Mental Health Experiences of the Paralysis Community During the COVID-19 Pandemic

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March 2023

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Methods

The Vanderbilt University team designed an online survey about the experiences of the paralysis community during the COVID-19 pandemic in collaboration with the Christopher & Dana Reeve Foundation staff. The goal of this survey was to gather feedback about 1) the mental health experiences of the paralysis community during the pandemic and 2) the Foundation resources they used and found helpful during the pandemic.

The brief online survey (~10-15 minutes) included 187 questions including: demographic questions, disability-specific questions, mental health scales, questions about experiences with vaccines and COVID-19, mental health experiences during the pandemic, and use of Reeve Foundation resources during the pandemic. Due to branching logic based on respondents' selections, relevant questions were presented to them, so no respondent was presented with all 187 possible questions. The survey was administered using REDCap. The Christopher & Dana Reeve Foundation staff recruited any individuals with paralysis or affected by paralysis to take the survey using their email list.

Data were collected during a four-month timeframe from August to November 2022. A total of 587 participants responded to the survey, 423 persons with disability (PWD; 389 persons with paralysis (PWP) and 34 persons with another disability) and a group of 157 individuals without paralysis or another disability. This group was made up of family members/caregivers, friends, healthcare professionals, and supporters of the Reeve Foundation, called the Foundation supporters group (FS group). Any respondent who did not indicate that they had paralysis or another disability are included in the FS group.

In the group comparisons throughout this report, we include indicators that quantify the magnitude of group differences. The *p*-values indicate whether a difference between groups is significant. A *p*-value less than 0.05 indicates a significant effect. For variables with only two groups, (i.e., PWD vs. FS), we also present Cohen's *d*, which represents the effect size (i.e., the magnitude of difference between the groups). Effect sizes with absolute values of less than 0.20 are considered small effects, effect sizes of 0.50 are considered moderate, and effect sizes of 0.80 or greater are considered large. The tables below show results from the overall sample and in the PWP, PWD, and FS groups. Key results showed some differences between PWD and FS, but also found important similarities between groups.

Summary of Key Findings

Group Differences on Mental Health Scales

- Analyses showed that the FS group had a significantly <u>lower</u> mean level of instrumental support than PWD, which could be due to the high prevalence of PWP who used caregivers in the PWD group.

COVID Experiences

- PWD were significantly <u>more</u> likely than FS to report that they had underlying conditions or take medications that put them at greater risk for severe COVID-19 symptoms.

- No groups were more likely than another to have received a COVID-19 vaccine or booster, and most respondents were fully vaccinated, and most fully vaccinated respondents had received at least one booster dose.

- Most respondents (61.5%) had never been diagnosed with or tested positive for COVID-19. However, there were significant differences between groups, more FS had had COVID-19 by the time they completed the survey. FS were significantly <u>more</u> likely to report a previous COVID-19 infection. Most respondents who had COVID-19 recovered from their infection at home.

- Respondents who had a previous COVID-19 infection were asked about their feelings about their infection. PWD had significantly lower average levels of shame, anger, guilt, meaning that on average, FS rated these feelings as <u>more</u> applicable to their experience with COVID-19 than PWD.

- Respondents were asked what behaviors they engaged in during COVID-19. Most respondents (68.0%) practiced social distancing, which was the most common activity, followed by isolating/quarantining and following media coverage related to COVID-19.

- PWD were significantly <u>more</u> likely than FS to indicate that there had been no changes to their life or behavior, a change in their use of health services, that they followed media coverage related to COVID-19, had a fear of getting COVID-19, frustration or boredom, and other difficulties or challenges.

- FS were <u>more</u> likely than PWD to indicate that they had cared for a person with paralysis, cared for children, cared for an individual with COVID-19, worked from home, lost their source of income due to COVID-19, experienced fear of giving COVID-19 to someone else, personal financial loss, increased alcohol or substance use, a change in sexual activity, and got emotional and social support.

Challenges Related to the Pandemic

- Respondents were asked an open-ended question about their biggest challenges related to the COVID-19 pandemic, and responses were coded for their main themes.

- The PWD and FS groups expressed some of the same themes, including: isolation/cancellation of group activities, worrying about/avoiding COVID-19, caregiving challenges for PWD, differing perceptions from friends and family about COVID risk and vaccines, worry about spreading COVID-19 to others, loss of family members, masks, nursing and medical facilities, vaccines, work challenges, and stress/anxiety.

- Social isolation/cancellation of group activities was the most common theme in both groups (27.1% of PWD responses and 26.7% of FS responses).

- There were a few themes that were shared by both groups but expressed by different proportions of groups, and these differences were also reflected in related close-ended survey responses. Financial concerns were expressed by almost twice as many FS as PWD. Worry about spreading COVID-19 to others and work/employment challenges were expressed by four times more FS than PWD.

- There were also themes only expressed by PWD about their biggest challenges related to the pandemic: COVID diagnoses/symptoms, access to supplies and resources, boredom, travel, personal difficulties, determining risk, getting back to "normal," and vaccine access. Uncertainty was the only theme expressed by FS and not PWD.

Engagement with the Reeve Foundation

- Respondents were asked to indicate the areas of the Reeve Foundation that they had engaged with since the start of the pandemic in March 2020. The most selected areas were webinars, Communications (bloggers, social media influencers, newsletter), and the Peer and Family Support Program. A quarter of respondents reported that they had not engaged with any areas of the Reeve Foundation.

- When comparing groups on the areas that they were engaged with, PWD were significantly more likely than FS to be engaged with webinars, the Peer and Family Support Program, Information Specialists, Advocacy, Communications, in-person or virtual conferences, and none of the areas. FS were more likely than PWD to engage with Team Reeve, the Reeve Summit, and the Quality of Life Grants Program.

- Across Reeve areas, most respondents stated that their level of engagement with areas did not change throughout the pandemic. PWD and FS whose engagement levels increased or decreased in Reeve areas reported a variety of reasons why their engagement levels changed. These results can be found in the close- and open-ended questions near the end of this report.

- All respondents were also asked which programs or services provided by the Reeve Foundation were most and least helpful to them during the pandemic. Respondents most often rated webinars, communications, and Information Specialists as the most helpful areas.

- PWD were more likely to rate webinars, the Peer and Family Support Program, Information Specialists, Advocacy, and none of the areas as the most helpful. FS were more likely to rate Team Reeve as a most helpful area. Respondents were asked to explain in an open-ended format why each of the areas that they selected was most helpful to them, these responses can be found below.

- Respondents most often rated none of Reeve's areas as the least helpful areas that Reeve offered during the pandemic.

- PWD were <u>more</u> likely than FS to indicate that Team Reeve, webinars, Information Specialists, the Military and Veterans Program, the Reeve Summit, In-person or virtual conferences, and none of the areas were <u>least helpful</u> to them. When asked open-ended questions about why each area was least helpful to them, many respondents wrote that they did not use these programs, so they were not helpful to them.

Further information is provided in the tables and figures below.

Respondent Demographics

All respondents were asked to answer a variety of demographic questions related to gender identity, age, race, ethnicity, area of residence, education, marital status, living arrangements, health insurance, social services, employment status, and military/veteran status. Tables 1 –16 show the wide distribution of respondents across these demographic categories and show differences and similarities between the PWP, PWD, and FS groups on these demographic variables.

Table 1. Respondents' Gender Identity

What gender do you identify as?	**Male**	**Female**	**Non-binary**	**Other**	**Prefer not to say**
Overall *(N = 579)*	260	312	4	1	2
%	44.9	**53.9**	0.7	0.2	0.3
Persons with Paralysis *(N = 385)*	205	175	3	1	1
%	**53.2**	45.5	0.8	0.3	0.3
Persons with Disability (PWP + Other Disabilities) *(N = 419)*	215	199	3	1	1
%	**51.3**	47.5	0.7	0.2	0.2
Foundation Supporters *(N = 153)*	44	107	1	0	1
%	28.8	**69.9**	0.7	0.0	0.7

Table 2. Respondents' Transgender Identity

Do you identify as transgender?	**Yes**	**No**	**Prefer not to say**
Overall *(N = 587)*	7	558	1
%	1.2	**98.6**	0.2
Persons with Paralysis *(N = 374)*	4	369	1
%	1.1	**98.7**	0.3

Do you identify as transgender?	**Yes**	**No**	**Prefer not to say**
Persons with Disability (PWP + Other Disabilities) *(N = 407)*	5	401	1
%	1.2	**98.5**	0.2
Foundation Supporters *(N = 152)*	2	150	0
%	1.3	**98.7**	0.0

Table 3. Respondents' Age Distribution

What is your age?	**13-19 years old**	**20-29 years old**	**30-39 years old**	**40-49 years old**	**50-59 years old**	**60-69 years old**	**70+ years old**
Overall *(N = 582)*	2	25	53	82	147	164	109
%	0.3	4.3	9.1	14.1	25.3	28.2	18.7
Persons with Paralysis *(N = 388)*	1	15	36	52	96	114	74
%	0.3	3.9	9.3	13.4	24.7	29.4	19.1
Persons with Disability (PWP + Other Disabilities) *(N = 422)*	1	19	38	56	109	119	80
%	0.2	4.5	9.0	13.3	25.8	28.2	19.0
Foundation Supporters *(N = 153)*	1	6	15	24	38	42	27
%	0.7	3.9	9.8	15.7	24.8	27.5	17.6

Table 4. Respondents' Self-Identified Race

Which race categories apply to you?	**American Indian or Alaska Native**	**African American/ Black**	**Native Hawaiian or Pacific Islander**	**White/ Caucasian**	**Asian**	**Middle Eastern or North African**	**Mixed Race**	**Other**
Overall *(N = 587)*	12	28	3	507	9	1	20	23
%	2.0	4.8	0.5	**86.4**	1.5	0.2	3.4	3.9
Persons with Paralysis	8	15	2	339	7	0	15	19

Which race categories apply to you?	**American Indian or Alaska Native**	**African American/ Black**	**Native Hawaiian or Pacific Islander**	**White/ Caucasian**	**Asian**	**Middle Eastern or North African**	**Mixed Race**	**Other**
(N = 389)								
%	2.1	3.9	0.5	**87.1**	1.8	0.0	3.9	4.9
Persons with Disability (PWP + Other Disabilities) *(N = 423)*	9	20	3	364	8	0	18	20
%	2.1	4.7	0.7	**86.1**	1.9	0.0	4.3	4.7
Foundation Supporters *(N = 157)*	3	7	0	138	1	1	2	2
%	1.9	4.5	0.0	**87.9**	0.6	0.6	1.3	1.3

Table 5. Whether Respondents are of Hispanic or Latino Origin

Are you of Hispanic, Latino, or Spanish origin?	**Yes**	**No**
Overall *(N = 572)*	37	535
%	6.5	**93.5**
Persons with Paralysis *(N = 380)*	23	357
%	5.9	**93.9**
Persons with Disability (PWP + Other Disabilities) *(N = 414)*	25	389
%	6.0	**94.0**
Foundation Supporters *(N = 151)*	11	140
%	7.3	**92.7**

Table 6. Respondents' Area of Residence

Please select the option that best describes the area where you live.	**A big city (population > 250,000)**	**A town/small city (population 10,000-250,000)**	**A small town/village (500-10,000)**	**Rural area (population < 500)**
Overall *(N = 569)*	186	274	81	28
%	32.7	48.2	14.2	4.9
Persons with Paralysis *(N = 380)*	121	195	44	20
%	31.8	**51.3**	11.6	5.3
Persons with Disability (PWP + Other Disabilities) *(N = 412)*	135	202	51	24

Please select the option that best describes the area where you live.	**A big city (population > 250,000)**	**A town/small city (population 10,000-250,000)**	**A small town/village (500-10,000)**	**Rural area (population < 500)**
%	32.8	49.0	12.4	5.8
Foundation Supporters *(N = 150)*	49	67	30	4
%	32.7	44.7	20.0	2.7

Table 7. Respondents' State of Residence

What state do you live in?	**Overall** ***(N = 515)*** ***N*** **(%)**
Alabama	6 (1.2)
Alaska	0 (0.0)
American Samoa	0 (0.0)
Arizona	9 (1.7)
Arkansas	4 (0.8)
California	67 (13.0)
Colorado	17 (3.3)
Connecticut	5 (1.0)
Delaware	1 (0.2)
Florida	29 (5.6)
Georgia	11 (2.1)
Guam	0 (0.0)
Hawaii	3 (0.6)
Idaho	1 (0.2)
Illinois	15 (2.9)
Indiana	7 (1.4)
Iowa	9 (1.7)
Kansas	4 (0.8)
Kentucky	3 (0.6)
Louisiana	6 (1.2)
Maine	4 (0.8)
Maryland	19 (3.7)
Massachusetts	23 (4.5)
Michigan	16 (3.1)
Minnesota	10 (1.9)
Mississippi	4 (0.8)
Missouri	9 (1.7)
Montana	4 (0.8)
Nebraska	1 (0.2)
Nevada	2 (0.4)

What state do you live in?	**Overall** ***(N = 515)*** ***N* (%)**
New Hampshire	2 (0.4)
New Jersey	19 (3.7)
New Mexico	6 (1.2)
New York	31 (6.0)
North Carolina	15 (2.9)
North Dakota	0 (0.0)
Northern Mariana Islands	0 (0.0)
Ohio	18 (3.5)
Oklahoma	1 (0.2)
Oregon	8 (1.6)
Pennsylvania	25 (4.9)
Puerto Rico	0 (0.0)
Rhode Island	1 (0.2)
South Carolina	10 (1.9)
South Dakota	0 (0.0)
Tennessee	9 (1.7)
Texas	18 (3.5)
Utah	9 (1.7)
US Virgin Islands	0 (0.0)
Vermont	0 (0.0)
Virginia	19 (3.7)
Washington	11 (12.1)
Washington, D.C.	4 (0.8)
West Virginia	1 (0.2)
Wisconsin	10 (1.9)
Wyoming	0 (0.0)
Outside of the US	9 (1.7)

Table 8. Respondents’ Education Level

What is the highest level of schooling you have completed?	**Overall** ***(N = 583)*** ***N* (%)**	**PWP** ***(N = 389)*** ***N* (%)**	**PWD** ***(N = 423)*** ***N* (%)**	**FS *(N = 153)*** ***N* (%)**
No schooling completed	1 (0.2)	0 (0.0)	0 (0.0)	1 (0.7)
Nursery (pre-K) to 8th grade	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Some high school, no diploma	10 (1.7)	7 (1.8)	8 (1.9)	2 (1.3)
High school graduate (or equivalent)	44 (7.5)	33 (8.5)	35 (8.3)	5 (5.9)
Some college, no degree	103 (17.7)	74 (19.0)	78 (18.4)	23 (15.0)
Trade, technical, or vocational training	19 (3.3)	14 (3.6)	17 (4.0)	2 (1.3)

What is the highest level of schooling you have completed?	**Overall** *(N = 583)* **N (%)**	**PWP** *(N = 389)* **N (%)**	**PWD** *(N = 423)* **N (%)**	**FS** *(N = 153)* **N (%)**
Associate degree	46 (7.9)	32 (8.2)	37 (8.7)	9 (5.7)
Bachelor's degree	168 (28.8)	101 (26.0)	110 (26.0)	56 (36.6)
Master's degree	128 (22.0)	86 (22.1)	93 (22.0)	34 (22.2)
Professional degree	29 (5.0)	19 (4.9)	21 (5.0)	7 (4.6)
Doctorate degree (or beyond)	35 (6.0)	23 (5.9)	24 (5.7)	10 (6.4)

Table 9. Respondents' Marital Status

What is your marital status?	**Married**	**Divorced/ Separated**	**Single**	**Widowed**	**Long-term partner/ Living with partner**
Overall *(N = 576)*	291	75	154	29	27
%	**50.5**	13.0	26.7	5.0	4.7
Persons with Paralysis *(N = 382)*	178	53	115	19	17
%	46.6	13.9	30.1	5.0	4.5
Persons with Disability (PWP + Other Disabilities) *(N = 416)*	195	55	125	20	21
%	46.9	13.2	30.0	4.8	5.0
Foundation Supporters *(N = 153)*	93	18	28	8	6
%	**60.8**	11.8	18.3	5.2	3.9

Table 10. Respondents' Use of Services

Do you receive or use any of the following services? Please check all that apply.	**Vocational Rehabilitation**	**Supplemental Security Income (SSI)**	**Social Security Disability Insurance (SSDI)**	**Social Security Retirement**	**I prefer not to respond**	**I do not receive or use any of these services**
Overall *(N = 587)*	43	60	162	141	28	203

Do you receive or use any of the following services? Please check all that apply.	**Vocational Rehabilitation**	**Supplemental Security Income (SSI)**	**Social Security Disability Insurance (SSDI)**	**Social Security Retirement**	**I prefer not to respond**	**I do not receive or use any of these services**
%	7.3	10.2	27.6	24.0	4.8	34.6
Persons with Paralysis *(N = 389)*	34	51	146	101	16	88
%	8.7	13.1	37.5	26.0	4.1	22.6
Persons with Disability (PWP + Other Disabilities) *(N = 423)*	40	56	156	107	19	98
%	9.5	13.2	36.9	25.3	4.5	23.2
Foundation Supporters *(N = 157)*	2	4	6	31	9	101
%	1.3	2.5	3.8	19.7	5.7	**64.3**

PWD respondents were significantly more likely than FS to report using Vocational Rehabilitation, *t*(585) = 47.7, *p* <.001, *d* = .26; Supplemental Security Income, *t*(585) = 78.0, *p* <.001, *d* = .30; Social Security Disability Insurance, *t*(585) = 918.7, *p* <.001, *d* = .42; and Social Security Retirement, *t*(585) = 5.8, *p* = .016, *d* = 43. Members of the FS group were significantly more likely to report that they did not receive or use any of these services, *t*(585) = 30.7, *p* <.001, *d* = .44.

Of the individuals who indicated that they used at least one of the services above, the total number of services selected by respondents were calculated, shown in Table 11. Responses of "I prefer not to respond" and "I do not use any of these services" were not included in these calculations.

Table 11. Number of Services Used by Respondents

Number of services used	**1**	**2**	**3**	**Mean**
Overall *(N = 346)*	296	40	10	1.2
%	**85.5**	11.6	2.9	
Persons with Paralysis *(N = 282)*	241	32	9	1.2
%	**85.5**	11.3	3.2	

Number of services used	**1**	**2**	**3**	**Mean**
Persons with Disability (PWP + Other Disabilities) *(N = 300)*	251	39	10	1.2
%	**83.7**	13.0	3.3	
Foundation Supporters *(N = 42)*	41	1	0	1.0
%	**97.6**	2.4	0.0	

Table 12. Respondents' Health Insurance Type

What type of health insurance do you currently have?	**Medicaid**	**Medicare**	**Employer - sponsored disability insurance**	**Private or group health insurance**	**National Health Insurance**	**Veterans Affairs/ Military**	**No insurance /self-pay**	**Unknown**	**Other**
Overall *(N = 582)*	55	265	32	162	6	20	13	1	28
%	9.5	45.5	5.5	27.8	1.0	3.4	2.2	0.2	4.8
Persons with Paralysis *(N = 389)*	44	201	19	84	3	13	4	1	20
%	11.3	**51.7**	4.9	21.6	0.8	3.3	1.0	0.3	5.1
Persons with Disability (PWP + Other Disabilities) *(N = 423)*	46	218	21	93	3	15	7	1	19
%	10.9	**51.5**	5.0	22.0	0.7	3.5	1.7	0.2	4.5
Foundation Supporters *(N = 152)*	8	45	11	67	3	5	6	0	7
%	5.3	29.6	7.2	44.1	2.0	3.3	3.9	0.0	4.6

The respondents who indicated that they had "other" health insurance were asked to write in the type of health insurance that they have. All these responses can be found below.

