



COVID-19 VACCINE &  
DISABILITY SURVEY: VACCINE  
HESITANCY AMONG ADULTS  
WITH DISABILITIES

**American Association on Health & Disability**

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***Dedicated to ensuring health equity for persons with disabilities through policy,  
research, and dissemination.***

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## A. Introduction

COVID-19 disease is caused by a coronavirus called SARS-CoV-2. This type of coronavirus has not been seen before and presents considerable challenges for adults with disabilities. Previous research has documented issues with how and when to follow public health safety recommendations and accessing health care, prescriptions, and mental health services (Drum et al., 2020). Several vaccines have been developed and are now available for persons with disabilities and others. Some people with disabilities have raised concerns with disability organizations and interest groups about the vaccine, its availability, and the accessibility of vaccine sites. *Little systematic information has been collected to date on the reasons why adults with disabilities have taken, will take, are not sure about taking, or will not take the COVID-19 vaccine.*

### Study & Report Purpose

The purpose of the COVID-19 Vaccine & Disability Survey was to conduct a rapid, real-time online study of the perspectives of adults with disabilities on the COVID-19 Vaccine. The self-report survey included demographic questions (disability identifiers, gender, ethnicity, race, and geographic area). Respondents that said that there were not going to be vaccinated (No Vaccine) or were not sure (Not Sure) received a set of Disability-Related and General Vaccine Hesitancy, Accessibility, and Availability questions. Respondents that said that they were planning on being vaccinated or already had been or were in process received two open-ended questions on whether they experienced any underlying concerns and what was their motivation for being vaccinated.

We used four of the six disability identifiers frequently used by federal agencies:

- Deaf or serious difficulty hearing (Hearing).
- Blind or serious difficulty seeing, even when wearing glasses (Vision).
- Serious difficulty walking or climbing stairs (Mobility).
- Because of a physical, mental, or emotional condition, have serious difficulty concentrating, remembering, or making decisions (Cognition).

Respondents with a Cognition disability were asked for an underlying cause. Respondents were asked if they experience multiple disabilities. We combined disability identifiers in this report, although we recognize the importance of examining results by type of disability. We intend to publish results by type of disability if funding is available.

### Purpose of the Report

The purpose of this report is to describe comparisons between adults with disabilities who will not be vaccinated (No Vaccine) and adults with disabilities who are not sure about being vaccinated (Not Sure) based on survey items in the categories of Disability-Related Vaccine Hesitancy, General Vaccine Hesitancy, Distrust, Accessibility of Vaccine sites, and Vaccine Availability. The No Vaccine and Not Sure groups were provided possible reasons in the five survey categories and asked if it was “Not a Reason,” “Little Reason,” or “Big

Reason” for their vaccine choice. This report is limited to examining the top five “Big Reasons” for vaccine choices in the interest of providing results as quickly as possible. Preliminary examination of the full survey data reveals other intriguing results that will be examined as time and resources allow. The overall goal of this study is to understand the factors that contribute to vaccine hesitancy and discuss potential strategies in the provision of vaccine information to adults with disabilities.

## B. Methodology

We reviewed existing vaccine hesitancy surveys and either modified existing items or created new ones consistent with our areas of interest. Print, electronic, and social media platforms were used to solicit responses from people with disabilities. AAHD distributed the survey through social media, existing partnerships and other organizations and individuals also distributed the survey link. The survey was available online from March 12th, 2021, until April 5th, 2021.

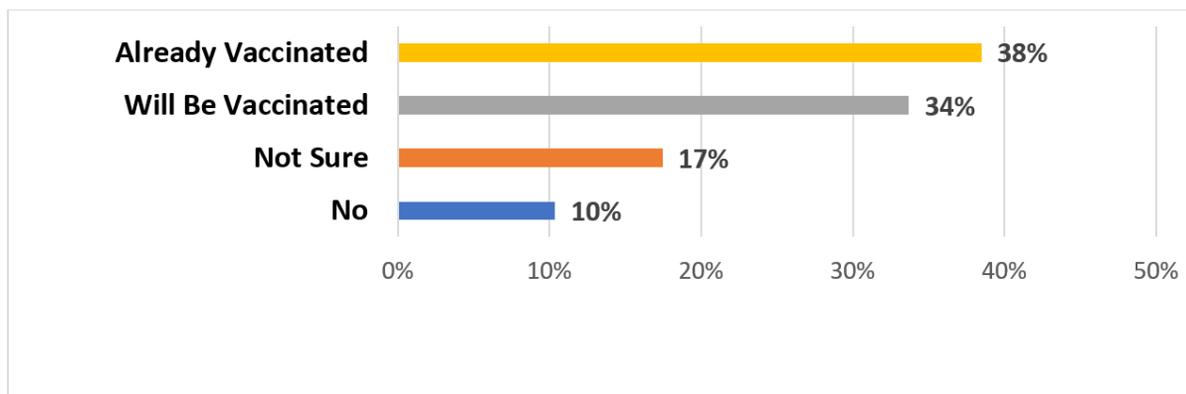
## C. Results

The final survey sample was 4,131 respondents after data cleaning. We eliminated youth (17 and younger), and respondents who did not identify their disability or if they were going to be vaccinated. The survey completion rate in the final sample varied by item, ranging from a low of 72% (Question 9) to 100% (Question 1). The overall completion rate was 78% (exclusive of skip patterns). All results are rounded.

### Willingness to Get Vaccinated

As displayed in Figure 1, 38% or 1,589 respondents reported that they had already been vaccinated or their vaccination was in progress, while 34% or 1,392 said they were going to be vaccinated. In total, 1,150 respondents or 27% of the sample said they were not going to be vaccinated or were not sure. Seventeen percent or 721 respondents said that they were not sure if they were going to get vaccinated and 10% or 429 respondents said that they were not going to be vaccinated. The rest of the report compares results from the No Vaccine and Not Sure groups.

**Figure 1. Vaccine Willingness (n=4,131)**



## Demographics of the Total Sample

Demographic data (n=4,131) is presented in Table 1 to create a better understanding of how the demographics of the No Vaccine and Not Sure groups differ from the total sample. Subsequently, the demographics of the No Vaccine and Nor Sure groups will be compared.

