ACL Rapid Cycle Research and Evaluation

ACL

Administration for Community Living

National Paralysis Resource Center Evaluation

2023 NPRC Evaluation Report

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Contents

Section **Page**

ACRONYMS

ACL	Administration for Community Living
ADRC	Aging and Disability Resource Center
AIRS	Alliance of Information and Referral Systems
ALS	amyotrophic lateral sclerosis
CDRF	Christopher & Dana Reeve Foundation
GAS	goal attainment scaling
HHS	U.S. Department of Health and Human Services
IS	Information Services
MS	multiple sclerosis
MVP	Military and Veterans Program
NPRC	National Paralysis Resource Center
OMB	Office of Management and Budget
PFSP	Peer and Family Support Program
PRG	Paralysis Resource Guide
PVA	Paralyzed Veterans of America
QOL	quality of life
SCI	spinal cord injury
TBI	traumatic brain injury

EXECUTIVE SUMMARY

The Christopher & Dana Reeve Paralysis Act, enacted in 2009, authorized the creation of a National Paralysis Resource Center (NPRC)[1] to help individuals living with paralysis, their caregivers, and their families navigate life after a paralysis diagnosis. Since 2014, the Administration on Disabilities within the Administration for Community Living (ACL), in collaboration with the Christopher & Dana Reeve Foundation (CDRF), has been charged with overseeing and administering the grant that funds the NPRC. In 2021, CDRF competed for and won the ACL grant for the current funding period through June 2026. This federal grant represents a major source of funding for the Foundation's Paralysis Resource Center. Over the years, various aspects of the NPRC have been studied, but this is the first independent evaluation conducted by ACL.

Since 2021, ACL has contracted with RTI International to evaluate four major activities of the NPRC and assess overall impact on the health and quality of life (QOL) of individuals living with paralysis. These four activities include the following:

- Information Services (IS), which employs trained Information Specialists to provide individualized support and resources for people with paralysis, their support networks, and professionals
- The Peer and Family Support Program, which matches individuals living with paralysis (peers) and their caregivers with peer mentors, who are individuals with related diagnoses who have personal experience with available paralysis resources and supports
- The Quality of Life grants program, which funds community-based organizations nationwide to provide a variety of services that will enhance QOL for people living with paralysis
- A Promotional Activities, Outreach, and Collaboration program, which conducts activities related to marketing, outreach, and community engagement; building and maintaining partnerships; public policy; and a special Military and Veterans Program (MVP) to meet the needs of military service members and veterans

RTI's mixed-methods evaluation includes process and outcome components to help ACL better understand the diversity of activities undertaken by the NPRC and to assess improvements in the lives of individuals living with paralysis. This report describes (1) the outcome-focused findings from the first 2 years of data collection, which included conducting key informant interviews with NPRC staff and staff at other organizations that support people living with paralysis; (2) the performance monitoring reports submitted by the NPRC to ACL; (3) surveys of people living with paralysis and caregivers who participate in NPRC-sponsored programs (peer and family mentoring or a QOL grantee's program); and (4) focus groups with peer and family

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[1] The Christopher & Dana Reeve Paralysis Act authorized the creation of the Paralysis Resource Center to promote paralysis research, rehabilitation research and care, and improve quality of life for people with paralysis and other physical disabilities. More information available at https://acl.gov/about-acl/authorizing-statutes.

mentoring participants, QOL grantee organizations, and people living with paralysis participating in NPRC-organized legislative and education efforts.

Key findings from the evaluation activities for each NPRC activity are shown in **Table 1**.

Table 1. Key evaluation findings by NPRC activities

NPRC Activity	Key Findings
Peer and Family Support Program	• Nearly all NPRC-organized peer mentoring is virtual (i.e., via telephone or video call), which differs from the in-person peer mentoring administered by other organizations serving a similar population. However, the 2% of responding NPRC peers and interviewed peer mentors reported no concerns with the virtual format of NPRC mentoring. • Although most peer mentors reported positive mentoring experiences that met their participation goals, some peer mentors said they were not being utilized as often as they hoped. Peers were less likely than peer mentors to report that their goals for participation were met. A newly developed NPRC database may address these concerns with improved peer matching. • Peer mentors reported that identification of local resources to support peer needs was the most frequent mentoring request. Given that most peers and mentors live in different communities and interact virtually, this need for local resources may represent an opportunity for the NPRC to educate and support mentors to guide people in finding local resources (e.g., in conjunction with the NPRC Information Specialists).
Quality of Life	• The terms of the grant require that one-third of the NPRC budget goes to community-based organizations through QOL grants, which fund innovative ideas, build capacity within communities, reach historically underserved populations, and facilitate partnerships across local organizations. • QOL grantee programs positively impact QOL for people living with paralysis and their support networks; on average grantee end-users improved their self-selected QOL-related outcomes by almost 2 points on a 7-point scale. • Grantees indicated that QOL grants program staff can be especially helpful when assisting grantee organizations with their implementation challenges, although they also requested more NPRC assistance with collecting evaluation data from end-users.
Promotional Activities, Outreach, and Collaboration Key Points	• The NPRC's promotional activities and outreach continuously expand the reach of its resources, including a steady increase in views of the educational videos posted to its YouTube channel. Partnerships with other organizations are increasing NPRC resource visibility, including outreach to some county veterans services offices. • Public policy education is meeting goals to increase empowerment and confidence among people living with paralysis • NPRC staff who run the Regional Champions program are key to its success.

(Table continues on next page.)

Table 1. Key evaluation findings by NPRC activities (continued)

NPRC Activity	Key Findings
Information Services Key Points	• NPRC client feedback suggests that IS program activities are contributing to improved health and QOL for people with paralysis. • The number of inquiries to Information Specialists has continued to decline in the first half of 2023 as compared to the previous year. This decline has been observed uniformly across various demographic characteristics (sex, language, ethnicity, and race) and may represent a change in demand, or a change in how people access the website because of the NPRC's website redesign. • IS continues to expand trainings, presentations, and accessible resources. Recent updates have included more captioned and subtitled videos and webinars, document accessibility, plain-language fact sheets using a Q&A format, and translated materials in multiple languages.

Taken together, these findings indicate that overall, the NPRC has had many positive effects on individuals living with paralysis, their caregivers, and their support networks. Our cross-program analyses show some variation across programs, with a net favorable perception of the NPRC's activities and programs. Notably, our evaluation received low response rates for some data collection activities, including some surveys, interviews, and focus groups, meaning all of our findings may not be generalizable to the entire population served by the NPRC. However, because we triangulated multiple data sources, we feel confident that our overall takeaways are appropriate.

Potential growth areas for the future may include additional efforts to document and track participant data across programs, increased focus on localized resources (e.g., for peer mentors to reference), and continued efforts to support historically underserved and unserved communities. The variety of outreach and promotional activities indicates widespread awareness of the NPRC, with a growing need to focus on social media outreach, rather than more traditional email and print methods. Lastly, ongoing efforts to evaluate the NPRC with their external evaluator, Vanderbilt University, will continue identifying successes and potential growth areas for the future.

INTRODUCTION

The Christopher & Dana Reeve Foundation (CDRF) created the Paralysis Resource Center in 1999 to provide information and educational support to individuals and families impacted by paralysis. In 2009, Congress passed the Christopher & Dana Reeve Paralysis Act, which authorized the creation of the National Paralysis Resource Center (NPRC) to assist individuals living with paralysis resulting from spinal cord injury (SCI), multiple sclerosis (MS), amyotrophic lateral sclerosis (ALS), stroke, and other conditions. Since 2014, the Administration on Disabilities within the Administration for Community Living (ACL), in collaboration with CDRF, has been charged with overseeing and administering the NPRC. The mission of the NPRC is to improve the quality of life (QOL) for people living with paralysis, their families, and caregivers by providing information, grants, resources, and support.[2]

In 2021, ACL contracted with RTI International to conduct a four-year process and outcome evaluation coinciding with the NPRC's most recent period of performance, which started July 2021.[3] The initial two years of the evaluation include the majority of data collection and analysis, with the subsequent two years serving as a maintenance period. This report includes findings from these first two years of data collection and analysis.

BACKGROUND

Understanding the current incidence of paralysis is a critical step in meeting the needs of people living with paralysis and their families and caregivers. An estimated 5.4 million people were living with paralysis in the United States in 2013—1.7% of the population.[4] In 2009 the Centers for Disease Control and Prevention and the CDRF initiated an extensive effort to develop, cognitively test, validate, and administer a nationally representative measure of paralysis based on the International Classification of Functioning, Disability and Health.[5] The associated two-part measure developed for survey-based surveillance consisted of two questions. First, respondents were asked, "Do you or does anyone in this household have any difficulty moving their arms or legs?" If respondents answered "yes," they were then asked if they had a qualifying diagnosis.[6] Respondents met the definition of paralysis if they provided affirmative responses to both the initial limb mobility and subsequent qualifying diagnosis questions. Using this question dyad, nationally representative telephone surveys administered in 2008 and again in 2012–2013 identified key characteristics of the more than 5 million people

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[2] ACL. *Paralysis Resource Center (PRC)*. https://acl.gov/programs/post-injury-support/paralysis-resource-center-prc

[3] ACL. *2023 Evaluation Plan*. https://acl.gov/sites/default/files/programs/2021-09/2023 Evaluation Plan-ACL.pdf

[4] Armour, B. S., Courtney-Long, E. A., Fox, M. H., Fredine, H., & Cahill, A. (2016). Prevalence and causes of paralysis—United States, 2013. *American Journal of Public Health, 106*(10), 1855–1857. doi: 10.2105/AJPH.2016.303270

[5] Fox, M. H., Krahn, G. L., Sinclair, L. B., & Cahill, A. (2015). Using the International Classification of Functioning, Disability and Health to expand understanding of paralysis in the United States through improved surveillance. *Disability and Health Journal, 8*(3), 457–463. doi: 10.1016/j.dhjo.2015.03.002

[6] Qualifying diagnoses included the following: SCI, traumatic brain injury (TBI), stroke, poisoning, complications from surgery, amyotrophic lateral sclerosis/Lou Gehrig's, Guillain Barre syndrome, MS, neurofibromatosis, epidural infection, Chiari malformation, syringomyelia, post-polio syndrome, spinal muscular atrophy, Fredrich's ataxia, transverse myelitis, cerebral palsy, and spina bifida.

living with paralysis, shown in **Table 2.** Based on the survey results, more than half of respondents living with paralysis were under age 65 (72%), identified as White (71%), had completed high school (65%), or were overweight or obese (62%).

Table 2. Demographic characteristics of those living with paralysis in 2013

Demographic characteristic	Prevalence among those with paralysis (%)	Approximate number with characteristic (N)
Total living with paralysis		5,357,980
Age <65	72.1	3,857,746
Female	51.7	2,770,076
Race = white	71.4	3,825,598
High school graduate	64.8	3,471,971
Married or living with partner	47.4	2,539,683
Unable to work	41.8	2,239,636
Household income $25,000 to $50,000	29.5	1,580,604
Household income of less than $15,000	28.1	1,505,592
Overweight or obese	61.8	3,311,232
Current cigarette smokers	30.5	1,634,184

Source: Armour, B. S., Courtney-Long, E. A., Fox, M. H., Fredine, H., & Cahill, A. (2016). Prevalence and causes of paralysis—United States, 2013. *American Journal of Public Health, 106*(10), 1855–1857. doi: 10.2105/AJPH.2016.303270

To meet the diverse needs of people living with paralysis, their support networks, and their communities, the NPRC offers many services and resources, including the four specific programs that are the foci of this evaluation.

1. The **Peer and Family Support Program (PFSP)** is a national peer-to-peer mentoring program launched in 2011 to better support people living with paralysis and their family members/caregivers. Certified mentors are trained to provide emotional support, guidance, and resources to individuals living with paralysis (peers) and their caregivers. Mentors provide encouragement and empathy, individualized guidance focused on peers' needs, practical assistance for integrating into the community, and help with identifying relevant resources. All mentors are recruited and screened for suitability, trained and certified, and then matched with demographically similar individuals who are also living with paralysis. The PFSP is currently staffed by four employees—the director, a program manager, and two program coordinators. **Table 3** provides basic descriptive information on the PFSP.

Table 3. Summary statistics for the Peer and Family Mentoring Program

Mentors	Number
Number of mentors nationwide (as of July 2023)	532
Total # of peers served since program initiation in 2011 (as of January 2023)	22,531
Total # of encounters between mentors and peers since program initiation in 2011 (as of January 2023)	54,180

Source: NPRC. *Semi-Annual Performance Monitoring Reports*, January 2023 and July 2023.

2. **Information Services (IS)** employs trained Information Specialists to answer questions on a variety of topics related to living with SCI, mobility impairment, and paralysis. Information Specialists provide individualized support and resources to people of all ages and at any stage of paralysis. Information Specialists are required to have a bachelor's degree to work at the NPRC and undergo 3–4 months of specialized NPRC training. Any specialist who has worked at the NPRC for at least 1 year is also required to get the Alliance of Information and Referral Systems (AIRS) certification, which guides specialists in provision of person-centered support. Specialists are required to attend additional training to maintain their AIRS certification and receive training in the Military and Veterans Program (MVP)[7] and in suicide prevention. IS also includes the design and development of materials and publications to educate and inform the public about paralysis. Because the IS website includes a wealth of material in English and in other languages, IS content reaches people in both the United States and internationally.
3. The **Quality of Life (QOL) grants program** offers funding to community-based organizations nationwide to improve the health and well-being of individuals impacted by paralysis as well as their families/support networks. The program offers three main types of grants: Direct Effect, Priority Impact, and Expanded Impact. Direct Effect grants can be used to pay for a variety of activities and services such as adaptive sports, facility accessibility modifications, therapeutic horseback riding, the arts, and others. Priority Impact Grants are awarded to projects related to certain priority areas (i.e., respite/caregiving, assistive technology, addressing social isolation because of the COVID-19 pandemic [ended Fall 2023], nursing home to community transition, employment, racial equity, and rural underserved and unserved populations). Expanded Impact Grants are awarded to previously awarded grantees who have demonstrated successful impact and will implement grant-supported programs or activities on a large scale. The size and length of the grant is dependent on the grant type.[8] Grants are awarded in the fall and spring. The NPRC is currently required to spend a minimum of 35% of its federal funds on QOL subawards.[9] See

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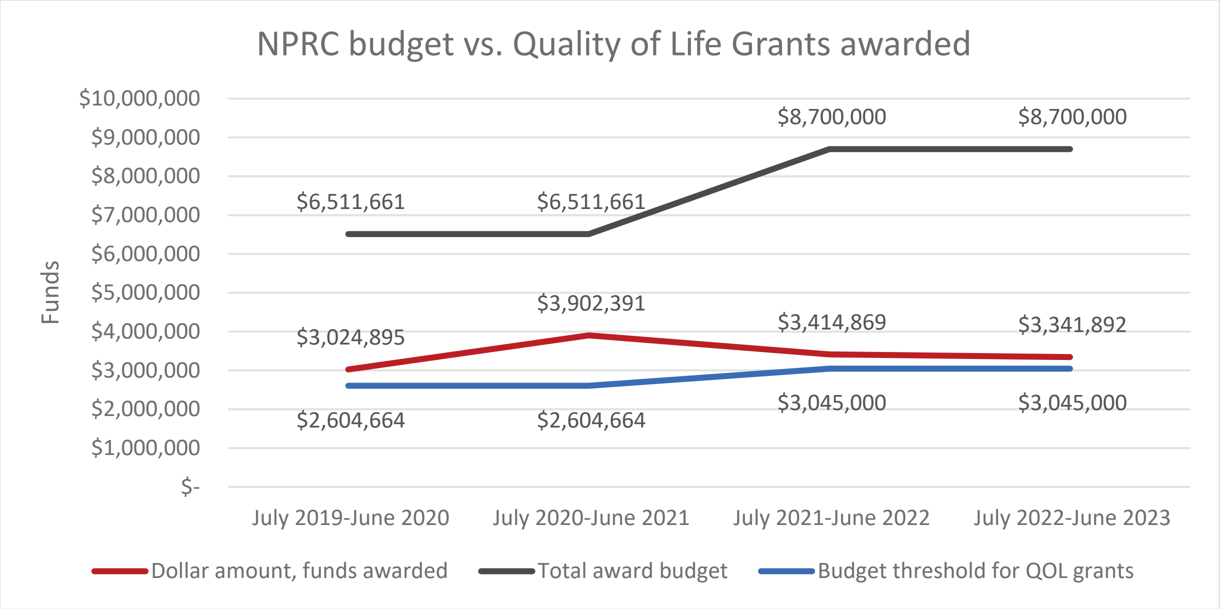
[7] The MVP offers specific outreach and resources to veterans and members of the U.S. military. More information on this program is available at https://www.christopherreeve.org/todays-care/get-support/military-veterans-program-mvp/.

[8] More information on grants is available at https://www.christopherreeve.org/get-support/grants-for-non-profits/program-overview.

[9] ACL. (2021). National Paralysis Resource Center 2021 Funding Opportunity Announcement, p. 16.

Exhibit 1 for the NPRC's total budget, the amount of money distributed in QOL subawards, and the budget threshold for QOL grants since July 2019.

Exhibit 1. Comparison of the NPRC budget, the budget threshold toward QOL grants, and the actual amount of money awarded in QOL grants, July 2019–June 2023



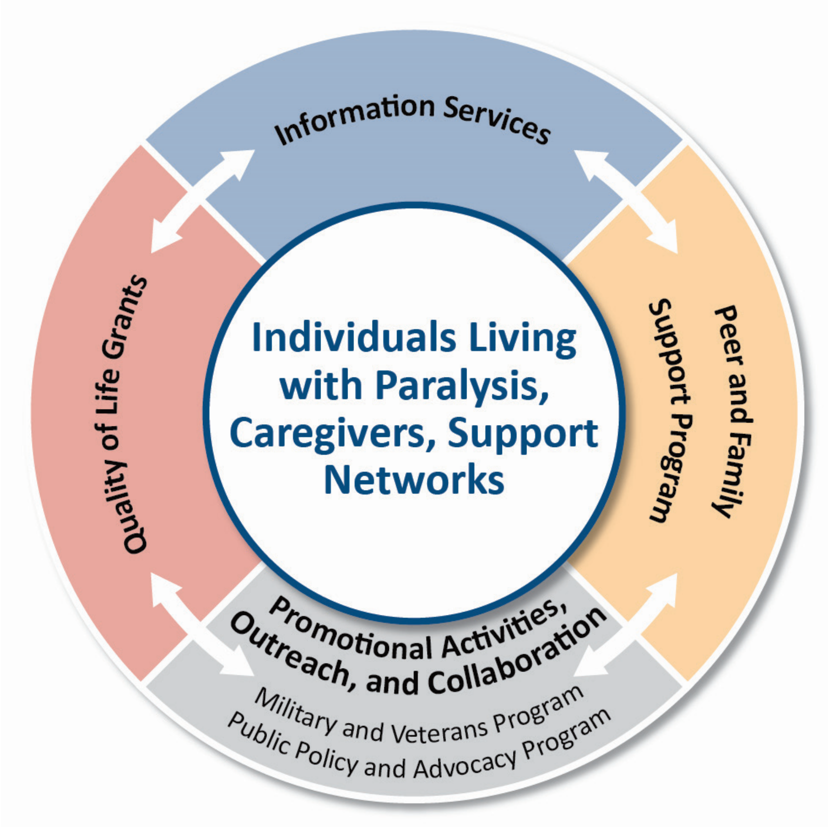
Sources: NPRC. *Semi-Annual and Final Performance Monitoring Reports*, July 2020–July 2023.

Note: July 2021 was the start of the new grant period with an increased total award budget and additional categories for awards; thus more awards were made in 2021 compared with 2020. The amount of QOL subawards funding increased, but it represents only a share of the total percentage of the budget required to go to subawards.

4. **Promotional Activities, Outreach, and Collaboration** encompass numerous efforts undertaken by the NPRC, including activities to expand awareness, increase community engagement, enhance collaboration across coalitions and partnerships, support the MVP, and engage with public policy. These activities support other parts of the NPRC (e.g., promotional activities are critical for informing the public about NPRC's services like availability of Information Specialists, peer mentorship, and QOL grantees). In turn, NPRC staff from other programs, such as IS and the PFSP, help with community outreach by attending conferences or help the MVP by connecting veterans with peer mentors.

By design, the synergy and communication between these four programs amplify their effectiveness in reaching the target audience. For example, Information Specialists who research local resources, new services, and assistive technologies serve as a resource for the PFSP staff and peer mentors. The overall infrastructure within the NPRC supports promotion, marketing, and community outreach about the NPRC's services, which benefits all other NPRC major activities by supporting recruitment, connection, and cross-promotion. **Figure 1** illustrates the interconnectedness of NPRC activities.

Figure 1. Interconnectedness of NPRC activities



OVERVIEW OF EVALUATION APPROACH

The goals for this evaluation are to develop an in-depth understanding of the activities and functions of the NPRC and how these activities achieve desired outcomes for individuals living with paralysis. To achieve these goals, the team employed both qualitative and quantitate data collection and analysis methods. The research questions that guided this evaluation are how and to what extent the NPRC does the following:

1. Improve the health and QOL of individuals living with paralysis of all ages, their families, and their support systems
2. Raise awareness about relevant services to members of the target populations
3. Increase access to relevant services to members of the target populations
4. Increase the empowerment, confidence, and independence of individuals living with paralysis
5. Strengthen support networks for individuals living with paralysis
6. Improve and increase opportunities for community living for individuals living with paralysis

This report highlights key findings to address these research questions, including discussions of each of the four major components of the NPRC. The *Cross-Program Analysis on NPRC Outcomes* section of the report describes the extent to which the NPRC as a whole addresses each outcome.

METHODS

To address the research questions, the team conducted both quantitative and qualitative data analysis of primary and secondary data. Primary data included data collected via focus groups, interviews, and surveys. Secondary data were abstracted from document reviews of NPRC Semi-Annual Performance Reports, including evaluation results from the NPRC's internal evaluation partner, submitted to ACL by the NPRC. See **Exhibit 2** for an overview of data sources associated with each NPRC program; a full discussion of all methods is included in **Appendix A**.

Exhibit 2. Data collection types for each NPRC program

NPRC activity	Document review	Staff interviews	Focus groups[a]	Surveys	Other interviews
Peer and Family Support Program	×	×	×	×	×
Quality of Life Grants Program	×	×	×	×	
Promotional Activities, Outreach, and Collaboration	×	×	×		
Information Services	×	×			

[a] Some planned PFSP focus groups became interviews because of decreased sample size.

Data Collection and Analysis

For primary data collection, the team conducted interviews, focus groups, and web surveys with NPRC program participants to understand both the NPRC processes and the associated outcomes for three of the four programs. **Table 4** details primary data collection activities.

