

Opportunities for Research to Improve Employment for People with Spinal Cord Injuries

Future Research on Employment for People with SCI

Lex Frieden and Andrew J Winnegar

Abstract

Study Design: Literature review.

Objectives: This paper includes a review of the literature pertaining to employment of people who experience Spinal Cord Injury (SCI) in the United States. Key areas and topics for future research to increase employment for people with SCI are identified.

Methods: Reference material for this review was obtained from many sources including scholarly publications and other literature, anecdotal reports and interviews with key informants.

Results: Only thirty-five percent of working age individuals with SCI are working compared with sixty-four percent of working age adults without disabilities. Employment is important for the health and economic well-being of individuals experiencing SCI. Literature and findings on key factors related to employment illustrate the multiple dimensions of work environments, health demands, employment selection and educational preparation which effect employment outcomes for people with SCI.

Conclusion: The paper includes a list of research recommendations that span the array of topics reviewed. Employment is important for people with SCI and valued in our society. People experiencing SCI need flexible work environments. Researchers and providers must understand the work demands for people with SCI to help identify suitable supports, training and job opportunities. Research must focus on understanding future employment demands, necessary work skills, differing work environments and methods for increasing and preserving employment.

Keywords: Subjects addressed in the literature for this paper include: employment and people with spinal cord injury (SCI); working from home and telework; education and distance education; vocational rehabilitation; vocational interest and Independent living and disability.

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Future Research on Employment for People with SCI

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1 **Introduction**

2 This is a review article. The objective of this paper is to recommend
3 future research about employment for people who experience Spinal Cord
4 Injury (SCI). One of the most important goals of rehabilitation and a key to
5 independent living for SCI is employment.¹ The need for employment in our
6 society and the dependence which we have on it will continue in the future.
7 Beginning with a brief review of the literature on employment and related
8 psychosocial considerations for people living with SCI, this paper aims to
9 provide a blueprint for future research related to employment and SCI. The
10 paper concludes with a list of research recommendations that span the array of
11 topics reviewed.

12 **Materials and Methods**

13 Reference material for this review was obtained from numerous
14 sources including scholarly publications and other literature, anecdotal reports
15 and interviews with key informants. The paper intends to illustrate the multiple
16 dimensions of work environments, health demands, employment selection and
17 educational preparation which effect employment outcomes for people with
18 SCI.

19 **Keywords**

20 Subjects addressed in literature for this paper include: employment and
21 people with spinal cord injury (SCI); working from home and telework;

22 education and distance education; vocational rehabilitation; vocational interest;
23 independent living and disability.

24 **Results**

25 The employment rate for people with SCI is low and there is little
26 reason to believe that it will improve in the near term.² Perhaps not
27 surprisingly, those without employment have less income, and die younger.³
28 One study on adults with pediatric-onset SCI identified 4 factors associated
29 with obtaining employment: education, community mobility, independence, and
30 decreased medical complications.⁴ Anderson et al. (2007) suggests more
31 reasons: education; type of employment; disability severity; age; time since
32 injury; gender; marital status and social support; vocational counseling;
33 medical problems related to SCI; employer's role; environment; and
34 professional interests.⁵

35 **Vocational Rehabilitation**

36 Vocational Rehabilitation is person centered. It focuses on
37 individualized planning that involves choice, individual participation to
38 maximize independence, and community living.⁶ The individual has the
39 personal responsibility to determine areas of interest and scholarly pursuit, to
40 find needed support services, to complete job searches and to gain
41 employment. Successful rehabilitation planning must match the business
42 needs of prospective employers with the psychological, social and economic
43 well-being of the individual.⁷

44 The practice of modern Vocational Rehabilitation provides resources to
45 individuals aimed at increasing skills for independent living and employment. A
46 study by Meade (2006) found SCI respondents held mixed feelings on
47 Vocational Rehabilitation, most seeking help in job skill development and job
48 placement.⁸ The literature suggests that longitudinal and qualitative research
49 will provide greater understanding for vocational rehabilitation and return to
50 work practice for those with physical disabilities.⁹ Research may help in
51 meeting the challenges of employment by documenting successful practices
52 and competencies.¹⁰ Research aimed at identifying best practices and
53 interventions may help to resolve future challenges and barriers and help to
54 improve Vocational Rehabilitation placement rates.

