

Aging with Disabilities: The Importance of the Right Information

By Susan Johnson Taylor, OTR/L

In the last 25 - 30 years, there has been a great deal of research into the effects of aging with disabilities. That information has been slow to make its way to the clinical environment. Aging with a disability is not age dependent or an “older age” problem; it relates to time since onset of the disability. For example, if a client had a spinal cord injury (SCI) at age 15 years old, 25 years post injury they would be 40, a young age at which to be experiencing issues related to aging with a SCI. Successful outcomes in the field of Complex Rehab Technology (CRT) can be difficult to achieve. Having the right information helps us, as clinicians and suppliers, provide successful clinical analysis and recommendation.

Half of the battle is asking the right questions, and then being attentive and listening to the answers with open ears and no judgment. The other half is being armed with the medical and functional information about certain populations of clients: in this case, those who are experiencing physical issues from aging with a disability.

As complex rehabilitation technology evaluators and providers, we need to understand all available information, from both the client and the medical community, and how this can contribute to the evaluation and provision processes. Analyzing this essential information, in combination with the cumulative experiences that we have through our clients, provides us with evidence informed interventions.

We are at a time in history that is unprecedented. Due to improvements in emergency and acute/chronic medical care, we now have a large group of individuals living with disabilities. Antibiotics were not widely available until the 1940's, and in the course of history, that is not very long ago.

The post-Polio population, the first large population of individuals living with disabilities, began to experience changes in function at relatively young ages. This was something that was not anticipated, as most thought the process to be stable throughout life. A focus on this area, spearheaded by the survivors themselves, began in the late 1960's - early 1970's. This continuing conversation and formal research has widened to other populations such as SCI and Cerebral Palsy (CP). Research and anecdotal information have assisted us in understanding not only the client who is sitting in front of us needing a new wheelchair, but also clients who are new to disabilities. Goals of rehabilitation for adults has changed over the years from “use it or lose it” to “conserve it to preserve it.”

If you work in the field of complex rehabilitation, you need to be aware of the effects of aging on those with acquired conditions, as well as those who have been affected from birth - whether you are a therapist who primarily works with adults, or one who works in pediatrics. One of the top research imperatives thru an American Academy of Cerebral Palsy and Developmental Medicine (AACPDM) associated group, the Cerebral Palsy Research Network (CPRN), are the effects of aging with CP. The research will look at how to mitigate the effects, as well as how this information might inform practice with children.

Understanding the medical, functional and psycho-social effects that can be experienced when a client is aging with a disability assists us in suggesting interventions. These effects would be considered secondary impairments. With this information, we can better determine when the client might benefit from new technology, or make the right referrals when technology itself is not the answer. Secondary impairments can range from those affecting functional capacities on a daily basis, such as pain, fatigue and new weakness, to medical issues such as pressure injuries, heart problems, incontinence or diabetes. (Taylor, 2017) Some secondary impairments can be addressed in the context of a wheelchair and seating evaluation and may be affected by seating and wheeled mobility selections. Some vary by diagnosis, but consistent issues are overuse syndromes and pressure injuries. We must understand the client's diagnoses, and conditions and effects of aging. For example, between 15 - 20 years post SCI, there has been shown to be a steady increase in the incidence of pressure injuries. (Chen, et al., 2005) Knowing a fact such as this can guide the clinical team to inform the client and suggest a cushion re-evaluation.

This is a field in which the practitioners are very busy. We are expected to see many clients per day and have to decipher and consider large amounts of information and inputs to make clinical recommendation and decisions. Sometimes it is hard to slow down and listen. Collecting the correct information for this population of clients, as well as staying current with available industry information, can make the overall process more smooth and successful.

The following resources are a good place to continue your learning on this topic.

- The University of Washington has a center for the study on healthy aging with disabilities
<http://agerrtc.washington.edu>
- Kemp BJ, Mosqueda L: Aging with a disability: What the clinician needs to know. Baltimore, MD: Johns Hopkins University Press; 2004. (can be found on Amazon.com)
- www.scireproject.com : PDF document of summary of research for SCI and aging. This website is full of all kinds of evidence-based information about SCI. This is a multi-center Canadian project.
- Chen, et al. Pressure Ulcer Prevention in People with SCI: age-period-duration Effects. Arch Phys Med Rehabil. June, 2005.
- Taylor, Susan J. Aging with a Disability, NRRTS Directions, 4/2017
- www.pva.org Clinical practice guidelines for SCI, including Preservation of Upper Limb Function Following SCI. Free.



About the Author

Susan Johnson Taylor, OTR/L is an occupational therapist who has been practicing in the field of seating and wheeled mobility for 35 years, primarily at the Rehabilitation Institute of Chicago. Susan has published and presented nationally and internationally, has consulted on product development for manufacturers and has actively participated in a variety of research studies at the Northwestern Sensory Motor Performance Program. Susan is a member and fellow with RESNA, and in the past has served on the Board of Directors. She is a member of the RESNA/ANSI Wheelchair Standards Committee and the Clinician's Task Force. Susan joined the Numotion clinical education team in 2015 as the Manager of Training and Education.