Please list the type of insurance you have. *(N = 28)*

- "AARP."
- "Blue Cross Blue Shield."
- "Disability medical access."
- "Employee-sponsored insurance."

- “Employee-sponsored health insurance.”
- “Employer, Medi-Cal, Medicare.”
- “I have Medicare and Medi-Cal.”
- “I’m in the UK so covered by NHS for all medical care and prescriptions.”
- “Individual.”
- “Insurance through my job.”
- “Medi-Cal. LA CARE/Kaiser Permanente.”
- “Medicaid & Medicare.”
- “Medicaid and Veterans.”
- “Medi-Cal.”
- “Medi-Cal.”
- “Medi-Cal Mutual.”
- “Medicare & Medicaid.”
- “Medicare and Medicaid.”
- “Obamacare.”
- “Private Health Insurance (Australia).”
- “Private insurance.”
- “Private insurance, workers compensation, and VA.”
- “Spanish Social Security.”
- “Tufts then HNE.”
- “United Healthcare Medicare Advantage.”
- “United Healthcare Medicare supplement.”
- “VA, Tricare, and Medicare.”
- “Viva Medicare (it is a Medicare advantage plan) and Medicaid (I barely use).”

Table 13. Who Respondents Live with Most of the Time

Who do you live with most of the time?	**Alone**	**With friends or roommates**	**With relatives**	**With spouse/ significant other**	**Group Home**	**Other**
Overall *(N = 574)*	138	14	83	311	8	20
%	24.0	2.4	14.5	**54.2**	1.4	3.5
Person with Paralysis *(N = 382)*	94	10	62	195	4	17
%	24.6	2.6	16.2	**51.0**	1.0	4.5

Who do you live with most of the time?	**Alone**	**With friends or roommates**	**With relatives**	**With spouse/ significant other**	**Group Home**	**Other**
Persons with Disability (PWP + Other Disabilities) *(N = 416)*	102	11	68	211	7	17
%	24.5	2.6	16.3	**50.7**	1.7	4.1
Foundation Supporters *(N = 151)*	34	3	15	96	1	2
%	22.5	2.0	9.9	**63.6**	0.7	1.3

Individuals who indicated that they had "other" living arrangements were asked to describe these arrangements in an open-ended question. These responses are found below.

Please describe your other living arrangements. *(N = 18)*

- "24 hour caregivers."
- "Assisted living facility."
- "Garage apartment with full-time caregiver."
- "Husband, mother, brother."
- "I have caregivers 24/7."
- "I am a single mom with a daughter."
- "I live in a skilled nursing facility in Hampton, Virginia."
- "I live in my home with a housemate and adult children."
- "I live together with my two young daughters."
- "I live with my best friend, my service dog. He identifies as a human."
- "I live with my ten year old daughter."
- "I live with my three children."
- "I live with my two younger sons."
- "I'm in a nursing home."
- "My partner wants to leave me, I don't know where to go that I can afford on Social Security. It is a living hell. I don't get any help from her."
- "Nursing home."
- "Skilled nursing facility."
- "Spouse and children."

Table 14. Respondents' School/Work Status

Which of the following describe you? Check all that apply.	**A student (part-time or full-time)**	**Working (part-time)**	**Working (full-time)**	**Retired**	**Not employed**
Overall *(N = 587)*	30	88	149	216	130
%	5.1	15.0	25.4	25.4	22.1
Persons with Paralysis *(N = 389)*	20	61	69	161	104
%	5.1	15.7	17.7	41.4	26.7
Persons with Disability (PWP + Other Disabilities) *(N = 423)*	22	67	76	168	115
%	5.2	15.8	18.0	39.7	27.2
Foundation Supporters *(N =157)*	8	20	71	45	12
%	5.1	12.7	45.2	28.7	7.6

FS respondents were more likely than PWD to be working full time, $t(585) = 105.2$, $p <.001$, $d = .421$. PWD were more likely to be retired, $t(585) = 28.7$, $p <.001$, $d = .48$ and unemployed, $t(585) = 137.5$, $p <.001$, $d = .41$.

Table 15. Whether Respondents are Military Personnel or a Veteran

Are you military personnel or a veteran?	**Yes**	**No**
Overall *(N = 581)*	45	536
%	7.7	**92.3**
Persons with Paralysis *(N = 388)*	39	349
%	10.1	**89.9**
Persons with Disability (PWP + Other Disabilities) *(N = 422)*	40	382
%	9.5	**90.5**
Foundation Supporters *(N = 152)*	5	147
%	3.3	**96.7**

Respondents' relationship to the paralysis community was determined using the question in Table 16 below. Most respondents indicated that they were a person living with paralysis.

Table 16. Respondents' Relationship to the Paralysis Community.

	A person living with paralysis	**A family member or caregiver of a person with paralysis**	**A friend of a person with paralysis**	**A person living with another disability**	**A healthcare professional who serves people with paralysis**	**Other**
Which of the following best describes your relationship to the paralysis community? *(N = 587)*	381	74	42	55	38	53
%	**64.9**	12.6	7.2	9.4	6.5	9.0

Individuals who selected that they were a person living with paralysis were included in the PWP group, even if they selected any of the other options. Individuals who indicated that they were a person living with another disability who did *not* also select that they were a PWP were included in the PWD group. Individuals who selected a family member or caregiver, a friend, or a healthcare professional and did *not* indicate that they were living with paralysis or another disability were included in the FS group.

Individuals who selected "other" as their relationship to the paralysis community were asked to further describe their identity. As the responses below show, some respondents indicated that they had a form of paralysis or disability. These open-ended responses were coded as PWD or non-PWD. In later analysis, individuals who indicated in the open-ended responses that they had a disability were included in the PWD group, while those who indicated they had another type of relationship to the paralysis/disability community were included in the FS group.

Please describe your relationship to the paralysis community. *(N = 52)*

Living with paralysis/disability *(N = 19)*

- "I have disabilities related to polio but am able to walk about 20 feet. I use a power wheelchair and van with automatic ramp."
- "Transverse myelitis."
- "A person with paralysis caring for an individual with a disability."
- "Classified as para, lost one leg AKA as well as one hip."

Nonprofit/service work *(N = 11)*

- "A non-profit executive fundraising for programs benefiting people with paralysis."
- "I work for a nonprofit that serves people with disabilities."
- "We are a service provider of sailing instruction for people with paralysis."

Interest in/support the Foundation ***(N = 11)***

- "Interested professional, no direct connection."
- "Just a small contributor."
- "I am passionate about finding a cure for paralysis. I don't know anyone who is paralyzed."

Family member/friend of a disabled person ***(N = 5)***

- "Wife of a person who is disabled (short-statured)."
- "Friend of a family with someone with paralysis."

Disability Demographics for the PWP Group

Respondents who indicated that they were living with paralysis were asked a series of demographic questions specific to their injury/disability. Results from these disability-related demographic questions are shown in Tables 17 - 22.

Table 17. PWP's Type of Injury

	Paraplegia (T1 and below)	**Quadriplegia (C8 and above)**	**Hemiplegia**	**Not sure**	**Other**
Which of the following best represents you? *(N = 378)*	180	170	9	7	12
%	47.6	45.0	2.4	1.9	3.2

Table 18. PWP Respondents' Ventilator Use

	Yes	**No**	**Not sure**
Do you require a ventilator? *(N= 377)*	17	359	1
%	4.5	**95.2**	0.3

Table 19. PWP Respondents' Mobility Aid Use

	Power wheelchair	**Manual wheelchair with power assist**	**Manual wheelchair**	**Crutches**	**Walker**	**Other**	**No mobility aids**
What types of mobility aid(s) do you use? *(N = 381)*	213	57	173	24	36	23	5
%	**55.9**	15.0	45.4	6.3	9.4	6.0	1.3

PWP respondents were asked to select all the types of mobility aids that they used, and the number of mobility aids used were calculated, as shown in Table 20.

Table 20. PWP Respondents' Sum of Types of Mobility Aids Used

	0	**1**	**2**	**3**	**4**	**5**	**6**
Number of mobility aids used *(N = 381)*	5	259	94	16	5	1	1
%	1.3	**68.0**	24.7	4.2	1.3	0.3	0.3

- The average number of mobility aids PWP used was 1.4, with most respondents using one type of mobility aid.

Table 21. Whether PWP Respondents Walk or Ambulate

	Yes, all of the time	**Yes, some of the time**	**No**
Do you walk or ambulate? *(N = 379)*	21	56	302
%	5.5	14.8	**79.7**

Table 22. PWP Respondents' Use of Family or Professional Caregivers

	Professional caregivers	**Family caregivers**	**Both professional and family caregivers**	**I do not have caregivers**
Do you have professional or family caregivers that assist you? *(N = 379)*	50	113	97	109
%	15.8	29.8	25.6	28.8

As the responses in Table 22 show, 71.2% of PWP respondents used caregivers.

Mental Health and Support Scales

PWP respondents were asked to complete the Spinal Cord Injury – Quality of Life Resilience (SCI – QOL Resilience) Scale, a previously validated measure used to assess facets of resilience in individuals with spinal cord injuries. In this scale, respondents rate the degree to which each statement applies to their lives and their experiences with paralysis on a 5-point scale ranging from Never (1) to Always (5). PWP participants' responses to each SCI – QOL Resilience Scale item can be found in Tables 23 and 24 below, along with the mean score on the 5-point scale for each item.

Table 23. SCI-QOL Resilience Scale, Part 1

Please respond to the following prompts and indicate the degree to which the following statements apply to you and your experience with paralysis.	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Often (4)**	**Always (5)**	**Mean**
I was able to manage my life. *(N = 356)*	12	13	74	135	122	3.96
%	3.4	3.7	20.8	37.9	34.3	
I felt motivated. *(N = 356)*	5	19	119	116	97	3.79
%	1.4	5.3	33.4	32.6	27.2	
I strived to improve myself. *(N = 355)*	4	8	74	139	130	4.08
%	1.1	2.3	19.4	36.5	34.1	
I was able to recognize and overcome challenges. *(N = 357)*	3	7	88	159	100	3.97
%	0.8	2.0	24.6	44.5	28.0	
I tried to see the positive side of things. *(N = 358)*	4	12	53	141	148	4.16
%	1.1	3.4	14.8	39.4	41.3	
I found new ways to solve problems. *(N = 356)*	4	11	69	157	115	4.03
%	1.1	3.1	19.4	44.1	32.3	
I could adapt easily to new situations. *(N = 358)*	5	17	132	136	68	3.68
%	1.4	4.7	36.9	38.0	19.0	

Please respond to the following prompts and indicate the degree to which the following statements apply to you and your experience with paralysis.	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Always (5)	Mean
I was confident that I could overcome my limitations. *(N = 359)*	6	24	134	117	78	3.66
%	1.7	6.7	37.3	32.6	21.7	
I was able to handle difficult situations. *(N = 356)*	4	16	111	149	76	3.78
%	1.1	4.5	31.2	41.9	21.3	
I was happy with my ability to cope with my injury. *(N = 355)*	17	32	106	123	77	3.59
%	4.8	9.0	29.9	34.6	21.7	
I found new things to enjoy. *(N = 353)*	16	36	118	109	74	3.54
%	4.5	10.2	33.4	30.9	21.0	

Table 24. SCI-QOL Resilience Scale, Part 2

Please respond to the following prompts and indicate the degree to which the following statements apply to you and your experience with paralysis.	Never (1)	Rarely (2)	Sometimes (3)	Often (4)	Always (5)	Mean
I felt I can get through difficult times. *(N = 357)*	5	15	88	162	87	3.87
%	1.4	4.2	24.6	45.4	24.4	
I had a positive attitude. *(N = 358)*	5	12	78	163	100	3.95
%	1.4	3.4	21.8	45.5	27.9	
I was driven to succeed in my life. *(N = 356)*	6	19	81	134	116	3.94
%	1.7	5.3	22.8	37.6	32.6	

Please respond to the following prompts and indicate the degree to which the following statements apply to you and your experience with paralysis.	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Often (4)**	**Always (5)**	**Mean**
I used positive ways to cope with my injury. *(N = 356)*	7	12	91	151	95	3.88
%	2.0	3.4	25.6	42.4	26.7	
I felt the things I went through made me a stronger person. *(N = 357)*	11	35	91	109	111	3.77
%	3.1	9.8	25.5	30.5	31.1	
I accepted my injury. *(N = 357)*	22	32	69	119	115	3.76
%	6.2	9.0	19.3	33.3	32.2	
I achieved emotional balance in my life. *(N = 357)*	11	37	106	123	80	3.63
%	3.1	10.4	29.7	34.5	22.4	
I felt good about how I have coped with my injury. *(N = 353)*	12	23	91	128	99	3.79
%	3.4	6.5	25.8	36.3	28.0	
I took action to improve my life. *(N = 352)*	6	20	77	141	108	3.92
%	1.7	5.7	21.9	40.1	30.7	
I had given up on myself. *(N = 357)*	194	83	58	14	8	1.76
%	**54.3**	23.2	16.2	3.9	2.2	

Scores for the SCI-QOL Resilience scale are calculated by adding together the value responses (1 through 5) for each item. A higher overall score represents a higher level of resilience. The last item, “I had given up on myself,” is reverse scored in this scale. This means that if a respondent selected Never (1), this 1 was coded as a 5 to accurately reflect the meaning of their response in their overall score.

Scores for the SCI-QOL Resilience Scale can theoretically range between 25 and 105, and in this sample, the lowest score was 25 and the highest was 105. The average SCI-QOL Resilience score in this sample was 80.4 with a standard deviation of 15.6.

All respondents (PWD and FS) were presented with four measures from the Patient-Reported Outcomes Measurement Information Systems (PROMIS) program – Emotional Support Short Form, Informational Support Short Form, Instrumental Support Short Form, and the Social Isolation Short Form. These measures are also 5-point scales that range from Never (1) to Always (5).

The PROMIS Emotional Support Scale assesses perceived feelings of being care for and valued as a person and having confidant relationships. The PROMIS Informational Support Scale assesses perceived availability of helpful information or advice. The PROMIS Instrumental Support Scale assesses perceived availability of assistance with material, cognitive, or task performance. The PROMIS Social Isolation Scale assesses perceptions of being avoided, excluding, detached, disconnected from, or unknown by others. Tables 25 – 40 below show the distribution of participants' responses to each measure on the scales, as well as the mean score for each group for each measure.

Overall mean scores of each scale can be found for each group in Table 41. Higher means for the Emotional Support, Informational Support, and Instrumental Support scales indicate higher perceived levels of support in these areas, which has been found to be positive. Higher means for the Social Isolation Scale indicate higher perceived levels of social isolation, which tends to have a negative impact on a person's life.

Table 25. PROMIS Emotional Support Scale – Overall Sample

PROMIS Emotional Support Short Form	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Usually (4)**	**Always (5)**	**Mean**
I have someone who will listen to me when I need to talk. *(N = 488)*	7	39	81	160	201	4.04
%	1.4	8.0	16.6	32.8	41.2	
I have someone to confide in or talk to about myself or my problems. *(N = 489)*	15	50	73	150	201	3.97
%	3.1	10.2	14.9	30.7	41.1	
I have someone who makes me feel appreciated. *(N = 489)*	13	42	89	145	200	3.98
%	2.7	8.6	18.2	29.7	40.9	
I have someone to talk to when I have a bad day. *(N = 486)*	16	54	83	124	209	3.94
%	3.3	11.1	17.1	25.5	43.0	

Table 26. PROMIS Emotional Support Scale – PWP Only

PROMIS Emotional Support Short Form	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Usually (4)**	**Always (5)**	**Mean**
I have someone who will listen to me when I need to talk. *(N = 327)*	6	29	55	109	128	3.99
%	1.8	8.9	16.8	33.3	39.1	
I have someone to confide in or talk to about myself or my problems. *(N = 328)*	13	32	52	103	128	3.92
%	4.0	9.8	15.9	31.4	39.0	
I have someone who makes me feel appreciated. *(N = 329)*	12	24	63	105	125	3.93
%	3.6	7.3	19.1	31.9	38.0	
I have someone to talk to when I have a bad day. *(N = 329)*	13	36	63	82	135	3.88
%	4.0	10.9	19.1	24.9	41.0	

Table 27. PROMIS Emotional Support Scale – PWD Only

PROMIS Emotional Support Short Form	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Usually (4)**	**Always (5)**	**Mean**
I have someone who will listen to me when I need to talk. *(N = 361)*	6	30	63	121	141	4.00
%	1.7	8.3	17.5	33.5	39.1	
I have someone to confide in or talk to about myself or my problems. *(N = 362)*	13	37	54	116	142	3.93
%	3.6	10.2	14.9	32.0	39.2	
I have someone who makes me feel appreciated. *(N = 362)*	12	27	70	113	140	3.94
%	3.3	7.5	19.3	31.2	38.7	

PROMIS Emotional Support Short Form	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Usually (4)**	**Always (5)**	**Mean**
I have someone to talk to when I have a bad day. *(N = 362)*	14	39	66	93	150	3.90
%	3.9	10.8	18.2	25.7	41.4	

Table 28. PROMIS Emotional Support Scale – FS Only

PROMIS Emotional Support Short Form	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Usually (4)**	**Always (5)**	**Mean**
I have someone who will listen to me when I need to talk. *(N = 122)*	1	8	18	37	58	4.17
%	0.8	6.6	14.8	30.3	47.5	
I have someone to confide in or talk to about myself or my problems. *(N = 122)*	2	13	18	32	57	4.06
%	1.6	10.7	14.8	26.2	46.7	
I have someone who makes me feel appreciated. *(N = 122)*	1	14	19	30	58	4.07
%	0.8	11.5	15.6	24.6	47.5	
I have someone to talk to when I have a bad day. *(N = 119)*	2	14	17	29	57	4.05
%	1.7	11.8	14.3	24.4	47.9	

Table 29. PROMIS Informational Support Scale – Overall Sample

PROMIS Informational Support Short Form	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Usually (4)**	**Always (5)**	**Mean**
I have someone to give me good advice about a crisis if I need it. *(N = 482)*	18	40	104	156	164	3.85
%	3.7	8.3	21.6	32.4	34.0	

PROMIS Informational Support Short Form	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Usually (4)**	**Always (5)**	**Mean**
I have someone to turn to for suggestions about how to deal with a problem. *(N = 479)*	15	39	88	155	182	3.94
%	3.1	8.1	18.4	32.4	38.0	
I have someone to give me information if I need it. *(N = 477)*	10	34	91	172	170	3.96
%	2.1	7.1	19.1	36.1	35.6	
I get useful advice about important things in life. *(N = 479)*	16	42	90	174	157	3.85
%	3.3	8.8	18.8	36.3	32.8	

Table 30. PROMIS Informational Support Scale – PWP Only

PROMIS Informational Support Short Form	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Usually (4)**	**Always (5)**	**Mean**
I have someone to give me good advice about a crisis if I need it. *(N = 325)*	15	22	82	100	106	3.80
%	4.6	6.8	25.2	30.8	32.6	
I have someone to turn to for suggestions about how to deal with a problem. *(N = 323)*	13	24	65	103	118	3.89
%	4.0	7.4	20.1	31.9	36.5	
I have someone to give me information if I need it. *(N = 323)*	7	24	66	112	114	3.93
%	2.2	7.4	20.4	34.7	35.3	
I get useful advice about important things in life. *(N = 323)*	13	26	69	112	103	3.82
%	4.0	8.0	21.4	34.7	31.9	

Table 31. PROMIS Informational Support Scale – PWD Only

PROMIS Informational Support Short Form	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Usually (4)**	**Always (5)**	**Mean**
I have someone to give me good advice about a crisis if I need it. *(N = 358)*	16	24	84	115	119	3.83
%	4.5	6.7	23.5	32.1	33.2	
I have someone to turn to for suggestions about how to deal with a problem. *(N = 356)*	13	26	69	117	131	3.92
%	3.7	7.3	19.4	32.9	36.8	
I have someone to give me information if I need it. *(N = 355)*	8	27	69	125	126	3.94
%	2.3	7.6	19.4	35.2	35.5	
I get useful advice about important things in life. *(N = 356)*	13	29	73	126	115	3.85
%	3.7	8.1	20.5	35.4	32.3	

