National Paralysis Resource Center (NPRC)

2023 Evaluation Findings Report

January 2024

Prepared by RTI International

Table of Contents

- Introduction, Timeline, and NPRC Structure
- Evaluation Goals and Questions
- Evaluation Methods
- Findings by Program
- Evaluation Conclusions and Next Steps

Introduction, Timeline, and NPRC Structure

Introduction

- The National Paralysis Resource Center (NPRC) assists individuals living with paralysis resulting from:
  - Spinal cord injury (SCI)
  - Multiple sclerosis (MS)
  - Amyotrophic lateral sclerosis (ALS)
  - Stroke
  - Other conditions.
- Mission:

  The NPRC seeks to improve the quality of life for people living with paralysis, their families, and caregivers by providing information, grants, resources, and support.

Timeline

1999

Christopher & Dana Reeve Foundation (CDRF) creates the Paralysis Resource Center

2009

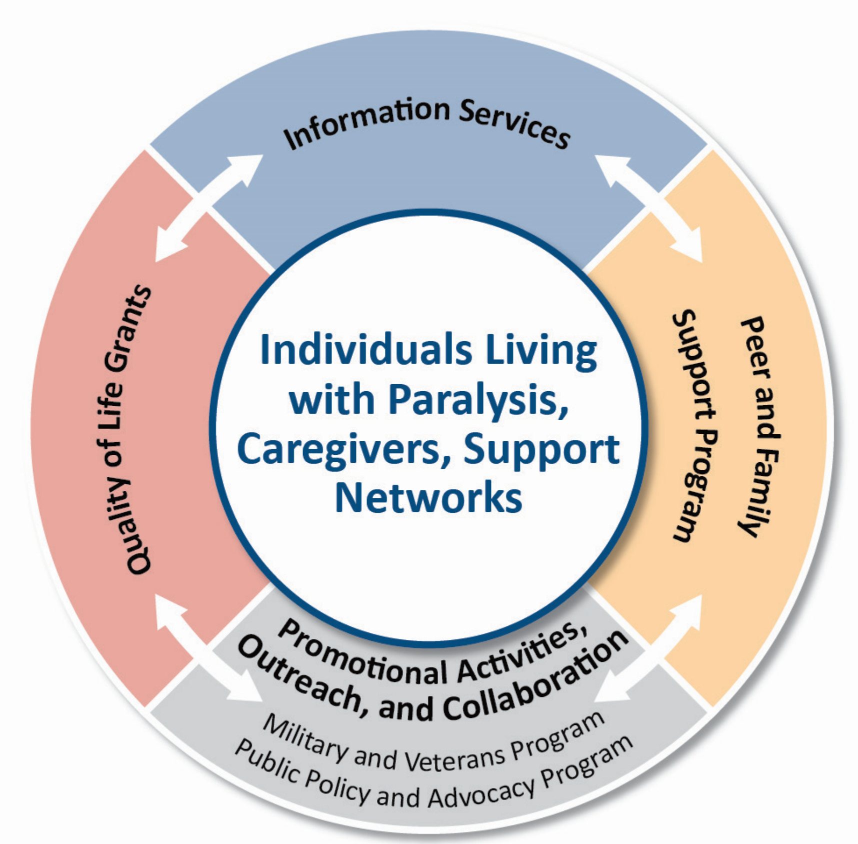
Congress passes the Christopher & Dana Reeve Paralysis Act, authorizing creation of the NPRC

2014-present

Administration for Community Living (ACL) is tasked with administration of the competitive grant process that supports the NPRC

NPRC Structure

The NPRC offers many services and resources, including Information Services, Quality of Life Grants, Peer and Family Support Program, and Promotional Activities, Outreach, and Collaboration.



Evaluation Goals and Questions

NPRC Evaluation Goals

Develop an in-depth understanding of the NPRC’s activities and functions.

Explore how these NPRC activities achieve desired outcomes for individuals living with paralysis.

Evaluation Questions

How did the NPRC:

- Improve the health and quality of life of individuals living with paralysis of all ages, their families, and their support systems?
- Raise awareness of members of the target populations about paralysis?
- Increase access of members of the target populations to services relevant to individuals living with paralysis?
- Increase the empowerment, confidence, and independence of individuals living with paralysis?
- Strengthen support networks for individuals living with paralysis?
- Improve and increase opportunities for community living for individuals living with paralysis and their caretakers?

Evaluation Methods

Methods

Quantitative and qualitative data analysis

- Primary data
    - Focus groups
    - Interviews
    - Surveys

- Secondary data
    - NPRC Semi-Annual Performance Reports
    - Evaluation results from the NPRC's internal evaluation partner, Vanderbilt University

Methods by Program

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

Program Detail Methods

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

*** Participation rates from peer mentors and peers were lower than expected, despite using mixed-methods data collection tools**

[a] **Counts exclude email addresses that were undeliverable.**

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

Program Detail Methods (Cont.)

