

COVID-19 Vaccines: Barriers, Motivators, and Trusted Sources of Information for Individuals with Disabilities in the State of Alaska

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Executive Summary

Studies on U.S. patient populations show that having an intellectual disability poses the strongest independent risk factor for having a COVID-19 diagnosis, in addition to increasing one's likelihood of hospitalization and mortality due to COVID-19 (Gleason et al., 2021). Data show there are disparities in access to COVID-19 vaccines between adults with disabilities and those without disabilities in the U.S. (Ryerson et al., 2021). A survey was conducted to obtain information on COVID-19 vaccine potential barriers, motivators, and trusted sources of information for individuals with disabilities. The results of this survey will be used to inform vaccine distribution and education efforts in the state of Alaska. Eligible participants included individuals residing in the state of Alaska who are adults with disabilities; caregivers, guardians, and family members of individuals with disabilities; and disability service providers. Disability service providers, guardians, caregivers, and family members of individuals with disabilities cited guardian biases, lack of transportation, and inability to go on one's own as top vaccine barriers that they perceived people with disabilities experience. Vaccinated individuals with disabilities reported they were concerned that the vaccine would worsen their medical conditions, that the vaccine could contain side effects, and that they couldn't obtain the vaccine on their own. They said their top motivators to getting vaccinated were protecting the health of themselves, their family/friends, and their community. Individuals with disabilities indicated that their primary care providers, the CDC, and the tribal health system are their most trusted sources for information about COVID-19 vaccines, while providers perceived that family and friends, primary care providers, and elders to be individuals with disabilities' most trusted sources about COVID-19 vaccines.

Introduction

Having an intellectual disability is the strongest independent risk factor for having a COVID-19 diagnosis among a large patient population in the U.S. (Gleason et al., 2021). If diagnosed with COVID-19, patients with intellectual disabilities were more likely than those without intellectual disabilities to be admitted to the hospital and experience mortality following an admission (Gleason et al., 2021). Yet, adults with disabilities were more likely than those without disabilities to report that they would definitely get vaccinated, and more likely to endorse the COVID-19 vaccine as protection (Ryerson et al., 2021). These data show that many individuals with disabilities may want the COVID-19 vaccine, but could face barriers to obtaining it. The Alaska COVID-19 Vaccine Accessibility Partnership formed to assess and address barriers individuals with disabilities in the state of Alaska face to obtaining the COVID-19 vaccine.

Methodology

A 34-item survey was developed by a team of researchers and collaborators from the Alaska COVID-19 Vaccine Accessibility Partnership. All survey instruments and protocols were approved through the UAA Institutional Review Board.

The survey was formatted using Qualtrics survey software, and participants were only required to complete information that pertained to exclusion criteria or survey logic. The survey was distributed between August 16 and September 6, 2021 using a shareable hyperlink and QR code. Survey participants were recruited as a snowball sample through email lists, organizational newsletters, Facebook groups, and word-of-mouth.

Consent and an introduction to the survey purpose were provided at the start of the survey. This section of the survey was written in plain language using lead questions for ease of reading. Eligible participants were 18 years of age or older and identified either as an individual with a disability, a disability service provider, or a caregiver, guardian, or family member of an individual with a disability. Respondents who did not self-identify as these criteria were directed to the end of the survey.

Questions for care providers

Respondents who identified as either a disability service provider or a caregiver, guardian, or family member of an individual with a disability (referred to in this paper as “care providers”) were led to a block of questions to answer where they work (e.g. state, non-profit, own home/apartment, shelter, local organization), the individuals with disabilities that they work with (e.g. Individuals with sensory sensitivities and/or intellectual, developmental, and/or cognitive disabilities; Individuals with sensory and/or mobility disabilities; Individuals with mental health needs), and which Alaskan borough they lived in during the last 30 days.

For the following block, care providers answered questions based on the disabilities group(s) they serve. If they selected more than one disability category they were led through this block for each selected group. In this block they were asked how comfortable the group they serve is with the COVID-19 vaccine, from 1 (Very uncomfortable) to 5 (Very comfortable), along with how comfortable they feel addressing COVID-19 vaccine concerns from the selected group on the same scale. They were asked to rate barriers to vaccination that the individuals they serve face, from 1 (Not a barrier) to 5 (Major barrier) (e.g. These individuals can’t go on their own; These individuals do not trust the vaccine; Vaccination sites are too far away, etc.). They rated a list of strategies to increase access to the vaccine for the populations they serve, from 1 (Least effective) to 5 (Most effective) (e.g. Provide transportation to vaccination sites; Provide vaccination sites for those with mobility challenges). Before finishing the survey, they were asked to identify how much the group(s) they selected would trust the following sources of information about COVID-19 vaccines, from 1 (Least trusted) to 5 (Most trusted) (e.g. Elders, CDC, Health insurers, Family and friends).

Questions for individuals with disabilities

Respondents who self-identified as an individual with a disability at the start of the survey were led to a block of questions where they were asked which disabilities they experience (e.g. Developmental disability, Mental health, Autism), their primary housing situation (e.g. Family home, Group home, Couch surfing/camping out), which Alaskan borough they lived in during the last 30 days, and whether they have received a COVID-19 vaccine.

All individuals with disabilities were asked to rate barriers to COVID-19 vaccination, strategies to increase access to the COVID-19 vaccine, and trusted sources of information about COVID-19 vaccines. Individuals who responded that they had received at least one dose of the vaccine were asked to rate based on barriers they personally encountered to vaccination. Individuals with disabilities who reported not having received the vaccine were asked whether they would get the vaccine if it were available to them, along with their thought process surrounding vaccination, and to rate their comfort level with the COVID-19 vaccine from 1 (Very uncomfortable) to 5 (Very comfortable). Vaccinated individuals with disabilities were asked what motivated them to get vaccinated (e.g. Protecting my health, Protecting health of co-workers, Wanting to resume travel).

Survey Results

Demographics

A total of 271 people entered the survey and responded to the eligibility questions. Forty-eight (17.7%) people did not meet the eligibility criteria and were exited from the survey. A total of 223 people met inclusion criteria and their responses were included in survey analysis. Of the eligible respondents, 40 (18%) identified as a person with a disability, 82 (37%) identified as a caregiver, family member, or guardian of an individual with a disability, 101 (45%) identified as a disability service provider (DSP) (Figure 1). The majority of respondents were from the Southcentral region of Alaska or other population centers on the Alaska road system (Figure 2). Of the 40 respondents who self-identified as individuals with disabilities, half identified as experiencing a mobility or physical disability (Appendix: Table 1). The majority of care providers (120/183) responding to the survey support individuals with sensory sensitivities and/or intellectual, developmental, and/or cognitive disabilities, followed by individuals with sensory and/or mobility disabilities (74/183) and individuals with mental health needs (69/183) (Figure 3).