**Table 1. Full Sample Characteristics By Vaccine Choice**

	<b>Already Vaccinated</b>	<b>Will Be Vaccinated</b>	<b>Not Sure</b>	<b>No</b>
<b>Disability</b>				
Cognition	48%	50%	49%	52%
Mobility	40%	43%	44%	37%
Hearing	8%	3%	4%	5%
Vision	4%	5%	6%	3%
Multiple Disabilities	63%	69%	69%	68%
<b>Age</b>				
18-44	45%	47%	45%	52%
45-64	36%	46%	47%	42%
65+	19%	6%	8%	7%
<b>Gender</b>				
Woman	60%	57%	64%	60%
Man	39%	41%	32%	36%
Other	1%	1%	1%	1%
<b>Race/Ethnicity</b>				
White / Caucasian	76%	54%	52%	61%
Black / African American	14%	27%	31%	23%
Hispanic	6%	12%	8%	8%
Asian	3%	4%	3%	2%
American Indian / Alaskan Native	2%	2%	3%	4%
Native Hawaiian / Pacific Islander	1%	<1%	<1%	<1%
<b>Community Location</b>				

Suburban	52%	53%	45%	41%
Urban	27%	30%	28%	25%
Rural	21%	16%	26%	32%
Frontier	1%	1%	1%	2%

**Demographics of the No Vaccine & Not Sure Groups**

**Disability Identifiers in the No Vaccine & Not Sure Groups**

The No Vaccine group (n=429) included the following four disability sample sizes:

- Cognition Disability (52% or 223).
- Mobility Disability (37% or 159).
- Blind or Serious Difficulty Seeing (6% or 24).
- Deaf or Serious Difficulty Hearing (5% or 23).

The Not Sure sample (n=721) included the following four disability sample sizes:

- Cognition disabilities (49% or 354).
- Mobility disabilities (44% or 316).
- Deaf or Serious Difficulty Hearing (4% or 26).
- Blind or Serious Difficulty Seeing (3% or 25).

Respondents were also able to identify if they experienced multiple disabilities. In the No Vaccine group (n=429), most respondents identified having a mobility disability as an additional disability (42% or 180), followed by a cognition disability (35% or 148), a vision disability, (17% or 75), and a hearing disability (14% or 59). Thirty-two percent of respondents (136) reported no additional disabilities.

In the Not Sure group (n=429), most respondents identified having a mobility disability as an additional disability (46% or 334), followed by a cognition disability (33% or 241), a vision disability, (15% or 111), and a hearing disability (10% or 70). Thirty-one percent of respondents (225) reported no additional disabilities.

**Age**

Respondents selected from the following age groups: a) 18 to 44; b) 45-64; or c) 65 and above. In the No Vaccine group (n=429), most of the respondents were 18-44 (52% or 221), followed by adults that were 45-64 (42% or 179), and adults 65 and older (7% or 29). In the Not Sure groups, most of the respondents were 45-64 (47% or 341), followed by adults that were 18-44 (45% or 322), and adults 65 and older (8% or 58).

**Gender**

The No Vaccine group (n =429) described themselves as a Woman (60% or 257), Man (36% or 154), or Some Other Way (1% or 5). Three percent (13) preferred not to answer. The Not Sure group (n=721) described themselves as a Woman (64% or 461), Man (32% or 233), or Some Other Way (1% or 7). Three percent (20) preferred not to answer.

## **Race and Ethnicity**

We combined an ethnicity identifier (Hispanic, Latino, or of Spanish Origin) with race for these results. The No Vaccine sample was primarily White or Caucasian (61% or 263), followed by Black or African American (23% or 970), Hispanic (8% or 34), American Indian or Alaska Native (4% or 18), Asian (2% or 8), and Native Hawaiian or Other Pacific Islander (.23% or 1). Eight percent or 34 respondents preferred not to answer.

The Not Sure sample (n=721) was also primarily White (52% or 373), followed by Black or African American (31% or 223), Hispanic (8% or 58), American Indian or Alaska Native (3% or 22), Asian (3% or 20), and Native Hawaiian or Other Pacific Islander (.28% or 2). Seven percent or 52 respondents preferred not to answer.

## **Community Location**

Respondents selected their location as Urban, Suburban, Rural, or Frontier. The largest percentage of No Vaccine respondents (n=429) were in Suburban locations (41% or 174), followed by Rural (32% or 138), Urban (25% or 109), and Frontier (2% or 8). The largest percentage of Not Sure respondents (n=721) were in Suburban locations (45% or 321), followed by Urban (28% or 204), Rural (26% or 186), and Frontier (1% or 10).

## **Disability-Related Vaccine Hesitancy (DRVH)**

We asked the No Vaccine and Not Sure groups six specific and one open-ended question on disability-related vaccine hesitancy. As noted above, the response options were "Not a Reason," "Little Reason," or "Big Reason" for their vaccine choice. Results are limited to the top five largest "Big Reasons." Figures 2 and 3 compare the five most frequently endorsed DRVH "Big Reasons" between the two groups.

### **Big Reasons- No Vaccine Group (n=352)**

The most frequently endorsed DRVH "Big Reasons" among persons not willing to get vaccinated were:

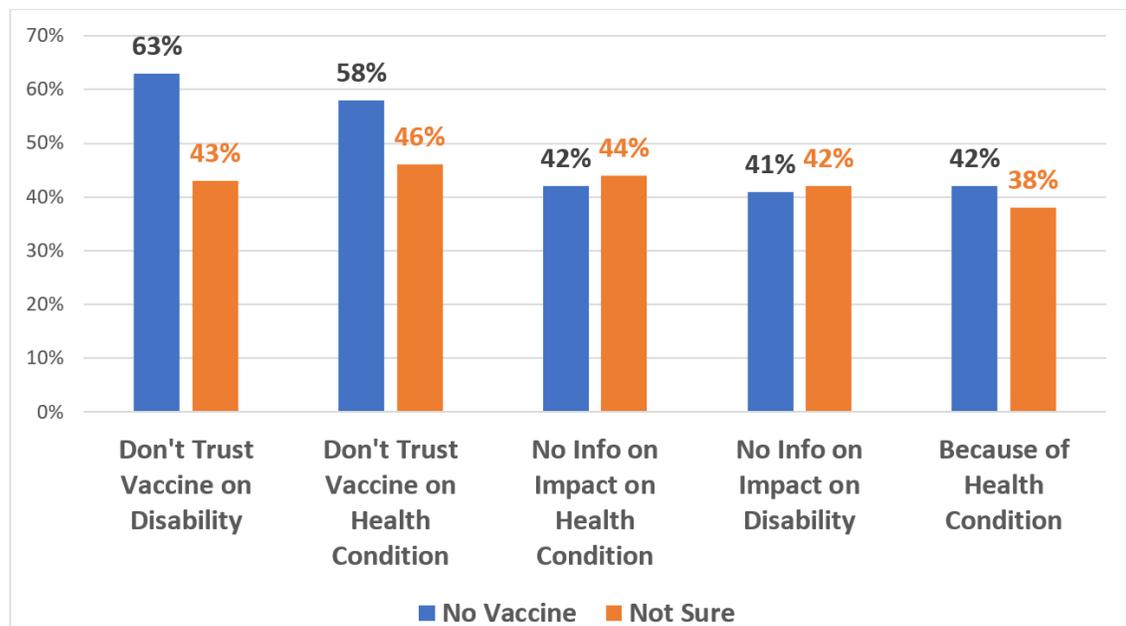
1. Not trusting the safety and/or effectiveness of the vaccine on respondent's disability (63%).
2. Not trusting the safety and/or effectiveness of the vaccine on respondent's underlying health condition (58%).
3. Not receiving reliable information on the impact of the vaccine on respondent's underlying health condition (42%).
4. Not receiving reliable information on the vaccine's impact on respondent's disability (41%).
5. Because of respondent's underlying health condition (42%).