Table 4. Primary data activities for the NPRC Evaluation

NPRC program	Eligibility criteria for data collection	Type of data collection	Number of people contacted [a]; Number of participants [b]	Data collection period
Peer and Family Support Program	**PFSP staff**	Group interviews (2)	Contacted: 4 (2022); 3 (2023) Interview participants: 4 (2022); 3 (2023)	May 2022 and June 2023
	Peer mentors living with paralysis **or their caregivers** working with the PFSP directly or with a partner organization, identified as active as of April 2023 (Active was defined as currently mentoring a peer or open to mentoring a peer.)	Survey	Contacted: 475 Survey participants: 79*	May through July 2023
		Focus groups (2) Interview (1)	Contacted: 475 Focus group participants: 10* Interview participants: 1*	May through July 2023
	Peers living with paralysis **or their caregivers** who had requested and received a peer mentoring encounter through the PFSP (not partner organizations) between July 2022 and March 2023	Survey	Contacted: 164 Survey participants: 24*	May through July 2023
		Interviews (2)	Contacted: 164 Interview participants: 2*	May through July 2023
	PFSP **partner organization** representatives	Interviews (3) Group Interviews (1)	Contacted: 5 Interview participants: 5	July through August 2023
	Representatives of **organizations similar** to the NPRC with peer mentoring programs.	Interviews (1) Group Interviews (1)	Contacted: 4 Interview participants: 4	August 2023
Quality of Life Grants	**QOL grants program staff**	Group interview (1)	Contacted: 3 Interview participants: 3	June 2022
	QOL grantee representatives from 2022 first Cycle Direct Effect QOL grants that ended in May 2023	Focus groups (3)	Contacted: 57 Focus group participants: 13	June and July 2023
	QOL grantee end-users from 2021 second Cycle Direct Effect and 2021 Priority Impact Grants identified by QOL grantees and received a survey link from the QOL grantee	Survey	Contacted: 51 organizations 32 organizations sent the survey to approximately [c] 1,734 end-users [d] Survey participants: 165	June and July 2023

(Table continues on next page.)

Table 4. Primary data activities for the NPRC Evaluation (continued)

NPRC program	Eligibility criteria for data collection	Type of data collection	Number of people contacted [a]; Number of participants [b]	Data collection period
Promotional Activities, Outreach, and Collaboration	**Promotional Activities, Outreach, and Collaboration staff**	Group interview (1)	Contacted: 3 Interview participants: 3	June 2022
	Regional Champions who were active as of March 31, 2023	Focus group (1)	Contacted: 58 Focus group participants: 4	June 2023
Information Services	**IS staff**	Interviews (3) Group interview (1)	Contacted: 5 Interview participants: 5	October 2022

* We had low participation from peer mentors and peers despite using active lists from the NPRC, an email from NPRC staff, and multiple reminder emails. Some previous evaluative efforts by internal evaluators showed low response rates as well. For example, only five peers (4.6% of all peers invited) participated in interviews led by internal evaluators in the fall of 2022.[10]

[a] Counts exclude email addresses that were undeliverable.

[b] Counts for surveys include complete and eligible responses.

[c] Some organizational representatives provided researchers the exact number of survey recipients, while others provided only rounded estimates. Researchers do not know if the numbers organizations provided excluded undeliverable email addresses.

[d] Many organizations indicated that they would not provide participant contact information. Therefore, researchers requested all organizations forward a survey link instead.

The team used semistructured protocols[11] to conduct interviews and focus groups via Zoom videoconferencing. Researchers used inductive coding to identify emerging themes and summarize them across the collected qualitative data.

For the surveys, the team developed web-based instruments and conducted cognitive testing with participants of the NPRC's programs. These cognitive tests resulted in minor revisions prior to survey launch. Each survey was open for at least three weeks, with initial invitations and reminders sent to NPRC participants via email. Response rates were 16.9% for peer mentors, 15.2% for peers, and 7.7% for QOL grant end-users. We used a retrospective pre-/post-test design to understand perceived differences in identified goals from before participation in NPRC programming to after participation.

The team conducted secondary analysis via a document review of the NPRC Semi-Annual and Final Performance Reports submitted to ACL, covering the time period from January 2020 through June 2023.[12] From these reports, we abstracted monitoring metrics, agreed upon by

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[10] NPRC. *Semi-Annual Performance Report,* January 2023, Appendices L-BB, p. 30.

[11] The Office of Management and Budget (OMB) reviewed and approved all data collection activities, in accordance with the Paperwork Reduction ACT (PRA).

[12] All citations to the *Semi-Annual Performance Reports* and *Final Performance Reports* provide the month and year of report submission, not the time period of the data.

ACL and the NPRC, into Excel and developed graphs to better visualize changes over time. From the most recent reports covering July 2021 through June 2023, we also abstracted information about program operations and internal evaluation efforts completed by the NPRC's external evaluation partner, Vanderbilt University.[13]

For additional details about the methods used in this evaluation, see Appendix A. For focus group protocols, survey specifications, and interview protocols see Appendix C.

FINDINGS

Findings are presented by each of the four programs, with NPRC-wide findings shared as the conclusion to the report.

Peer and Family Support Program

The PFSP works closely with approximately 22 partner organizations across the country to recruit and train peer mentors. As shown in **Table 5**, most peer mentors contacted the NPRC directly or were recruited from a hospital or rehabilitation center, with some also being recruited by partner associations.

Table 5. Peer mentor recruitment sources

Recruitment Source	Number of Peers Recruited
CDRF PFSP	175
Partner Hospitals or Rehabilitation Centers	194
Other Partner Associations	117

Source: NPRC list of peer mentors active as of April 2023

Mentors who volunteer by contacting the NPRC directly are screened after completing an application, which is then reviewed and approved by program staff. According to staff interviews in June 2023, PFSP staff are enhancing recruitment of mentors by expanding outreach to physical and occupational therapy associations, including the American Occupational Therapy Association and American Physical Therapy Association. Consequently, the total

PFSP Mentor Eligibility Requirements

- One year of experience living with paralysis or one year of experience as a family member or caregiver of an individual living with paralysis
- Active and engaged in the paralysis community
- Optimistic attitude about life
- Good interpersonal and listening skills
- Ability to make a commitment to being a mentor

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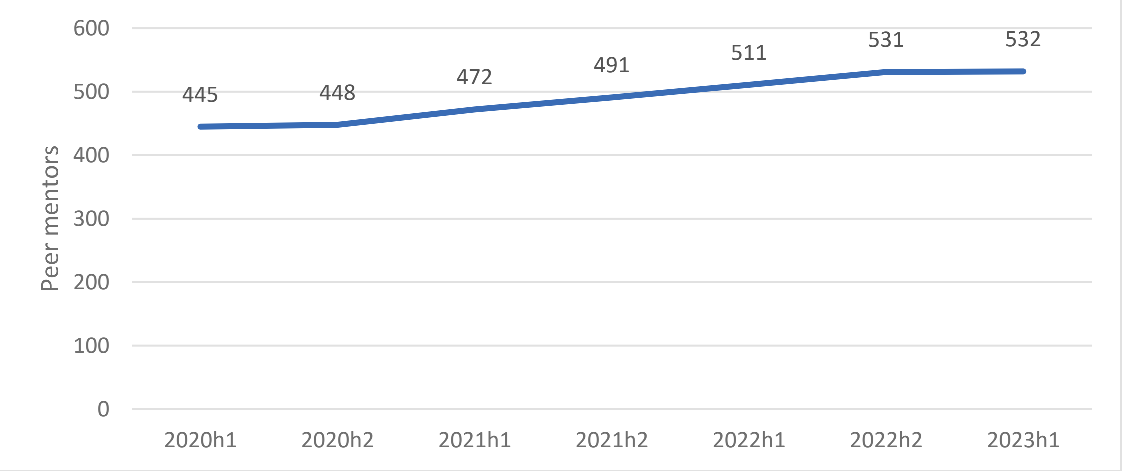
[13] All ACL-supported resource centers are required to have an external evaluation partner. Vanderbilt University serves as the external evaluator for the NPRC, determining whether the proposed intervention achieved its anticipated outcome(s), and documenting the "lessons learned"—both positive and negative—from the project that will be useful to people interested in replicating the intervention.

number of peer mentors has increased steadily over time, with a current total of 532 mentors (**Figure 2**).

Figure 2. Number of certified peer mentors



Source: NPRC. *Semi-Annual and Final Performance Monitoring Reports*, July 2020–July 2023.
Note: h1 represents the 6-month time period from January through June, and h2 represents the 6-month time period from July through December.

Outreach to Historically Underserved Populations

A key requirement of the NPRC grant funding is targeted service delivery to historically underserved communities. However, for the peer mentoring program, it is difficult to assess the degree to which peer mentors come from historically underserved populations. For example, although the four organizations with which the NPRC partners to implement peer mentoring collect data on the number of their affiliated mentors from underserved and underrepresented groups, NPRC staff do not systematically analyze these data. As of 2022, NPRC staff reported that 39 of the 511 peer mentors speak languages other than English. The majority (28 of 39) speak Spanish, and the remaining bilingual mentors speak German or Japanese. One partner organization interviewee described using the partnership with CDRF as a way to increase access to Spanish-speaking mentors, since their organization's population had a demand for that support and the organization did not have resources to meet those needs.

All four peer mentoring partner organizations acknowledge the importance of mentors from specific communities, but only one actively engages in targeted recruitment. The organization highlighted a demand for "culturally relevant" mentors, with specific reference to adolescent and Spanish-speaking individuals. NPRC expanded efforts to reach historically underrepresented groups and further diversify the PFSP mentor population include promoting the PFSP among women in communities of color, target matching of adolescent/young adult peers with similar aged mentors, and partnering with Paralyzed Veterans of America (PVA) to recruit more veterans as mentors.[14]

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[14] NPRC. *Semi-Annual Performance Report*, July 2023, Activities and Accomplishments, p. 12.

Training & Matching

To become certified, every peer mentor must complete a background check and attend an initial half-day training session. Of peer mentor survey respondents who indicated they had attended the initial certification training, 72% rated it moderately or extremely helpful (see peer mentor survey results, **Tables B-4 through B-5** in **Appendix B**). Similarly, peer mentors in the focus groups described it as thorough, comprehensive, and not overly difficult to complete. The initial training has been modified and adapted over time to reflect current needs. The initial certification training consists of four modules which address a range of topics:

1. **Finding a new normal after paralysis** – Managing change, rediscovery, enhancing QOL
2. **How to be an effective peer mentor** – The dos and don'ts of mentoring: Ethics of mentoring
3. **Interpersonal communication** – Communication tips, using verbal and nonverbal methods of communication
4. **Diversity, Equity, and Inclusion & Accessibility (DEIA**) – Promoting enhanced awareness and understanding of how peers with diverse backgrounds, cultures, ages, races, genders, sexualities, religions, types of injury, and beliefs can work together harmoniously

After training and screening, mentors are matched to a peer using demographic information obtained during the screening process (i.e., injury level and type of injury, age, sex, interests, and hobbies). Geographic location is not prioritized in matching, as most relationships are virtual. According to focus groups, overall, peer mentors were happy with their matches and agreed that matching based on level of injury was important. Peer mentor survey respondents recommended level of injury over any other characteristic as most important for matching mentors to peers, followed by age (average rank of 1.9 and 3.1, respectively, on a scale of 1 [most important] to 9 [least important]). See **Table B-5a** in **Appendix B**.

Communication and Mentoring Relationship

Peer mentors communicate with their peers through a variety of means, including telephone, text, email, videoconferencing, and face-to-face, though telephone is the most common communication methodology. NPRC staff indicated that a peer mentor may have one to three peers at any time, and the average number of encounters (any contact between a peer and their mentor) is between two and three, though nearly half of survey respondents (43%) indicated that mentoring relationships may also include just one or two interactions. **Exhibit 3** summarizes some of the differences between peer mentoring as organized by the NPRC and peer mentoring organized by other organizations.

Exhibit 3. Comparison of peer mentoring features, NPRC and other organizations

Feature of peer mentoring	NPRC's PFSP	Other organizations' peer mentoring for individuals with limited mobility
Matching criteria	Type of injury, paralyzing condition, sex, marriage (if appropriate), peer interest	Type of injury, location, sex, educational background, vocational background, peer interests, children, age range
Setting	Mostly virtual	Mostly in person and rarely virtual
Duration of relationship	Varies from 1–2 sessions to multiple years	Time-limited The relationships can be as short as a single week or visit, or as long as a few years.

Notably, focus group respondents indicated that nonresponse is sometimes a challenge in the peer mentoring program. Someone may request a mentor and not respond when their assigned peer mentor reaches out to them, or peers sometimes "disappear" or "drop off" from time to time. This lack of contact (52%) was also the most frequently mentioned challenge among peer mentor survey respondents (see **Table B-5b** in **Appendix B**).

Key PFSP Opportunities

Across data sources, a few key themes emerged from the team's evaluation of the NPRC's peer mentoring program.

- **Explore differences in peer mentor and peer mentee experiences with the PFSP.** Overall, most peer mentors had a positive experience with mentoring and felt their goals for participation were met. In contrast, the interviewed peers reported some challenges, and only some of the surveyed peers reported that their goals for participation were met.[15] **Table 6** summarizes the outcomes of peer mentor and peer survey responses.

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[15] Peer findings need to be interpreted with caution because of low response; 24 peers completed a survey and 2 peers were interviewed.

Table 6. Comparison of peer mentor and peer survey responses regarding outcomes

Outcome	Peer Mentor	Peer
In general, participation had effect on well-being that participant expected	84.8%	58.3%
Average improvement in selected goals before and after participation	0.9 (unweighted) 1.0 (weighted)	0.6 (unweighted) 0.6 (weighted)

Note: Participants were asked to rate the status of their selected goal before and after participation on a scale of 1 to 7. The average rating before participation was 5 for peer mentors and 3.4 for peers. Improvement was calculated by subtracting the rating prior to participation from the rating after participation, and then weighted by the rating the participant gave for how much paralysis impacts their selected goal.

Varied peer and peer mentor goals may explain some of these differences, with peer mentors describing a desire to give back to others (81% of survey respondents). Likewise, one focus group participant expressed seeing the program as “a great way to share my experience and help other people.” Peers have more complex priorities that may be more difficult to achieve solely from participating in the PFSP, including a desire to “learn about services for those living with paralysis” (46% of respondents), “gain practical advice about living with paralysis” (46% of respondents), and achieve “better mental health” (42% of respondents). See **Tables B-6 and B-7** in **Appendix B**.

- **Explore whether PFSP’s virtual mentoring format could be enhanced through different modes of communication (e.g., other organizations that serve a similar population use in-person peer mentoring), though PFSP participants did not describe virtual communication as a barrier in the mentoring relationship**. Rather, participants embraced a general perception that peer mentors could help any peer, regardless of location. All focus group participants were mentoring peers virtually in another state. See **Figure 3** for settings for all peer mentoring encounters for the PFSP January 2020 to June 2023.[16] Additionally, some focus group participants indicated that relationships that include texting with peers may be more satisfying and supportive than relationships without text communication.

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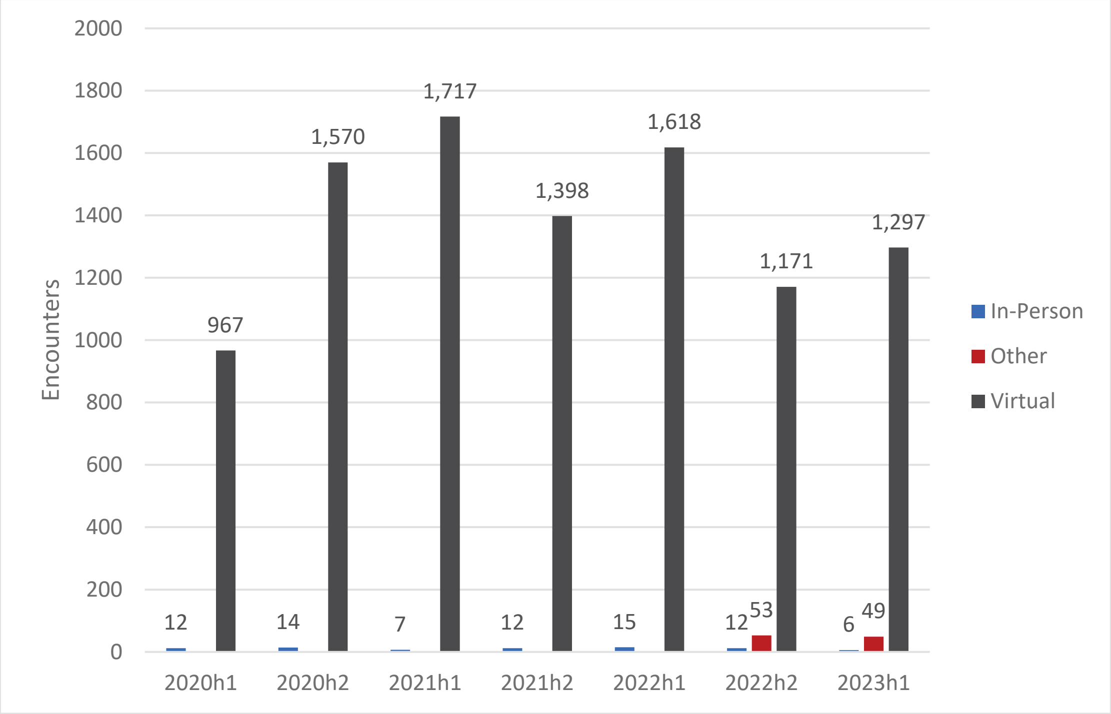
[16] Of note, this covers the reporting period during the time of the COVID-19 pandemic where in-person activities were limited.

Figure 3. Number of encounters between peers and mentors, by setting



Source: NPRC. Semi-Annual and Final Performance Monitoring Reports, July 2020–July 2023
Note: h1 represents the 6-month time period from January through June, and h2 represents the 6-month time period from July through December.

- **Enhance opportunities for peer mentors to be utilized by the PFSP program.** Peer mentors indicated disappointment in having fewer opportunities to mentor than anticipated. When asked about peer mentoring challenges, the most common response from surveyed peer mentors was receipt of too few requests to mentor (43%). See **Table B-5b** for all responses. Additionally, peer mentors described match "droughts," where the peer mentors would go for many months without being matched to any peers. A few focus group participants also expressed disappointment with the brief nature of some mentoring interactions, though most mentors were simply happy to help a peer in any capacity.

  The NPRC has recently taken the step to develop a peer mentor utilization report in the Paralysis Resource Center Database, which is intended to better identify mentors and help match them with compatible peers. This matching process should increase mentor matches and yield stronger relationships between peers and mentors.

- **Support peer mentors in helping peers find local resources.** In focus groups, peer mentors spoke positively about the volume of resources available to them, including webinars, blogs, videos, written materials, and the Facebook group. Similar survey findings show that the resource topic selected by peer mentors as the most helpful was how to find community-based resources (32%).

See **Table B-5b** for all responses.

Taken together, these findings indicate that there is an opportunity for the NPRC to ensure that mentors are aware of other ACL programs or other ways to coach peers in finding local services. For example, ACL also supports Aging and Disability Resource Centers (ADRCs). The NPRC might find ways to offer information on ADRCs and related resources for people living with paralysis and their caregivers. Given that most peers and mentors live in different communities and interact virtually, this need for local resources may represent an opportunity for NPRC to educate and support mentors.

Quality of Life Grants

QOL grants fund innovative ideas, build community capacity to expand access to activities for people living with paralysis, and facilitate partnerships across local organizations. As of 2022, key program activities include pre-award processes (e.g., outreach), selection of grantees, grantee support, and monitoring.

To learn more about the QOL grants program and to assess the outcomes of the QOL grants program for people living with paralysis, the team interviewed QOL grants program staff; conducted focus groups with QOL grantee representatives (N = 13 grants represented); administered a survey (N = 165 respondents representing 25 grants) to QOL grant end-users (i.e., people living with paralysis and their caregivers who participated in a QOL grantee program); and reviewed data collected by the NPRC and the NPRC's evaluation partner.[17] See **Table 7** for types of grant topics represented in focus groups and surveys. See the *Methods* section and the methods appendix (**Appendix A**) for more details.

Table 7. QOL grantee representation in data collection

Grant type		N grants represented in grantee focus groups	N grants represented in end-user survey
	Adaptive sports	3	11
	Fitness and wellness	1	4
	Respite or caregiving	--	4
	COVID-19 addressing social isolation	--	4
	Arts	1	1
	Therapeutic horseback riding	--	1

(Table continues on next page.)

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[17] Focus group participants included "2022 1st Cycle Direct Effect grants" grantees. In contrast, survey respondents were grant end users who were "2021 2nd Cycle Direct Effect and 2021 Priority Impact grantees." This difference explains the differing sample size for focus group and survey efforts. We selected a subset of prospective participant grantees based on those that met specific inclusion criteria (e.g., contact information, list of identifiable end-users).

Table 7. QOL grantee representation in data collection (continued)

Grant type	N grants represented in grantee focus groups	N grants represented in end-user survey
Accessible beach/dock/pier	2	--
Facility accessibility modifications	2	--
Transportation	1	--
Education	1	--
Service animal program	1	--
Assistive technology	1	--

As part of the grant award process, an external review committee of stakeholders (i.e., people living with paralysis, their caregivers, health care professionals, lawyers, and others in their support network) and an internal review committee (i.e., NPRC board members and select NPRC staff such as Information Specialists) work together to review grant applications and make awards. Following award, grantees are required to develop interim and final reports, which include project goals, measures, output, outcomes, impact, sustainability challenges and lessons learned. Grantees must also submit an evaluation survey.

Quality of Life Grant Projects

QOL grants often support unique projects that build community capacity, increasing access and opportunities for people living with paralysis and their supports. In turn, these grants also help the NPRC learn from existing projects how best to provide guidance or best practices for similar types of projects in the future. For example, one QOL grantee created accessible docks at multiple public marinas, using grant funds to help purchase and install solar-powered Hoyer lifts to support people living with paralysis to access boats. The grantee organization then hosted boating activities with local community members living with paralysis. This example highlights how QOL grants "create[d] fair and equitable experiences" for people living with paralysis, as a focus group participant noted. Another participant added, "[The NPRC's] broad definition of paralysis has opened up the grant process to more conditions and more organizations," highlighting the fact that NPRC QOL grants support direct participant benefits (e.g., improving accessibility for people living with paralysis), compared to other grant opportunities that tend to fund research and other indirect activities.

Participants appreciate that QOL grants help support specific projects that may not be funded through any other means.

Participants also shared that QOL grants help develop partnerships to improve community-wide capacity that supports people living with paralysis and other types of disabilities. For example, one participant described a partnership with several local organizations that serve diverse disability diagnoses. The individuals served by these other organizations can also benefit from projects funded by QOL grants (e.g., facility accessibility modifications, such as accessible playgrounds). Similarly, 60% of survey respondents strongly agreed that their QOL grant-funded project led to new collaborations with other organizations, and 65% strongly agreed that their project led to furthering existing collaborations.[18]

Quality of Life for People Living with Paralysis

Survey participants, including people living with paralysis, rated their experiences with QOL grantee organizations on a scale from 1 to 7, with 7 representing the best possible rating. The average improvement derived from QOL grants was 1.8 points weighted[19] and 1.9 unweighted (**Table 8**).[20] Additionally, 96.4% of respondents reported participation had the effect on their well-being that they expected.