Table 32. PROMIS Informational Support Scale – FS Only

PROMIS Informational Support Short Form	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Usually (4)**	**Always (5)**	**Mean**
I have someone to give me good advice about a crisis if I need it. *(N = 119)*	2	15	20	39	43	3.89
%	1.7	12.6	16.8	32.8	36.1	
I have someone to turn to for suggestions about how to deal with a problem. *(N = 118)*	2	12	19	36	49	4.00
%	1.7	10.2	16.1	30.5	41.5	
I have someone to give me information if I need it. *(N = 117)*	2	6	22	45	42	4.02
%	1.7	5.1	18.8	38.5	35.9	

PROMIS Informational Support Short Form	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Usually (4)**	**Always (5)**	**Mean**
I get useful advice about important things in life. *(N = 118)*	3	12	16	47	40	3.92
%	2.5	10.2	13.6	39.8	33.9	

Table 33. PROMIS Instrumental Support Scale – Overall Sample

PROMIS Instrumental Support Short Form	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Usually (4)**	**Always (5)**	**Mean**
Do you have someone to help you if you are confined to bed? *(N = 474)*	37	29	59	156	193	3.93
%	7.8	6.1	12.4	32.9	40.7	
Do you have someone to take you to the doctor if you need it? *(N = 475)*	23	28	56	148	220	4.08
%	4.8	5.9	11.8	31.2	46.3	
Do you have someone to help with your daily chores if you are sick? *(N = 479)*	26	42	62	151	198	3.95
%	5.4	8.8	12.9	31.5	41.3	
Do you have someone to run errands if you need it? *(N = 479)*	22	31	69	156	201	4.01
%	4.6	6.5	14.4	32.6	42.0	

Table 34. PROMIS Instrumental Support Scale – PWP Only

PROMIS Instrumental Support Short Form	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Usually (4)**	**Always (5)**	**Mean**
Do you have someone to help you if you are confined to bed? *(N = 321)*	19	17	28	112	145	4.08
%	5.9	5.3	8.7	34.9	45.2	

PROMIS Instrumental Support Short Form	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Usually (4)**	**Always (5)**	**Mean**
Do you have someone to take you to the doctor if you need it? *(N = 324)*	16	15	28	103	162	4.17
%	4.9	4.6	8.6	31.8	**50.0**	
Do you have someone to help with your daily chores if you are sick? *(N = 324)*	13	20	30	113	148	4.12
%	4.0	6.2	9.3	34.9	45.7	
Do you have someone to run errands if you need it? *(N = 325)*	9	17	40	112	147	4.14
%	2.8	5.2	12.3	34.5	45.2	

Table 35. PROMIS Instrumental Support Scale – PWD Only

PROMIS Instrumental Support Short Form	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Usually (4)**	**Always (5)**	**Mean**
Do you have someone to help you if you are confined to bed? *(N = 355)*	22	18	36	124	155	4.05
%	6.2	5.1	10.1	34.9	43.7	
Do you have someone to take you to the doctor if you need it? *(N = 356)*	19	17	36	112	172	4.13
%	5.3	4.8	10.1	31.5	48.3	
Do you have someone to help with your daily chores if you are sick? *(N = 358)*	15	25	38	122	158	4.07
%	4.2	7.0	10.6	34.1	44.1	
Do you have someone to run errands if you need it? *(N = 359)*	12	9	48	122	158	4.10
%	3.3	5.3	13.4	34.0	44.0	

Table 36. PROMIS Instrumental Support Scale – FS Only

PROMIS Instrumental Support Short Form	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Usually (4)**	**Always (5)**	**Mean**
Do you have someone to help you if you are confined to bed? *(N = 114)*	15	9	23	31	36	3.56
%	13.2	7.9	20.2	27.2	31.6	
Do you have someone to take you to the doctor if you need it? *(N = 114)*	4	10	19	35	46	3.96
%	3.5	8.8	16.7	30.7	40.4	
Do you have someone to help with your daily chores if you are sick? *(N = 116)*	10	16	24	28	38	3.59
%	8.6	13.8	20.7	.24.1	32.8	
Do you have someone to run errands if you need it? *(N = 115)*	10	10	21	33	41	3.74
%	8.7	8.7	18.3	28.7	35.7	

Table 37. PROMIS Social Isolation Scale – Overall Sample

PROMIS Social Isolation Short Form	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Usually (4)**	**Always (5)**	**Mean**
I feel left out. *(N = 480)*	72	109	202	70	27	2.73
%	15.0	22.7	42.1	14.6	5.6	
I feel that people barely know me. *(N = 477)*	118	122	150	61	26	2.49
%	24.7	25.6	31.4	12.8	5.5	
I feel isolated from others. *(N = 479)*	90	117	175	66	29	2.64
%	18.9	24.5	36.7	13.8	6.1	
I feel that people are around me but not with me. *(N = 478)*	118	123	157	61	19	2.46
%	24.7	25.7	32.8	12.8	4.0	

Table 38. PROMIS Social Isolation Scale – PWP Only

PROMIS Social Isolation Short Form	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Usually (4)**	**Always (5)**	**Mean**
I feel left out. *(N = 325)*	49	59	150	48	19	2.78
%	15.1	18.2	46.2	14.8	5.8	
I feel that people barely know me. *(N = 323)*	79	76	107	44	17	2.52
%	24.5	23.5	33.1	13.6	5.3	
I feel isolated from others. *(N = 325)*	55	81	121	48	20	2.68
%	16.9	24.9	37.2	14.8	6.2	
I feel that people are around me but not with me. *(N = 323)*	76	86	106	45	10	2.46
%	23.5	26.6	32.8	13.9	3.1	

Table 39. PROMIS Social Isolation Scale – PWD Only

PROMIS Social Isolation Short Form	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Usually (4)**	**Always (5)**	**Mean**
I feel left out. *(N = 357)*	53	66	164	54	20	2.78
%	14.8	18.5	45.9	15.1	5.6	
I feel that people barely know me. *(N = 356)*	89	82	117	50	18	2.51
%	25.0	23.0	32.9	14.0	5.1	
I feel isolated from others. *(N = 356)*	62	86	132	54	22	2.69
%	17.4	24.2	37.1	15.2	6.2	
I feel that people are around me but not with me. *(N = 355)*	83	93	114	51	14	2.49
%	23.4	26.2	32.1	14.4	3.9	

Table 40. PROMIS Social Isolation Scale – FS Only

PROMIS Social Isolation Short Form	**Never (1)**	**Rarely (2)**	**Sometimes (3)**	**Usually (4)**	**Always (5)**	**Mean**
I feel left out. *(N = 118)*	19	43	34	15	7	2.56
%	16.1	36.4	28.8	12.7	5.9	
I feel that people barely know me. *(N = 117)*	29	39	30	11	8	2.40
%	24.8	33.3	25.6	9.4	6.8	
I feel isolated from others. *(N = 116)*	28	30	41	11	6	2.46
%	24.1	25.9	35.3	9.5	5.2	
I feel that people are around me but not with me. *(N = 118)*	35	30	39	9	5	2.31
%	29.7	25.4	33.1	7.6	4.2	

Table 41 shows the mean scores in each group for each of the PROMIS scores. Further analyses were conducted to determine whether the average scores were significantly different between groups.

Table 41. Mean Scores for PROMIS Scales

Means for each PROMIS Scale	**Emotional Support**	**Informational Support**	**Instrumental Support**	**Social Isolation**
Overall *(N = 482)*	15.9	15.6	16.0	10.3
Persons with Paralysis *(N = 329)*	15.7	15.4	16.6	10.4
Persons with Disability (PWP + Other Disabilities) *(N = 358)*	15.7	15.5	16.4	10.5
Foundation Supporters *(N = 122)*	16.4	15.8	14.8	9.8

We conducted independent t-tests to determine whether there were significant differences between groups on these items. For the PROMIS Scale means, the only significant difference between the PWD and FS groups was on the Instrumental Support Scale. Table 42 shows the significant difference between the PWD and FS groups on the mean Instrumental Support Scale.

PWD had a significantly higher mean than FS, with a Cohen's *d* of 0.38, indicating a small-to-moderate effect size.

This significant difference between groups could be because PWD, especially those with paralysis, have family or professional caregivers in their daily lives that provide the type of instrumental support included in this PROMIS scale. Over 70% of the PWP in this sample used caregivers, which could explain why PWD expressed higher levels of instrumental support than FS.

Table 42. PWD vs. FS Group Comparison of Instrumental Support

	PWD		FS					
	M	*SD*	*M*	*SD*	*df*	*t*	*p*	Cohen's *d*
PROMIS Instrumental Support Scale	16.4	4.1	14.8	4.6	465	-3.6	.011	0.38

COVID Risks and Vaccination Status

All respondents were asked a series of questions about their risk related to COVID-19 and vaccination status. As shown in Table 43, 47.3% of PWD indicated that they had underlying conditions or took medication that put them at greater risk for severe COVID-19 symptoms, while 29.0% of FS indicated that they did.

Table 43. Whether Respondents Had Conditions or Medications at a Higher Risk for COVID

Do you have any underlying conditions or take medications that put you at greater risk for severe COVID-19 symptoms?	**Yes**	**No**
Overall *(N = 531)*	226	305
%	42.6	**57.4**
Persons with Paralysis *(N = 353)*	159	194
%	45.0	**55.0**
Persons with Disability (PWP + Other Disabilities) *(N = 423)*	183	204
%	47.3	**52.7**
Foundation Supporters *(N = 138)*	40	98
%	29.0	**71.0**

We conducted an independent samples t-test to determine if this difference was significant. For this question, "Yes" answers were coded as 1 and "No" answers were coded as 0. This means that for the mean scores (*M*) for each group shown below in Table 44, mean values closer to 1 indicate more "Yes" responses, while mean values closer to 0 indicate more "No" responses.

This comparison shows that PWD were significantly *more* likely to answer yes to this question than FS. PWD had a significantly higher mean than FS, with a Cohen's *d* of 0.35, indicating a small-to-moderate effect size.

Table 44. PWD vs. FS Differences in Underlying Conditions/Medications

	PWD		FS					
	M	*SD*	*M*	*SD*	*df*	*t*	*p*	Cohen's *d*
Do you have any underlying conditions or take medications that put you at greater risk for severe COVID-19 symptoms?	0.47	0.50	0.30	0.49	529	-3.65	<.001	0.36

All respondents were asked if they had received the first two doses of a COVID-19 vaccine. These results are presented in Table 45.

Table 45. Respondents' Vaccination Status

Have you received the first two doses of the COVID-19 vaccine?	**Yes, I have received one dose of a two-dose COVID-19 vaccine (Pfizer, Moderna).**	**Yes, I have received two doses of a two-dose COVID-19 vaccine (Pfizer, Moderna).**	**Yes, I have received three doses of a two-dose vaccine because I am immuno-compromised.**	**Yes, I have received one dose of a one-dose COVID-19 vaccine (Johnson & Johnson).**	**No, I have not received any doses of the COVID-19 vaccine.**
Overall *(N = 538)*	60	287	101	26	64
%	11.2	**53.3**	18.8	4.8	11.9
Persons with Paralysis *(N = 357)*	33	190	67	17	50
%	9.2	**53.2**	18.8	4.8	14.0
Persons with Disability (PWP + Other Disabilities) *(N = 391)*	40	203	79	19	50
%	10.2	**51.9**	20.2	4.9	12.8
Foundation Supporters *(N = 140)*	20	81	21	6	12
%	14.3	**57.9**	15.0	4.3	8.6

Overall, most respondents (77.0%) were fully vaccinated, as they had either received two or three doses of a two-dose vaccine or one dose of a one-dose vaccine. 11.2% of respondents were partially vaccinated and 11.9% were unvaccinated. In the PWP group, 76.8% of respondents were fully vaccinated. None of the groups were more likely than another to be fully vaccinated or unvaccinated.

Fully vaccinated respondents were asked if they had received any booster doses of a COVID-19 vaccine, these results are reported below. These responses in Table 46 show that most fully vaccinated respondents (81.8%) had received at least one booster dose after their initial vaccines.

Table 46. Respondents' Booster Status

Have you received any booster doses of a COVID-19 vaccine?	**Yes, I have received one booster dose of a COVID-19 vaccine.**	**Yes, I have received two booster doses of a COVID-19 vaccine.**	**No, I have not received a booster dose of a COVID-19 vaccine.**
Overall *(N = 411)*	145	191	75
%	35.3	46.5	18.2
Persons with Paralysis *(N = 273)*	98	129	46
%	35.9	47.3	16.8
Persons with Disability (PWP + Other Disabilities) *(N = 300)*	104	142	54
%	34.7	47.3	18.0
Foundation Supporters *(N = 106)*	38	47	21
%	35.8	44.3	19.8

COVID Infection Experiences

All participants were asked if they have ever been diagnosed with or tested positive for COVID-19. As shown below in Table 47, most respondents (61.5% of the sample) had never been diagnosed or tested positive.

Table 47. Whether Respondents had been Diagnosed with COVID-19

Have you ever been diagnosed with or tested positive for COVID-19?	**Yes**	**No**
Overall *(N = 533)*	205	328
%	38.5	**61.5**
Persons with Paralysis *(N = 355)*	127	228
%	35.8	**64.2**
Persons with Disability (PWP + Other Disabilities) *(N = 389)*	137	252
%	35.2	**64.8**

Have you ever been diagnosed with or tested positive for COVID-19?	**Yes**	**No**
Foundation Supporters *(N = 138)*	64	74
%	46.4	**53.6**

We conducted an independent samples t-test to determine if there was a significant difference between PWD and FS. For this question, "Yes" answers were coded as 1 and "No" answers were coded as 0. This means that for the mean scores (*M*) for each group shown below in Table 48 mean values closer to 1 indicate more "Yes" responses, while mean values closer to 0 indicate more "No" responses. This comparison shows that FS were significantly more likely to answer yes to this question than PWD, meaning that FS were more likely to report a previous COVID-19 infection than PWD. This comparison showed a Cohen's *d* of 0.25, indicating a small effect size.

Table 48. PWD vs. FS Comparisons on Previous COVID Diagnosis

	PWD		FS					
	M	*SD*	*M*	*SD*	*df*	*t*	*p*	Cohen's *d*
Have you ever been diagnosed with or tested positive for COVID-19?	0.35	0.48	0.47	0.50	531	2.54	<.001	0.25

Respondents who indicated that they have had COVID were asked when their diagnosis/positive test was in relation to their COVID-19 vaccinations. These results are presented in Table 49.

Table 49. Timing of COVID-19 Diagnosis in Relation to Vaccinations

When was your COVID-19 diagnosis/positive test in relation to your vaccination status?	**Before I had received any doses of a COVID-19 vaccine.**	**When I had received only one dose of a two-dose COVID-19 vaccine.**	**When I was fully vaccinated (two or three shots of a two-shot vaccine or one shot of the single shot).**	**After I was fully vaccinated and had received at least one booster shot.**	**I have not received any vaccine doses and do not plan to.**
Overall *(N = 202)*	33	13	50	80	26
%	16.3	6.4	24.8	39.6	12.9
Persons with Paralysis *(N = 124)*	21	7	28	49	19
%	16.9	5.6	22.6	39.5	15.3
Persons with Disability (PWP + Other Disabilities) *(N = 134)*	23	10	29	53	19
%	17.2	7.5	21.6	39.6	14.2

When was your COVID-19 diagnosis/positive test in relation to your vaccination status?	**Before I had received any doses of a COVID-19 vaccine.**	**When I had received only one dose of a two-dose COVID-19 vaccine.**	**When I was fully vaccinated (two or three shots of a two-shot vaccine or one shot of the single shot).**	**After I was fully vaccinated and had received at least one booster shot.**	**I have not received any vaccine doses and do not plan to.**
Foundation Supporters *(N = 64)*	9	3	19	27	6
%	14.1	4.7	29.7	42.2	9.4

Respondents with a previous COVID diagnosis were asked to select the symptoms they experienced due to COVID. Table 50 shows the number of individuals in each group that had a COVID diagnosis that selected each symptom, along with the percentage of the group with a COVID diagnosis that selected each symptom. The last row shows the average number of symptoms selected in each group. This calculation did not include selections of "I was asymptomatic/had no symptoms."

Table 50. COVID-19 Symptoms Expressed by Respondents

Which of the following symptoms did you exhibit when you had COVID-19? Please check all that apply.	**Overall** ***(N = 205)*** ***N*** **(%)**	**PWP** ***(N = 127)*** ***N*** **(%)**	**PWD** ***(N = 137)*** ***N*** **(%)**	**FS** ***(N = 64)*** ***N*** **(%)**
Fever or chills	121 **(59.0)**	76 **(59.8)**	84 **(61.2)**	35 **(54.7)**
Cough	128 **(62.4)**	75 **(59.1)**	83 **(60.6)**	43 **(67.2)**
Shortness of breath or difficulty breathing	67 (32.7)	41 (32.3)	46 (33.6)	19 (29.9)
Fatigue	158 **(77.1)**	98 **(77.2)**	106 **(77.4)**	49 **(76.7)**
Muscle or body aches	115 **(56.1)**	74 **(58.3)**	78 **(56.9)**	34 **(53.1)**
Headache	110 **(53.7)**	67 **(52.8)**	71 **(51.8)**	36 **(56.3)**
New loss of taste or smell	68 (33.2)	41 (32.3)	44 (32.1)	23 (35.9)
Sore throat	89 (43.4)	58 (45.7)	63 (46.0)	25 (39.1)
Congestion or runny nose	123 **(60.0)**	76 **(59.8)**	79 **(57.7)**	41 **(64.1)**
Nausea or vomiting	35 (17.1)	18 (14.2)	23 (16.8)	10 (15.6)
Diarrhea	37 (18.0)	22 (17.3)	24 (17.5)	12 (18.8)
Other (please describe)	18 (8.8)	12 (9.4)	13 (9.5)	3 (4.7)
I was asymptomatic/had no symptoms	10 (4.9)	6 (4.7)	6 (4.4)	4 (6.3)
Average number of symptoms selected (out of 12 possible)	5.21	5.18	5.21	5.16

Respondents who selected that they had "other symptoms" were asked to describe any other symptoms they experienced in an open-ended format. All responses are included below.

Please list any other symptoms you have had due to COVID-19. *(N = 18)*

- "Brain fog almost like I had another TBI, many symptoms commonly associated with long haulers."
- "A brief post-polio 'attack' of extreme shaking lower leg muscles."
- "Excessive sweating followed by period of time of symptoms of constant chills/cold. Had SARS-CoV2 twice: once before vaccinations were available and once after both shots of Moderna, no boosters."
- "Extreme hunger and sweating all the time."
- "Extreme itching, feeling overheated, rashes, ears filled with fluid and hearing loss, balance problems, difficulty walking. My ears are still bad four months after COVID."
- "Fever of 103° for days. Thought I was going to die."
- "I developed transverse myelitis from having COVID-19."
- "I had a sore throat and headache but got over it quickly. However, post COVID, my dysreflexia triggered because my body became severely inflamed (bursitis, sciatic nerves, muscle nerves, etc.) and I had to be hospitalized and treated with strong steroids and nerve blockers."
- "I had teeth chattering."
- "I have also an underlying heart condition and my heart struggled to cope with COVID."
- "Itching, numbness, tingling, loss of strength, could not urinate, tightness in chest."
- "Itchy skin, constipation, loss of appetite."
- "Memory and speechless."
- "My blood sugars went incredibly high."
- "My mind was pretty foggy."
- "Pink eye."
- "Severe constipation, entire gut shut down."
- "Very hungry, weird nerve stuff, memory issues among other things long term."