### **Big Reasons- Not Sure Group (n=721)**

The most frequently endorsed DRVH "Big Reasons" among persons not sure about being vaccinated were:

1. Not trusting the safety and/or effectiveness of the vaccine on respondent's underlying health condition (46%).
2. Not receiving reliable information on the impact of the vaccine on respondent's underlying health condition (44%).
3. Not trusting the safety and/or effectiveness of the vaccine on respondent's disability (43%).
4. Not receiving reliable information on the impact of the vaccine on respondent's disability (42%).
5. Because of respondent's underlying health condition (38%).

**Figure 2. Disability-Related Hesitancy Big Reasons**



### General Vaccine Hesitancy (GVH)

We asked 15 General Vaccine Hesitancy (GVH) questions, including one open-ended question, ranging from fearing needles to vaccine specific concerns such as possible long-term side effects. Figure 3 displays the five most frequently endorsed GVH "Big Reasons" between the two respondent groups.

#### Big Reasons- No Vaccine Group (n=352)

As displayed in Figure 3, among respondents not getting the vaccine, the five most frequently endorsed GVH "Big Reasons" were:

1. Worry about possible long-term side effects from the vaccine (69%).
2. Belief that development of the vaccine was rushed (60%).
3. Worry about possible short-term side effects from the vaccine (46%).

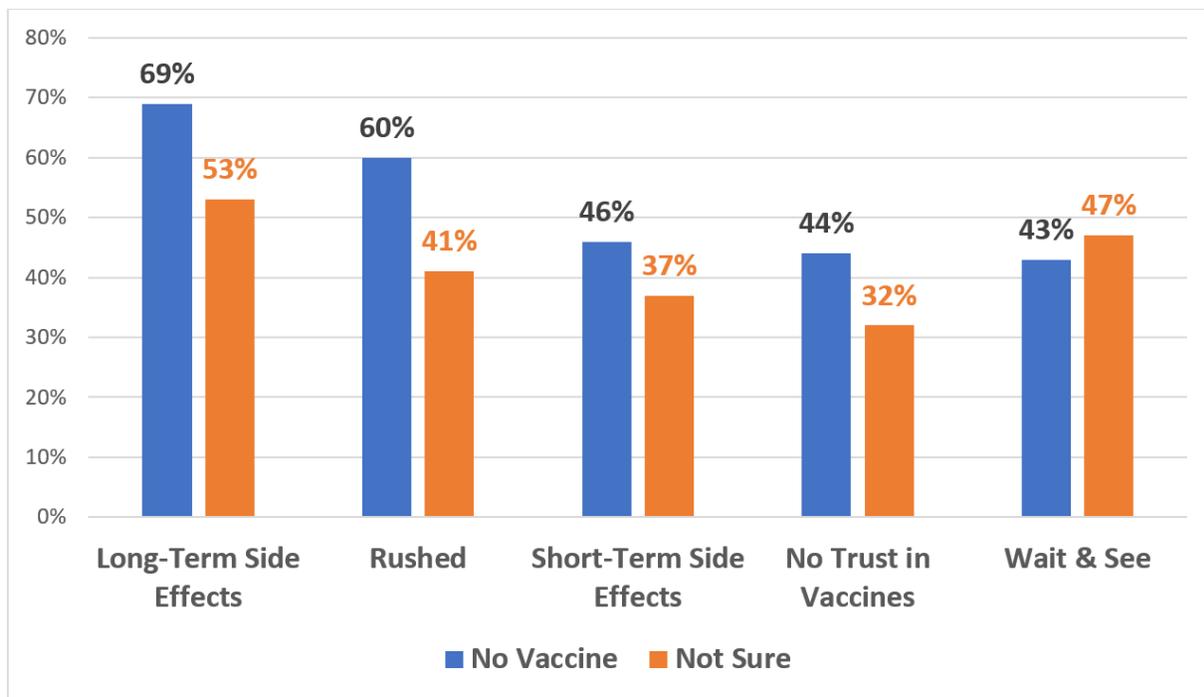
4. Not trusting vaccines in general (44%).
5. Wanting to wait and see how vaccine works with other people (43%).

**Big Reasons- Not Sure Group (n=549)**

As displayed in Figure 3, among respondents not sure about being vaccinated, the five most frequently endorsed GVH “Big Reasons” were:

1. Worry about possible long-term side effects from the vaccine (53%).
2. Wanting to wait and see how the vaccine impacts others (47%).
3. Belief that development of the vaccine was rushed (41%).
4. Worry about possible short-term side effects from the vaccine (37%).
5. Wanting to wait and see how vaccine works with other people (47%).

**Figure 3. General Vaccine Hesitancy Big Reasons**



**Lack of Trust in Organizations & Individuals: Vaccine Safety & Effectiveness**

We asked 11 specific questions and one open-ended question about whether respondent’s lack of trust in organizations and individuals ensuring the safety and effectiveness of the COVID-19 vaccine contributed to their unwillingness to be vaccinated or being unsure. Distrust

Organizations and individuals included Vaccine Manufacturers, the Federal Government, Federal Government Officials, State Government, State Government Officials, County Government, County Government Officials, Local Public Health Department, Local Public

Health Department Officials, Health Care Systems, and Health Care Providers. The rationale for differentiating between a government and a governmental official was to separate governmental entities from officials that have been designated to communicate about the vaccine.