Table 8. Quality of Life grant end-user ratings on selected outcomes

Question	Physical health (N = 66)	Improvement in abilities, skills, or knowledge (N = 64)	Access to services (N = 62)	Average across all outcomes (N = 446)
Before contacting this organization, to what extent did paralysis affect…?				
Average [on 1–7 scale]	5.2	5.1	4.5	4.6
Just prior to contact with this organization, how was…?				
Average [on 1–7 scale]	4.1	4.2	3.7	4.1
After contact with this organization, how is…?				
Average [on 1–7 scale]	5.8	5.9	5.9	5.9
Estimated improvement in…				
Average [pre/post change in 1–7 scale rating]	1.7	1.8	2.1	1.9
Average (weighted by extent of paralysis effect)	2	1.8	2.2	1.8

These favorable ratings may be attributable, in part, to alignment between the QOL grant projects and participant-selected goals. The most commonly reported participant goals were improved physical health (40.0% of respondents selected as one of their three goals); improved skills, abilities, and knowledge (38.8%); and increased access to services (37.6%). Grant types

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[18] NPRC. *Semi-Annual Performance Report*, July 2023, Appendices L-BB, pp. 105–106.

[19] Participants were asked to select up to three goals they hoped to achieve through participation. They were then asked to rate how impacted that goal is by paralysis, the status of the goal before participation, and the status of the goal after participation. Improvement was weighted by the extent to which the outcome is affected by paralysis.

[20] The average rating before participation was 4.1 on the 1–7 scale; therefore, on average, participants could only improve by 2.9.

represented in the survey included adaptive sports, fitness and wellness activities, caregiving or respite services, and others, which align with participant goals (see **Table 7**). See **Table B-8** for more information about selected goals and ratings of outcomes.

Participants also reported satisfaction with QOL grant projects, describing new opportunities the projects provide to people living with paralysis. Activities aim to provide a positive outlook on life and inclusion for people living with paralysis. Some QOL grantee focus group participants explained that QOL grant funds help reopen a door that some people living with paralysis thought was permanently closed. One shared, “It's a big emotional boost to people to realize you don't have to give up your old lifestyle completely, you know, because of an accident.” Another participant whose grant funded adaptive sports shared that the self-empowerment of the individuals they serve has improved, reporting, “We understand the power in adaptive recreation […] in increasing athletic identity, promoting confidence.”

Survey responses detailed in NPRC documents provided similar findings, with one respondent writing that “it was encouraging to see that life can go on happily, even with [paralysis].” The highest QOL outcome score for the end-user survey was for the statement “the program positively affected feelings of social/community inclusion,” with 57.6% selecting strongly agree. One theme developed from open-ended responses on outcomes in the end-user survey was “learning new possibilities of life with a disability.” Grantee representatives also rated some of the most significant outcomes as “inclusion or community integration” and “increased interactions between persons living with paralysis and community members” (more than 6.5 on a 7-point scale).[21] Separate surveys of QOL grantees and QOL grant end-users found that grant-supported programs positively affected feelings of social/community inclusion and helped respondents learn about new possibilities of life with a disability.

QOL grant recipients appreciate NPRC staff support for operationalizing their grants and increasing opportunities for successful grant implementation.

Role of NPRC QOL Grants Program Staff

When QOL grantees face project implementation challenges, NPRC staff are available to provide support. For example, QOL grants program staff members connect grantees to a variety of internal and external resources. Technical support examples include identifying accessible equipment installation vendors, addressing supply chain delays, supporting insurance-related questions, and recovering from internal staff turnover. A focus group participant described a scenario in which their organization sought to purchase equipment to implement their project, and NPRC staff connected them with known vendors that had the equipment for sale within the grantee’s budget. Interviewed NPRC staff added that these types of support enable the QOL grants program to develop relationships with grantees and promote successful implementation. Grantees also indicated that QOL staff support is invaluable, especially the webinars, guidance

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[21] NPRC. *Semi-Annual Performance Report*, July 2023, Appendices L-BB, p. 107.

on language regarding disability, and overall communication from staff throughout the grant process.

When asked about potential needs, QOL grantees provided ideas for additional supports the NPRC could provide that would be helpful such as more assistance with their internal evaluation tasks. Some of the Vanderbilt focus group participants also requested additional NPRC resources related to data collection and project assessment. Similarly, one of our focus group participant grantees noted that if there is a specific set of outcomes that the NPRC would like the grantees to evaluate, it would be helpful to develop and share a standard qualitative protocol of questions that grantees could pose to participants.

QOL Grantee Outreach to Historically Underserved Populations

Surveyed QOL grant end-users (i.e., people who benefit from the programs or services that the grants fund) are representative of the overall population living with paralysis in being mostly female (53%) and mostly white, with only 26% of respondents responding as non-white (see **Table B-1** for demographics of survey respondents). These findings suggest that the QOL grants program is reaching diverse participants by funding local programs in various communities. Notably, QOL grant end-users are slightly younger (81% under age 65) than the overall population living with paralysis (72% under age 65), which may not be surprising, given that many of the QOL grant-funded programs may appeal to a younger audience.

According to NPRC documents, in the past grant year, 37.4% of grants went to organizations in medically underserved areas. Late in 2022, the NPRC launched two new priority grant areas—Rural Unserved and Underserved, and Racial Equity—and these new grants represent 44.1% of all priority grants awarded in 2023 (i.e., 15 grants of 34 total).[22] The NPRC also provided a Diversity, Equity, Inclusion, Accessibility, and Cultural Awareness Training for current QOL grantees for the first time in the first half of 2023 which received high reviews from attendees.[23]

Interviewed QOL grants program staff described multiple partnerships with organizations that serve historically underserved populations, such as the Association of Programs for Rural Independent Living,[24] Tribal communities, historically Black colleges and universities (HBCUs), and others. According to the NPRC website, the QOL grants program "gives special consideration to organizations that serve returning wounded military and their families, and to those that provide targeted services to diverse cultural communities and/or underserved populations."[25]

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[22] NPRC, *Semi-Annual Performance Monitoring Reports*, January and July 2023, Performance Monitoring Tool.

[23] NPRC, *Semi-Annual Performance Monitoring Report*, Activities and Accomplishments, July 2023, p. 52. (The evaluation of the webinar only had seven respondents, however.)

[24] Within the Association, the program has connected with the University of Montana's Rural Institute for Inclusive Communities.

[25] CDRF. (2023). *Program Overview*. Christopher & Dana Reeve Foundation. https://www.christopherreeve.org/todays-care/get-support/grants-for-non-profits/program-overview/. Accessed September 2023.

Staff discussed challenges reaching historically underserved communities such as needing time to build trust and limited access to and low use of costly electronic technologies in some communities. Because the grant application is web-based, communities with limited computer or internet access (i.e., digital divide) may experience difficulty applying for QOL grants.

Key QOL Grant Opportunities

- **Enhance data collection.** Although QOL grants staff identify organizations that serve medically underserved areas and populations as part of their outreach efforts, they do not require grantees to collect demographic data from end-users with paralysis. Providing guidance to grantees to collect these individual participant data and share findings with ACL may make it easier to assess reach and impact on underserved and underrepresented populations. Beyond general data collection guidance, grantees also may benefit from more NPRC resources related to general program evaluation.
- **Build community capacity.** A prior evaluation that compared NPRC mini grants in four pilot states noted that the QOL program tends to fund organizations that are well established in the community.[26] The newer Building Community Capacity Initiative limits recent grantees from applying repeatedly within a 5-year period,[27] with the goal of creating more opportunities for new and lesser-known applicants. QOL staff also may want to offer additional capacity building grants to smaller or less mature organizations,[28] as recommended by the prior evaluation of pilot states, which could also extend reach into underserved areas.
- **Assess community alignment of QOL grants.** Our findings indicate that program participant goals are well aligned with the types of programs that NPRC QOL grants support. However, non-participants may have other goals or unmet needs. Future evaluative activities may include a more thorough assessment of the needs of the paralysis community broadly, not just existing program end-users, to determine how these needs are being met by QOL grants.

Both web pages and written resources are offered in multiple languages: Spanish, Chinese, Japanese, Korean, Vietnamese, Tagalog, Hindi, French, Russian, Portuguese, Italian, and German.

Promotional Activities, Outreach, and Collaboration

The NPRC engages in a number of activities to promote awareness of and access to their resources.

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[26] New Editions & The Lewin Group. (2021). *Paralysis Resource Center Evaluation: A Comparison of State and National Quality of Life Grant Programs*. https://acl.gov/sites/default/files/programs/2022-02/PRC_Pilot Evaluation_2020_Final report.pdf.

[27] CDRF. (2023). *Program Overview*. Christopher & Dana Reeve Foundation. https://www.christopherreeve.org/todays-care/get-support/grants-for-non-profits/program-overview/. Accessed September 22, 2023.

[28] New Editions & The Lewin Group, 2021.

Promotion with Digital Tools

NPRC relies heavily on their website to promote available services and resources for people living with paralysis, their families, and their support networks. The website connects members of the public to both written resources and Information Specialists, and it also serves as the vehicle for requesting peer and family mentors.

With the goal of increasing accessibility and community engagement, the NPRC completed its major website redesign in April 2023.[29] It is too soon to determine whether the website improvements affect user experience and engagement, though the number of global website page views continued to decrease in the first half of 2023, perhaps because pf prospective inquiries seeking information in other ways (e.g., social media). Nonetheless, the website seems to be optimized to attract visitors who are searching for information about paralysis, with over 63% of January–June 2023 website views originating from organic internet searches.[30]

The NPRC also continues to develop new online publications and resources that may help drive traffic to the website and reach new audiences. The number of English and Spanish blogs hosted on the website has increased, with 207 published as of June 2023, compared with 184 in 2022.[31] Although the number of website views has continued to decline, social media engagement across platforms has grown (see **Table 9**). The development and release of new online content, such as the December 2022 wheelchair comparison video series on CDRF's YouTube channel, appears to drive engagement with online resources. The continued growth of the NPRC social media presence may be suggestive of a shift in online engagement trends, underscoring the importance of participation on these platforms. More than 6% of the NPRC website traffic originates from social media posts, significantly more than generated by the paid search ads or links from emails.[32]

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[29] NPRC. *Semi-Annual Performance Report*, July 2023, Activities and Accomplishments, p. 20.

[30] Internal memo from the NPRC to RTI International.

[31] NPRC. *Semi-Annual Performance Report*, January 2023–June 2023, Appendix A, pp. 17–29.

[32] Internal memo from the NPRC to RTI International.

Table 9. Reach of NPRC promotion through digital media

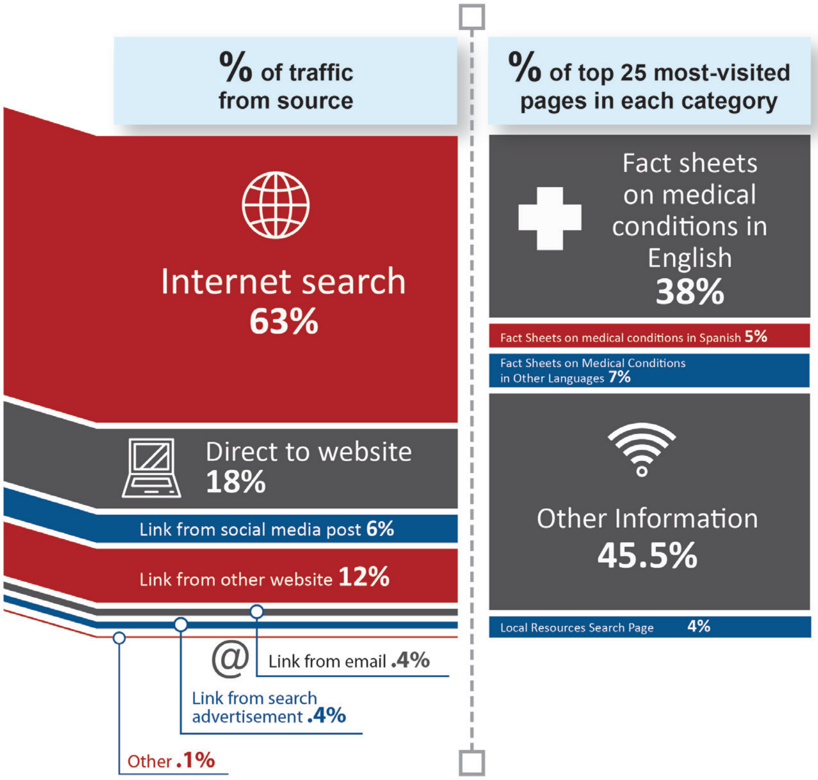
Digital media presence	As of June 2022	As of June 2023
Website views in most recent 6-month period	Approximately 2 million	Approximately 1.7 million
Number of blogs posted in most recent 6-month period	195 (177 in English, 18 in Spanish)	207 (184 in English, 23 in Spanish)
Facebook	More than 66,000 followers	More than 68,000 followers
YouTube	About 8,000–15,000 videos viewed per month, with 6,600 subscribers	About 14,000–15,500 videos viewed per month, with 7,110 subscribers
X (formerly Twitter)	More than 22,000 followers	More than 22,000 followers
Instagram	More than 17,000 followers	More than 18,000 followers

Sources: NPRC, *Semi-Annual Performance Monitoring Report*, July 2022, Appendix A, pp. 18–19, 21–22; NPRC, *Semi-Annual Performance Monitoring Report*, July 2023, Appendix A, pp. 9–10, Appendix I, pp. 17–29.

The NPRC also continues to expand the reach of its resources through virtual events, which attract increased participation by new individuals.

Community Outreach

The NPRC offers in-person and virtual outreach to individuals living with paralysis, their caregivers, and their support networks. Virtual outreach includes multiple webinar series, including "Ask Nurse Linda" and "Living Well with Dr. John," which address practical issues, physical health, mental health, and overall well-being while living with paralysis or caring for someone who is living with paralysis.



The COVID-19 pandemic and associated quarantines and staff limitations reduced some of the opportunities for NPRC outreach and education, ushering in an opportunity for NPRC staff to evaluate and redesign some of the previously existing services. The recent redesign of the NPRC Outreach & Education initiative represents one of the biggest changes to take place over the past year, pivoting the initial design to a fully staffed program.[33] The team now includes six full-time staff members, including a director, dedicated to outreach and community education. These staff conducted a total of 30 webinars and 27 presentations between January and June 2023.[34] One of these presentations was hosted at a new venue for the NPRC: the South by Southwest (SXSW) conference,[35] which boasts an attendance of approximately 300,000 individuals.

Webinars in particular have proven a useful means by which to engage community members. Between July 2022 and June 2023, community education webinars have had 3,446 attendees.[36] The webinars not only educate viewers on available NPRC programs and services, but they also facilitate day-to-day living and life planning for individuals with paralysis. For example, the NPRC hosted a financial literacy webinar that helped viewers explore investment options and programs, such as the ABLE account[37] and its benefits for people living with disabilities.

Collaboration and Partnership with Other Organizations

CDRF, which operates the NPRC, is an active member in several multi-organizational coalitions with similar interests and policy priorities. NPRC staff participate on coalition steering committees or on coalition task forces that target specific policy topics. NPRC staff also cultivate partnerships with other organizations to share educational policy materials, such as policy briefs, for broader dissemination to their respective communities. **Table 10** highlights some of these coalition partnerships. Between January and June 2023, NPRC staff attended 53 Coalition meetings.[38]

Table 10. Coalitions in which NPRC staff participate

Coalition
Air Carrier Access Act
Consortium for Constituents with Disabilities
Coalition to Preserve Rehabilitation
Disability Rights and Resources Center
Independence through Enhanced Medicare and Medicaid Coalition
National Pressure Injury Advisory Panel Patient Advisory Council

Source: NPRC. *Semi-Annual Performance Report*, July 2023, Appendix A, pp. 14–15.

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[33] NPRC. *Semi-Annual Performance Report*, July 2023, Activities and Accomplishments, p. 25.

[34] NPRC. *Semi-Annual Performance Report*, July 2023, Appendix I, pp. 30–31.

[35] SXSW is a nationally acclaimed arts festival (film, music, technology, education, and culture) held annually in Austin, TX. https://www.sxsw.com

[36] NPRC. Semi-Annual Performance Monitoring Reports, January 2023 and July 2023.

[37] ABLE National Resource Center. (2023). *What is ABLE?* https://www.ablenrc.org/get-started/what-is-able/

[38] NPRC. *Semi-Annual Performance Report*, July 2023, Activities and Accomplishments, p. 39.

Military and Veterans Program (MVP)

The MVP offers specific NPRC outreach and resources to veterans and members of the U.S. military. MVP volunteers are retired service members or civilians who help forge links between Reeve Foundation programming and supports offered via the Department of Veterans Affairs (VA) or other veteran services. MVP resources include written materials, videos, and live presentations on topics related to active military and veterans benefits, such as those available through the VA. Facebook advertising campaigns around Memorial Day and Veterans Day also promote the availability of focused MVP materials. In addition, the MVP tracks the numbers of MVP-produced materials distributed and downloaded, as well as how many active military and veterans receive services from the other NPRC programs.

By increasing partnerships between the MVP and other veteran services organizations, the NPRC is increasing awareness of both the MVP services and NPRC resources. For example, the MVP was added to the Wounded Warrior Project resource directory, which expands program reach and services to individuals who may not have already been aware of MVP.[40] The MVP also formed partnerships with some state veterans' affairs offices and county veterans service offices, including offices in South Carolina, Florida, Georgia, and Alabama.[41] These partnerships enable the NPRC to better engage and support individuals with paralysis in rural and historically medically underserved areas.

Between January and June 23, 2023, MVP staff held 36 meetings and presentations (16 virtual) and exhibited at 8 events to educate staff on MVP supports. A total of 608 attendees were present at meetings, and 1,443 attendees were present at exhibiting events.[39]

Public Policy

The NPRC's Public Policy work educates the public on key policy priorities pertinent to the paralysis community. NPRC staff roles include the Director of Public Policy, the Director of Coalitions, and the Grassroots Director. Program priorities include educating policymakers on the experiences of individuals living with paralysis, building coalitions and grassroots relationships for localized policy education, and providing the paralysis community with education to pursue their own personal advocacy. Although the Reeve Foundation may engage in privately-funded advocacy activities, the ACL grant that supports the NPRC may be used only for educational purposes.

NPRC's policy staff have focused on setting policy priorities to guide education activities, often via NPRC participant polling and supporting public policy education work developed in collaboration with coalitions (see above). As of 2022, they have also focused on education around insurance coverage for services relevant for individuals living with paralysis, including

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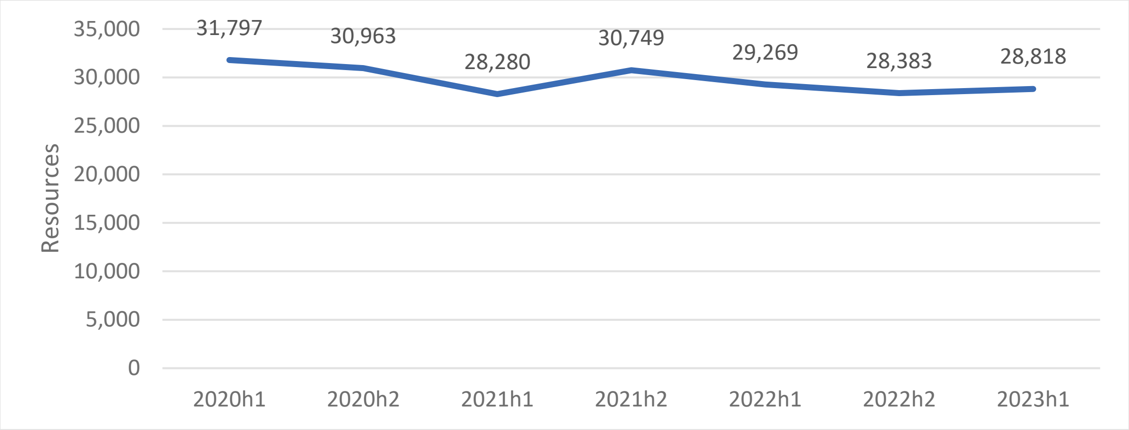
[39] NPRC. *Semi-Annual Performance Report*, July 2023, Activities and Accomplishments, p. 43.
[40] NPRC. *Semi-Annual Performance Report*, July 2023 Activities and Accomplishments, p. 42.
[41] NPRC. *Semi-Annual Performance Report*, July 2023, Activities and Accomplishments, p. 41.

coverage for Durable Medical Equipment, and on topics like air travel for people living with disabilities.

Information Services

IS produces and distributes resources (e.g., guides, fact sheets, videos, brochures, booklets, and wallet cards) to help people living with paralysis make informed decisions about their own health and livelihood. These resources are distributed via the NPRC website, direct mailings to people who have contacted Information Specialists, outreach events, and at conferences. IS resource distribution declined steadily between the second half of 2021 and the second half of 2022, increasing between the second half of 2022 and the first half of 2023 (see **Figure 4** below)—perhaps, in part, because there are more conference and in-person meeting opportunities in the aftermath of COVID-19 quarantines. Notably, the increase in distribution of Paralysis Resource Guides during this reporting period is particularly large, increasing from 2,909 in the second half of 2022 to 5,572 in the first half of 2023 (see **Figures 4 and 5** below).

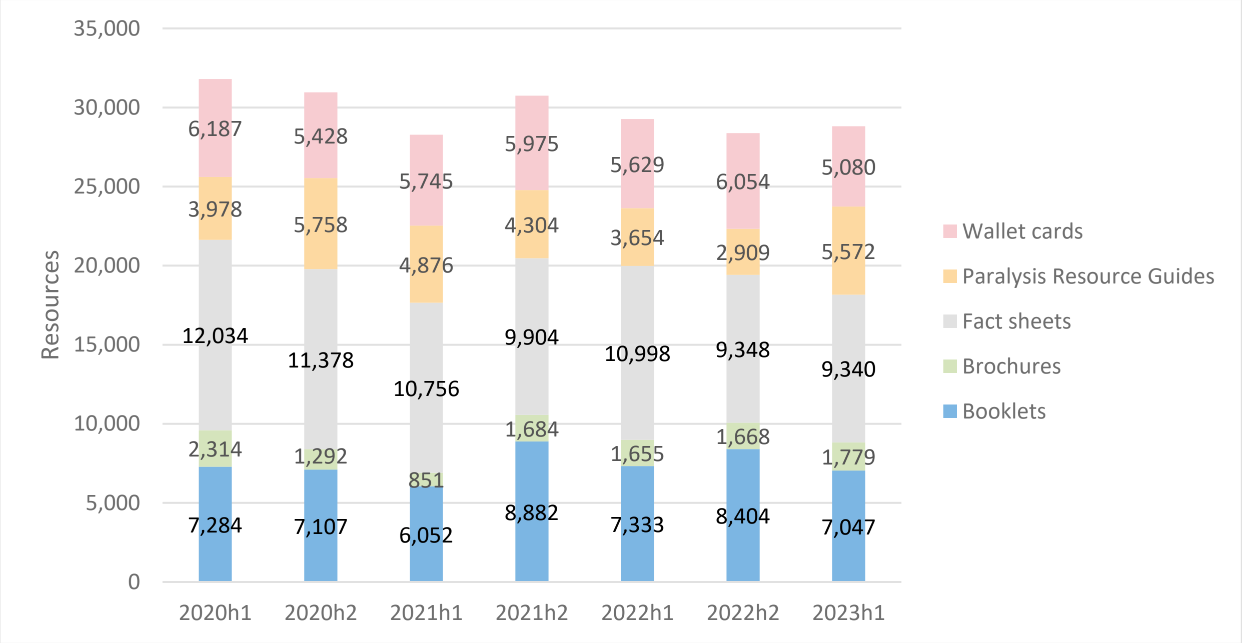
Figure 4. IS resources distributed, 2020–2023



Source: NPRC. *Semi-Annual and Final Performance Monitoring Reports*, July 2020–July 2023.

