\_

I like it when health professionals do (describe) \_\_\_\_\_

I do not like it when health professionals do (describe) \_\_\_\_\_

My other communication preferences are (e.g., do not ask me yes or no questions, ask me open-ended questions, ask me multiple choice questions) \_\_\_\_\_

### Communication

How I communicate best (check all that apply)

Talking  Writing or typing  Pictures  Using Sign Language

Pointing to words  Using a voice app

I do not communicate in a way you will understand, please ask my family member or caregiver.

Their name is \_\_\_\_\_

Other (describe) \_\_\_\_\_

### Other Accommodations or Preferences

I use assistive devices for mobility. You may see me use \_\_\_\_\_

I have sensory triggers that may make it difficult for me to have a successful appointment (being touched, trauma, doctors of a particular gender, noises, lighting, smells, textures). The following are known sensory triggers for me \_\_\_\_\_

When I experience a sensory trigger, I may respond by \_\_\_\_\_

When I respond this way, you can help me by \_\_\_\_\_

I have diagnoses, medical issues, or behaviors that may make it difficult for me to have a successful appointment (e.g., aggression, biting, pica, aspiration risk): \_\_\_\_\_

This may cause me to \_\_\_\_\_

You can help me by \_\_\_\_\_

Additional information \_\_\_\_\_

\_\_\_\_\_

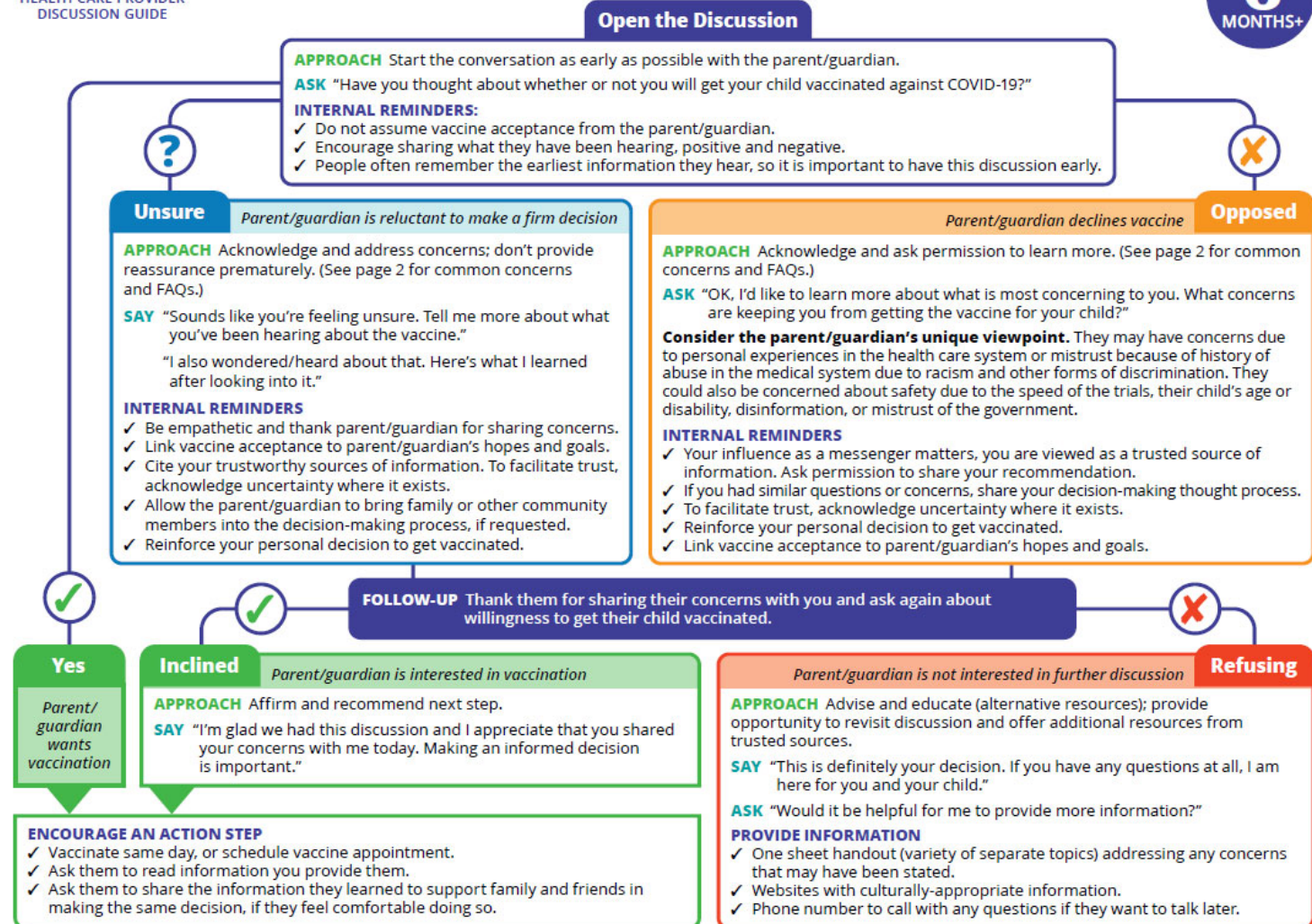
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# Building Confidence Discussion Guide

