

Mortality Review And Quality Improvement
For Persons Living With Intellectual And
Developmental Disabilities

-- *OR* --

How We Can Improve Care for Persons Living
With I/DD by Learning About Those Who
Died.



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Neither presenter has conflicts of interest
to disclose.

DDSD REVIEWS DEATHS OF PARTICIPANTS IN THE FOLLOWING DOH-FUNDED PROGRAMS:

- DD Waiver
- Medically Fragile Waiver
- Mi Via Waiver
- State General Fund
- Supports Waiver

THE NEW MEXICO DEPARTMENT OF HEALTH I/DD MORTALITY REVIEW PROCESS

- Initial RN Mortality Review
- Mortality Review Committee
 - Strict Confidentiality
 - Meets monthly to review mortality review reports
 - Multidisciplinary –
 - Nursing, Medical, Case Management, DDSD Management
 - Most members are from DDSD and DHI
 - Representative from the Governor's Commission on Disability

PURPOSE: SYSTEM IMPROVEMENT

- Mortality Review identifies opportunities for quality improvement through reviews of individual deaths and trends.
- Recommendations should support service system improvement
- Does not replace responsibility to report, review, investigate deaths

MORTALITY REVIEW...

- Is **NOT** an investigation to find blame...



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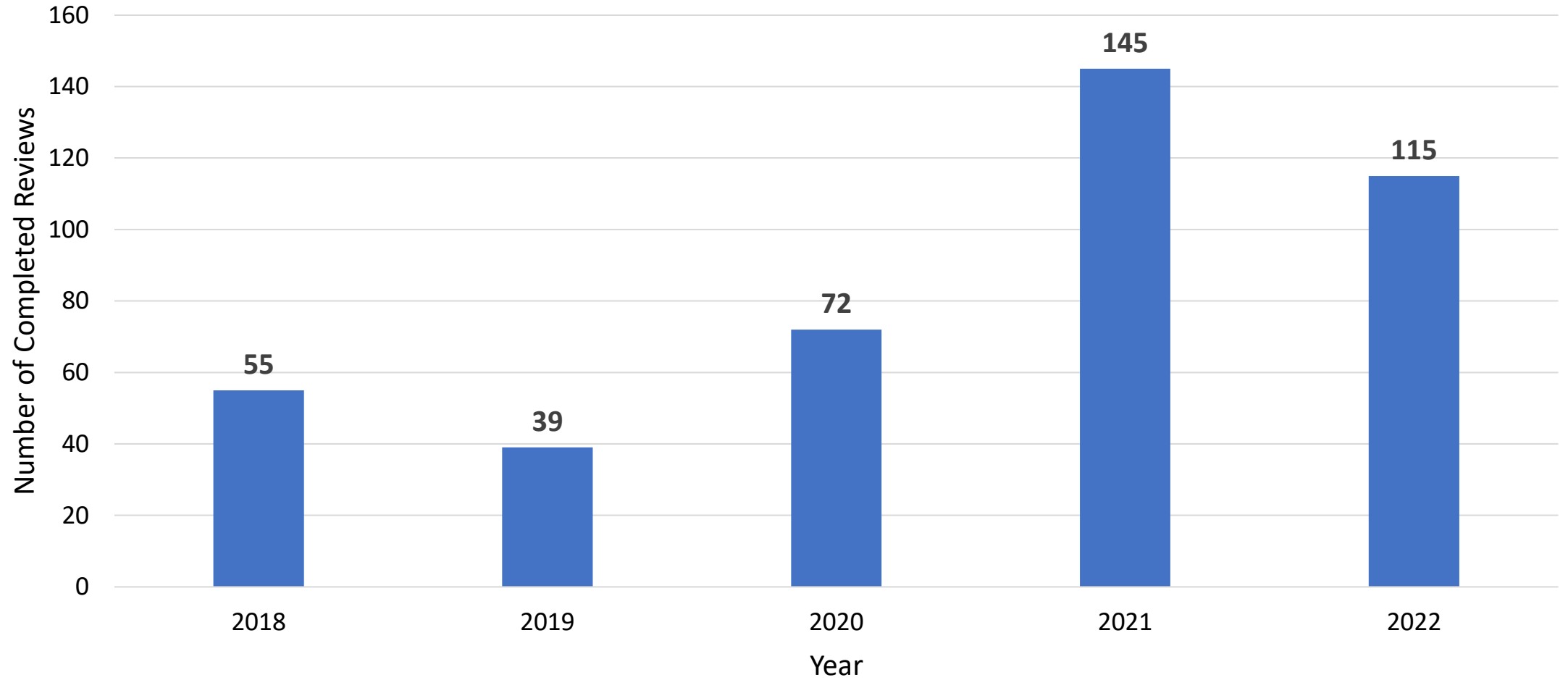


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- ▶ Mortality Review **IS** a way to identify better ways to serve persons with Intellectual and/or Developmental Disabilities

- Mortality review is a learning opportunity in order to improve supports and services for others.
- Mortality review is an opportunity to reflect on and honor the life of the individual who died.
- Mortality Review may identify issues of Quality Assurance (*i.e.*, *non-compliance with Standards*), but the main purpose is Quality Improvement (QI) - to promote competent and caring services and supports to individuals receiving services

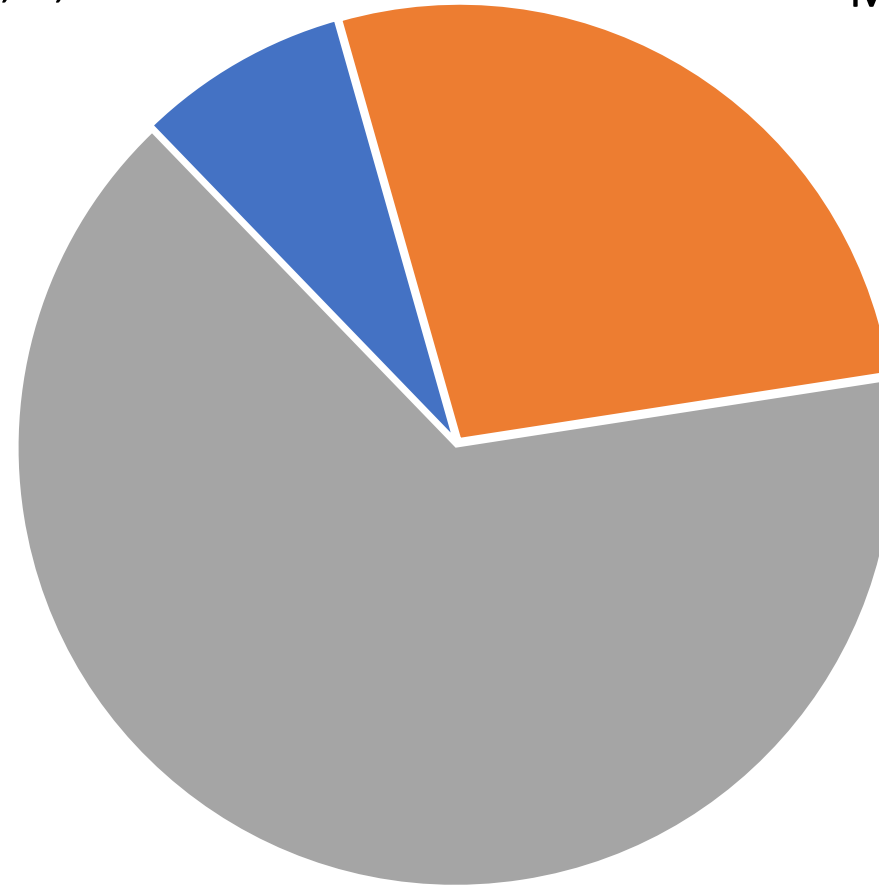
Number of Reviews Completed by the New Mexico I/DD Mortality Review Committee, State Fiscal Years 2018 to 2022