Figure 1 Participant self-identification (n = 223)

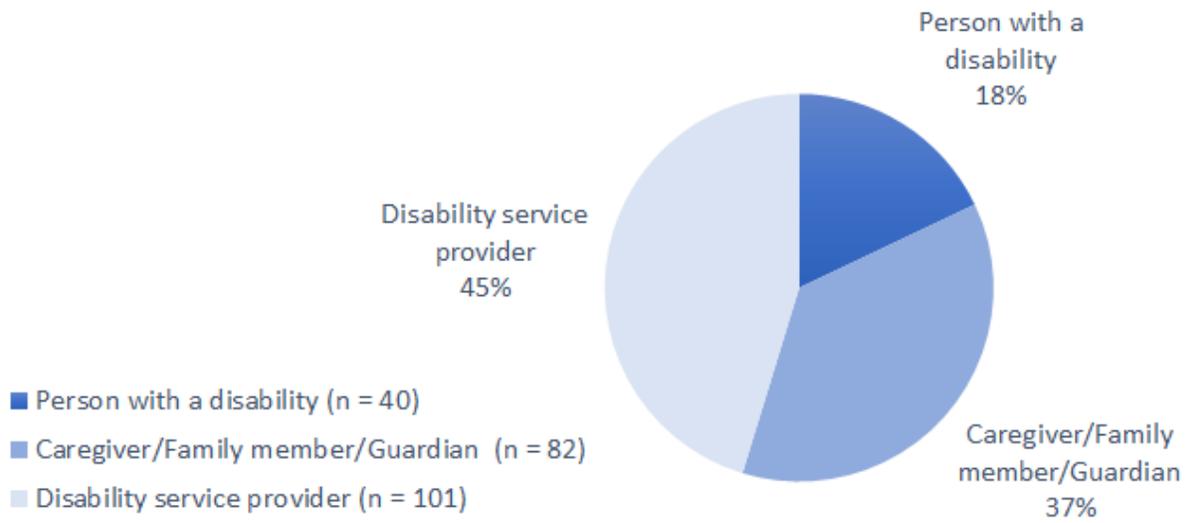


Figure 2 Boroughs participants lived in during the last 30 days (n = 173)

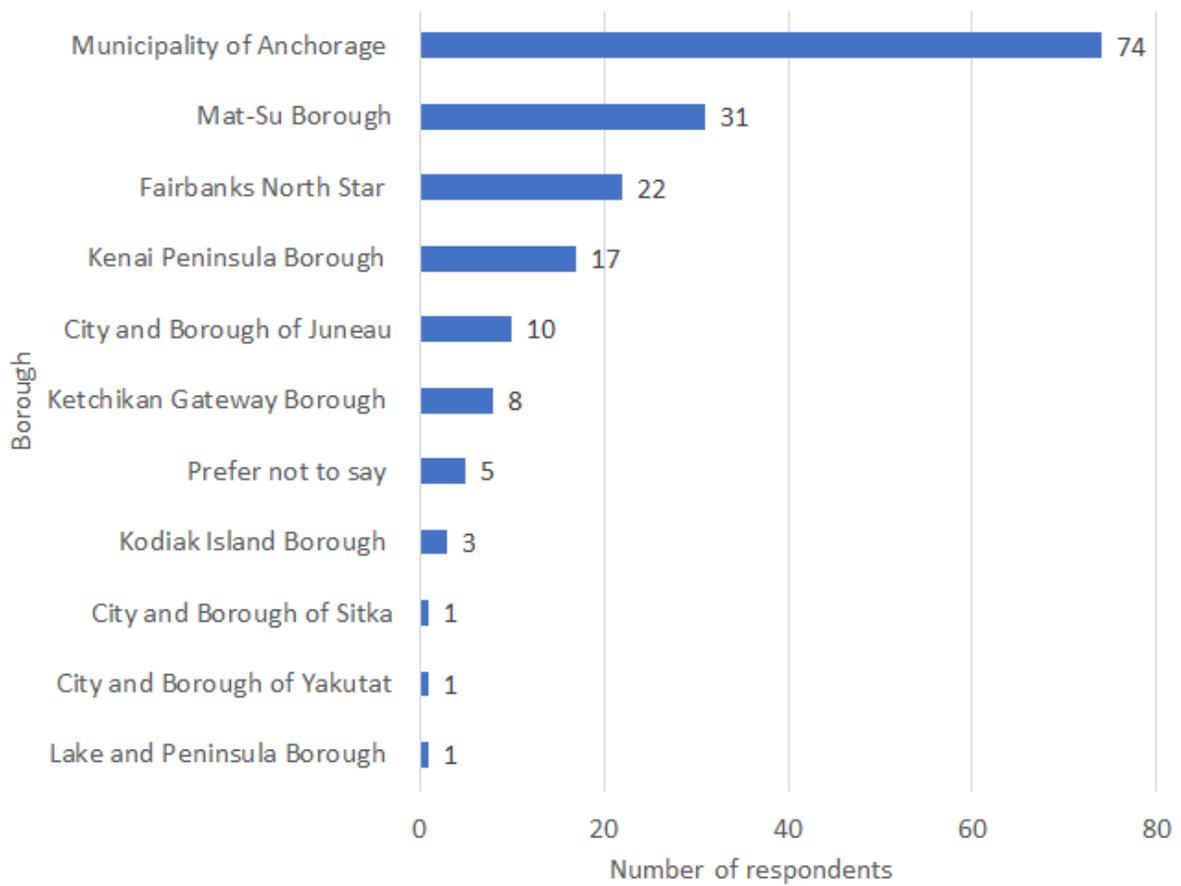
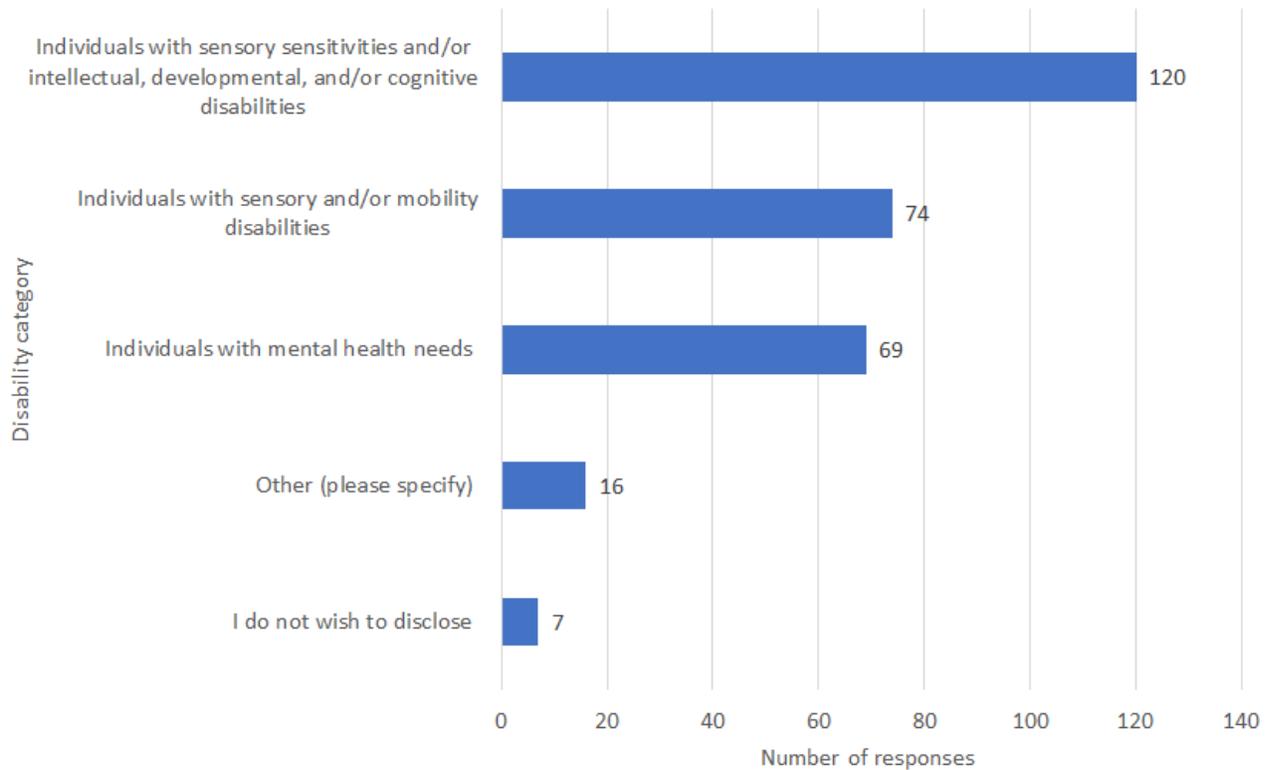