Note: h1 represents the 6-month time period from January through June, and h2 represents the 6-month time period from July through December.

Figure 5. IS resource distribution, by type



Source: NPRC. *Semi-Annual and Final Performance Monitoring Reports*, July 2020–July 2023.
Note: h1 represents the 6-month time period from January through June, and h2 represents the 6-month time period from July through December.

Findings indicate that fact sheets and booklets were among the most frequently distributed resources (**Table 11**).

Table 11. Summary statistics for Information Services, January 2020–June 2023

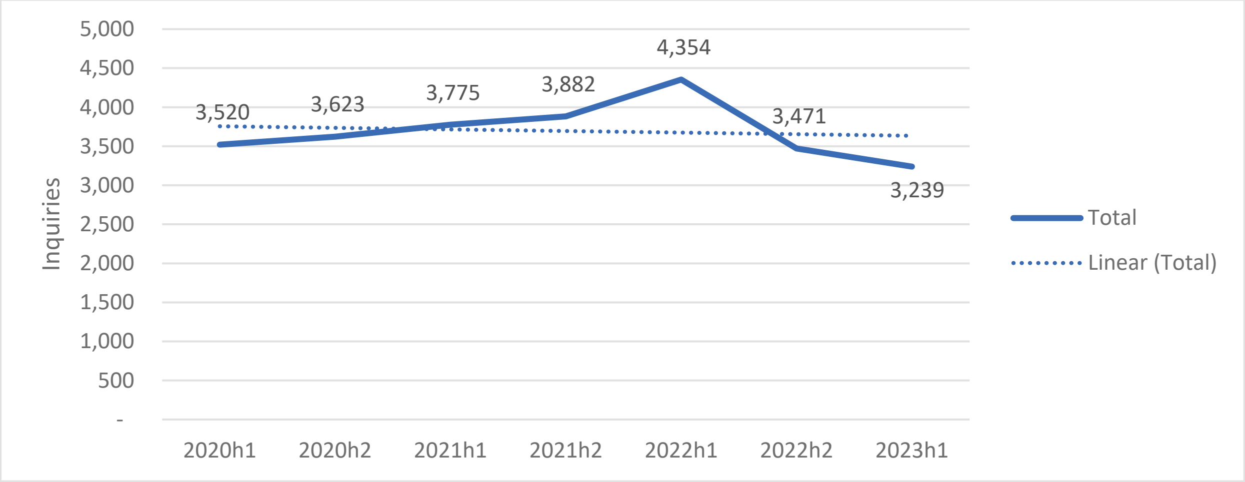
Key Information Services metrics	Half-year averages [a]
Information Specialist inquiries	**3,695 inquiries**
Total resources distributed	**29,751 resources distributed**
Fact sheets distributed	10,537 fact sheets distributed
Booklets distributed	7,444 booklets distributed
Wallet cards distributed	5,728 wallet cards distributed
Paralysis Resource Guides (PRG) distributed	4,436 PRGs distributed
Brochures distributed	1,606 brochures distributed

Source: NPRC. *Semi-Annual and Final Performance Monitoring Reports*, July 2020–July 2023.

[a] Averages are based on the reported numbers from CDRF for each 6-month reporting period, January–June (the July reports) or July–December (the January reports). The averages for the five time periods reported between January 2020 and June 2023 were added together and divided by 5 to derive the averages.

As demonstrated in **Figure 6**, the number of inquiries to Information Specialists has declined since the high of 4,354 in the first half of 2022. Fewer inquiries may be explained, in part, by the website redesign, since both the inquiry decrease and website update occurred during the second half of 2022 and the first half of 2023. Notably, for the second half of 2022, 33% of inquiries were from caregivers,[42] suggesting that the IS team is a key resource for strengthening support networks for those living with paralysis. The proportion of inquiries by various demographic characteristics (i.e., sex, language, ethnicity, and race) remained consistent across years (data not shown).

Figure 6. Number of inquiries to Information Specialists



Source: NPRC. *Semi-Annual and Final Performance Monitoring Reports*, January 2020–June 2023.
Note: h1 represents the 6-month time period from January through June, and h2 represents the 6-month time period from July through December.

IS Inquiries and Referrals

Once an individual contacts IS, inquiries are assigned to one of the six Information Specialists. Information Specialists are instructed to make multiple attempts to reach an individual to ensure that they receive the help they need (see **Figure 7** for an overview of the inquiry response process). If Information Specialists are unable to address all questions, callers will be referred to other NPRC programs and contracted services. If needed, Specialists may also refer callers to community resources outside of the NPRC.

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[42] NPRC. Semi-Annual and Final Performance Monitoring Reports, July–December 2022, p. 2.

The NPRC has created state-specific fact sheets to help clients find local resources, and a map on the NPRC website enables individuals to navigate local resources. Information Specialists also refer individuals to the United Way 2-1-1 help line for information and referral services to health, human, and social service organizations in their area.

Examples of External Resources

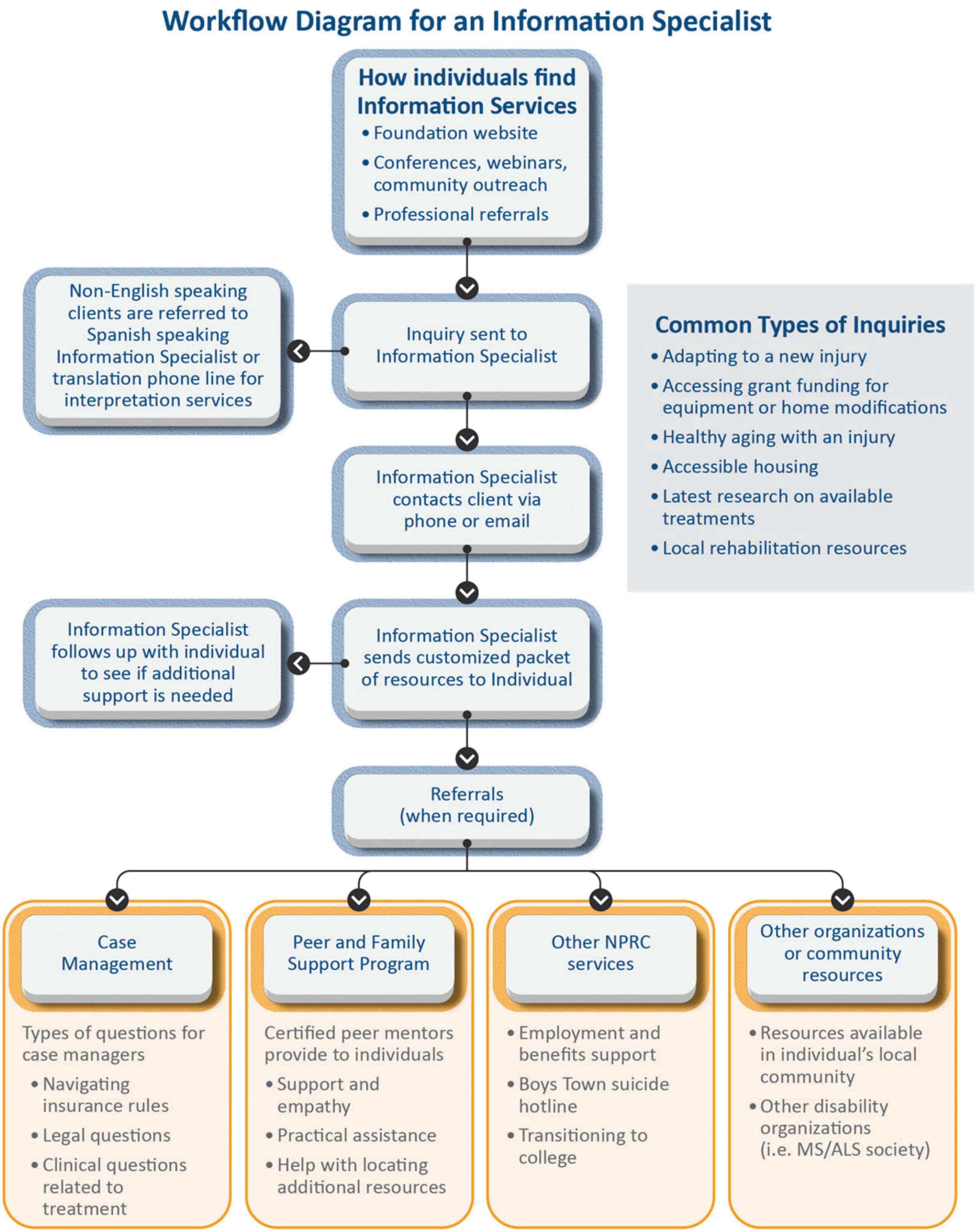
- 2-1-1 help line
- National Multiple Sclerosis Society
- Local agencies on aging
- Independent living centers
- Medical equipment loaning programs

Common Internal Referrals

- Case Manager Services
- Ask Nurse Linda
- Peer and Family Support Program
- Transitioning to College Services
- Boys Town Suicide Hotline
- Grantees of the QOL grants program
- Military and Veterans Program
- Pre-employment benefits analyst

Lastly, Information Specialists may refer clients to condition-specific organizations. For example, someone living with MS may receive a referral to the National Multiple Sclerosis Society. Specialists have access to fact sheets describing the services provided by other national and community-based organizations, including local area agencies on aging, independent living centers, and loan closets where clients may be able to borrow needed medical equipment.

Figure 7. IS Workflow Diagram



How individuals find Information Services
- Foundation website
- Conferences, webinars, community outreach
- Professional referrals

Inquiry sent to Information Specialist

Non-English speaking clients are referred to Spanish speaking Information Specialist or translation phone line for interpretation services

Information Specialist contacts client via phone or email

Information Specialist sends customized packet of resources to Individual

Information Specialist follows up with individual to see if additional support is needed

Referrals (when required)

Common Types of Inquiries
- Adapting to a new injury
- Accessing grant funding for equipment or home modifications
- Healthy aging with an injury
- Accessible housing
- Latest research on available treatments
- Local rehabilitation resources

Case Management

Types of questions for case managers
- Navigating insurance rules
- Legal questions
- Clinical questions related to treatment

Peer and Family Support Program

Certified peer mentors provide to individuals
- Support and empathy
- Practical assistance
- Help with locating additional resources

Other NPRC services
- Employment and benefits support
- Boys Town suicide hotline
- Transitioning to college

Other organizations or community resources
- Resources available in individual's local community
- Other disability organizations (i.e. MS/ALS society)

IS Outreach to Historically Underserved Populations

The IS team makes a concerted effort to meet the needs of all populations. For example, the team recently expanded assistance hours to 7am–12am ET, where previously the hours were 9am–8pm ET.[43] This change increases accessibility across time zones and enables individuals with daytime obligations to have more opportunities to call outside of traditional business hours. To reach historically underrepresented groups, Information Specialists also attend conferences to expand their reach to specific populations.

Focusing on rural populations, IS partners with the QOL grants program, which has grantees who support rural underserved and unserved communities. In addition, the NPRC has worked to connect with rural independent living centers and has increased awareness by posting billboards in rural areas.

Between 2022 and 2023, the NPRC also continued its work on subtitling and translating resources into additional languages. The IS team has developed specific social media campaigns and targeted outreach materials, including NPRC webpages available as "microsites" in seven languages: Spanish, Vietnamese, Hindi, Tagalog, Portuguese, French, and Chinese. Of note, they subtitled 90 videos in Hindi and Portuguese during the second half of 2022, produced and printed a fifth edition of the Spanish Paralysis Resource Guide in August 2022, updated both NPRC factsheets on COVID-19 and made them available in nine languages, and created a new fact sheet specifically about Hispanic and Latino Disability Resources.[44] The NPRC also worked on translating materials into the seven aforementioned languages, as well as Korean and Italian.[45]

NPRC is working to widen its reach by producing materials that can be viewed with a screen reader, translating certain resources into Braille, offering American Sign Language interpretation at events, and adopting live captioning on videos. The NPRC also makes its resources available on a flash drive, so clients may use eye gaze technology to access them.[46]

When scheduling an appointment with Information Specialists, clients are able to choose their preferred spoken language and reach interpreters in real time. Interviewees reported that besides English, Spanish and Hindi are the most common language requests they receive. Spanish-speaking clients are directly assigned to one of two bilingual Information Specialists, while other specialists can assist callers in any language with translation services. Information Specialists also have access to Trados[47] software to assist with translation. Resources and materials are readily available in Spanish, and other resources are translated as needed.

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[43] NPRC. *Semi-Annual and Final Performance Monitoring Reports*, July 2023, Activities and Accomplishments, p. 1.

[44] NPRC. *Semi-Annual and Final Performance Monitoring Reports*, July 2023, Activities and Accomplishments, pp. 5–6.

[45] NPRC. *Semi-Annual and Final Performance Monitoring Reports*, July 2023, Activities and Accomplishments, p. 6.

[46] NPRC. *Semi-Annual and Final Performance Monitoring Reports*, July 2023, Activities and Accomplishments, pp. 6–7.

[47] Trados. (n.d.) *Trados Studio*. https://www.trados.com/product/studio/. Accessed September 2023.

Individual resources which have been previously translated are saved so they can be used again as needed.

Reporting and Feedback

The IS program ensures consistency and quality in Information Specialists' client interactions by maintaining a detailed database of IS interactions. Senior IS staff members have developed a quality check process to review other specialists' responses to clients. To track the work completed by Information Specialists, IS has a database with each specialist's caseload, the number of emails sent, and how quickly specialists respond to inquiries. Through this database, the IS program is able to track topic trends broadly. Each specialist must meet certain goals every month based on database metrics. A specialist's goals might include closing every inquiry within a week or closing a certain number of inquiries every month.

To help IS staff improve their performance, the NPRC conducts an annual client interactions survey in partnership with Vanderbilt University to gather feedback. The most recent Vanderbilt survey findings suggest that the IS team and online resources are critical for clients: when asked if they recalled seeking information from an Information Specialist by telephone or by website, 129 of 144 survey respondents in the second half of 2022 (90%) and 132 of 148 respondents in the first half of 2023 (89%) responded affirmatively. Additionally, survey respondents appeared to be very satisfied with the IS program: On a scale of 1–6, they reported 4.3–5.1 satisfaction in 2022 and 4.6–5.3 satisfaction in 2023.[48]

Key Information Services Opportunities

- **Continue assessing resource distribution.** Since use of some IS resources has trended downward in recent years, while interest in other resources (e.g., fact sheets) has remained strong, assessing which resources are most popular will ensure that the NPRC program staff are prioritizing creation and distribution of the most useful resources.
- **Evaluate website use.** Since the website was recently updated, it will be important to track web traffic in the coming months to determine how the website updates are impacting site use and access.
- **Track effectiveness of expanded outreach efforts.** Recent efforts to enhance access (e.g., extended IS telephone hours, specific outreach to rural communities) can expand the reach of IS. It will be important to evaluate how successful these changes may be (e.g., reviewing what percentage of IS calls come in during the newly extended hours, reviewing how many callers may reside in rural zip codes).

CROSS-PROGRAM FINDINGS

Recognizing that all four programs within the NPRC support individuals living with paralysis, their families, and their caregivers in varied ways, the team examined cross-respondent findings

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[48] NPRC. Semi-Annual and Final Performance Monitoring Reports, January–June 2023, Appendix A.

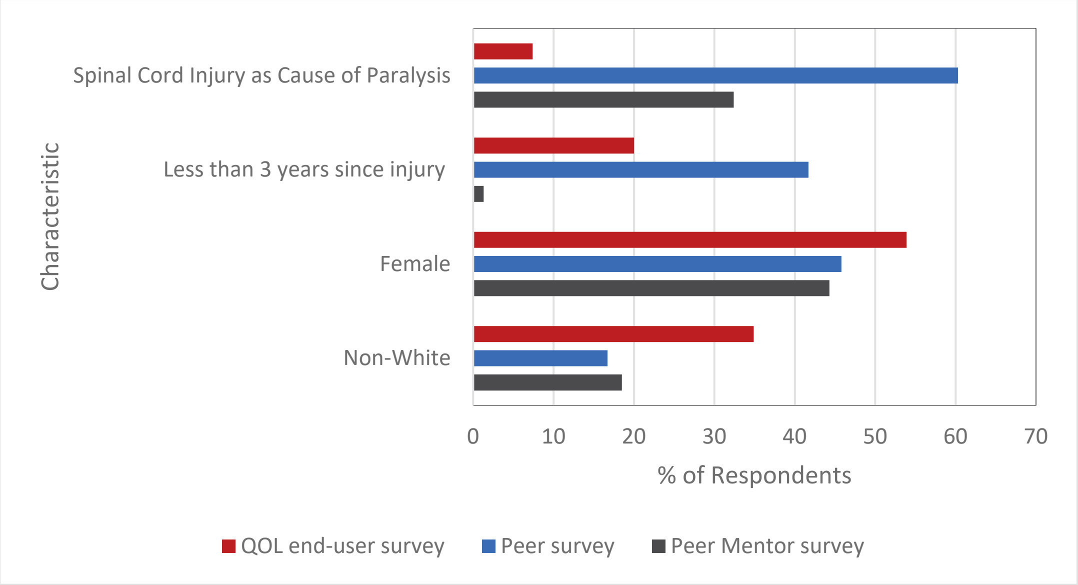
to the three surveys in demographics, experiences, and program outcomes. Understanding these findings together helps to provide a bigger-picture view of what is working well and where there may be new opportunities for the NPRC. The main findings from this comparison were:

- Although demographic characteristics of mentor respondents and QOL grantee end-user respondents were broadly similar, there were some differences in sex, cause of paralysis, and time since paralysis onset.
- In general, QOL grantee end-user respondents and respondents to the survey of peers were seeking tangible improvements to their daily lives. Conversely, respondents to the survey of peer mentors were looking for deeper connections to the community.
- Across all goals, QOL grantee end-user respondents reported the greatest average improvement, while respondents to the survey of peer mentors and respondents to the survey of peers reported only modest average improvement.
- Peer mentor respondents and QOL grantee end-user respondents overwhelmingly reported that the program had the expected effect on their well-being. In contrast, only a narrow majority of respondents to the survey of peers reported that participation had the expected effect.

Demographic and Other Characteristics of Survey Respondents

Although we conducted three surveys, only two surveys had sufficient numbers of responses to compare the respondent characteristics: the peer mentor survey and the QOL end-user survey. We found generally similar populations responding to each survey, with some exceptions for sex, cause of paralysis, and time since paralysis onset between the two groups of respondents (**Figure 8** and **Table 12** below). The difference in the sex distribution is unlikely to be explained by a characteristic of the programs themselves. Respondents to the survey of peer mentors were nearly evenly split between female and male, while respondents to the survey of QOL grantee end-users were more likely to be female.

Figure 8. Survey respondent characteristics



On the other hand, the differences in cause of paralysis and time since paralysis may reflect a true difference in the types of people inclined to participate in each type of program. Among respondents to the survey of peer mentors, a large majority reported an SCI that occurred more than 5 years ago. If peer mentor survey respondents are representative of the population of peer mentors, this finding may indicate that some peer mentor partner organizations are recruiting more mentors with this cause of paralysis. It is also expected that mentors would have had more time living with an injury than others, since they are providing advice about their experiences to others. In contrast, respondents to the survey of QOL grantee end-users were more evenly distributed in terms of cause of paralysis and time since paralysis, with notable representation by those with spinal cord injury, disease, or syndrome; stroke; or brain injury; and time since paralysis ranging from 1 year to 10 years or more. See **Table B-1** in **Appendix B** for complete sociodemographic and other characteristics of survey respondents.

Table 12. Sociodemographic and other characteristics of survey respondents

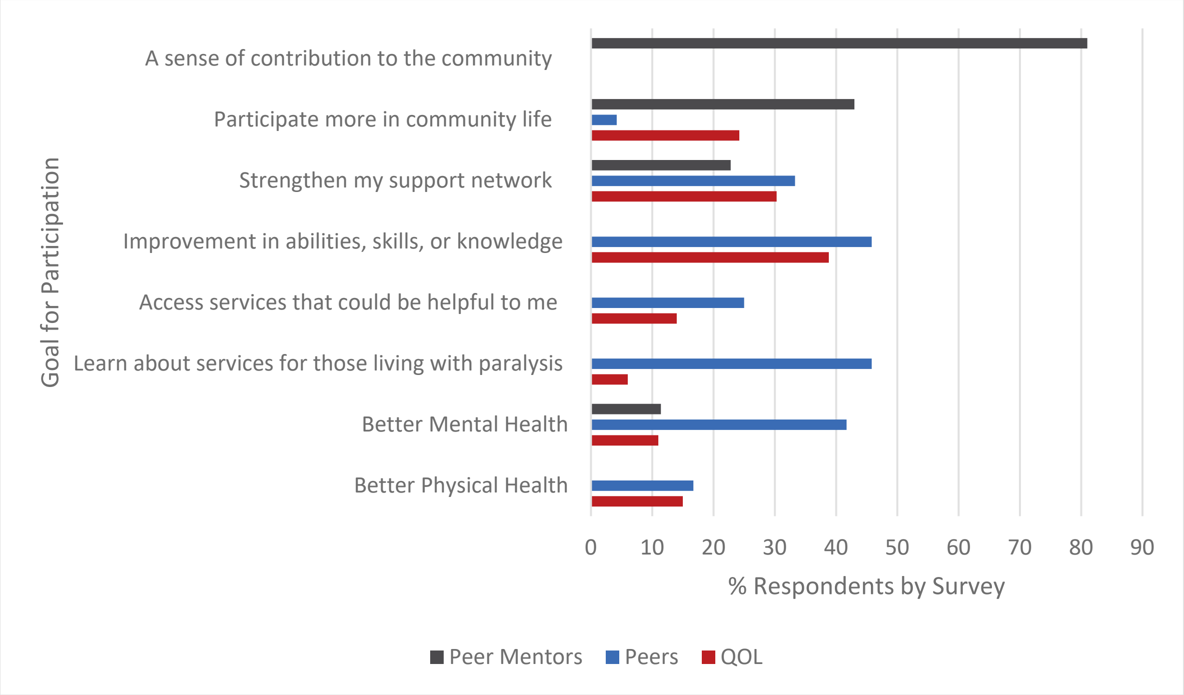
Characteristic	Respondents to the survey of peer mentors		Respondents to the survey of QOL grantee end-users	
Variable	N	%	N	%
Gender identity				
Female	35	44.3	89	53.9
Male	38	48.1	67	40.6
Transgender	--	--	1	0.6
Two-Spirit	--	--	--	--
Other	--	--	--	--
DK, PNA, Missing	6	7.6	8	4.8
Paralysis cause*				
Spinal cord injury	68	80.0	52	28.6
Brain injury	4	4.7	20	11.0
Disease or syndrome	4	4.7	65	35.7
Result of surgical or medical procedure	4	4.7	5	2.7
Stroke	--	--	21	11.5
Other	--	--	5	2.7
DK, PNA, Missing	5	5.9	14	7.7
Time since paralysis onset				
Less than 1 year	--	--	2	1.2
1 year to less than 3 years	1	1.3	31	18.8
3 years to less than 5 years	4	5.1	19	11.5
5 years to less than 10 years	11	13.9	27	16.4
10 or more years	57	72.2	68	41.2
DK, PNA, Missing	6	7.6	19	10.9

* Respondents could select all that apply.
DK = don’t know; PNA = prefer not to answer

Participation Goals

Respondent goals also differed by program (**Figure 9** below). Broadly speaking, QOL grantee end-user respondents and respondents to the survey of peers were seeking tangible improvement (e.g., improvement in abilities, skills, or knowledge; access to services that could be helpful; or practical advice about living with paralysis). In contrast, respondents to the survey of peer mentors were more community minded, hoping to gain a sense of contribution to the community, participate more in community life, or improve ability to relate to others. See **Tables B-6 through B-8** in **Appendix B** for details of goals and ratings of improvement for respondents to each survey.