Proportion of reviews in FY2022, by waiver type

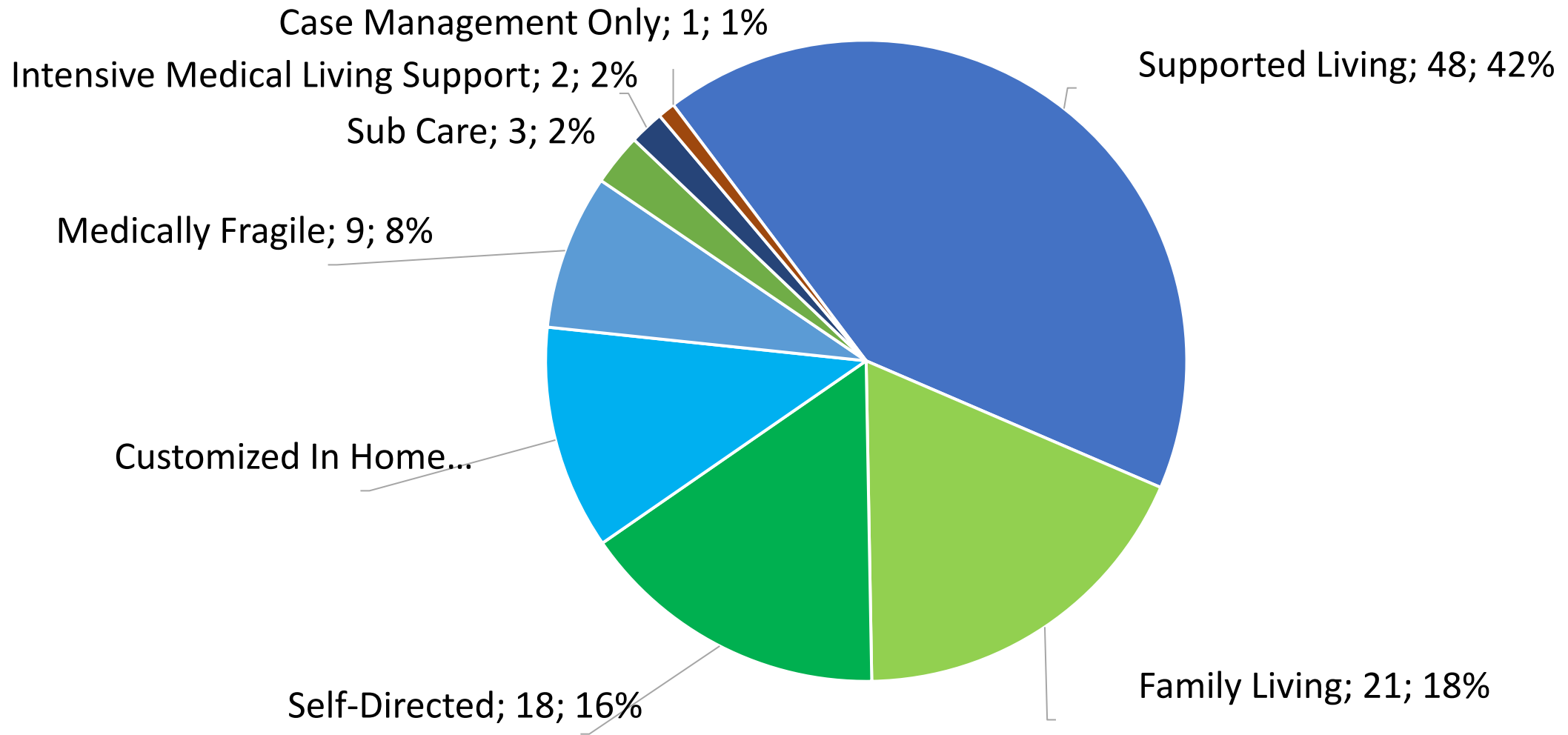
Medically Fragile Waiver; 9; 7.8%

Mi Via; 31; 27.0%

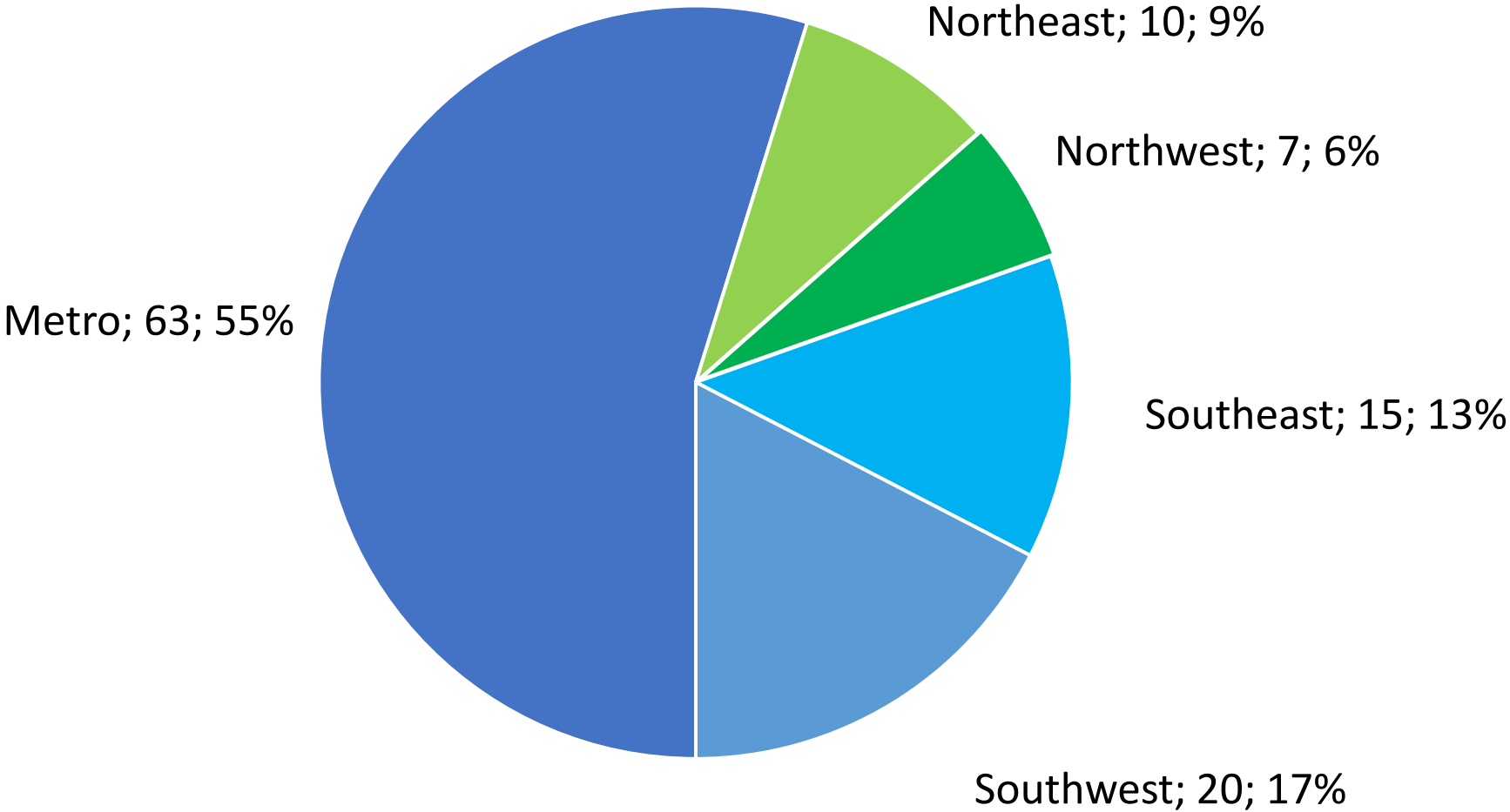


Traditional DD Waiver; 75; 65.2%

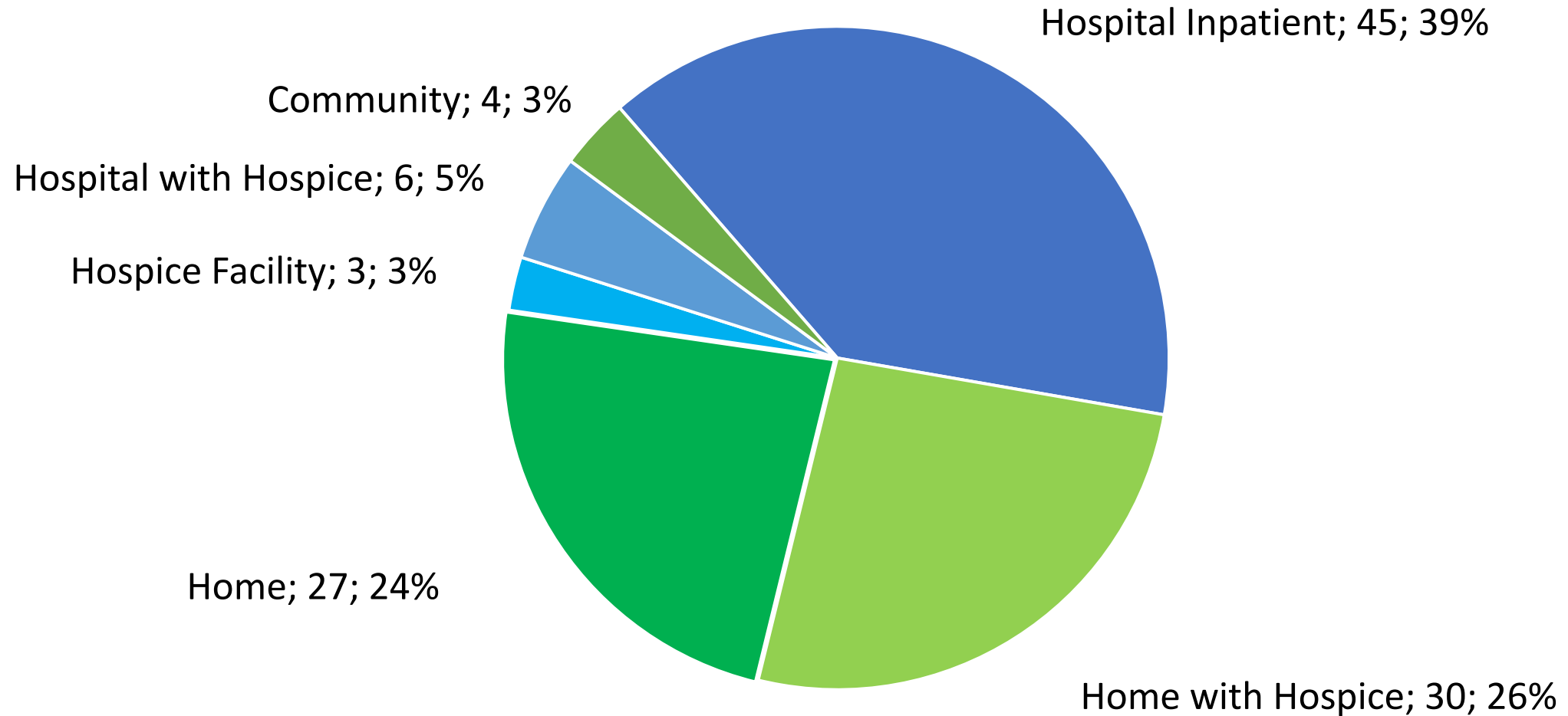
Type of Supports for reviewed deaths, FY2022



