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ABSTRACT

This report presents the activities, accomplishments, and outcomes of a study of the long-term outcomes of augmentative and alternative communication (AAC) interventions with individuals with severe communication disabilities. The study evaluated long-term outcomes for 7 young men (ages 19-23 years) who had used AAC systems for at least 15 years. Outcomes were measured in the following domains: (1) receptive language; (2) reading comprehension; (3) communicative interaction; (4) functional communication; (5) educational and vocational achievement; (6) self-determination; and (7) quality of life. In addition, qualitative interviews were conducted to identify contextual factors that may have contributed to the measured outcomes. The study provided data regarding the feasibility of the outcome measurement tools used. It identified four factors believed to contribute, positively and negatively, to outcomes and communicative competence. These were: (1) attitudes of family members, professionals, peers and the general public; (2) cultural issues; (3) technological issues such as the operational demands of AAC systems; and (4) service delivery (a team approach is critical). (Contains approximately 135 references.) (DB)

FIFTEEN YEARS LATER: AN INVESTIGATION OF THE LONG-TERM OUTCOMES OF AUGMENTATIVE AND ALTERNATIVE COMMUNICATION INTERVENTIONS

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ABSTRACT

Individuals with severe communication disabilities face significant challenges developing the skills required for future employment and independent living. The development of augmentative and alternative communication (AAC) systems (e.g., communication boards, computer-based voice output systems) has offered these individuals the potential to participate more fully in educational, vocational, and community environments. In the past ten to fifteen years, there have been many advances in the field of AAC. However, despite these advances, at present there are no data on the long-term outcomes of AAC interventions. This study evaluated the long-term outcomes for a group of seven young men (ages 19-23 years) who had used AAC systems for at least 15 years. Outcomes were measured in the following domains: (a)receptive language (i.e., comprehension of single word vocabulary, grammatical morphemes, and syntactic structures); (b) reading comprehension; (c) communicative interaction (i.e., turn taking patterns, communicative functions, and modes of communication used during interactions with three different partners: a caregiver, an unfamiliar partner, and a peer); (d) functional communication; (e) educational and vocational achievement; (f) self-determination; and (g) quality of life. In addition, qualitative interviews were conducted to identify contextual factors that may have contributed (both positively and negatively) to the measured outcomes. This study described outcomes for the participants in a broad range of domains, identified factors that were believed to contribute to positive outcomes, suggested implications of this study to improve practice, and provided directions for future research.

SECTION 1: INTRODUCTION

Significance of the Problem

There are an estimated 2 million Americans who have severe communication disabilities and are unable to use their speech to meet their daily communication needs (National Institute on Disability and Rehabilitation Research, 1992). This group of people includes individuals with a variety of congenital disabilities (e.g., cerebral palsy, mental retardation, autism) or acquired disabilities (e.g., amyotrophic lateral sclerosis, stroke, traumatic brain injury). Students with severe communication disabilities face significant challenges developing the skills required for employment and independent living. Without access to functional speech, these students are excluded from full participation in an appropriate education and are at risk for their cognitive, academic, and socio-emotional development. The development of augmentative and alternative communication (AAC) systems (e.g., communication boards, computer-based voice output systems) has offered these students the potential to participate fully in educational programs.

In the past ten to fifteen years, the knowledge base in AAC has grown significantly. Research investigating the interaction patterns of individuals who use AAC has shown that a wide range of skills are needed to become a competent communicator (e.g., Beukelman & Yorkston, 1982; Calculator & Dollaghan, 1982; Light, Collier, & Parnes, 1985a,b,c, Light, 1989). Instructional methods to teach skills that build communicative competence have been identified (e.g., Calculator & Jorgensen, 1991; Light & Binger, 1998). At the same time, the assistive technology available to individuals who use AAC has improved vastly. Due to the advent of Public Law 99-457 in 1986 and the reauthorization of the Individuals with Disabilities Education Act in 1997, children have had increased opportunity for access to AAC services at an early age. Many children are receiving AAC services during their preschool years. However, despite these advances, at present there are only a few studies that document the outcomes of AAC interventions (e.g., Bryen, Slesaransky, & Baker, 1995; Dowden, Beukelman, & Lossing, 1986; Romski & Sevcik, 1996). These studies have focused solely on short-term outcomes and no data exist on the long-term outcomes of AAC interventions.

Investigating the outcomes of AAC interventions and determining factors that contribute to the success or failure of AAC have been identified as research priorities by the National Institute on Deafness and Other Communication Disorders (NIDCD) (Beukelman & Ansel, 1995) and the National Institute on Disability and Rehabilitation Research (NIDRR, 1992). Consumers, families, the general public, administrators, and funding agencies want assurances that AAC intervention programs have value, both to the individuals served and to society (Blackstone, 1995). It is imperative that the long-term outcomes of AAC interventions be documented, because only then can the field ensure accountability, justify cost, guide clinical intervention, and establish best practices in order to improve services to children with severe communication disabilities. In addition, by identifying factors that contribute to outcomes (positive or negative), improved interventions to build communicative competence can be developed.

