Fact Sheet

Social Support and Community Participation Among Adults With Spinal Cord Injury

Summary

- This fact sheet summarizes self-reported information on social connection and community participation among people living with spinal cord injury (SCI). Data were collected from 1,149 participants who had a mean age of 59 years and an average of 26 years since a traumatic SCI.
- All analyses in this fact sheet are based on NIH PROMIS and Neuro-QoL scores assessing social connection and community participation among people with SCI.[1, 2]
- Most participants reported social connection and community involvement similar to the general population.
- In general, most participants had regular contact with family and friends and took part in social and community activities outside the home.
- Volunteer work was less common. Many participants did not volunteer, while others volunteered at different levels.
- Compared to the general population, most participants felt able to engage in important social activities and were generally satisfied with their social roles.
- About 31% of participants were working for pay. Among those employed, 74% reported being satisfied with their job.

Connection, Support, and Participation After SCI


Photo Credit

Overview

Staying connected to friends, family, and the community is an important part of health and well-being after spinal cord injury (SCI). Emotional support, practical help, and opportunities to participate in daily and social activities may help people feel more connected, supported, and engaged in everyday life.

Social Connection

Overall, most people with SCI reported social connection levels similar to adults in the general U.S. population.

9 in 10

Reported feeling socially connected.

About 1 in 10 participants (11%) reported higher social isolation than adults in the general U.S. population.

Visits From Others

Out of 10 people

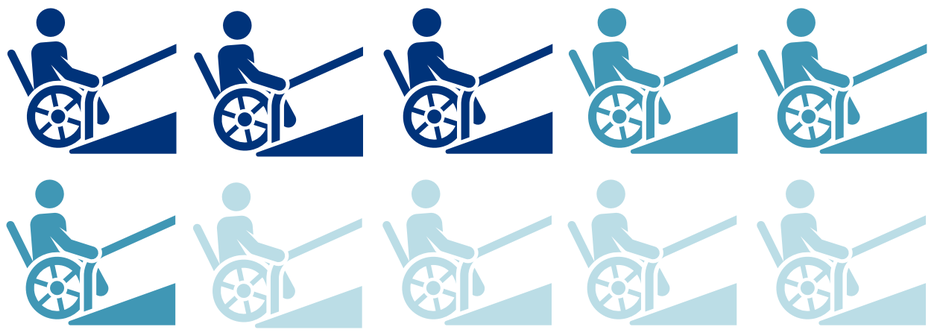
- About 3 in 10 received frequent visits.
- About 4 in 10 received regular visits.
- About 3 in 10 received less frequent visits.

Feeling socially connected can support emotional well-being, relationships, and participation in the community after SCI.

Make a difference, today!

Getting Out for Social and Entertainment Activities

Many participants shared that they regularly spent time outside the home doing things they enjoy, such as visiting friends or family, going to events, eating out, shopping, or taking part in community activities.



Out of 10 people

- About 3 (34%) people went out more than twice a week.
- About 3 (29%) people went out 1–2 times per week.
- About 4 (37%) people did not go out regularly (rarely or once/twice a month).

Volunteer work (Hours per week)

Most participants did not do regular volunteer work.

Out of 10 people

No volunteer work
(0 Hours per week)

About 7 out of 10 people did not do any volunteer work.

Some volunteer work
(1-10 Hours per week)

About 2 out of 10 people did some volunteer work.

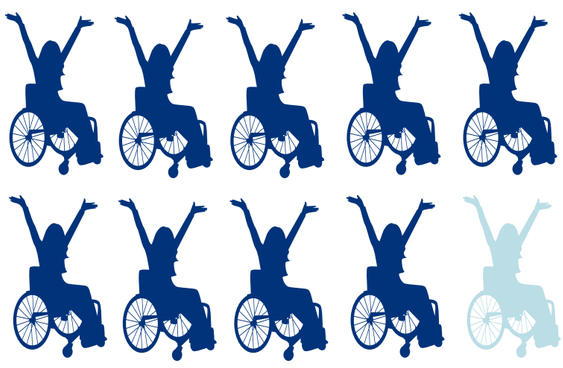
High involvement (>10 Hours per week

About 1 out of 10 people volunteered more than 10 hours per week.