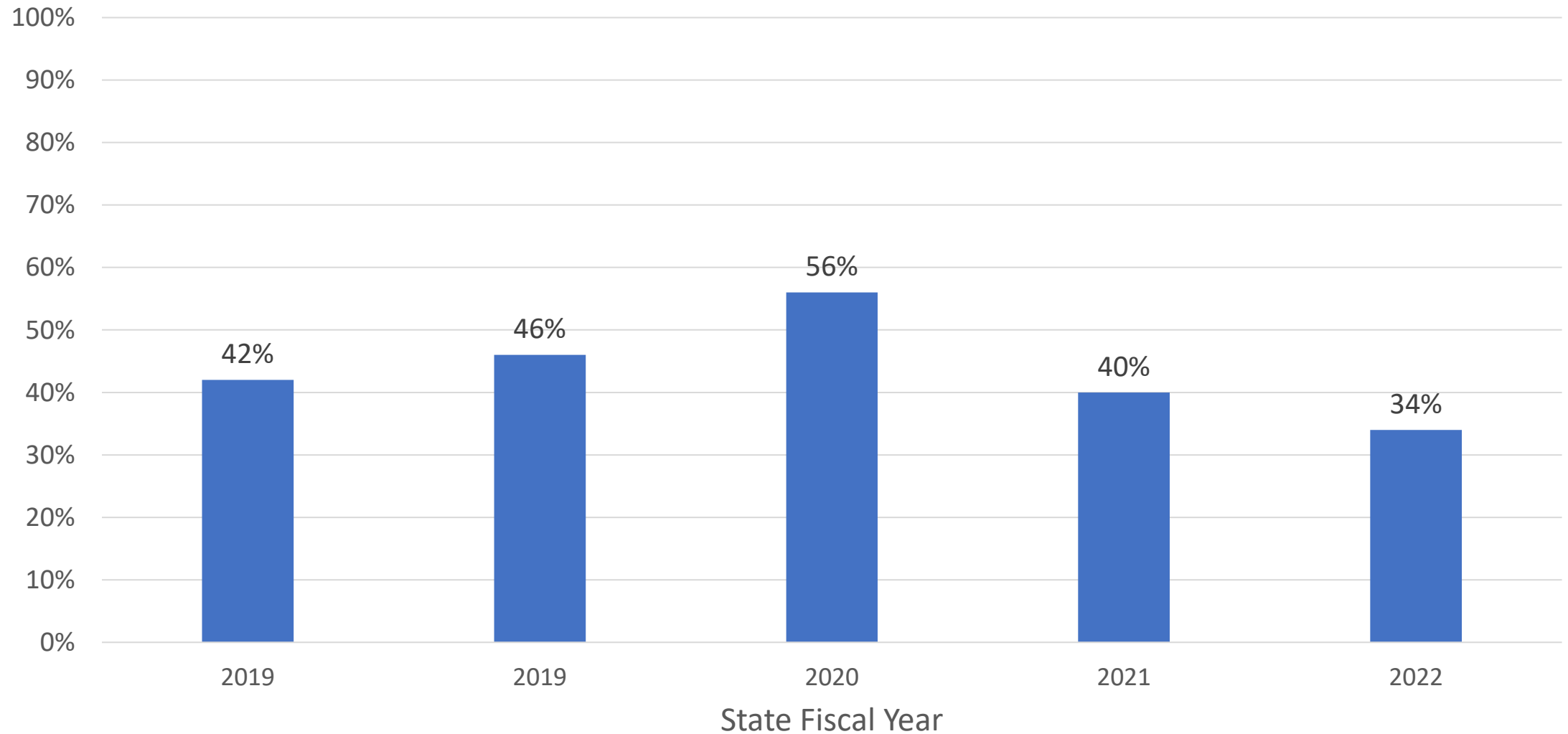
Region of Reviewed Deaths, FY2022



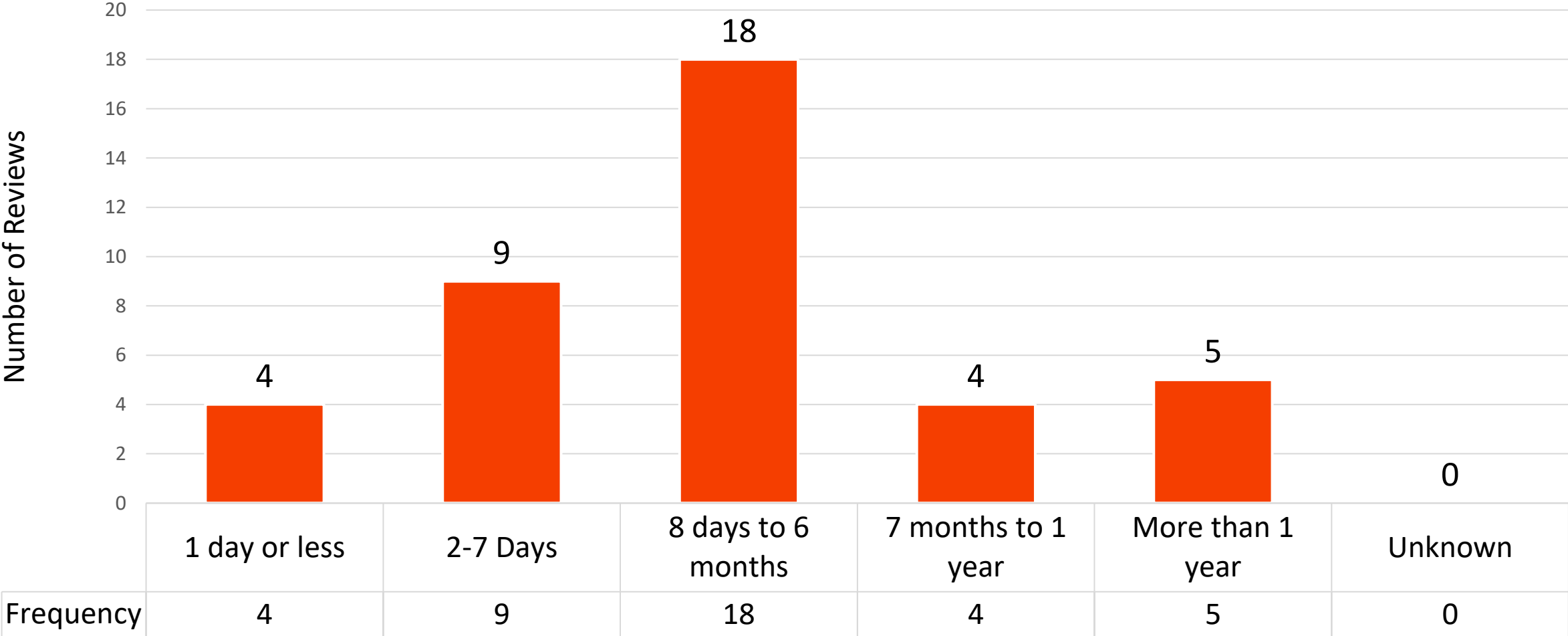
Place of Death for reviewed deaths, FY2022



Percentage of MRC-reviewed deaths in which the individual received hospice supports, by state fiscal year

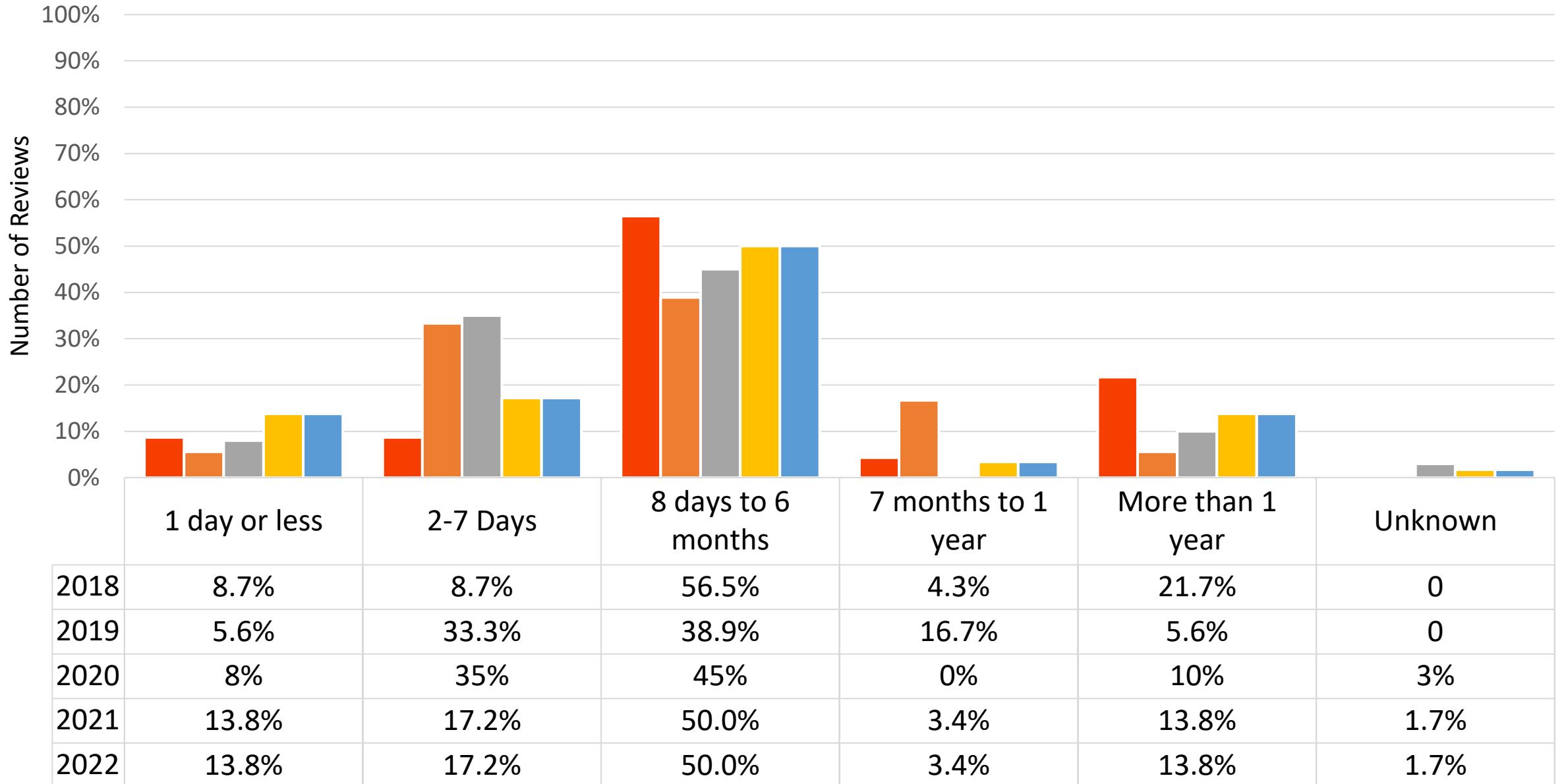


Duration of hospice services among MRC reviews for which hospice was utilized, FY2022

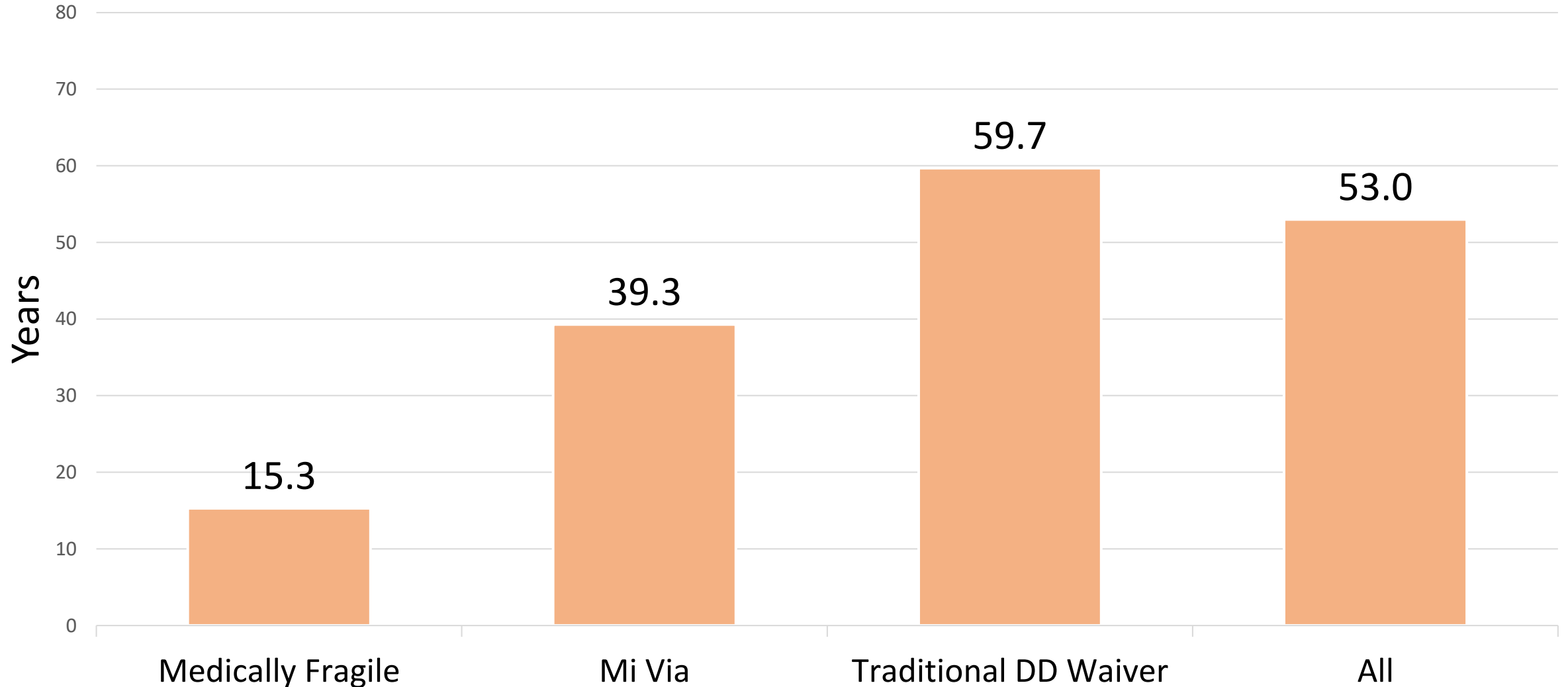


Duration of Hospice

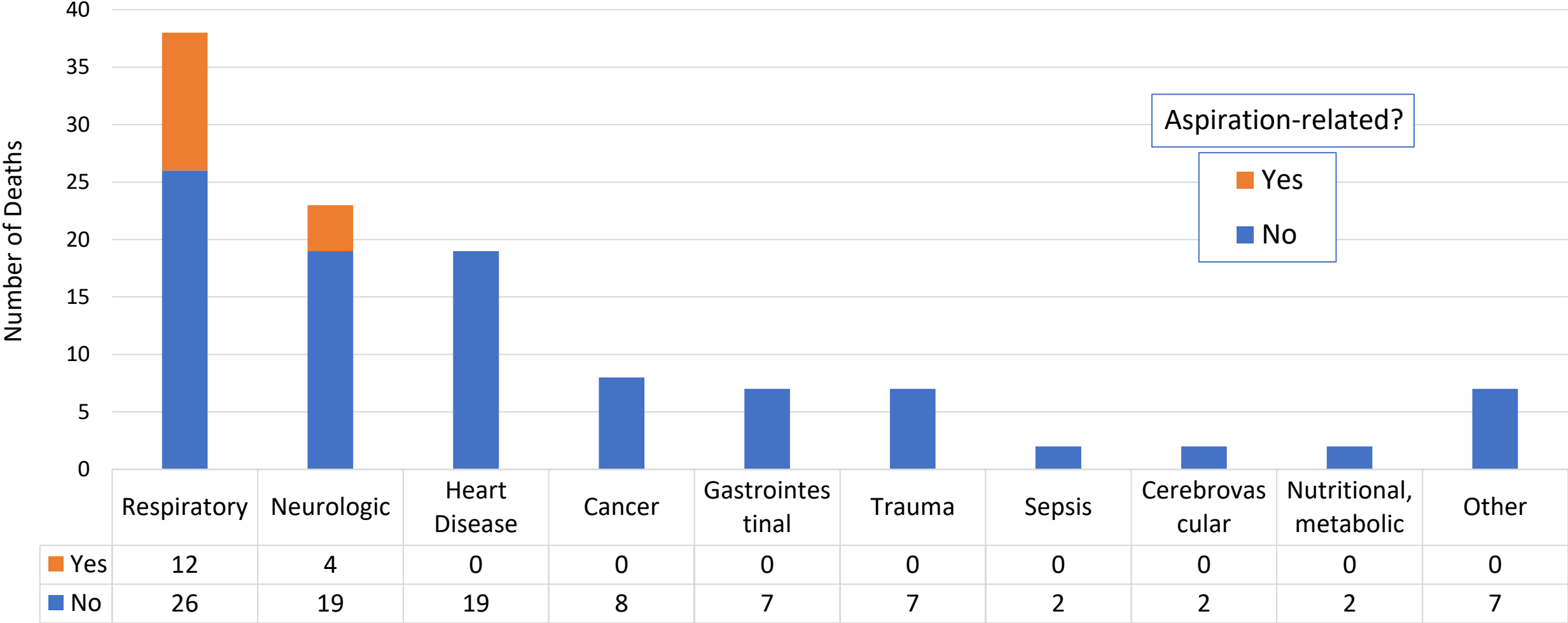
Duration of hospice services when hospice was utilized, FY2018-2022