NPRC program	Eligibility criteria for data collection	Type of data collection	Number of people contacted[a]; Number of participants[b]	Data collection period
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
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

[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.**

Findings by Program

Peer and Family Support Program

The **Peer and Family Support Program (PFSP)** is a national peer-to-peer mentoring program begun in 2011 to support people living with paralysis, their family members, and caregivers.

PFSP Key Findings

Interviews, Focus Groups, Surveys, and Document Review found that:

Identification of local resources is the most requested service, but many peers are not in the same geographic communities as their peer mentors.

NPRC-organized peer mentoring is usually virtual; peers/peer mentors are comfortable with that format (no desire for in-person).

Peer mentors reported positive experiences, but some hoped for more mentoring opportunities.

Some peers reported that peer mentoring had not met all their goals, though a new peer-matching NPRC database may address this concern.

Few peers and peer mentors responded to the evaluation surveys, interviews, and focus groups, meaning these findings may not represent the perspectives of the broader population.

Quality of Life Grants

One-third of the total NPRC budget is spent on the **Quality of Life (QOL)** grants program, which funds community-based organizations to develop innovative ideas, build capacity within communities, reach historically underserved populations, and facilitate partnerships across local organizations.

These efforts improve the health and well-being of individuals and their families/support networks impacted by paralysis.

QOL Key Findings

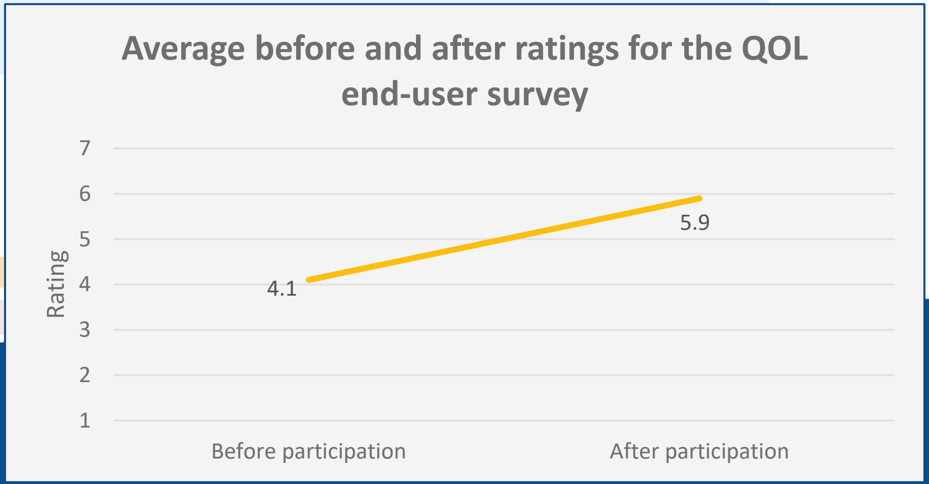
Interviews, Focus Groups, Surveys, and Document Review found that:

QOL grant programs positively impact QOL for people living with paralysis and their support networks.

On average, end-users of QOL grant-funded initiatives improved their self-selected QOL-related outcomes by almost 2 points on a 7-point scale.

Grantees indicated that QOL program staff are especially helpful with supporting grantees' program implementation challenges.

Grantees would like more NPRC assistance with collecting evaluation data from end-users.


Average before and after ratings for the QOL end-user survey

Promotional Activities, Outreach, and Collaboration

Promotional Activities, Outreach, and Collaboration (PAOC) encompass activities to expand NPRC awareness, increase community engagement, enhance collaboration across coalitions and partnerships, support the Military and Veterans Program, and engage with public policy.

PAOC Key Findings

Interviews, Focus Groups, and Document Review found that:

NPRC promotional activities and outreach have increased views of NPRC YouTube channel.

Partnerships with other organizations are increasing NPRC resource visibility (e.g., new outreach to Department of Veterans Affairs offices).

Public policy education is meeting goals to increase empowerment and confidence among people living with paralysis (e.g., Regional Champions program for empowerment).

NPRC staff who run the Regional Champions program are key to its success.

Information Services

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.

IS Key Findings

Interviews and Document Review found that:

NPRC client feedback suggests that IS program activities contribute to improved health and quality of life.

IS inquiries have been declining in recent years and may represent a change in demand or a change in how people access the NPRC information.

The recent NPRC website redesign has the potential to increase future IS inquiries.

IS continues to expand trainings, presentations, and resource accessibility (e.g., more captioned and subtitled videos/webinars, plain-language fact sheets, and materials translated in multiple languages).

Evaluation Conclusions and Next Steps

Conclusions and Next Steps

- The NPRC is having positive effects on individuals living with paralysis, their caregivers, and their support networks.
- Cross-program analyses show a net favorable perception of the NPRC's activities and programs, though findings are based on a small respondent pool that may not represent the entire population.

Potential opportunities include:

- Additional efforts to document and track participant data across programs
- Increased focus on local opportunities and resources
- Continued efforts to support historically underserved communities
- Ongoing evaluation efforts will continue to identify successes and potential growth areas for the future

Administration for Community Living