# A STUDY OF LITERACY IN THREE ADULTS WITH MODERATE-TO-SEVERE INTELLECTUAL IMPAIRMENTS WHO USE AUGMENTATIVE AND ALTERNATIVE COMMUNICATION SYSTEMS

by

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### ABSTRACT

This study was undertaken to explore (a) the everyday literacies of three adults with moderate-to-severe intellectual impairment (M/SII) who use augmentative and alternative communication systems (AAC) and (b) the nature of the conditions under which their communication goals were successfully addressed. Data were gathered using multi-contextual observations, interviews with communication partners, external ratings of communication partners' interaction style, and explorations of each participant's AAC system.

The data collected were organized using a data management system organized in relation to (a) the specific literate behaviors used by the individuals studied; (b) the interactive behaviors used by their communication partners; (c) the types of goals pursued across interactions and (d) the success with which communication goals were pursued and met. These data were examined to give an account of the everyday literacies of each participant as well as the issues and challenges he or she faced in pursuing and meeting communication goals with partners.

The data also show that the individuals using AAC in this study generally pursued goals generated by their partners, rather than goals they generated. Furthermore, during the occasions when they initiated interaction toward a goal, the participants were much less efficient compared to those occasions when they pursued goals generated by their partners. The participants were also found to be significantly less successful in general in pursuing and achieving goals they initiated, compared to those generated by their partners.

The data were also discussed in relation to the theoretical assumption that, for the individuals in this study, AAC is viewed *as* literacy. Theoretical and practical implications of the data were explored in relation to ways helping professionals can thoughtfully examine literacy in individuals with intellectual impairment. These implications include, but are not limited to, providing regular opportunities for individuals to use their AAC systems and everyday literacies to pursue goals they initiate, allowing people consistent access to their AAC system for meaningful communication, and facilitating efficiency through the use of person-specific message organization strategies. Questions that emerged with respect to future investigations of literacy in individuals with intellectual impairment who use AAC were also explored.

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### Chapter 1: Introduction and Statement of the Problem

#### An Encounter with Jackie

Jackie is a twenty six year-old woman with profound physical impairments secondary to Cerebral Palsy, a diagnosis of intellectual impairment, and profound speech impairment requiring the use of an electronic device to communicate. My first encounter with Jackie occurred when I was walking down a hallway in a vocational day program for adults with developmental disabilities. Jackie was moving toward me in her electric wheel chair, which she controlled by touching any of four small round switches attached to the lap tray on her wheelchair. As she approached I noticed some pictures taped to her lap tray. They depicted family and friends engaging in a range of social activities. Jackie's arms were straight and rigid, with her hands in fist-like positions. She stopped her wheelchair in front of me and I noticed her entire body was flexing and relaxing, causing her facial expressions to change severely as her body tension changed. Hanging off the side of her wheelchair was a metal apparatus which I assumed to be a device that allowed Jackie to use her to head point to objects or to control her electronic communication device. The device was made of lightweight flat metal bars covered with padding, shaped like a hat designed to fit Jackie's head. It also had a large piece of Velcro hanging from it, which looked like a strap for the pointer to be secured to Jackie's head. The apparatus had a large (approximately twenty four inch) protruding piece of metal (about the width of a pencil) stemming from its front. As I would learn, when this device was attached to Jackie's head, it allowed her to touch buttons on her electronic communication device. Jackie made eye contact with me and vocalized. Her electronic communication device, a Liberator made by Prentke-Romich ©, was situated about two feet from her face, directly in front of her (see Figure 1). It was attached via a metal arm bracket connected to the frame of her wheelchair.



Figure 1. A Picture of Liberator Electronic Communication Device Similar to the One

### Jackie Used

It was obvious that Jackie wanted to tell me something. I asked her if I should place the pointing device on her head and she responded with a loud vocalization and head movement to indicate "no" -or at least that was my interpretation of her behavior. I looked at her communication device and noticed that it was not turned on. After a series of fruitless interactions with me in which I attempted to guess what she wanted to say, and pointed to pictures of people on her lap tra, I noticed that Jackie was moving her eyes in a well controlled up and down, side-to-side, and sometimes circular motion. As I observed this behavior pattern a staff member named Stan, who knew Jackie very well, approached. He said, "She's spelling with her eyes". Jackie smiled and vocalized, apparently confirming Stan's statement. I looked closely at her eye movements and noticed that she was, in fact, moving her eyes to "write" letters in space. After about a minute of "eye spelling" to Stan, he said to Jackie, "You missed the bus?" to which Jackie responded with a smile and a vocalization. Jackie had spelled the word bus with her eyes to indicate that she had missed the bus to go home. Interestingly, when Jackie used her eyes to spell words, she did so from her perspective, causing a communication partner to observe eye movements from the opposite perspective of Jackie's. In other words, from a communication partner's perspective, the shapes of letters were reversed as Jackie produced them. Imagine two people standing on either side of a window. One

person uses a marker to write messages on the window. The person reading the message from the other side would see letters and words backwards, making it extremely difficult to decipher messages.

Stan placed the head pointer on Jackie's head, secured the Velcro strip and asked her what happened. Jackie assembled a message using her Liberator after touching several icons with her head pointer. Jackie's communication device produced the following message: "Eleanor (a staff person working with Jackie) says I'm sick". Stan responded saying, "Eleanor told the bus driver you were sick so he left without you?". Jackie smiled and vocalized loudly to confirm Stan's interpretation of her comment.