Median Age at death among MRC reviews, by waiver type, FY2022



Categorized cause of death among MRC-reviewed deaths, FY2022

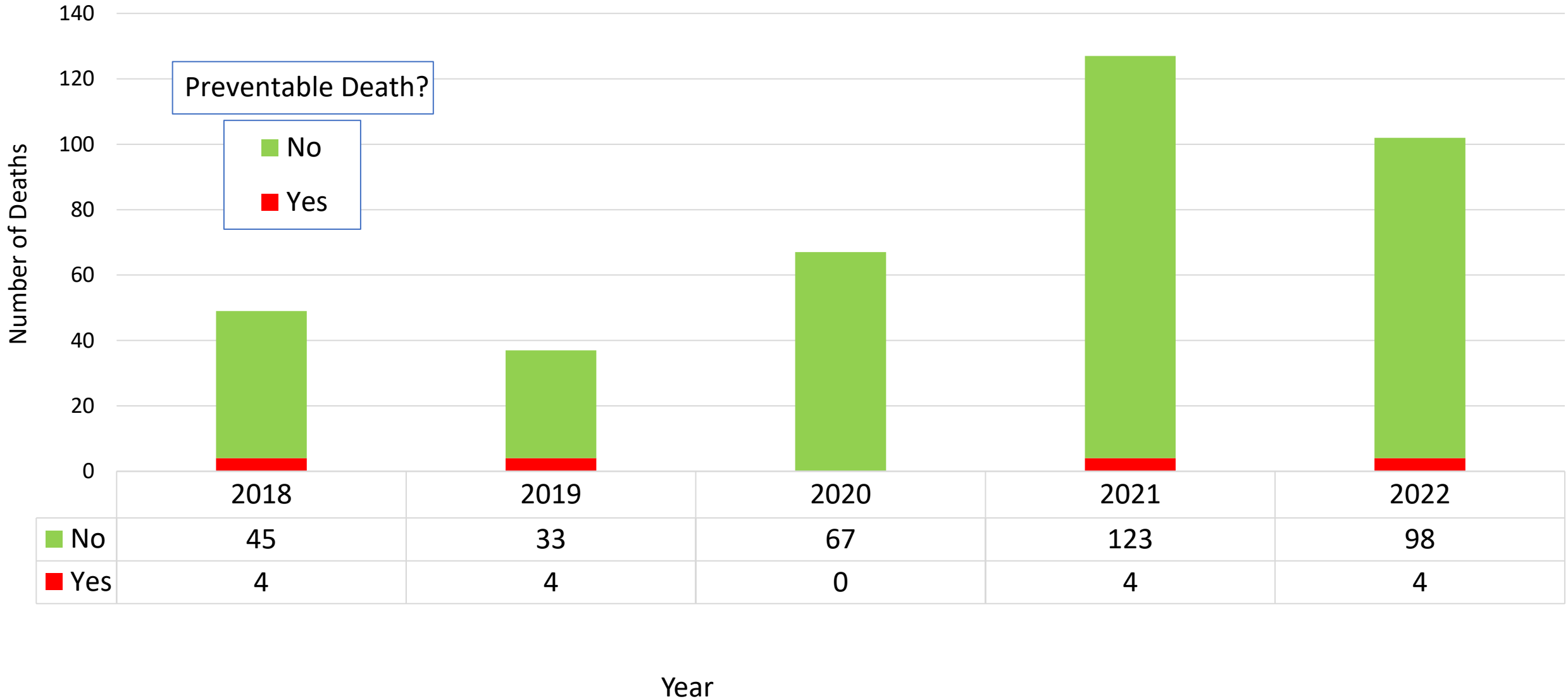


Category of Cause of Death

Were Deaths Expected or Unexpected?

MRC - Death Expected/Unexpected	Number	Percent
Expected	81	70%
Unexpected	33	29%
Undetermined	1	0.9%
Total	115	100.0%

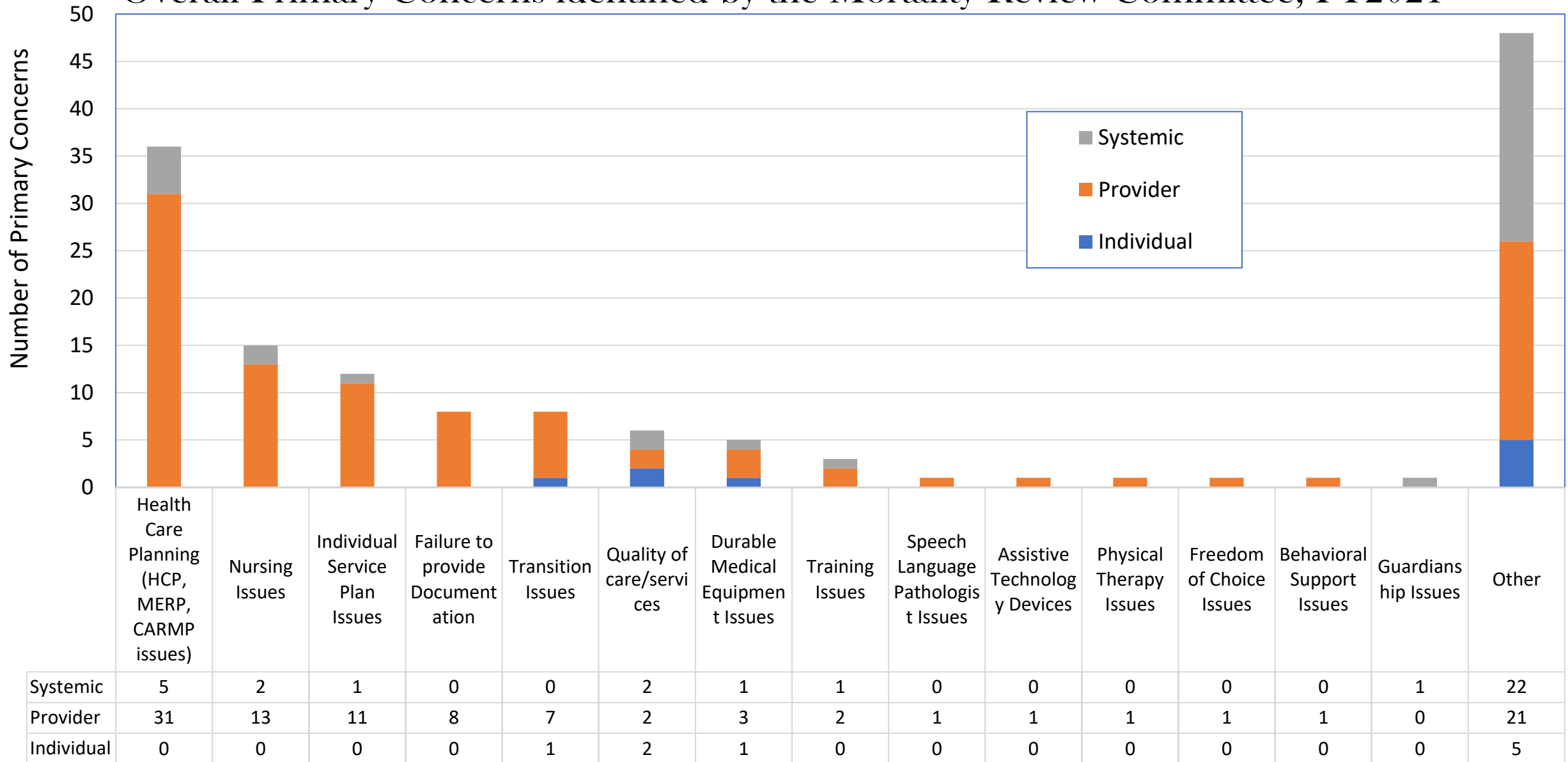
Were deaths preventable?



Did care issues contribute to the death?

Identification of Care Issues	Number	Percent
No: Death occurred despite appropriate care	105	91.3%
Unknown	5	4.3%
Yes	5	4.3%
Total	115	100.0%

Overall Primary Concerns identified by the Mortality Review Committee, FY2021



Individual-level Issues

Individual Level Category	Frequency	Percent
Medical care	4	44%
Health Care Planning	2	22%
Communication	1	11%
Documentation	1	11%
ID/Response to Condition	1	11%
Total	9	100%

Provider-Level Issues

CATEGORY	Frequency	Percent
Health Care Planning and Coordination Issues	38	49%
Nursing Issues	16	21%
Documentation Issues	7	9%
Identification or Response to Change in Condition	5	6%
Training Issues	3	4%
Human Rights Issues	2	4%
Therapy concerns	2	3%
Case Management Issues	1	1%
Guardianship Issues	1	1%
Medical care Issues	1	1%
Staffing Issues	1	1%
Total	78	100%

System-Level Issues

Systemic Category	Frequency	Percent
Training/Education Issues	12	63%
Provider Education needed	6	
Nursing Education needed	2	
Individual and provider education	1	
Developing provider mentoring	1	
Health Alert needed	1	
ISP Training	1	
Standards modification needed	3	16%
Need CSB Assessment of safety equipment	1	5%
MCO issue	1	5%
Therap issue	1	5%
Waiver templates review needed	1	5%
Total	19	100%

CASE PRESENTATION - 1

- *In your Small Group:*
 - Review the information on Page 1
 - As a group, discuss:
 - What are you **thinking** about this person's health at this point?
 - What **additional information** do you want to know?
 - What do you **want to do** and **when**?

LARGE-GROUP DISCUSSION

CASE PRESENTATION - 2

- *In your Small Group:*

- Review the information on Page
- Based on the additional information, discuss:
 - **What are you thinking now about this person's health?**
 - **What additional information do you want to know?**
 - **What do you want to do and when?**

LARGE-GROUP DISCUSSION

CASE PRESENTATION - 3

- *In your Small Group:*

- Review the new information on Page 3
- Based on the additional information, discuss :

- **What do you think is happening?**

- **What do you think is causing this to happen?**

- List potential diagnoses.

LARGE-GROUP DISCUSSION



BREAK

CASE PRESENTATION – 4a

- **January 11, 2022** – HHA called Nurse who reported to DHI/IMB that Daniel had become lethargic, and has had a cough for 2-3 days.

CASE PRESENTATION – 4b

- **January 11, 2022** – HHA called Nurse who reported to DHI/IMB that Daniel had become lethargic, and has had a cough for 2-3 days.
- January 13 – Daniel and his mother tested + for COVID-19. Over the next several days, the PCP consulted remotely with the HHA, responding to reported changes in condition, and prescribed a regimen of steroids, antibiotics, alprazolam, oxygen per nasal cannula and nebulizer treatments.

CASE PRESENTATION – 4c

- **January 11, 2022** – HHA called Nurse who reported to DHI/IMB that Daniel had become lethargic, and has had a cough for 2-3 days.
- January 13 – Daniel and his mother tested + for COVID-19. Over the next several days, the PCP consulted remotely with the HHA, responding to reported changes in condition, and prescribed a regimen of steroids, antibiotics, alprazolam, oxygen per nasal cannula and nebulizer treatments.
- January 18 – HHA administered oxygen/NC and called EMS because of Daniel's shortness of breath. EMS found Daniel's oxygen saturation in the 90's with no fever, and clear lung sounds. Daniel was not transported to the hospital.

