

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 renaissance of fueled 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

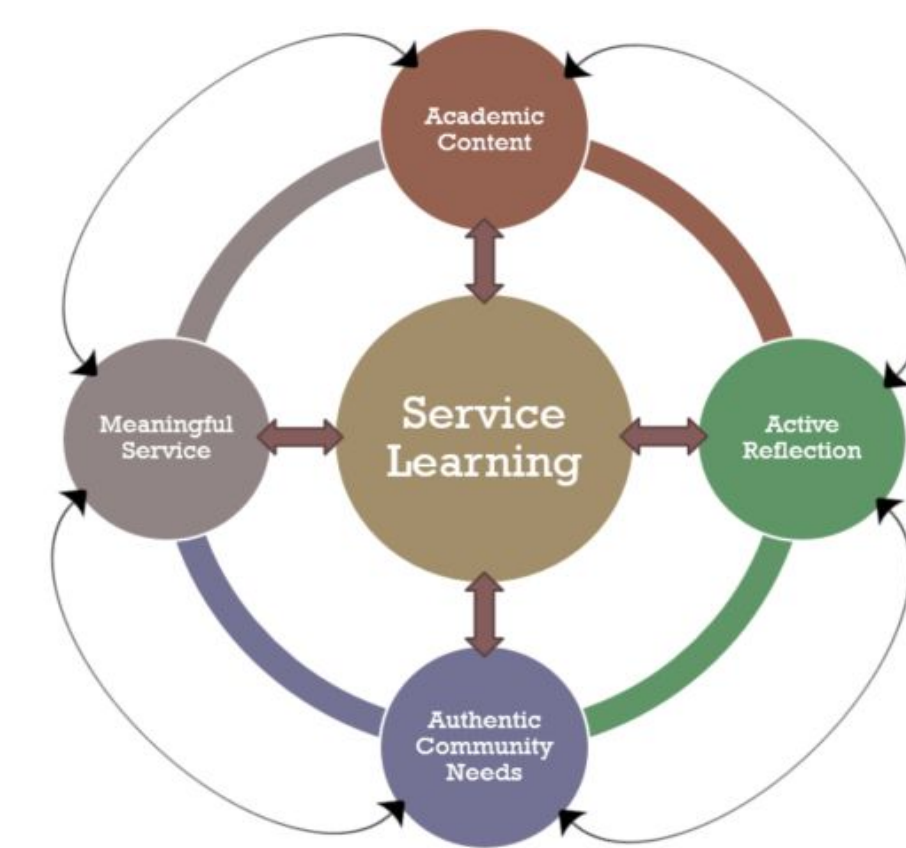
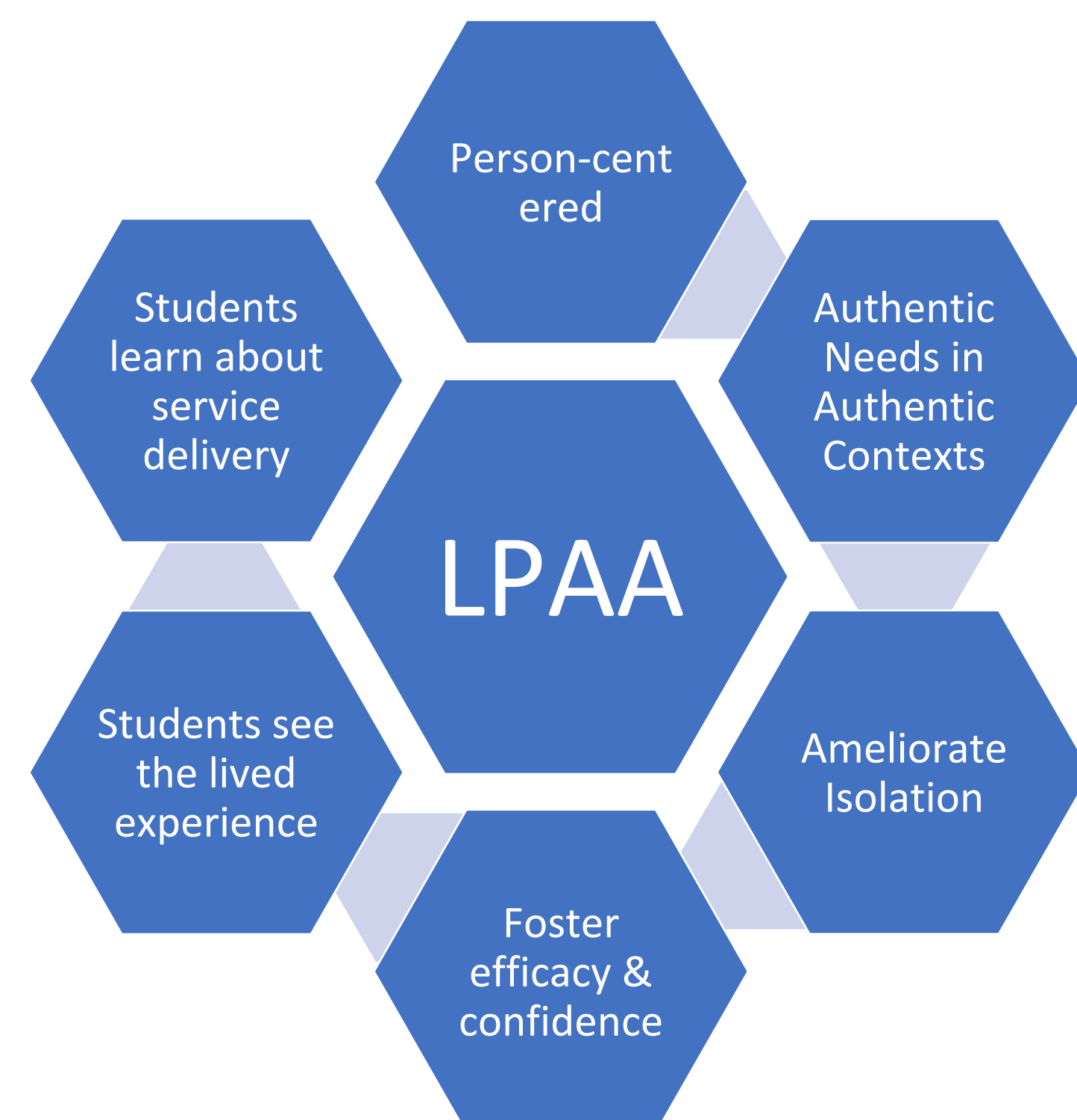
Student opportunities:

- 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

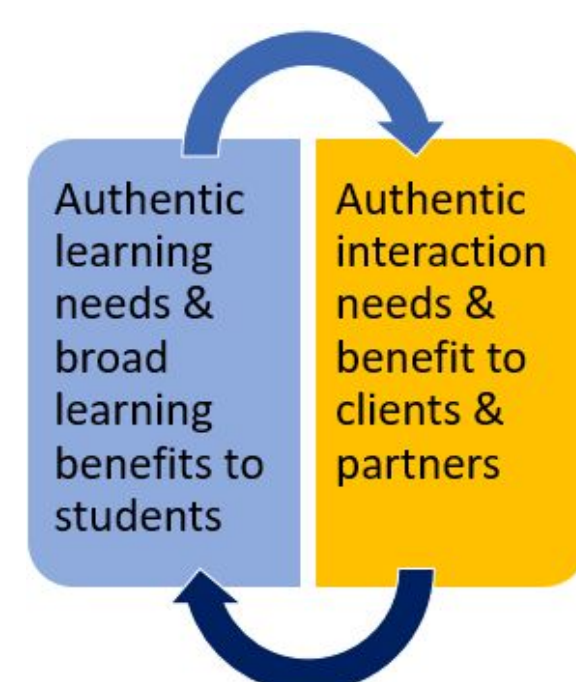
Opportunities for persons with acquired neurogenic disorders:

- A broad range of different types of services across different contexts
- Peer networking
- Social engagement
- Return to meaningful activity and interactions

Core Values



Framework for service learning. Used with permission (Kent-Walsh, 2012; modified from Berger-Kaye, 2004)