**Big Reason- No Vaccine Group (n=352)**

As displayed in Figure 4, the most frequently identified organizations or individuals that were not trusted regarding vaccine safety and effectiveness and a “Big Reason” for not getting vaccinated were:

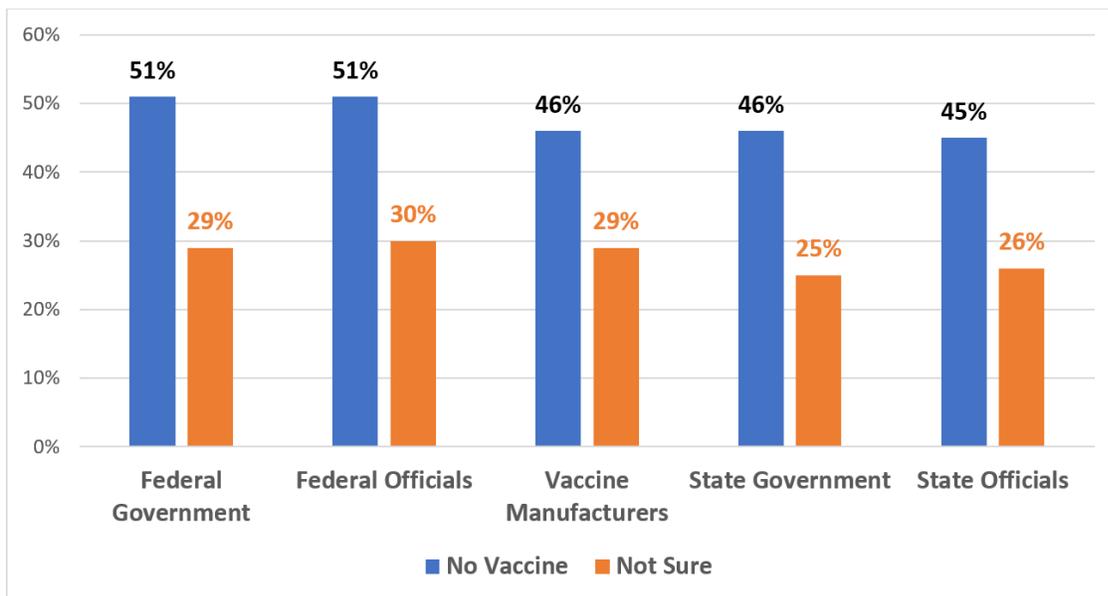
1. The Federal Government (51%).
2. Federal Government Officials (51%).
3. Vaccine Manufacturers (46%).
4. State Government (46%).
5. State Government Officials (45%).

**Big Reason- Not Sure Group (n=549)**

As displayed in Figure 4, the most frequently identified organizations or individuals that were not trusted regarding vaccine safety and effectiveness and a “Big Reason” for not being sure about being vaccinated were:

1. Federal Government Officials (30%).
2. The Federal Government (29%).
3. Vaccine Manufacturers (29%).
4. State Government Officials (26%).
5. State Government (25%).

**Figure 4. Not Trusted Over Safety & Effectiveness- Big Reasons**



## **Lack of Trust in Organizations & Individuals: Reliable Information**

We asked 11 specific questions and one open-ended question about whether respondent's lack of trust in organizations and individuals in providing reliable information about the COVID-19 vaccine contributed to their not getting the vaccine or being unsure. Organizations and individuals included Vaccine Manufacturers, the Federal Government, Federal Government Officials, State Government, State Government Officials, County Government, County Government Officials, Local Public Health Department, Local Public Health Department Officials, Health Care Systems, and Health Care Providers.

### **Big Reason- No Vaccine Group (n=352)**

As displayed in Figure 5, the most frequently identified organizations or individuals that were not trusted to provide reliable COVID-19 vaccine information and a "Big Reason" for not getting vaccinated were:

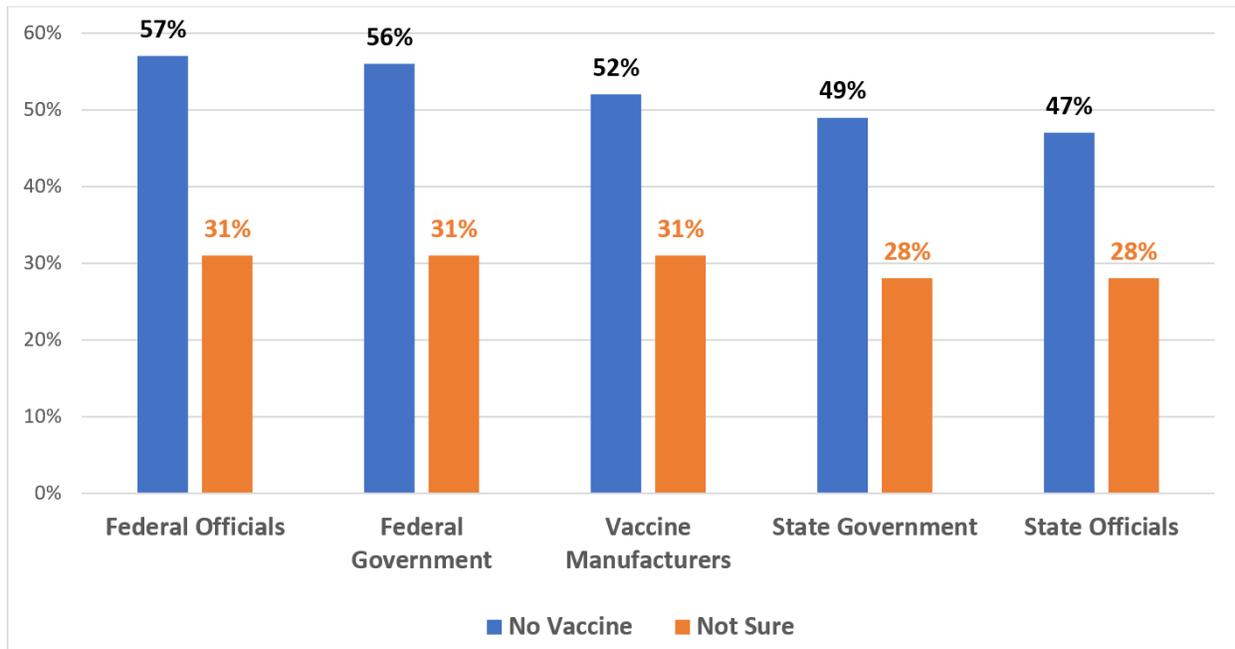
1. Federal Government Officials (57%).
2. The Federal Government (56%).
3. Vaccine Manufacturers (52%).
4. State Government (49%).
5. State Government Officials (47%).

### **Big Reason- Not Sure Group (n=549)**

As displayed in Figure 5, the most frequently identified organizations or individuals that were not trusted to provide reliable COVID-19 vaccine information and a "Big Reason" for not being sure were:

1. Federal Government Officials (31%).
2. The Federal Government (31%).
3. Vaccine Manufacturers (31%).
4. State Government (28%).
5. State Government Officials (28%).