CASE PRESENTATION – 4d

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- January 18 – HHA administered oxygen/NC and called EMS because of Daniel’s shortness of breath. EMS found Daniel’s oxygen saturation in the 90’s with no fever, and clear lung sounds. Daniel was not transported to the hospital.
- January 19 and 20 – HHA reported Daniel was doing much better: no SOB, up walking around, eating and drinking.

CASE PRESENTATION – 4 - Final

- **January 11, 2022** – HHA called Nurse who reported to DHI/IMB that Daniel had become lethargic, and has had a cough for 2-3 days.
- January 13 – Daniel and his mother tested + for COVID-19. Over the next several days, the PCP consulted remotely with the HHA, responding to reported changes in condition, and prescribed a regimen of steroids, antibiotics, alprazolam, oxygen per nasal cannula and nebulizer treatments.
- January 18 – HHA administered oxygen/NC and called EMS because of Daniel’s shortness of breath. EMS found Daniel’s oxygen saturation in the 90’s with no fever, and clear lung sounds. Daniel was not transported to the hospital.
- January 19 and 20 – HHA reported Daniel was doing much better: no SOB, up walking around, eating and drinking.
- January 21 – HHA Marco, and his wife Maria got Daniel up for the day at 6:30 AM. Daniel took two steps from the bed and collapsed on the floor. EMS was called and Marco started CPR. After EMS arrived, they attempted resuscitation for about 30 minutes, but efforts were unsuccessful.
- OMI reported to the scene and pronounced the death. The death certificate notes time of death at 7:54 AM and is signed by the PCP. Cause of death is listed as pneumonia secondary to COVID-19.

CASE DISCUSSION - 1

What were Daniel's risk factors in getting COVID-19 and dying?

CASE DISCUSSION - 2

What were Daniel's risk factors in getting COVID-19 and dying?

- Age over 65
- Chronic health conditions: COPD, DM, HTN.
- Past medical history of recurrent lung infections since infancy
- History of heavy second-hand smoke exposure
- Hospitalized in 2015 for pneumonia
- High risk of aspiration/GERD

CASE DISCUSSION - 3

Vaccination record?

CASE DISCUSSION - 4

Vaccination record:

- Last influenza vaccine 2016
- TDAP, tetanus and shingles 2015
- Pneumonia 2015
- In the medical record there was no indication of the need for or discussion of the appropriateness of COVID-19 vaccination.
- Post-mortem interview of mother and HHA indicated that they were “fearful of how the vaccination would react with his underlying health conditions.”



Covid-19 Among Persons in the New Mexico I/DD Waiver Population:

What happened to people on the DD Waiver in
New Mexico during the Covid pandemic?

How well as a system did we do at preventing it?

Covid-19 among persons receiving DD Waiver
Supports in New Mexico
2020 through December 2022:

Cases of Covid-19: 2,080



Prevention of Covid was with social distancing and vaccination.

S ocial distancing was very difficult, especially in supported living...

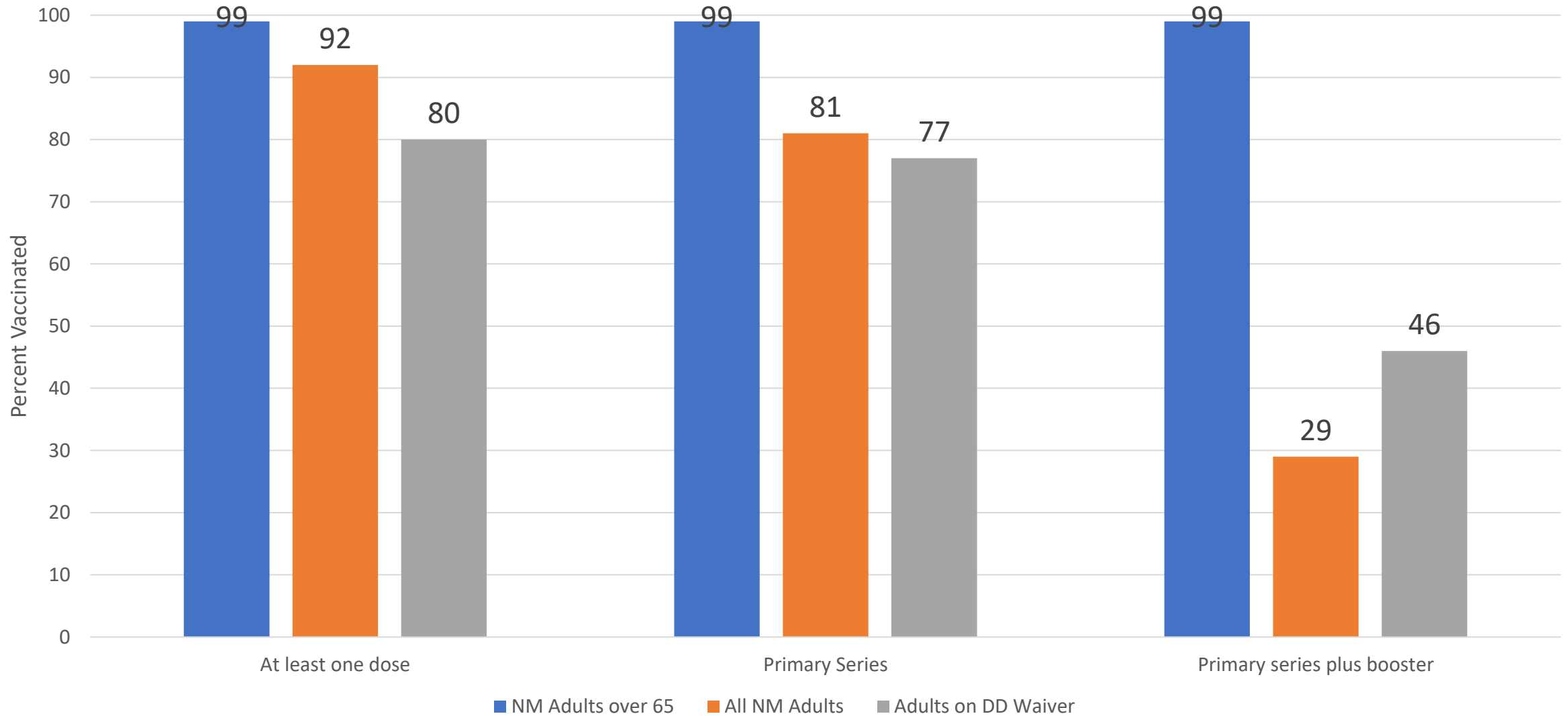
WHEN WAS COVID-19 VACCINE AVAILABLE?

- December 2020 –
 - Recorded US death toll > 300,000.
 - First American (outside clinical trials) receives COVID-19 vaccine.
- 1 year prior to Daniel's death, **prioritization** of vaccination was suggested until supply of vaccine became plentiful.
- Priorities were listed as:
 - Healthcare workers and **older adults in long term care**
 - **Essential workers** and all persons > 75 years old
 - All persons 65-74, and **all persons 16-64 with a medical condition that increases risk of severe disease from COVID.**

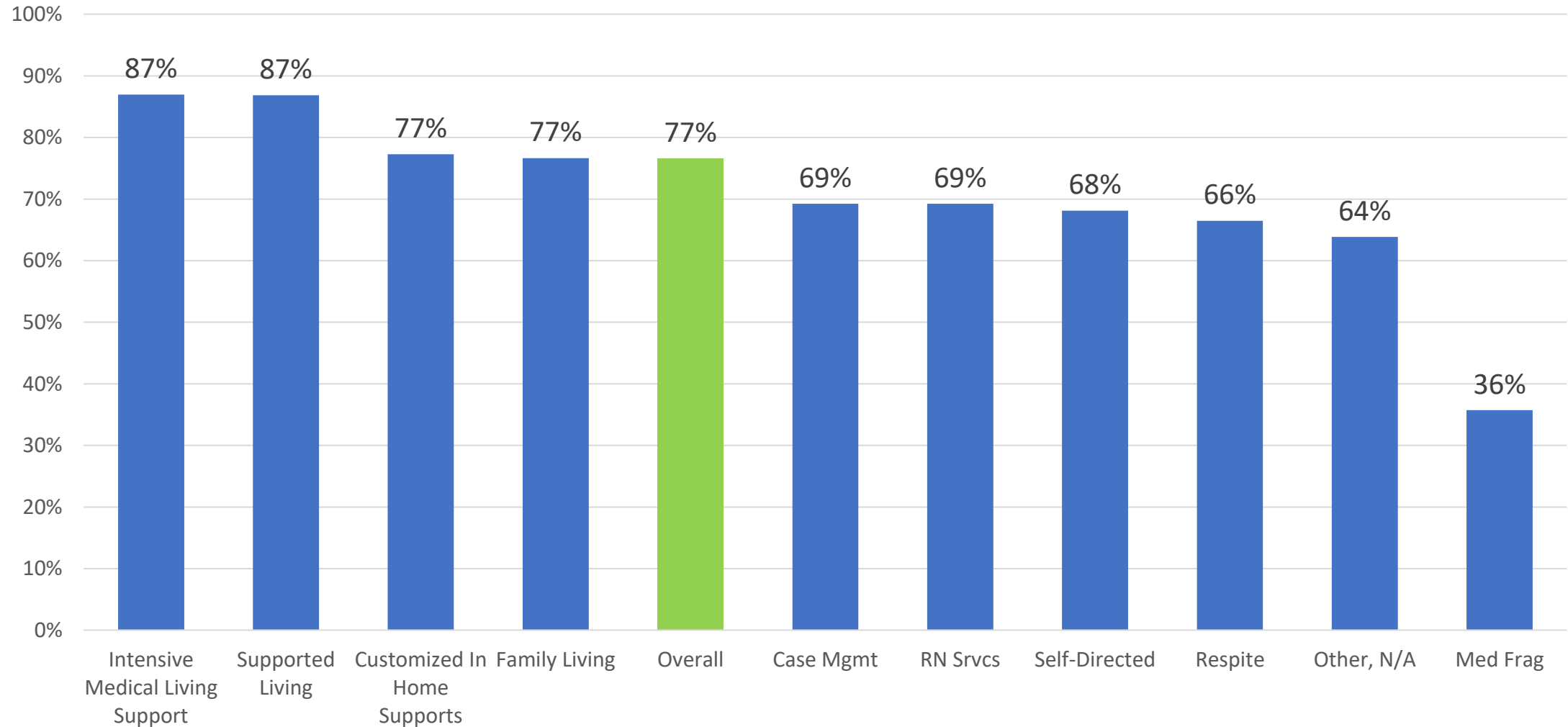
The slide features a teal gradient background with white decorative circuit-like lines in the corners. The main text is centered in a bold, white, sans-serif font.

HOW WELL DID NEW MEXICO VACCINATE HIGH-RISK PERSONS LIVING WITH I/DD?