Respondents who had received a COVID diagnosis or positive test were asked where they were treated while they were sick. Responses are found in Table 51.

Table 51. How Respondents Received Treatment for COVID-19

If you were sick with COVID-19 symptoms, how did you receive treatment(s)? Please select all that apply.	**I didn't, I wasn't sick**	**I recovered at home**	**I spoke with a healthcare provider and wasn't admitted to the hospital**	**I was admitted to the hospital for at least one night**
Overall *(N = 205)*	9	144	70	15
%	4.4	**70.2**	34.1	7.3

If you were sick with COVID-19 symptoms, how did you receive treatment(s)? Please select all that apply.	**I didn't, I wasn't sick**	**I recovered at home**	**I spoke with a healthcare provider and wasn't admitted to the hospital**	**I was admitted to the hospital for at least one night**
Persons with Paralysis *(N = 127)*	4	90	44	11
%	3.1	**70.9**	34.6	8.7
Persons with Disability (PWP + Other Disabilities) *(N = 137)*	4	97	48	12
%	2.9	**70.8**	35.0	8.8
Foundation Supporters *(N = 64)*	5	45	20	2
%	7.8	**70.3**	31.3	3.1

Respondents who had a COVID diagnosis were also presented with a matrix asking them to rate the degree to which they experienced various emotions about their COVID infection on a 5-point scale ranging from *Not at all like me* (1) to *Very much like me* (5). Tables 52 – 56 show responses from each group. The means on this 5-point scale for each emotion are shown for each group in Table 56.

Table 52. Feelings about COVID-19 Infection – Overall Sample

Please indicate the degree to which you felt the following emotions about your COVID-19 infection.	**Not at all like me (1)**	**A little bit like me (2)**	**Neither like me nor not like me (3)**	**Somewhat like me (4)**	**Very much like me (5)**
Shame *(N = 190)*	133	18	19	13	7
%	**70.0**	9.5	10.0	6.8	3.7
Fear *(N = 190)*	77	40	17	35	21
%	40.5	21.1	8.9	18.4	11.1
Anxiety *(N = 190)*	64	42	18	39	27
%	33.7	22.1	9.5	20.5	14.2
Depression *(N = 189)*	97	32	18	26	16
%	**51.3**	16.9	9.5	13.8	8.5
Worry *(N = 191)*	56	55	10	42	28
%	29.3	28.8	5.2	22.0	14.7
Anger *(N = 189)*	92	33	20	29	15

Please indicate the degree to which you felt the following emotions about your COVID-19 infection.	**Not at all like me (1)**	**A little bit like me (2)**	**Neither like me nor not like me (3)**	**Somewhat like me (4)**	**Very much like me (5)**
%	48.7	17.5	10.6	15.3	7.9
Loneliness *(N = 189)*	90	25	26	27	21
%	47.6	13.2	13.8	14.3	11.1
Stress *(N = 189)*	59	38	17	46	29
%	31.2	20.1	9.0	24.3	15.3
Guilt *(N = 189)*	128	21	20	15	5
%	**67.7**	11.1	10.6	7.9	2.6
Hopelessness *(N = 186)*	124	15	24	13	10
%	**66.7**	8.1	12.9	7.0	5.4

Table 53. Feelings about COVID-19 Infection – PWP Only

Please indicate the degree to which you felt the following emotions about your COVID-19 infection.	**Not at all like me (1)**	**A little bit like me (2)**	**Neither like me nor not like me (3)**	**Somewhat like me (4)**	**Very much like me (5)**
Shame *(N = 119)*	84	13	14	5	3
%	**70.6**	10.9	11.8	4.2	2.5
Fear *(N = 119)*	50	27	11	19	12
%	42.0	22.7	9.2	16.0	10.1
Anxiety *(N = 119)*	43	25	12	22	17
%	36.1	21.0	10.1	18.5	14.3
Depression *(N = 119)*	65	21	10	12	11
%	**54.6**	17.6	8.4	10.1	9.1
Worry *(N = 119)*	39	34	7	22	17
%	32.8	28.6	5.9	18.5	14.3
Anger *(N = 118)*	62	22	11	15	8
%	**52.5**	18.6	9.3	12.7	6.8
Loneliness *(N = 119)*	60	16	17	15	11
%	**50.4**	13.4	14.3	12.6	9.2

Please indicate the degree to which you felt the following emotions about your COVID-19 infection.	**Not at all like me (1)**	**A little bit like me (2)**	**Neither like me nor not like me (3)**	**Somewhat like me (4)**	**Very much like me (5)**
Stress *(N = 119)*	38	27	11	26	17
%	31.9	22.7	9.2	21.8	14.3
Guilt *(N = 119)*	82	16	11	7	3
%	**68.9**	13.4	9.2	5.9	2.5
Hopelessness *(N = 117)*	75	9	15	12	6
%	**64.1**	7.7	12.8	10.3	5.1

Table 54. Feelings about COVID-19 Infection – PWD Only

Please indicate the degree to which you felt the following emotions about your COVID-19 infection.	**Not at all like me (1)**	**A little bit like me (2)**	**Neither like me nor not like me (3)**	**Somewhat like me (4)**	**Very much like me (5)**
Shame *(N = 128)*	93	14	14	5	2
%	**72.7**	10.9	10.9	3.9	1.6
Fear *(N = 129)*	53	27	13	22	14
%	41.1	20.9	10.1	17.1	10.9
Anxiety *(N = 128)*	46	26	14	24	18
%	35.9	20.3	10.9	18.8	14.1
Depression *(N = 127)*	68	21	13	15	10
%	**53.5**	16.5	10.2	11.8	7.9
Worry *(N = 130)*	41	36	8	25	20
%	31.5	27.7	6.2	19.2	15.4
Anger *(N = 127)*	67	22	14	17	7
%	**52.8**	17.3	11.0	13.4	5.5
Loneliness *(N = 129)*	64	16	19	18	12
%	49.6	12.4	14.7	14.0	9.3
Stress *(N = 128)*	41	27	12	31	17
%	32.0	21.1	9.4	24.2	13.3
Guilt *(N = 128)*	88	17	12	7	4
%	**68.8**	13.3	9.4	5.5	3.1

Please indicate the degree to which you felt the following emotions about your COVID-19 infection.	**Not at all like me (1)**	**A little bit like me (2)**	**Neither like me nor not like me (3)**	**Somewhat like me (4)**	**Very much like me (5)**
Hopelessness *(N = 126)*	82	10	17	11	6
%	**65.1**	7.9	13.5	8.7	4.8

Table 55. Feelings about COVID-19 Infection – FS Only

Please indicate the degree to which you felt the following emotions about your COVID-19 infection.	**Not at all like me (1)**	**A little bit like me (2)**	**Neither like me nor not like me (3)**	**Somewhat like me (4)**	**Very much like me (5)**
Shame *(N = 59)*	40	4	5	6	4
%	**67.8**	6.8	8.5	10.2	6.8
Fear *(N = 59)*	24	11	4	13	7
%	40.7	18.6	6.8	22.0	11.9
Anxiety *(N = 59)*	18	15	4	14	8
%	30.5	25.4	6.8	23.7	13.6
Depression *(N = 59)*	29	10	5	11	4
%	49.2	16.9	8.5	18.6	6.8
Worry *(N = 59)*	15	18	2	17	7
%	25.4	30.5	3.4	28.8	11.9
Anger *(N = 59)*	25	9	6	12	7
%	42.4	15.3	10.2	20.3	11.9
Loneliness *(N = 57)*	26	8	7	8	8
%	45.6	14.0	12.3	5.1	5.1
Stress *(N = 58)*	18	10	5	15	10
%	31.0	17.2	8.6	25.9	17.2
Guilt *(N = 58)*	39	3	8	7	1
%	**67.2**	5.2	13.8	12.1	1.7
Hopelessness *(N = 57)*	42	5	7	1	2
%	**73.7**	8.8	12.3	1.8	3.5

Table 56. Mean Scores Across Groups for Emotions about COVID Infection

Mean scores for each feeling about COVID infection (5-point scale)	**Overall** ***(N = 191)***	**PWP** ***(N = 119)***	**PWD** ***(N = 130)***	**FS** ***(N = 59)***
Shame	1.65	1.57	1.51	1.81
Fear	2.38	2.29	2.36	2.46
Anxiety	2.59	2.54	2.55	2.64
Depression	2.11	2.02	2.04	2.17
Worry	2.64	2.53	2.59	2.71
Anger	2.16	2.03	2.02	2.44
Loneliness	2.28	2.17	2.21	2.37
Stress	2.72	2.64	2.66	2.81
Guilt	1.67	1.60	1.61	1.76
Hopelessness	1.76	1.85	1.80	1.53

Group comparisons were conducted to determine whether there were significant differences between groups of their means on these emotion ratings on the 5-point scale. The significant differences from this scale are shown in Table 57.

Table 57. PWD vs. FS – Significant Differences on Emotions about COVID-19 Infection

	PWD		FS					
	M	*SD*	*M*	*SD*	*df*	*t*	*p*	Cohen's *d*
Infection Feelings: Shame	1.51	0.95	1.94	1.41	188	2.47	<.001	0.38
Infection Feelings: Anger	2.02	1.30	2.47	1.50	187	2.13	.012	0.33
Infection Feelings: Guilt	1.61	1.06	1.79	1.20	187	1.03	.052	0.16

PWD had significantly *lower* means for shame, anger, and guilt than the FS group. The Cohen's *d* values for the shame and anger scales reflect small-to-moderate effect sizes. The difference between groups on the guilt scale approaches significance with a *p* value of 0.052, but are not considered to be statistically significant, as this requires a *p* value of 0.05. These comparisons show that FS were more likely to rate their feelings of shame, anger, and guilt related to their COVID-19 diagnosis as higher than PWD.

Respondents who had not been diagnosed with or tested positive for COVID-19 were asked to rate the degree to which they had experienced various feelings when thinking about the possibility of being infected with COVID-19 on the same 5-point scale. Tables 58 – 61 show participant responses for each emotion, while Table 62 shows the mean scores for each emotion in each group.

Table 58. Feelings about Possibility of COVID-19 Infection – Overall Sample

Please rate the degree to which you have experienced the following feelings when thinking about the possibility of being infected with COVID-19.	**Not at all like me (1)**	**A little bit like me (2)**	**Neither like me nor not like me (3)**	**Somewhat like me (4)**	**Very much like me (5)**
Fear *(N = 316)*	87	78	41	77	33
%	27.5	24.7	13.0	24.4	10.4
Anxiety *(N = 316)*	83	78	37	80	38
%	26.3	24.7	11.7	25.3	12.0
Depression *(N = 315)*	153	53	45	47	17
%	48.6	16.8	14.3	14.9	5.4
Worry *(N = 316)*	88	86	30	86	26
%	27.8	27.2	9.5	27.2	8.2
Hopelessness *(N = 313)*	190	39	48	25	11
%	**60.7**	12.5	15.3	8.0	3.5
Stress *(N = 311)*	88	86	43	64	30
%	28.3	27.7	13.8	20.6	9.6

Table 59. Feelings about Possibility of COVID-19 Infection – PWP Only

Please rate the degree to which you have experienced the following feelings when thinking about the possibility of being infected with COVID-19.	**Not at all like me (1)**	**A little bit like me (2)**	**Neither like me nor not like me (3)**	**Somewhat like me (4)**	**Very much like me (5)**
Fear *(N = 219)*	60	57	26	52	24
%	27.4	26.0	11.9	23.7	11.0
Anxiety *(N = 219)*	61	53	25	57	23
%	27.9	24.2	11.4	26.0	10.5
Depression *(N = 218)*	109	37	30	30	12
%	**50.0**	17.0	13.8	13.8	5.5

Please rate the degree to which you have experienced the following feelings when thinking about the possibility of being infected with COVID-19.	**Not at all like me (1)**	**A little bit like me (2)**	**Neither like me nor not like me (3)**	**Somewhat like me (4)**	**Very much like me (5)**
Worry *(N = 219)*	61	66	18	56	18
%	27.9	30.1	8.2	25.6	8.2
Hopelessness *(N = 217)*	132	26	33	15	11
%	**60.8**	12.0	15.2	6.9	5.1
Stress *(N = 216)*	61	61	30	41	23
%	28.2	28.2	13.9	19.0	10.6

Table 60. Feelings about Possibility of COVID-19 Infection – PWD Only

Please rate the degree to which you have experienced the following feelings when thinking about the possibility of being infected with COVID-19.	**Not at all like me (1)**	**A little bit like me (2)**	**Neither like me nor not like me (3)**	**Somewhat like me (4)**	**Very much like me (5)**
Fear *(N = 242)*	64	65	29	57	27
%	26.4	26.9	12.0	23.6	11.2
Anxiety *(N = 242)*	64	61	29	60	28
%	26.4	25.2	12.0	24.8	11.6
Depression *(N = 241)*	117	43	34	33	14
%	48.5	17.8	14.1	13.7	5.8
Worry *(N = 242)*	67	70	22	62	21
%	27.7	28.9	9.1	25.6	8.7
Hopelessness *(N = 240)*	145	31	36	17	11
%	**60.4**	12.9	15.0	7.1	4.6
Stress *(N = 238)*	66	68	33	47	24
%	27.7	28.6	13.9	19.7	10.1

Table 61. Feelings about Possibility of COVID-19 Infection – FS Only

Please rate the degree to which you have experienced the following feelings when thinking about the possibility of being infected with COVID-19.	**Not at all like me (1)**	**A little bit like me (2)**	**Neither like me nor not like me (3)**	**Somewhat like me (4)**	**Very much like me (5)**
Fear *(N = 72)*	23	13	12	19	5
%	31.9	18.1	16.7	26.4	6.9
Anxiety *(N = 72)*	19	17	8	19	9
%	26.4	23.6	11.1	26.4	12.5
Depression *(N = 72)*	36	10	10	13	3
%	**50.0**	13.9	13.9	18.1	4.2
Worry *(N = 72)*	21	16	8	22	5
%	29.2	22.2	11.1	30.6	6.9
Hopelessness *(N = 71)*	45	8	10	8	0
%	**63.4**	11.3	14.1	11.3	0.0
Stress *(N = 71)*	22	18	10	15	63
%	31.0	25.4	14.1	21.1	8.5

Table 62. Mean Scores Across Groups for Emotions about Possibility of COVID Infection

Mean scores for each feeling about possibility of COVID infection (5-point scale)	**Overall** ***(N = 316)***	**PWP** ***(N = 219)***	**PWD** ***(N = 242)***	**FS** ***(N = 72)***
Fear	2.66	2.65	2.66	2.58
Anxiety	2.72	2.67	2.70	2.75
Depression	2.12	2.08	2.10	2.13
Worry	2.61	2.56	2.59	2.64
Hopelessness	1.81	1.83	1.82	1.73
Stress	2.56	2.56	2.56	2.51

There were no significant differences between groups on their mean scores for their feelings about the possibility of getting COVID-19.

Beliefs and Experiences in the COVID-19 Pandemic

All respondents were asked to rate whether they believed that they could protect themselves and others from COVID-19, shown below in Tables 63 & 64.

Table 63. Respondents' Belief that They Can Protect Themselves from COVID-19

I believe I can protect myself from COVID-19.	**Yes**	**No**	**Unsure or Don't Know**
Overall *(N = 536)*	348	64	124
%	**64.9**	11.9	23.1
Persons with Paralysis *(N = 356)*	234	41	81
%	**65.7**	11.5	22.8
Persons with Disability (PWP + Other Disabilities) *(N = 390)*	257	43	90
%	**65.9**	11.0	23.1
Foundation Supporters *(N = 139)*	88	19	32
%	**63.3**	13.7	23.0

Table 64. Respondents' Belief that They Can Protect Others from COVID-19

I believe I can protect others from COVID-19.	**Yes**	**No**	**Unsure or Don't Know**
Overall *(N = 536)*	286	118	132
%	**53.4**	20.1	24.6
Persons with Paralysis *(N = 356)*	185	79	92
%	**52.0**	22.2	25.8
Persons with Disability (PWP + Other Disabilities) *(N = 390)*	205	83	102
%	**52.6**	21.3	26.2
Foundation Supporters *(N = 139)*	77	34	28
%	**55.4**	24.5	20.1

Almost 65% of respondents believed that they could protect themselves from COVID-19, while 53.4% of respondents believed that they could protect others from COVID-19. There were no differences between groups related to their responses on these items.

Participants were asked if recommendations for social distancing caused stress for them and their loved ones, and as Tables 65 & 66 show, there was a wide range of responses across the sample. There were no significant differences between groups on their responses to either of these questions, indicating that no group was more likely to indicate that recommendations for socially distancing caused stress for them or their loved ones.

Table 65. Whether Social Distancing Recommendations Caused Stress for Respondents

Have recommendations for socially distancing caused stress for you?	**Not at all**	**A little**	**Somewhat**	**A lot**
Overall *(N = 537)*	137	180	144	76
%	25.5	33.5	26.8	14.2
Persons with Paralysis *(N = 357)*	82	127	99	49
%	23.0	35.6	27.7	13.7
Persons with Disability (PWP + Other Disabilities) *(N = 423)*	91	133	114	53
%	23.3	34.0	29.2	13.6
Foundation Supporters *(N = 139)*	45	46	28	20
%	32.4	33.1	20.1	14.4

Table 66. Whether Social Distancing Recommendations Caused Stress for Respondents' Loved Ones

Have recommendations for socially distancing caused stress for your loved ones?	**Not at all**	**A little**	**Somewhat**	**A lot**
Overall *(N = 537)*	106	154	168	109
%	19.7	28.7	31.3	20.3
Persons with Paralysis *(N = 357)*	70	111	107	69
%	19.6	31.1	30.0	19.3
Persons with Disability (PWP + Other Disabilities) *(N = 391)*	75	119	120	77
%	19.2	30.4	30.7	19.7

Have recommendations for socially distancing caused stress for your loved ones?	**Not at all**	**A little**	**Somewhat**	**A lot**
Foundation Supporters *(N = 139)*	30	35	46	28
%	21.6	25.2	33.1	20.1

To better understand the experiences of the paralysis community during the COVID-19 pandemic, respondents were asked to indicate any activities they engaged in/are engaging in during the pandemic. As Table 67 shows, the most common activity in all groups was practicing social distancing.

Table 67. Respondents' Behaviors during COVID-19

What are you doing/did you do during COVID-19?	**Overall** ***(N = 587)*** ***N* (%)**	**PWP** ***(N = 389)*** ***N* (%)**	**PWD** ***(N = 423)*** ***N* (%)**	**FS** ***(N = 157)*** ***N* (%)**
No changes to my life or behavior	58 (9.9)	43 (11.1)	45 (10.6)	12 (7.6)
Practicing social distancing	399 **(68.0)**	268 **(68.9)**	296 **(70.0)**	99 **(63.1)**
Isolating or quarantining yourself	290 (49.4)	187 (48.1)	208 (49.2)	78 (49.7)
Caring for an individual with paralysis	39 (6.6)	1 (0.3)	3 (0.7)	36 (22.9)
Caring for children who could not attend in-person learning	49 (8.3)	25 (6.4)	26 (6.1)	23 (14.6)
Caring for an individual with COVID-19	42 (7.2)	13 (3.3)	17 (4.0)	24 (15.3)
Working from home	144 (24.5)	86 (22.1)	96 (22.7)	46 (29.3)
Not working	80 (13.6)	51 (13.1)	58 (13.7)	20 (12.7)
A change in use of health services	163 (27.8)	117 (30.1)	134 (31.7)	27 (17.2)
Following media coverage related to COVID-19	252 (42.9)	173 (44.5)	194 (45.9)	55 (35.0)
Changing travel plans	197 (33.6)	119 (30.6)	132 (31.2)	60 (30.2)

Group comparison analyses were conducted to look at any potential differences between groups on their actions during the COVID-19 pandemic. On these items, a respondent checking the box for each item was coded as 1, while unchecked boxes were coded as 0. Group means (*M*) in the table below that are closer to 1 indicate that more individuals in this group checked this box, while means closer to 0 indicate that fewer individuals in this group checked this box.