**Figure 5. Not Trusted Reliable Information Providers- Big Reasons**



### **Disability Accessibility**

We developed eight specific questions and one open-ended question about accessibility issues contributing to not getting vaccinated or being not sure.

#### **Big Reason- No Vaccine Group (n=352)**

As displayed in Figure 6, the most frequently identified accessibility issues that were a Big Reason for not getting vaccinated were:

1. Vaccine sites weren't physically accessible (6%).
2. Information on site location not offered in alternate formats (large print, Braille, plain language) (5%).
3. No transportation to vaccine sites (4%).
4. Can't leave home (4%).
5. No accessible parking at vaccine sites/Unable to register online for vaccine because the website wasn't working (tie)(2%).

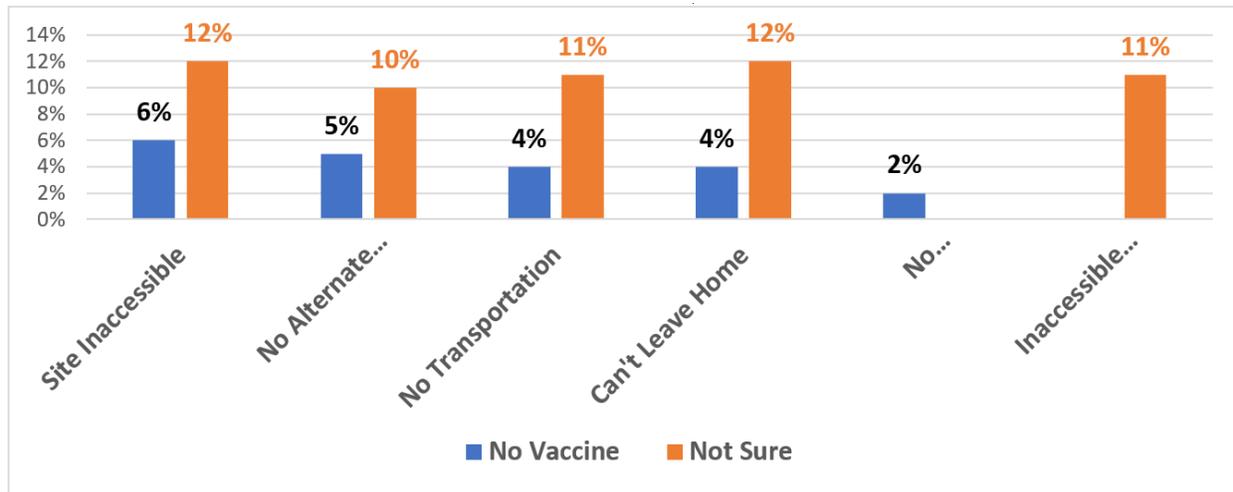
#### **Big Reason- Not Sure Group (n=549)**

As displayed in Figure 6, the most frequently identified accessibility issues that were a Big Reason for being unsure were:

1. Vaccine sites weren't physically accessible (12%).
2. Can't leave home (12%).
3. No transportation to vaccine sites (11%).
4. Inaccessible online registration system (11%).

5. Information on site location not offered in alternate formats (large print, Braille, plain language) (10%).

**Figure 6. Disability Inaccessibility Big Reasons**



### **Availability of the Vaccine**

We developed four Vaccine Availability questions -- including a ranking of a preferred vaccine location – for the two respondent groups.

#### **Big Reason- No Vaccine Group (n=343)**

As displayed in Figure 7, the most frequently identified availability issues that were a Big Reason for not getting vaccinated were:

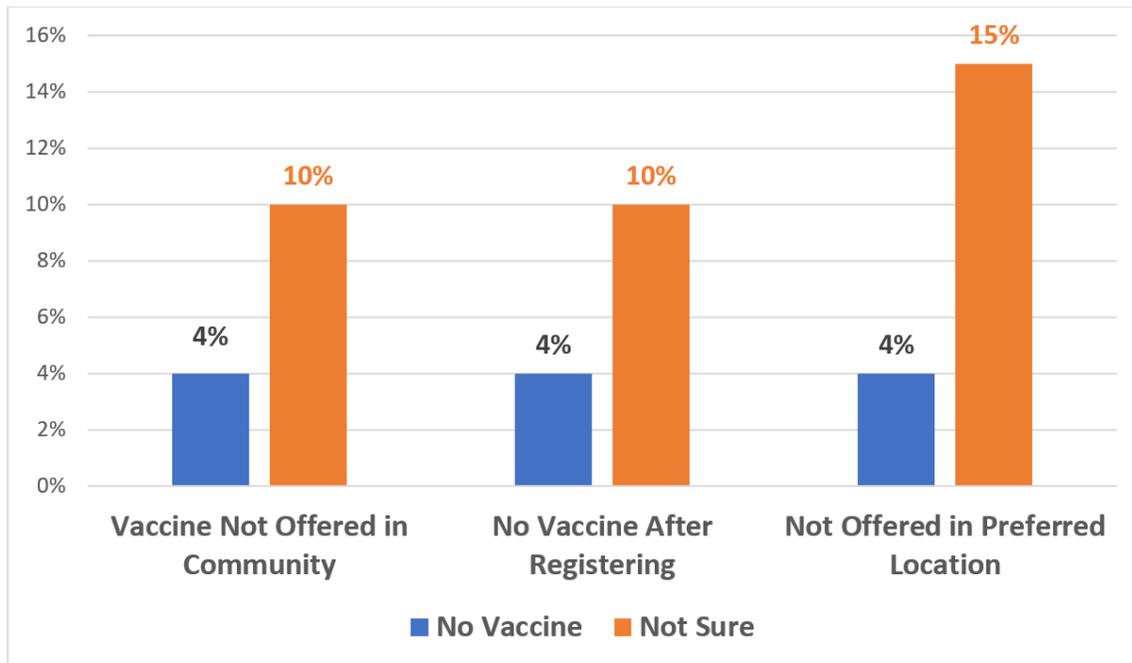
1. Vaccines not offered in local community (4%).
2. After registration, no vaccines available (4%).
3. Vaccines not offered in preferred location (4%).

#### **Big Reason- Not Sure Group (n=540)**

As displayed in Figure 7, the most frequently identified availability issues that were a Big Reason for not being sure were:

1. Vaccines not offered in local community (10%).
2. After registration, no vaccines available (10%).
3. Vaccines not offered in preferred location (15%).

**Figure 7. Vaccine Availability Big Reasons**



### **Preferred Vaccination Site**

We asked respondents to individually rank each vaccine site as either a first, second, or third choice among the two respondent groups. For example, Mass Vaccine sites were ranked first by 11% of the Not Sure group, second by 16%, and a third choice by 73%.