55 **Vocational Interest**

56 An early study by Rohe and Athelstan (1982) of young men and women
57 experiencing traumatic SCI found vocational interests outside the subjects'
58 physical capabilities.¹¹ Similarly, in a study by Rohe and Krause (1999),
59 middle-aged men (a majority having decades of experience with quadriplegia)
60 scored high in their interest in physical and manual dexterity occupations.¹²
61 Anecdotally, when I (co-author Frieden) was injured, I was a freshman in
62 college. My vocational interests were in electrical engineering and I suspect a
63 vocational interest inventory might still reflect those preferences. Ultimately,
64 however, my occupational choice was influenced mostly by environmental and

65 social realities. Research about the dynamics of occupational choice for people
66 with SCI is needed to advance rehabilitation practice.

67 Occupational choice and job opportunities are not always in sync with
68 life events. Work and personal identity merge in American culture. You are
69 what you do, yet employment doesn't always reflect personal choice and
70 interests. If the person perceives few barriers, the likelihood of success
71 reinforces the career choice, but if the barriers are viewed as significant there
72 is a weaker influence of interest and choice.¹³ Career outcome expectations
73 after SCI are negatively impacted and opportunities for employment may seem
74 limited. Yet, career paths are dynamic, and with opportunity, new interests and
75 supportive influences, there are successful employment outcomes.¹⁴

76 John Fig, a project analyst at Wakefern Food Corporation had just
77 completed his master's degree in Economics when he experienced his SCI.
78 While in rehabilitation at the Kessler Institute, Donna Walter Kozberg, CEO of
79 Lift Inc., a non-profit IT training and placement company, convinced Mr. Fig to
80 try computer programming. Although he had programming experience in
81 college, he was not convinced easily. One year out of rehabilitation, Mr. Fig
82 was working from home as a programmer trainee. He soon graduated to full-
83 time employment. According to Mr Fig: "I began by going in to the office once a
84 week to review my lessons with my mentor and continued going in once a
85 week for the first half of my consultant work, but for the past eleven years my

86 schedule has been three days at home and two days in the office. I think the
87 arrangement has been a win-win for both Wakefern and me.”

88 **Working from Home**

89 Employers continue to be resistant to work-at-home accommodation for
90 people with disabilities. A Circuit by Circuit legal review (Yastrow & Edelson,
91 2008) found support for only three of seventy-one ADA work-at home
92 challenges.¹⁵ Employers successfully argued to the courts that their need for
93 teamwork, compliance, supervision, ready access, on-site meetings and cost-
94 effectiveness outweighed the work-at-home accommodations sought by
95 employees with disabilities. There were no people with SCI identified in the
96 referenced case reviews, yet litigation research may provide answers for the
97 future.

98 There is little research on how working from home may impact the lives
99 of people experiencing SCI. A review on the subject by Bricout (2004)
100 documented only nine published empirical studies on telework for people with
101 disabilities.¹⁶ Working from home may reduce barriers to employment for
102 individuals with SCI by reducing the need for transportation and by improving
103 access to personal support, which may be more available in the home.
104 Working from home would allow people with SCI to work in prone and supine
105 positions reducing risk or preventing exacerbation of pressure sores that are of
106 great concern to wheelchair users.¹⁷ Research is needed to help document the
107 benefits and justify the use of work at home strategies as accommodations.

108 Many employers are willing to offer part-time or contractual work at
109 home opportunities when the need arises and if the employee has positive job
110 performance. If possible, new employees need to adjust to the organizational
111 culture in an office setting with their peers. At the same time, they must
112 develop independent work skills for productive work from home.¹⁸ Research
113 may identify best practices for helping employees to adjust to new work
114 environments and for assisting them in moving between employment sites
115 while establishing or maintaining relationships with co-workers.

