



# How the CDC Supports People with Down Syndrome & An Update on COVID-19 Vaccinations

Welcome Remarks from

Michelle Sie Whitten  
President & CEO, GLOBAL

*Thursday, July 29, 2021 • 12:00pm - 1:00pm MT*



# Today's Speaker - Dr. Karen Remley



- ❖ **Karen Remley, MD, MBA, MPH, FAAP**, Director of the Centers for Disease Control and Prevention's National Center on Birth Defects and Developmental Disabilities
- ❖ Dr. Remley has more than 30 years of experience in public health and health care. Her “north star” has always been children and families, and she has shaped her career around helping every family have the best opportunity for health and well-being.





# How the CDC Supports People with Down Syndrome & An Update on COVID-19 Vaccinations

Welcome Remarks from

Yadira Carrillo  
Fierce GLOBAL Advocate

*Thursday, July 29, 2021 • 12:00pm - 1:00pm MT*



# Welcome!

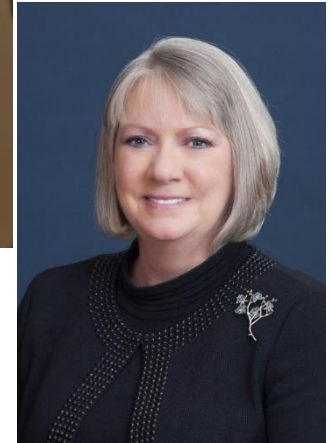
- ❖ Welcome to GLOBAL's Summer Webinar! Thank you, Michelle and GLOBAL for bringing us this wonderful Webinar Series.
- ❖ My name is Yadira Carrillo. I'm from Colorado, and I love working with GLOBAL. I spoke at their AcceptAbility Gala, co-hosted GLOBAL's Morning Social, and modeled in the famous Be Beautiful Be Yourself Fashion Show. I'm so happy to be working with GLOBAL again for this webinar with the CDC!
- ❖ This webinar is very important to me personally, because in November 2020, I contracted Covid-19 and was hospitalized with pneumonia for a week. It was scary for me and my family, but I recovered and am now healthy and vaccinated.
- ❖ I am thankful to the CDC for prioritizing people with Down syndrome for the COVID-19 vaccine and to GLOBAL for creating the COVID-19 & Down syndrome Resource so that people with Down syndrome could be as safe as possible during the pandemic.





# Introducing Today's Speaker

- ❖ Thanks to research and medical care supported by GLOBAL, I can continue living a full life to my motto, “Down with Style and Uniqueness!”
- ❖ And thanks to the CDC’s COVID-19 efforts and work to improve the health of people with Down syndrome, other people with Down syndrome are getting vaccinated and living healthier lives, too!
- ❖ Today’s webinar on [How the CDC Supports People with Down Syndrome & An Update on COVID-19 Vaccinations](#) will help show us how much progress is being made and what’s next for Down syndrome research and advocacy!
- ❖ And now I am pleased to introduce today’s speaker, Dr. Remley!





## CDC Efforts to Promote the Health of People with Down Syndrome

July 29, 2021

Karen Remley, MD, MBA, MPH, FAAP  
Director

National Center on Birth Defects and Developmental Disabilities  
Centers for Disease Control and Prevention





# Why I am here...





(NCBDDD).

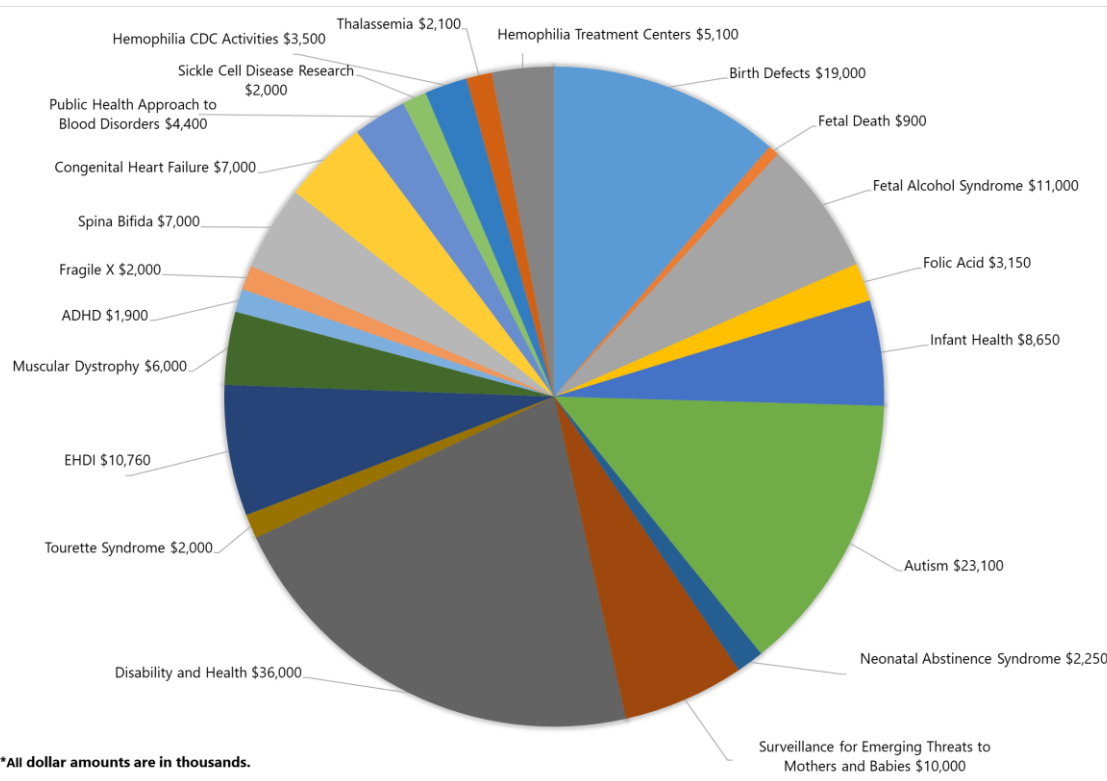




# NCBDDD FY2021 Budget



NCBDDD FY 2021 Appropriations (in thousands)	
Birth Defects	\$19,000
Fetal Death	\$900
Fetal Alcohol Syndrome	\$11,000
Folic Acid	\$3,150
Infant Health	\$8,650
Autism	\$23,100
Neonatal Abstinence Syndrome	\$2,250
Surveillance for Emerging Threats to Mothers and Babies	\$10,000
Disability and Health	\$36,000
Tourette Syndrome	\$2,000
EHDI	\$10,760
Muscular Dystrophy	\$6,000
ADHD	\$1,900
Fragile X	\$2,000
Spina Bifida	\$7,000
Congenital Heart Failure	\$7,000
Public Health Approach to Blood Disorders	\$4,400
Sickle Cell Disease Research	\$2,000
Hemophilia CDC Activities	\$3,500
Thalassemia	\$2,100
Hemophilia Treatment Centers	\$5,100
<b>NCBDDD Total</b>	<b>\$167,810</b>





# NCBDDD's Thematic Areas



**SAVING BABIES**  
THROUGH BIRTH DEFECTS  
PREVENTION AND RESEARCH



**HELPING CHILDREN**  
LIVE TO THE FULLEST BY UNDERSTANDING  
DEVELOPMENTAL DISABILITIES



**PROTECTING PEOPLE**  
AND PREVENTING COMPLICATIONS  
OF BLOOD DISORDERS



**IMPROVING HEALTH**  
OF PEOPLE WITH DISABILITIES



# Stigma – Hidden and Seen Disability



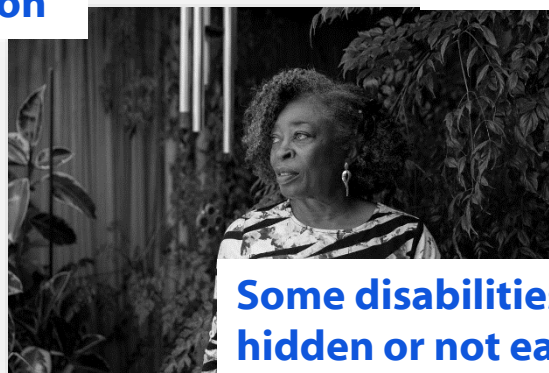
**Mental health of children and parents —a strong connection**