Figure 9. Respondent participation goals



Ratings of Improvement

Across all goals, QOL grantee end-user respondents reported the greatest improvement from before to after participation with an average improvement of 1.9 (unweighted).[49] Respondents to the survey of peer mentors and respondents to the survey of peers reported only modest average improvement, with improvements of 0.9 and 0.6 (unweighted), respectively (**Figure 10** below). With respect to specific goals, QOL grantee end-user respondents reported moderate improvement on nearly every outcome they sought to improve through participation in the QOL grantee's program, with the greatest improvements to learning about services for those living with paralysis and accessing services that could be helpful. Mentor respondents reported modest improvement to strengthening support networks and sense of contribution to the community—areas that align with their reported goals. Finally, peer survey respondents reported improvement on average as well, though it was smaller than that reported by mentor respondents. See **Tables B-6 through B-8** in **Appendix B** for details of goals and ratings of improvement for respondents to each survey.

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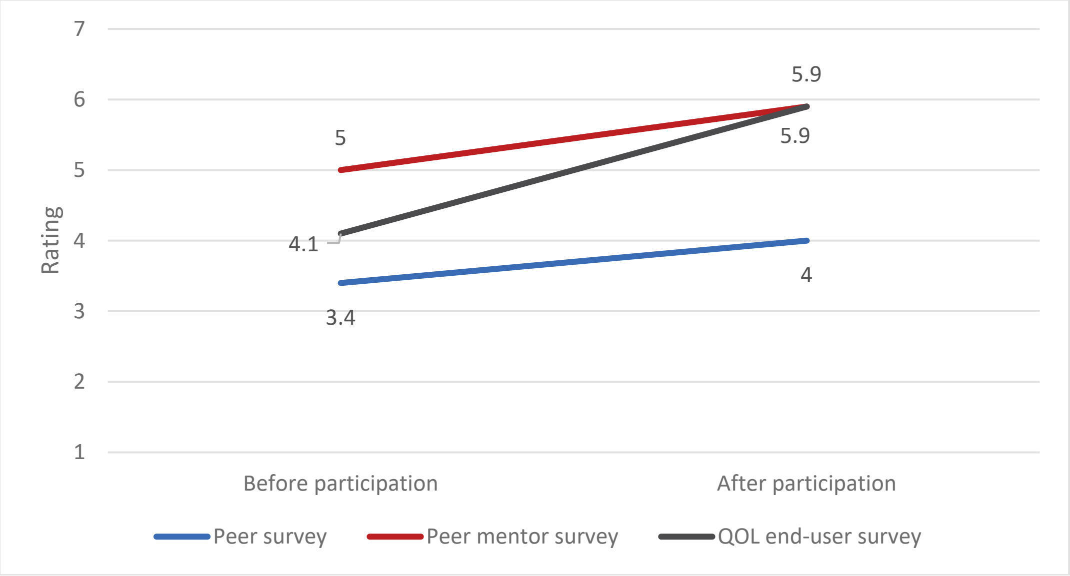
[49] Survey respondents provided ratings of a selected goal just prior to contact with the program compared to after contact with the program, each given on a 7-point scale for which 1 represents "poor" and 7 represents "excellent." Improvement ratings were calculated by comparing these before and after ratings. A calculated value of -6 represents the largest possible decline, and a value of 6 represents the largest possible improvement.

Figure 10. Comparison of average ratings (unweighted) before and after peer mentoring participation, by survey



Note: This figure illustrates the average, unweighted ratings just prior to program participation, compared to those after participation, for all outcomes that respondents reported they sought to improve through participation by survey. The left column corresponds to the pre-participation rating, and the right column corresponds to the post-participation rating, each on a seven-point scale, where a rating of 1 is "poor" and a rating of 7 is "excellent."

A separate survey question asked if participation in the given program had the expected effect on well-being (**Table 13** below). Respondents to the survey of peer mentors and respondents to the survey of QOL grantee end-users overwhelmingly reported that the program did have the expected effect (84.8% of peer mentor respondents and 96.4% of QOL grantee end-user respondents), whereas just over half of peer survey respondents reported that participation had the expected effect on well-being (58.3%).

Table 13. Programs meeting participants' expectations

Question/Response	Respondents to survey of peer mentors		Respondents to survey of peers		Respondents to survey of QOL grantee end-users	
Overall, did participation in [program] have the effect on your well-being that you expected?	N	%	N	%	N	%
Yes	67	84.8	14	58.3	159	96.4
No	7	8.9	10	41.7	6	3.6
Missing	5	6.3	--	--	--	--

One possible explanation for the larger improvement reports among QOL grantee end-user respondents compared to peers and mentors may be the receipt of tangible activities and services. In contrast, peer mentoring is an activity that might be attempting to address a more complex set of individualized goals. Such goals may take longer to improve or may not be as easily measured as those community-level goals impacted by the QOL grantee program. In addition, while the peer mentoring program seems to align with the goals of mentors, there may be some misalignment with the goals of peer mentees. Survey results and focus group/interview findings point to a difference between mentor and mentee experiences with the PFSP. Compared with peer mentors, fewer surveyed peers reported that their goals for participation were met. This difference may be attributed to the different goals each had for participation (e.g., giving back to the community for mentors vs. improved mental health and information to services for peers), as previously discussed.

DISCUSSION

Six research questions guided this evaluation to understand the outcomes the NPRC has for individuals living with paralysis, their caregivers, and their support networks. **We found that various components of the NPRC contributed to these outcomes to a differing degree, but there is evidence that the NPRC is positively affecting these outcomes through the combination of services and programming.**

To what extent do individuals living with paralysis of all ages, their families, and their support systems realize improvement in health and quality of life?

Various aspects of QOL are addressed by each NPRC program, and the extent of the impact differs by program as well. <u>The QOL grants program</u>, which is the largest NPRC program, appears to have the largest impact on QOL, per survey findings. The program improves various aspects of QOL including physical health and feelings of inclusion/belonging through funding community activities and accessibility improvements (e.g., adaptive sports). The <u>PFSP</u> improves QOL for peer mentors through an opportunity to help others and may improve mental health for peers. The <u>IS team</u> provides one-on-one support to callers in times of crisis and serves as a first stop for information. IS addresses QOL needs by developing health-related content and resources that equip individuals with paralysis and those caring for these individuals with knowledge relevant to their day-to-day lives and needs.

To what extent does the NPRC raise awareness about relevant services to members of the target populations?

The NPRC's Promotional Activities, Outreach, and Collaboration and IS raise awareness about relevant services to people living with paralysis and their support networks in general and among historically underserved or unserved populations. A major part of the NPRC's Promotional Activities, Outreach, and Collaboration involves developing partnerships with organizations that have shared audiences, thus enhancing the possibility of reaching more individuals who could benefit from the NPRC's programs and services. For example, the NPRC's MVP formed partnerships with county veterans service offices in four states as a way to connect with veterans living in rural settings and raise awareness about services available to them. The NPRC also leverages Promotional Activities, Outreach, and Collaboration and IS to reach culturally diverse populations that may benefit from relevant services. One approach is strategic attendance at conferences and events, such as making sure that Spanish-speaking Information Specialists attend conferences taking place in cities with known large Spanish-speaking populations. Ongoing translation efforts and development of resources into multiple languages also are critical to reaching diverse communities.

The PFSP may raise awareness about relevant services to peers, with survey respondents indicating modest improvement in this area and peer mentors stating that topics on local resources were the most helpful in their peer mentoring relationship. However, in interviews, peers discussed being interested in increased assistance accessing resources and services beyond what they were getting through their mentoring relationship. PFSP staff are recently increasing the amount of follow-up they have with peers to promote greater access to relevant services. There are active NPRC efforts to expand the PFSP's reach to underserved and underrepresented populations, such as holding mentor trainings specifically for members of PVA to certify more veterans as mentors, and partnering with Divas with Disabilities to host a webinar to reach women of color living with paralysis.

To what extent does the NPRC increase access of members of the target populations to services relevant to individuals with paralysis?

As described in the *Findings* section, the QOL grants program increases access to relevant services for people living with paralysis and their support networks by funding the creation or increased accessibility of activities, programs, and services for people with paralysis, their support network, and for people with disabilities broadly in the community. The NPRC's work through IS and Promotional Activities, Outreach, and Collaboration to make documents, online resources, and presentations accessible to people with disabilities demonstrates a commitment to making sure that members of target populations have access to services. Continued investments in activities such as captioning of videos and webinars, providing live captioning and American Sign Languages during webinars, and remediation of all publications ensures that individuals navigating the intersection of multiple disabling conditions can access the information and services that they need. Additionally, work in the IS and Promotional Activities, Outreach, and Collaboration to subtitle, translate, and develop content and resources into multiple languages helps individuals with limited English proficiency to access services.

To what extent does the NPRC increase the empowerment, confidence, and independence of individuals living with paralysis?

The NPRC supports individuals living with paralysis through its various activities. Regional Champions reported that the Regional Champions program helps them feel empowered and engaged and imbues in them the sense that they have the agency to create systemic change. The QOL grants program increases confidence and independence of individuals living with paralysis and their caregivers as reported in surveys and focus groups. QOL grantee end-users in surveys reported increased confidence to take action to achieve life goals, and a grantee representative in a focus group noted the impact of their adaptive sports program on the self-confidence of participants. Grantee representatives discussed how accessibility improvements and assistive technology purchased through grant funds promotes greater independence for people living with paralysis. Lastly, the PFSP program has modest improvement on the confidence of peer mentors as evidenced by survey results.

To what extent does the NPRC strengthen support networks for individuals living with paralysis?

Overall, the NPRC seems to have strengthened support networks for people living with paralysis by adding resources to communities and providing opportunities for people living with paralysis to connect with one another. The QOL grants program strengthens support networks as reported by end-users and grantees. Some grantee representatives described services provided by the QOL grant as reducing caregiver stress and burden. QOL grantee end-users reported improvement in their support network. The program also opened doors for collaboration with various local organizations in the community that cater to individuals with disabilities. Our insight into how the NPRC strengths support networks through the PFSP is limited because of the small number of responses from peers in surveys and focus groups/interviews. Peers reported a weakened support network through participation, but peer mentors reported a strengthened support network.

To what extent does the NPRC improve and increase opportunities for community living for individuals living with paralysis?

The resources provided through the various aspects of the NPRC can support community living for individuals living with paralysis through strengthening their support networks, connecting them to relevant services, and funding accessibility improvements, adaptive equipment, and assistive technologies. The QOL grants program, in particular, may increase opportunities for community living as evidence by a substantial improvement in this goal reported by QOL end-users.

LIMITATIONS

This evaluation applied multiple sources of data, allowing for greater confidence in and depth to the findings.[50] Although each data type (web-based surveys, web-based interviews/focus groups, and document reviews) has limitations, reviewing their content together reduces the impact of bias or limitation from any single data source. However, the response rates to some of these data approaches were very low, particularly for some of the surveys (e.g., peer mentoring) and interviews/focus groups. Because few people provided feedback to us, their opinions may not adequately represent the sentiments of the broader population. Our team has approached these results with caution, being clear to state what we learned while including frequent reminders that the full population is not represented in our results.

CONCLUSION

Taken together, these findings indicate that overall, the NPRC has had many positive effects on individuals living with paralysis, their caregivers, and their support networks. Our cross-program analyses show variation across programs, with a net favorable perception of the NPRC's activities and programs. Some potential growth areas for the future may include additional efforts to document and track participant data across programs, increased focus on localized resources (e.g., for peer mentors to reference), and continued efforts to support historically underserved and unserved communities. The variety of outreach and promotional activities indicate widespread awareness of the NPRC, with a growing need to focus on social media outreach, rather than more traditional email and print methods. Lastly, ongoing efforts to

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[50] Heale, R., & Forbes, D. (2013). Understanding triangulation in research. *Evidence-based nursing, 16*(4), 98. https://doi.org/10.1136/eb-2013-101494.

evaluate the NPRC with their internal evaluator will continue identifying successes and potential growth areas for the future.

APPENDIX A. METHODS

Data Sources

To answer ACL's evaluation questions, we conducted primary and secondary data collection and analysis. Primary data collection included focus groups, interviews, and surveys. Secondary data were abstracted from document reviews of Semi-Annual Performance Reports, including evaluation results from the NPRC's evaluation partner, submitted to ACL by the NPRC.

Surveys

Four surveys were developed for the purpose of this evaluation: a peer mentor survey, a peer (mentee) survey, a QOL end-user survey, and a non-response follow-up survey for peer mentors and peers.

Survey Design

Each survey developed for this evaluation aimed to gather three main types of information: how the respondent participated, their outcomes, and their demographics. To gauge outcomes from these surveys, we adapted an approach called goal attainment scaling (GAS). GAS is an approach that allows individuals to identify personalized goals and track their progress on those goals over time through quantitative measurement.[51] GAS is a promising method of measuring outcomes for care planning, decision-making, evaluation, research[52] and for value-based payment systems[53] with various populations.[54] We used a retrospective pre-/post-test to understand perceived differences in identified goals from before participation in NPRC programming to after participation.

Cognitive Testing

We conducted cognitive testing with the peer mentor survey, peer survey, and QOL end-user survey to assess the effectiveness of the newly developed surveys in capturing the intended information with people living with paralysis and their support network. Cognitive testing included interviews with 25 individuals from the paralysis community referred by the Christopher & Dana Reeve Foundation (CDRF).

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[51] Clair, C. A., Sandberg, S. F., Scholle, S. H., Willits, J., Jennings, L. A., & Giovannetti, E. R. (2022). Patient and provider perspectives on using goal attainment scaling in care planning for older adults with complex needs. *Journal of Patient-Reported Outcomes, 6*(37). doi: 10.1186/s41687-022-00445-y

[52] Stolee, P., Mallinson, S., Kernoghan, A., Brierley, M., Tong, C., Elliott, J., & Abdallah, L. (2023). Feasibility of Goal Attainment Scaling as a patient-reported outcome measure for older patients in primary care. *Journal of Patient-Reported Outcomes, 7*(1), 78. doi: 10.1186/s41687-023-00615-6

[53] Giovannetti, E. R., Clair, C. A., Jennings, L. A., Sandberg, S. F., Bowman, A., Reuben, D. B., & Scholle, S. H. (2021). Standardised approach to measuring goal-based outcomes among older disabled adults: Results from a multisite pilot. *BMJ Quality & Safety, 30*(2), 157–166. doi: 10.1136/bmjqs-2019-010742

[54] Logan, B., Jegatheesan, D. K., Viecelli, A. K., Pascoe, E., & Hubbard, R. E. (2021). Goal Attainment Scaling as an Outcome Measure for Randomised Controlled Trials: A Systematic Scoping Review [Preprint]. In Review. doi: 10.21203/rs.3.rs-1062629/v1

The surveys that underwent cognitive testing included five GAS-informed questions. Respondents were presented with a list of possible goals, and asked to select up to three goals they had hoped to achieve from participation in NPRC activities. The list included outcomes of interest as identified by the Administration for Community Living for this evaluation and as recommended by NPRC staff, as well as an option for a “Other, please specify.” For each selected goal, the goal became fill-ins for the next four questions: (1) to what extent paralysis affects the goal, (2) how important the selected goal is, (3) the status of the selected goal before participation, and (4) the status of the selected goal after participation. For example, in response to the question, “When you started volunteering as a mentor, what did you hope to achieve from participating in the Peer Mentor program?” a respondent could select “improve mental health” as a goal. Then, the questions that followed would use “your mental health” as a fill-in (e.g., “On a scale from 1 to 10, being 1 ‘Worst possible’ and 10 ‘Best possible,’ how was <u>your mental health</u> prior to becoming a peer mentor?”).

Cognitive testing results indicated that in general, participants were able to distinguish and rate their experience on selected goals prior to and after participation. However, some of the fill-in responses were unclear, as was the wording for the scale ratings like “worst possible” and “best possible.” Additionally, cognitive testing participants questioned the need for a 10-point scale as it was difficult to differentiate one point from another. As a result of testing, we updated the wording of both the fill-ins and scale ratings and changed the 10-point scale to a 7-point scale. The following are additional specific findings and adjustments that were made to the outcome questions:

- The question **“what did you hope to achieve from participating”** allowed participants to select up to three responses. Most participants found three to be an acceptable maximum number of responses, although some participants were interested in selecting more.
- For the question **“to what extent does paralysis (in yourself or in a person you care about) affect [selected goal],”** cognitive testing recommendations included adding a time frame to account for the impact of time on the nature of response, as well as modifying the language of the question to broaden the spectrum of health conditions experienced beyond paralysis. Time frames such as “just before being matched with a peer mentor” or “just after …” were added to the questions; however, we did not broaden the spectrum of health conditions experienced as “paralysis” is a term that can be broadly applied and this is an evaluation of a *paralysis* resource center.
- After evaluating the analytic value of **“On a scale from 1 to 10, being 1 “Not important” and 10 “Most important”, how important to you is [selected goal]”,** the question was removed from the survey as there was little variation in ratings, with most participants rating highly, and therefore did not appear to provide analytic value.
- The questions “On a scale from 1 to 10, being 1 “Worst possible” and 10 “Best possible”, how was [selected goal] prior to becoming a peer mentor and “after becoming a peer mentor,” worst possible” determined the language “worst possible” to be too negative

so it was reworded to “On a scale from 1 to 7, with 1 being “poor” and 7 being “excellent”, how is [selected goal] after volunteering as a peer mentor?”.

In addition to its value in helping to refine the outcome questions used across all surveys, cognitive testing results revealed feedback specific to each survey as well. Based on recommendations for changes that emerged from cognitive testing, we adjusted other questions as well. See Appendix C for a link to the survey specifications.

Survey Recruitment and Response Rates

The NPRC provided the name and email contact information for individuals that met eligibility criteria for recruitment for peer mentors, peers, and QOL grantees.

Peer mentor survey. The contact list received from the NPRC included peer mentors working with the PFSP directly or with a partner organization identified as active as of April 2023. Active was defined as currently mentoring a peer or open to mentoring a peer. The contact list also included information on what partnering organizations mentors were associated with, if any.

Surveys were fielded from May through June 2023. Peer mentors screened out of the survey if they responded that they are not currently volunteering as a mentor through the Reeve Foundation or a partnering organization, and if they indicated they were not living with paralysis themselves or were not a caregiver to a person living with paralysis. The survey invitation was successfully sent to 475 peer mentors, which excludes undeliverable contacts. We received 79 complete and eligible and 7 ineligible responses. A complete response was defined as 60% of process related questions in addition to survey eligibility questions. This results in a response rate of 16.9% (79 / (475 − 7) = 0.169).

Peer survey. Researchers requested the contact list only include peers that had requested and received a peer mentoring encounter through the PFSP (and not partner organizations) between July 2022 and March 2023. The list also included demographic information on peers. Researchers removed contacts that were not identified as a person living with paralysis or a caregiver to a person living with paralysis.

Surveys were fielded from May through June 2023. The survey contained two questions to screen-out ineligible contacts. Contacts tested out of the survey if they indicated they were not living with paralysis themselves, were not a caregiver to a person living with paralysis, or not a caregiver assisting a person living with paralysis with take the survey. Additionally, peers were screened out if they responded that they had not received mentorship from the Reeve Foundation. The survey was successfully sent to 164 peers, which excludes undeliverable e-mail addresses. A complete response was defined as having answered all questions including or excluding demographic questions. We received 24 complete and eligible and 6 ineligible responses, resulting in a response rate of 15.2% (24 / (164 − 6) = 0.152).

QOL grantee end-user survey. To develop a list of QOL grantees whose participants would be recruited for this survey, researchers obtained the list of 2021 2nd Cycle Direct Effect and 2021 Priority Impact grantees from the NPRC. Researchers removed organizations with grants that pertained to transportation, facility or other accessibility modifications, and durable medical equipment because the grantee presumably would not have identifiable participants or be appropriate for this outcomes survey. We contacted the remaining grantees via email requesting confirmation that the grantee (a) had identifiable participants that benefitted from their grant-supported activities, (b) had email contact information for those participants, and (c) and were willing to share that contact information with researchers. Researchers removed QOL organizations from the list that responded they did not have identifiable participants and/or did not have contact information for participants. Many grantees stated they would not share contact lists with researchers because of data privacy concerns. Thus, researchers instead asked grantees to forward an organization-specific survey link to participants, to notify researchers when they had sent the email out, and to report how many people to whom they sent the email.

Surveys were fielded in June and July 2023. We identified 51 eligible organizations for the study. Of these, 32[55] organizations sent 1,734 questionnaires to individual participants. At the organizational level, the response rate is 62.7% (32 / 51). From the surveys sent to individuals, we received 165 complete and eligible and 47 ineligible responses (165 + 47 = 212). A complete response was defined as all questions answered including or excluding demographic questions. Participants were ineligible if they indicated they did not have an interaction with the organization, or they were not a person living paralysis, a caregiver of a person living with paralysis, or a caregiver assisting a person living with paralysis take the survey. The estimated number of eligible participants from the 1,734 who were sent e-mails is 77.8% (165 / 212) for an estimated total of 1,350 (1,734 × 0.778) eligible participants. The individual response rate is 12.2% (165 / 1,350). Given the organizational response rate of 62.7% and individual response rate of 12.2%, the overall response rate is 7.7% (62.7% × 12.2%).

Nonresponse follow-up survey. After the surveys closed, researchers administered nonresponse follow-up surveys for peer mentors and peers. These nonresponse follow-up surveys were abbreviated versions of the full surveys, and a complete response was defined as all questions answered. The peer nonresponse follow-up survey had too few responses for analysis (n = 8 complete responses). Analysis of the peer mentor nonresponse follow-up survey (n = 28 complete responses) indicated no notable differences between respondents to the main survey and respondents to the nonresponse follow-up on items common to both surveys. See Appendix C for a link to the survey specifications.

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[55] Technically 31 organizations reported sending the survey out to 1,733 respondents; however, one organization did not confirm they had sent out the survey nor how many people they had sent it to but had a complete survey response. We added 1 to the numerator to reach 32 and to the denominator to reach 1,734.

Interviews and Focus Groups

Exhibit A-1. The RTI Team's approach for conducting virtual focus groups and interviews for evaluation

1: Develop study materials (interview and focus group guides, focus group screeners).	2: Submit guides and recruitment material to ACL for feedback and final approval.	3: Conduct moderator training and mock focus group.	4: Recruit participants.	5: Conduct the focus groups and interview using Zoom.	6: Analyze focus group and interview data using a thematic analysis approach to yield rapid results.	7: Draft evaluation report and presentation incorporating key themes/findings from focus groups and interviews.