Review of the Literature

Outcomes Research

To date, research on the effectiveness of AAC interventions has tended to focus on four different approaches: studies of the frequency of system use, reports of consumer satisfaction, case study reports, and efficacy studies of specific teaching strategies. For example, some investigations into the results of AAC interventions have evaluated the frequency with which individuals used their AAC systems (e.g., Culp, Ambrosi, Berniger & Mitchell, 1986; Allaire, Gressard, Blackman & Hostler, 1991). These reports have been disheartening because they found that many individuals used their systems infrequently (less than 50% of the time). However, communicating via AAC is much more than simply using a communication device. Individuals who use AAC typically utilize many modalities (e.g., speech, gestures) in addition to their AAC devices in order to communicate in a functional manner. Therefore it is essential that judgments regarding the effectiveness of AAC interventions do not rely solely on measures of device usage. Rather, it is important to "document the value of such [AAC] systems in improving the quality of these individuals' daily lives" (Calculator, 1988 p. 179).

Other studies evaluating the effectiveness of AAC have adopted a different perspective focusing on the evaluation of outcomes through consumer satisfaction measures (e.g., Smith-Lewis & Ford, 1987; Huer & Lloyd, 1990; Jinks & Sinteff, 1994). These studies reported what consumers liked and disliked about AAC service delivery, but failed to document the effectiveness of interventions in changing communication function, performance, or quality of life. Detailed case study reports (e.g., Goossens', 1989; Kraat & Brune, 1997) have recorded communicative behavior and described the AAC intervention and teaching strategies used, but did not establish a cause and effect relationship between the AAC intervention and the changes observed. These case studies are limited to an "n" of one and thus have limited generalization. Frequently these studies provide data in limited domains. There is a need for experimental studies which establish a cause and effect relationship between the AAC intervention and changes in communication, self-determination, and quality of life. The efficacy of specific intervention techniques has been documented in a number of experimental studies (e.g., Harris, Doyle, & Haaf, 1996; Light, Binger, Agate, & Ramsay, 1999) but these studies have focused on the short term effect of focused instruction on a specific target behavior (e.g., use of multi-symbol messages, use of partner focused questions). While these four different methods provide valuable data, they only provide information on outcomes in one specific area and are limited in scope. To date there has been no research to document the wide-reaching and long-term outcomes of AAC interventions. There is an urgent need for studies to fill this void.

Whereas efficacy studies evaluate the results of a specific intervention (i.e., did it work?) (Frattali, 1998a), outcome studies must measure the impact of intervention on the individual's life (Granlund & Blackstone, 1999). Ysseldyke, Thurlow, and Bruininks (1992) defined educational outcomes as the results of interactions between individuals and their educational experiences. Communication impacts all aspects of life. Therefore, in order to evaluate communication outcomes, interactions between individuals must be considered within a larger context. "Meaningful outcomes measurement requires documentation of changes in [the individual's] participation in educational, vocational, family, and community activities" (Blackstone, 1995, p. 3).

The World Health Organization Model

The World Health Organization's International Classification of Functioning, Disability and Health (WHO, 2001) provides a useful framework upon which to structure an evaluation of outcomes (Blackstone, 1995; Beukelman, 1986). The ICIDH-2 model provides a structure to organize information regarding human functioning and disability. The model is organized in two parts: (1) Functioning and Disability, and (2) Contextual Factors. Each part has two components. Table 1 presents an overview of the ICIDH-2.

Each component measures a different domain. The two components of functioning and disability are Body Functions and Structure and Activities and Participation. Each component is described in terms of the individual's abilities and disabilities. The first component, Body

Functions and Structure, consists of *body functions* (i.e., physiological functions) and *body structure* (i.e., anatomic parts of the body). Problems in body function or structure are defined as *impairments*. For example, an individual who has cerebral palsy may have severe spasticity and thus impaired motor control of his/her articulators.

Table 1
Overview of the ICIDH-2 (from WHO, 2001)

	Functioning and Disability		Contextual Factors	
	Body Function & Structures	Activities & Participation	Environmental Factors	Personal Factors
Domain	Body functions Body structures	Life areas (i.e., tasks, actions)	External influences on functioning and disability	Internal influences on functioning and disability
Constructs	Change in body function Change in body structures	Capacity (executing tasks in a standard environment) Performance (executing tasks in the current environment)	Facilitating or hindering impact of features of the physical, social, and attitudinal world	Impact of attributes of the person
Positive aspect	Functional and structural integrity	Activities Participation	Facilitators	Not applicable
Negative aspect	Impairment	Activity limitation Participation restriction	Barriers/ hindrances	Not applicable

The second component, Activities and Participation, addresses functioning from both an individual and societal perspective. Activities are defined as the "execution of tasks or actions by and individual" and participation is defined as "involvement in life situations" (WHO, 2001, p. 12). Activities and Participation are grouped into the following categories by the WHO:

learning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interactions and relationships; major life areas (e.g., education, employment); and community, social, and civic life (WHO, 2001). Difficulties in the performance of activities are defined as *activity limitations* and problems in the manner or extent of involvement are called *participation restrictions*. For example, in the area of communication, the individual with cerebral palsy described above may have activity limitations in the area of speaking (i.e., dysarthria) which may restrict his ability to participate in conversations or maintain social relationships with others.