As displayed in Table 2, among the No Vaccine group (n=21), Hospitals (80%), Doctor's Offices (59%), and Mass Vaccine sites (33%) received stronger endorsements as a first choice. Centers for Independent Living or other Disability Organizations (67%), Pharmacies (33%), and Doctor's Offices (29%) received stronger endorsements as a second choice. Home (75%), Mass Vaccine Site (44%), and Pharmacies (42%) received stronger endorsements as a third choice.

As displayed in Table 3, among the Not Sure group (Table 2) (n=182), Home (59%), Doctor's Offices (57%), and Pharmacies (27%) received stronger endorsements as a first choice. Hospitals (49%), Centers for Independent Living or other Disability Organizations (44%), and Pharmacies (35%) received stronger endorsements as a second choice. Mass Vaccine Site (73%), Centers for Independent Living or other Disability Organizations (38%), and Pharmacies (38%) received stronger endorsements as a third choice.

**Table 2. Comparative Ranking of Vaccine Sites- No Vaccine Group**

	<b>No Vaccine</b>	<b>No Vaccine</b>	<b>No Vaccine</b>
<b>Vaccine Site</b>	<b>1<sup>st</sup> Choice</b>	<b>2<sup>nd</sup> Choice</b>	<b>3<sup>rd</sup> Choice</b>
Mass Vaccine Site	33%	22%	44%
Doctor's Office	59%	29%	12%
Hospital	80%	20%	0%
Pharmacy	25%	33%	42%
CIL/Disability Org	0%	67%	33%
Home	13%	13%	75%

**Table 3. Comparative Ranking of Vaccine Sites- Not Sure Group**

	<b>Not Sure</b>	<b>Not Sure</b>	<b>Not Sure</b>
<b>Vaccine Site</b>	<b>1<sup>st</sup> Choice</b>	<b>2<sup>nd</sup> Choice</b>	<b>3<sup>rd</sup> Choice</b>
Mass Vaccine Site	11%	16%	73%
Doctor's Office	57%	33%	10%
Hospital	18%	49%	32%
Pharmacy	27%	35%	38%
CIL/Disability Org	18%	44%	38%
Home	59%	16%	25%

## **D. Discussion**

Since January of 2021, Gallup has been tracking the percentage of Americans who are fully or partially vaccinated and willing to be vaccinated and persons unwilling to be vaccinated using a nationally representative panel (Gallup, 2021). According to the latest findings released March 30th, 74% of respondents were willing to be vaccinated (Fully Vaccinated: 19%; In Process: 13%; and Plan to: 42%). Twenty-six percent of respondents said that they would not be vaccinated (Brenan, 2021).

Importantly, the Gallup survey does not include a "Not Sure" response option. From a public health perspective, including a "Not Sure" category is important in understanding the strength of opinions among persons who experience vaccine hesitancy. This may provide important information regarding vaccine messaging factors that may impact respondent's shifting from "Not Sure" to willing to be vaccinated.

Given the use of a convenience sample, we did not have a prior assumption regarding our sample's willingness to be vaccinated. Like the Gallup results, 72% of the COVID-19 Vaccine and Disability survey sample had been, were in progress, or planned to be vaccinated. Ten percent of the Disability survey sample were not willing to be vaccinated and 17% were "Not Sure."

Because of the non-probability sampling technique used in this research, the No Vaccine and Not Sure distribution and specific hesitancy results have limitations in generalizability. However, the present sample is not a conventional convenience sample (no limitation on participation) because the sampling frame was limited to adults with disabilities (in fact, persons who refused to respond to the disability identifiers were eliminated from the final sample). Convenience samples with limits on participation through socio-demographic variables are considered a homogeneous convenience sample. Homogeneous convenience samples provide clearer generalizability because they intentionally constrain the chance of bias in sampling (Jager et al., 2017). Our results are generalizable to the original sample and may apply more narrowly to the population of adults with disabilities but should be considered conservatively because of the use of only one homogenous factor (disability status) as opposed to two or three.

Because of time and resources, we were only able to conduct a basic descriptive comparison between the No Vaccine and Not Sure groups. Some findings from the sampling frame should be considered conservatively given the absence of chi-squared or other statistical testing. Specific findings are discussed below.

### **Disability-Related Vaccine Hesitancy**

From a descriptive perspective, the COVID-19 Vaccine and Disability survey samples of No Vaccine and Not Sure groups demonstrate many similarities in which “Big Reasons” were impactful, but some interesting differences in the weight of the Big Reasons that we explore below.

The top five most frequently endorsed DRVH Big Reasons were the same for each group (lack of trust in vaccine safety and/or effectiveness on respondent’s disability, on respondent’s underlying health condition, lack of reliable information on vaccine impact on respondent’s underlying health condition, on respondent’s disability, and because of respondent’s underlying health condition). Notably, while the Not Sure group had a tighter Big Reason endorsement range (from 38% to 46% with four items having percentages in the 40s), the No Vaccine group had a higher and wider endorsement range (41% to 63%).

Among the No Vaccine group, three Big Reasons (insufficient information on vaccine’s impact on underlying health condition and disability and because of health condition) clustered from 41% to 42% endorsement levels. Within the No Vaccine group, not trusting the safety and/or effectiveness of the vaccine on one’s disability (63%) or underlying health condition (58%) was endorsed more frequently as contributing to vaccine hesitancy compared to other Big Reasons.

This suggests that for the No Vaccine group, a lack of information about the impact of the vaccine on one’s disability or underlying health condition is not solely driving higher Big Reason endorsement percentages, otherwise all the Big Reason endorsement

percentages would be similar. Put more simply, factors in addition to lack of information may be driving mistrust in the vaccine among the No Vaccine group given the differences in endorsement percentages among the top five Big Reasons.

A reasonable interpretation of this finding is that providing information alone may not be sufficient to shift the perspective of many members of the No Vaccine group. On the other hand, given lower percentages of Big Reason endorsement among the Not Sure group, their opinions may be more malleable if information and trustworthiness messages are provided to this group.

### **General Vaccine Hesitancy**

The top five most frequently endorsed GVH Big Reasons were the same for the No Vaccine and Not Sure groups. This was a surprising finding given that the GVH category included a total of 14 specific questions. The most frequently endorsed GVH Big Reasons were concern about long-term effects, short-term effects, belief that vaccine development was rushed, mistrusting vaccines in general, and wanting to take a “wait and see” approach about the impact of the vaccine on others.