Clearly, Stan's understanding of Jackie's idiosyncratic communication style (i.e., her use of eye spelling) facilitated their interaction. Stan and Jackie seemed to have a shared literate code as they interacted. That is, they both knew that Jackie's use of eye spelling, an undeniably literate behavior, was the conduit through which communication occurred.

After observing Jackie interact with Stan, I could not help but wonder about the way she learned this unique method of communication and how it was so clearly connected to her literacy skills. I thought, if Jackie is considered to be a person with

intellectual impairment, how is it that she earned that she could use her eyes to spell words? I also thought, how did Jackie learn how to spell words, or word combinations? and how might one describe Jackie's literacy abilities in relation to the ways she uses her communication device?

#### The Population

Jackie is one among an estimated two million people in the United States who use a communication device to communicate with others (Matas, Mathy-Laikko, Beukelman, & Legresley, 1985). She is also one among an estimated one and a half million adults with intellectual impairment in the United States (Massey, 1993). Many adults with intellectual impairments (or other developmental disabilities) are unable to live with their families because of their need for ongoing specialized care or because the family members do not have the financial, medical, or physical/environmental means to care for their children. In these cases, individuals live in community residences or homes run by private agencies or state-funded agencies.

Many agencies also provide vocational day programs for individuals so that they can spend the majority of their workweek engaged in meaningful activities with peers and staff. Although many agencies have attempted to make vocational centers more home-like in their appearance, most vocational programs exist in large warehouse-like settings, with a very industrial look and feel to them. Large vocational centers also have several rooms in which people are grouped for several hours a day. Individuals attending vocational programs typically work with peers in a designated area or room in the building. They typically are grouped with people who have similar physical, cognitive, behavioral, communicative, and social abilities, which allows the agency to supply appropriate amount of staff and appropriate vocational experiences during the day. The amount of staff in a group room depends on the needs of the individuals in the room. In general, individuals with the most significant intellectual and physical challenges require the largest number of staff to meet their needs. The staff hired to help these individuals have varying levels of experience, expertise, and training related to helping adults with intellectual impairments. Individuals from particular professional disciplines such as speech-language pathology, physical therapy, occupational therapy, nursing, and special education are also part of the team of staff serving the people attending the vocational program.

A typical day in a vocational center for adults with intellectual impairment lasts approximately six hours. Within this time, a person might engage in life skill, vocational, educational/learning, community-based, and social activities with peers and staff. These activities might include cooking, personal hygiene activities, attending group activities, shopping, or attending a social event. In each case, staff are expected to interact positively with individuals receiving service, using whatever communication means necessary.

Adults with intellectual impairment live either with their biological parents, or in community residences run by private or state-funded agencies. These homes typically serve approximately five to ten people with disabilities, depending on the size and space available. Like the vocational center, the home setting includes staff members who are employed by the agency to support the individual in various ways. Ideally, the individual is able to live at home with his or her parents and family. However, this is much less common with this population because of the complex physical, medical, cognitive, and communication needs they have. For people living in state or privately funded homes, routines vary from brief interactions with peers, to watching television, to participating in activities of daily living (e.g., grooming, dressing, personal hygiene). In general, staff are responsible for meal preparation, social interaction, assisting with personal hygiene, and supplying residents with opportunities for community-based experiences. During the workweek, the evening routines are mainly centered around meal preparation, personal hygiene, and helping people go to bed.

### Issues and Challenges

Many adults carrying the diagnosis of intellectual impairment (historically known as mental retardation) are given this classification or label by a licensed psychologist or and otherwise qualified health professional, after formal testing. While there has been a movement in the field toward more holistic and contextualized assessment, diagnoses are often based on standardized, office-bound assessments. These assessments result in measures of intelligence (e.g., intelligence quotients (IQ)), adaptive behavior, receptive and expressive language ability, and are generally focused on identifying areas of weakness or impairment in an individual Adults carrying a diagnosis of moderate or severe intellectual impairment, in particular, face a challenge with respect to the inaccurate perceptions or assumptions others have about their language, cognition, communication, literacy, and problem-solving abilities. These assumptions seem particularly robust in the realm of literacy in this population in that people often think, "If Sally has a diagnosis of severe intellectual impairment, she must not have any literacy skills". This assumption may also be based on or connected to individuals' perceptions of "literacy" rather than or in addition to the diagnosis of moderate or severe intellectual impairment. Whether it is an inaccurate perception of the individual or of the term "literacy", however, escaping the idea that a person with moderate or severe intellectual

impairment can not or does not posses literacy skills remains a primary challenge in supplying effective service to individuals with intellectual impairment. To summarize, current assessment systems used to describe and label the intellectual functioning of adults with intellectual impairments do not yield a full appreciation of the individual's language, literacy and related abilities.

Another challenge faced by adults with intellectual impairment is that they are often supplied with devices or systems that are thought to facilitate effective and efficient communication, but without a thorough investigation of their "fit" with the individual and his or her abilities and needs. That is, the devices are thought to help the person communicate what they would like, and to have their wants and needs met. However, it is not clear as to the degree to which the devices facilitate effective and efficient communication. This may be because the device is matched to the individual under the assumption that the symbol systems (e.g., icons, picture-symbols) will, in fact, facilitate meaningful interaction with others. In practical terms, however, communication devices may exist as a barrier to effective and efficient communication because of the amount of time needed to produce messages, because of the communication partners' interaction style, and/or because of negative perceptions a communication partner has about an individual's language/literacy ability.