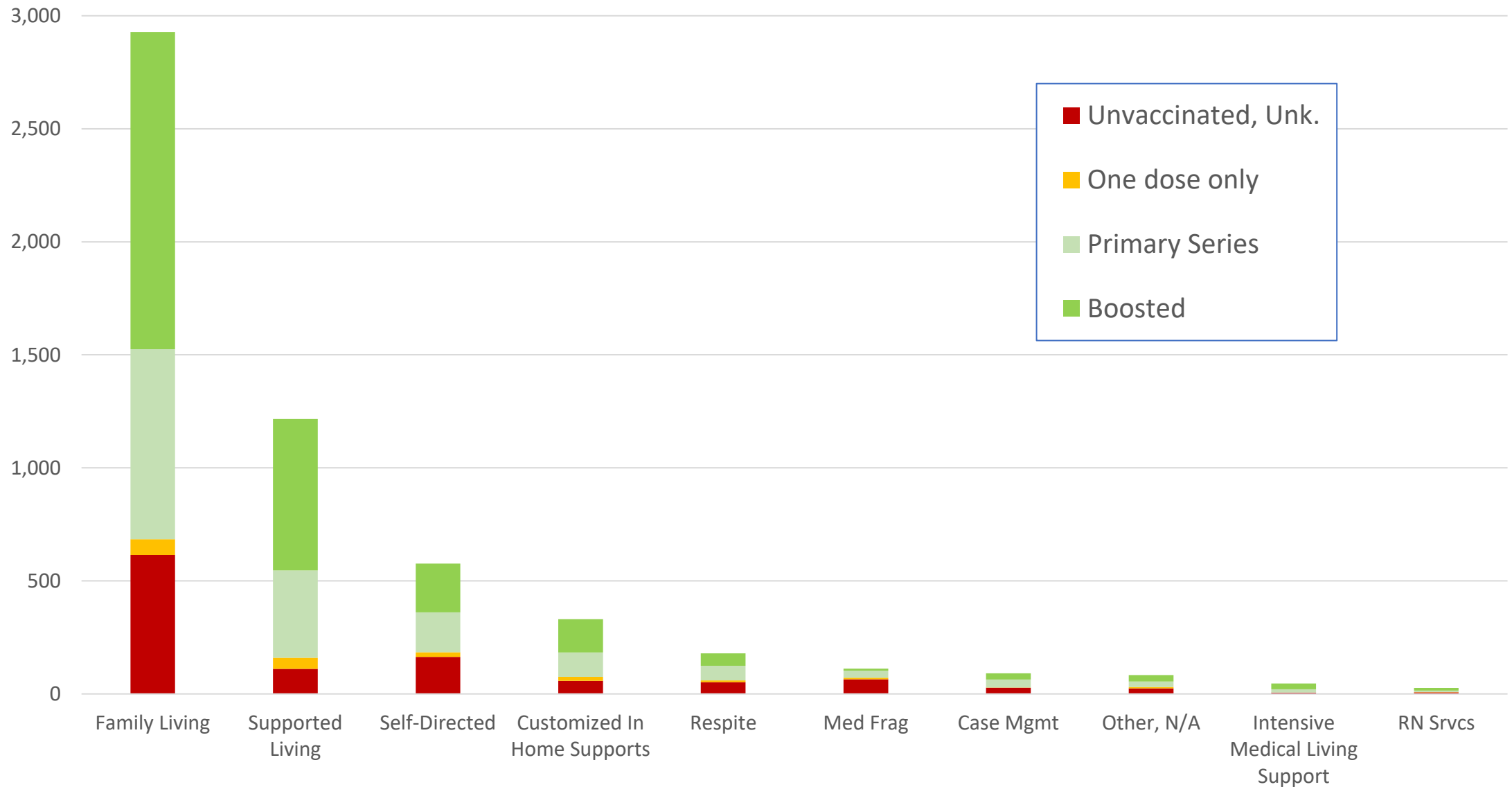
New Mexico Covid-19 Vaccination Rates General Population and DD Waiver



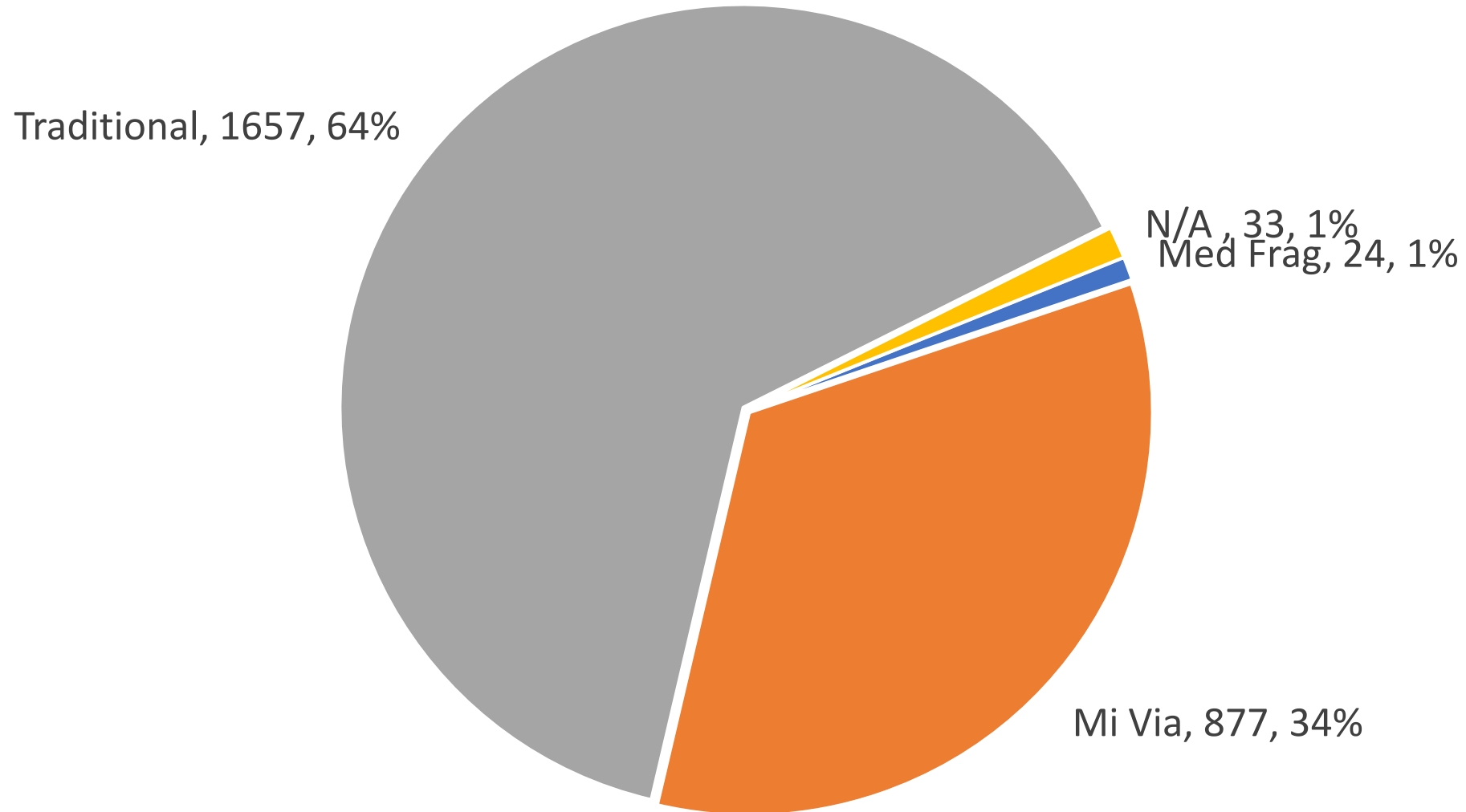
Percentage of waiver participants who received at least the primary series of Covid-19 vaccine, by Primary Service, FY2022



Number of persons who were vaccinated against COVID-19, by Primary Service



Number of unvaccinated I/DD individuals, by Waiver Type



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WHAT HAPPENS WHEN PEOPLE
LIVING WITH INTELLECTUAL AND/OR
DEVELOPMENTAL DISABILITIES AREN'T
VACCINATED AGAINST COVID-19?

2022

UCD - 15 Leading Causes of Death ↓	→ Deaths ↑↓
#Diseases of heart (I00-I09,I11,I13,I20-I51)	703,041
#Malignant neoplasms (C00-C97)	608,341
#Accidents (unintentional injuries) (V01-X59,Y85-Y86)	227,664
#COVID-19 (U07.1)	186,555
#Cerebrovascular diseases (I60-I69)	165,391
#Chronic lower respiratory diseases (J40-J47)	147,367
#Alzheimer disease (G30)	120,109
#Diabetes mellitus (E10-E14)	101,199
#Nephritis, nephrotic syndrome and nephrosis (N00-N07,N17-N19,N25-N27)	57,931
#Chronic liver disease and cirrhosis (K70,K73-K74)	54,817
#Intentional self-harm (suicide) (*U03,X60-X84,Y87.0)	49,513
#Influenza and pneumonia (J09-J18)	47,044
#Essential hypertension and hypertensive renal disease (I10,I12,I15)	43,286
#Septicemia (A40-A41)	42,253
#Parkinson disease (G20-G21)	39,915

Centers for Disease Control and Prevention, National Center for Health Statistics. National Vital Statistics System, Provisional Mortality on CDC WONDER Online Database.

Covid-19 among persons receiving DD Waiver
Supports in New Mexico
2020 through December 2022:

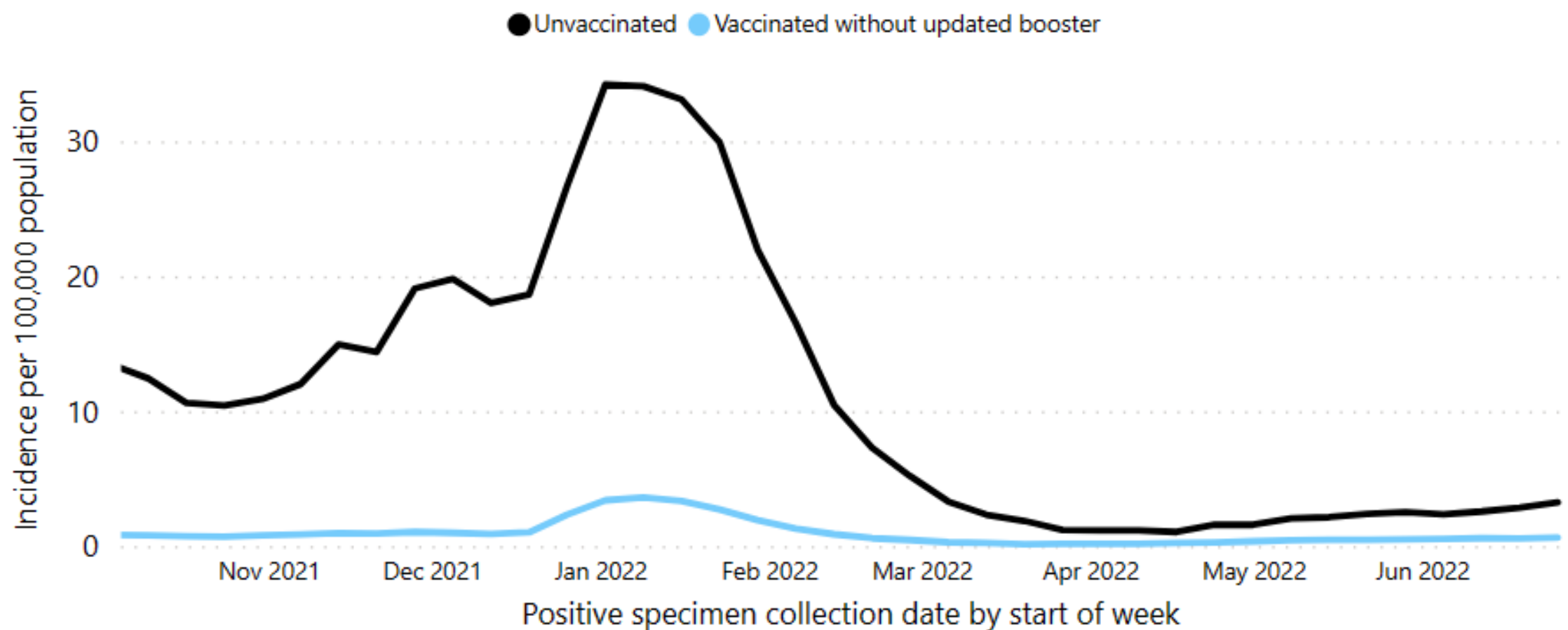
Cases of Covid-19: 2,080

Deaths due to Covid-19: 49

Population	Covid-19 deaths	Number in Population	Covid-19 deaths per 100,000
New Mexico General Population	8,815	2,113,344	417.1
New Mexico I/DD Waiver Population	49	5,587	877.0