Figure 3 Disability care providers: Individuals with disabilities served.



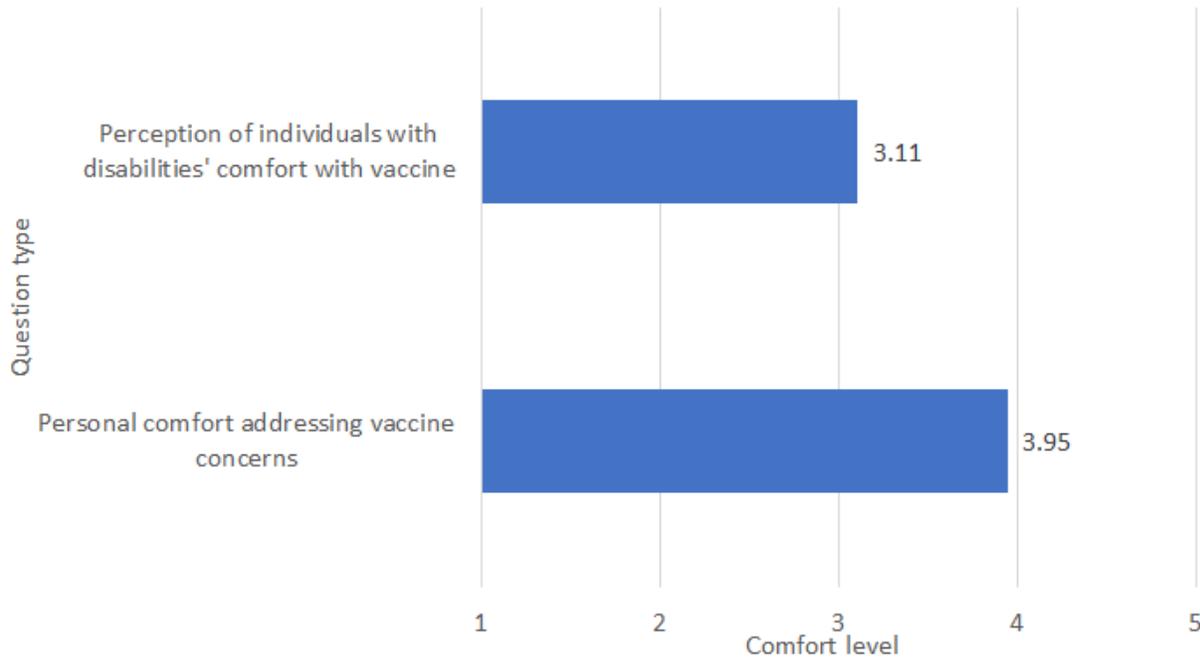
Note: Disability care providers were asked to select all that apply.

Care Providers

How comfortable do care providers feel addressing vaccine concerns of individuals with disabilities?

Care providers (including DSPs, caregivers, guardians, and family members of individuals with disabilities) perceived the individuals with disabilities they support to be relatively comfortable with the COVID-19 vaccine on a scale of 1 (Very uncomfortable) to 5 (Very comfortable) ($M = 3.11, n = 183$). They rated their personal comfort addressing vaccine concerns of the individuals with disabilities they support as higher on a scale of 1 (Very uncomfortable) to 5 (Very comfortable) ($M = 3.95, n = 185$) (Figure 4).

Figure 4 Disability care providers: Perception of COVID-19 vaccine comfort of individuals with disabilities (n = 183) and comfort addressing those vaccine concerns (n = 185).



Note: Disability care providers rated comfort levels on a scale from 1 (Very uncomfortable) to 5 (Very comfortable).

What barriers to COVID-19 vaccination do care providers perceive individuals with disabilities face?

Note: we used a list of barriers to vaccination provided from the CDC (see Literature Cited) and separated them into personal barriers (barriers relating to the individual) and other barriers (barriers beyond an individual's control).

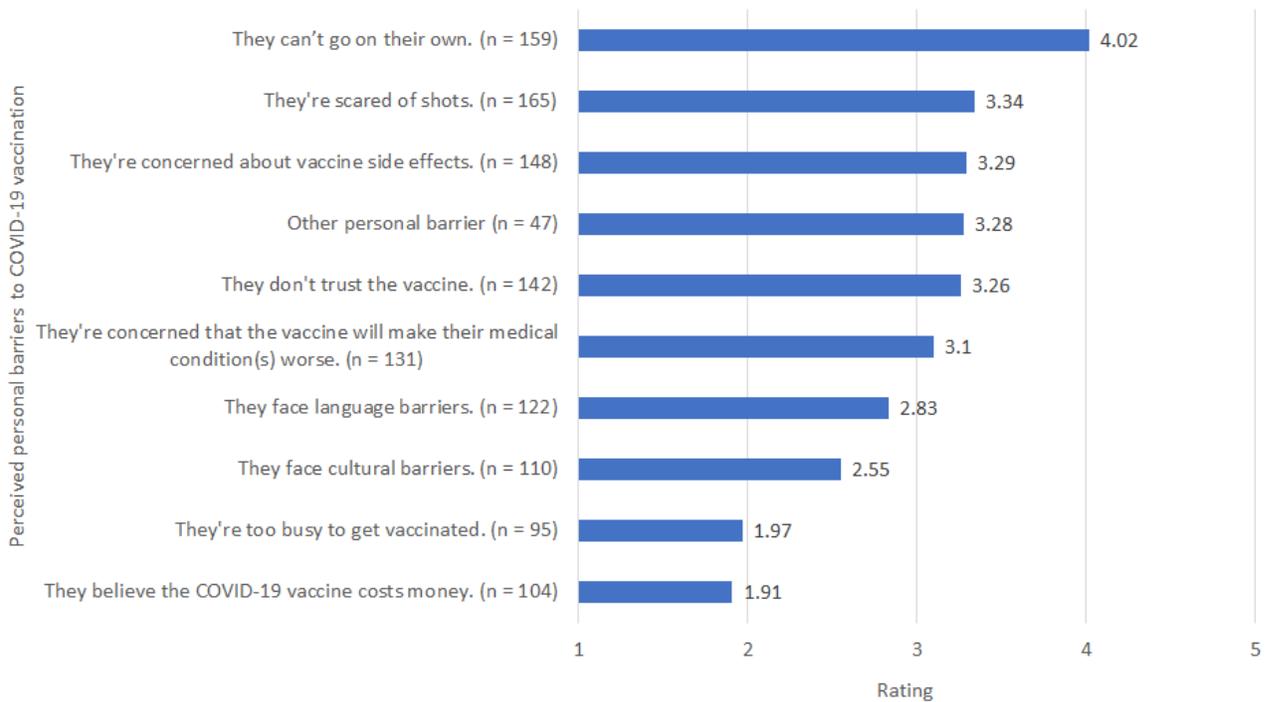
Personal barriers. According to care providers, the greatest personal barriers to COVID-19 vaccination faced by individuals with disabilities, on a scale of 1 (Not a barrier) to 5 (Major barrier), were “They can’t go on their own” ($M = 4.02$, $n = 159$), “They’re scared of shots” ($M = 3.34$, $n = 165$), “They’re concerned about vaccine side effects” ($M = 3.29$, $n = 148$), “Other personal barrier (please specify)” ($M = 3.28$, $n = 47$), and “They don’t trust the vaccine” ($M = 3.26$, $n = 142$) (Figure 5).