[COVIDvaccineWA.org](https://COVIDvaccineWA.org)

## Building Parental/Guardian Confidence in COVID-19 Vaccination





# Building Confidence Discussion Guide

[COVIDvaccineWA.org](https://COVIDvaccineWA.org)

## Concerns & Example Responses

**They share concerns about fertility or developmental concern with vaccinating children before they reach puberty.**

"The COVID-19 vaccine has been monitored closely and there is no evidence that the COVID-19 vaccine causes female or male fertility problems as well as no evidence that it will affect puberty. The ingredients and antibodies developed following the COVID-19 vaccination have not been found to cause any problems with becoming pregnant. Professional medical organizations serving people of reproductive age, including adolescents emphasize that it strongly recommended for all to receive the vaccine."

**They shared that they believe there is no point in getting their child vaccinated if they can still get infected.**

"I understand. Although there is still a chance of breakthrough COVID-19 infection after vaccination, the vaccines were designed to prevent severe illness, hospitalization, and death from COVID-19 and are still successful at doing so. If your child does get sick after they're fully vaccinated, they will still have some benefit from the vaccine because they may only get a mild case instead of a serious case."

**They expressed concern that they don't want their child to be a research experiment.**

"I understand your hesitation, but vaccine developers didn't skip any testing steps following the appropriate safety measures including a rigorous three phase clinical trials process with very clear outcomes. The technology used for the COVID-19 vaccine has been studied for decades. There have been over 12 billion vaccine doses administered safely worldwide and there are very strong vaccine safety systems to catch any warning signs early."

**They've shared that their child experienced racism or faced another form of discrimination.**

"I'm sorry that happened to your child. It was horrible and wrong. Your experience sounds frustrating and hurtful." After listening and further exploring their concerns, consider saying: "The vaccine will help prevent your child from getting really sick from COVID-19. It is strongly recommended, but completely voluntary."

**They mention harmful medical practices or experiments on Black and Indigenous people in the past.**

"You're absolutely right. The history of medical harm should not be ignored. Scientists have engaged in many harmful and racist practices in the name of medicine. The COVID-19 vaccine is being handled very differently. Can I tell you what I know about the vaccine and the vaccine trials? I want to make sure this feels like the right decision for you."



DOH 825-025 December 2022 To request this document in another format, call 1-800-525-0127. Deaf or hard of hearing customers, please call 711 (Washington Relay) or email [civil.rights@doh.wa.gov](mailto:civil.rights@doh.wa.gov).

## Frequently Asked Questions & Example Responses

**Is COVID-19 vaccination safe for my child?**

"Yes, the vaccine is considered very safe for children, and I strongly recommend getting your child vaccinated against COVID-19. The FDA approved emergency use authorization based on extensive clinical trials showing the vaccine was safe and effective. No serious side effects were detected in clinical trials of the vaccine in youth and the U.S. has very strong vaccine safety systems to catch any warning signs early."

**How severe is COVID-19 in children?**

"Children can be infected with COVID-19, get sick or die from COVID-19, spread COVID-19 to others, and get serious complications from COVID-19. New COVID-19 variants are more dangerous and infectious to children than the original strains. Since the beginning of the pandemic, over 15 million children in the U.S. have gotten COVID-19 and new COVID-19 variant surges led to peak COVID-19 hospitalizations among youth. Vaccination is the best way to keep children healthy and safe."

**What are common side effects of the COVID-19 vaccine in children?**

"Like other vaccines, the most common side effects are a sore arm, tiredness, headache, and muscle pain, which were generally reported to be mild to moderate in severity and occurred within two days after vaccination, and most went away within one to two days. Side effects were more common after the second dose than the first dose. These symptoms are a sign that the vaccine is prompting an immune response as intended. The health risks if a child is infected with COVID-19 are much higher than the risk of vaccine side effects."

**How long does COVID-19 vaccination protection last and does it protect against infection of new variants?**

"Scientists are continuing to monitor how long COVID-19 vaccine protection lasts. Recent studies show that protection against the virus may decrease over time, but vaccines are still preventing against serious illness, hospitalizations, and death from COVID-19. This reduction in protection has led CDC to recommend a booster dose for those ages 6 months and older after completing their primary vaccination series."