The second part of the model addresses contextual factors that affect outcomes. Contextual factors include environmental factors and personal factors that may have a positive or negative impact on the individual. Five areas of environmental factors have been identified by the WHO: products and technology; natural environment and human-made changes to environment; support and relationships; attitudes; and services, systems, and policies. For example, facilitating contextual factors affecting the individual with cerebral palsy described earlier may include: using an AAC device, having an educational assistant, and having supportive friends and family. Examples of contextual barriers for this individual may include negative attitudes of society, physically inaccessible environments, and lack of funding to upgrade his communication system.

A comprehensive approach to measuring outcomes should include measures that evaluate all dimensions of the WHO classification system (body, activities, participation, and contextual factors). Specifically, outcomes should be measured in the following areas:

- Body function and structures: function of voice and speech mechanism, sensory functions (i.e., vision, hearing), and cognitive functions

- Activities and participation: speech intelligibility, receptive language skills, reading comprehension, written expression, discourse skills, interaction skills, functional communication, interpersonal relationships, educational achievement, vocational status, self-determination, and quality of life
- Contextual factors: products and technology; environment; support and relationships; attitudes; and services, systems, and policies.

The present study addressed the need for a comprehensive investigation of long-term outcomes by targeting the following activity and participation domains: receptive language, reading comprehension, communicative interaction skills, functional communication, educational and vocational achievement, self-determination, and quality of life. The following sections summarize what is known about each of these domains for people who use AAC.

Language

Receptive Language. The primary emphasis of the research literature has been on development of expressive language skills (Light, 1997; Roth & Cassatt-James, 1989). However, the importance of receptive language skills (i.e., comprehension) cannot be neglected. Participation in communicative exchanges requires individuals to take two roles: that of sender (i.e., speaker) and receiver (i.e., listener) (Romski & Sevcik, 1996). Comprehension skills are essential for individuals to participate in the listener role.

Individuals who use AAC may vary widely in their receptive language abilities. Therefore, it is not safe to assume that language comprehension is intact for all individuals who use AAC (Nelson, 1992). Because comprehension happens internally and can not be directly observed, assessing receptive language skills is a difficult task (Miller & Paul, 1994). Therefore, assessment of receptive language is dependent upon evaluating a person's response to questions or observing a physical response such as pointing to pictures. Physical limitations and limited expressive abilities often make it difficult to assess the comprehension of individuals who use AAC. As a result, comprehension deficits may not be identified and may further compromise language development (Roth & Cassatt-James, 1989).

Semantics. Children who use aided AAC have access to a severely restricted expressive vocabulary compared to their speaking peers (Light, 1997). Children who speak can express thousands of concepts by the time they are preschoolers, whereas those who use AAC systems seldom have access to more than a few hundred concepts in their AAC systems (Light, 1997). Currently very little is known about the semantic development of children who use AAC.

Much research in the area of semantics has been devoted to evaluating how children learn AAC symbols. Previous research has evaluated symbol learning with regard to the type of representation used (e.g., Fuller, 1997; Mirenda & Locke, 1989). These studies have revealed that children learn symbols that are iconic (i.e., guessable) more quickly than symbols that are not iconic. Recent studies have begun to investigate how children who use AAC learn new symbols that are not iconic. These studies have revealed some evidence of "fast mapping" skills (i.e., learning novel symbols given limited exposure) in children who use AAC (Wood & Beukelman, 1998; Sutton, Dench & Head, 1999). The extent to which children utilize fast mapping when learning new symbols has not yet been determined, however it appears that children may be able to learn non-iconic symbols with little instruction.

Syntax/morphology. There has been recent interest in the development of syntax and morphology by individuals who use ACC. Sutton and Dench (1998) reported the case study of a child who acquired functional speech late in development, whose syntactic abilities were further developed than would have been expected based on his productive experience. As a result, they proposed that syntax can develop in the absence of productive practice (Sutton & Dench, 1998).

However, stating that syntax can develop without productive practice does not mean that it will develop in a typical manner. Research suggests that individuals who use AAC demonstrate difficulty acquiring morphology and syntax expressively (Kelford Smith, et al., 1989) and receptively (Blockberger & Johnston, 1998). These results may suggest that, although productive practice is not required, it does play a role in the development of syntactic and morphological skills.