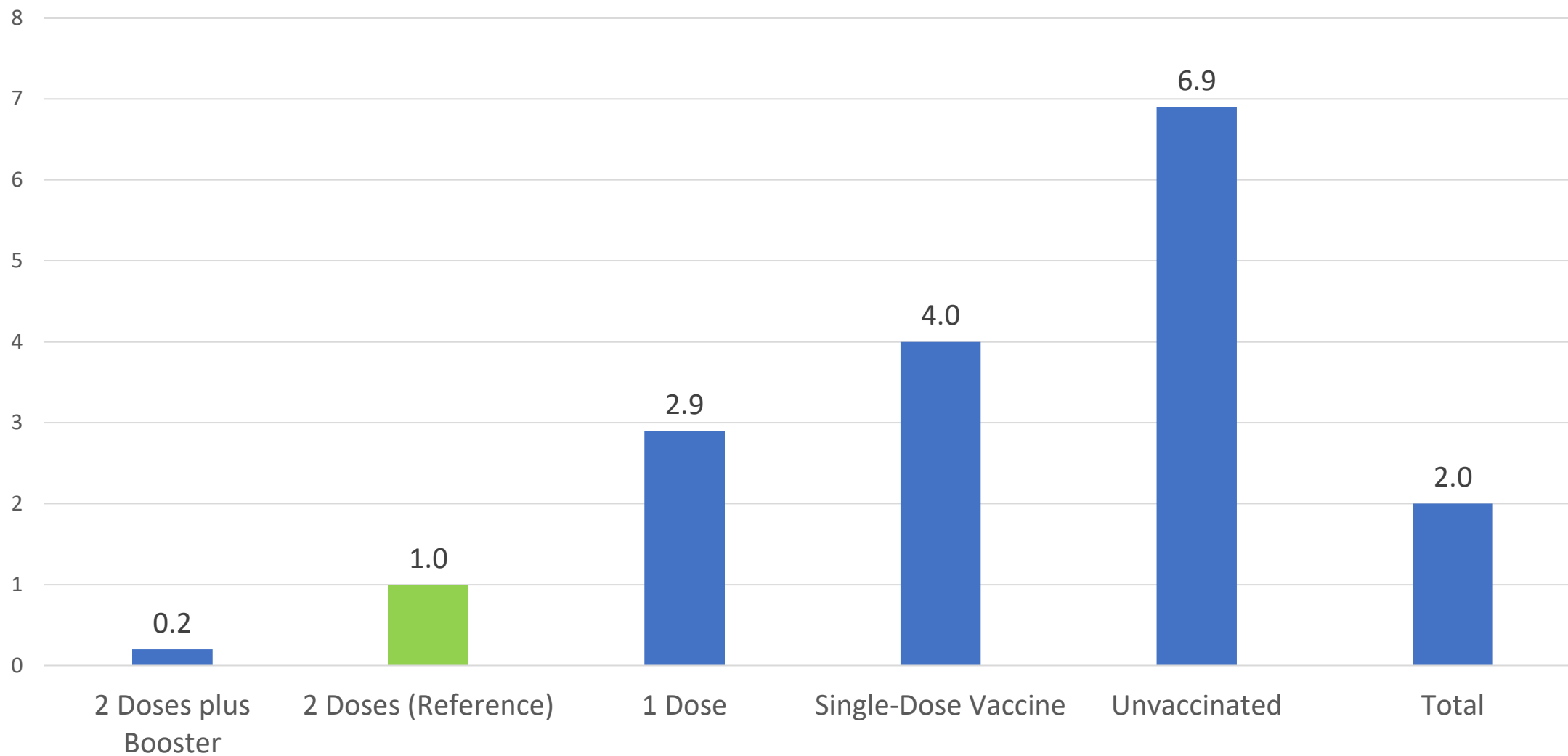
Rates of COVID-19 Deaths by Vaccination Status in Ages 18 and Older

October 03, 2021–July 02, 2022 (24 U.S. jurisdictions)



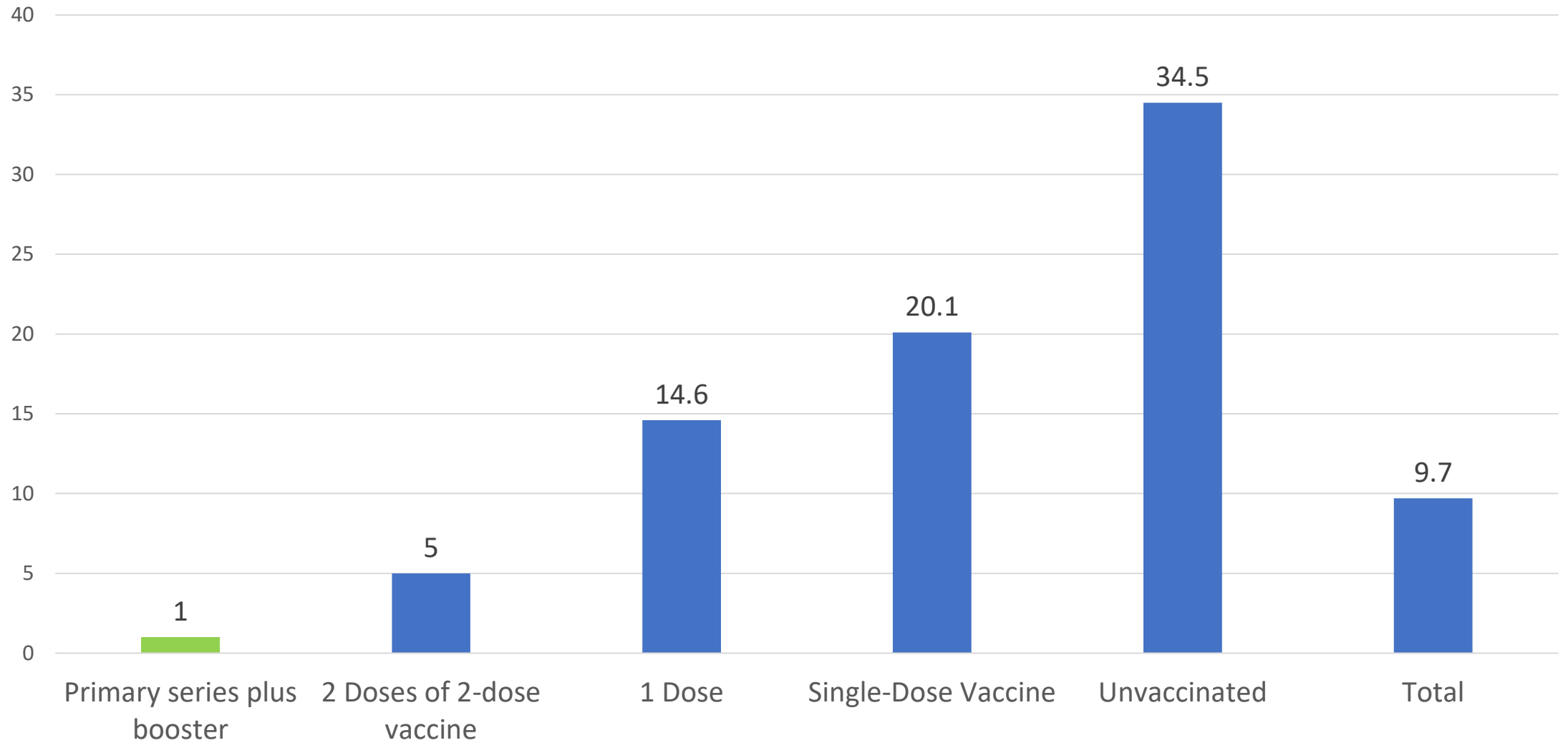
Risk of dying from Covid-19 in SFY2022.

Risk ratio is relative to persons who received primary series without booster

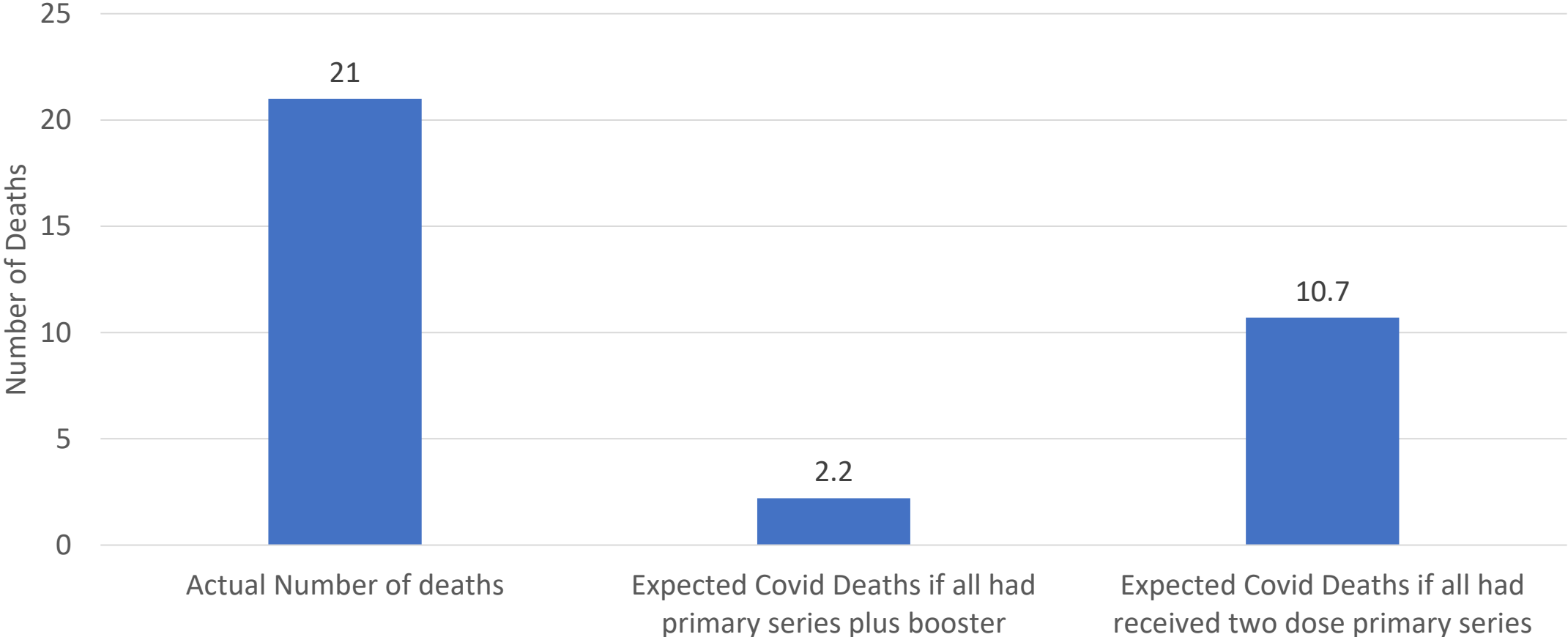


Risk of dying from Covid-19

Risk ratio is relative to persons who received primary series plus booster



Observed and expected number of Covid-19 deaths in 2022 among DD Waiver participants.



January 2022 – The month that Daniel died...

- 1M new infections – highest daily total of any country in the world
- Number of hospitalized COVID patients rose nearly 50% in just 1 week.
- Antiviral medications found to be effective against delta and omicron variants.
- To date, vaccines were estimated to have saved at least a quarter of a million lives and prevented more than 1 million hospitalizations.

However, in 1 month the daily average of new infections in US spiked from 119,215 to 805,062...

One was Daniel...

The following week another victim was his unvaccinated 87 y/o mother.

Do you have any concerns for the actions or inactions of those responsible for Daniel's safety and well-being?

- Mother and HHA?
- Nurse?
- EMS?
- Primary Care Provider?
- The DD Waiver system as a whole?

Aren't you TIRED of COVID-19? Why are we still talking about it?

