

The Communicative Participation Research Project

All of us have roles that we fill in our lives. For many of us, our roles at work or at school are very important, not only because we need to earn a paycheck, but also because much of our identities or “who we are” are formed in what we do in our jobs or at school. There are many other roles we play in addition to our “professional” roles. Most of us spend time with hobbies, community activities or volunteer activities that we enjoy or want to contribute to in some way. We all also have relationship roles. Our relationships range from parent-child and other family ties to friendships and romantic relationships.

Communication is vital to playing our part in all of these different roles. Whether we are communicating by talking to people face to face, talking over the phone, or sending emails and letters, we need to interact with people almost every day. We communicate for many reasons. Some reasons are practical in that we need to get things done. Other times, we communicate for our own enjoyment or fulfillment - to just feel connected to our world and to each other.

When the ability to communicate is disrupted by a communication disorder, the ability to participate in life activities and to fulfill life roles is compromised. People with communication disorders may not be able to speak clearly enough or understand other people easily enough to successfully communicate on their own. They might communicate very slowly and not be able to keep up with the pace of conversations. They might become very tired trying to communicate, making it difficult to get through daily activities. The end consequence is that people with communication disorders often “drop out” of life roles. They participate in fewer activities and are able to only do a portion of what they want or need to do. What they do attempt to do, they often do with difficulty. The consequences of reduced participation in life activities are many. For some people who must change or quit jobs because of communication disorders, the loss of income and job potential poses serious financial hardships. For people who are not affected in this way, there is often still much frustration and disappointment over things that they are not able to do because of their communication problems. People do fewer things, have less contact with other people, and often feel isolated.

Ideally, communication disorders would be treated, or even cured, in ways that would allow people to return to full participation in all of their life roles. Unfortunately, many communication disorders, such as those caused by neurologic damage, currently do not have any cure. Sometimes treatments or therapies may alleviate symptoms or help with partial recovery, but many people are left with long-term communication challenges.

How can we help people with long-term communication disorders maximize their participation in their life roles? That question is at the core of our research, and has many possible answers. Helping people with communication disorders to find techniques and strategies to “work around” the problems caused by the communication disorder is one option. Other options are to try to change the environment around the person to make it

easier for him or her to participate in activities. Family, friends and coworkers can learn how to communicate more successfully and easily with someone with a communication disorder. People in public and service roles ranging from customer service representatives to healthcare providers could receive training in how to communicate more effectively with people with communication disorders. The general public could benefit from greater awareness of the challenges faced by people with communication disorders.

The impact of health conditions on participation in life roles is receiving greater attention in healthcare. For example, the World Health Organization (World Health Organization, 2001) has added the concept of “participation” to its model for describing the social consequences of health conditions. Many researchers are exploring ways to measure, understand, and increase social participation while clinicians work directly with their clients to try to improve participation one person at a time. One important part of this work is to have a way to “measure” participation. Good methods for measuring and describing participation are essential in order to identify problems for individual clients and to evaluate changes in response to intervention.

Kathryn Yorkston, Professor in the Department of Rehabilitation Medicine at the University of Washington in Seattle, WA is currently developing an instrument to measure participation restrictions caused by communication disorders. Development of this Communicative Participation Item Bank has been funded by grants from the NIH (National Institutes of Health). The Communicative Participation Item Bank is designed to be an outcomes tool that can assess the degree to which communication disorders affecting speech interfere with life participation before and after intervention. We are developing a second questionnaire, The Levels of Speech Usage to be a descriptive tool to systematically report individuals’ daily speech communication needs. Together, these tools can be used to assess the needs and goals of participants, and to evaluate progress towards those goals during intervention. These tools will also be useful in future research to investigate the impact of different interventions on communicative participation; and to provide valuable information about key variables that impact participation outcomes.