

In 1990, Huer & Lloyd analyzed over 425 pages worth of different autobiographical and biographical accounts regarding individuals with severe communication impairments. Since then a combination of printed publications and online journals have led to continued increases available person accounts written specifically by individuals using AAC (e.g., Bauby, 1997; Fried-Oken & Bersani, 2000; Fried-Oken, Howard, & Stewart, 1991). In particular individuals with severe communication disabilities have become more active in online communication through listservs like ACOLUG (AAC Online Communication User Group) and through personal weblogs. Currently there is no central repository for people to read personal stories written by individuals who use AAC although preliminary evidence suggests reading narratives can be effective in changing attitudes toward individuals with disabilities (McCarthy, Donofrio, Dempsey, Birr, & Pratt, 2006). Thematic analysis in the study by Huer and Lloyd (1990) was useful in defining user priority areas for research.

Evidence is needed to support best practices on encouraging and supporting individuals in generating personal narratives, collecting narratives, distributing the narratives, analyzing the features of narratives, and engaging others with narratives to help change attitudes toward individuals who use AAC. These principles formed the foundation of the "Share Your Stories Project".

Based on feedback from pilot users, a web-based interface was designed to collect 1st person narratives written by individuals who use AAC. The platform chosen was open-source to ultimately allow for modification and customization by any stakeholder groups. The design of the site was also such that individuals using a wide variety of interface techniques could access and enter content. To date, the "Share Your Stories Project" has 6 participants. The completed project will contain stories from 15 participants. Participants were assigned a unique login and password. Only users with a login were able to view submitted content on the site. Following login, participants were asked to post at least 4 different personal stories at least 50 words in length. Content of submissions was to be no more than 5 years old (for individuals cutting and pasting from other stories). Postings were allowed to be done all at once or over time (maximum of two months). Individuals experiencing difficulty generating personal stories were given example readings of other narratives (through viewing existing postings) as well as open ended questions to help guide their submissions. After submitting the required number of narratives, participants completed an evaluation of the site noting strengths and areas for improvement.

Submissions were analyzed for emerging themes. A process similar to that in Huer and Lloyd (1990) was used. Narratives were read and significant quotations from each reading were selected. The process continued until all significant quotes were identified. Subsequently, the quotes were compiled into a table and analyzed for similarities in themes. Themes were then generated and tested against the existing corpus. Themes were modified to fit the maximum number of quotations while still creating a distinct category from others developed. Currently themes consist of obstacles encountered, strategies to overcome obstacles initiated by the individual using AAC, strategies to overcome obstacles initiated by people other than the individual using AAC, civil rights, and advocacy. Feedback on the site indicated users found the site easy to navigate but would like more guidance on what narratives to write in the future.

An open dialog with individuals using AAC is important in the future of this project. In particular, it is critical that individuals submitting narratives maintain the copyright to the work and have input in any decisions about how their words could be used in future research. Ideally the project is to enlighten and inform.

References

- Bauby, J.B. (1997). *The diving bell and the butterfly: A memoir of life in death*. New York: Alfred A. Knopf.
- Dal Cin, S., Zanna, M. & Fong, G. (2004). Narrative persuasion and overcoming resistance. In E. Knowles & J.Linn (Eds.), *Resistance and persuasion* (pp. 175-191). Mahwah, NJ: Lawrence Erlbaum Associates.
- Fried-Oken, M. and Bersani, H. A. (2000) *Speaking up and spelling it out*. Baltimore, MD: Paul H. Brookes.
- Fried-Oken, M., Howard, J.M., & Stewart, S.R. Feedback on AAC intervention from adults who are temporarily unable to speak. (1991). *Augmentative and Alternative Communication*, 7(1), p. 43-50.
- Huer, M. B. & Lloyd, L. (1990). AAC Users' perspectives on augmentative and alternative communication. *Augmentative and Alternative Communication*, 6, 242-249.
- McCarthy, J., Donofrio, L., Dempsey, L., Birr, K, & Pratt, S. (2006, November). *Influence of Personal Narratives on Businesspeople's Attitudes Toward AAC Users*. Paper presented at the annual meeting of the American Speech-Language-Hearing Association, Miami, FL.
- McCarthy, J., & Light, J. (2005). Attitudes toward individuals who use augmentative and alternative communication: Research review. *Augmentative and Alternative Communication*, 21, 41-56.