Other barriers. Care providers perceived the greatest other barriers to COVID-19 vaccination faced by individuals with disabilities, on a scale of 1 (Not a barrier) to 5 (Major barrier), were “They don’t have transportation” ($M = 3.62$, $n = 151$), “It is difficult for them to find or make an appointment” ($M = 3.27$, $n = 136$), “They don’t know where to go to get vaccinated” ($M = 2.97$,

$n = 131$), “They do not have access to the internet” ($M = 2.72$, $n = 121$), and “It is difficult for them to arrange for childcare” ($M = 2.65$, $n = 2.52$) (Figure 6).

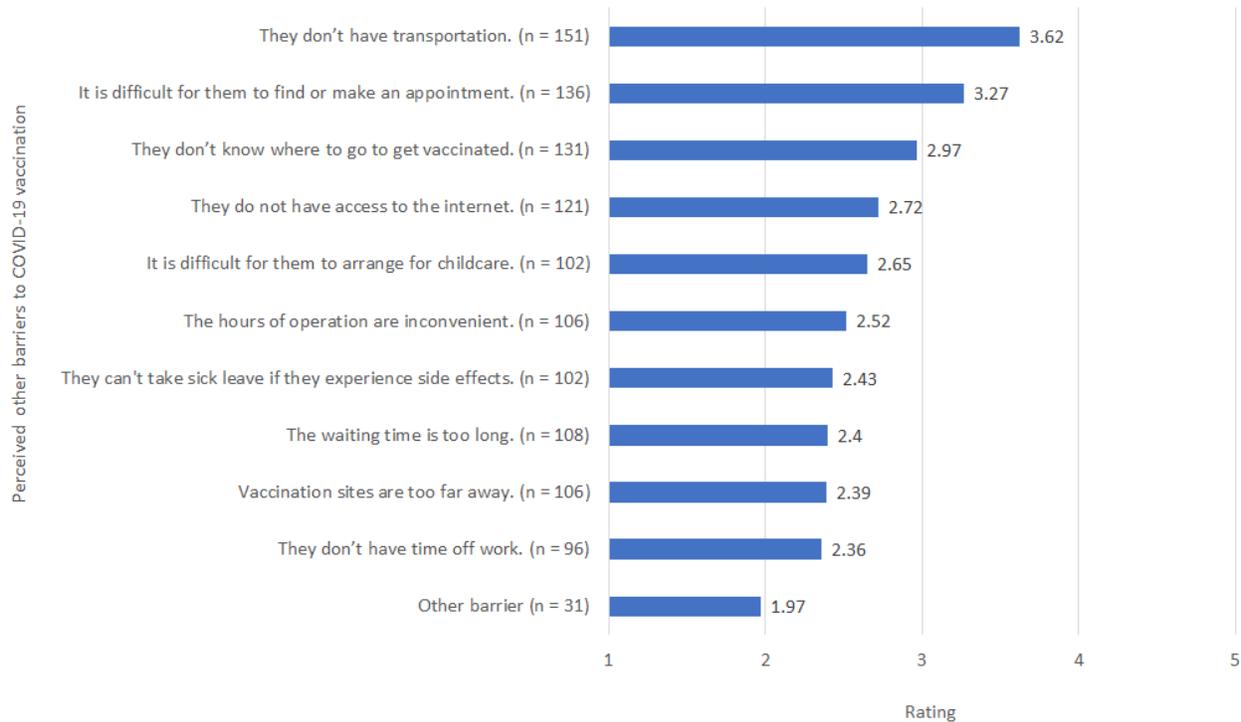
Written responses to “Other (please specify)” for both questions included: “Need computer skills [for] misinformation,” “Misinformation and anti-vaxers are all over out here,” “Guardian/family will not let them,” “Mistrust of pharma and government,” “Understanding its importance,” “Uncomfortable at clinics & hospitals,” and “Ability to clearly communicate adverse side effects” (Appendix: Table 2). There were 10 distinct written responses pertaining to guardian barriers and most answers regarded guardians imposing their beliefs on the individual(s) they represent (Appendix: Table 2). There were also five written responses pertaining to lack of transportation.

Figure 5 Disability care providers: Perceived personal barriers individuals with disabilities face to COVID-19 vaccination.



Note: Disability care providers rated barriers on a scale from 1 (Not a barrier) to 5 (Major barrier).

Figure 6 Disability care providers: Perceived other barriers individuals with disabilities face to COVID-19 vaccination.