**Delayed Identification of Infants and Children**



**Bullying**



**Some disabilities may be hidden or not easy to see.**

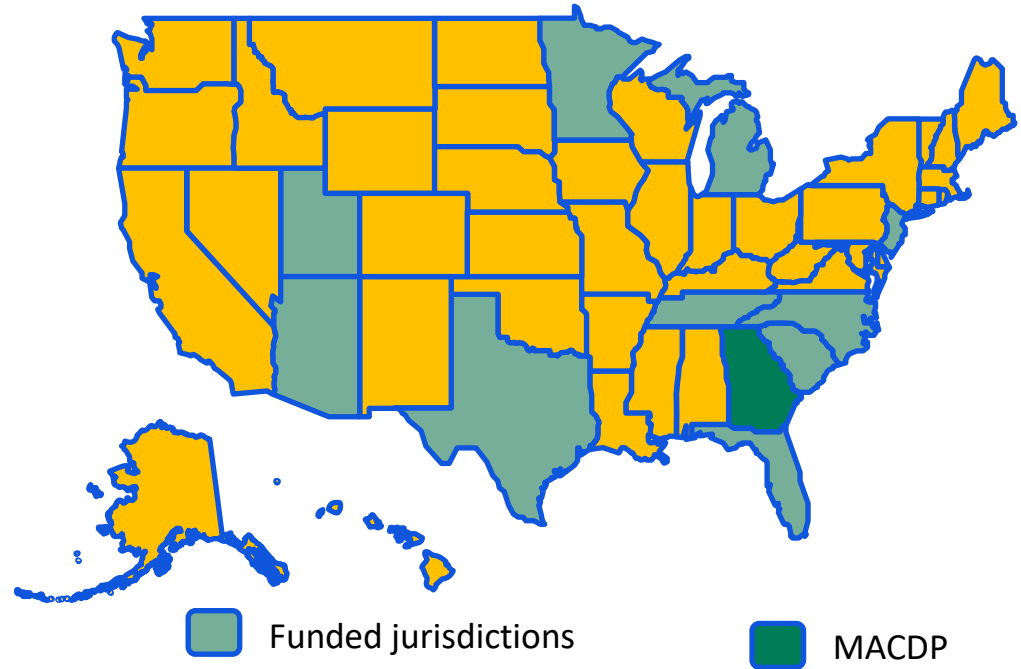


# CDC State-Based Birth Defects Tracking



CDC collects data on Down syndrome, as well as additional co-occurring major birth defects

Data improve planning for needed services and supports





# Congenital Heart Defect: Areas of Focus



## Prevalence

Estimate the number of babies born with and people living with heart defects



## Physical Health

Understand the physical health and long-term survival of people with heart defects



## Risk Factors

Identify environmental and genetic factors that may cause heart defects



## Reproductive Health

Understand the reproductive health of women with heart defects



## Screening

Study the impact of newborn screening for critical congenital heart defects, as well as ways to improve screening



## Quality of Life

Characterize the quality of life of people living with heart defects, including social, educational, and behavioral aspects



## Healthcare Access & Use

Characterize healthcare access and use among people living with heart defects



## Awareness

Disseminate information about heart defects as a lifelong condition



# Birth Defects Among Infants With Down Syndrome



**CDC researchers and partners are looking at survival of people with Down syndrome who do or do not have critical congenital heart defects**

- Among 13,376 children with Down syndrome, 75% had at least one reported co-occurring birth defect diagnosis code
- Among 6,210 of these children identified by active tracking programs, 66% had a heart defect
- Up-to-date population-based data on birth defects among children with Down syndrome can aid clinical evaluation and monitoring



# Infant Hearing loss



More and more babies who are born deaf or hard of hearing are being **identified early** in the United States



2005



**2,634**  
babies

2019



**5,934**  
babies



**1**

**Before one month of age: Hearing Screening**



**3**

**Before three months of age: Hearing evaluation**



**6**

**Before six months of age: Early Intervention**



# Disability and Health



One in four American adults has a **disability**.\*

\*2016 Behavioral Risk Factor Surveillance System (BRFSS)





# Special Olympics International: Creating a Tipping Point towards Inclusive Health for People with Intellectual Disabilities



**IN THE NEWS**

Prevent Flu and Get a Flu Vaccine: What You Need to Know

Learn more.

Infographic: What You Should Know About the Flu

The Flu: A Guide for Parents

**PROTECT YOURSELF AGAINST THE FLU**

**MASK UP**

**LATHER UP**

**SLEEVE UP**

**Social Media Graphics**

Access graphics you can use for Facebook, Instagram and Twitter.



## IN THE NEWS

Caring for People With Intellectual Disabilities During COVID-19: 4 Tips for Healthcare Professionals



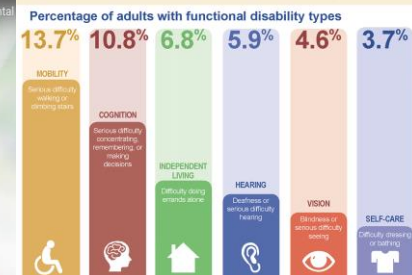
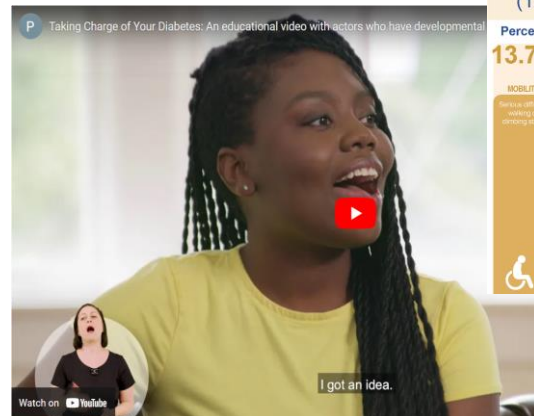
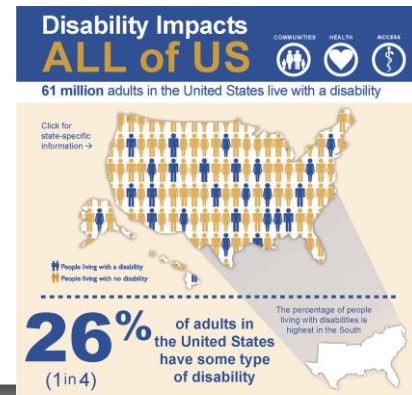
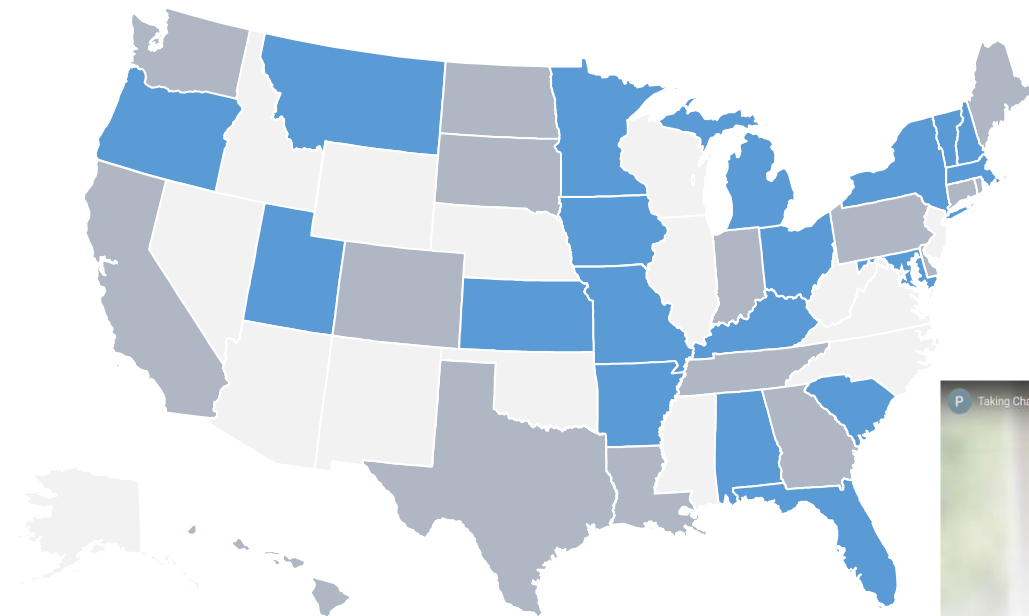
## FITNESS MOVIES

