

Research In Focus: A Weekly Digest of New Research from the NIDILRR Community

SCI Advocates and SCI Practitioners Share Their Strategies for Successfully Navigating the Complex Healthcare System

A spinal cord injury (SCI) is damage to the spinal cord or the spinal nerve roots within the spinal canal and resulting in temporary or permanent loss of movement and/or feeling. Individuals with SCI often experience complex health issues making them high users of primary care. At the same time, they face many barriers to receiving quality healthcare such as inaccessible medical offices or equipment, problems with transportation, lack of SCI knowledge among primary healthcare providers, issues with insurance and benefits, and difficulties coordinating services among multiple providers. One NIDILRR-funded study asked self-advocates with SCI and SCI practitioners what persons with SCI could do to become their own best advocates for their primary care and equipment needs.

Researchers from the [New England Regional Spinal Cord Injury Center](#) (NERSCIC) model system conducted interviews with seven consumer-advocates with SCI who were 9 to 46 years post injury, as well as four practitioners with 10+ years of experience supporting individuals with SCI locally and nationally in self-advocacy efforts. The practitioners included a nurse, a social worker, a physical therapist, and an information specialist. The consumer-advocates were asked about their experiences in navigating primary care visits and equipment needs and then their recommendations on the most important self-advocacy skills and navigation strategies based on those experiences. For comparison, the practitioners were also asked to make recommendations of skills, strategies, and resources that individuals with SCI could use for promoting self-advocacy. Recommendations from both groups are presented below.

[Navigating Primary Care Visits](#)

The consumer-advocates shared the following strategies for choosing a primary care provider (PCP) and building a strong relationship:

- Strategies for choosing a PCP included reviewing insurance company directories, identifying staff at preferred hospitals, and interviewing potential physicians by phone or in-person. Qualities to consider in a provider included accessibility of the clinic or facility as well as provider's responsiveness, experience with SCI, and willingness to listen. Consumer-advocates also recommended that consumers consider whether they are willing to work with a physician who has less direct experience or knowledge of SCI but who is open to working collaboratively with patients and other specialists.
- Strategies for building the physician-patient relationship included consistent and open communication. Consumer-advocates recommended communication strategies like preparing lists or questions before appointments or bringing a person who knows the consumer's health history and can provide coaching or support for difficult topics.
- Strategies for resolving problems of access to facilities and equipment included inquiring about home visits or calling ahead to address accessibility issues. To address communication problems with the physician or office staff, consumer-advocates suggested in-person visits when faced with a lack of phone response, expressing concerns to the physician, and role-playing before appointments to practice and build confidence. If problems cannot be resolved, consumer-advocates recommended finding a new doctor. Similarly, consumer-advocates emphasized that even though a consumer's PCP may have been a good fit for them prior to a SCI, they may not be anymore, and it is OK to look for a doctor that can better address the primary care needs of a person with a SCI.

The practitioners agreed with the consumer-advocates on the importance of interviewing potential physicians and offered several additional sources for finding compatible providers, such as SCI support groups, SCI-specific organizations, and independent living centers. The practitioners focused on experience and accessibility as the most important qualities to consider in a PCP, and emphasized the need for consumers to take the lead in establishing an open and honest relationship and educate physicians on their care needs. They offered similar advice to resolve problems of

communication, such as role-playing and changing providers, and also recommended adding case managers and SCI nurses as potential advocates.

Navigating Equipment Needs

The consumer-advocates shared the following strategies for obtaining a wheelchair and other equipment, including dealing with insurance claims and denials:

- Strategies for choosing the correct wheelchair included using services of a wheelchair clinic to ensure proper measurement and fit, reading Internet reviews and gathering input from support groups to inform decision-making, and trying out equipment in a therapist's office.
- Communication, patience and persistence were key to navigating equipment needs, including speaking with the appropriate staff. The consumer-advocates recommended maintaining a positive, assertive, and proactive approach in dealing with equipment providers. They also recommended remaining actively involved throughout the process of getting new equipment and monitoring progress in approvals or delivery closely.
- Strategies for managing insurance requests and appeals processes included documenting justification for any equipment before communicating with insurance representatives, being persistent in following up on claims, and asking to speak with supervisors or managers when necessary. The consumer-advocates also recommended asking a physician to place the request to speed the process and engaging a professional advocate or a lawyer if claims continue to be unjustly denied.