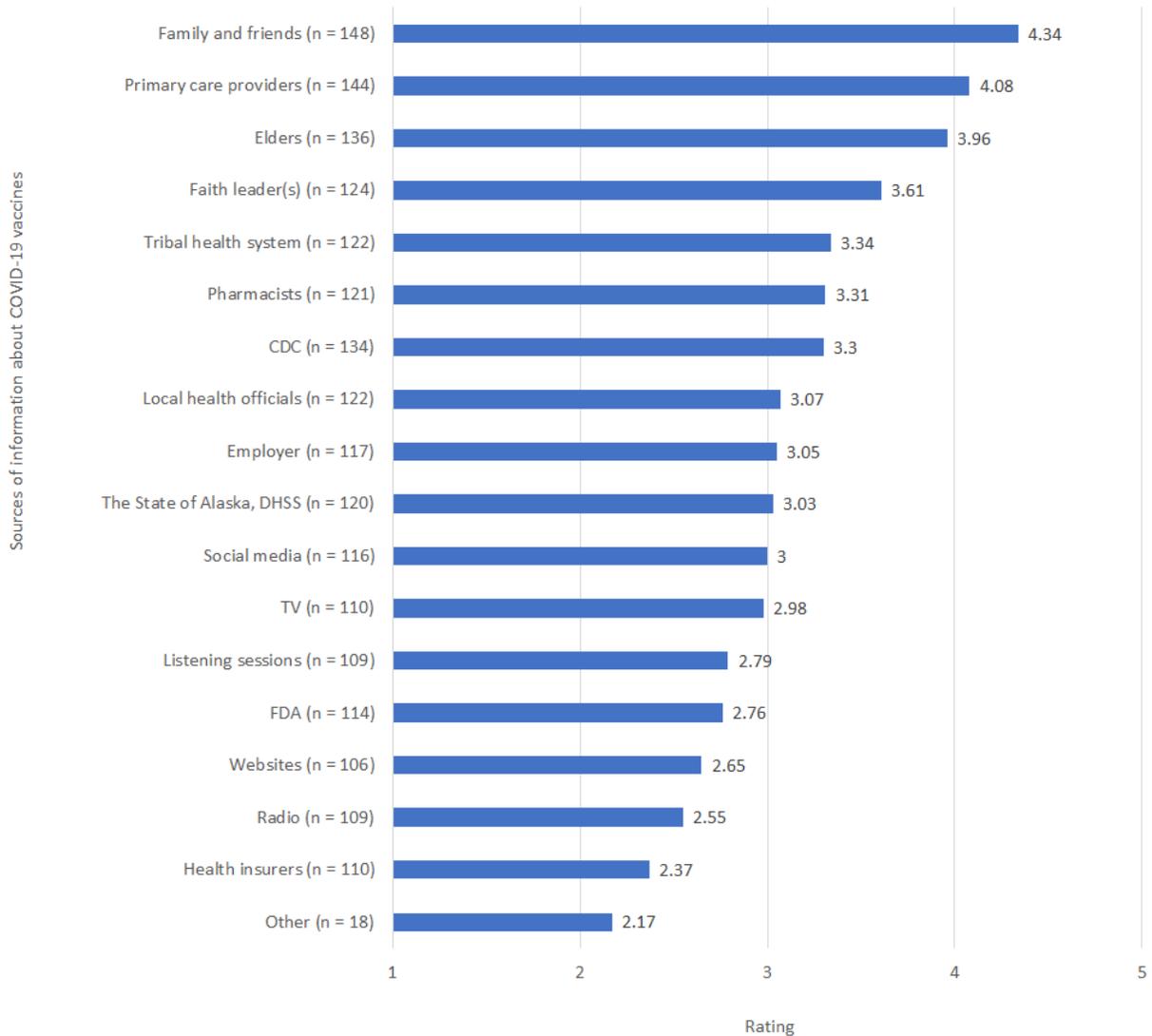


Note: Disability care providers rated barriers on a scale from 1 (Not a barrier) to 5 (Major barrier).

What are care providers' perceptions of sources about COVID-19 vaccine information that individuals with disabilities trust?

On a scale of 1 (Least trusted) to 5 (Most trusted) care providers rated that the individuals with disabilities they serve place the trust in "Family and friends" ($M = 4.34$, $n = 148$), "Primary care providers" ($M = 4.08$, $n = 144$), "Elders" ($M = 3.96$, $n = 136$), "Faith leader(s)" ($M = 3.61$, $n = 124$), and "Tribal health system" ($M = 3.34$, $n = 122$) for COVID-19 vaccine information (Figure 7). Other written responses included: "Their specialist doctors who understand what medications they are on and what their current status is," "Native corporations leadership, agencies delivering medical waiver services, advertising that features people with disabilities and examples of desensitizing the experience," "Personal care attendant," "Misinformation," "COVID patients and family," and "Ads featuring people representative of population and accommodations that work for the individual" (Appendix: Table 2).

Figure 7 Disability care providers: Perceived trusted sources of information about COVID-19 vaccines for individuals with disabilities.



Note: Disability care providers rated barriers on a scale from 1 (Least trusted) to 5 (Most trusted).

Individuals with Disabilities

How many individuals with disabilities reported receiving the COVID-19 vaccine?

Twenty-eight individuals with disabilities reported that they had received both doses of a two-dose vaccine product or one dose of a single-dose vaccine product. Four individuals reported they had not received at least one COVID-19 vaccine dose. Eight respondents did not answer this question.

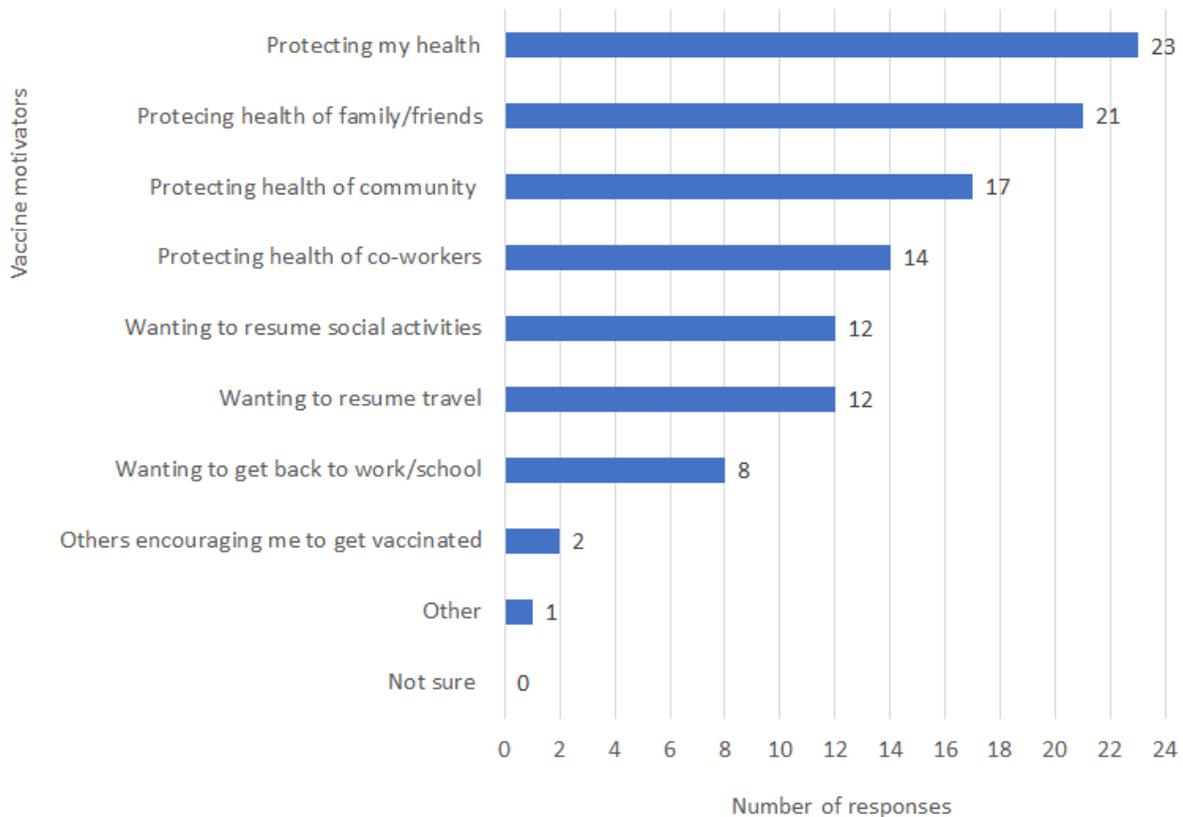
One individual who disclosed not receiving at least one dose of the COVID-19 vaccine wrote: “Why would I put something in my body that we don’t know the long-term effects of???”
People still get Covid with vaccinations AND masks. What about natural immunity??”