116 Work and home environments are becoming more integrated with
117 boundaries blurred.¹⁹ Research on work-home preferences found that to
118 separate work from home is becoming more difficult, even for those who prefer
119 to keep the domains apart.²⁰ Employees are often unpaid for extra work hours
120 at home expected by employers.²¹ Research is needed to better understand
121 and to improve management of work at home demands, time management
122 issues and functional business practices. Research methods must include
123 observation, interviews, and careful documentation of personal experiences.²²
124 Research findings will be important in preparing workers to deal with conflict,
125 set boundaries, develop skills and find the right work-life balance.

126 **Employment**

127 Many individuals experiencing SCI have low expectations for
128 employment with only thirty-five percent employed compared with sixty-four
129 percent of working age adults without disabilities in the United States.²³ One of

130 the biggest barriers to employment is the severity of the disability and
131 concomitant impairment-related health issues.²⁴ People with disabilities who
132 are working will leave jobs at faster rates after age 40 than the general
133 population, even those with advanced degrees.²⁵ Studies continue to show
134 concerns of people with SCI about the potential loss of health and income
135 benefits (Hills & Cullen, 2007),²⁶ about the challenges finding personal
136 assistance (Nosek & Walter, 1998)²⁷ and about the need for additional
137 supports at home, in the community and on-the-job (Vissers et al. 2008).²⁸
138 Rehabilitation research can help people experiencing SCI in finding solutions
139 for acquiring and maintaining employment and living productive lives by
140 gaining a better understanding of employment related demands on stamina
141 and challenges to psychological and physical well-being.

142 Employment interrupted by injury and illness leaves long breaks on
143 resumes, lessens skills and hinders employment chances.²⁹ Research is
144 needed to help understand how to best support injured employees as they
145 communicate about their status with managers, human resources offices,
146 insurance and other benefit programs, and physician practices. Methods for
147 improving communications between workers with disabilities, doctors and
148 employers need to be identified and studied.

149 Health-related issues may have an enormous effect on employment for
150 individuals experiencing SCI. Psychosocial history and current emotional
151 readiness to return to work must be considered when preparing for continued

152 employment.³⁰ Infections and complications of urologic and other body
153 systems must be continuously monitored and managed in the context of
154 employment. Pressure on the skin due to sitting for long periods of time may
155 prevent work or interrupt work, may delay task accomplishments, and may
156 restrict travel and training. Treatment of pressure sores in the U.S. costs more
157 than \$1.5 billion annually.³¹ Even the type of bladder catheter impacts
158 employment success.³² Research aimed at reducing and preventing secondary
159 health conditions is vital to helping people with SCI obtain and maintain
160 employment.

161 People experiencing SCI have much higher rates of depression and
162 mood related disorders than those in the general population.³³ Workers with
163 SCI may experience significant stress related to work adjustment, scheduling
164 specialized transportation, finding dependable skilled personal assistance
165 providers and organizing other needed accommodations. It is not surprising
166 that as depression and apprehension increases, quality of life decreases.³⁴
167 Some analysts suggest future research efforts should focus on the individual
168 challenges of resilience and understanding the coping process.³⁵ Research is
169 needed to better understand and to help ameliorate the psychological and
170 physical problems associated with employment.

171 **Employers**

172 Increasing employment for people experiencing SCI is also the
173 responsibility of employers. Literature examining peer review studies on key

174 predictors for employment success found employer goodwill and the
175 attachment between the worker and the employer important for continued
176 employment.³⁶ Research, however, continues to show negative attitudes of
177 employers on hiring individuals with disabilities.³⁷ Employers have few
178 incentives to hire individuals with disabilities: only 33% of large corporations
179 include disability status as part of their diversity hiring plans. A recent Harris
180 Interactive survey (October, 2010) sponsored by the Kessler Foundation and
181 the National Organization on Disability indicates the corporate world believes
182 the costs of hiring people with disabilities is just too high and risky.

183 While the Americans with Disabilities Act (ADA) is not an affirmative
184 action employment law, many observers believed the equal opportunities
185 provisions of the law would result in increasing employment rates for people
186 with disabilities. This has not proved to be the case.³⁸ In fact, there is little or no
187 evidence that the employment rate for people with disabilities is improving.³⁹
188 Research on the impact of the ADA on employers may help to establish dialog
189 on important employment issues. Policy analyses of prospective legislative and
190 regulatory interventions, including set-asides, affirmative action, tax benefits
191 and hiring preferences for people with SCI and other disabilities are needed.