Table 68. PWD vs. FS Differences on Respondent Behaviors During COVID-19

	PWD		FS					
	M	*SD*	*M*	*SD*	*df*	*t*	*p*	Cohen's *d*
No changes to my life or behavior	0.11	0.31	0.08	0.27	585	-.99	.045	0.30
Caring for an individual with paralysis	0.01	0.08	0.22	0.42	585	10.02	<.001	0.23
Caring for children who could not attend in-person learning	0.06	0.24	0.14	0.35	585	3.12	<.001	0.28
Caring for an individual with COVID-19	0.04	0.20	0.15	0.36	585	4.82	<.001	0.25
Working from home	0.23	0.42	0.29	0.46	585	1.67	.002	0.43
A change in use of health services	0.32	0.47	0.18	0.38	585	-3.43	<.001	0.44
Following media coverage related to COVID-19	0.46	0.50	0.35	0.48	585	-2.31	<.001	0.49

As Table 68 shows, PWD were significantly *more likely* than FS to indicate that there had been no changes to their life or behavior, that there had been a change in their use of health services, and that they had followed media coverage related to COVID-19. PWD were significantly *less likely* than FS to indicate that they had cared for a person with paralysis, cared for children who could not attend in-person learning, cared for an individual with COVID-19, and worked from home.

All respondents were asked if they lost their source of income because of COVID-19. Most participants did not lose their income because of COVID-19. These responses are shown in Table 69.

Table 69. Whether Respondents Lost Their Source of Income Due to COVID-19

Did you lose your source of income because of COVID-19?	**Yes**	**No**
Overall *(N = 506)*	50	456
%	9.9	**90.1**
Persons with Paralysis *(N = 337)*	22	315
%	6.5	**93.5**
Persons with Disability (PWP + Other Disabilities) *(N = 370)*	30	340
%	8.1	**91.9**
Foundation Supporters *(N = 130)*	18	112
%	13.8	**86.2**

Table 70 shows a significant difference between the PWD and FS groups on whether they lost their income because of COVID-19. For this question, "Yes" responses were coded as 1, while

"No" responses were coded as 0. This means that group means (*M*) that are closer to 1 indicate more "Yes" responses, while means closer to 0 indicate more "No" responses.

As Table 70 shows, PWD were significantly *less* likely to indicate that they lost their source of income due to COVID-19. In our sample, 57.9% of FS indicated that they had part-time or full-time employment and 7.6% were not employed, while 33.8% of PWD had full-time or part time employment and 27.2% of PWD were not employed. Because more FS were employed, it is likely that more FS were in a position to lose their employment due to COVID-19 than FS were.

Table 70. PWD vs. FS Differences on Loss of Income Source During COVID-19

	PWD		FS					
	M	*SD*	*M*	*SD*	*df*	*t*	*p*	Cohen's *d*
Did you lose your source of income because of COVID-19?	0.08	0.27	0.15	0.36	504	-2.21	<.001	0.30

Individuals who did lose their income were asked to indicate why this occurred. These responses are shown in Table 71.

Table 71. Reasons Respondents Lost Their Income During COVID-19

Why did you lose your income?	**Because I am/was sick or under quarantine**	**Because someone in my household was sick/under quarantine**	**Because my place of work was closed and didn't offer a remote option**	**Because I was laid off or lost my employment**	**Because I was caring for someone at home**
Overall *(N = 50)*	10	1	14	19	6
%	20.0	2.0	28.0	38.0	12.0
Persons with Paralysis *(N = 22)*	7	0	8	7	0
%	31.8	0.0	36.4	31.8	0.0
Persons with Disability (PWP + Other Disabilities) *(N = 30)*	6	0	11	11	2
%	20.0	0.0	36.7	36.7	6.7
Foundation Supporters *(N = 18)*	3	1	3	7	4
%	16.7	5.6	16.7	38.9	22.2

The most selected reasons for participants losing their income were being laid off/losing employment, workplace closings with no remote options, and because of illness/quarantine.

To better understand participants' mental health experiences during the pandemic, respondents were asked to select any of the following experiences that applied to their life during COVID-19. As Table 72 shows, there was a wide range of responses. The most selected responses were worrying about friends, family, partners, etc., fear of getting COVID-19, frustration or boredom, and feelings of contributing to the greater good by preventing self or others from COVID-19.

Table 72. Respondents' Mental Health Experiences During COVID-19

Which of the following are you experiencing (or did you experience) during COVID-19?	**Overall** *(N = 587)* *N* **(%)**	**PWP** *(N = 389)* *N* **(%)**	**PWD** *(N = 423)* *N* **(%)**	**FS** *(N = 157)* *N* **(%)**
Being diagnosed with COVID-19	156 (26.6)	101 (26.0)	109 (25.8)	44 (28.0)
Fear of getting COVID-19	271 (46.2)	184 (47.3)	206 (48.7)	60 (38.2)
Fear of giving COVID-19 to someone else	175 (29.8)	96 (24.7)	112 (26.5)	60 (38.2)
Worrying about friends, family partners, etc.	317 **(54.0)**	201 **(51.7)**	227 **(53.7)**	85 **(54.1)**
Personal financial loss	86 (14.7)	48 (12.3)	54 (12.8)	30 (19.1)
Frustration or boredom	246 (41.9)	176 (45.2)	189 (44.7)	53 (33.8)
Not having enough basic supplies	53 (9.0)	34 (8.7)	39 (9.2)	12 (7.6)
More anxiety	185 (31.5)	126 (32.4)	137 (32.4)	43 (27.4)
More depression	119 (20.3)	78 (20.1)	87 (20.6)	30 (19.1)
More sleep, less sleep, or changes to your normal sleep pattern	157 (26.7)	102 (26.2)	111 (26.2)	42 (26.8)
Increased alcohol or other substance use	44 (7.5)	22 (5.7)	27 (6.4)	17 (10.8)
A change in sexual activity	43 (7.3)	23 (5.9)	27 (6.4)	15 (9.6)
Loneliness	174 (29.6)	117 (30.1)	129 (30.5)	40 (25.5)
Confusion about what COVID-19 is, how to prevent it, or why social distancing/isolation/quarantines are needed	55 (9.4)	34 (8.7)	39 (9.2)	16 (10.2)
Feeling that I was contributing to the greater good by preventing myself or others from getting COVID-19	222 (37.8)	143 (36.8)	161 (38.1)	58 (36.9)
Getting emotional or social support from family, friends, partners, a counselor, or someone else	118 (20.1)	65 (16.7)	77 (18.2)	38 (24.2)
Getting financial support from family, friends, partners, an organization, or someone else	35 (6.0)	19 (4.9)	26 (6.1)	8 (5.1)
Other difficulties or challenges	86 (14.7)	57 (14.7)	66 (15.6)	16 (10.2)

Group comparisons were conducted on these items to determine if there were any significant differences between groups. On these items, a respondent checking the box for each item was coded as 1, while unchecked boxes were coded as 0. Group means (*M*) in the table below that are closer to 1 indicate that more individuals in this group checked this box, while means closer to 0 indicate that fewer individuals in this group checked this box.

As Table 73 shows, PWD were *more likely* than FS to check that they experienced a fear of getting COVID-19, frustration or boredom, and other difficulties or challenges. PWD were *less likely* than FS to check that they experienced fear of giving COVID-19 to someone else, personal financial loss, increased alcohol or substance use, a change in sexual activity, and getting emotional and social support.

Table 73. PWD vs. FS Differences on Mental Health Experiences During COVID-19

	PWD		FS					
	M	*SD*	*M*	*SD*	*df*	*t*	*p*	Cohen's *d*
Fear of getting COVID-19	0.49	0.50	0.40	0.49	585	-1.98	<.001	0.50
Fear of giving COVID-19 to someone else	0.26	0.44	0.38	0.49	585	2.85	<.001	0.46
Personal financial loss	0.13	0.33	0.20	0.40	585	2.08	<.001	0.35
Frustration or boredom	0.45	0.50	0.35	0.48	585	-2.19	<.001	0.49
Increased alcohol or other substance use	0.06	0.25	0.10	0.31	585	1.65	.001	0.26
A change in sexual activity	0.06	0.25	0.10	0.31	585	1.41	.006	0.26
Getting emotional or social support from family, friends, partners, a counselor, or someone else	0.18	0.39	0.25	0.43	585	1.85	<.001	0.40
Other difficulties or challenges	0.16	0.36	0.12	0.33	585	-1.05	.032	0.35

All of the Cohen's *d* values above show small or moderate effect sizes of the grouping variable (PWD vs. FS). The increased likelihood that PWD would check that they experienced a fear of getting COVID-19 aligns with the previous finding that PWD were significantly more likely to indicate that they had a medical condition or medication that puts them at greater risk of severe COVID-19 symptoms. FS were more likely to indicate a fear of giving COVID-19 to someone else, which could be interpreted with common themes expressed in the open-ended responses (expressed later in this report) about fears of infecting a vulnerable loved one.

The significant difference on the personal financial loss item also aligns with the previous survey item that showed that FS were more likely than PWD to indicate that they lost their source of income due to the COVID-19 pandemic. Interestingly, FS were also more likely to indicate that they had gotten emotional or social support during the pandemic, although there were no significant differences between the FS and PWD on mean PROMIS scores of Emotional Support and Social Isolation.

Respondents were presented with a matrix asking them to indicate whether the amount that they experienced various feelings and experiences decreased, stayed the same, or increased during the pandemic. Tables 74 – 77 show the overall and group responses for each of these items. Table 78 shows the means of each group for each feeling or experience.

Table 74. Whether Feelings or Experiences Decreased, Stayed the Same, or Increased – Overall

Please indicate whether the amount you experienced the following feelings or experiences decreased, stayed the same, or increased during the pandemic.	**Decreased**	**Stayed the same**	**Increased**
Sleep *(N = 491)*	109	290	92
%	22.2	**59.1**	18.7
Anxiety *(N = 487)*	12	215	260
%	2.5	44.1	**53.4**
Time with family *(N = 490)*	242	155	93
%	49.4	31.6	19.0
Depression *(N = 485)*	25	326	134
%	5.2	**67.2**	27.6
Stress *(N = 487)*	20	221	246
%	4.1	45.4	**50.5**
Exercise *(N = 492)*	186	235	71
%	37.8	47.8	14.4
Time spent on hobbies *(N = 488)*	117	261	110
%	24.0	**53.5**	22.5
Productivity at work *(N = 438)*	97	300	41
%	22.1	**68.5**	9.4

Table 75. Whether Feelings or Experiences Decreased, Stayed the Same, or Increased – PWP

Please indicate whether the amount you experienced the following feelings or experiences decreased, stayed the same, or increased during the pandemic.	**Decreased**	**Stayed the same**	**Increased**
Sleep *(N = 329)*	70	199	60
%	21.3	**60.5**	18.2
Anxiety *(N = 328)*	8	147	173
%	2.4	44.8	**52.7**
Time with family *(N = 328)*	153	110	65
%	46.6	33.5	19.8
Depression *(N = 324)*	17	221	86
%	5.2	**68.2**	26.5
Stress *(N = 326)*	14	156	156
%	4.3	47.9	47.9
Exercise *(N = 330)*	125	165	40
%	37.9	**50.0**	12.1
Time spent on hobbies *(N = 326)*	74	187	65
%	22.7	**57.4**	19.9
Productivity at work *(N = 294)*	59	215	20
%	20.1	**73.1**	6.8

Table 76. Whether Feelings or Experiences Decreased, Stayed the Same, or Increased – PWD

Please indicate whether the amount you experienced the following feelings or experiences decreased, stayed the same, or increased during the pandemic.	**Decreased**	**Stayed the same**	**Increased**
Sleep *(N = 364)*	75	222	67
%	20.6	**61.0**	18.4
Anxiety *(N = 362)*	10	161	191
%	2.8	44.5	**52.8**
Time with family *(N = 362)*	171	121	70
%	47.2	33.4	19.3

Please indicate whether the amount you experienced the following feelings or experiences decreased, stayed the same, or increased during the pandemic.	**Decreased**	**Stayed the same**	**Increased**
Depression *(N = 359)*	19	243	97
%	5.3	**67.7**	27.0
Stress *(N = 360)*	16	170	174
%	4.4	47.2	48.3
Exercise *(N = 364)*	137	181	46
%	37.6	49.7	12.6
Time spent on hobbies *(N = 360)*	81	199	80
%	22.5	**55.3**	22.2
Productivity at work *(N = 326)*	66	237	23
%	20.2	**72.7**	7.1

Table 77. Whether Feelings or Experiences Decreased, Stayed the Same, or Increased – FS

Please indicate whether the amount you experienced the following feelings or experiences decreased, stayed the same, or increased during the pandemic.	**Decreased**	**Stayed the same**	**Increased**
Sleep *(N = 123)*	32	67	24
%	26.0	**54.5**	19.5
Anxiety *(N = 120)*	2	54	64
%	1.7	45.0	**53.3**
Time with family *(N = 123)*	68	33	22
%	**55.3**	26.8	17.9
Depression *(N = 122)*	6	82	34
%	4.9	**67.2**	27.9
Stress *(N = 122)*	4	51	67
%	3.3	41.8	**54.9**
Exercise *(N = 123)*	48	52	23
%	39.0	42.3	18.7

Please indicate whether the amount you experienced the following feelings or experiences decreased, stayed the same, or increased during the pandemic.	**Decreased**	**Stayed the same**	**Increased**
Time spent on hobbies *(N = 123)*	34	59	30
%	27.6	48.0	24.4
Productivity at work *(N = 109)*	31	62	16
%	28.4	**56.9**	14.7

To look at differences between groups on the above "decreased, stayed the same, or increased" matrices, "decreased" was coded as -1, "stayed the same" was coded as 0, and "increased" was coded as +1. This means that when the mean responses shown below in Table 75 were calculated, means closer to 1 indicate more "increased" responses, while means closer to -1 indicate more "decreased" responses. There were no significant differences between groups on their mean scores on these items.

Table 78. Mean Scores for Feelings or Experiences Decreasing, Staying the Same, or Increasing

Mean scores for changes in feelings/experiences during COVID-19	**Overall** ***(N = 492)***	**PWP** ***(N = 330)***	**PWD** ***(N = 364)***	**FS** ***(N = 123)***
Sleep	-0.03	-0.03	-0.02	-0.07
Anxiety	0.51	0.50	0.50	0.52
Time with family	-0.30	-0.27	-0.28	-0.37
Depression	0.22	0.21	0.22	0.23
Stress	0.46	0.44	0.44	0.52
Exercise	-0.23	-0.26	-0.25	-0.20
Time spent on hobbies	-0.01	-0.03	0.00	-0.03
Productivity at work	-0.13	-0.13	-0.13	-0.14

All participants were asked an open-ended question about the biggest challenge for them and their family related to the pandemic. Each open-ended response was coded by its main theme. Due to the large number of responses, a selection from each theme are included. The number in parentheses next to each theme is the number of participants with a response that fell under that theme.

Open-Ended Responses: Biggest Challenges

What has been the biggest challenge for you and your family related to the pandemic? *(N = 344)*

PWD *(N = 258)*

Social isolation/cancellation of group activities ***(N = 70)***

- "Canceling church for a month…my social network."
- "Isolation. Multiple immune-compromised family members in different households meant near total isolation."
- "No family. Just getting through it on my own."
- "Not being able to spend time together."
- "Not being together for holidays, birthdays, and other important family events (i.e., funerals, births)."
- "Not seeing my children and grandchildren."

Worry about contracting/trying to avoid COVID ***(N = 25)***

- "Trying not to get infected."
- "Working to ensure that my partner and I are not infected with COVID-19. Wearing masks inside shopping malls, businesses, and public transport."
- "Trying not to get sick so we can go to work and live our lives."

Caregiving challenges for individuals with disabilities ***(N = 21)***

- "Absences of caregivers due to exposure and/or testing positive for COVID."
- "Finding and keeping caregivers. And then keeping caregivers who maintain COVID precautions in their personal lives."
- "Lack of being able to bring in outsiders for caregiver roles due to fear of bringing the virus in the home even while being vaxed and boosted."
- "Loss of outside caregivers, more stress on spouse to care for me. Family anger/depression."

Differing perceptions of vaccines, COVID, and/or prevention strategies ***(N = 19)***

- "Close family is not vaccinated so we can spend time together safely because 'they don't want to live in fear.' Also, they believe 'it's just a cold.' This is very aggravating since I would have hoped that they would have wanted to do something where we could be together and not cause me harm (even though the vaccinations do not prevent one from catching the virus). They are the same people that only wore masks when it was a state requirement."
- "Frustration with other people who did not mask or practice social distancing."
- "My family refused vaccines, so I have not been with them for holidays since COVID-19 began. All of them contracted it but weren't seriously ill as they are pretty healthy. This has caused a rift in the family as they think I am overly cautious. I have had a heart attack, have asthma, and am 82, have difficulty walking at all, etc."
- "Others in the household not being careful in public, so I have to distance/isolate from them."

Financial challenges ***(N = 14)***
- "Dealing with inflation and financial hardships."
- "Much of what I needed had to be delivered. Delivery fees make all more expensive."
- "Loss of income due to furlough and national fiscal impact, and lack of grace, understanding, and/or flexibility from part-time employers."

Pandemic information ***(N = 11)***
- "Getting accurate information that could be trusted as being accurate medically and not politically driven."
- "The biggest challenge was wanting to hear the truth was about this pandemic and why were there was not a preventative protocol issued earlier. Also the challenge was the shot went to you need one to you will need more and more. Not knowing the truth was the biggest challenge."
- "Fighting the pressure from media, advertising, propaganda, misinformation, pharmaceutical and medical lies about masks, distancing, shut-downs, and peer pressure to take the untested, experimental genetic experiments falsely labelled as 'vaccines.'"
- "Understanding what COVID19 was and wasn't in reality. Realizing the media coverage was pushing a false narrative of the Coronavirus Pandemic in order to create fear in people in order to control them. Discovering the truth about who really runs the world (the Elites like Bill Gates, The Rockefellers, the Roth Childs, Klaud Schwab, Dr. Fauci, the Bushes, Clinton's, etc.), and has been financially supporting and causing World Wars, as well as the source creating conflicts and division among the people to control them, preparing for the 'Great Reset' the elite are enforcing to depopulate the Earth's inhabitants."

COVID diagnosis/symptoms ***(N = 10)***
- "I contracted COVID in October 2020, and I have not recovered from fatigue and decline in motor control, balance, bladder function, etc."
- "Everything was good, I was working from home. Then I got sick and had to live with family until I was able to walk again."
- "Getting infected."

Access to resources and supplies ***(N = 10)***
- "Getting medical supplies, especially sterile gloves."
- "PPE supplies were difficult to come by. Same with COVID tests."

No challenges ***(N = 8)***
- "I think disability and living with difficulties prepared me to keep going. I learned new things, read new books, and loved less traffic. I discovered online shopping and that saved me a lot of energy, exposure, and time!"
- "My family's life hasn't changed."
- "We were already introverts, so not much changed."

Loss of health services ***(N = 7)***
- "Limited medical appointments, SCI adaptive sports programs are/were canceled."

- "Unable to receive medication for the extreme pain I am in. I have been a quadriplegic for 36 years and during COVID they started to take my medication away."
- "Not being able to see doctor."

Worry about spreading COVID to others *(N = 6)*

- "I work in a hospital and making sure I was not bringing COVID home to my family that had underlying health issues."
- "Making sure the elderly family members stayed well."

Boredom *(N = 5)*

- "Boredom."
- "Not having anything to do."