In summary, the research literature has begun to describe the receptive and expressive language skills of individuals who use AAC. Most studies have focused on the early stages of language acquisition and have evaluated expressive language, specifically pragmatics. There are few descriptions of the receptive language skills of individuals who use AAC, especially those of young adults. It is important that receptive language is assessed throughout development. During later stages of language acquisition, the focus of development is further refinement of semantic, syntactic, and pragmatic skills (Paul, 1995).

Reading

The ability to read and write is important for all people. Literacy skills are critical for participation in many aspects of life. In school, students read to learn new information and write to display their knowledge through writing papers and tests. Literacy skills are needed at work where 85% of jobs require literacy skills at grade 9 or above (Taylor, 1989). At home, people read to follow printed instructions such as recipes or information about medications. And on a personal level, literacy skills allow people to read for enjoyment, keep in touch with friends and family through letters and e-mail, and reflect on our lives by keeping a journal (Light & Kelford Smith, 1993).

Literacy is of utmost importance for individuals who communicate via AAC. In addition to the reasons stated above, literacy provides communicative freedom for individuals who use AAC. The ability to spell allows AAC users generative capacity and opens a world of infinite messaging possibilities. Being literate frees them from a pre-selected vocabulary chosen by someone else (Koppenhaver, Evans, & Yoder, 1991).

In addition, literacy can open the doors to the Internet and electronic mail. The Internet allows individuals access to a wide range of information and experiences that were previously inaccessible to many individuals with disabilities. E-mail allows the individual who uses AAC to bypass many of the limitations of face to face communication (Cardona, 2000). Communicating via AAC is very slow. However, when using e-mail individuals who use AAC can compose messages at their own speed – rate is no longer an issue. Many individuals who use AAC use the Internet and e-mail to establish and maintain friendships, obtain and share information, and gain world knowledge (Price, 2000).

Unfortunately, many individuals who use AAC do not develop functional literacy skills. It is estimated that 50% of children who use AAC (with average intelligence) read significantly below grade level and most lag behind age level peers (Koppenhaver & Yoder, 1992). Of those who achieve some level of literacy, most continue to demonstrate difficulty with the form (i.e., syntax and morphology) of written language (Kelford Smith et al., 1989).

There are many barriers to literacy learning for individuals who use AAC. These barriers may include limitations in the individual's capabilities such as sensory/perceptual deficits, cognitive differences, language comprehension deficits, and limited world knowledge (Smith, 1992). Other barriers result from environmental limitations such as limited expectations (Light & McNaughton, 1993), limited role models (Pierce & McWilliam, 1993), limited access to books and print, limited professional expertise, lack of instruction (Koppenhaver & Yoder, 1993), and inappropriate instruction.

Children who use AAC have quantitatively different early literacy experiences than their non-disabled peers. Preschoolers with severe speech and physical impairments have less access to printed materials and early writing or drawing activities (Pierce & McWilliam, 1993). Once they reach school age, students who use AAC have less instruction in literacy than their non-disabled peers. In his study of children with severe speech and language impairments, Koppenhaver (1991) found that teachers allocated approximately one hour per day for literacy instruction. However, only half of this time was spent engaged in instructional tasks. On average, 17-29 minutes per day were spent on reading instruction, and 7-15 minutes per day were spent on writing.

While developing literacy skills is a challenge for many individuals who use AAC, some individuals who use AAC do develop competencies in reading and writing and a small number are highly skilled (Koppenhaver et al., 1991). Adults who use AAC and are highly literate attribute their literacy success to parental support and high expectations, positive self-perception, persistence, and regular opportunities for appropriate instruction and practice (Koppenhaver et al., 1991).

Research has begun to address issues surrounding emergent literacy for individuals who use AAC, however there is still a paucity of research conducted in the area of conventional literacy (Koppenhaver, 2000). Conventional literacy refers to reading and writing that adhere to conventional form including skills such as understanding the main idea of texts and using written language that others can read and understand (Koppenhaver, 2000). While emergent literacy skills are necessary for further literacy development, they are not sufficient alone (Koppenhaver, 2000). There has been no research bridging the gap between emergent and conventional literacy for individuals who use AAC.

Communicative Interaction

There is a significant body of research that focuses on the communicative interaction skills of children with congenital disabilities who require AAC. There have been a number of studies involving pragmatic analyses of adult-child interactions (e.g., Light, Collier, & Parnes, 1985 a, b, c; Harris, 1982). All studies have found individual variation across dyads, however general patterns of interaction did emerge across studies.

Discourse management.

The research has shown that turn taking patterns between individuals who use AAC and speaking partners tend to be asymmetrical. Individuals who use AAC occupied less of the conversational space than their speaking partners (Light, 1988). In a study of the interaction patterns between eight physically disabled children between four and six years of age of and their caregivers, Light et al. (1985a) reported that the interactions were dominated by the speaking partner, who took up to twice as many turns as the children. The children fulfilled approximately half of their turn opportunities, forfeited their non-obligatory turns, and only communicated when the context obligated it (Light, Collier, & Parnes, 1985a). Similar patterns were found in other studies as well (e.g., Calculator & Dollaghan 1982; Harris 1982).