Video 1: Welcome and Warm Up

Want to get right to the exercises? **Start at 1:56.**



# Disability and Health State Programs





# COVID-19: Major Implications for NCBDDD populations



**CLD\_GSU** @CLD\_GSU · Jul 26

...

Hear from Evan & his DSP, Andrew, about why they got the COVID-19 vaccine.

CLD is working with @AUCDNews to ensure all eligible people with disabilities have access to the COVID-19 vaccine by the #ADA anniversary today. [youtube.com/watch?v=giBAyQ...](https://youtube.com/watch?v=giBAyQ...)

[#VaccinateByADA](#) [#AUCDSleeveUP](#)



Erin Vinoski Thomas, PhD, MPH (she/her) and 6 others



# People with Certain Medical Conditions

Updated May 13, 2021 Languages ▾ Print

Vaccine Information for People with [Certain Medical Conditions](#).



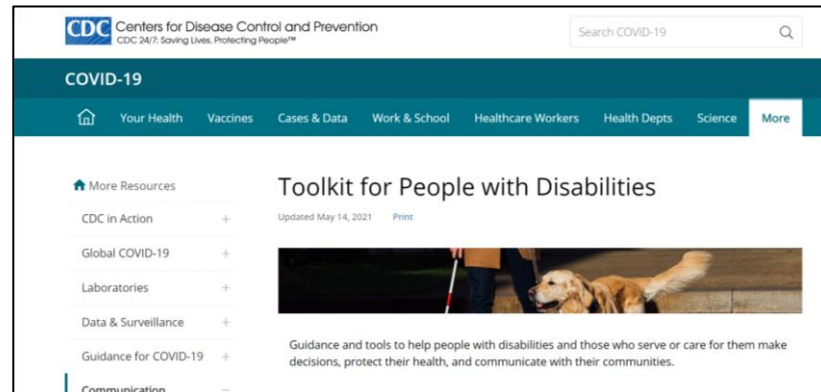
This information is intended for a general audience. Healthcare providers should see [Underlying Medical Conditions Associated with High Risk for Severe COVID-19](#) for more detailed information.

## Down syndrome

Having Down syndrome **can make you more likely** to get severely ill from COVID-19.

Get more information:

- [Down syndrome | CDC](#)



**CDC** Centers for Disease Control and Prevention  
CDC 24/7: Saving Lives. Protecting People™

Search COVID-19

**COVID-19**


Home Your Health Vaccines Cases & Data Work & School Healthcare Workers Health Depts Science More

More Resources

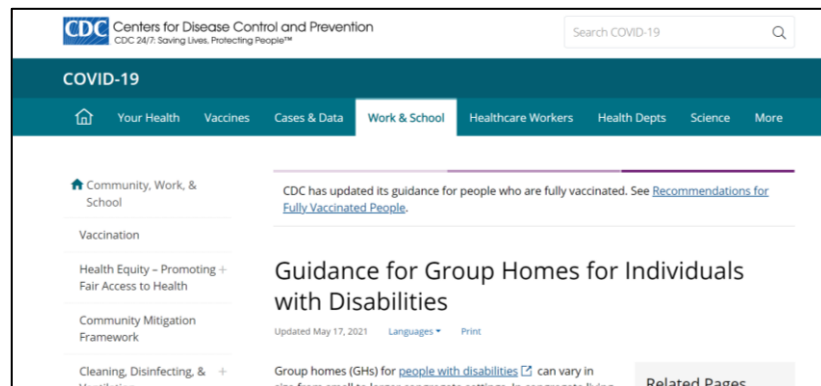
- CDC in Action +
- Global COVID-19 +
- Laboratories +
- Data & Surveillance +
- Guidance for COVID-19 +
- Communication -

### Toolkit for People with Disabilities

Updated May 14, 2021 Print



Guidance and tools to help people with disabilities and those who serve or care for them make decisions, protect their health, and communicate with their communities.



**CDC** Centers for Disease Control and Prevention  
CDC 24/7: Saving Lives. Protecting People™

Search COVID-19

**COVID-19**

Home Your Health Vaccines Cases & Data Work & School Healthcare Workers Health Depts Science More

Community, Work, & School

Vaccination

Health Equity - Promoting + Fair Access to Health

Community Mitigation Framework

Cleaning, Disinfecting, & Ventilation

CDC has updated its guidance for people who are fully vaccinated. See [Recommendations for Fully Vaccinated People](#).

### Guidance for Group Homes for Individuals with Disabilities

Updated May 17, 2021 Languages ▾ Print

Group homes (GHs) for [people with disabilities](#) can vary in size from small to larger congregate settings. In congregate living

Related Pages



# White House Virtual Forum: *Breaking Down Barriers for People Who Have Challenges Accessing COVID-19 Vaccination* (April 21, 2021)



**SLEEVES UP, NOLA!**

The COVID vaccine is our shot to get back to normal.