Loss of family members *(N = 5)*

- "Lost my mother and uncle."
- "It was when my mom was in a memory care facility and died from COVID. I could not be with her. My dad survived and is alone now."

Challenges related to masks *(N = 5)*

- "Trying to get others to wear masks! Staying alone 19 hours in my iron lung ventilator, trying to exercise enough to get my muscle strength back."
- "Making sure I had a quality mask."
- "I have a difficult time putting a mask on. At work I also have to wear a shield which again, is difficult to put on."

Challenges related to nursing facilities/medical facilities *(N = 5)*

- "Since I was still adjusting to my T3-5 injury and living in an assisted living facility, it was a very hard time for me to be so separated from my family and for a long period of time, confined to my room due to so many cases of COVID in the facility."
- "In a nursing home rehabbing a broken leg. Other complications arose sending me back to hospital and then isolating when back at nursing home. Getting no therapy while isolated. This happened several times, with abundance of NO therapy and facilities responding to no Medicare coverage running out for therapy…therapists tell me they can no longer justify to insurance to continue getting me back on my feet again. Can no longer walk and now using power chair. I blame the pandemic and I blame Medicare for not compensating for time lost in therapy to all the isolating time."

Travel *(N = 5)*

- "Not being able to travel."
- "Restrictions on travel to visit family."

Too much time with family/in lockdown *(N = 4)*

- "Being close together is stressful. My mom isn't able to go out anywhere for fear of getting me sick."
- "Spending time together."

Vaccines ***(N = 4)***

- "Having side effects of the vaccine – great increase in my nerve pain and now have brain fog."
- "Since I became paralyzed because of a vaccine, not being vaccinated for COVID because it can trigger by GBS is quite sad. What happened to me is rare, 1.8 million to 1, so not a lot of others this has happened to."
- "It's been a challenge to receive respect for my decision not to vaccinate."

Personal difficulties ***(N = 4)***

- "Other health matters."
- "I got a divorce."
- "I started drinking way more."

Caregiving challenges for caregivers ***(N = 3)***

- "Stress in caring for wife with Alzheimer's."
- "Caring for our elderly parents."

Challenges related to work ***(N = 3)***

- "Couldn't work."
- "My inability to get a job due to being immunocompromised."

Change in responsibilities ***(N = 3)***

- "Changed everything. I was the main cook, grocery shopper, cleaner of home, laundry, and don't drive (counting on family to help). Work and activity level."
- "Could not go out to eat at restaurants so my wife had to cook every single meal."

Childcare/school ***(N = 3)***

- "Loss of childcare at times. Trying to work and parent."
- "Managing school needs for my daughter."

Determining risk ***(N = 3)***

- "Living life to its fullest pre-COVID times. Always thinking of the risks involved whatever you do, wherever you go because of others. Continuous masking everywhere."
- "Deciding whether it was worth the risk to do 'normal' life activities (get the car fixed, eat inside a restaurant, go to a party at someone else's home, hire someone to do repairs inside the home."

Getting back to "normal" ***(N = 2)***

- "Trying to go back to some semblance of normalcy."

Stress/anxiety ***(N = 2)***

- "My family's anxiety and added control of my movements."
- "My wife is a nurse, so she has a lot of stress at work."

Vaccine access ***(N = 1)***

- "Access to vaccinations/boosters."

<u>FS *(N = 86)*</u>

Social isolation/cancellation of group activities ***(N = 23)***

- "Being alone for months on end."
- "Great decrease in social life. World became much smaller!"
- "Loss of socialization with others and the inability to hug family and friends."
- "Not being able to visit 98 year old mother and 28 year old nephew who is quadriplegic."
- "Not attending common group activities such as ball games, movies, concerts, etc."

Differing perceptions of vaccines, COVID, and/or prevention strategies ***(N = 8)***

- "Agreeing about social distancing and mask wearing."
- "Family differences in regard to the vaccinations. Not able to get with family members."
- "Navigating the different feelings of family members and friends about COVID."

Worry about spreading COVID to others ***(N = 8)***

- "Keeping my grandson, quadriplegic, safe from COVID. It could be life threatening for him."
- "Keeping my SCI/ABI daughter (age 26) safe. She has not yet had COVID. We remain really afraid for her. A friend with spina bifida, age 28, died fast at home from COVID, making us even more afraid."
- "Worrying about two daughters who are at high risk for complications if exposed to COVID."

Worry about contracting/trying to avoid COVID ***(N = 6)***

- "Staying healthy to protect my paralyzed mom and financially."
- "Staying safe and healthy."

Financial challenges ***(N = 6)***

- "Dealing with soaring inflation and economic uncertainty due to the financially irrational spending by the federal government in response to COVID."
- "Prices went up and we don't have more income. Also doctors would not let you come to be treated."
- "Financial help."

No challenges ***(N = 5)***

- "Nothing."
- "None."

Challenges related to work ***(N = 5)***

- "Already working from home, it was very difficult to draw boundaries between work and 'home.' Trying to divide my time as a full-time working parent, a full-time student, and

being home in the same place for every aspect of life, with everyone I also was responsible for around me all of the time, was by far the biggest challenge."
- "Getting back to work."

Stress/anxiety *(N = 3)*
- "My 15 year old daughter's mental health suffered. She struggled with being home all the time and not going to school. She became depressed and gained weight."

Uncertainty *(N = 3)*
- "So much unknown."
- "Uncertainty of end state."

Pandemic information *(N = 3)*
- "Fake media."
- "Filtering out the liberal hysteria."

Challenges related to masks *(N = 2)*
- "Masks, taking care of me."
- "Trying to breathe with the mask on. The myriad of excuses for everything that they blame on COVID. Carrying this on. Still wondering what happened to the flu last year. This is all a scam perpetuated by the government."

Challenges related to outside caregivers *(N = 2)*
- "Reliability of caregivers and recruiting new caregivers. Fewer people want to work in healthcare, and this was significantly reduced the candidate pool."
- "Caregivers not showing up, calling off last minute, and not being responsible to the client, i.e., my son or other clients. Me having to change my plans because of caregivers not being able to do their job out of fear or laziness. I take care of my son AMAP."

Loss of family members *(N = 2)*
- "Dealing with the COVID loss/death of my 49 year old son."
- "Loss of my son to COVID prior to the availability of vaccines."

Vaccines *(N = 2)*
- "Getting the shots and still got COVID."
- "I had an adverse reaction to the vaccine and now have cardiac problems making caring for myself and my patients difficult."

Caregiving challenges for family caregivers *(N = 2)*
- "As a caregiver, it was difficult to juggle remote work and caring for my loved one. Because I was in the house, it was assumed that I could be on call at all times."
- "I am a caregiver for my son who is paralyzed who also got COVID. His fiancé and his father also got COVID, and they are also caregivers."

Childcare/school ***(N = 2)***

- "Balancing work and childcare schedules. Cancelling travel plans."

Too much time with family/in lockdown ***(N = 1)***

- "Spending time together."

Loss of health services ***(N = 1)***

- "The forced closure of our Adult Day Health Care center for six months at the beginning of the pandemic."

Change in responsibilities ***(N = 1)***

- "Trying to stay organized with food and cleaning in caring for my family."

Challenges related to nursing facilities/medical facilities ***(N = 1)***

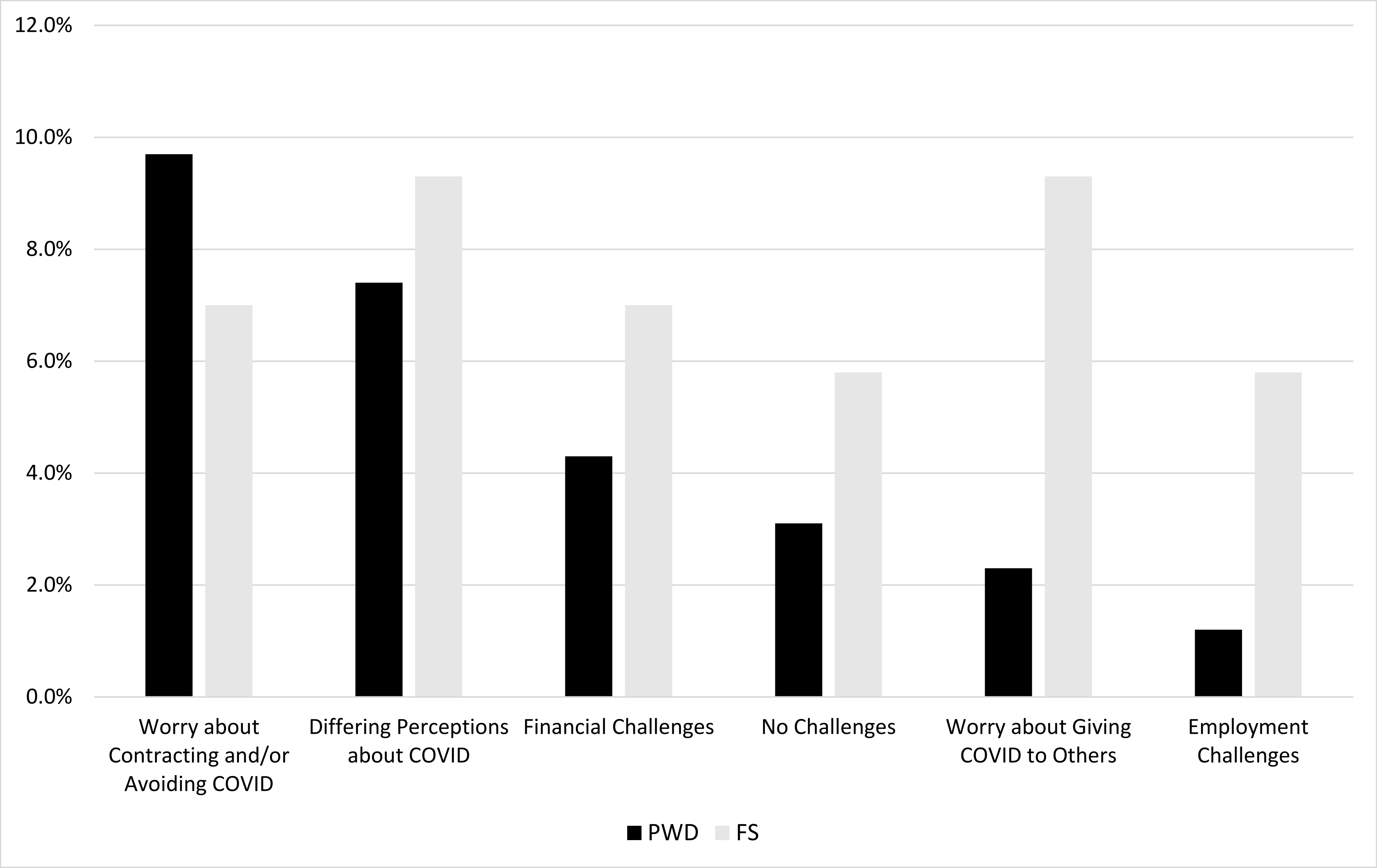
- "A family member needs 24 hour skilled nursing care. He was quarantined continually during the pandemic – paralysis due to stroke – 100% requirement for physical care in nursing home setting makes him unavailable to family."

As shown in the open-ended responses above, PWD and FS groups expressed some of the same themes: isolation/cancellation of group activities, worrying about/avoiding COVID-19, caregiving challenges for PWD, differing perceptions from friends and family about COVID risk and vaccines, financial challenges, pandemic information, a loss of health services, worry about spreading COVID-19 to others, loss of family members, masks, nursing and medical facilities, too much time with family, vaccines, caregiving challenges for caregivers, work challenges, changes in responsibilities, childcare/school, stress/anxiety, and having no challenges.

Social isolation/cancellation of group activities was the most common theme in both groups (27.1% of PWD responses and 26.7% of FS responses).

There were a few themes that were shared by both groups but expressed by different proportions of groups, and these differences were also reflected in related close-ended survey responses. Financial concerns were expressed by 7.0% of FS and 4.3% of PWD. Worry about spreading COVID-19 to others was expressed by 9.3% of FS and 2.3% of PWD. Work/employment challenges were expressed by 5.8% of FS and 1.2% of PWD. Figure 1 below shows the proportions of each group that expressed many of the shared themes.

Figure 1. Proportion of PWD and FS That Expressed Shared Themes



There were also themes only expressed by PWD about their biggest challenges related to the pandemic: COVID diagnoses/symptoms, access to supplies and resources, boredom, travel, personal difficulties, determining risk, getting back to "normal," and vaccine access. Uncertainty was the only theme expressed by FS and not PWD.

Use of Reeve Foundation Resources During the Pandemic

To understand how respondents utilized Reeve Foundation resources during the pandemic, participants were asked to select all of the areas of the Foundation that they had engaged with since March 2020 (the beginning of shutdowns in the United States). As Table 79 shows, the most selected areas were webinars, communications, and the Peer and Family Support Program. Almost one quarter of respondents (24.9%) indicated that they had not been engaged with any areas of the Reeve Foundation.

Table 79. Respondents' Areas of Engagement Since March 2020

Please indicate which of the following areas of the Reeve Foundation you have been engaged with since March 2020. Please check all that apply.	**Overall** *(N = 587)* *N* **(%)**	**PWP** *(N = 389)* *N* **(%)**	**PWD** *(N = 423)* *N* **(%)**	**FS** *(N = 157)* *N* **(%)**
Team Reeve	34 (5.8)	15 (3.9)	19 (4.5)	15 (9.6)
Webinars	158 (26.9)	115 (29.6)	123 (29.1)	33 (21.0)
Peer and Family Support Program	84 (14.3)	72 (18.5)	75 (17.7)	9 (5.7)
Information Specialists	63 (10.7)	46 (11.9)	51 (12.1)	12 (7.6)
Military and Veterans Program	7 (1.2)	4 (1.0)	4 (0.9)	3 (1.9)
Annual Reeve Summit	24 (4.1)	13 (3.3)	14 (3.3)	10 (6.4)
Advocacy	62 (10.6)	48 (12.3)	52 (12.3)	10 (6.4)
Quality of Life Grants	36 (6.1)	19 (4.9)	20 (4.7)	15 (9.6)
Communications	115 (19.6)	81 (20.8)	89 (21.0)	25 (15.9)
In-person or virtual conferences or presentations	20 (3.4)	18 4.6)	18 (4.3)	2 (1.3)
Other (please describe)	24 (4.1)	15 (3.9)	17 (3.8)	7 (4.5)
None	146 (24.9)	99 (25.4)	114 (27.0)	31 (19.7)

Respondents who indicated that they engaged with another area of the Reeve Foundation that was not listed were asked to further describe these areas. All these responses are included below.

Please describe what other areas of the Reeve Foundation you engage with. *(N = 24)*

PWD *(N = 17)*

- "A couple years ago, I submitted a narrative to attend the summit when it was online. I never heard from anyone. When I communicated with another poster on a FB post and I mentioned about it, someone said I was approved and they reached out to me. No one did – not by email, phone, or mail. Not sure if that was spam who made that post, but no one had been in touch with me. I very much would have liked to have gone. I can't go now, not when they are in person. I don't have the financial means to do that and I can't take off the time to do it safely to make sure I don't get sick. It would have been a great connection for me. I reached out to someone else as well a few months ago with a question...never heard back. Why bother trying to communicate and make connections when I have tried and no one responds? Apparently, it's not important to anyone else but me."

- "Been a part of clinical trials as soon as the foundation reopened during the pandemic. They gave me somewhere to go and help me stay active."
- "Connecting with other attendees."
- "Donator."
- "I have received hours to pay a caregiver from the Reeve foundation using CareLinx."
- "I need assistance now, to find a place to live and help to get to my MD. I don't have a car and can't manage my heavy wheelchair. I need cataract surgery ASAP."
- "I read the emails and articles."
- "I receive and read email from the Foundation and participate in surveys/questionnaires."
- "Most. I work here."
- "My wife aka sole caregiver depends on getting information, the social media and some of the webinars."
- "On email list – nothing mentioned was of interest."
- "Online exercise."
- "Only just discovered Reeve online – so very helpful!"
- "Peer support."
- "Referrals to resource center, resources available, and information specialists."
- "Sending emails to Congress."
- "Website."

FS *(N = 7)*

- "Amazon Smile."
- "Annual online donation."
- "External Nurse Case Manager helping clients referred by the Information Specialists."
- "Learning about ways to help fund projects that benefit individuals with disabilities."
- "Reeve newsletters and emails."
- "Visited Dana and Christopher and Will years ago and keep praying for scientific advances to ease suffering and pain. Also went horseback riding at same time of accident so even though I have PTSD and Dana had cancer and Chris had suffered injury I remember that positive interaction and friendship and believe that progress will be made during my lifetime."
- "We are listed on your webpage as a resource organization."

Table 80. PWD vs. FS Group Differences on Areas of Engagement

	PWD		FS					
	M	*SD*	*M*	*SD*	*df*	*t*	*p*	Cohen's *d*
Engaged with Team Reeve	0.04	0.21	0.09	0.29	585	2.17	<.001	0.23
Engaged with Webinars	0.29	0.46	0.21	0.41	585	-1.90	<.001	0.44
Engaged with PFSP	0.18	0.38	0.05	0.23	585	-3.84	<.001	0.35
Engaged with IS	0.12	0.33	0.07	0.26	585	-1.67	<.001	0.31
Engaged with Reeve Summit	0.03	0.24	0.06	0.24	585	1.53	.002	0.20
Engaged with Advocacy	0.12	0.33	0.06	0.24	585	-2.20	<.001	0.31
Engaged with QOL grants	0.05	0.21	0.10	0.30	585	2.28	<.001	0.24
Engaged with Communications	0.21	0.41	0.16	0.37	585	-1.42	.003	0.40
Engaged with In-person or Virtual Conferences	0.04	0.20	0.01	0.11	585	-1.82	<.001	0.18
Engaged with No Areas	0.27	0.44	0.20	0.40	585	-1.87	<.001	0.43

As with the previous "check all that apply" questions, a participant's checking of a box was coded as 1, while unchecked boxes were coded as 0. This means that the higher the group means, the greater the proportion of the group that checked the box for each area. Table 80 above shows the significant differences between PWD and FS in the areas that they had been engaged with since March 2020.

PWD were *more likely* to have engaged with Webinars, the Peer and Family Support Program, Information Specialists, Advocacy, Communications, In-person or Virtual Conferences, and None of the areas. FS were more likely to have engaged with Team Reeve, the Reeve Summit, and the Quality of Life Grants Program.

When respondents indicated that they engaged with an area of the Foundation, they were presented with a follow-up question asking them to indicate whether their engagement with each area decreased, stayed the same, or increased during the pandemic. Participants were not asked this question about areas that they did not indicate that they were engaged with since March 2020. Tables 81 – 84 show the overall and group responses for each area. Generally, respondents indicated that their level of engagement across areas stayed the same during the pandemic.