The research investigating discourse strategies has shown that speaking partners tended to control the focus of the interaction initiating 85% of the topics (Light, Collier, & Parnes, 1985a). Individuals using AAC systems were often relegated to a respondent role and seldom initiated during their interactions (e.g., Calculator & Dollaghan, 1982; Harris, 1982). Dyads did share a communicative focus most of the time, however the augmented communicators tended to maintain, but did not extend the conversation (Light, Collier, & Parnes, 1985a).

Communicative functions. As mentioned previously, individuals who use AAC tend to fall into a respondent role during interactions with speaking partners. As a result, many studies have found that individuals who use AAC tend to primarily issue yes/no responses and other short provisions of information in response to partners' questions (e.g., Harris, 1982; Light et al., 1985b).

In their study of eight preschool children who used AAC, Light, Collier, and Parnes (1985b) observed that the children used limited communicative functions during natural interactions with their caregivers. The children produced a greater range of functions during eliciting contexts with a clinician, however the range of functions used was still limited. The children rarely asked questions or asked for clarification, even in eliciting contexts.

Mode of communication. Communication via AAC is not restricted to use of an AAC system, rather it is a multi-modal process. Individuals who use AAC use multiple modes, both aided and unaided, during communicative interactions (Light, et al., 1985c, Smith, 1994). Many studies have found that individuals tend to use unaided modes of communication (e.g., vocalizations, gestures) more frequently than communication boards or voice output communication aids (e.g., Calculator & Dollaghan, 1982; Calculator & Luchko, 1983; Light, et al., 1985c). However, that is not to say that communication aids did not play an important role in these individuals' communication. Individuals initiated more frequently, used more complex statements, and demonstrated greater conversational control when using aided AAC systems than when not (Light, 1988).

Studies have also shown that the mode of communication used is related to the communicative demands of the situation. Variables such as proximity of the conversational partner, familiarity of the partner, discourse status of the utterance, and propositional content of the message have been shown to influence the mode of communication used (Light, 1988). With familiar partners individuals who use AAC tended to use vocal modes, however with less familiar partners they used communication aids more frequently (Light, 1988). To initiate interaction, individuals who use AAC were noted to use unaided forms of communication such as vocalizations and gesture most frequently (Light, 1988). Light, Collier, and Parnes (1985c) conducted a detailed analysis of the relationship between mode of communication and communicative function of eight children who used AAC during interactions with their caregivers. This analysis revealed that the children who used AAC were most likely to use their communication boards to provide information and provide clarification. Confirmations and denials were conveyed through vocalizations or gestures and requests for objects or actions were communicated via gesture or eye pointing. For the most part, the children appeared to use modes which were appropriate, effective, and efficient given the content and role of the message (Light, Collier, & Parnes, 1985c).

Interaction patterns are highly dependent upon the context and communicative partner. Therefore, when analyzing discourse skills, it is extremely important to evaluate interactions in a variety of contexts and with a range of partners before making generalizations about an individual's interaction skills (Light, 1988). The studies to date have looked at single samples of interaction, usually with partners in higher status relationships (e.g., parent-child, teacher-student) (Light, 1988). In addition, the studies to date of communicative interaction of individuals who use AAC have focused primarily on children or young adults who have been fairly novice AAC users. Moreover, these studies have been a static evaluation of interaction skills, only looking at interaction skills at one point in time. No studies have evaluated changes in interaction skills over time. Only now is the field of AAC at a point in time where the effects of having access to AAC systems since early childhood can be evaluated.

This study evaluated the interaction patterns of a group of young adults who had used AAC systems since preschool. Interaction patterns were evaluated across three partners: a caregiver, an unfamiliar partner, and a peer. In addition to describing current skills, the present interaction patterns with caregivers were compared to those from when the individuals were in preschool.

Self-Determination

Self-determination is an important area to address when evaluating outcomes because self-determination is the ultimate goal of adulthood - to be in charge of one's own life. Wehmeyer (1996) defined self-determination as "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference" (p. 24). According to Wehmeyer (1996) there are four essential characteristics of self-determined behavior, it is (1) autonomous, (2) psychologically empowered, (3) self-realizing and (4) self-regulated. A behavior is autonomous when individuals act independently, according to their own preferences. Individuals who act in a psychologically empowered manner do so because they have a belief that they have control over their circumstances. They also believe that they possess the skills required to achieve their goals (i.e., self-efficacy) and have the expectation that the desired outcome will occur if they apply their skills (i.e., outcome expectations). Individuals who act in a self-realizing manner understand their strengths and weaknesses and know how to use their skills to achieve their goals. Finally, self-regulation refers to the ability to solve problems, make decisions, set goals, and develop plans to work towards those goals.