Since so few respondents ($n = 4$) from our sample answered that they did not receive the COVID-19 vaccine, we are omitting their data from analyses, as four responses is not sufficient to understand potential trends in the data.

What motivated individuals with disabilities to get the vaccine?

The highest motivators to get vaccinated pertained to protecting the health of oneself or others: “Protecting my health” ($n = 23$), “Protecting health of family/friends” ($n = 21$), “Protecting health of community” ($n = 17$), “Protecting health of co-workers” ($n = 14$) (Figure 8). These were the top motivations to receiving the vaccine, even amongst other incentives such as wanting to resume social activities or wanting to resume travel. One individual wrote that another vaccine motivator was a job requirement.

Figure 8 Vaccinated individuals with disabilities: COVID-19 vaccine motivators.



Note: Respondents were asked to select all motivators that apply.

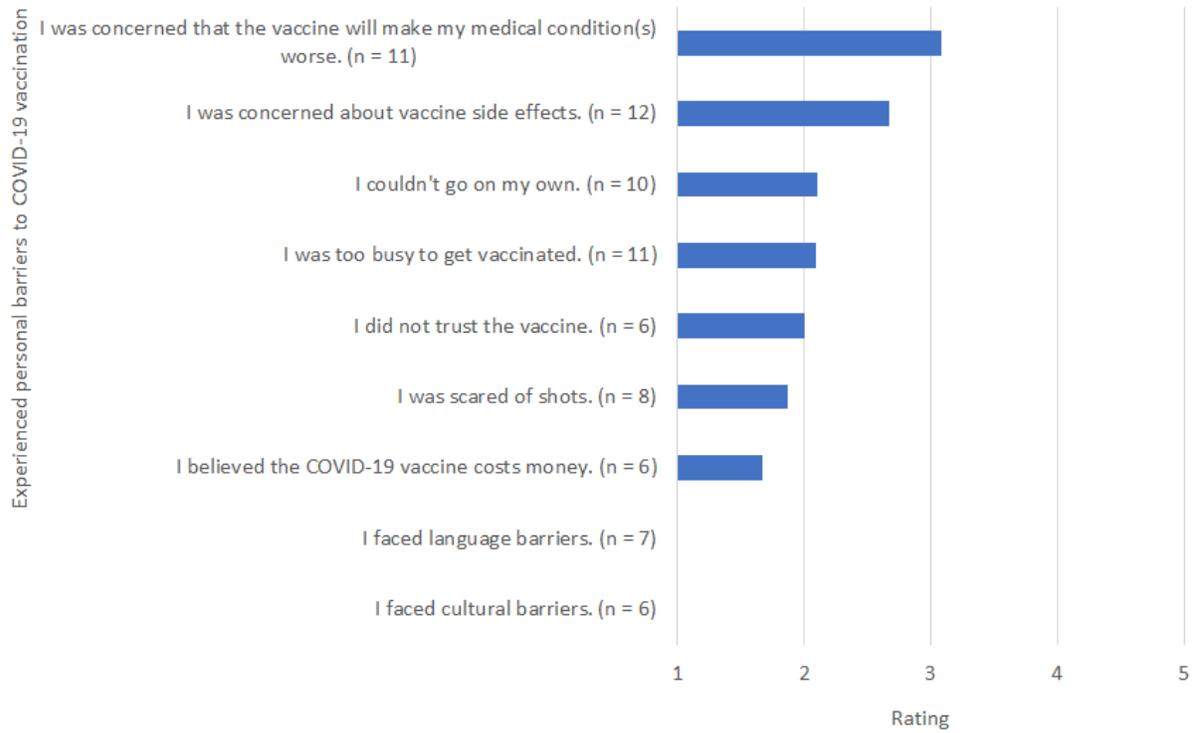
What barriers did vaccinated individuals with disabilities face surrounding the COVID-19 vaccine?

Personal barriers. The greatest reported personal barriers to COVID-19 vaccination faced by individuals with disabilities, on a scale of 1 (Not a barrier) to 5 (Major barrier), were: “I was concerned that the vaccine will make my medical condition(s) worse” ($M = 3.09, n = 11$), “I was concerned about vaccine side effects” ($M = 2.67, n = 12$), “I couldn’t go on my own.” ($M = 2.10, n = 10$), and “I was too busy to get vaccinated” ($M = 2.09, n = 11$) (Figure 9). Written responses included: “Almost all the clinics were inside and I would have to break my quarantine to get the shot” and “Did not want to take from others who were of a higher risk” (Appendix: Table 2). Two different respondents wrote, “Missing work after side effects.”

Other barriers. The greatest reported other barriers to COVID-19 vaccination faced by individuals with disabilities, on a scale of 1 (Not a barrier) to 5 (Major barrier), were: “I couldn’t take sick leave if I experienced side effects” ($M = 3.00, n = 8$), “It was difficult to find or make an appointment” ($M = 2.60, n = 10$), “Vaccination sites were too far away” ($M = 2.50, n = 8$), and “I didn’t know where to go to get vaccinated” (Figure 10). Written responses included: “Anxiety,” “Availability of non-single dose, required for medical reasons,” “If I was too sick to take care of my daughter if [there] were side effects,” and “Only 1 drive up vaccine site! Drive up testing but no drive up shots? Dumb” (Appendix: Table 2).