**What is Myocarditis and is there a connection to COVID-19 vaccination?**

"Myocarditis (and pericarditis) are terms to describe inflammation in or around the heart. The body's immune system can often cause this inflammation in response to an infection, such as viruses."

Myocarditis is not very common and rarely fatal, with less than 200,000 cases in the United States each year and less than 2% of these cases fatal. The risk of myocarditis after COVID-19 vaccination is extremely rare, but there have been a few reported cases. There have been no deaths from myocarditis determined to be caused by COVID-19 vaccination in the United States. An individual is more likely to develop myocarditis after infection with COVID-19 than from the vaccine."

**Does the COVID-19 vaccine change my child's DNA? What's in the vaccine?**

"The vaccines contain the active ingredient, messenger RNA (mRNA), along with fat, salts, and sugars to protect the mRNA and help it work better in the body. COVID-19 vaccines do not contain any egg proteins, gluten, pork products, metals, tracking devices, or fetal material. COVID-19 mRNA vaccines also do not change or alter your DNA in any way. mRNA vaccines teach our body's cells how to make a protein that triggers an immune response. That immune response and making antibodies is what protects us from getting infected if the real virus enters our bodies."

**Does my child need to get vaccinated if they already had COVID-19?**

"Yes, your child should still get the COVID-19 vaccine even if they already had COVID-19 but they should wait to receive the vaccine until after they recover and complete their isolation period. Getting a COVID-19 vaccine after they recover from COVID-19 infection provides added protection to their immune systems. People who already had COVID-19 and do not get vaccinated after their recovery are more likely to get COVID-19 again than those who get vaccinated after their recovery."

For more information and resources, visit: [vaccinatewa.org/kids](https://vaccinatewa.org/kids)



The best way for parents/guardians to get up-to-date information about when and how to get their child vaccinated is by visiting [vaccinatewa.org/kids](https://vaccinatewa.org/kids) or by calling the Department of Health phone line 1-800-525-0127, then press #. (For interpretive services, say your language when the call is answered.)

Adapted from:

1. Communication skills for the COVID vaccine. VitalTalk. [vitaltalk.org/guides/communication-skills-for-the-covid-vaccine/](https://vitaltalk.org/guides/communication-skills-for-the-covid-vaccine/). Published January 8, 2021.
2. Gagneur A. Motivational interviewing: A powerful tool to address vaccine hesitancy. *Can Commun Dis Rep*. 2020;46(4):93-97. Published 2020 Apr 2. doi:10.14745/ccdr.v46i04a06
3. Opel DJ, Lo B, Peek ME. Addressing Mistrust About COVID-19 Vaccines Among Patients of Color. *Ann Intern Med*. Published online February 9, 2021 at [doi:10.7326/M21-0055](https://doi.org/10.7326/M21-0055). doi:10.7326/m21-0055



## Human Development and Disability

< [Human Development and Disability Home](#)

[Print](#)

# COVID-19 Vaccination for Children and Teens with Disabilities

## What You Need to Know

- COVID-19 vaccination for children and teens is [safe and effective](#).
- Everyone 6 months and older, including those with [disabilities](#) and [underlying medical conditions](#), should get vaccinated against COVID-19.
- Everyone 6 months and older should get a booster, if eligible.
- Use [CDC's COVID-19 booster tool](#) to learn if and when your child or teen can get boosters to stay up to date with their COVID-19 vaccines.

**CDC**



Children with service animals are allowed by law to have them accompany them at COVID-19 vaccination sites.

<https://www.cdc.gov/ncbddd/humandevlopment/covid-19-vaccination-for-youth.html>



## Human Development and Disability

[< Human Development and Disability Home](#)

CDC

# COVID-19 Materials for People with Intellectual and Developmental Disabilities

[Español \(Spanish\)](#) | [Print](#)

COVID-19 is challenging to explain, live through, and communicate about. The materials on this page were created to help make communicating about COVID-19 a little easier. Choose from videos, posters, social stories, and interactive activities to best meet your communication needs.

These materials ([also available in Spanish](#)) will cover 5 basic topics: getting the COVID-19 shot, washing your hands, getting a COVID-19 test, as well as wearing a mask and keeping a safe distance until you have gotten your shot.

## Getting a COVID-19 Shot

### Social Story

Stay safe from COVID-19



This social story

### Poster

Stay safe from COVID-19

This poster reminds



healthychildren.org



## Safety & Prevention

### ● Immunizations

- RSV Quiz
- Conversations About Vaccines

### All Around

### At Home

### At Play

### On The Go

Healthy Children > Safety & Prevention > Immunizations



# Immunizations

Today, most children in the United States lead much healthier lives and parents live with much less anxiety and worry over infections during childhood. Immunizations are one of the success stories of modern medicine.