## Disability is a part of vaccine equity

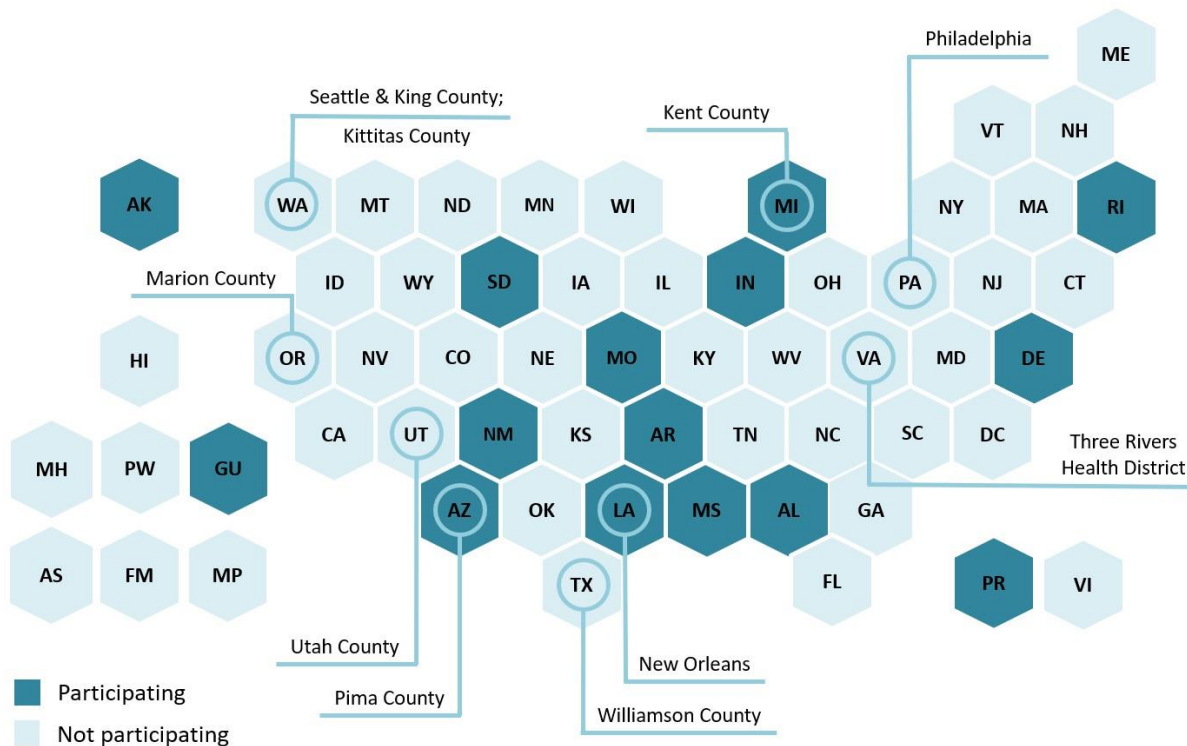








# Addressing Needs of People with Disabilities in COVID-19 Local Preparedness Planning, Mitigation and Recovery





# CDC COVID Data Tracker July 27, 2021

## COVID Data Tracker

### United States At a Glance

**Cases Total** 34,548,847

Last 30 Days



**Deaths Total** 609,012

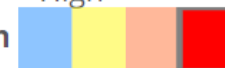
Last 30 Days



**69.1% of Adults with At Least  
One Vaccination**



**Community  
Transmission** High

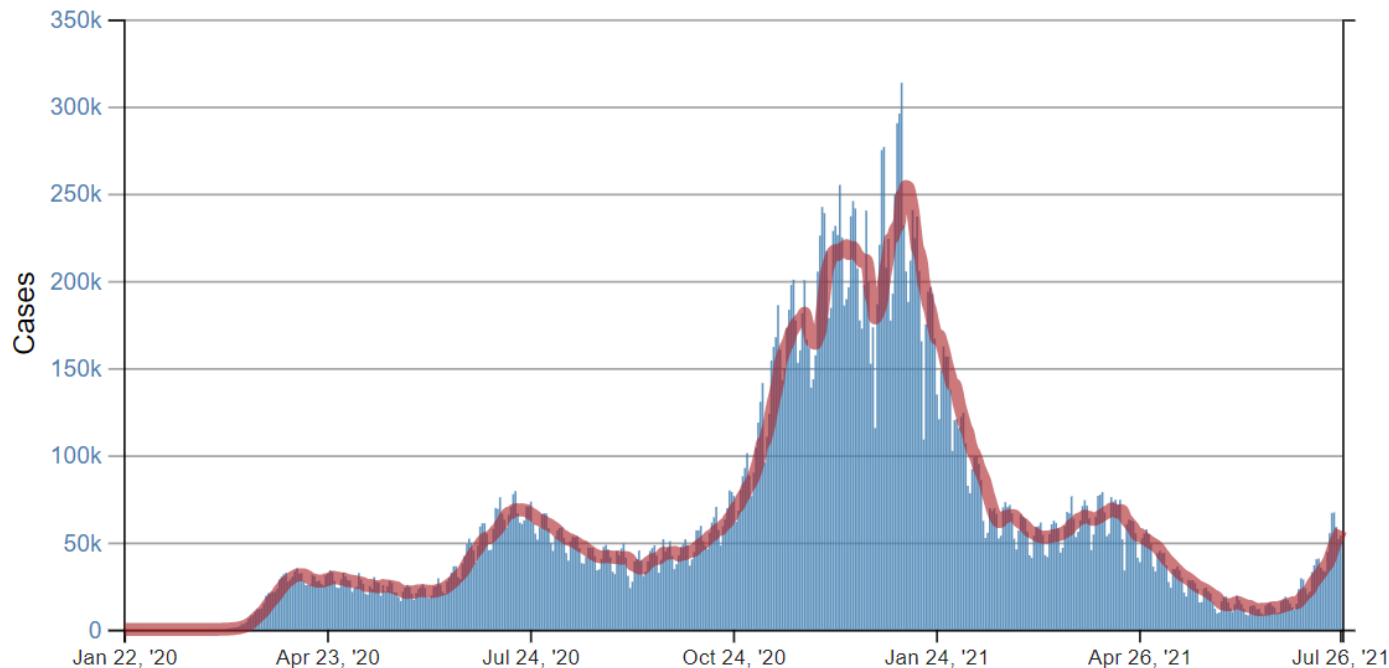




# COVID-19 Daily Case Trend - US



Daily Trends in Number of COVID-19 Cases in the United States Reported to CDC



July 8, 2020 – July 26, 2021



# COVID-19 Hospitalizations



## New Admissions of Patients with Confirmed COVID-19, United States August 01, 2020 – July 25, 2021



**2,369,943**

Total Admissions

Aug 01, 2020 – Jul 25, 2021

**4,981**

Current 7-Day Average

Jul 19, 2021 – Jul 25, 2021

**3,376**

Prior 7-Day Average

Jul 12, 2021 – Jul 18, 2021