Key Informant Interviews. Key informant interviews with NPRC staff from the PFSP, QOL, and Public Policy programs were conducted in June 2022, and interviews with Information Services (IS) program managers and staff were conducted in October 2022. An additional interview with the NPRC staff from the PFSP was conducted in June 2023 as well. The RTI evaluation team conducted a total of eight 90-minute interviews: one interview with staff from each of the four programs (except for the PFSP program, which had two interviews) and three individual interviews with full-time Information Specialists. One of the IS interviews was conducted with a bilingual staff member (speaks English and Spanish).

Focus Groups. For the focus groups, first the RTI evaluation team developed focus group guides (see **Appendix C)**, which were submitted to ACL staff familiar with the NPRC for feedback and final approval before these documents were submitted as part of an application to the Office of Management and Budget (OMB) in accordance with the Paperwork Reduction Act. The project received OMB approval on March 31, 2023. NPRC staff provided the RTI evaluation team contact lists for peers, peer mentors, Regional Champions, and Quality of Life (QOL) grantee representatives who met predetermined eligibility criteria (as described in **Table 4**) to participate.

Focus group recruitment occurred in June and July 2023. RTI staff conducted a total of six 90-minute focus groups between June and July 2023. There was one focus group with Regional Champions, which had 4 participants. There were two focus groups with peer mentors. The first had 2 participants, and the second had 8 participants. There were three focus groups with QOL grantee representatives. The first had 5 participants, the second had 3 participants, and the third one had 5 participants.

Peer Interviews. The RTI evaluation team conducted individual interviews with two peers when we received insufficient response to the invitation to participate in focus groups.

Peer Mentor Interview. The RTI evaluation team conducted one individual interview with a peer mentor.

Reeve Foundation PFSP Partner Organization Interviews. First, the RTI evaluation team drafted and sent a memo to NPRC staff regarding data collection related to PFSP partner organizations. In the memo, RTI identified three types of collaborative relationships between the PFSP and its partner organizations—(1) Formal "Train the Trainer," (2) Referral, and (3) Hybrid/Mixed—and requested that PFSP provide contact information for at least two partner organizations (name and email address) that fall into each of these categories. Next, RTI drafted a separate protocol for each of the three types of partner organizations which were submitted to ACL staff familiar with the NPRC for feedback and final approval. RTI conducted a total of four 1-hour PFSP partner organization interviews in July–August 2023: 2 interviews were with staff from formal "Train the Trainer" partner organizations, and the other 2 interviews were with staff from Hybrid partner organizations.

Other Peer Mentoring Organization Interviews. The evaluation team conducted interviews in August 2023 with two organizations with peer mentoring programs similar to the NPRC.

All focus groups and interviews were facilitated by 2 representatives of RTI International, with one person focused on facilitating discussion and the others focused on taking notes. The discussions were semistructured and allowed for attendees to share as much as they were comfortable with. Each focus group session and interview were recorded using the Zoom platform. The recording, transcript, and notes were used to document key ideas, themes, and suggestions from the focus group sessions and interviews.

Document Review

Researchers reviewed NPRC Semi-Annual Performance Reports submitted to the ACL covering the time period from January 2020 through June 2023. We abstracted metrics from these reports that the NPRC defined consistently across time periods. From the most recent reports covering July 2021 through June 2023, we also abstracted information about program operations and the evaluative efforts of the NPRC's evaluation partner, Vanderbilt University.

Analysis Methods and Limitations

Survey

With only 24 complete and eligible responses to the survey of peers, the results of these analyses cannot be generalized to the population of peers participating in the PFSP. Those who responded to the survey may be a select group of participants, and thus their ratings of satisfaction, for example, may be different than those of non-respondents—this is known as nonresponse bias. One method to adjust for observed differences between respondents and non-respondents is to weight the sample of respondents so that it better represents the characteristics of non-respondents. However, with so few respondents, we decided that this approach would not be effective. Because sampling frame data was available for peers, we were able to compare some demographic characteristics of peer respondents to those of non-respondents, which indicated that peer respondents were disproportionately older, male, white/Caucasian, non-Hispanic, and experiencing paraplegia compared to non-respondents. These differences provide some evidence of non-response bias and further reinforce the caveat that the results of these analyses cannot be generalized to the population of peers participating in the PFSP.

As described above, we administered nonresponse follow-up surveys to both peers and peer mentors. One of the goals of nonresponse follow-up surveys is to get a sense of the characteristics of those who did not respond to the original survey. When the characteristics of nonresponse follow-up survey respondents are similar to those of respondents to the main survey, then that provides some confidence that nonresponse bias is limited. For the survey of peers, we compared the characteristics of the 24 respondents to the main survey to those of the 8 nonresponse follow-up survey respondents, and the two groups appeared to be broadly similar. However, because there were only eight respondents to the nonresponse follow-up survey, it is impossible to draw any conclusions from this comparison. For the survey of peer mentors, we made a similar comparison between the 79 complete and eligible respondents to the main survey and the 28 complete and eligible responses to the nonresponse follow-up survey. Again, the two groups were generally similar on items that were common to both versions of the survey. While this does lend some confidence that nonresponse bias is limited among respondents to the survey of peer mentors, we nonetheless cannot generalize the results of our analyses to the population of peer mentors participating in the PSFP due to the relatively small number of responses.

Paperwork Reduction Act Package

A Paperwork Reduction Act Package was submitted to the Office of Management and Budget with all survey and focus group data collection tools and was approved March 31, 2023 (OMB CONTROL NUMBER: 0985-0077).

APPENDIX B. FULL SURVEY RESULTS

Table B-1. All surveys: Sociodemographic and other characteristics of respondents.

Characteristic	Respondents to survey of peer mentors		Respondents to survey of peers		Respondents to survey of QOL grantee end-users	
	N	%	N	%	N	%
Participant Type*						
Person living with paralysis	68	86.1	22	91.7	111	67.3
Caregiver of a person living with paralysis	11	13.9	2	8.3	35	21.2
Did not participate in program but recorded the answers for someone who did	N/A	N/A	--	--	19	11.5
Age						
18 to 24	2	2.5	1	4.2	5	3.0
25 to 34	6	7.6	1	4.2	18	10.9
35 to 44	10	12.7	3	16.7	29	17.6
45 to 54	16	20.3	6	25.0	35	21.2
55 to 64	18	22.8	5	20.8	46	27.9
65 or over	22	27.8	7	29.2	32	19.4
DK, PNA, Missing	5	6.3	--	--	--	--
Race**						
American Indian/Alaska Native	--	--	--	--	2	1.1
Black/African American	6	7.4	1	4.2	21	12.0
Native Hawaiian/Pacific Islander	--	--	--	--	2	1.1
Asian	1	1.2	1	4.2	11	6.3
White/Caucasian	66	81.5	20	83.3	114	65.1
Some other race	1	1.2	--	--	10	5.7
DK, PNA, Missing	7	8.6	2	8.3	15	8.6
Hispanic/Latino/Spanish origin						
Yes	2	2.5	--	--	20	12.1
No	71	89.9	22	91.7	124	75.2
DK, PNA, Missing	6	7.6	2	8.3	21	12.7
Education						
Less than high school	--	--	--	--	1	0.6
High school or equivalent	4	5.1	9	37.5	19	11.5
Some college/university, no degree	17	21.5	5	20.8	31	18.8
College or university degree	30	38.0	9	37.5	68	41.2
Postgraduate degree	23	29.1	1	4.2	46	27.9
DK, PNA, Missing	5	6.3	--	--	--	--

Table B-1. All surveys: Sociodemographic and other characteristics of respondents. (continued)

Characteristic	Respondents to survey of peer mentors		Respondents to survey of peers		Respondents to survey of QOL grantee end-users	
	N	%	N	%	N	%
Sex						
Female	35	44.3	11	45.8	89	53.9
Male	38	48.1	13	54.2	68	41.2
DK, PNA, Missing	6	7.6	--		8	4.8
Gender Identity						
Female	35	44.3	11	45.8	89	53.9
Male	38	48.1	13	54.2	67	40.6
Transgender	--	--	--	--	1	0.6
Two-Spirit	--	--	--	--	--	--
Other	--	--	--	--	--	--
DK, PNA, Missing	6	7.6	--	--	8	4.8
Sexual orientation						
Lesbian or gay	3	3.8	--	--	6	3.6
Straight, that is, not gay or lesbian	64	81.0	19	79.2	131	79.4
Bisexual	4	5.1	1	4.2	4	2.4
Two-Spirit	--	--	--	--	--	--
Other	--	--	--	--	4	2.4
DK, PNA, Missing	8	10.1	4	16.7	21	12.1
Paralysis cause**						
Spinal cord injury	68	80.0	17	54.8	52	28.6
Brain injury	4	4.7	--	--	20	11.0
Disease or syndrome	4	4.7	5	16.1	65	35.7
Result of surgical or medical procedure	4	4.7	6	19.4	5	2.7
Stroke	--	--	3	9.7	21	11.5
Other	--	--	--	--	5	2.7
DK, PNA, Missing	5	5.9	--	--	14	7.7
Type of paralysis						
Paraplegia (T1 and below)	29	36.7	15	62.5	52	31.5
Hemiplegia	1	1.3	--	--	11	6.7
Quadriplegia (C8 and above)	43	54.4	8	33.3	26	15.8
Other – ALS/MS	DNA	DNA	DNA	DNA	26	15.8
Other – Spina Bifida or CP	DNA	DNA	DNA	DNA	4	2.4
Other	1	1.3	--	--	8	4.9
DK, PNA, Missing	5	6.3	1	4.2	38	23.0

Table B-1. All surveys: Sociodemographic and other characteristics of respondents. (continued)

Characteristic	Respondents to survey of peer mentors		Respondents to survey of peers		Respondents to survey of QOL grantee end-users	
	N	%	N	%	N	%
Time since paralysis onset						
Less than 1 year	--	--	1	4.2	2	1.2
1 year to less than 3 years	1	1.3	9	37.5	31	18.8
3 years to less than 5 years	4	5.1	5	20.8	19	11.5
5 years to less than 10 years	11	13.9	1	4.2	27	16.4
10 or more years	57	72.2	8	33.3	68	41.2
DK, PNA, Missing	6	7.6	--	--	19	10.9

* This question is required for a complete response.

** Respondents could select all that apply.

N/A = not applicable; DK = don’t know; PNA = prefer not to answer; DNA = did not ask; ALS = amyotrophic lateral sclerosis; MS = multiple sclerosis; CP = cerebral palsy

Table B-2. Peer mentor survey: Sociodemographic and other characteristics by length of involvement.

Demographic characteristic	When did you mentor your first peer?					
	2 years ago or less		More than 2 years ago		Have not mentored a peer yet	
	N	Row %	N	Row %	N	Row %
Participant Type*						
Person living with paralysis	23	33.8	39	57.4	6	8.8
Caregiver of a person living with paralysis	4	36.4	6	54.6	1	9.1
Age						
18 to 24	1	50.0	--	--	1	50.0
25 to 34	--	--	6	100.0	--	--
35 to 44	4	40.0	6	60.0	--	--
45 to 54	8	50.0	7	43.8	1	6.3
55 to 64	6	33.3	11	61.1	1	5.6
65 or over	7	31.8	13	59.1	2	9.1
DK, PNA, Missing	1	20.0	2	40.0	2	40.0
Race (select all that apply)						
American Indian/Alaska Native	--	--	--	--	--	--
Black/African American	--	--	6	100.0	--	--
Native Hawaiian/Pacific Islander	--	--	--	--	--	--
Asian	--	--	1	100.0	--	--
White/Caucasian	24	36.4	37	56.1	5	7.6

Table B-2. Peer mentor survey: Sociodemographic and other characteristics by length of involvement. (continued)

Demographic characteristic	When did you mentor your first peer?					
	2 years ago or less		More than 2 years ago		2 years ago or less	
	N	Row %	N	Row %	N	Row %
Some other race	--	--	1	100.0	--	--
DK, PNA, Missing	3	42.9	2	28.6	2	28.6
Hispanic/Latino/Spanish origin						
Yes	--	--	2	100.0	--	--
No	25	35.2	41	57.8	5	7.0
DK, PNA, Missing	2	33.3	2	33.3	2	33.3
Education						
Less than high school	--	--	--	--	--	--
High school or equivalent	--	--	3	75.0	1	25.0
Some college/university, no degree	8	47.1	8	47.1	1	5.9
College or university degree	7	23.3	20	66.7	3	10.0
Postgraduate degree	11	47.8	12	52.2	--	--
DK, PNA, Missing	1	20.0	2	40.0	2	40.0
Sex						
Female	11	31.4	22	62.9	2	5.7
Male	14	36.8	21	55.3	3	7.9
DK, PNA, Missing	2	33.3	2	33.3	2	33.3
Gender identity						
Female	11	31.4	22	62.9	2	5.7
Male	14	36.8	21	55.3	3	7.9
Transgender	--	--	--	--	--	--
Two-Spirit	--	--	--	--	--	--
Other	--	--	--	--	--	--
DK, PNA, Missing	2	33.3	2	33.3	2	33.3
Sexual orientation						
Lesbian or gay	1	33.3	2	66.7	--	--
Straight, that is, not gay or lesbian	20	31.3	40	62.5	4	6.3
Bisexual	3	75.0	1	25.0	--	--
Two-Spirit	--	--	--	--	--	--
Other	--	--	--	--	--	--
DK, PNA, Missing	3	37.5	2	25.0	3	37.5

Table B-2. Peer mentor survey: Sociodemographic and other characteristics by length of involvement. (continued)

	When did you mentor your first peer?					
	2 years ago or less		More than 2 years ago		2 years ago or less	
Demographic characteristic	N	Row %	N	Row %	N	Row %
Paralysis cause (select all that apply)						
Spinal cord injury	22	32.4	41	60.3	5	7.4
Brain injury	1	25.0	3	75.0	--	--
Disease or syndrome	2	50.0	2	50.0	--	--
Result of surgical or medical procedure	3	75.0	1	25.0	--	--
Stroke	--	--	--	--	--	--
Other	--	--	--	--	--	--
DK, PNA, Missing	1	20.0	2	40.0	2	40.0
Type of paralysis						
Paraplegia (T1 and below)	13	44.8	15	51.7	1	3.5
Hemiplegia	--	--	1	100.0	--	--
Quadriplegia (C8 and above)	12	27.9	27	62.8	4	9.3
Other	1	100.0	--	--	--	--
DK, PNA, Missing	1	20.0	2	40.0	2	40.0
Time since paralysis onset						
Less than 1 year	--	--	--	--	--	--
1 year to less than 3 years	1	100.0	--	--	--	--
3 years to less than 5 years	3	75.0	--	--	1	25.0
5 years to less than 10 years	4	36.4	5	45.5	2	18.2
10 or more years	17	29.8	38	66.7	2	3.5
DK, PNA, Missing	2	33.3	2	33.3	2	33.3

* This question is required for a complete response.
N/A = not applicable; DK = don't know; PNA = prefer not to answer

Table B-3. QOL end-user survey: Sociodemographic and other characteristics by length of involvement

	Length of involvement with QOL grantee organization			
	2 years or less		More than 2 years	
Demographic characteristic	N	Row %	N	Row %
Participant type*				
Person living with paralysis	50	45.0	61	55.0
Caregiver of a person living with paralysis	20	57.1	15	42.9
I did not participate, but I am a caregiver of someone who participated	8	42.1	11	57.9

Table B-3. QOL end-user survey: Sociodemographic and other characteristics by length of involvement (continued)

Demographic characteristic	Length of involvement with QOL grantee organization			
	2 years or less		More than 2 years	
	N	Row %	N	Row %
Age				
18 to 24	1	20.0	4	80.0
25 to 34	7	38.9	11	61.1
35 to 44	12	41.4	17	58.6
45 to 54	17	48.6	18	51.4
55 to 64	26	56.5	20	43.5
65 or over	15	46.9	17	53.1
DK, PNA, Missing	--	--	--	--
Race (select all that apply)				
American Indian/Alaska Native	--	--	2	100.0
Black/African American	9	42.9	12	57.1
Native Hawaiian/Pacific Islander	2	100.0	--	--
Asian	4	36.4	7	63.6
White/Caucasian	53	46.5	61	53.5
Some other race	5	50.0	5	50.0
DK, PNA, Missing	7	46.7	8	53.3
Hispanic/Latino/Spanish origin				
Yes	9	45.0	11	55.0
No	59	47.6	65	52.4
DK, PNA, Missing	10	47.6	11	52.4
Education				
Less than high school	--	--	1	100.0
High school or equivalent	10	52.6	9	47.4
Some college/university, no degree	15	48.4	16	51.6
College or university degree	32	47.1	36	52.9
Postgraduate degree	21	45.7	25	54.3
DK, PNA, Missing	--	--	--	--
Sex				
Female	44	49.4	45	50.6
Male	31	45.6	37	54.4
DK, PNA, Missing	3	37.5	5	62.5

Table B-3. QOL end-user survey: Sociodemographic and other characteristics by length of involvement (continued)

Demographic characteristic	Length of involvement with QOL grantee organization			
	2 years or less		More than 2 years	
	N	Row %	N	Row %
Gender identity				
Female	43	48.3	46	51.7
Male	31	46.3	36	53.7
Transgender	1	100.0	--	--
Two-Spirit	--	--	--	--
Other	--	--	--	--
DK, PNA, Missing	3	37.5	5	62.5
Sexual orientation				
Lesbian or gay	4	66.7	2	33.3
Straight, that is, not gay or lesbian	62	47.3	69	52.7
Bisexual	1	25.0	3	75.0
Two-Spirit	--	--	--	--
Other	2	50.0	2	50.0
DK, PNA, Missing	9	45.0	11	55.0
Paralysis cause (select all that apply)				
Spinal cord injury	20	38.5	32	61.5
Brain injury	5	25.0	15	75.0
Disease or syndrome	34	52.3	31	47.7
Result of surgical or medical procedure	3	60.0	2	40.0
Stroke	8	38.1	13	61.9
Other	3	60.0	2	40.0
DK, PNA, Missing	8	57.1	6	42.9
Type of paralysis				
Paraplegia (T1 and below)	22	42.3	30	57.7
Hemiplegia	3	27.3	8	72.7
Quadriplegia (C8 and above)	12	46.2	14	53.8
Other – ALS/MS	18	69.2	8	30.8
Other – Spina Bifida or CP	1	25.0	3	75.0
Other	5	62.5	3	37.5
DK, PNA, Missing	17	44.7	21	55.3

Table B-3. QOL end-user survey: Sociodemographic and other characteristics by length of involvement (continued)

Demographic characteristic	Length of involvement with QOL grantee organization			
	2 years or less		More than 2 year	
	N	Row %	N	Row %
Time since paralysis onset				
Less than 1 year	2	100.0	--	--
1 year to less than 3 years	27	87.1	4	12.9
3 years to less than 5 years	9	47.4	10	52.6
5 years to less than 10 years	10	37.0	17	63.0
10 or more years	20	29.4	48	70.6
DK, PNA, Missing	10	55.6	8	44.4

* This question is required for a complete response.

N/A = not applicable; DK = don’t know; PNA = prefer not to answer; ALS = amyotrophic lateral sclerosis; MS = multiple sclerosis; CP = cerebral palsy

Table B-4a. Peer mentor survey: Mentoring experience results

Item	N	%
How many peers have you mentored?		
1–2 peers	16	20.3
3–5 peers	28	35.4
6–10 peers	11	13.9
More than 10 peers	17	21.5
DNA*	7	8.86
How common is it that a peer has only one or two interactions with you?		
Uncommon	16	20.3
Neither common nor uncommon	20	25.3
Common	34	43.0
Not sure	2	2.8
DNA*	7	8.9
How many months have you been in contact with the peer that you’ve mentored the longest?		
Less than 3 months	18	22.8
3–6 months	15	19.0
More than 6 months but less than 1 year	7	8.9
1–3 years	21	26.6
More than 3 years	11	13.9
DNA*	7	8.9
How do you communicate most often with your peer mentees?		
In face-to-face meetings	2	2.5
By telephone	37	46.8
Using video conferencing	7	8.9

Table B-4a. Peer mentor survey: Mentoring experience results (continued)

Item	N	%
By email	7	8.9
By chat or text messaging	19	24.1
Other	--	--
DNA*	7	8.9
How frequent are your communications with the peer you communicate with most frequently?		
Every day	--	--
A few times per week	14	17.7
A few times per month	35	44.3
A few times per year	23	29.1
DNA*	7	8.9

DNA = did not ask

* If respondents selected they had not mentored a peer yet, they were not asked questions about the mentoring experience. Seven respondents had not yet mentored a peer.

Table B-4b. Peer mentor survey: Mentoring experience results

Item	Mean	SD	p50	p75	N*
How many peers did you communicate with in the last month?	2.2	4.0	1.0	2.0	72

SD = standard deviation; p50 = 50th percentile (median); p75 = 75th percentile

* If respondents selected they had not mentored a peer yet, they were not asked questions about the mentoring experience. Seven respondents had not yet mentored a peer.

Table B-5a. Peer mentor survey: Mentoring resources results

Item	Mean	SD	p50	p75	N*
With 1 being most important and 9 being least, rank the following in order of importance to you in matching mentors to peers.					
Age	3.1	1.8	3.0	4.0	65
Gender identity	4.4	2.4	4.0	6.0	38
Sexual orientation	6.6	2.0	6.5	8.3	28
Cause of paralysis	4.3	2.2	4.0	6.0	60
Level of injury	1.9	1.4	1.0	2.0	66
Race	7.5	2.2	9.0	9.0	47
Ethnicity	7.3	1.8	8.0	8.0	41
Veteran status	6.5	1.8	7.0	8.0	44
Interests	4.7	1.9	5.0	6.0	60
Where you live	5.6	2.0	6.0	7.0	59
Time since paralysis	4.8	1.7	4.5	6.0	58

SD = standard deviation; p50 = 50th percentile (median); p75 = 75th percentile

* 13 participants did not respond to this question at all and 22 people did not provide rankings all the way to 9 (which includes the 13).