[Click here](#) to view the most up-to-date immunization schedules.

## Featured Article

### Multiple Vaccinations at One Time

The vaccines recommended by the American Academy of Pediatrics (AAP) for use in all children do not interfere with each other and, as needed, can be safely given together during a single visit. The immunization schedule is created to ensure they are as effective as possible to protect your child from dangerous diseases.

[View](#)

<https://www.healthychildren.org/English/safety-prevention/immunizations/Pages/default.aspx>





# Vaccine Education Center at Children's Hospital of Philadelphia

**COVID-19: THE DISEASE VS THE VACCINE**

**ABOUT COVID-19 DISEASE**

**Typical Length of Illness**  
Symptoms appear about 6 days after exposure and last 1-2 weeks in most people, but some can have symptoms for 6 weeks to several months.

**Symptoms of COVID-19**

- Fever
- Fatigue
- Sore throat
- Dry cough
- Headache
- Nasal congestion

Other symptoms can include: loss of taste or smell, pink eye, muscle or joint pain, nausea or vomiting, diarrhea, loss of appetite, and rash or discoloration of fingers or toes.

**Possible Complications:**

- Infection of the lungs
- Respiratory failure
- Bloodstream infection
- Multisystem inflammatory syndrome (MIS-C or MIS-A)
- Death

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**ABOUT COVID-19 VACCINES**

**Types of Vaccines (in U.S.)**

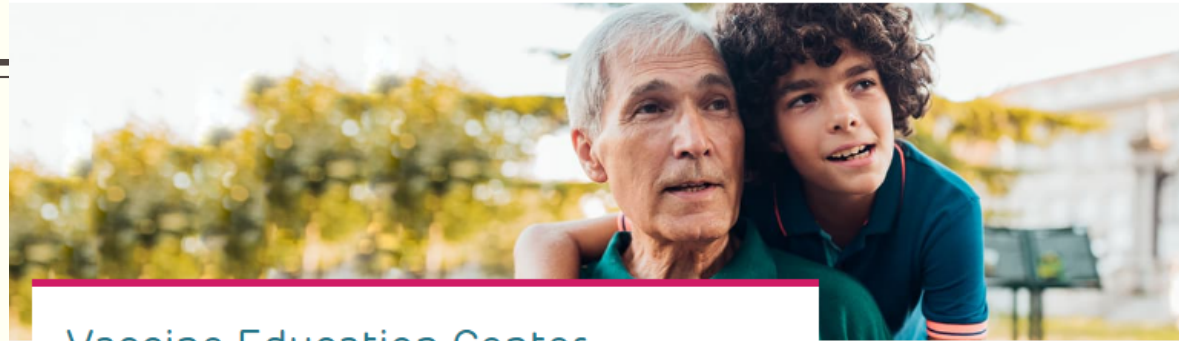
- mRNA**  
mRNA that is the blueprint for the spike protein from the virus is used as the vaccine.  
The Pfizer & Moderna COVID-19 vaccines are this type.
- PROTEIN**  
The spike protein from the virus is used as the vaccine.  
Novavax COVID-19 vaccine is this type.

**Vaccine Side Effects**  
In most cases vaccine side effects last 1 to 2 days.

GO TO [VACCINE.CHOP.EDU](https://www.chop.edu) FOR MORE INFORMATION.

Children's Hospital of Philadelphia Vaccine Education Center

<https://www.chop.edu/centers-programs/vaccine-education-center>



## Vaccine Education Center



The Vaccine Education Center at Children's Hospital of Philadelphia provides complete, up-to-date and reliable information about vaccines to parents and healthcare professionals. We are a member of the World Health Organization's (WHO) Vaccine Safety Net because our website meets the criteria for credibility and content as defined by the Global Advisory Committee on Vaccine Safety. [Learn more about the WHO's Vaccine Safety Net.](#)

[Learn more about the Vaccine Education Center](#)

### Preventing RSV in Babies: A Scientific Milestone — August 2023 News Brief

Dr. Paul Offit discusses the use of nirsevimab, a monoclonal antibody that protects infants from RSV. He talks about its effectiveness in clinical trials, who should receive it and when.

[View more](#)

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**VACCINE EDUCATION CENTER**

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VEC MAIN MENU

ABOUT THIS SECTION

ANTHRAX VACCINE

CHOLERA VACCINE

COVID-19 VACCINE

DIPHtheria, Tetanus and Pertussis Vaccines

# Questions? Answers?