- Well, this case is about more than COVID-19.
- It's about more than vaccinations.
- It's about delivering quality healthcare to people with disability:
 - through vaccinations
 - with screening tests
 - with other preventive interventions
 - by meeting standards in chronic disease management
 - by equitably meeting the current medical standard of care for our clients and patients.
- IT'S ABOUT DEALING PATIENTLY WITH INFORMATION, MISINFORMATION, AND PERHAPS SOME DISINFORMATION, SO THAT OUR CLIENTS AND GUARDIANS CAN MAKE **INFORMED DECISIONS.**

MORTALITY REVIEW IS ALL ABOUT QUALITY IMPROVEMENT:

- **The reason we brought this case was to stimulate brainstorming on questions like:**
 - **What changes are needed** to keep persons with IDD meeting standards of care consistently, not just during a pandemic? Not just with vaccines? But with quality preventive care and acute/chronic disease management. COVID-19 vaccine is just one example of preventive care.
 - **How can we make those changes happen?** In Daniel's case it was a matter of having an **informed discussion** with a competent guardian about a fast moving, confusing, scary, potentially fatal disease.

POTENTIAL SYSTEM CHANGES:

- Use of Decision Consultation Process?
 - We require for CARMPs and some screenings – why not also for life-saving vaccines?
- Promoting use of established prevention guidelines when clients see their providers:
 - US Preventive Services Task Force
 - US Centers for Disease Control *and Prevention*
 - Summarized at [MyHealthfinder | health.gov](https://myhealthfinder.health.gov)
 - just enter age and gender and it lists all recommended screenings and vaccines

Potential system changes, continued:

- MCO trainings on healthcare planning, preventive screenings and immunizations
- Training for families/guardians on healthcare planning, preventive screenings and immunizations for persons with I/DD
- Require discussion of vaccinations and preventive screenings at the annual ISP Meeting
- Add immunizations section to eCHAT

Daniel's caregivers expressed their concern with giving him the COVID-19 vaccine: they were “fearful of how the vaccination would react with his underlying health conditions.”

- **How do we respond with an informed discussion?**

Let's start with informed discussion:

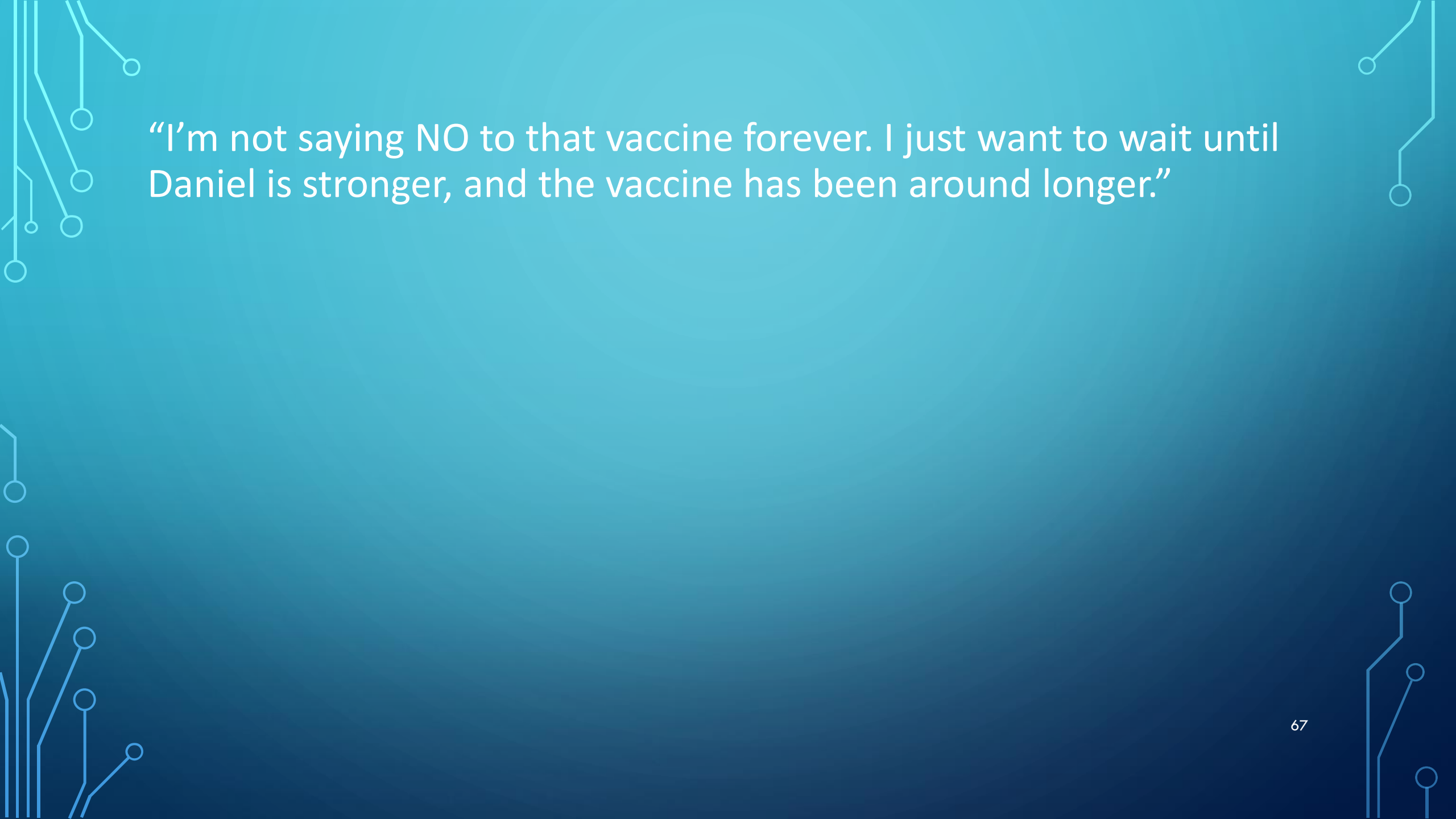
- Let's listen.
- Let's talk - Stay civil.
- Keep in mind these are just ordinary people trying to figure out what is best for themselves and their loved ones.
- Be kind. Walk the talk.

How can we have a positive impact?

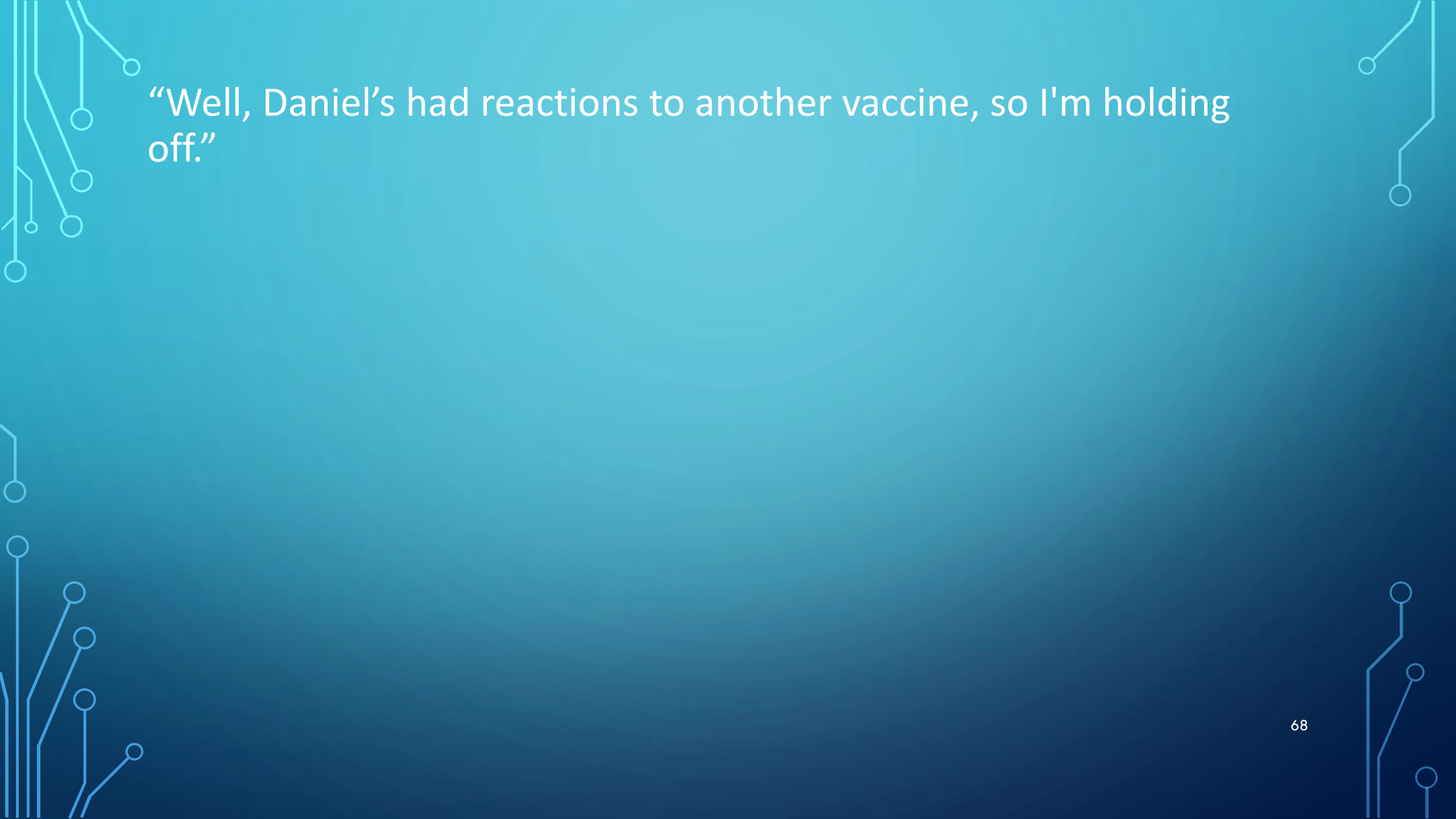
Suggestions on how to Discuss Vaccinations and Other Preventive Interventions with skeptical Clients and Guardians.

(Not just vaccines: try substituting cancer screens, dementia screening, CARMP planning, *etc.*)


When these concerns arise what are you going to say?

The background is a dark teal gradient. In the corners, there are decorative white circuit-like lines with small circles at the end of the lines, resembling a stylized PCB or network diagram.

“I’m not saying NO to that vaccine forever. I just want to wait until Daniel is stronger, and the vaccine has been around longer.”

The background is a dark teal gradient. In the corners, there are decorative white circuit-like lines with small circles at the ends, resembling a printed circuit board or a network diagram. These lines are positioned in the top-left, top-right, bottom-left, and bottom-right corners.

“Well, Daniel’s had reactions to another vaccine, so I'm holding off.”



How Will We Reduce Mortality From Preventable Diseases?

Prevention, Treatment, And System Change

RESOURCES: COVID

- **Timeline:** <https://www.cdc.gov/museum/timeline/covid19.html>
- **Tracker:** <https://covid.cdc.gov/covid-data-tracker/>

- **Covid-19 with Medical Conditions:** <https://cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>

- **Covid and I/DD (Clients and Providers):**
<https://www.cdc.gov/ncbddd/humandevelopment/COVID-19-Materials-for-People-with-IDD.html>

OTHER RESOURCES:

[Vaccine Skeptics: Opinion | 10 Common Concerns About Vaccines And How To Respond To Them - The Washington Post](#)

Prevention Recommendations: [myhealthfinder | health.gov](#)

Prevention Resources at U.Mass: [dds preventive health screenings for adults with intellectual disabilities \(umassmed.edu\)](#)

Future Pandemics and Climate Change:

<https://www.washingtonpost.com/climate-environment/2024/05/08/climate-change-disease-pandemics/#:~:text=evidence%20is%20mounting%20that%20human,according%20to%20a%20new%20study.&text=as%20humans%20degrade%20earth's%20environment,apt%20to%20fester%20and%20multiply.>



Stand strong and advocate for yourself and for your clients.

How can preventive care happen
where YOU work?

How can you influence positive change
where YOU are?

A decorative graphic on the left side of the slide consists of white and light blue lines forming a circuit-like pattern. The lines are vertical and horizontal, with small circles at various points, resembling a stylized tree or a network diagram. The background is a gradient of blue, darker at the bottom and lighter at the top.

THANK YOU FOR ALL YOU DO!