Table 81. Changes in Levels of Engagement in Reeve Areas – Overall Sample

Please choose the option that best represents the change in your engagement in the following programs during the pandemic.	**Decreased**	**Stayed the same**	**Increased**
Team Reeve *(N = 32)*	2	22	8
%	6.3	**68.8**	25.0
Webinars *(N = 154)*	5	84	65
%	3.2	**54.5**	42.2
Peer and Family Support Program *(N = 82)*	11	47	24
%	13.4	**57.3**	29.3
Information Specialists *(N = 61)*	3	43	15
%	4.9	**70.5**	24.6
Military and Veterans Program *(N = 6)*	0	6	0
%	0.0	**100.0**	0.0
Annual Reeve Summit *(N = 23)*	3	13	7
%	13.0	**56.5**	30.4
Advocacy *(N = 61)*	2	38	21
%	3.3	**62.3**	34.4
Quality of Life Grants *(N = 36)*	3	23	10
%	8.3	**63.9**	27.8
Communications *(N = 113)*	2	86	25
%	1.8	**76.1**	22.1
In-person or virtual conferences or presentations *(N = 19)*	2	8	9
%	10.5	42.1	47.4
Other *(N = 21)*	2	15	4
%	9.5	**71.4**	19.0

Table 82. Changes in Levels of Engagement in Reeve Areas – PWP Only

Please choose the option that best represents the change in your engagement in the following programs during the pandemic.	**Decreased**	**Stayed the same**	**Increased**
Team Reeve *(N = 15)*	2	9	4
%	13.3	**60.0**	26.7
Webinars *(N = 112)*	3	67	42
%	2.7	**59.8**	37.5
Peer and Family Support Program *(N = 72)*	11	43	18
%	15.3	**59.7**	25.0
Information Specialists *(N = 45)*	3	32	10
%	6.7	**71.1**	22.2
Military and Veterans Program *(N = 4)*	0	4	0
%	0.0	**100.0**	0.0
Annual Reeve Summit *(N = 13)*	3	9	1
%	23.1	**69.2**	7.7
Advocacy *(N = 47)*	1	32	14
%	2.1	**68.1**	29.8
Quality of Life Grants *(N = 19)*	1	11	7
%	0.3	**57.9**	36.8
Communications *(N = 79)*	1	63	15
%	1.3	**79.7**	19.0
In-person or virtual conferences or presentations *(N = 17)*	2	7	8
%	11.8	41.2	47.1
Other *(N = 12)*	0	8	4
%	0.0	**66.7**	33.3

Table 83. Changes in Levels of Engagement in Reeve Areas – PWD Only

Please choose the option that best represents the change in your engagement in the following programs during the pandemic.	**Decreased**	**Stayed the same**	**Increased**
Team Reeve *(N = 19)*	2	12	5
%	10.5	**63.2**	26.3
Webinars *(N = 120)*	3	71	46
%	2.5	**59.2**	38.3
Peer and Family Support Program *(N = 74)*	11	44	19
%	14.9	**59.5**	25.7
Information Specialists *(N = 50)*	3	37	10
%	6.0	**74.0**	20.0
Military and Veterans Program *(N = 4)*	0	4	0
%	0.0	**100.0**	0.0
Annual Reeve Summit *(N = 14)*	3	9	2
%	21.4	**64.3**	14.3
Advocacy *(N = 51)*	1	34	16
%	2.0	**66.7**	31.4
Quality of Life Grants *(N = 20)*	1	13	6
%	5.0	**65.0**	30.0
Communications *(N = 87)*	1	67	19
%	1.1	**77.0**	21.8
In-person or virtual conferences or presentations *(N = 17)*	2	7	8
%	11.8	41.2	47.1
Other *(N = 14)*	0	10	4
%	0.0	**71.4**	28.6

Table 84. Changes in Levels of Engagement in Reeve Areas – FS Only

Please choose the option that best represents the change in your engagement in the following programs during the pandemic.	**Decreased**	**Stayed the same**	**Increased**
Team Reeve *(N = 13)*	0	10	3
%	0.0	**76.9**	23.1
Webinars *(N = 32)*	2	12	18
%	6.3	37.5	**56.3**
Peer and Family Support Program *(N = 8)*	0	3	5
%	0.0	37.5	**62.5**
Information Specialists *(N = 11)*	0	6	5
%	0.0	**54.5**	45.5
Military and Veterans Program *(N =2)*	0	2	0
%	0.0	**100.0**	0.0
Annual Reeve Summit *(N = 9)*	0	4	9
%	0.0	44.4	**55.6**
Advocacy *(N = 10)*	1	4	5
%	10.0	40.0	**50.0**
Quality of Life Grants *(N = 15)*	2	10	3
%	13.3	**66.7**	20.0
Communications *(N = 25)*	1	18	6
%	4.0	**72.0**	24.0
In-person or virtual conferences or presentations *(N = 2)*	0	1	1
%	0.0	**50.0**	**50.0**
Other *(N = 7)*	2	5	0
%	28.6	**71.4**	0.0

If respondents indicated that their level of engagement decreased in an area in the pandemic, they were asked why their level of engagement decreased with a multiple choice question with an optional write-in choice to further explain why their engagement decreased in an area during the pandemic. Tables 85 – 88 show responses from individuals who indicated that their engagement decreased in any of Reeve's areas, along with open-ended responses related to other reasons why their engagement level decreased with each area.

In these tables, the percentages shown reflect the percentage of the respondents who selected each answer rather than the percentage of responses, since participants could select as many answers as they felt applied to them. For example, in Table 85, in the Peer and Family Support Program, there were 11 respondents, but some respondents selected more than one answer, as there are 16 responses. The percentages were calculated using the 11 respondents so that it reflects the proportion of respondents who felt that each option applied to them.

Table 85. Reasons for Foundation Area Engagement Decreases – Overall Sample

Why did your level of engagement with each Reeve area decrease during the pandemic? Please check all that apply.	**I did not have the time**	**I became sick with COVID-19**	**A family member became sick with COVID-19**	**No longer relevant to me during the pandemic**	**I had other priorities during the pandemic**	**Other (please explain)**
Team Reeve *(N = 3)*	0	0	0	0	2	1
%	0.0	0.0	0.0	0.0	**66.7**	33.3
Webinars *(N = 5)*	1	0	0	1	3	0
%	20.0	0.0	0.0	20.0	**60.0**	0.0
Peer and Family Support Program *(N = 11)*	0	1	2	2	8	3
%	0.0	9.1	18.2	18.2	**72.7**	27.3
Information Specialists *(N = 3)*	0	1	0	0	2	0
%	0.0	33.3	0.0	0.0	**66.7**	0.0
Annual Reeve Summit *(N = 3)*	1	0	0	0	0	2
%	33.3	0.0	0.0	0.0	0.0	**66.7**
Advocacy *(N = 2)*	1	0	0	0	2	0
%	**50.0**	0.0	0.0	0.0	**100.0**	0.0
Quality of Life Grants *(N = 3)*	1	0	0	0	2	0
%	33.3	0.0	0.0	0.0	**66.7**	0.0
Communications *(N = 2)*	0	1	0	0	2	0
%	0.0	**50.0**	0.0	0.0	**100.0**	0.0

Why did your level of engagement with each Reeve area decrease during the pandemic? Please check all that apply.	**I did not have the time**	**I became sick with COVID-19**	**A family member became sick with COVID-19**	**No longer relevant to me during the pandemic**	**I had other priorities during the pandemic**	**Other (please explain)**
In-person or virtual conferences or presentations *(N = 2)*	0	0	0	1	0	1
%	0.0	0.0	0.0	**50.0**	0.0	**50.0**
Other *(N = 2)*	0	0	1	0	0	1
%	0.0	0.0	**50.0**	0.0	0.0	**50.0**

Table 86. Reasons for Foundation Area Engagement Decreases – PWP Only

Why did your level of engagement with each Reeve area decrease during the pandemic? Please check all that apply.	**I did not have the time**	**I became sick with COVID-19**	**A family member became sick with COVID-19**	**No longer relevant to me during the pandemic**	**I had other priorities during the pandemic**	**Other (please explain)**
Team Reeve *(N = 2)*	0	0	0	0	2	1
%	0.0	0.0	0.0	0.0	**100.0**	**50.0**
Webinars *(N = 3)*	0	0	0	1	2	0
%	0.0	0.0	0.0	33.3	**66.7**	0.0
Peer and Family Support Program *(N = 11)*	0	1	2	2	8	3
%	0.0	9.1	18.2	18.2	**72.7**	27.3
Information Specialists *(N = 3)*	0	1	0	0	2	0
%	0.0	33.3	0.0	0.0	**66.7**	0.0
Annual Reeve Summit *(N = 3)*	1	0	0	0	0	2
%	33.3	0.0	0.0	0.0	0.0	**66.7**
Advocacy *(N = 1)*	1	0	0	0	1	0
%	**100.0**	0.0	0.0	0.0	**100.0**	0.0
Quality of Life Grants *(N = 1)*	1	0	0	0	0	0
%	**100.0**	0.0	0.0	0.0	0.0	0.0

Why did your level of engagement with each Reeve area decrease during the pandemic? Please check all that apply.	**I did not have the time**	**I became sick with COVID-19**	**A family member became sick with COVID-19**	**No longer relevant to me during the pandemic**	**I had other priorities during the pandemic**	**Other (please explain)**
Communications *(N = 1)*	0	1	0	0	1	0
%	0.0	**100.0**	0.0	0.0	**100.0**	0.0
In-person or virtual conferences or presentations *(N = 2)*	0	0	0	1	0	1
%	0.0	0.0	0.0	**50.0**	0.0	**50.0**

Table 87. Reasons for Foundation Area Engagement Decreases – PWD Only

Why did your level of engagement with each Reeve area decrease during the pandemic? Please check all that apply.	**I did not have the time**	**I became sick with COVID-19**	**A family member became sick with COVID-19**	**No longer relevant to me during the pandemic**	**I had other priorities during the pandemic**	**Other (please explain)**
Team Reeve *(N = 2)*	0	0	0	0	2	1
%	0.0	0.0	0.0	0.0	**100.0**	**50.0**
Webinars *(N = 3)*	0	0	0	1	2	0
%	0.0	0.0	0.0	33.3	**66.7**	0.0
Peer and Family Support Program *(N = 11)*	0	1	2	2	8	3
%	0.0	9.1	18.2	18.2	**72.7**	27.3
Information Specialists *(N = 3)*	0	1	0	0	2	0
%	0.0	33.3	0.0	0.0	**66.7**	0.0
Annual Reeve Summit *(N = 3)*	1	0	0	0	0	2
%	33.3	0.0	0.0	0.0	0.0	**66.7**
Advocacy *(N = 1)*	1	0	0	0	1	0
%	**100.0**	0.0	0.0	0.0	**100.0**	0.0
Quality of Life Grants *(N = 1)*	1	0	0	0	0	0

Why did your level of engagement with each Reeve area decrease during the pandemic? Please check all that apply.	**I did not have the time**	**I became sick with COVID-19**	**A family member became sick with COVID-19**	**No longer relevant to me during the pandemic**	**I had other priorities during the pandemic**	**Other (please explain)**
%	**100.0**	0.0	0.0	0.0	0.0	0.0
Communications *(N = 1)*	0	1	0	0	1	0
%	0.0	**100.0**	0.0	0.0	**100.0**	0.0
In-person or virtual conferences or presentations *(N = 2)*	0	0	0	1	0	1
%	0.0	0.0	0.0	**50.0**	0.0	**50.0**

Table 88. Reasons for Foundation Area Engagement Decreases – FS Only

Why did your level of engagement with each Reeve area decrease during the pandemic? Please check all that apply.	**I did not have the time**	**I became sick with COVID-19**	**A family member became sick with COVID-19**	**No longer relevant to me during the pandemic**	**I had other priorities during the pandemic**	**Other (please explain)**
Webinars *(N = 2)*	1	0	0	0	1	0
%	**50.0**	0.0	0.0	0.0	**50.0**	0.0
Advocacy *(N = 1)*	0	0	0	0	1	0
%	0.0	0.0	0.0	0.0	**100.0**	0.0
Quality of Life Grants *(N = 2)*	0	0	0	0	2	0
%	0.0	0.0	0.0	0.0	**100.0**	0.0
Communications *(N = 1)*	0	0	0	0	1	0
%	0.0	0.0	0.0	0.0	**100.0**	0.0
Other *(N = 2)*	0	0	1	0	0	1
%	0.0	0.0	**50.0**	0.0	0.0	**50.0**

Please explain what other factors led to a decrease in your engagement with each area during the pandemic. *(N = 8)*

PWD *(N = 7)*

Team Reeve ***(N = 1)***
- "Could not visit patients!"

Peer and Family Support Program ***(N = 3)***
- "I used to have home visits with peers. That all changed. I stopped."
- "Not able to meet patients in person in rehab hospital to provide mentor services."
- "There wasn't as much outreach as before."

Annual Reeve Summit ***(N = 2)***
- "It was not held in person during the pandemic."
- "The Summit was canceled."

In-person or virtual conferences or presentations ***(N = 1)***
- "They were offered in person."

FS *(N = 1)*

Other ***(N = 1)***
- "I had severe injury and personal safety issues, almost died, moved several times, and lost my family."

If respondents indicated that their level of engagement increased in an area in the pandemic, they were asked why their level of engagement increased with a multiple choice question with an optional write-in choice to further explain why their engagement increased in an area during the pandemic. Tables 89 – 92 show responses from individuals who indicated that their engagement increased in any of Reeve's areas, along with open-ended responses related to other reasons why their engagement level increased with each area.

Table 89. Reasons for Foundation Area Engagement Increases – Overall Sample

Why did your level of engagement with each Reeve area increase during the pandemic? Please check all that apply.	**Opportunities for social connection**	**Provided helpful information**	**Helped feelings of isolation/ loneliness**	**Made me aware of new resources**	**Made me feel useful/ like I was a part of something bigger than myself**	**Other (please explain)**
Team Reeve *(N = 8)*	4	5	2	6	5	0
%	**50.0**	**62.5**	25.0	**75.0**	**62.5**	0.0

Why did your level of engagement with each Reeve area increase during the pandemic? Please check all that apply.	**Opportunities for social connection**	**Provided helpful information**	**Helped feelings of isolation/ loneliness**	**Made me aware of new resources**	**Made me feel useful/ like I was a part of something bigger than myself**	**Other (please explain)**
Webinars *(N = 65)*	30	54	17	46	20	3
%	46.2	**83.1**	26.2	**70.8**	30.8	4.6
Peer and Family Support Program *(N = 24)*	14	13	8	10	12	5
%	**58.3**	**54.2**	33.3	41.7	**50.0**	20.8
Information Specialists *(N = 15)*	4	13	3	13	3	0
%	26.7	**86.7**	20.0	**86.7**	20.0	0.0
Annual Reeve Summit *(N = 7)*	1	3	1	5	4	1
%	14.3	42.9	14.3	**71.4**	**57.1**	14.3
Advocacy *(N = 21)*	10	15	7	13	16	0
%	47.6	**71.4**	33.3	**61.9**	**76.2**	0.0
Quality of Life Grants *(N = 10)*	3	4	2	6	3	3
%	30.0	40.0	20.0	**60.0**	30.0	30.0
Communications *(N = 25)*	11	17	7	15	14	1
%	44.0	**68.0**	28.0	**60.0**	**56.0**	4.0
In-person or virtual conferences or presentations *(N = 9)*	6	6	4	6	4	1
%	**66.7**	**66.7**	44.4	**66.7**	44.4	11.1
Other *(N = 4)*	2	3	1	2	2	1
%	**50.0**	**75.0**	25.0	**50.0**	**50.0**	25.0

Table 90. Reasons for Foundation Area Engagement Increases – PWP Only

Why did your level of engagement with each Reeve area increase during the pandemic? Please check all that apply.	**Opportunities for social connection**	**Provided helpful information**	**Helped feelings of isolation/ loneliness**	**Made me aware of new resources**	**Made me feel useful/ like I was a part of something bigger than myself**	**Other (please explain)**
Team Reeve *(N = 4)*	3	3	1	3	2	0
%	**75.0**	**75.0**	25.0	**75.0**	**50.0**	0.0
Webinars *(N = 42)*	19	36	14	30	14	1
%	45.2	**85.7**	33.3	**71.4**	33.3	2.4
Peer and Family Support Program *(N = 18)*	11	10	8	8	10	3
%	**61.1**	**55.6**	44.4	44.4	**55.6**	16.7
Information Specialists *(N = 10)*	3	10	3	8	2	0
%	30.0	**100.0**	30.0	**80.0**	20.0	0.0
Annual Reeve Summit *(N = 1)*	0	1	0	1	1	0
%	0.0	**100.0**	0.0	**100.0**	**100.0**	0.0
Advocacy *(N = 14)*	8	10	4	7	11	0
%	**57.1**	**71.4**	28.6	**50.0**	**78.6**	0.0
Quality of Life Grants *(N = 7)*	3	3	2	3	2	3
%	42.9	42.9	28.6	42.9	28.6	42.9
Communications *(N = 15)*	7	8	4	7	9	1
%	46.7	**53.3**	26.7	46.7	**60.0**	6.7
In-person or virtual conferences or presentations *(N = 8)*	5	5	3	6	4	1
%	**62.5**	**62.5**	37.5	**75.0**	**50.0**	12.5
Other *(N = 4)*	2	3	1	2	2	1
%	**50.0**	**75.0**	25.0	**50.0**	**50.0**	25.0

Table 91. Reasons for Foundation Area Engagement Increases – PWD Only

Why did your level of engagement with each Reeve area increase during the pandemic? Please check all that apply.	**Opportunities for social connection**	**Provided helpful information**	**Helped feelings of isolation/ loneliness**	**Made me aware of new resources**	**Made me feel useful/ like I was a part of something bigger than myself**	**Other (please explain)**
Team Reeve *(N = 5)*	3	4	2	4	3	0
%	**60.0**	**80.0**	40.0	**80.0**	**60.0**	0.0
Webinars *(N = 46)*	22	39	17	33	17	1
%	47.8	**84.8**	37.0	**71.7**	37.0	2.2
Peer and Family Support Program *(N = 19)*	12	10	8	8	10	3
%	**63.2**	**52.6**	42.1	42.1	**52.6**	15.8
Information Specialists *(N = 10)*	3	10	3	8	2	0
%	30.0	**100.0**	30.0	**80.0**	20.0	0.0
Annual Reeve Summit *(N = 2)*	0	2	0	2	1	0
%	0.0	**100.0**	0.0	**100.0**	**50.0**	0.0
Advocacy *(N = 16)*	9	12	6	9	13	0
%	47.4	**75.0**	37.5	47.4	**81.3**	0.0
Quality of Life Grants *(N = 6)*	3	3	2	3	2	2
%	**50.0**	**50.0**	33.3	**50.0**	33.3	33.3
Communications *(N = 19)*	9	12	7	10	13	1
%	47.4	**63.2**	36.8	**52.6**	**68.4**	5.3
In-person or virtual conferences or presentations *(N = 8)*	5	5	3	6	4	1
%	**62.5**	**62.5**	37.5	**75.0**	**50.0**	12.5
Other *(N = 4)*	2	3	1	2	2	1
%	**50.0**	**75.0**	25.0	**50.0**	**50.0**	25.0

Table 92. Reasons for Foundation Area Engagement Increases – FS Only

Why did your level of engagement with each Reeve area increase during the pandemic? Please check all that apply.	**Opportunities for social connection**	**Provided helpful information**	**Helped feelings of isolation/ loneliness**	**Made me aware of new resources**	**Made me feel useful/ like I was a part of something bigger than myself**	**Other (please explain)**
Team Reeve *(N = 3)*	1	1	0	2	2	0
%	33.3	33.3	0.0	**66.7**	**66.7**	0.0
Webinars *(N = 18)*	8	14	0	12	3	2
%	44.4	**77.8**	0.0	**66.7**	16.7	11.1
Peer and Family Support Program *(N = 5)*	2	3	0	2	2	2
%	40.0	**60.0**	0.0	40.0	40.0	40.0
Information Specialists *(N = 5)*	1	3	0	5	1	0
%	20.0	**60.0**	0.0	**100.0**	20.0	0.0
Annual Reeve Summit *(N = 9)*	1	1	1	3	3	1
%	11.1	11.1	11.1	33.3	33.3	11.1
Advocacy *(N = 5)*	1	3	1	4	3	0
%	20.0	**60.0**	20.0	**80.0**	**60.0**	0.0
Quality of Life Grants *(N = 3)*	0	1	0	3	1	0
%	0.0	33.3	0.0	**100.0**	33.3	0.0
Communications *(N = 6)*	2	5	0	5	1	0
%	33.3	**83.3**	0.0	**83.3**	16.7	0.0
In-person or virtual conferences or presentations *(N = 1)*	1	1	1	0	0	0
%	**100.0**	**100.0**	**100.0**	0.0	0.0	0.0

Please explain what other factors led to an increase in your engagement with each area during the pandemic. *(N = 15)*

PWD *(N = 10)*

Webinars ***(N = 1)***

- “Abundance of time.”