Table B-5b. Peer mentor survey: Mentoring resources results

Item	N	%
Thinking across all your mentor-peer relationships, how would you rate the Reeve Foundation´s approach to resolving issues in case of a poor match between you and your peer?		
Poor	1	1.3
Fair	7	8.9
Good	17	21.5
Very good	8	10.1
Excellent	10	12.7
Does not apply	28	35.4
Participant was not asked the question*	7	8.9
Missing	1	1.3
How helpful to you was the initial certification training from the Reeve Foundation in helping you meet peer needs?		
I never attended	1	1.3
Not at all helpful	--	--
Slightly helpful	7	8.9
Somewhat helpful	15	19.0
Moderately helpful	25	31.7
Extremely helpful	31	39.2
Missing	--	--
How helpful to you were the occasional webinar-based trainings from the Reeve Foundation in helping you meet peer needs?		
I have never attended webinar-based trainings.	23	29.1
Not at all helpful	1	1.3
Slightly helpful	8	10.1
Somewhat helpful	14	17.7
Moderately helpful	18	22.8
Extremely helpful	15	19.0
Missing	--	--
How helpful to you were the written resources from the Reeve Foundation in helping you meet peer needs?		
I have never used the written resources.	9	11.4
Not at all helpful	--	--
Slightly helpful	6	7.6
Somewhat helpful	18	22.8
Moderately helpful	17	21.5
Extremely helpful	29	36.7
Missing	--	--

Table B-5b. Peer mentor survey: Mentoring resources results (continued)

Item	N	%
How helpful to you was the Reeve Foundation´s Facebook group for mentors in helping you meet peer needs?		
I have never used the Facebook group.	48	60.8
Not at all helpful	3	3.8
Slightly helpful	9	11.4
Somewhat helpful	10	12.7
Moderately helpful	5	6.3
Extremely helpful	4	5.1
Missing	--	--
How helpful was talking directly to Reeve Foundation staff for you in meeting peer needs?		
I have never talked with Reeve Foundation staff about peer mentor needs.	14	17.7
Not at all helpful		
Slightly helpful	5	6.3
Somewhat helpful	7	8.9
Moderately helpful	16	20.3
Extremely helpful	37	46.8
Missing	--	--
Which resource from the Reeve Foundation is most helpful in supporting you to be a peer mentor?		
Initial certification training	29	36.7
Occasional webinar-based trainings	7	8.9
Written resources	16	20.3
Facebook group for mentors	--	--
Reeve Foundation staff	24	30.4
Other	2	2.5
Missing	1	1.3
Within the Reeve Foundation resources, which topic has been most helpful to you as a peer mentor?		
How to do motivational interviewing	13	16.5
How to improve communication skills	9	11.4
How to help someone manage depression	9	11.4
How to find community-based resources	25	31.7
Other	4	5.1
None of the above	3	3.8
I have not used resources	16	20.3
Missing	--	--

Table B-5b. Peer mentor survey: Mentoring resources results (continued)

Item	N	%
Now thinking about organizations other than the Reeve Foundation, in the past 12 months, have you accessed any mentoring resources (e.g., books, websites) offered by these other organizations?		
Yes	34	43.0
No	45	57.0
Missing	--	--
In the past 12 months, how many trainings for mentors offered by organizations other than the Reeve Foundation have you attended?		
I have not attended any trainings in the past 12 months	55	69.6
1 training	9	11.4
2 to 5 trainings	11	13.9
6 to 10 trainings	1	1.3
More than 10 trainings	2	2.5
Missing	1	1.3
Thinking across all your mentor-peer relationships, what has been your most frequent challenge when in a mentoring relationship?		
Lack of contact from peer	41	51.9
Not being able to provide emotional support	5	6.3
Not knowing the peer’s needs well enough	2	2.5
Not having enough information to address my peer’s concerns	6	7.6
Not being able to build a relationship with a peer	11	13.9
Lack of resources available to support a peer	6	7.6
Other	3	3.8
N/A Have not mentored a peer	2	2.5
None	2	2.5
Missing	1	1.3
What is your greatest challenge in volunteering as a mentor through the Reeve Foundation?		
Receiving too many requests to mentor	4	5.1
Receiving too few requests to mentor	34	43.0
Too much training required	2	2.5
Inadequate training or preparation	3	3.8
Inadequate ongoing support from the Reeve Foundation	1	1.3
Lack of stipend or payment	2	2.5
Other	4	5.1
Time constraints**	9	11.4
Poor match**	2	2.5
Building relationship/effective communication**	5	6.3
None**	10	12.7
Missing	3	3.8

* Participants were not asked the question if they had not mentored a peer yet.

** Indicates categories researchers created after reviewing "other" fill in responses.

Table B-6. Peer survey: Respondent goals and improvement ratings

Survey question		Better physical health	Better mental health	Learn about services for those living with paralysis	Access services that could be helpful to me	Gain practical advice about living with paralysis	Increase sense of control over decisions	Feel more confident to take action to achieve life goals	Greater independence	Strengthen my support network	Participate more in community life
When you started participating in peer mentoring, what did you hope to achieve?*	N	4	10	11	6	11	2	5	4	8	1
	%	6.5	16.1	17.7	9.7	17.7	3.2	8.1	6.5	12.9	1.6

Survey question	Your physical health	Your mental health	Your knowledge about these services	Your access to these services	Your knowledge about practical tips for those living with paralysis	Your sense of control	Your sense of confidence to take action to achieve life goals	Your independence	Your support network	Your ability to participate in community life
Before being matched with a peer mentor, to what extent did paralysis affect…?	N=4	N=10	N=11	N=6	N=10	N=2	N=5	N=4	N=8	N=1
Average [on 1–7 scale (not at all – to a great extent)]	5.0	5.2	4.1	2.8	3.4	5.5	5.6	5.8	4.9	7.0
% with rating of 6 or above	50.0	50.0	18.2	16.7	10.0	50.0	80.0	50.0	50.0	100.0
% with rating of 2 or below	0.0	10.0	18.2	66.7	30.0	0.0	0.0	0.0	12.5	0.0
Just prior to being matched with a peer mentor, how was…?	N=4	N=10	N=11	N=6	N=11	N=2	N=5	N=4	N=8	N=1
Average [on 1–7 scale (poor – excellent)]	2.8	2.9	3.5	2.3	3.5	4.0	4.2	4.8	3.6	1.0
% with rating of 6 or above	0.0	0.0	9.1	0.0	0.0	50.0	20.0	25.0	25.0	0.0
% with rating of 2 or below	50.0	40.0	36.4	66.7	18.2	50.0	20.0	25.0	37.5	100.0
After being matched with a peer mentor, how is…?	N=4	N=10	N=11	N=6	N=11	N=2	N=5	N=4	N=8	N=1
Average [on 1–7 scale (poor – excellent)]	3.0	3.9	4.0	2.8	4.5	5.5	4.8	4.0	3.5	7.0
% with rating of 6 or above	0.0	20.0	18.2	0.0	9.1	50.0	60.0	25.0	25.0	100.0
% with rating of 2 or below	50.0	30.0	18.2	50.0	9.1	0.0	20.0	50.0	37.5	0.0

Table B-6. Peer survey: Respondent goals and improvement ratings (continued)

Survey question	Your physical health	Your mental health	Your knowledge about these services	Your access to these services	Your knowledge about practical tips for those living with paralysis	Your sense of control	Your sense of confidence to take action to achieve life goals	Your independence	Your support network	Your ability to participate in community life
Estimated improvement in…	N=4	N=10	N=11	N=6	N=11	N=2	N=5	N=4	N=8	N=1
Average [in terms of pre/post change in 1–7 scale rating]	0.3	1.0	0.5	0.5	0.9	1.5	0.6	-0.8	-0.1	6.0
Average [weighted by extent of paralysis effect]	-0.3	1.0	0.4	0.8	0.6	1.9	0.9	-0.8	-0.3	6.0

Note: Ratings of improvement can range from -6 to 6. Negative values indicate decline, and positive values indicate improvement. The percentages represent the percent of responses, not the percent of respondents.

* Respondents could select and respond to up to three goals.

Table B-7. Peer mentor survey: Respondent goals and improvement ratings

Survey question		Better mental health	Feel more confident to take action to achieve life goals	Strengthen my support network	Participate more in community life	Improve ability to relate to others	A sense of contribution to the community	Other (opportunities to help others)*
When you started participating in peer mentoring, what did you hope to achieve?**	N	9	10	18	34	21	64	7
	%	5.5	6.1	11.0	20.9	12.9	39.3	4.3

Survey question	Your mental health	Your sense of confidence to take action to achieve life goals	Your support network	Your ability to participate in community life	Your ability to relate to others	Your sense of contribution to the community	Other (your opportunities to help others)*
Before becoming a peer mentor, to what extent did paralysis affect…?	N=9	N=10	N=18	N=33	N=19	N=61	N=7
Average [on 1–7 scale (not at all – to a great extent)]	3.6	3.7	4.9	3.8	3.5	3.9	4.1
% with rating of 6 or above	11.1	20.0	44.4	30.3	26.3	21.3	42.9
% with rating of 2 or below	44.4	30.0	11.1	39.4	52.6	29.5	28.6
Just before becoming a peer mentor, how was…?	N=9	N=10	N=18	N=33	N=19	N=61	N=7
Average [on 1–7 scale (poor – excellent)]	5.1	5.2	5.3	5.3	5.5	4.7	3.4
% with rating of 6 or above	44.4	40.0	44.4	54.5	63.2	29.5	28.6
% with rating of 2 or below	0.0	0.0	0.0	6.0	10.5	13.1	42.9

Table B-7. Peer mentor survey: Respondent goals and improvement ratings (continued)

Survey question	Your mental health	Your sense of confidence to take action to achieve life goals	Your support network	Your ability to participate in community life	Your ability to relate to others	Your sense of contribution to the community	Other (your opportunities to help others)*
After volunteering as a peer mentor, how is…?	N=9	N=10	N=18	N=32	N=19	N=61	N=7
Average [on 1–7 scale (poor – excellent)]	5.3	5.7	6.4	6.2	5.8	5.9	5.9
% with rating of 6 or above	55.6	60.0	88.9	81.3	73.7	72.1	71.4
% with rating of 2 or below	11.1	0.0	0.0	6.3	5.3	4.9	0.0
Estimated improvement in…	N=9	N=10	N=18	N=32	N=19	N=61	N=7
Average [in terms of pre/post change in 1–7 scale rating]	0.2	0.5	1.2	0.8	0.3	1.2	2.4
Average [weighted by extent of paralysis effect]	0.4	0.6	1.3	0.9	0.0	1.1	2.4

Note: Ratings of improvement can range from -6 to 6. Negative values indicate decline, and positive values indicate improvement.

* Indicates categories researchers created after reviewing "other" fill in responses. The percentages represent the percent of responses, not the percent of respondents.

** Respondents could select and respond to up to three goals.

Table B-8. Quality of Life end-user survey: Respondent goals and improvement ratings

Survey question		Better physical health	Better mental health	Learn about services for those living with paralysis	Access services that could be helpful to me	Increase sense of control over decisions	Feel more confident to take action to achieve life goals	Greater independence	Strengthen my support network	Participate more in community life	Improvement in abilities, skills, or knowledge
When you started contact with this organization, what did you hope to achieve?*	N	66	51	27	62	12	39	35	50	40	64
	%	14.7	11.4	6.0	13.8	2.7	8.7	7.8	11.2	8.9	14.3

Survey question	Your physical health	Your mental health	Your knowledge about these services	Your access to these services	Your sense of control	Your sense of confidence to take action to achieve life goals	Your independence	Your support network	Your ability to participate in community life	Improvement in abilities, skills, or knowledge
Before contacting this organization, to what extent did paralysis affect… ?	N=66	N=50	N=27	N=62	N=12	N=39	N=35	N=49	N=40	N=64
Average [on 1–7 scale (not at all – to a great extent)]	5.2	4.6	4.2	4.5	4.7	4.3	5.1	3.8	3.7	5.1
% with rating of 6 or above	53.0	28.0	22.2	35.5	33.3	33.3	40.0	16.3	20.0	42.2
% with rating of 2 or below	10.6	10.0	11.1	17.7	16.7	20.5	5.7	24.4	27.5	6.3
Just prior to contact with this organization, how was…?	N=66	N=51	N=27	N=62	N=12	N=39	N=35	N=50	N=40	N=64
Average [on 1–7 scale (poor – excellent)]	4.1	4.4	3.6	3.7	4.8	4.2	4.2	3.9	4.0	4.2
% with rating of 6 or above	22.7	23.5	7.4	24.2	25.0	20.5	25.7	14.0	25.0	20.3
% with rating of 2 or below	21.2	7.8	14.8	35.5	8.3	7.7	17.1	14.0	20.0	20.3
After contact with this organization, how is…?	N=66	N=51	N=26	N=62	N=12	N=39	N=35	N=50	N=40	N=64
Average [on 1–7 scale (poor–excellent)]	5.8	5.7	6.2	5.9	5.8	6.3	5.6	6.1	6.1	5.9
% with rating of 6 or above	62.1	70.6	84.6	66.1	66.7	82.1	54.3	78.0	85.0	68.8
% with rating of 2 or below	1.5	5.9	3.8	6.5	0.0	0.0	2.9	2.0	2.5	1.6
Estimated improvement in…	N=66	N=51	N=26	N=62	N=12	N=39	N=35	N=50	N=40	N=64
Average [in terms of pre/post change in 1–7 scale rating]	1.7	1.4	2.6	2.1	1.0	2.1	1.4	2.2	2.1	1.8
Average (weighted by extent of paralysis effect))	2.0	1.3	2.3	2.2	0.7	1.9	1.3	2.0	1.9	1.8

Note: There were two responses to a write-in “other” category; these are not shown to conserve space. Ratings of improvement can range from -6 to 6. Negative values indicate decline, and positive values indicate improvement. The percentages represent the percent of responses, not the percent of respondents.

* Respondents could select and respond to up to three goals.

Table B-9. All surveys: Average improvement ratings aggregated across all goals

Estimated improvement among…	Respondents to survey of peer mentors	Respondents to survey of peers	Respondents to survey of QOL grantee end-users
Average [in terms of pre/post change in 1–7 scale rating]	0.9	0.6	1.9
Average (weighted by extent of paralysis effect)	1.0	0.6	1.8

Note: Ratings of improvement can range from -6 to 6. Negative values indicate decline, and positive values indicate improvement.

Table B-10. Peer mentor survey: Average ratings of improvement aggregated across all goals by demographic categories

Demographic characteristic	N	Average extent of paralysis effect (on 1–7 scale)	Average improvement (in terms of pre/post change in 1–7 scale rating)	Average improvement (weighted by extent of paralysis effect)
Age				
18 to 54	80	3.7	0.8	0.9
55 or over	75	4.2	1.1	1.0
Sex				
Female	71	3.8	1.2	1.4
Male	82	4.0	0.7	0.7
DK, PNA, Missing	3	5.5	0.7	0.8
Type of paralysis				
Paraplegia (T1 and below)	64	3.6	0.9	0.8
Quadriplegia (C8 and above)	86	4.1	1.0	1.1
Other	6	4.4	0.8	0.9

Note: Ratings of improvement can range from -6 to 6. Negative values indicate decline, and positive values indicate improvement.

Table B-11. QOL end-user survey: Average improvement ratings aggregated across all goals by demographic categories

Demographic characteristic	N	Average extent of paralysis effect (on 1–7 scale)	Average improvement (in terms of pre/post change in 1–7 scale rating)	Average improvement (weighted by extent of paralysis effect)
Age				
18 to 54	239	6.1	1.9	1.9
55 or over	208	5.8	1.8	1.7
Sex				
Female	243	6.0	2.1	2.1
Male	183	5.9	1.6	1.5
DK, PNA, Missing	21	6.0	1.9	2.1
Type of paralysis				
Paraplegia (T1 and below)	143	6.0	1.9	1.9
Hemiplegia	33	5.8	2.0	2.1
Quadriplegia (C8 and above)	76	6.2	1.9	1.9
Other – ALS/MS	63	5.7	2.2	2.2
Other, DK, PNA, Missing	132	5.9	1.7	1.4

Note: Ratings of improvement can range from -6 to 6. Negative values indicate decline, and positive values indicate improvement.

Table B-12. All surveys: Whether participation in program met respondents' expectations

	Respondents to survey of peer mentors		Respondents to survey of peers		Respondents to survey of QOL grantee end-users	
Overall, did participation in peer mentoring have the effect on your well-being that you expected?	**N**	**%**	**N**	**%**	**N**	**%**
Yes	67	84.8	14	58.3	159	96.4
No	7	8.9	10	41.7	6	3.6
Missing	5	6.3	--	--	--	--

May 20, 2022

APPENDIX C. SURVEY SPECIFICATIONS, FOCUS GROUP PROTOCOLS, AND INTERVIEW GUIDES

C1. Survey specifications and focus group protocols were approved by OMB and are available here: https://www.reginfo.gov/public/do/PRAICList?ref_nbr=202302-0985-007. The peer focus group protocol was used for the interviews with peers and the peer mentor focus group protocol was used for the interview with a peer mentor.

Other interviews did not require OMB approval since they included nine people or less per data collection activity. The interview guides follow (C2–C10).

C2. PFSP Staff Interview Protocol 2022

Introductions

We would first like to begin with introductions.

1. [For each interview respondent participating in the call] What is your title and main responsibilities related to administering the Peer and Family Mentoring Program?
2. How did the program start?

Recruitment and Selection of Peer Mentors

I'd like to talk about how you go about recruiting and selecting individuals to become peer mentors.

3. Please summarize how you find and select individuals to become peer mentors? What are your primary outreach strategies to identify mentors?
4. Do you have any outreach or recruitment activities in place to directly recruit mentors from certain groups? (i.e.. underserved populations, racial and ethnic minorities, individuals with limited English proficiency, children/adolescents, military veterans, etc.)
5. What screening do you perform of mentors prior to selection?
6. How has this process changed over the years? Any examples of changes you made specifically in response to something that wasn't working well in the past?
7. How well are these outreach activities working and how do you monitor their effectiveness?
    a. Do you have a breakdown of how many of the mentors are caregivers, people living with paralysis, etc.
    b. Could you share a summary of mentors with sociodemographic characteristics and language abilities?
8. Are there any gaps in geographic areas served or gaps in populations represented by mentors that you are trying to address?
9. What challenges are you facing in the recruitment or selection of peer mentors? Is the number adequate to meet the need? Are there mentors with specific characteristics that you would like to recruit but have had difficulties finding?
10. What other strategies have you employed or do you intend to employ to retain and/or increase the number of peer mentors?

Matching of Mentors to Mentees

Next we'd like to ask you some questions about how you match your mentors with mentees.

11. Please summarize your process for matching peer mentors to mentees.
    a. What criteria do you use and how do you make decisions on who gets paired with who?

   b. How do you prioritize which characteristics are the most important to match on? What are the least important?
   c. How many new mentors do you train per year?
12. Any adaptations or changes you made to this process in recent years and reasons for changes?
13. What challenges have you experienced with this matching process? What lessons have you learned about what makes a successful match?

Training for Peer Mentors

14. Can you briefly summarize the training you provide to every mentor? (Frequency, topics, virtual, # of hours, etc.). How do you decide what's a best practice related to peer mentoring and then incorporate into your curriculum?
15. What types of resources or training are you providing related to health equity or cultural competence?
16. What best practices/lessons learned do you have related to training? Are there particular frameworks or theories that guide your training?
17. How do you assess your training efforts to see what's working/what's not working?
    Are you aware of any gaps in your training/resources to assist peers that you are currently working to address?
18. What type of regular communication/ongoing training do you have with peer mentors?

Mentor and Mentee Relationship

19. Can you talk about the topics/concerns mentors typically help mentees address?
20. What qualities/characteristics make a successful mentor?
21. How often do mentors meet with their mentees and how long is the typical relationship?
    a. How many mentees does the typical peer mentor work with?
    b. Do you have an idea for how long you think the relationship should last to have a lasting impact?
    c. Are there certain needs that result in longer relationships?
    d. Do you have a sense for what % of the relationships are long-term vs. short-term?
22. What resources are provided to peer mentors to help them build their relationship with their mentee? (i.e., financial resources, stipends, technical assistance, support groups, website resources, etc.)
23. What has been the impact of the pandemic on mentors? How did you address any challenges that arose? (meeting via phone, meeting virtually, etc.)
24. What extra supports do you provide to mentors that are having difficulty establishing or building a relationship?

Concluding Thoughts

25. Are there any specific accomplishments/success that you would like to highlight in regard to your PFMP?
26. From your perspective, what are the key elements of an effective peer mentoring program?
27. What are some of the most significant challenges you are facing with administering this type of program?

Are there things that make your program unique from other similar programs? What lessons learned would you offer other Centers developing a similar type of peer mentoring initiative?

C3. PFSP Staff interview Protocol 2023

Updates since last year

28. When we spoke in early summer 2022, you indicated that you would like to increase the number of family caregivers, adolescent mentors, mentors from rural areas and medically underserved populations.
29. Can you describe any changes you've made to your program that may have helped to reach this goal?
30. Have you observed increases in these numbers as you had hoped?

31. Are there any other changes/updates to the PFSP you have made that you would like to share with us? Any new training, practices implemented?

Role of Partners

32. We know you partner with a number of rehabilitation facilities and health care providers to recruit, screen, and train mentors. Can you tell us more about how these partnerships work?
    a. How do you find these partners? Is there an onboarding process for new partners?
    b. What role do partners play in the following activities with mentors:
        i. Recruitment
        ii. Screening
        iii. Training
        iv. Matching
        v. Ongoing relationship management between mentors and peers
    c. How do you support partners with these functions? Who are your most active partners? Least active?
    d. Do any partners handle these responsibilities independently?
33. Are there any functions handled solely by the NPRC which partners do not participate in? *(i.e., background checks, etc.)*
    a. Are there any functions handled solely by partners which require less involvement from the NPRC staff?
34. What supports and resources do NPRC staff provide to mentors to help them manage their ongoing relationships with peers?
    a. How are these resources and supports shared with partner organizations to further support established matches?
    b. What barriers (if any) do NPRC staff face in ongoing support of partners?
35. How do you oversee the mentors volunteering with these partner organizations?
36. What data collection and reporting activities are they required to complete?
    a. What are the challenges to consistent data reporting from mentors?
37. Is any additional training on data collection and reporting activities provided for mentors or partners?
    a. What internal staffing support do you have for data analytics, reporting, and training?
38. For you or partner organizations, does geography or location play a role in determining a match between a peer and a peer mentor?
39. Last time we spoke, you indicated that partner organizations do track number of mentors from underserved and underrepresented groups but are not reported to you. Is this still the case?

Data Questions – Defining and Tracking Peer Contacts

We had some questions that arose when comparing the number of people on the contact list of peers that have requested a peer mentor to the number of peers reported in the Semi-Annual Performance Report as "New records for peers."

In response to a request for contact information for people who requested a peer mentor or were served by a peer mentor in the time period July 2022 to March 2023, you sent a description of the contacts indicating that this list was manually filtered so only those who had an encounter with a Peer Mentor were counted.

40. Can you describe who is counted in the "New records for peers" number reported in the Semi-Annual Reports?
41. For peer clients who do not have an encounter with a peer mentor, are they referred to Information Services? Would PFSP respond via email?
42. Does the Reeve Foundation count an individual who requests a peer mentor, but then does not proceed to get matched, as a "Peer" new record in all cases, or do some get counted as new requests to an Information Specialist?

43. Is there a way you can track how many peers are receiving mentoring from NPRC partner organizations?
44. Are you able to track when a peer becomes inactive or is no longer receiving mentoring assistance?

C4. QOL Grants Staff Interview Protocol 2022

Introductions

We would first like to begin with introductions.

45. [For each interview respondent participating in the call] What is your title and main responsibilities related to administering the QOL grant Program?

QOL Goals and Priorities

First we'd like to talk to you about your key priority areas for the QOL initiative.

46. We understand that you currently use a 5-Tier structure to organize your grant opportunities:
    a. Tier 1: Direct Effect
    b. Tier 2: Respite/Caregiving, Assistive Technology, COVID-19: Addressing Social Isolation – **High Impact/Priority Impact**
    c. Tier 3: Nursing Home Transition, Racial Equity - *forthcoming*, Rural Underserved and Unserved – *forthcoming;* **High Impact/Priority Impact**
    d. Tier 4: Employment – High Impact/Priority Impact
    e. Tier 5: Expanded Impact

    Could you talk about how you arrived at these 5 Tiers and how you define them? What does it mean to be a "direct effect" vs. "high Impact" grant, etc.? Are there other considerations you consider when creating these categories for awards?
47. Could you talk about how you prioritize selecting and awarding grants among these 5 Tiers?
48. How have your goals and priorities for the QOL grant initiative changed and evolved over the last 2-3 grant cycles? What factors have driven these changes? Are there any goals or priorities that have been abandoned and if so why?