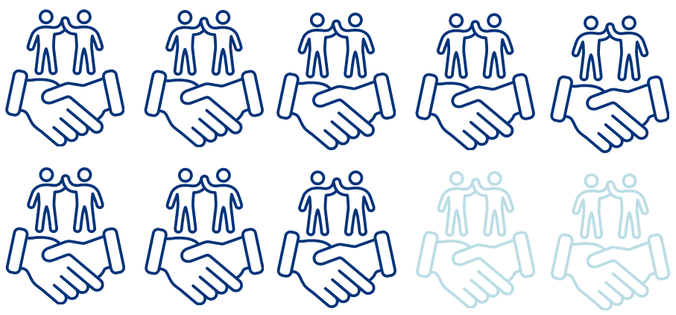
Participation and Satisfaction in Everyday Life

Overall, most participants felt satisfied with their social roles, felt able to take part in activities, and stayed involved in things that mattered to them. However, some participants reported more difficulties than adults in the general U.S. population.

Participation Ability | Actual Participation | Social Role Satisfaction



Nearly 9 in 10 people felt able to participate in important social activities.



Nearly 8 in 10 people reported taking part in important social activities.

About 4 in 5 people felt satisfied with their social roles and activities

Being able to participate supports independence, confidence, and overall well-being.

Taking part in activities can help build relationships, brings joy, and strengthens a sense of community.

Feeling satisfied with social roles can help people feel valued, connected, and supported.

Why Community Participation Matters?

Being involved in social, family, and community activities can support emotional well-being, independence, confidence, and quality of life after SCI.

Everyday Ways People Stay Connected

Spending Time with Friends & Family
Sharing meals, talking, and enjoying time together.

Volunteering and Helping Others
Giving time to support others and make a difference.

Going Out in the Community
Shopping, dining out, attending events, or enjoying activities around town.

Hobbies and Recreation
Doing activities you enjoy can help you relax, stay active, and feel good.

What Can Make Participation Easier?

Accessible Spaces
Accessible buildings, transportation, and community spaces help remove barriers.

Supportive Relationships
Support from family, friends, caregivers, peers, and providers can make a big difference.

Social Opportunities
Programs, events, and group activities create more chances to connect and participate.

Flexible Choices
Different activity options can help people participate in ways that work best for them.

Resoruces:

Volunteer Opportunities

Community Support

Living with SCI

Statewide resources for SCI

References

1. Hahn EA, DeVellis RF, Bode RK, Garcia SF, Castel LD, Eisen SV, Bosworth HB, Heinemann AW, et al. Measuring social health in the Patient-Reported Outcomes Measurement Information System (PROMIS): item bank development and testing. *Qual Life Res*. 2010;19:1035-1044.

2. Hahn EA, DeWalt DA, Bode RK, Garcia SF, DeVellis RF, Correia H, et al. New English and Spanish social health measures will facilitate evaluating health determinants. *Health Psychol*. 2014;33(5):490-499.

About This Fact Sheet

This fact sheet was created using data from the Health, Employment, and Longevity Project (HELP) aging 50 database at the Center for Rehabilitation Research in Neurological Conditions (CRRNC). It is supported by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) grant 90DPCP0009. This fact sheet is not meant to replace the advice of your physician or other healthcare provider. You should always consult your physician or healthcare provider before making changes to behavior, treatment, or use of medicine.

Director of the Center for Rehabilitation Research in Neurological Conditions (CRRNC): James S. Krause, PhD

Authorship: Social Support and Community Participation was developed by Kavita Talaviya, MPH, with analytic support from Ana Zeledon, MPH and published by the CRRNC at the Medical University of South Carolina.

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Contact: aust@musc.edu

MUSC Medical University of South Carolina