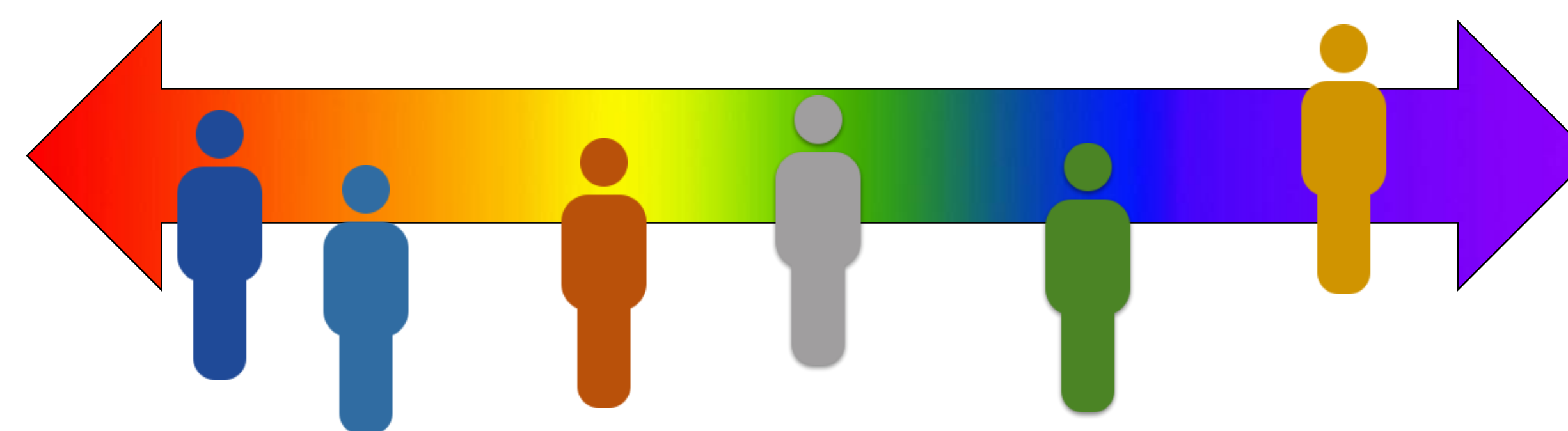
<ul style="list-style-type: none"> Serves an authentic community need Social model of intervention Provides hands-on experience Apprenticeship and relationships Graduate student clinicians <p>Blugold Aphasia Group</p>	<ul style="list-style-type: none"> The area's only exercise program designed specifically for aphasia Inter-professional - Kinesiology and CSD Bridges physical, communication, and psychosocial needs <p>Aphasia Exercise Program</p>	<ul style="list-style-type: none"> Trained students are matched with community members with aphasia Biweekly home visits for conversation and communication practice Undergraduate student volunteers <p>Communication Partners</p>	<ul style="list-style-type: none"> Partners students with community practitioners Undergraduate and graduate clinicians in clinic Builds cultural awareness – living with disability 20 years of community based group experience <p>Chippewa Valley Aphasia Group</p>
<ul style="list-style-type: none"> Summer group with undergraduate students Grad students in course & clinic during school year Connect to lived experience fosters cultural competence Apprenticeship model <p>Blugold Brain Injury Group</p>	<ul style="list-style-type: none"> Partnership between group members and students Grad students learn from clients and collaborate 1:1 Partnership between universities (College of St. Rose – Albany, NY) <p>PEP Talks</p>	<ul style="list-style-type: none"> Connects coursework to profession Follows apprenticeship model Groups provide a broader insight into a continuum of people <p>Mayo TBI Group</p>	<ul style="list-style-type: none"> Partnership between university and BIAW of Eau Claire Local group homes for persons living with severe brain injuries Grad students in course & clinic <p>BIAW 3rd Thursday Group</p>
<ul style="list-style-type: none"> Grad students in course learn collaboratively with support of instructor Authentic practice with a safety net Apprenticeship model <p>Collaborative Counseling</p>	<ul style="list-style-type: none"> Connects coursework to clinical practice Follows medical model, improving impaired skills Students work in pairs, authentic schedule – back to back... <p>Surge Week Impairment-E</p>	<ul style="list-style-type: none"> Connects coursework to clinical practice Grad and UG students collaborate with instructors Groups provide a broader insight into a continuum of people <p>Surge Week LPAA Model</p>	<ul style="list-style-type: none"> Participation-based camp Implements WHO-ICF structure with adults throughout Midwest and US with aphasia Interprofessional service learning and immersion <p>Chippewa Valley Aphasia Camp</p>



A variety of outcomes...and challenges

12	Number of Adult Neurogenic Community-based programs
134	Annual sessions of Adult Neurogenic programs
899	Total hours of student involvement in Adult Neurogenic programs
\$22,184	Monetary value of student volunteer contributions*
??	Many questions and challenges remain regarding outcomes and measurement

*Based on Independent Sector 2018 valuation



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, & Mulhern, 2017; Sheepway, Lincoln, & Togher, 2011)

What's in it for people with aphasia?

- An aphasia-friendly environment is created
- Scaffolding success 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 a 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)