**16,492**

Peak 7-Day Average

Jan 03, 2021 – Jan 09, 2021

**+47.5%**

Percent change from prior 7-day  
avg. of Jul 12, 2021 – Jul 18, 2021

**-69.8%**

Percent change from peak 7-day  
avg. of Jan 03, 2021 – Jan 09, 2021

By Jurisdiction

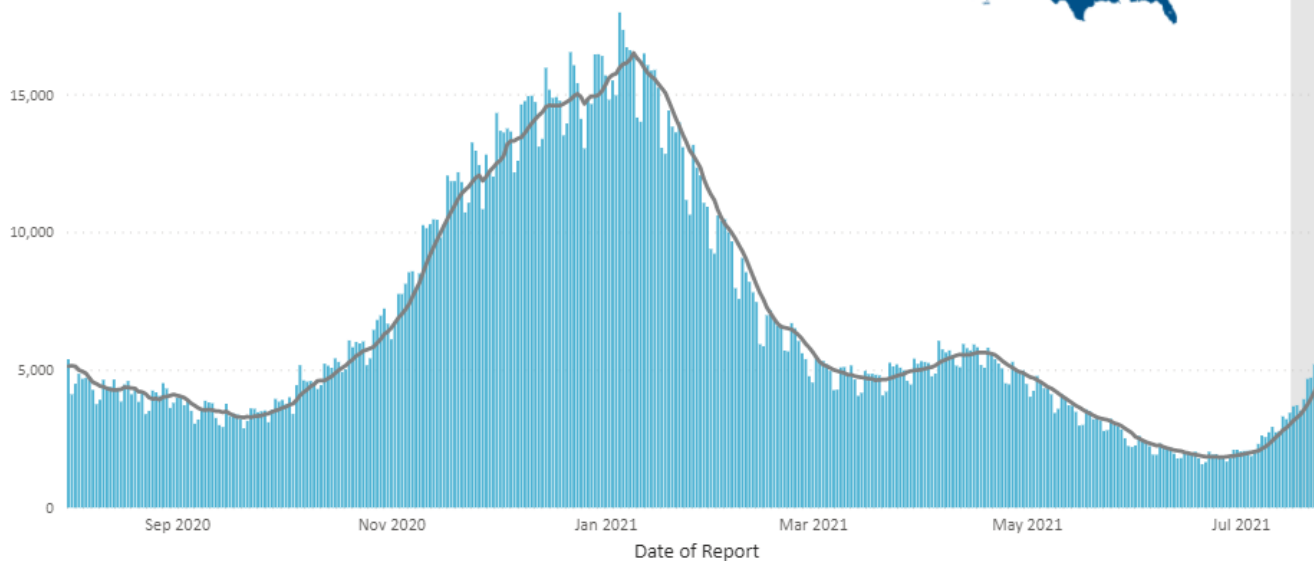
By Jurisdiction and Age Group

Select a Jurisdiction

United States



New Admissions of Patients with Confirmed COVID-19



● Daily Admissions of Patients with Confirmed COVID-19 — 7-Day Moving Average

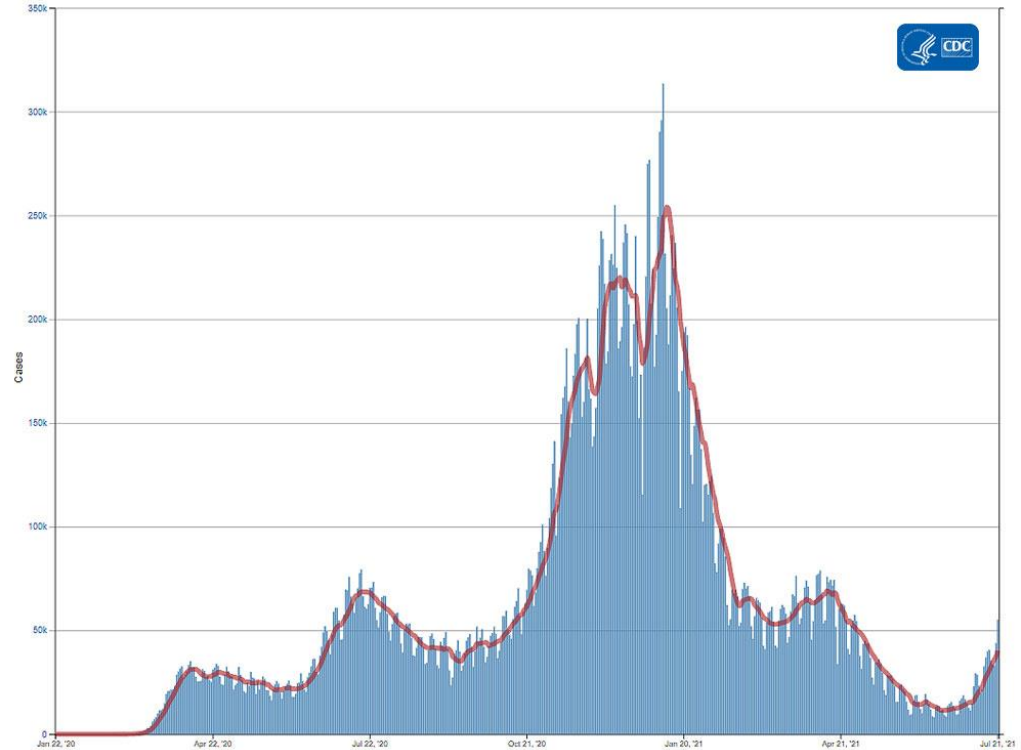


# COVID-19 Deaths

January 21, 2020 – July 28, 2021



## Daily Trends in COVID-19 Cases in the United States Reported to CDC



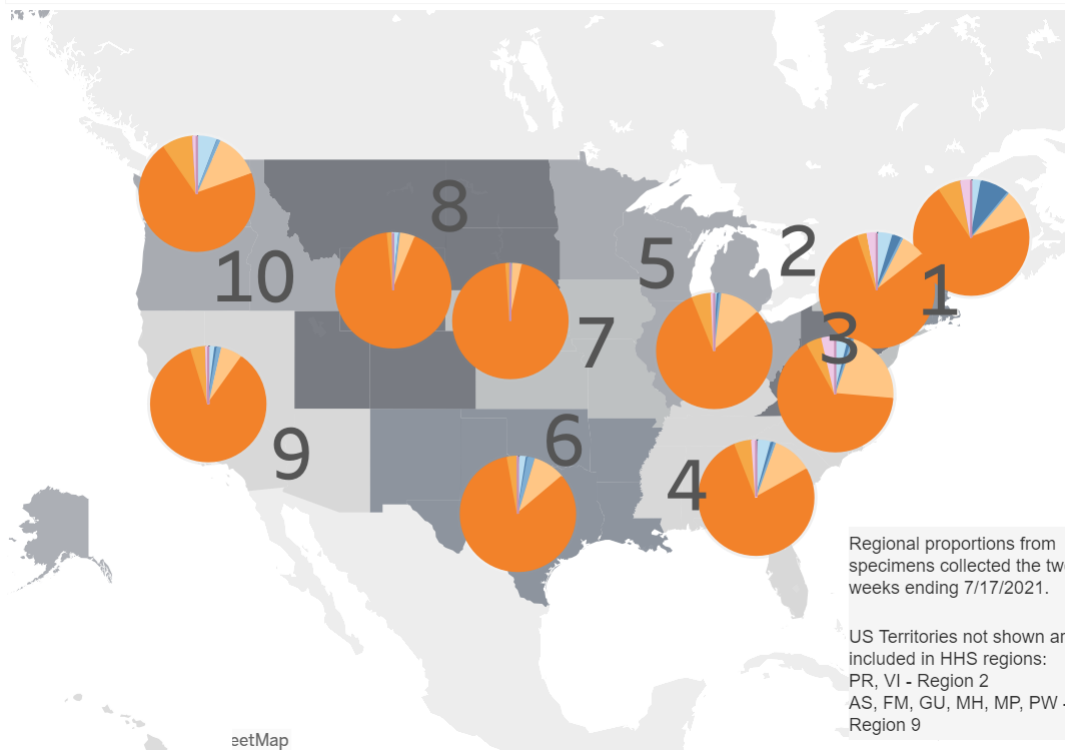


# Emerging Variant Virus Cases in the United States

As of July 28, 2021



## United States: 7/4/2021 – 7/17/2021 NOWCAST



Lineage	Type
B.1.617.2	Delta VOC
B.1.1.7	Alpha VOC
P.1	Gamma VOC
B.1.621	
B.1.526	Iota VOI
B.1.351	Beta VOC
B.1.427	Epsilon VOI
B.1.525	Eta VOI
B.1.617.3	VOI
B.1.429	Epsilon VOI
Other	