Defining Activities

49. We have identified the following categories of work needed to administer QoL grants: Outreach, Selection of Grantees, Grantee Support, Grantee Evaluation, and Partnerships. Are there any other components of grant administration that demand your attention and resources? What are those additional categories?

Outreach Activities

Next we'd like to ask you some questions about how you educate and recruit potential applicants to participate in the QOL grant initiative.

50. Could you briefly describe your outreach activities to inform and educate potential applicants about the QOL grant program? What specifically are you doing to expand the reach of the QOL initiative?
    a. How do you inform and educate grantees about a new area of focus?
51. What specific outreach do you conduct to encourage participation from applicants from underserved communities or underserved populations? *(i.e., racial and ethnic minorities, rural populations, individuals with limited English proficiency, children and adolescents, military personnel, individuals with multiple conditions)*
52. Have you identified any gaps in geographic areas served or gaps in populations represented among applicants? If so, what are they?
53. What activities (if any) are you employing to increase the number of applicants from underrepresented areas or underrepresented populations?

54. Any lesson learned or best practices for conducting this type of outreach that you'd like to share?
55. What challenges have you experienced in reaching underserved populations or underserved communities?

Selection of Grantees

56. Can you briefly summarize how you select applicants for awards? What criteria do you use and how did you determine these criteria?
57. What is the composition of your grantee selection committee and how do you identify and select members to participate? (do they change each cycle, how many members are there, how long does the process take, etc.)
58. Has your grantee award process changed in recent years and if so, how? How do you stay abreast of best practices in the area of grant administration and management?
59. What trends have you seen over the years in the characteristics or types of applicants that have applied for these grants? What gaps exist in the types of grantees that are applying or not applying and do you have plans to address these gaps?
60. What are the most pressing challenges that arise during your grant selection process? Any lessons learned in the selection process that you would like to share for other entities implementing a similar initiative?
61. What has been the impact of the pandemic on your process? How did you address any challenges that arose? (meeting via phone, meeting virtually, etc.)

Grantee Support and Evaluation

62. Do you ever provide technical assistance or resources to help grantees implement their grant? If so, what types of assistance do you provide?
63. Are there certain implementation topics/issues that grantees need more support in than others? How do you evaluate the effectiveness of the resources or technical assistance provided?
64. Broadly, how do you monitor and evaluate grantees' progress towards reaching their goals? Could you please tell us about the data you collect? (*i.e., site visits, quarterly reporting, etc*.)
    a. How do you collect information on # of people reached, demographics, etc.?
65. How do you then analyze the findings from your evaluation and monitoring activities to help grantees address problems/issues that arise? Please provide some examples.

Role of Partners

66. What types of organizations/entities have you partnered with in the implementation of the QOL initiative and what role do they play? *(i.e., creating awareness of grants, recruiting grantees, providing TA, etc.)*
67. How have partners aided and contributed to the QOL grant program?
68. Do you have specific partnerships that represent underserved or underrepresented groups, or partners that help you address any gaps in services that you are hoping to address? Could you provide some examples of what's worked/not worked with these partnerships?

Concluding Thoughts

69. Are there any specific accomplishments/success that you would like to highlight in regard to your QOL grant program?
70. What are the most significant challenges you are experiencing in administering this type of grant program? Or in serving this population?
71. What lessons learned can you offer other Resource Centers operating a similar type of grant initiative?

C5. Informational Specialist (IS Program) Staff Interview Protocol 2022

Introduction

We would first like to begin with introductions.

1. What attracted you to the Information Specialist position with the Reeve Foundation?
2. Please briefly summarize your roles and responsibilities. Does your role differ from that of other Information Specialists? If so, how?

Client Interaction

3. How do clients find out about IS services?
4. What are common types of inquiries you receive from clients?
5. Can you walk me through the process of how you help a client?
    a. How do you receive inquiries and how are assignments made?
    b. What happens after you receive an inquiry?
6. How do you follow up with clients after your initial response to their inquiry?
7. Do you follow up with all clients, certain clients, and in what sort of a timeframe?
8. How long do you typically work with a client? Is it common to just answer one question or do you often have multiple interactions?
9. How do you determine what language to speak to a client in? For example, if a client calls and seems to be struggling with English.
10. What challenges do you face in assisting clients?
11. How often do you encounter situations where you feel unable to assist a client? What do those situations look like?
12. How do you use or apply ACL- funded language translation services in your interactions with clients? How often do you have to bring in a translator?

Coordination with Other Services

13. Can you provide an overview of the services you can provide to a client?
14. How and when do you decide to refer a client to services outside the Reeve Foundation? Can you provide some examples of what those services may be?
    a. How often do you refer clients to services in their own community? What are those services?
15. Is this referral process any different for a non-English speaking client? For example, are there interpretation services clients may access with referrals?
16. How do you coordinate with other Information Services offerings ? (i.e., crisis prevention, employment and benefits support, nurse case management, Transitioning to College Services, Boys Town [suicide hotline], other)
    a. Have you referred a client to a nurse case manager?
    b. What criteria do you use for referring a client to a nurse case manager?
    c. How often does this happen?
17. Are there any gaps in the services/support you would like to be providing but are unable to? If so, what are those gaps?
18. How do you intersect with other Reeve Foundation activities such as the Peer and Family Support Program, Quality of Life grants program, or outreach and advocacy program?
    a. Do you often refer to the peer and family support program?
    b. Are many clients referred to you from Quality-of-Life grantees?
    c. Other examples?

Materials Development and Distribution

19. What is your involvement in the development of publications for clients? How much of your time is spent on making materials vs. working directly with clients or other tasks?
20. How are publications developed in languages other than English? How are translations of key vocabulary terms determined?
21. Does Information Services provide any help accessing materials for individuals who are not able to read or are sight impaired?

Outreach/Unserved and Underserved Populations

22. What roles or tasks do you take on related to outreach and specifically outreach to underserved populations?
23. Do you feel like you have adequate resources and training available to you to assist non-English speaking clients or clients from underserved or minority populations?
24. [*Question for bilingual information specialist*] As the only bilingual Information Specialist, do you feel you are able to adequately handle your case load?

Training

25. How has training provided or sponsored by the Reeve Foundation impacted your ability to assist clients?
    a. What resources have they provided to you to aid you in this role? Have they been helpful?
26. Is there any additional training you think could be valuable?
27. [*Question for bilingual information specialist*] Did the Reeve Foundation provide specialized training for you as a bilingual Information Specialist? If yes, what additional training did you receive?

Client feedback

28. How do you track and monitor your activities? How do you know when a case is closed?
29. How do you receive and integrate client feedback into your process?
30. Can you provide any examples of how you have changed your process for working with a client based on client feedback?

Conclusion

31. What resources are most helpful to you in meeting clients' needs?
32. Any lessons learned from your work as an Information Specialist that you would like to share with other similar programs?
33. What changes/ improvements (if any) would you make to the program if you could?
34. Is there anything else we have not asked you today about your work in the Information Services program that you would like to share with us?

C6. IS Management Staff Interview Protocol 2022

Introductions

We would first like to begin with introductions.

35. [For each interview respondent participating in the call] What is your title and main responsibilities related to administering the Information Services and Referral Program with the NPRC?
36. Please briefly describe the mission and objectives of the Information Specialist program.

Outreach and Promotion of Information Specialist Program

37. How do clients find out about your Information Specialist program? What activities and outreach do you engage in to educate the public about these services?

Responsibilities and Activities of Information Specialists

38. Please summarize the key role and responsibilities of the information specialists.
39. Are responsibilities the same for each information specialist or do their tasks vary based on expertise and background?
40. In your opinion, what function or task (s) do the information specialists spend most of their time doing? (Answering questions over the phone, creating print materials, referring clients to community services and supports, etc.)
41. Can you provide an overview of the scope of services an information specialist can provide to a client?
    a. How does an information specialist intersect with other referral services you offer as part of the IS program? *(i.e., crisis prevention, employment and benefits support, case management, other)*
    b. Do you have a sense for how often clients are referred to these alternative services?
    c. How equipped are information specialists to refer clients to services/supports in their own community?
42. Can you briefly describe some of the top issues and concerns raised by clients contacting information specialists in recent years?
43. Can you estimate the average length of time an information specialist works with a client? Are they typically answering one question only or does an Information Specialist often have multiple contacts with a client over time?
44. How do the information specialists use or apply translation services when working with clients?
45. Have you made changes to the IS program or to the responsibilities of the information specialists in recent years and what was the rationale for these changes?
46. In your opinion, what are the key challenges information specialists face in doing their work?

Outreach and Recruitment of Information Specialists

47. How do you recruit individuals to serve as information specialists? What education, experience, and qualifications do you look for when recruiting?
48. How many of your information specialists speak more than one language and what languages do they speak? Are any of your information specialists from underserved or underrepresented areas?
49. Do you have any specific outreach or recruitment activities in place to recruit individuals from certain underserved or underrepresented groups? *(i.e., racial and ethnic minorities, individuals with limited English proficiency, military veterans, etc.)*
    a. If so, what are these activities?
50. If not, do you have plans to modify or enhance your recruitment approach to attract more individuals from these populations?
    a. Are there information specialists with specific characteristics that you would like to recruit but have had difficulties finding?
51. Is the number of information specialists you have on staff adequate to meet the need? If not, what needs are you struggling to address and what plans (if any) do you have to meet these needs in the future?

Training and Support

52. What training do you provide information specialists to assist them in their work?
53. We understand that all members of the IS team are certified by the Alliance for Information and Referral Systems (AIRS) which helps train IS professionals to provide quality referral services to clients. Can you tell us a bit more about the type of training offered by AIRS and how it guides the work of the information specialists? What benefits does this training provide and how often is recertification required?
    a. Are there other types of training you provide to information specialists?

54. What other resources do you provide to information specialists to help them be successful in their work?

Publications and Material Distribution

55. We understand the types of materials you produce for dissemination (guides, articles, issue briefs, fact sheets, newsletters, pamphlets, videos, etc.). How do you decide which materials to produce in a given year?
56. How much of what you produce is created in-house vs. through contractors or partnerships with provider or community organizations?
57. You produce materials for people from all backgrounds, ages, races, genders, sexualities. How do you consider the characteristics of your diverse audience when creating your materials? How do you address cultural competence?

Data Collection and Evaluation

58. How do you assess the effectiveness or impact of the IS services you are providing?
    a. Do you use google analytics to track progress? If so, how?
59. Can you provide an example of how this research informed any changes in the types of services you provide or how they are delivered?

Intersection with Other NPRC Activities

60. Do you have a sense for how many clients that contact the IS program are then referred to the PFSP program? Do many of your IS clients receive services from QOL grantees?
61. How does what you learn from IS clients inform the other NPRC programs (if at all)?

Concluding Thoughts

62. What are some of the challenges you face in administering this type of program?
63. From your perspective, what are the key elements of an effective IS program? What lessons learned would you offer other Centers developing a similar type of program?
64. Is there anything else we have not asked you today about your IS program that you would like to share with us?

C7. Public Policy and Advocacy Staff (Promotional Activities, Outreach, and Collaboration Program) Interview Protocol 2022

Introductions

We would first like to begin with introductions.

65. [For each interview respondent participating in the call] What is your title and main responsibilities related to administering the Public Policy and Advocacy Program?

Financing

Before we get into the details of your specific advocacy activities, we would like to ask you about funding.

66. Can you confirm which NPRC activities are supported by the ACL grant?
    a. Regional champion meetings and trainings
    b. Advocacy summit
    c. Are there any other public policy activities that are supported by this grant that we are missing?

Advocacy Goals and Objectives

Now we'd like to ask some big picture questions to get a sense for your advocacy goals for supporting individuals living with paralysis.

67. What is your policy agenda related to supporting individuals living with paralysis? What are your advocacy goals for the current year or next few years?
68. How do you determine what the needs are of the paralysis community and how are those needs incorporated into your policy agenda?
69. How are members of the paralysis community involved in both setting the agenda and advocating for change?

Regional Champions

70. Could you please briefly describe what activities the regional champions are involved in and how they fit into your overarching policy agenda for individuals living with paralysis?
71. How (if at all) are champions involved in setting the policy agenda for the individuals living with paralysis?
72. How do you choose or recruit participants for the regional champions program? Is there a screening or interview process when onboarding new participants? Are regional champions only people with paralysis or can allies or caregivers also be regional champions?
73. Do you recruit regional champions from underserved populations and if so, how? (i.e., underserved populations, racial and ethnic minorities, individuals with limited English proficiency, children/adolescents, military veterans, etc.)
74. Are you aware of any gaps in regional champions you have participating? (certain geographic or demographic populations)
75. What challenges have you had with recruiting and selecting regional champions? And how have you responded to these challenges with recruiting and selecting participants?
76. How has the pandemic affected the work of the regional champions?
77. From your perspective, what makes a successful regional champion?

Training for Regional Champions

78. Can you briefly describe the training you provide to your regional champions? (*frequency of trainings/webinars, topics discussed, # of participants)*
79. When training the regional champions how do you assess what is working vs. what is not working? What changes have you made to the training program to improve it in recent years?
80. What data do you collect to help you monitor and assess this initiative?

Advocacy Summit

81. How are participants recruited for the Advocacy Summit? *(i.e., only regional champions, or others)*
82. In documents we've read from the Reeve Foundation, we understand that the Advocacy Summit is where participants learn about public policy priority issues. What are these priority issues and how are they determined?
83. In documents we've read from the Reeve Foundation, we understand that the Advocacy Summit is also meant to help attendees develop advocacy skills. What advocacy skills are they trained in?

Concluding Thoughts

84. Are there any specific accomplishments/success that you would like to highlight about the regional champions and annual conference? Anything from the public policy/advocacy program more broadly that you would like to mention?
85. What are any significant barriers/challenges you face in implementing these activities?

86. What lessons learned would you offer other resource centers developing a regional champions or other similar initiative?

C8. Other Peer Mentoring Organizations Interview Protocol 2023

Introductions

We would first like to begin with introductions.

87. [For each interview respondent participating in the call] What is your title and role in your organization? What are your main responsibilities related to administering a peer visiting program?
88. Please briefly describe your organization.
    a. How long has your organization had a peer visiting program?

Overview of program

89. Could you give me a brief overview of how your program operates?
    a. About how many peer visitors do you currently have volunteering with your organization? What is the scope of your program in terms of number of supporting staff?

Outcomes from Peer Visiting

90. What does your organization hope to gain from having a peer visiting program? What outcomes do you expect peer visitors to have? What outcomes do you expect peers to have?

Recruitment and Selection of Peer Visits

91. Do you have any outreach or recruitment activities in place to directly recruit visitors from certain groups? (i.e., underserved populations, racial and ethnic minorities, individuals with limited English proficiency, children/adolescents, military veterans, etc.)
92. What screening do you perform of visitors prior to selection? Specifically, what criteria do you use? Do you conduct background checks?
93. How well would you say the screening process works? Any examples of changes you made specifically in response to something that wasn't working well in the past?
94. What challenges are you facing in the recruitment or selection of peer visitors? Is the number adequate to meet the need? Are there visitors with specific characteristics that you would like to recruit but have had difficulties finding?

Training for Peer Visit

95. Can you briefly summarize the training you provide to every visitor? (Frequency, topics, virtual, # of hours, etc.). How do you decide what's a best practice related to peer visiting and then incorporate into your curriculum?
96. What expectations do you set, if any, for whether visitors reach out to mentees, time spent with mentees, etc.? Do you set an expected time commitment upfront?

Matching of Visits to Mentees

97. Do visitors and mentees usually have in-person or phone/Zoom-based relationships?
98. What criteria do you use and how do you make decisions on who gets paired with who?
    a. How do you prioritize which characteristics are the most important to match on? What are the least important?
99. Any adaptations or changes you made to this process in recent years and reasons for changes?

100. Do you have a feedback mechanism to track whether you had a successful match or not? If so, what actions do you take if a peer or peer visitor is dissatisfied with the match?
101. What challenges have you experienced with this matching process? What lessons have you learned about what makes a successful match?

Visit and Mentee Relationship

102. How often do peer visitors meet with their peers and how long is the typical relationship?
    a. How many mentees does the typical peer visitor work with?
    b. Are there certain needs that result in longer relationships?
    c. Do you have a sense for what percent of the relationships are long-term vs. short-term?

    Do your staff provide resources or support to visitors to help them manage their ongoing relationships with peers? If so, what kinds of resources and supports?
103. What data collection and reporting activities are visitors required to complete during their visiting process? If you collect data, how do you use it?

Concluding Thoughts

104. From your perspective, what are the key elements of an effective peer visiting program? How do you evaluate your program and learn what's working and not working?
105. Are there things that make your program unique from other similar programs? What lessons learned would you offer other centers developing a similar type of peer visiting program?

C9. PFSP Partner Organization with a Hybrid Relationship Interview Protocol 2023

Introductions

We would first like to begin with introductions.

1. Could you state your name and position, how long you have been with [name of organization] and provide us with a brief background about your organization or center.

Origin of Relationship with PFSP

2. How long has [*organization name*] been partnering with or collaborating with the Reeve Foundation PFSP?
3. How did the relationship begin and what was [*organization name*] rationale for creating this type of collaboration?
4. Did you have your own mentoring program already established and need additional support?
    a. Did you want to start a new mentoring program?
    b. Were there other organizations or providers that provide similar service that you considered partnering with?
5. What were your goals and expectations for this type of partnership?

PFSP Training

6. We understand the PFSP does virtual trainings for your mentors, is that correct? How many trainings have they conducted for your mentors?
7. How has this training enhanced your capacity to recruit and train mentors? Was there anything particularly helpful about the training? Would you suggest any improvements?
8. How often do you hold a training for new mentors at your facility? Approximately how many mentors do you train annually?

Recruitment and Selection of Peer Mentors

I'd like to talk about how you go about recruiting and selecting individuals to become peer mentors.

9. Please summarize how you find and select individuals to become peer mentors at your facility?
10. Do you have any specific outreach or recruitment activities in place to directly recruit mentors from certain groups? (i.e., underserved populations, racial and ethnic minorities, individuals with limited English proficiency, children/adolescents, military veterans, etc.)
11. How do you screen mentors for participation in the program?
    a. PFSP screening criteria
    b. Your own criteria (Can you provide us with a screener)
12. How has the PFSP helped you recruit and screen mentors?
13. How have the number of mentors and peers changed in recent years? Have you seen an increase/decrease/remain the same? Please discuss reasons if known.

Matching of Mentors to Mentees

Next, we'd like to ask you some questions about how you match your mentors with mentees.

14. Please summarize your process for matching peer mentors to peers.
    a. What criteria do you use and how do you make decisions on who gets paired with who?
    b. How do you prioritize which characteristics are the most important to match on? What are the least important?
    c. How does the PFSP support you in this matching process?
15. What challenges have you experienced in matching? What lessons have you learned about what makes a successful match?

Mentor and Mentee Relationship

16. How often do mentors meet with their peers and how long is the typical relationship?
    a. How many peers does the typical mentor work with?
    b. Are there certain needs that result in longer relationships?
    c. Do you have a sense for what % of the relationships are long-term vs. short-term?
    d. Do you have some mentors that have been mentoring for a long time?
    e. Do you think mentors should be compensated for their time and expense?
17. Does the PFSP provide you with resources *(i.e., materials, advice/guidance from program coordinator, other)* to help mentors build their relationship with their peers? If so what types of resources/support?
18. Are there extra supports you provide to mentors that are having difficulty establishing or building a relationship? Do you provide stipends?

Data Collection

19. Can you describe how you track the number of mentors and peers you are serving and their activities?
20. What support do you receive from the PFSP to help you report these numbers?
21. What challenges do you face with reporting? Would additional support be helpful?

Concluding Thoughts

22. What are some of the most significant challenges you are facing with running this type of program?
23. Are there any additional resources or supports that you could use to help administer an effective mentoring program?
24. Any lessons learned you'd like to share?

C10. PFSP Partner Organization with a Formal Partnership Interview Protocol 2023

Introductions

We would first like to begin with introductions.

1. Could you state your name and position, how long you have been with [name of organization] and provide us with a brief background about your organization or center.

Origin of Relationship with PFSP

2. How long has [*organization name*] been partnering with or collaborating with the Reeve Foundation PFSP?
3. How did the relationship begin and what was [*organization name*] rationale for creating this type of collaboration?
4. Did you have your own mentoring program already established and need additional support?
    a. Did you want to start a new mentoring program?
    b. Were there other organizations or providers that provide similar service that you considered partnering with?
5. What were your goals and expectations for this type of partnership?

"Train the Trainer" Training

6. How has this training enhanced your capacity to recruit and train mentors? Was there anything particularly helpful about the training? Would you suggest any improvements?
7. How often do you hold a training for new mentors at your facility? Approximately how many mentors do you train annually?

Recruitment and Selection of Peer Mentors

I'd like to talk about how you go about recruiting and selecting individuals to become peer mentors.

8. Please summarize how you find and select individuals to become peer mentors at your facility?
9. Do you have any specific outreach or recruitment activities in place to directly recruit mentors from certain groups? (i.e., underserved populations, racial and ethnic minorities, individuals with limited English proficiency, children/adolescents, military veterans, etc.)
10. How do you screen mentors for participation in the program?
    a. PFSP screening criteria
    b. Your own criteria (Can you provide us with a screener)
11. How has the PFSP helped you recruit and screen mentors?
12. How do you pay for background checks?
13. How have the number of mentors and peers changed in recent years? Have you seen an increase/decrease/remain the same? Please discuss reasons if known.

Matching of Mentors to Mentees

Next, we'd like to ask you some questions about how you match your mentors with mentees.

14. Please summarize your process for matching peer mentors to peers.
    a. What criteria do you use and how do you make decisions on who gets paired with who?
    b. How do you prioritize which characteristics are the most important to match on? What are the least important?
    c. How does the PFSP support you in this matching process?

15. What challenges have you experienced in matching? What lessons have you learned about what makes a successful match?

Mentor and Mentee Relationship

16. How often do mentors meet with their peers and how long is the typical relationship?
    a. How many peers does the typical mentor work with?
    b. Are there certain needs that result in longer relationships?
    c. Do you have a sense for what % of the relationships are long-term vs. short-term?
    d. Do you have some mentors that have been mentoring for a long time?
    e. Do you think mentors should be compensated for their time and expense?
17. Does the PFSP provide you with resources *(i.e., materials, advice/guidance from program coordinator, other)* to help mentors build their relationship with their peers? If so what types of resources/support?
18. Are there extra supports you provide to mentors that are having difficulty establishing or building a relationship? Do you provide stipends?

Data Collection

19. Can you describe how you track the number of mentors and peers you are serving and their activities?
20. What support do you receive from the PFSP to help you report these numbers?
21. What challenges do you face with reporting? Would additional support be helpful?

Concluding Thoughts

22. How has this partnership aided you in your work? What has been the impact of this partnership on your services/program?
23. What are some of the most significant challenges you are facing with running this type of program?
24. Are there any additional resources or supports that you could use to help administer an effective mentoring program?
25. Any lessons learned you'd like to share?