Like the DRVH findings, two of the No Vaccine group’s Big Reasons were endorsed at much higher proportions than the other three Big Reasons. Specifically, 69% and 60% of the No Vaccine group endorsed concern about the vaccine’s long-term effects (69%) and development being rushed (60%) compared to other endorsement percentages in the 40s. The Not Sure group had two Big Reasons that were endorsed at higher proportions: concern about long-term effects (53%) and wanting to take a wait and see approach (47%). This contrasts with the Not Sure DRVH findings which were clustered together in frequency.

Four of the top five Big Reasons for both groups (concern about long-term and short-term side effects and rushed development) are very specific to the COVID-19 vaccine, as opposed to some of the general vaccine hesitancy survey questions, (i.e., scared of needles, vaccines opposed by religion/philosophy/culture). Given the lack of data on the COVID-19 vaccine’s impact on people with disabilities, addressing these concerns could present a considerable programmatic challenge to increasing vaccine rates.

We had also anticipated that information from the media or social media and persons advocating against the vaccine would have played a larger role in the two group’s vaccine decisions. However, among the No Vaccine group, information from the media or social media was the 7<sup>th</sup> most frequently endorsed Big Reason (20%) for their vaccine decision, family and/or friends advocating against the vaccine was 9<sup>th</sup> (14%), and community leaders advocating against the vaccine was 13<sup>th</sup> (6%). Among the Not Sure group, information from the media or social media was the 6<sup>th</sup> most frequently endorsed Big Reason (18%), family and/or friends advocating against the vaccine was 12<sup>th</sup> (5%), and community leaders advocating against the vaccine was 14<sup>th</sup> (3%).

## **Lack of Trust in Organizations & Individuals: Vaccine Safety/Effectiveness & Provision of Reliable Information**

One of the primary activities in addressing pandemics is to create trust within the public that governmental organizations and individuals and others are ensuring the safety and effectiveness of vaccine responses (when needed) and providing reliable information about a developed vaccine. We asked respondents if a lack of trust in certain organizations and individuals in ensuring vaccine safety and effectiveness and providing reliable information was Not a Reason, a Little Reason, or a Big Reason for their vaccine choice. The 11 organizations and individuals were Vaccine manufacturers, Federal, State, and County Government and officials, local public health departments and officials, Healthcare systems, and Health Care Providers.

Out of 11 organizational and individual choices, both samples endorsed the same five response categories (Federal Government, Federal Officials, Vaccine Manufacturers, State Officials, and State Government) as most distrustful and a Big Reason for their vaccine decisions, although in a slightly different order.

The level of distrust proportions among the No Vaccine was substantial and tightly clustered. For example, the No Vaccine group distrust endorsement levels ranged from a low of 45% for State Officials to a high of 51% for the Federal Government and Federal Officials. In comparison, the Not Sure group was lower but also tightly clustered. For example, the distrust endorsement levels ranged from 25% (State Government) to a high of 30% (Federal Officials). The gap between the No Vaccine and Not Sure proportions averaged 20 percentage points, revealing a substantial average difference.

Similarly, there were considerable distrust levels among the two groups among organizations and individuals providing reliable information about the vaccine. The No Vaccine group distrust endorsement ranged from a low of 47% (State Officials) to a high of 57% (Federal Officials) and was tightly clustered. The Not Sure group distrust endorsement ranged only three percentage points between State Government and State Officials (both at 28%) and Federal Officials, Federal Government, and Vaccine Manufacturers (all at 31%). The gap between the No Vaccine and Not Sure proportions was also substantial, averaging 22 percentage points.

Taken together, the No Vaccine group had high levels of distrust endorsement and the Not Sure group had considerable levels of distrust endorsement for the entities and individuals with primary responsibility for addressing the COVID-19 pandemic: Federal Government and Officials and State Government and Officials, and a major contributor to safety/effectiveness and reliable information, i.e., Vaccine Manufacturers. This is of grave concern.

In general, local public health and health care providers and systems were considered more trustworthy than other organizations and individuals. Or rather, lack of trust in

them was less likely to be endorsed as a Big Reason for being unwilling to be vaccinated or unsure (which is not quite the same as “trustworthy”). They were also more likely to be endorsed as “Not a Reason” for vaccine choices (data not reported). This suggests relying solely on ensuring safety and providing information may need to be augmented with additional approaches.

### **Accessibility & Availability of the Vaccine**

Due to our involvement with several disability coalitions and groups, we had anticipated that a lack of accessibility and availability would have been significant reasons that contributed to respondents deciding not to get vaccinated or being unsure.

Consequently, we were initially surprised that among the Not Sure group only 10% to 12% of the respondents cited accessibility issues as a Big Reason for not being sure about being vaccinated. Similarly, among the No Vaccine group, 2% to 6% of the respondents cited accessibility factors as Big Reasons for not getting vaccinated.

Vaccine availability also played a small role in overall vaccine decision-making (as measured in frequency as a Big Reason). For the Not Sure group, 10% of respondents identified the vaccine not being offered in the respondent’s local community, 10% identified vaccines not being available after registering, and 15% identified vaccines not being offered in their preferred location as Big Reasons for being unsure about getting vaccinated. For the No Vaccine group, percentages were even lower: 4% identified lack of local access, 4% identified post-registration unavailability, and 4% identified lack of preferred location as Big Reasons for not getting vaccinated.

We also asked each group to individually rank six different potential vaccine sites as their first, second, and third choice. While not strictly a rank order analysis, there were differences in frequency of choice selection between the No Vaccine and Not Sure groups. Since the No Vaccine group dropped to an n of 21, of more value are the preferences of the Not Sure group of which respondents to endorse Home, Hospitals, and a Mass Vaccine site more frequently as first, second, and third choices, respectively.

Although we did not initially expect the accessibility and availability responses, we believe that the seeming discrepancy between anecdotal reports and these findings relates to who we collected data from on these issues: the No Vaccine and Not Sure groups. We believe that accessibility and vaccine availability are much more significant factors for persons with disabilities who are planning to be vaccinated and may have been experienced by those already vaccinated compared to persons who are not sure or are unwilling to be vaccinated.

## **E. Recommendations**

### **Disability-Related Vaccine Hesitancy**

Since the top five items most frequently endorsed DRVH Big Reasons were the same for each group, it is important to assess true statistical difference in the proportions

between the two groups. The results on their face suggest that the No Vaccine group (the smaller of the two groups) may not be easily persuadable as it relates to issues of trust regarding the impact of the vaccine on disability and underlying health conditions given the high frequency endorsements levels even if additional information is provided.