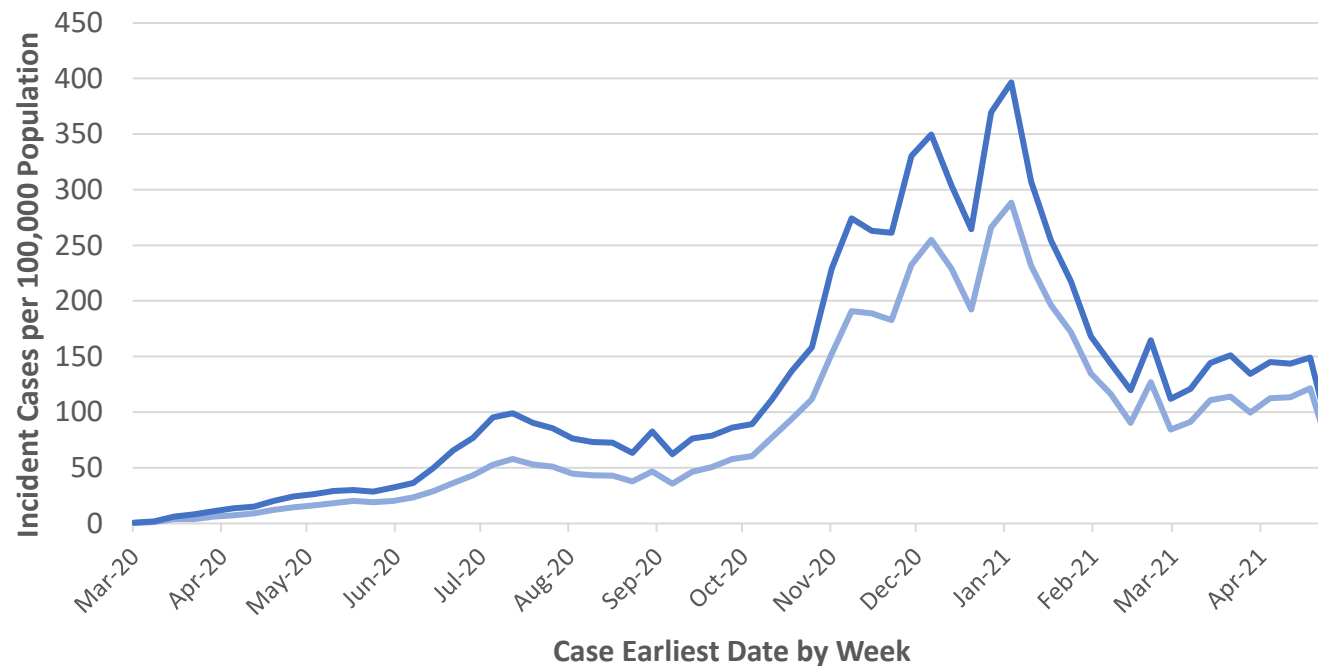
\* Other represents lineages each the last 12



# COVID-19 Incidence among Adolescents



March 1, 2020 – April 30, 2021



**>1.5 million**  
cases among  
adolescents 12-17  
years of age

— 12 - 15 Years  
— 16 - 17 Years



#VaccinateByADA



Join  AUCD in Celebrating

**ADA 31**



Americans with Disabilities Act

July 26, 2021



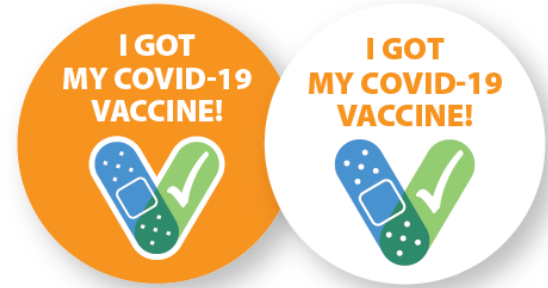


# Currently Authorized Vaccines

- Pfizer-BioNTech
- Moderna



mRNA vaccines  
Require two doses



- Johnson & Johnson/Janssen



Viral vector vaccine  
Requires one dose

- All three vaccines were tested in tens of thousands of adults from diverse backgrounds, including older adults and communities of color.
- All three vaccines have been proven effective at preventing serious illness, hospitalization, and death from COVID-19 disease.
- It is unknown how long protection from vaccines might last.

<https://www.pfizer.com/news/press-release/press-release-detail/pfizer-and-biontech-conclude-phase-3-study-covid-19-vaccine>

<https://investors.modernatx.com/news-releases/news-release-details/modernas-covid-19-vaccine-candidate-meets-its-primary-efficacy>

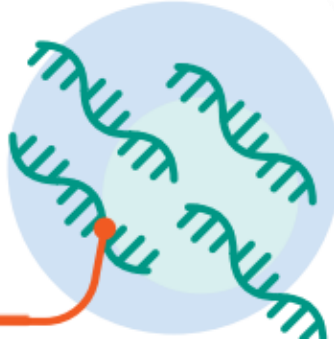


# How mRNA COVID-19 Vaccines Work



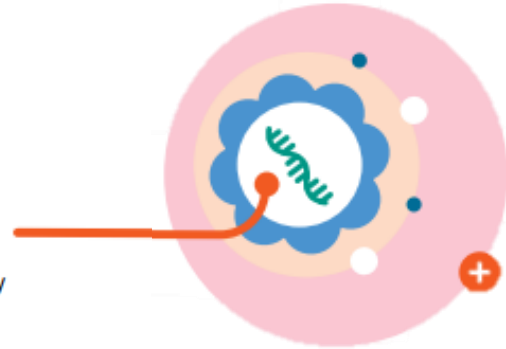
## What is mRNA?

Messenger RNA, or mRNA, is genetic material that tells your body how to make proteins.



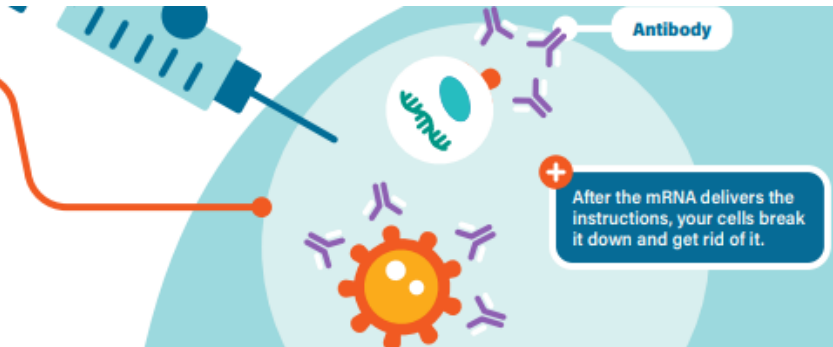
## What is in the vaccine?

The vaccine is made of mRNA wrapped in a coating that makes delivery easy and keeps the body from damaging it.



## How does the vaccine work?

The mRNA in the vaccine teaches your cells how to make copies of the **spike protein**. If you are exposed to the real virus later, your body will recognize it and know how to fight it off.





# How Viral Vector COVID-19 Vaccines Work

## What is a viral vector vaccine?

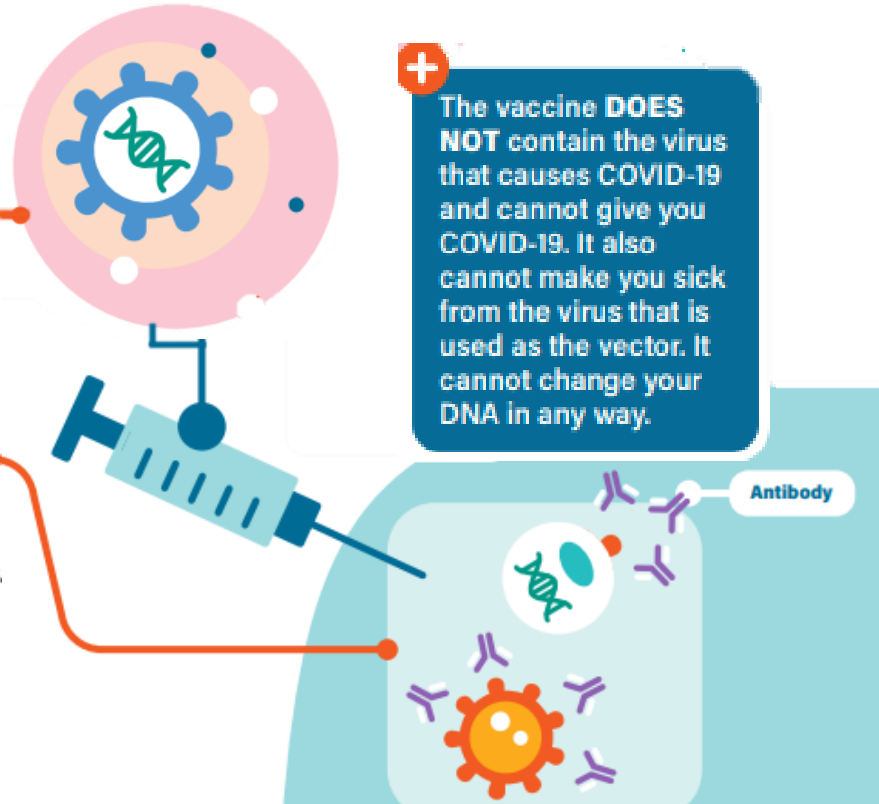
A viral vector vaccine uses a harmless version of a different virus, called a "vector," to deliver information to the body that helps it protect you.



