

The WIKI Project: A Multimedia Tool for Adults with Disabilities

Barb Chevront, Kimberly Mack, Shreya Malhotra, Alison Riith, *LEND Trainees*
Patricia A. Patrick, DrPH, *LEND Faculty*

Leadership Education in Neurodevelopmental and related Disabilities (LEND) Program

**Westchester Institute for Human Development
University Center for Excellence in Developmental Disabilities and
New York Medical College**

Team Project Abstract 2016-2017

Background: Technology offers innovative ways to promote learning of skills, thereby, increasing the chance for self-advocacy and self-determination among individuals with intellectual and/or developmental disabilities. The RIX “WIKI” is an archetype of digital storytelling. This person-centered approach allows individuals to create a customizable website to upload pictures, video, and text to communicate abilities, routines, preferences, and goals. The WIKI is a transitional tool that may lead to a greater capacity for self-determination.

Objective: This study evaluates the impact of an online, multimedia tool designed to promote self-advocacy among adult patients within a healthcare setting.

Specific aims:

1. Determine whether a multimedia tool improves the self-advocacy skills of adults with mild to moderate intellectual and/or developmental disabilities.
2. Evaluate the extent and ways in which adults with disabilities utilize the tool.
3. Explore the perceptions of adults with disabilities and their family members/caregivers on the usability, feasibility, and satisfaction of the tool.

Methods: A Cohort Study will be used to follow adults (18 years +) that utilize the Adult Health Center at the Westchester Institute for Human Development. Research assistants will approach eligible participants and provide an invitation packet. If there is

interest, the research assistant will walk the person and/or their caregiver through the program documents and administer informed consent. Investigators hypothesize there will be an increase in self-advocacy skills among students who use the WIKI tool. This hypothesis will be tested using the Self-Advocacy Skills Survey (SAS Adult). The SAS Adult is an online, 5-point Likert scale survey with audio and visual prompts used to evaluate changes in self-advocacy at multiple times throughout the study (baseline, 6, 12, and 18 months). A one-time “satisfaction survey” will be administered at the 1-month study mark to collect information on general impressions of the WIKI tool, ease of use, and planned use.

Community Partner: Andy Minnion, MBE, Director, RIX Research and Media at the University of East London

Progress-to-Date: Preliminary data exists from a 2015 survey, “Use of Assistive Technology and Social Media by Individuals with Disabilities.” The results provide insight that informs our pilot study and the implementation of the WIKI pilot program.

1. Target population: The age group that expressed the greatest interest in creating a personalized web page is comprised of 18-29 year olds. This may be the ideal target for the WIKI project.
2. Recruitment: During recruitment, show a video demo of how the WIKI tool is used. This may help reduce the uncertainty of assistive technology, increase user accessibility, and improve participants’ confidence.
3. WIKI training sessions: Due to a high degree of individual needs, several staff members with varying expertise should be made available for the best outcome. In addition to the minimum baseline training, an optional training protocol is recommended to provide supplemental support.

Next Steps: IRB approval has recently been obtained. Study recruitment period will begin in April 2017.