It is important to measure self-determination when evaluating outcomes because self-determination is the ultimate objective of education. The U.S. Department of Education has identified self-determination as a critical outcome for youth with disabilities (Wehmeyer, 1996). Self-determination allows individuals with disabilities to have more control over their lives. Individuals who use AAC stress the importance of self-determination and have expressed that using AAC places additional challenges on developing self-determination (Bersani & Fried-Oken, 2000).

Communicative competence and self-determination are separate concepts, but highly linked (Light & Gulens, 2000). Without communicative competence, individuals are unable to express their preferences and choices. Individuals who use AAC often have significant physical disabilities and are dependent upon others for many basic tasks of daily living. It is critical that augmented communicators are able to express their preferences and choices, and are able to direct others to do the things that they cannot do independently. Currently, there is no research investigating the self-determination skills of individuals who use AAC. This study was the first to assess the self-determination skills of a group of young adults who use AAC.

Quality of Life

Quality of life is also an important construct to measure in the evaluation of outcomes. The meaning of "quality of life" is commonly understood, yet difficult to operationally define. Early evaluations of quality of life measured external conditions presumed to dictate quality of life such as education, income, housing, and living conditions (Day & Jankey, 1996). However, the statistical relationships between socio-demographic variables and quality of life are weak

(Day & Jankey, 1996). It is clear that other factors contribute to quality of life. The reason that it is so difficult to define quality of life lies in the fact that the meaning varies from person to person. The basic components of quality of life are the same for all people, however the importance attached to the components differs from person to person (Brown, Renwick & Nagler, 1996).

Quality of life has recently been identified as an important aspect of measuring outcomes (Frattali, 1998a). Improved quality of life is the objective of rehabilitation and educational interventions (Brown, Renwick & Nagler, 1996; Fratttali, 1997). "Communication is the essence of human life" (article II, section 1, USSAAC Bylaws). Communicating and interacting with others is at the core of human existence. Therefore communication has a profound affect on quality of life, and it is only within the context of quality of life that the full effect of communication interventions can be determined. Currently, there are no studies investigating issues of quality of life for individuals with congenital disabilities who use AAC. This study was the first to use quality of life as an outcome measure for individuals who use AAC.

Research Objective

In light of the need to document outcomes for individuals who use AAC and the lack of research in this area, this study investigated the long-term outcomes of AAC interventions using a theoretical model based on the ICIDH-2. Specifically, this study investigated the long-term outcomes for a group of seven young men (ages 19-23 years) who had used AAC systems for at least 15 years. The research objective of the study was to measure outcomes at all levels of the WHO ICIDH-2 model and to identify possible factors that contributed to these outcomes. The specific research questions were as follows:

1. What were the outcomes for a group of young men who had used AAC systems for at least 15 years in the areas of: (a)receptive language (i.e., comprehension of single word vocabulary, grammatical morphemes, and syntactic structures); (b) reading comprehension; (c) communicative interaction (i.e., turn taking patterns, communicative functions, and modes of communication used during interactions with three different partners: a caregiver, an unfamiliar partner, and a peer); (d) functional communication (i.e., basic communication skills required for daily life); (e) educational and vocational achievement; (f) self-determination; and (g) quality of life?
2. How have the participants' interaction patterns changed since they were preschoolers?
3. What factors contributed both positively and negatively to these outcomes?

SECTION 2: METHODS

Participants

Six of the eight participants from the Light, Collier and Parnes (1985 a, b, c) interaction studies were invited to participate in this study. These individuals were invited to participate because they had received AAC services since preschool from an internationally-recognized children's rehabilitation center. Moreover, information regarding their interaction skills as preschoolers was available from the previous study and records regarding their intervention history were available for review. One of the participants from the original study could not be located and one was not included because he had a diagnosis of Lesch-Nyhan Syndrome, a progressive neurologic disease. In order to increase the number of participants, an additional individual was recruited for whom preschool data was be available. As a result, seven young men participated in the study. The participants (a) had cerebral palsy, (b) were between 19 and 23 years of age, (c) had significant speech impairments (i.e., their speech was inadequate to meet their daily communication needs), (d) had used AAC systems for at least 15 years, and (e) had data available regarding their communication and interaction skills as preschoolers. Demographic information regarding the participants is presented in Table 2.

