The Internet and Social Media May Offer Valuable Support and Information for People with TBI

A traumatic brain injury (TBI) is damage to the brain resulting from an external force, such as a fall or car accident. TBI can be mild, moderate, or severe. People with TBI, like people without disabilities, may benefit from online resources such as support groups, discussion boards, or social media sites like Facebook and Twitter, to expand their support networks and feel more connected. However, past studies have found that people with TBI may be less likely to use the Internet than people without disabilities. In a recent NIDILRR-funded study, researchers looked at Internet and social media usage habits among adults with TBI. Researchers wanted to find out whether people with TBI use the Internet more or less than people without disabilities, and which subgroups of people with TBI were most and least likely to use the Internet. The researchers also wanted to find out the reasons that people with TBI gave for using or not using the Internet.

Researchers at Traumatic Brain Injury Model System Centers in Alabama, Colorado, Massachusetts Minnesota, Ohio, Pennsylvania, and Texas interviewed 337 English-speaking adults with moderate or severe TBI about their Internet usage between April 2014 and March 2015. All of the participants had been treated at a TBI Model System Center and had experienced their TBI at least one year before the interview. The participants were asked whether or not they used the Internet regularly and, if they did, what device(s) they used to access the Internet. The participants were also asked about their involvement with social media sites such as Facebook and Twitter. Finally, the participants answered questions about their reasons for using or not using the Internet, their self-confidence in using the Internet and posting to social media sites, and any barriers or challenges they faced when using the Internet. To compare Internet usage patterns between the study participants with TBI and the general adult population, the researchers compared the participants’ responses to those from a 2014 U.S. population survey conducted by the Pew Research Center.

The researchers found that about 75% of the participants with TBI reported using the Internet regularly, while about 84% of adults in the general population reported regular Internet usage. The difference between the two groups came from specific subgroups within the study’s sample who were less likely to use the Internet when compared to the general population. The specific subgroups included those over the age of 30, those living in rural or urban areas, those who were unemployed, and those without college degrees. Younger adults with TBI, those living in suburban areas, those with college degrees, and those who were employed used the Internet at about the same rate as the general population.
When the researchers took a closer look at Internet usage among the participants with TBI, they found that three-quarters of the participants who used the Internet did so via a smart phone and more than half also reported using a laptop or desktop computer. About two-thirds of the participants who used the Internet reported using it for either social purposes (such as sending emails or social networking) or non-social purposes (such as banking, looking up news or health information, or searching for directions), while the rest reported using it for both. Among the participants with TBI who used the Internet regularly, 79% reported using at least one social media site, and almost half used at least two. Facebook was the most commonly used social media site. Nearly a quarter of the respondents reported having an account on LinkedIn, a site used for professional networking and job searching.

The participants who used the Internet generally reported feeling confident about their ability to navigate the Internet and search for information, although they felt less confident about posting on discussion boards or seeking help from an online discussion group. Almost one-fourth of these participants said they sometimes encountered challenges related to their TBI when using the Internet, such as trouble remembering passwords, problems concentrating, or headaches from looking at a computer screen.

Among the 25% of participants who reported not using the Internet, about half of them said they simply were not interested. Other reasons included a lack of technical knowledge, not owning a computer, or Internet service being too expensive.

The authors noted that social media sites and online discussion groups may offer valuable resources to people with TBI, including opportunities to exchange support with others who have TBI, build social and professional networks, and receive updated health information. However, some people with TBI may not be taking full advantage of these resources, particularly older people and those who are unemployed. These individuals may benefit from personalized support and training to overcome barriers to Internet access. Further, in this study, participants were more likely to use smart phones than computers to access the Internet, even those who reported low Internet use overall. Social networking and health-related apps for these devices may offer additional opportunities for people with TBI to access reliable information and support resources online.

To Learn More
The Rehabilitation Research and Training Center on Disability in Rural Communities offers a Telecom Toolbox, a website dedicated to helping people with disabilities find employment using online career development tools. The toolbox includes a section on using social tools for career development, including building and managing a social media presence. [http://telecomtoolbox.ri.umt.edu/](http://telecomtoolbox.ri.umt.edu/)

Coglink is an email program developed by Personal Technologies under NIDILRR’s Small Business Innovation Research program. It is designed to help people with cognitive disabilities stay in touch with friends and family and build their social network
in a safe online space.

http://www.personaltechnologies.com/home/per/page_70/coglink.html?ctpl=buy

To Learn More About this Study


Research In Focus is a publication of the National Rehabilitation Information Center (NARIC), a library and information center focusing on disability and rehabilitation research, with a special focus on the research funded by NIDILRR. NARIC provides information, referral, and document delivery on a wide range of disability and rehabilitation topics. To learn more about this study and the work of the greater NIDILRR grantee community, visit NARIC at www.naric.com or call 800/346-2742 to speak to an information specialist.

NARIC operates under a contract from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Administration for Community Living, Department of Health and Human Services, contract #GS-06F-0726Z.