Peer and Family Support Program ***(N = 3)***

- “I became a peer mentor after the pandemic. I never used the peer program for myself, just to help others.”
- “I was attempting to volunteer/become a peer mentor. My request went largely on unanswered.”
- “I’m a mentor and was connected to a new peer.”

Quality of Life Grants ***(N = 3)***

- “Found a new activity (wheelchair ballroom dancing) and I want to share the experience with everybody and get more people involved.”
- “My organization is a grantee. I wanted to understand more about the programs. I shared links out for others to join in.”
- “Supporting nonprofit organizations that have been negatively financially impacted by the global pandemic.”

Communications ***(N = 1)***

- “I thought the materials were good and wanted to share them.”

In-person or virtual conferences or presentations ***(N = 1)***

- “Referrals.”

Other ***(N = 1)***

- “Novel opportunities due to technology advances. Appreciation of new learnings.”

FS *(N = 5)*

Webinars ***(N = 2)***

- “Being a mom of a paralyzed son when everything was going crazy during the pandemic made me frustrated on so many fronts but that I wasn’t gonna leave him alone. I’m always there to protect him and I needed a lot more help and resources to do so and I was grateful for the Foundation.”
- “Had more time to sit and listen.”

Peer and Family Support Program ***(N = 2)***

- “More people asking for support.”
- “Work schedule changes allowed me to be more accessible to assist others.”

Annual Reeve Summit ***(N = 1)***

- "Online option made attendance possible without the need for travel."

Most Helpful Reeve Resources During the Pandemic

Participants were asked to select the Reeve Foundation programs or services that were most helpful or beneficial to them during the pandemic. As Table 93 shows, webinars, communications, and Information Specialists were most selected as the most helpful. Over one fourth (29.1%) of respondents indicated that none of the Foundation's programs or services were most helpful to them during the pandemic.

Table 93. Most Helpful/Beneficial Reeve Areas

Which program(s) or service(s) provided by the Reeve Foundation were the MOST helpful or beneficial to you during the pandemic? Please check all that apply.	**Overall** *(N = 587)* *N* (%)	**PWP** *(N = 389)* *N* (%)	**PWD** *(N = 423)* *N* (%)	**FS** *(N = 157)* *N* (%)
Team Reeve	17 (2.9)	7 (1.8)	7 (1.7)	10 (6.4)
Webinars	108 (18.4)	80 (20.6)	87 (20.6)	19 (12.1)
Peer and Family Support Program	47 (8.0)	36 (9.3)	41 (9.7)	6 (3.8)
Information Specialists	54 (9.2)	37 (9.5)	42 (9.9)	11 (7.0)
Military and Veterans Program	7 (1.2)	6 (1.5)	6 (1.4)	1 (0.6)
Annual Reeve Summit	10 (1.7)	6 (1.5)	7 (1.7)	3 (1.9)
Advocacy	31 (5.3)	24 (6.2)	26 (6.1)	5 (3.2)
Quality of Life Grants	27 (4.6)	18 (4.6)	18 (4.3)	8 (5.1)
Communications	98 (16.7)	65 (16.7)	74 (17.5)	23 (14.6)
In-person or virtual conferences or presentations	15 (2.6)	12 (3.1)	12 (2.8)	3 (1.9)
Other (please describe)	14 (2.4)	8 (2.1)	11 (2.6)	3 (1.9)
None	171 (29.1)	121 (31.1)	135 (31.9)	35 (22.3)

What other areas were the most beneficial program/service the Reeve Foundation offered to you during the pandemic? *(N = 13)*

PWD *(N = 11)*

- "Clinical trials."
- "Don't know of most of these."
- "Facebook articles, posts, website articles."
- "I only listened to one webinar on 11/8/22."
- "Information."
- "Information available on website."

- "Most of this is new to me."
- "Myself, doing the research and not listening to fear based media, doctors, etc."
- "N/A."
- "So far, nothing. Please read my response just before this one. I have tried to engage and connect; I have been ignored and turned away."
- "Updating my knowledge base about research studies, new advances, new possibilities."

FS *(N = 2)*

- "Emails."
- "Just to better help my son with different kinds of resources."

Group comparisons were conducted on this question to determine whether there would be any significant differences between PWD and FS related to their selections of each area as most helpful. As with the previous "check all that apply" questions, a participant's checking of a box was coded as 1, while unchecked boxes were coded as 0. This means that the higher the group means, the greater the proportion of the group that checked the box for each area.

Table 94 below shows the significant differences between PWD and FS in the areas that they checked as most helpful. PWD had significantly higher means for Webinars, the Peer and Family Support Program, Information Specialists, Advocacy, and None of the areas – this means that PWD were more likely than FS to check these areas as most helpful. FS were more likely than PWD to rate Team Reeve as a most helpful area.

Table 94. PWD vs. FS Group Comparisons of Selected Most Helpful Areas

	PWD		FS					
	M	*SD*	*M*	*SD*	*df*	*t*	*p*	Cohen's *d*
Most helpful: Team Reeve	0.02	0.13	0.06	0.24	585	2.90	<.001	0.17
Most helpful: Webinars	0.21	0.41	0.13	0.36	585	-2.18	<.001	0.39
Most helpful: PFSP	0.10	0.30	0.04	0.19	585	-2.43	<.001	0.27
Most helpful: IS	0.10	0.30	0.07	0.26	585	-0.98	.046	0.29
Most helpful: Advocacy	0.06	0.24	0.03	0.17	585	-1.51	.002	0.22
Most helpful: None	0.32	0.47	0.22	0.42	585	-2.40	<.001	0.45

When participants selected each area as most helpful or beneficial to them, they were presented with an open-ended question asking them to explain why this area had been most helpful to them during the pandemic. The open-ended responses provided below explain respondents' reasoning for selecting each area as the most helpful or beneficial and shed light on potential reasons for the significant differences between PWD and FS on these selections.

<u>Why</u> was each area the most beneficial program/service the Reeve Foundation offered to you during the pandemic? *(N = 362)*

<u>PWD *(N = 297)*</u>

Team Reeve ***(N = 2)***
- "Allow me to create online events."
- "It connected me when we could not physically be together and made me feel like I was/am doing something."

Webinars ***(N = 54)***
- "A way to connect with peers across the country and learn and share experiences and information."
- "Because they were easy to participate in and provided helpful information."
- "Can have access to information while at home."
- "Gave me something to do and provided very useful information."
- "Had a nurse available talking about her experiences and that of those she cared for."
- "I gain insight and methods in learning new ways to cope with life."
- "They made me feel less alone."
- "Vital information provided."

Peer and Family Support Program ***(N = 26)***
- "A lot of the time I need to talk and feel like I am heard, and that's what happened."
- "Connecting with others is an essential part of life."
- "I could still talk with peers on the phone or computer. It helped me to stay connected."
- "It kept me connected with real-time information from other quadriplegics."
- "Virtual support groups were the only way to keep the SCI community together and mutually supported."
- "Was able to talk to other people living with paralysis and what they are dealing with."

Information Specialists ***(N = 28)***
- "Any questions I had; they had the information I needed."
- "Helped me learn. But I am able to walk. Reeve Foundation helps me explain my conditions to others. Nurse Jaimie is warm and amazing. I need more help with bowel information."
- "I was able to go online and get information."
- "They helped me find resources for the things I needed."
- "When I had a specific problem I needed help with right away it was so reassuring that someone would contact me with answers and also direct me to references and resources. Big help."

Military and Veterans Program ***(N = 4)***
- "Provide helpful information."
- "Yes, provided great information of programs for veterans."

Annual Reeve Summit ***(N = 2)***

- "In person connection."

Advocacy ***(N = 18)***

- "Facilitating the voice in the national conversation and easy access to representation in Washington."
- "Felt like I was contributing to helping others with disability, increased connection with others."
- "It made me feel like I was a part of something much bigger than myself."
- "Loved having more opportunities for advocacy to do from my computer that didn't require me to personally be present."
- "The emails reminded me that they were always available, advocating, and creating hope."

Quality of Life Grants ***(N = 14)***

- "Assisting nonprofit organizations providing well-needed services to the community."
- "Because they were easy to participate in and offered an opportunity to connect with others."
- "Gave me a chance to focus on helping others."
- "Get equipment necessary for my disability."
- "I run an adapted sport program. The funds helped keep our programs going when funding was down."

Communications ***(N = 48)***

- "As a referral source for others."
- "Constant source of information and encouragement."
- "It connected me when we could not physically be together and made me feel like I was/am doing something constructive."
- "It kept me informed about what was going on in the world."
- "It was easy to check out on my own time."
- "Lots of cool ideas and sharing of people in similar situations!"
- "Provided information/tips on how others like me were dealing with the pandemic."
- "They provided me with information whenever I needed it, with instances of how to cope with the pandemic."

In-person or virtual conferences or presentations ***(N = 6)***

- "Good for me and to share with my disabled friends."
- "Need for info."

Other ***(N = 7)***

- "Good information easily accessible."
- "Got me out of the house, kept me engaged, and provided lots of occupational therapy as part of the trial."
- "Peer support."

None ***(N = 88)***

- "Did not need to access any services."
- "Did not use any of these resources, didn't know some of them existed."
- "Haven't reached out but may in the future."
- "I didn't have time."
- "I just read the articles that came on email. That's all I needed from the Foundation."
- "I was paralyzed at the beginning of the pandemic. Many of these activities haven't been my focus at this stage of my injury."
- "Many of them I cannot access since I do not have an adaptive computer and can't afford the Summit."
- "None seemed to apply to my polio."

FS *(N = 65)*

Team Reeve ***(N = 3)***

- "I learned this year that I can actually run and am training for a half marathon. Raising money for the Reeve Foundation has given me additional purpose and inspiration to keep training and complete my race."
- "We participated during the pandemic, and it was nice the race was virtual, and we had something to focus on."

Webinars ***(N = 11)***

- "Easy to attend and generally full of good information."
- "Gave me something to look forward to and great information."
- "I could gain new info from my home."
- "Reliable and could be rewatched when they were available in a recorded format."

Peer and Family Support Program ***(N = 2)***

- "Great opportunity to share and encourage others."
- "It met twice a month online."

Information Specialists ***(N = 7)***

- "Able to assess individual needs of clients and refer for further assistance when extra help was needed."
- "Clarifying unknown details."
- "Provide good information."
- "Very knowledgeable."

Annual Reeve Summit ***(N = 2)***

- "Connecting with the issues that are most relevant to the community that is impacted the most, including the issues that impact me."

Quality of Life Grants ***(N = 3)***

- "It allowed an opportunity for my child with paralysis to still participate in programs/have the program funded to be able to continue when many cuts were being made due to the pandemic."
- "The grants were valuable to support the programs we hold for people with paralysis."

Communications ***(N = 12)***

- "Getting informed helps me being comfortable and waiting."
- "Helps to hear what is going on with other people."
- "I like the sense of community from the newsletters and website."
- "It remained constant and a source of information that was always available."

In-person or virtual conferences or presentations ***(N = 1)***

- "Advocates and experts talking on the topics that directly impact all people with disabilities."

Other ***(N = 2)***

- "Updated information."
- "When everything else is falling apart in the world it seems to be very beneficial that the Reeve Foundation is available, supportive, and helpful."

None ***(N = 22)***

- "Didn't need them. They would have been helpful if I needed them."
- "I am new with learning about the organization."
- "I didn't seek info from the Reeve Foundation."
- "No personal need for any."
- "Was unaware of these programs."

Least Helpful Reeve Resources During the Pandemic

Participants were asked to select the Reeve Foundation programs or services that were least helpful or beneficial to them during the pandemic. As Table 95 shows, the most selected response for the least helpful area was none of the areas (44%). The Military and Veterans Program, Team Reeve, and the Annual Reeve Summit were the most selected areas that were least helpful or beneficial for respondents.

Table 95. Least Helpful/Beneficial Reeve Areas

Which program(s) or service(s) provided by the Reeve Foundation were the LEAST helpful or beneficial to you during the pandemic? Please check all that apply.	**Overall** ***(N = 587)*** ***N*** **(%)**	**PWP** ***(N = 389)*** ***N*** **(%)**	**PWD** ***(N = 423)*** ***N*** **(%)**	**FS** ***(N = 157)*** ***N*** **(%)**
Team Reeve	52 (8.9)	42 (10.8)	43 (10.2)	9 (5.7)
Webinars	14 (2.4)	9 (2.3)	13 (3.1)	1 (0.6)

Which program(s) or service(s) provided by the Reeve Foundation were the LEAST helpful or beneficial to you during the pandemic? Please check all that apply.	**Overall** *(N = 587)* *N* **(%)**	**PWP** *(N = 389)* *N* **(%)**	**PWD** *(N = 423)* *N* **(%)**	**FS** *(N = 157)* *N* **(%)**
Peer and Family Support Program	22 (3.7)	13 (3.3)	15 (3.5)	7 (4.5)
Information Specialists	15 (2.6)	10 (2.6)	13 (3.1)	2 (1.3)
Military and Veterans Program	66 (11.2)	48 (12.3)	52 (12.3)	14 (8.9)
Annual Reeve Summit	34 (5.8)	23 (5.9)	27 (6.4)	7 (4.5)
Advocacy	18 (3.1)	13 (3.3)	14 (3.3)	4 (2.5)
Quality of Life Grants	24 (4.1)	17 (4.4)	19 (4.5)	5 (3.2)
Communications	20 (3.4)	16 (4.1)	16 (3.8)	3 (1.9)
In-person or virtual conferences or presentations	21 (3.6)	16 (4.1)	18 (4.3)	3 (1.9)
Other (please describe)	11 (1.9)	6 (1.5)	8 (1.9)	3 (1.9)
None	260 (44.3)	181 (46.5)	201 (47.5)	56 (35.7)

What other areas were the least beneficial program/service the Reeve Foundation offered to you during the pandemic? *(N = 10)*

PWD *(N = 7)*

- “All but online info.”
- “I didn’t know about most of these things.”
- “I do not require paralysis-related services.”
- “N/A.”
- “N/A.”
- “Not sure because I have not received any additional services. The veterans program would help.”
- “They, technically, are all the ‘least’ because I’ve never used them.”

FS *(N = 3)*

- “All of the above.”
- “Did not use the other programs so cannot speak to their helpfulness.”
- “I feel bad as a parent, that as many times as I’ve asked for help, there’s never a time that I can get a grant to help him.”

Table 96 below shows the significant differences between PWD and FS in the areas that they checked as least helpful. As these results show, PWD were more likely than FS to indicate that all of the areas in Table 92 were least helpful to them. Notably, PWD were more likely to indicate that none of the areas were least helpful to them.

Table 96. PWD vs. FS Group Comparisons of Selected Least Helpful Areas

	PWD		FS					
	M	*SD*	*M*	*SD*	*df*	*t*	*p*	Cohen's *d*
Least helpful: Team Reeve	0.10	0.30	0.05	0.23	585	-1.79	<.001	0.28
Least helpful: Webinars	0.03	0.17	0.01	0.08	585	-1.76	<.001	0.15
Least helpful: IS	0.03	0.17	0.01	0.11	585	-1.28	.010	0.16
Least helpful: Military and Veterans Program	0.12	0.33	0.09	0.28	585	-1.29	.008	0.32
Least helpful: Reeve Summit	0.06	0.26	0.04	0.20	585	-0.98	.047	0.23
Least helpful: In-person or virtual conferences	0.04	0.20	0.02	0.13	585	-1.42	.004	0.19
Least helpful: None	0.48	0.50	0.36	0.48	585	-2.54	<.001	0.50

When participants selected each area as least helpful or beneficial to them, they were presented with an open-ended question asking them to explain why this area had been least helpful to them during the pandemic. The open-ended responses provided below explain respondents' reasoning for selecting each area as the least helpful or beneficial and shed light on potential reasons for the significant differences between PWD and FS on these selections.

Why was each area the least beneficial program/service the Reeve Foundation offered to you during the pandemic? *(N = 316)*

PWD *(N = 285)*

Team Reeve ***(N = 34)***

- "Did not participate."
- "Fundraising doesn't help depression."
- "Fundraising tickets are too expensive."
- "I don't think they had any events during the pandemic. If they did, I can't participate in the events."
- "I live in a rural area far from races. It doesn't apply to me."
- "I'm not able to attend those events. It's kind of depressing."

Webinars ***(N = 7)***

- "Based on other communications I didn't think they would tell me anything useful that I didn't already know."
- "I had no involvement with these programs."
- "Just hard to schedule and commit time."

Peer and Family Support Program ***(N = 9)***

- "I emailed requesting information and never heard back from anyone."

- “It was very difficult to get a peer mentor to contact me even after one was requested. As mentioned above, I submitted a request to obtain what qualifications are necessary to become a mentor. The request went unanswered.”
- “Never heard back.”

Information Specialists ***(N = 11)***
- “I didn’t need them.”
- “Limited ability to help.”
- “They answered my question as well as they could.”

Military and Veterans Program ***(N = 49)***
- “I am not a veteran.”
- “I did not qualify but I am certainly glad those groups had a special support from the Foundation.”
- “I retrieve most of the veteran information from other veterans service organizations.”
- “It is not related to my needs.”
- “It is not applicable to me and my situation.”

Annual Reeve Summit ***(N = 21)***
- “Could not attend.”
- “Didn’t get enough information about why I should participate.”
- “It’s somewhere else. For people who live on the east coast.”
- “Never understood that I could participate.”
- “Tickets are too expensive.”

Advocacy ***(N = 10)***
- “I didn’t know it was open to anyone with a spinal cord injury.”
- “I don’t know how to reach out for advocacy.”
- “I was not engaged with these processes. Found no value.”

Quality of Life Grants ***(N = 18)***
- “Don’t think we could qualify.”
- “I had no need to use them.”
- “Was attempting to get a quality of life grant to pursue increased wellness of SCI population in community. Did not receive grant.”

Communications ***(N = 12)***
- “I really do not have a big social media presence nor know how to use the different social media platforms effectively.”
- “Nothing for people with ischemic injuries, most info is dumbed down to being useless and a waste of time.”
- “Was not engaged with us.”

In-person or virtual conferences or presentations ***(N = 16)***

- "Because the conferences and presentations were in-person and I don't have wheelchair accessible transportation."
- "Didn't bother as I doubt they would provide any useful information."
- "Time conflicts but they are great when I could attend."
- "Too expensive."

Other ***(N = 4)***

- "I did not need them."
- "No answer for this question."

None ***(N = 105)***

- "All are helpful to someone, even if I'm not using them personally."
- "All that I knew about were helpful. Did not interact with most of these so I cannot be critical of them."
- "Didn't know I had access to them. I utilized other SCI nonprofits and their resources."
- "Haven't used any services."
- "I don't know most of these programs so didn't use them."
- "I really haven't invested time in exploring available services."
- "Reeve does excellent programming."
- "The information and service areas I required from the Reeve Foundation were always available when and if I needed them."
- "The Reeve Foundation is always providing info and is very useful and helpful."

FS *(N = 31)*

Military and Veterans Program ***(N = 1)***

- "I am not a veteran."

Other ***(N = 2)***

- "Because I didn't use them."
- "Did not use or access them."

None ***(N = 28)***

- "All provided some benefit even if not applicable to me directly."
- "I did not seek out services from the Reeve Foundation."
- "I didn't really use anything from the Reeve Foundation during COVID."
- "I don't use any of the programs. I am just an annual contributor."
- "New with learning about the Foundation."
- "They all provided information that was needed."
- "We rarely use the resources but it's nice to know it's all there."

This publication was supported by the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling $160,000 with 100% funding by ACL/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by, ACL/HHS or the U.S. government.