Lower endorsement proportions among the Not Sure group suggests that messaging to address the Big Reasons may influence future vaccine decisions, i.e., shifting from not sure to willing to be vaccinated. Where lower percentages of Big Reason endorsement exist, opinions may be more malleable if information and trustworthiness messages are directed to this group. Given an absence of direct information on the impact of the vaccine on disability and underlying health conditions, messaging focusing on analogies (lack of deleterious impact on disability and underlying health conditions of prior vaccines). This may prove helpful in shifting the choice of persons with disabilities who are not sure.

### **General Vaccine Hesitancy**

Four of the top five Big Reasons (concern about long-term side effects, short-term side effects, and rushed development) for both groups are specific to the COVID-19 vaccine. Yet, the hesitations themselves may not be easily overcome; some persons with concerns about long-term effects may require long-term data to overcome their concerns. Perhaps even more easily than addressing DRVH hesitations, messaging targeting the Not Sure group demonstrating a lack of side effects and safety levels at different stages of development from other vaccines may diminish concerns about the COVID-19 vaccine. The combined effect of messaging by analogy (to other vaccines) and integrating this information with available data from the COVID-19 vaccine may have the greatest impact.

It was unanticipated that both groups would endorse the same top five Big Reasons. The "top five" reporting choice was taken because there were natural breaks in endorsement of the top five compared to the other hesitancy factors. Nevertheless, review of all 14 Big Reasons may reveal endorsement combinations of endorsements (i.e., community leaders, family/friends, social media influencers from the media/social media question) that can be targeted with an integrated messaging promoting the vaccine. A closer examination of all 14 GVH factors may present a more complete picture of what a multi-dimensional vaccine promotion program would look like. In addition to the combination of Big Reasons, it will also be important to examine the combination of Little Reasons and Big Reasons (see below).

While the endorsement levels of media/social media were unanticipated, a 20% and 18% endorsement level are not unsubstantial and needs to be addressed. It would also be valuable to assess if media/social media plays a role in supporting willingness to be vaccinated (as opposed to opposition).

### **Lack of Trust in Organizations & Individuals**

Since the top five distrust items in ensuring safety/effectiveness and proving reliable information were the same for the No Vaccine and Not Sure groups, it is important to assess true statistical difference in the proportions between the two groups. The results on their face suggest that the No Vaccine group may be less persuadable as it relates to issues of trust because of the high distrust levels. Given that the Not Sure group shares similar distrust issues held by nearly a third of the group, this presents a unique challenge for the largest public health entities (Federal and State) that are typically in the forefront of responding to public emergencies.

In this case, the involvement of local public health and (local) health systems/providers as message carriers should be considered to augment other public health initiatives. Although not directly supported by this research, many persons with disabilities have trust-worthy relations at the local level with Centers for Independent Living, other local disability organizations and programs, durable medical equipment providers, and local employers that are supportive of the employment of persons with disabilities. These organizations and others may be effective in transmitting vaccine messages to local disability communities. This may be a particularly effective strategy in rural communities where research has identified high proportions of rural dwellers saying they will “definitely not” get the vaccine (no information available on disability status)(Kirzinger, et al., 2021).

### **Research Recommendations**

While this research focused on descriptive comparisons among the top five Big Reasons between the No Vaccine and Not Sure groups, additional analysis to determine statistically significant differences is recommended. These results would establish not just “true differences” emitting in the higher proportions among the No Vaccine group, but where the Big Reasons between both groups are not different. We generally recommend focusing on the Not Sure group as a target for shifting vaccine choice. In cases where there is no statistical difference in items (generally, with lower endorsement levels) there is a possibility that the No Vaccine group may be affected by messages promoting the vaccine.

More importantly for additional research is the analysis of all Big Reasons (as noted previously) and the analysis of “Little Reasons” versus or in conjunction with Big Reasons. Intriguingly, a quick scan revealed that in the No Vaccine group only one Little Reason survey item was endorsed at a higher percentage compared to the same Big Reason survey item, but the Not Sure group demonstrated considerable variability. This may have implications for the use of Little Reasons and Big Reasons for public health vaccine promotion targeting the Not Sure group. Similarly, factors that result in items not being a reason for vaccine choices are an untapped area of research.

Each of the Vaccine Hesitancy, Distrust, Accessibility, and Availability findings in the present report should also be analyzed by type of disability, race/ethnicity, gender, age, and type of community (urban, rural, etc.). The survey includes a significant number of open-ended responses in each of the survey hesitancy categories. Analysis of this data could provide additional areas of hesitancy that can be addressed or clarification of the endorsed concerns.

In addition, a quick review of the open-ended results of the willing vaccine respondents revealed that they share many of the same concerns identified by the No Vaccine and Not Sure groups: concerns about the impact of the vaccine on one's disability or underlying health conditions, side effects, who to trust, and access and availability. Given open-ended responses for the willing vaccine respondents numbering in the thousands, analysis of this data may also provide important insights into how to shift the Not Sure into the willing group. Similarly, because we built a survey item asking if we could re-contact the survey respondents it would be insightful to re-survey persons who were planning on getting vaccinated to determine if they were vaccinated, if not, why not, and if they faced accessibility and availability barriers.

For future research, the use of a homogenous convenience sample could be improved by increasing the socio-demographic factors beyond disability or the use of quota sampling. Preferably, future research will rely on probability samples to generalize findings to the larger population of persons with disabilities and conducted on a longitudinal basis. Ideally, given that future pandemics and other natural disasters are inevitable, we recommend the creation of a national representative Disability and Public Health panel recruited through probability-based, random sampling methods so that health and public health issues are analyzed in real-time or near real-time.

## **Limitations**

The findings in this report are subject to at least seven limitations. First, the survey data are self-reported and may be subject to reporting or recall bias. Second, the responses represent a snapshot between March 12, 2021, until April 5, 2021, and the coronavirus vaccine situation may have changed since this time. Third, persons without internet access were unable to access the survey introducing bias. Fourth, the survey completion rate among adults varied among items, suggesting some response bias. Fifth, because of the use of a homogenous convenience sample, the results are narrowly generalizable to the overall population of persons with disabilities. Sixth, persons with multiple equivalent disabilities may not be accurately identified since we asked for a person's "main" disability. Seventh, the report combines all disability group responses for summary purposes.

## **F. Conclusion**

The results of this survey provide beginning insights into a unique and challenging moment in time for persons with disabilities and for public health during the coronavirus

pandemic. The frequently used summary that “more research is needed” is, in this case, a recognition that COVID-19 is a life-or-death situation for many persons with disabilities and others. Recommendations contained in this report reflect the belief of the American Association on Health and Disability that the task of our applied research is to identify the knowable but not let the unknowable limit our commitment to ensuring health equity for persons with disabilities.

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