The vaccine **DOES NOT** contain the virus that causes COVID-19 and cannot give you COVID-19. It also cannot make you sick from the virus that is used as the vector. It cannot change your DNA in any way.

## How does the vaccine work?

The vaccine teaches your body how to make copies of the **spike proteins**. If you are exposed to the real virus later, your body will recognize it and know how to fight it off.





# COVID-19 Vaccine Effectiveness

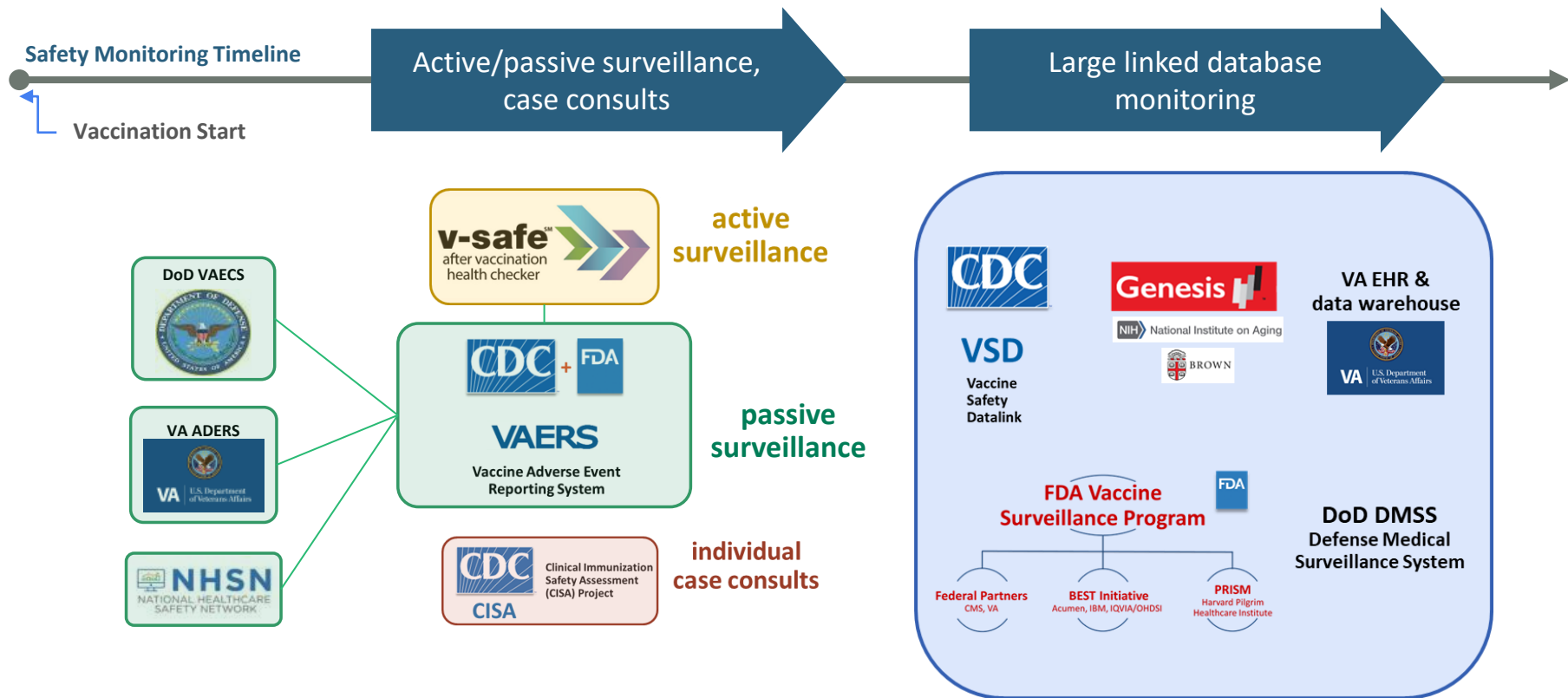


- All three vaccines authorized for use in US are effective at preventing COVID-19.
- Pfizer-BioNTech and Moderna vaccines had >94% vaccine effectiveness (VE) in phase 3 clinical trials.
  - 100% VE against severe disease
  - No deaths occurred in the vaccinated group.
- Johnson & Johnson's Janssen vaccine had 72% VE in U.S. clinical trial sites and 66% worldwide.
  - 85% VE against severe disease
  - No deaths occurred in the vaccinated group.





# Vaccine Safety Monitoring





# Possible Side-Effects After Getting a COVID-19 Vaccine



## Common side effects:

On the arm where you got the shot:



- Pain
- Redness
- Swelling

Throughout the rest of your body:



- Tiredness
- Headache
- Muscle pain
- Chills
- Fever
- Nausea

## You may consider:

To reduce pain and discomfort where you got the shot



- Apply a clean, cool, wet washcloth over the area.
- Use or exercise your arm.

To reduce discomfort from fever



- Drink plenty of fluids.
- Dress lightly.

It is not recommended you take over-the-counter medicine such as ibuprofen, aspirin, or acetaminophen before vaccination for the purpose of trying to prevent vaccine-related side-effects.



# Persons with underlying medical conditions



- Vaccine may be administered to persons with underlying medical conditions who have no contraindications to vaccination
- Clinical trials demonstrate similar safety and efficacy profiles in persons with underlying medical conditions, including those that place them at increased risk for severe COVID-19, compared to persons without comorbidities



## Total Vaccine Doses

Delivered 395,974,515

Administered 343,361,524

**Learn more about  
the distribution of  
vaccines.**

# 163.6M

**People fully  
vaccinated**

People Vaccinated	At Least One Dose	Fully Vaccinated
Total	189,494,180	163,588,042
% of Total Population	57.1%	49.3%
Population ≥ 12 Years of Age	189,271,132	163,458,560
% of Population ≥ 12 Years of Age	66.8%	57.6%
Population ≥ 18 Years of Age	178,887,734	155,409,480
% of Population ≥ 18 Years of Age	69.3%	60.2%
Population ≥ 65 Years of Age	49,008,552	43,678,577
% of Population ≥ 65 Years of Age	89.6%	79.9%



About these data

CDC | Data as of: July 28, 2021 6:00am ET. Posted: Wednesday, July 28, 2021 2:40 PM ET



# PEDIATRICS

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

## Important Considerations for COVID-19 Vaccination of Children With Developmental Disabilities

Sarah C Tinker, PhD, MPH, Mary E Cogswell, RN, DrPH, Georgina Peacock, MD, MPH,  
A Blythe Ryerson, PhD, MPH

DOI: 10.1542/peds.2021-053190

Journal: *Pediatrics*

Article Type: Pediatrics Perspectives

Citation: Tinker SC, Cogswell ME, Peacock G, Ryerson AB. Important Considerations for COVID-19 Vaccination of Children With Developmental Disabilities. *Pediatrics*. 2021; doi: 10.1542/peds.2021-053190



- 1) Children with developmental disabilities (DDs) may be at higher risk from COVID-19 illness because of increased prevalence of underlying health conditions, suboptimal vaccination rates, and systemic inequities.
- 2) Strategies can be implemented and supported by pediatricians to ensure that children with DDs, their caregivers, family members, and service providers receive the COVID-19 vaccine to reduce negative outcomes.
- 3) Highlighting the unique considerations for COVID-19 vaccination for children with DDs can support equitable access of vaccination for children with DDs and their families



## SHOULD I BE CONCERNED ABOUT THE DELTA VARIANT?

New data show Delta is different than past versions of the virus: it is much more contagious.