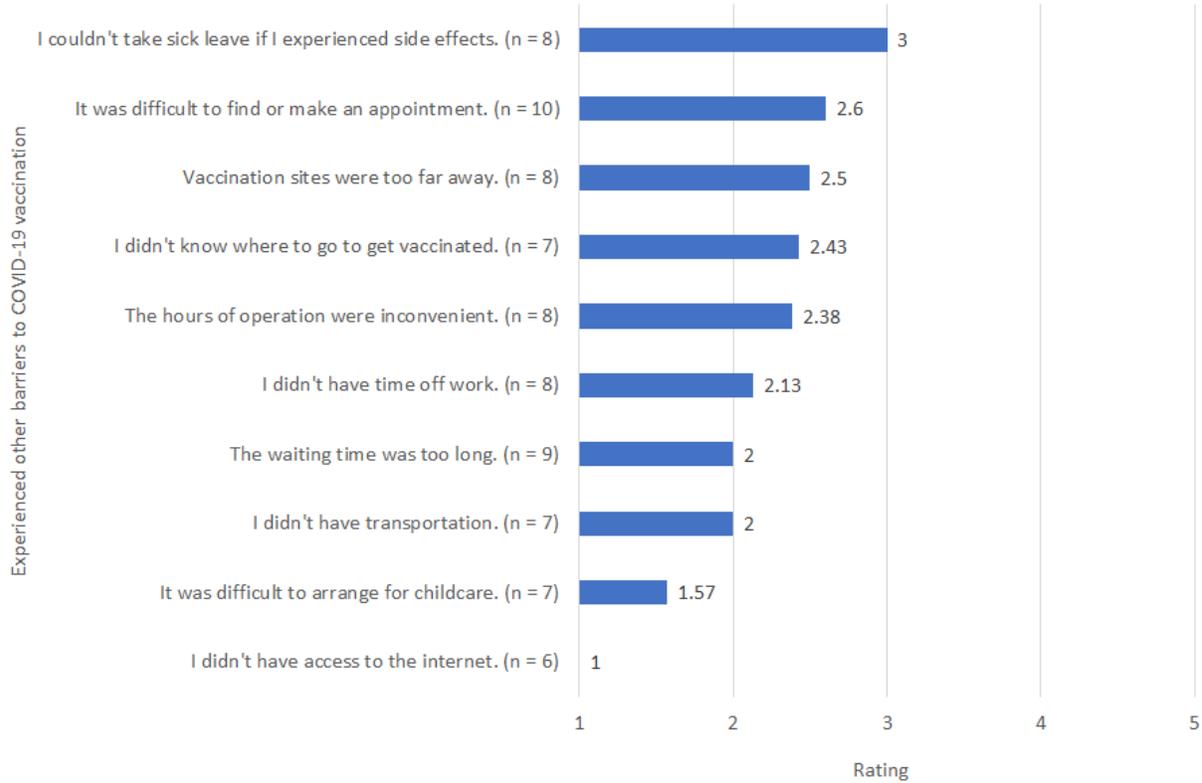
Notes on barriers. Since this population was fully vaccinated, it was expected that these means would be low, as these individuals would not have experienced barriers to COVID-19 vaccination to the extent that they were unable to get vaccinated. Many individuals who disclosed that they did receive the COVID-19 vaccine did not respond to these questions. Please note the smaller sample size (n) for each of these questions, which means that these results may not be fully representative of the diversity of the disability populations in Alaska.

Figure 9 Vaccinated individuals with disabilities: Personal barriers to COVID-19 vaccination.



Note: Individuals rated barriers on a scale from 1 (Not a barrier) to 5 (Major barrier).

Figure 10 Vaccinated individuals with disabilities: Other barriers to COVID-19 vaccination.

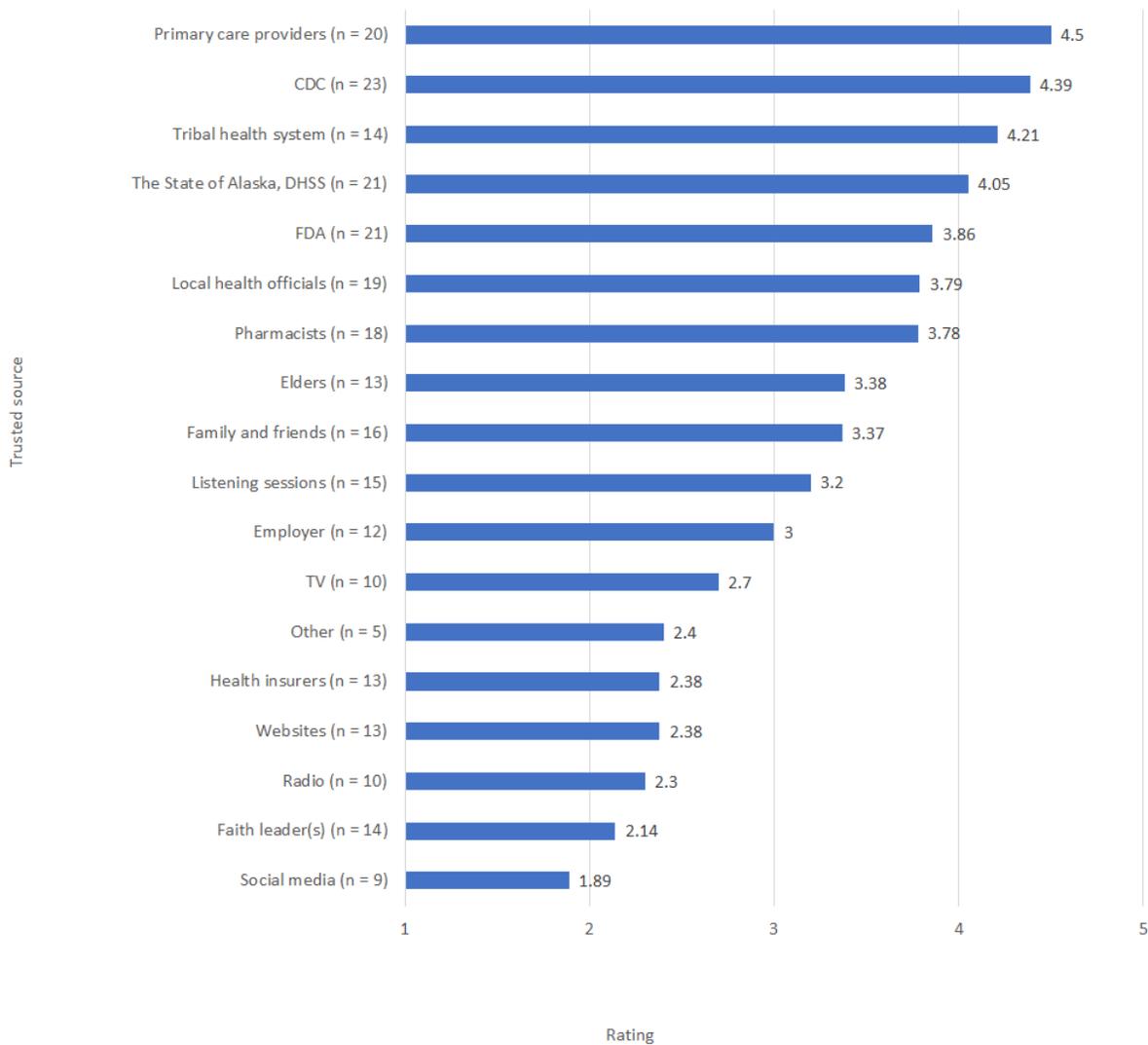


Note: Individuals rated barriers on a scale from 1 (Not a barrier) to 5 (Major barrier).

Which sources about COVID-19 vaccine information do individuals with disabilities trust?

On a scale of 1 (Least trusted) to 5 (Most trusted) individuals with disabilities answered that they most trust the following sources for COVID-19 vaccine information: “Primary care providers” ($M = 4.50, n = 20$), “CDC” ($M = 4.39, n = 23$), “Tribal health system” ($M = 4.21, n = 14$), and “The State of Alaska, Department of Health and Social Services” ($M = 4.05, n = 21$) (Figure 11). Written responses include: “News,” “Reputable websites,” and “Researchers” (Appendix: Table 2).

Figure 11 Vaccinated individuals with disabilities: Trusted sources of information about COVID-19 vaccines.



Note: Individuals rated trusted sources on a scale from 1 (Least trusted) to 5 (Most trusted). One individual who self-identified as unvaccinated said they did not trust any of the listed sources.

