

Article from **RERC on Communication Enhancement eNews**
(http://www.imakenews.com/aac-rerc/e_article000295732.cfm?x=b11,0,w)

August 24, 2004

Tracy's Story

by David McNaughton

This article was written by David McNaughton and originally published in Success Stories 2004. We thank the National Center for Dissemination of Disability Research (NCDDR) for allowing us to reprint this article.

Tracy Rackensperger is a determined young woman with a bachelor's degree in radio-television and a master's degree in communication. She also has cerebral palsy, which significantly impairs her motor skills and speech intelligibility.

Tracy uses augmentative and alternative communication (AAC) to interact with other people. While her disability has at times made completing her academic activities and her search for employment more challenging, Tracy has always been interested in using her knowledge of disability resources and strategies to assist others.



Dr. David McNaughton, a Penn State faculty member and member of the Rehabilitation Engineering Research Center on Communication Enhancement (AAC-RERC), first learned of Tracy's skills when he read her postings to an electronic mailing list that focuses on the experiences of individuals who use AAC.

Knowledge of Tracy's writing skills led McNaughton to ask her to join an AAC-RERC research project, TECH 2010. The goal of the project was to gain a better understanding of the challenges and supports of effective AAC device use as reported by individuals who use AAC and the parents of such individuals.

Tracy fulfilled a wide variety of roles in her work with the TECH 2010 project. She worked with the team to develop the research questions for the project; acted as a moderator for two Internet-based focus groups; recruited participants for the two focus group discussions; assisted in the analysis of the focus group discussions; presented the research findings at conferences; and assisted in the development of two manuscripts to be published. Results of the study served to highlight the importance of a consumer-driven approach to assessment and to the provision of appropriate supports (including learning from peers, professional support, and opportunities for use in the community) for successful device use.

The collaboration has been a success on a variety of levels. "We were very pleased when Tracy agreed to help us with this project," McNaughton said. "Our goal was to gain an insider's perspective on learning to use an AAC device-participants in a focus group are more likely to share information with someone who has a common life experience." McNaughton noted another way that Tracy's participation helped the AAC-RERC. "We were determined to develop new research methodologies that would enable us to live up to the principle of 'nothing about us without us' - the idea that any research about people with disabilities should include people with disabilities in leadership roles," he said. "We believe that this project has been a successful implementation of this principle and provides more useful information as a result."

The results of this study have been of high interest to individuals who use AAC, their parents, and device manufacturers. To date, Tracy has made three national presentations highlighting

the main findings of the project, and two manuscripts are in preparation. "We titled the first manuscript [which features the views of individuals who use AAC- 'When I First Got It, I Wanted to Throw It off a Cliff: The Challenges and Benefits of Learning AAC Technologies as Described by Adults Who Use AAC,'" said Tracy with a laugh. "This is an actual quote from one of the participants because it really can be a love-hate relationship with an AAC device. When they work it is great, but it is so frustrating when they break down. Fortunately, things are getting better, and devices are getting more powerful and more durable."

Tracy's experience with the AAC-RERC was her first with a federally funded research project and has led to many new developments in her life. Along with her work on the presentation and publication activities associated with the TECH 2010 project, Tracy has also started work on two other AAC-RERC projects. She acts as the AAC-RERC liaison to the Augmentative Communication On-Line Users Group (ACOLUG) electronic mailing list, and she also is a charter participant in the AAC Writer's Brigade, an initiative to involve individuals who use AAC in writing and disseminating information on AAC-RERC activities.

"Becoming involved with the TECH 2010 project has led to experiences that have benefited me both on a personal and professional level," said Tracy. "For me personally, my involvement with the project has enabled me to take an active role in furthering a research agenda that includes meaningful consumer involvement. On a professional level, becoming involved with the TECH 2010 project aided me in acquiring the skills to begin a career involving research and writing."

Acknowledgement: This research is part of the Rehabilitation Engineering Research Center on Communication Enhancement (the AAC-RERC), a collaborative virtual research center, funded by the National Institute on Disability and Rehabilitation Research (NIDRR) through grant H133E030018. The opinions expressed are those of the grantees and do not necessarily reflect those of the granting agency. For further information about this grant, email David McNaughton at dbm2@psu.edu

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