All of the participants had received services from a specialized AAC team at an internationally-recognized children's rehabilitation center. The center served as a regional specialty center in AAC (Beukelman & Mirenda, 1992). The services provided by the center encompassed three areas: recommendation of AAC systems, intervention planning, and

Table 2
Participant's demographic information

Participant	Age	Gender	Disability	AAC Systems	Access to system
Anthony	21	M	Cerebral Palsy	Eyepointing; head shake/nod; communication board on laptray with 179 Blissymbols and the letters of the alphabet; supplemental book of 786 Blissymbols, words, letters and numbers	Eye pointing and partner-assisted scanning
Leo	22	M	Cerebral Palsy	Eyepointing; head shake/nod; eye codes; Macintosh computer with Co:Writer and Write:OutLoud software	Ke:nx with Morse code via two head switches and a chin switch
Chad	22	M	Cerebral Palsy	Vocalizations; head shake/nod; gestures; LightWriter	Direct selection with index finger of right hand
Josh	19	M	Cerebral Palsy	Vocalizations; head shake/nod; communication board with alphabet and frequently used words on laptray (face-to face communication); IBM compatible lap top computer with WiVik and WiVox software and DecTalk speech synthesizer	Direct selection with thumb of left hand (communication board); directed scanning with a joystick (lap top computer)
Carson	22	M	Cerebral Palsy	Speech approximations; head shake/nod; IBM compatible lap top computer with WiVik and WiVox software and DecTalk speech synthesizer	Quartering with an array of 6 head switches
Bradley	23	M	Cerebral Palsy	Eye pointing; communication book with 808 words and phrases; Freestyle computer with Speaking Dynamically software	Partner assisted scanning (communication book); Single switch automatic scanning with a head switch (Freestyle)
Douglas	23	M	Cerebral Palsy	Eye pointing; Dynavox 3100 with 1216 pre-programmed words and phrases.	Directed scanning with an array of 4 head switches

facilitator[1] training. These services were delivered through consultative or direct service models. The center conducted assessments and provided recommendations for intervention and consulted with professionals in the participants' local community who implemented direct services. Some participants also received direct services from the center.

The first participant , Anthony, was a 21 year old man who had cerebral palsy. Anthony was referred to as Subject #7 in the Light, Collier, and Parnes (1985 a) study. He had no functional use of his hands or legs and poor head control. He was usually seated in a manual wheelchair with no method of independent mobility. He was learning to operate a motorized wheelchair using an array of head switches. Anthony's hearing and vision were reported to be within normal limits.

Anthony had received AAC services since the age of three. These services were delivered through a direct service model from ages 3 through 10, and a consultative model from age 10 until the time of the study. A summary of the intervention Anthony has received is presented in Appendix A. At the time of the study, Anthony communicated through a variety of modalities: vocalizations, head nods/shakes, eye pointing to items in his environment, and a communication board of 179 Blissymbols[2] on the laptray of his wheelchair. To select items on

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[1] The term facilitator is used to describe significant others (e. g., parents, siblings, teachers) in the lives of individuals who use AAC. Facilitators are more than just communication partners, they support and assist individuals who use AAC to develop communicative competence (Light & Binger, 1998). As used in this context, the term facilitator does not refer to Facilitated Communication, as described by Biklen (1990).

[2] Blissymbols are graphic symbols used to represent language that were originally developed for the purpose of international communication. Currently composed of over 2,000 graphic symbols, Blissymbols can be combined and recombined to create new symbols. Additional information is available from Blissymbolics

his communication board, Anthony used a combination of eye pointing and partner-assisted scanning. He eye-pointed to the area on his board containing the symbol, then relied upon his communication partner to scan (i.e., point to) the items in that area row by row and item by item. When his partner reached the desired item, Anthony indicated "yes" by raising his eyes or nodding. Anthony used his Blissymbols to generate multi-symbol utterances. These messages typically included key content words and omitted functors (e.g., what-dinner). Anthony lived at home in a suburban area of a large metropolitan city with his parents, his twin brother and his younger brother who were not disabled. Anthony was in his final year of high school. He was integrated for two of four class periods during the day (English and Ancient Civilizations). During the other two periods he attended special education life-skills training classes.

The second participant, Leo, was a 22 year-old man. Leo was referred to as Participant #8 in Light, Collier, and Parnes (1985a). He had severe athetoid cerebral palsy and had no functional use of his arms or legs, but had moderately good head control. He was typically seated in a manual wheelchair with a custom insert. Due to severe athetoid movements of his arms, he usually kept them tucked under the lap belt of his wheelchair. He had no access to independent mobility in his current living situation. Leo's hearing and vision were reported to be within normal limits.