192 **Education**

193 On the bright side, research suggests educational attainment for
194 individuals with SCI is higher for those who are 10 years post injury than for the
195 general population of the United States.⁴⁰ Research identifying employment

196 trends may give educators insight into business needs and future occupational
197 and career opportunities.

198 There is substantial evidence that education provides a positive return
199 on investment.⁴¹ Obviously, people experiencing SCI may benefit from
200 furthering their education. Skills and knowledge gained during education
201 should result in higher wages and sustained employment. Nonetheless,
202 improved educational outcomes for people with SCI are not consistently
203 translating into improved employment outcomes. In 2008, nine percent of
204 workers with disabilities left their jobs, nearly twice the rate of job exit than for
205 workers without disabilities.⁴² Research is needed to help us understand these
206 dynamics.

207 As higher education continues to offer more educational and course
208 opportunities on-line, there will be new educational and training opportunities
209 for people with SCI. Students will need strong computer skills and access to
210 appropriate technologies in order to benefit from these advances. The ability to
211 work independently, achieve production and engage in on-line classes, while
212 coping with distracting family and home life demands is difficult. As new
213 distance education technology becomes available, addressing the accessibility
214 issues for class assignments, readings and new media are a must. Research
215 is needed to determine how best to accommodate people with disabilities in an
216 online educational environment.⁴³

217 Related to the discussion of online educational strategies is the concept
218 of social presence in the electronic classroom.⁴⁴ Internet users with health
219 concerns now rank e-mail as their principal reason for using the internet.⁴⁵
220 However, usage patterns are evolving from e-mail to texting, and from simple
221 browsing to engagement with social media. In this context, studies have
222 indicated that web-based social presence may provide positive personal
223 support and group discussions may produce greater emotional satisfaction
224 among users.⁴⁶ Likewise, reduced isolation may increase the students' sense
225 of community and satisfaction.⁴⁷ The ADA has significantly improved
226 postsecondary campus accessibility, increasing the social presence of
227 individuals with disabilities and educational support.⁴⁸ Will it have the same
228 impact on education in the virtual world? Information gained from research will
229 help people with SCI realize the full potential of the internet revolution in
230 education, and otherwise.

231 **Discussion**

232 Besides the research questions stated or implied above, the following
233 are particularly pertinent:
234 How can employment outcomes improve, considering individuals' work history
235 and vocational interests?
236 What will be the barriers and facilitators for individuals experiencing SCI in the
237 future?

238 What do we still need to know about rehabilitation practices and the role of
239 self-determination and individual choice in employment success?
240 What are the challenges for employers and individuals with SCI on work-at-
241 home accommodations and employment?
242 How can Return to Work and Vocational Rehabilitation practitioners contribute
243 to employment research?
244 What are the psychosocial dimensions of loss, coping and traumatic injury to
245 employment?
246 Is there a role for participatory research in education, vocational rehabilitation
247 and employment that includes people with SCI, their families, peers and health
248 providers?
249 How will research help physicians work with their patients to keep their jobs,
250 stay healthy and communicate needs to employers?

251 **Conclusion**

252 Employment is important for people with SCI and valued in our society.
253 People experiencing SCI need flexible work environments. Rehabilitation and
254 medical providers must understand the work demands for people with SCI in
255 order to facilitate the most appropriate support, training and job opportunities.
256 People with SCI must maintain health to remain employed. Research must
257 focus on understanding future employment demands, necessary work skills,
258 differing work environments and methods for increasing and preserving
259 employment. Recommendations for future research related to employment of

260 people with SCI must be accompanied by proposals to fund the needed
261 research. While there is a clear need for further exploratory research, available
262 literature documents many areas that need more in-depth study. In order for
263 research to be adequately funded and to have a measurable impact, it must
264 have support from both public and private sources, and it must be aimed at
265 increasing economic opportunities for individuals living with SCI.

266 **Conflict of Interest**

267 The authors declare no conflicts of interest.

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