Not just one and done: Establishing a culture of authentic, reciprocal programming for persons with acquired neurogenic disorders

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The Opportunity and History

A common context:
• The current healthcare system front end loads rehabilitation and recovery services following events like stroke and brain injury
• People affected by aphasia and other neurogenic disorders often run out of coverage long before their needs resolve (and of course, some never fully resolve)
• This creates a tremendous, growing group of persons with underserved and unmet needs, living in the chronic phases of recovery

A bit of history:
• In 1997, a core group of colleagues developed the Chippewa Valley Aphasia Group, at the outset of a research network funded by the work of Jon Lyons, Robert Marshall, Roberta Elman, Jan Avent, and Ellen Bernstein-Ellis, along with the first Speaking Out conference
• In 1999, we followed suit for acquired cognitive disorders with development of the Mayo Brain Injury Group
• Over these years, we have become more aware of the substantive underserved and unmet needs, creating a recognition of the need for even more diverse services
• As the partnership between UW-Eau Claire, Mayo, and other community collaborators grew, we recognized an opportunity to meet two or three needs in a mutually beneficial fashion

Beyond one and done solutions:
• We recognize the large numbers of students in our CSD major who could benefit from authentic “clinic-like” experiences, and the immense benefits of these experiences
• We recognize authenticity: meeting multiple authentic needs and authentic learning in authentic contexts

Student opportunities:
• Across the continuum from freshman to graduate students
• Within and outside of courses
• Intentionally selecting some students who may not stand out as top academic students, addressing issues associated with opportunity gap and diverse learners
• Experience often precedes formal education related to the populations served

Opportunities for persons with acquired neurogenic disorders:
• A broad range of different types of services across different contexts
• Peer networking
• Social engagement
• Return to meaningful activity and interactions

Core Values

The Power of “Group” contexts

Interacting with a variety of individuals of different severity, type, background, interests, values, and needs provides insight into the diversity and complexity of an impairment and function
(Wilson, Chasson, Jozhowski, & Mulhem, 2017; Sheepway, Lincoln, & Togher, 2011)

What’s in it for people with aphasia?
• An aphasia-friendly environment is created
• Scaffolding succeeds in the aphasia/tbi community as well as in the larger community
• Peer support and social network development
• Different types of opportunities for different people – not one size fits all
• Both intensive (event-based) and ongoing opportunities

Implications & Takeaways

• Meeting authentic community needs and building momentum and infrastructure through WHO-ICF foundational programs
• Success and challenges of sustainability including evolving participant and staff roles
• Impact at the micro-community level and macro-community level (Big C, little c)
• Challenges of outcome measurements
• What are the potential cost savings of such programs? (e.g., physical & mental health)