Summary of Key Findings

This survey was conducted to understand the barriers and motivators experienced by people with disabilities in Alaska when accessing the COVID-19 vaccine. Though the generalizability of the survey results are limited by the methodology (See Survey Limitations), there are notable key findings. These findings may help inform State of Alaska vaccine distribution and access strategies as well as any future surveys or research on this topic.

Care provider perceptions of vaccine barriers versus barriers experienced by people with disabilities

The perceived barriers to COVID-19 vaccination by care providers were different from those explicitly expressed by individuals with disabilities. Care providers cited guardians, lack of transportation, and inability to go on one's own as top vaccine barriers experienced by people with disabilities they support. Vaccinated individuals with disabilities reported they were concerned that the vaccine would worsen medical conditions, about vaccine side effects, and that they couldn't obtain the vaccine on their own.

Vaccine accessibility

The accessibility of the COVID-19 vaccine stands out as a major barrier. Respondents cited a lack of transportation to vaccine sites, in addition to the inability for many individuals with disabilities to go on their own to receive the vaccine. One respondent with a disability wrote-in that making drive-in vaccine clinics more available would have been helpful to them. Vaccine programs should consider whether vulnerable populations, such as individuals with disabilities, have the resources to get vaccinated or find a way to bring vaccine clinics to them.

Guardians

Ten different care providers wrote-in that guardians were a barrier to COVID-19 vaccination for their protected person(s). In particular, many of these responses explained that guardians impose their personal vaccine beliefs on the individual(s) they serve and that they will not allow them to get vaccinated. Guardian biases against the COVID-19 vaccine, when they misalign with those of the individuals they support, could hinder individuals with disabilities from getting vaccinated.

Vaccine motivators for individuals with disabilities

The highest-rated motivators all pertained to protecting community health, even among other options such as resuming travel and going back to work in-person. Individuals with disabilities who reported being fully vaccinated against COVID-19 said their top motivators to get vaccinated were protecting the health of themselves, family/friends, and community.

Trusted sources of information about COVID-19 vaccines for individuals with disabilities

Primary care providers were considered a critical source in sharing reputable information about the COVID-19 vaccine by both care providers and individuals with disabilities. Individuals with disabilities reported that they most trust their primary care providers, the CDC, and the tribal health system. Care providers perceived individuals with disabilities' most trusted sources as their family and friends, their primary care providers, and elders.

It is possible that there is a response bias with these answers and that individuals with disabilities who responded to the survey feel more comfortable disclosing that they trust reputable medical sources more than family/friends or social media. Still, this could mean that the individuals with disabilities who were vaccinated had been informed by reputable sources in their decision-making to later receive the vaccine.

Since care providers support individuals with a wider range of vaccination statuses compared to the respondents of fully-vaccinated individuals with disabilities, it is possible that they see more individuals with disabilities consulting their family or friends for vaccine information.

Survey Limitations

Reading ability. The survey in its electronic form required participants to have independent reading ability. Though the survey administrators provided an option for people to call-in and take the survey verbally, doing so is more tedious and could be reason why no one took this extra step. Individuals who have limited independent reading ability may rely more on family and friends to provide them with information, and this may not be reflected in these survey results.

Difficulties for mobile device users. The use of sliders in the survey design was intended to eliminate difficulties individuals might have selecting answer choices. However, the sliders required fine-tuned movements, which may have been difficult for some users. One mobile device user reported that they faced difficulties adjusting sliders because the action prompted their device to constantly refresh the page.

Survey repetitiveness. Caregivers, disability service providers, guardians, and family members of individuals with disabilities were asked to select which of three types of individuals with disabilities they serve. Respondents who selected more than one category were taken through the survey one time for each selected category. Many respondents quit the survey before answering the questions again for subsequent categories. Some respondents reached out saying that they thought this was a glitch in the survey design, but may not have noticed that the questions pertain specifically to a selected disability group.

Recruitment limitations. This “snowball sample survey” was active for three weeks and distributed through word-of-mouth channels. As a result of being a snowball sample, the survey results are not generalizable but rather provide useful perspectives to consider in vaccine distribution and access strategies. In addition, urban areas of the state were primarily

represented in the sample and the survey has little representation from individuals who reside in rural areas of Alaska.

Future Steps

This survey was designed to be administered only one time and is not a longitudinal study. The intention of the survey was to inform the State of Alaska vaccine distribution and access strategies. At the time this was written, the survey information had been briefed to the COVID-19 Vaccine Accessibility Partnership, The Alaska Disability Advisory Group, the UAA Center for Human Development, the COVID-19 Vaccine Providers ECHO, The Governor's Council on Disabilities and Special Education Meeting, The Leadership Education in Neurodevelopmental and related Disabilities Meeting, and the Family ECHO.

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Appendix: COVID-19 survey result tables

Table 1 Individuals with disabilities: Please indicate which disabilities you experience. (Select all that apply.)

Disability type	Number of responses
Mobility/physical	20
Mental health	9
Intellectual disability	4
Sensory sensitivities	4
Brain injury	4
Developmental disability	2
Hearing impairment	2
Vision impairment	2
Autism	2
I do not wish to disclose	1
Total responses	40

Table 2 Select written responses to survey questions

Type of question	Total responses	Select responses
Disability care providers: Perceived barriers	46	<p>“Guardian/family will not let them” (Written 10 times)</p> <p>“Transportation” (Written 5 times)</p> <p>“Need computer skills [for] information”</p> <p>“Misinformation and anti vaxxers are all over out here”</p> <p>“Mistrust of pharma and government”</p> <p>“Understanding its importance”</p> <p>“Uncomfortable at clinics & hospitals”</p>

		“Ability to clearly communicate adverse side effects”
Disability care providers: Guardian barriers	10	<p>“Guardian will not let them”</p> <p>“Guardian views on the vaccine”</p> <p>“Rely on guardians for these [supports]”</p> <p>“Guardians have these concerns or are too busy”</p> <p>“Guardian/Caregiver Bias”</p> <p>“Guardian's believe Vaccine will cause other health issues”</p> <p>“Guardian will not allow”</p> <p>“Friends, guardians coerce with personal beliefs”</p> <p>“Belief of family members or guardians”</p> <p>“Anti-vaxx Guardians”</p>
Disability care providers: Trusted sources	9	<p>“Their specialist doctors who understand what medications they are on and what their current status is”</p> <p>“Personal care attendant”</p> <p>“Native corporations leadership , agencies delivering medical waiver services , advertising that features people with disabilities and examples of desensitizing the experience”</p> <p>“Misinformation”</p> <p>“COVID patients and family”</p> <p>“Ads featuring people representative of population and accommodations that work for the individual”</p>
Vaccinated individuals with disabilities: Barriers	8	<p>“Almost all the clinics were inside and I would have to break my quarantine to get the shot”</p> <p>“Did not want to take from others who were of a higher risk”</p> <p>“Missing work after side effects” (2 responses)</p> <p>“Anxiety”</p> <p>“Availability of non-single dose, required for medical reasons”</p> <p>“If I was too sick to take care of my daughter if there were side effects”</p> <p>“Only 1 drive up vaccine site! Drive up testing but no drive up shots? Dumb.”</p>
Vaccinated individuals with disabilities: Trusted sources	3	<p>“News”</p> <p>“Reputable websites”</p> <p>“Researchers”</p>