- Vaccinated people can get breakthrough infections of Delta variant and may be contagious.
- Vaccinated individuals represent a very small amount of total transmission.



## DO I NEED TO WEAR A MASK?

In areas of substantial or high transmission, everyone should wear a mask in public indoor settings to help prevent the spread of Delta variant and protect others.





## ARE VACCINES EFFECTIVE?

**Yes!** Getting vaccinated prevents severe illness, hospitalization, and death; it also helps reduce the spread of the virus in communities.

With the Delta variant, vaccination is more urgent than ever.

Protected from	Vaccinated	Unvaccinated
Severe Symptoms	✓	✗
Hospitalization	✓	✗
Death	✓	✗

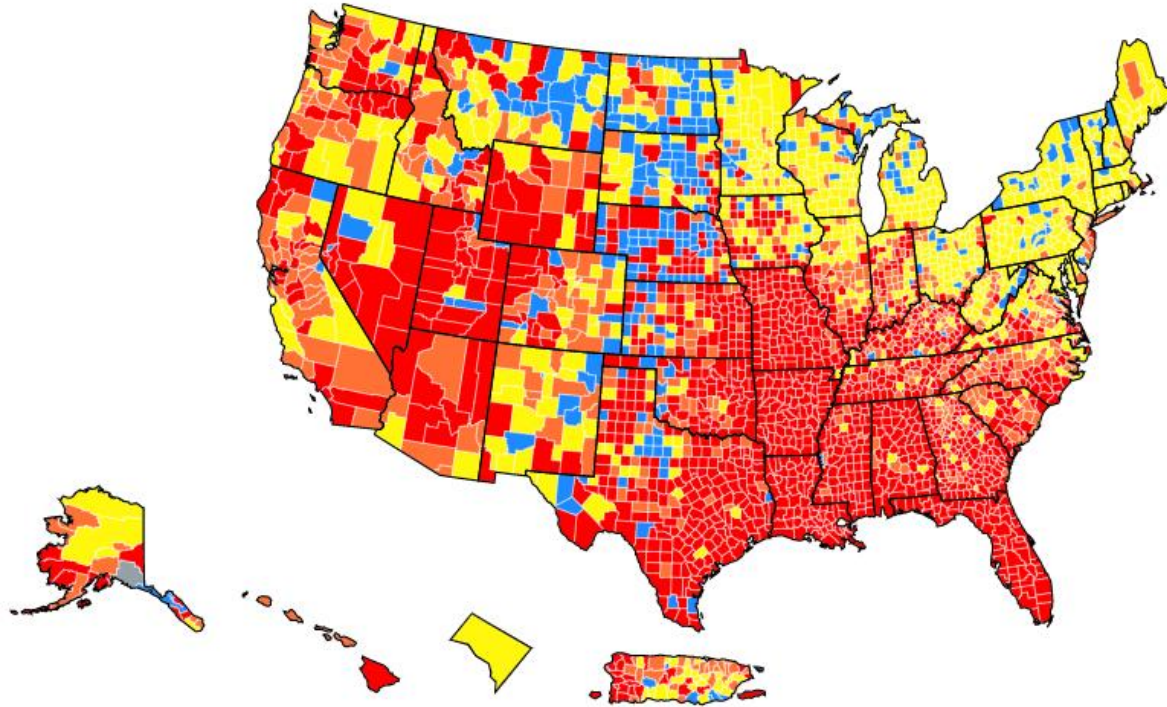
## WHAT SHOULD SCHOOLS DO?

CDC recommends universal indoor masking for all teachers, staff, students, and visitors to K-12 schools, regardless of vaccination status. Children should return to full-time in-person learning in the fall with layered prevention strategies in place.





# COVID-19 Hot Spots: Jul 19 2021 - Jul 25 2021



● High    ● Substantial    ● Moderate    ● Low    ● No Data

<https://covid.cdc.gov/covid-data-tracker/#county-view>



# Looking Ahead

COVID-19 vaccine implementation efforts are focused on:



## Continued surveillance of variant viruses

To prepare and adapt with a vaccine response



## Continued vaccine effectiveness studies

To understand how the vaccines are working



## Expanding vaccine-eligible populations

To vaccinate groups like children and adolescents



## Combating vaccine hesitancy

And offering vaccines to groups that declined initially



## Continuing focus on vaccine equity

To include disproportionately affected communities



# Future Directions



## Health Equity in Action

Updated May 28, 2021 Languages ▼ Print



To help the United States succeed against COVID-19, CDC is working with state, territorial, local, and tribal partners, and community-serving organizations, to ensure all public health actions address health disparities for all populations.

### Populations of Focus

- Racial and ethnic minority populations
- People living in rural or frontier areas
- People experiencing homelessness
- **People with disabilities**
- People with substance use disorders
- People who are justice-involved

**CDC** Centers for Disease Control and Prevention  
CDC 24/7: Saving Lives, Protecting People™

Search

Advanced Search

### Disability and Health Promotion

Disability & Health Home > Articles & Key Findings

- Disability & Health Home
- Disability & Health Overview
- Disability Inclusion +
- Disability & Health Healthy Living +
- Disability & Health Emergency Preparedness +
- Data & Statistics +
- Articles & Key Findings -
- Mental Health for All
- Physical Activity for People with Disability

## Primary Care Providers' Level of Preparedness for Recommending Physical Activity to Adults with Disabilities

### Are Primary Care Providers Recommending Physical Activity to Patients with Disabilities?

The Centers for Disease Control and Prevention's (CDC's) *Preventing Chronic Disease* journal published a new study that looked at how prepared primary care providers (PCPs) feel to recommend physical activity to adults with disabilities. CDC scientists found that PCPs, specifically family doctors, internists, and nurse practitioners, are more likely to recommend physical activity to their patients with disabilities on a regular basis if they feel prepared to do so. However, just over 1 in 3 PCPs strongly agreed that they felt prepared to discuss physical activity with their adult patients with disabilities. Currently, half of PCPs recommend physical activity to their patients with disabilities at most visits.



# Additional Resources for Healthcare Providers

- NIH Treatment Guidelines:  
<https://www.covid19treatmentguidelines.nih.gov/therapeutic-management/>
- CDC Clinical Care Guidelines: <https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care.html>
- CDC's COVID-19 Data Tracker: [https://covid.cdc.gov/covid-data-tracker/?CDC\\_AA\\_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronaviruses%2F2019-ncov%2Fcases-updates%2Fcases-in-us.html#cases\\_casesper100klast7days](https://covid.cdc.gov/covid-data-tracker/?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronaviruses%2F2019-ncov%2Fcases-updates%2Fcases-in-us.html#cases_casesper100klast7days)
- CDC's COVID-19 Vaccination Guidelines:  
<https://www.cdc.gov/vaccines/covid-19/index.html>



# CDC Webpages on Underlying Conditions

- CDC webpages on underlying conditions
  - For the general public:  
<https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>
  - For clinicians:
    - <https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/underlyingconditions.html>
    - <https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/underlying-evidence-table.html>





# **MAKING A DIFFERENCE ACROSS THE LIFESPAN**

National Center on Birth Defects and Developmental Disabilities



# Thank you for attending!

## ❖ Additional Resources:

- [GLOBAL Medical Guidelines for Adults with Down Syndrome](#)
- [COVID-19 & Down Syndrome Resource](#)
- [GLOBAL COVID-19 & Down Syndrome Vaccine Tracker by State](#)