Practitioners' recommendations for finding and obtaining equipment largely mirrored strategies recommended by consumer-advocates. They acknowledged the lengthy process of evaluation and obtaining equipment. They also stressed the importance of knowing and understanding insurance coverage up front, including any limitations that might require trade-offs in preferred equipment. In addition, the practitioners recommended a broad array of tips and resources for overcoming barriers to obtaining equipment, including funding, that did not come up in interviews with consumer-

advocates. These included utilizing social workers and independent living centers to navigate appeals and the importance of support groups for emotional support.

Most Important Recommendations

Lastly, the consumer-advocates were asked to summarize the most important recommendations overall to self-advocate and navigate the healthcare system. Their recommendations were as follows:

- Individuals with SCI should recognize the importance of self-advocating and that they have the best knowledge about their injury and health needs.
- It is important to develop key self-advocacy skills such as becoming knowledgeable about one's own injury and health needs, speaking up and being persistent, practicing communication skills, being organized, engaging peer mentors and others who can teach essential self-management skills, and keeping a positive attitude.
- To navigate the complexities of the healthcare system, individuals with SCI should identify and engage support networks including support groups, advocacy services and organizations, and health professionals with SCI knowledge and experience such as physicians, social workers, and wound care nurses.

Here again, practitioners agreed with consumer-advocates about the need to self-advocate and the skills that were most important. Both groups stressed the need for support in navigating the system, suggesting that consumers have at least one person who knows their health history and who can be a coach or helper. The practitioners and consumer-advocates highlighted the need for systemic change in transportation, physician training and knowledge, and insurance practices to reduce barriers.

The authors noted that two themes overlapped across all three areas: active consumer participation and finding professional and emotional support to navigate the system. The practitioners interviewed also recognized their potential roles as advocates and supporters for their clients with SCI. According to the authors, practitioners with knowledge of support organizations and funding sources may represent an untapped resource for consumers in this often frustrating area.

Another significant theme was about making trade-offs in both choosing a primary care physician and in obtaining equipment. According to the authors, some consumers may choose a provider who has less experience with or knowledge of SCI if that provider has other positive qualities such as willingness to listen and learn from their patients as well as collaborate with other specialists. The authors noted that people with complex health needs such as SCI are often frequent users of emergency rooms for preventable conditions, suggesting that future research may look at whether choosing a provider with less SCI knowledge and experience but with other positive qualities has an impact in this area. This study focused on people who were highly satisfied with their primary care and were actively self-advocating in order to understand their most effective strategies. The authors noted that SCI consumers who are less active in self-advocacy may require more social support as well as education and confidence building. They also suggested that practitioners could play an important role in educating their patients about health disparities and supporting them as they make decisions for their health care needs. Going forward, the authors are developing and testing a peer-led telephone intervention designed to empower consumers with chronic SCI to become advocates in their own primary health care.

[To Learn More](#)

The New England Regional Spinal Cord Injury System and Gaylord Specialty Healthcare developed the New England SCI Toolkit to be a resource for building capacity at healthcare facilities that may not treat patients with SCI often enough to have developed expertise. To access the SCI Toolkit, please visit:

<http://www.gaylord.org/Our-Programs/Spinal-Cord/Spinal-Cord-Injury-Model-System/Spinal-Cord-Injury-Toolkit>

The Paralysis Resource Center has extensive resources to help people with SCI find healthcare, equipment, and support. <http://www.paralysis.org>

United Spinal Association also offers a wealth of SCI-related resources. <http://www.spinalcord.org>

To Learn More about this Study

Houlihan, B., Brody, M., Plant, A., Skeels, S.E., Zazula, J., Pernigotti, D., Green, C., Hasiotis, S., and Jette, A. (2016) [Health care self-advocacy strategies for negotiating health care environments: Analysis of recommendations by satisfied consumers with SCI and SCI practitioners](#). Topics in Spinal Cord Injury Rehabilitation, 22(1), 13-26. This article is available from NARIC under Accession Number J73144.

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