Leo had received AAC services since the age of three. These services were delivered through a direct service model from ages 3 through 10, and again at age 14. A consultative model was used from age 10 until the time of the study. A summary of the intervention Leo has received is presented in Appendix A. At the time of the study, Leo communicated through head

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Communication International, 1630 Lawrence Avenue, West, Suite # 104, Toronto, ONT M6L 1C5, CANADA and at http://home.istar.ca/~bci nods/shakes, vocalizations, eye pointing to items in his environment, and a series of idiosyncratic eye codes (e.g., looking at his pocket to indicate concepts related to money such as "money", "expensive", "cost"). He also had a desktop computer with Co:Writer[3] and Write:OutLoud[4] software. He accessed the computer using Ke:nx[5] and Morse code. He used switches placed on each side of his head to enter the "dits" and "dahs" of Morse code and signaled that his selection was complete by using his chin to activate a switch on his chest. He used this computer primarily for graphic design and written communication however, at times, he used this system for face-to-face communication. The majority of Leo's communication was accomplished through eye pointing, eye codes, and his communication partners asking him series of yes/no questions. Leo lived at home with his parents in a large city. The family spent half of the year in North America and half in Portugal. At the time of the study, it was reported that Leo used a motorized wheelchair controlled by a head switch array while in Portugal. His family spoke Portuguese in the home. Leo's primary language was Portuguese, however he understood English as well. Leo had attended separate schools for children with disabilities from preschool

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[3] Co:Writer is a computer software program that provides word prediction. Additional information is available from Don Johnston Incorporated, 26799 West Commerce Drive, Volo, IL, 60073 or www.donjohnston.com

[4] Write:OutLoud is a talking word processor computer software program. Additional information is available from Don Johnston Incorporated, 26799 West Commerce Drive, Volo, IL, 60073 or www.donjohnston.com

[5] Ke:nx is a computer interface system for people with disabilities. The Morse code option allows one to use Morse code to write or enter commands for computer functions and mouse emulation. Additional information is available from Don Johnston Incorporated, 26799 West Commerce Drive, Volo, IL, 60073 or www.donjohnston.com

through eighth grade. In ninth grade Leo was placed in the high school in his community. He was integrated for 1-2 courses per semester. Leo dropped out of high school when he was in the tenth grade because he reported that he had been frustrated and bored with his educational program and elected to stop attending school. Since that time, he had not attended any further educational or vocational training. He spent most of his time during the day creating drawings using his computer.

Chad was a 22 year-old man who had cerebral palsy. Chad was referred to as Participant #2 in Light, Collier, and Parnes (1985a). He used a power wheelchair for mobility which he controlled through a hand operated joystick. When at home, he spent most of the time out of his wheelchair sitting on the floor, couch, or in a typical kitchen chair. He lived at home with his mother and father in a small city. He moved independently around his home by scooting with his arms.

Chad had received AAC services since the age of three. These services were delivered through a consultative model. See Appendix A for a summary of the intervention Chad has received. At the time of the study, Chad communicated using vocalizations, head nods/shakes, gestures, and a LightWriter[6] voice output communication device. He accessed his LightWriter via direct selection using the index finger of his right hand. Chad's primary language was French, however he was fluent in both French and English and was able to switch easily between

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[6] The LightWriter is a portable keyboard device with voice output featuring DECtalk synthesized speech. The device consists of a keyboard and two liquid crystal displays: one display faces the person typing and the other faces the message recipient. The device is capable of storing messages using letter/number abbreviations. Additional information is available from: ZYGO Industries, Inc., PO Box 1008, Portland, OR 97207-1008 or www.zygo-usa.com

both languages both expressively and receptively. Chad's LightWriter had the capability for speech synthesis in both French and English, however the quality of the French synthesizer was quite poor. Therefore, when communicating in French, he spelled the message on his LightWriter for his partner to read. Chad used letter-by-letter spelling to communicate with a series of typing shortcuts he developed for efficiency (e.g., using the numeral 4 to represent "for"). Chad had attended French speaking schools throughout elementary and high school. At the time of this study, he was attending an English speaking college studying business and computers.

The fourth participant, Josh, was a 19 year old young man who had cerebral palsy. Josh did not participate in the original Light, Collier, and Parnes (1985a) study, but was invited to participate in the study to increase the number of participants. He had no functional use of his legs and limited use of his left arm. He was typically seated in a power wheelchair which he drove with his left hand using a small joystick. He wore glasses for far-sightedness. His corrected vision was within normal limits. His hearing was also within normal limits.

Josh had received AAC services since the age of three. These services were delivered through a consultative model. A summary of Josh's intervention is presented in Appendix A. At the time of the study, Josh communicated through speech approximations (i.e., yeah, no), gestures, a communication board on the laptray of his wheelchair, and an IBM compatible laptop computer with WiVik[7] and WiVox[8] software and a speech synthesizer. Josh used pre-stored

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[7] WiVik (Windows Visual Keyboard) is a software program which provides the user with a customized on-screen keyboard. Additional information is available from Bloorview MacMillan Centre, 350 Rumsey Road, Toronto, ONT M4G 1R8, CANADA or Prentke Romich Company, 1022 Heyl Road, Wooster, OH 44691, (800) 262-1984, and at www.wivik.com

phrases as well as letter by letter spelling with word prediction when retrieving messages from his computer-based system. Josh used his communication board for the majority of his communication, reserving his computer-based system for public speaking, writing, and gaining attention from a distance. His communication board consisted of letters, numbers, and 61 commonly used words and phrases (e.g., what, because, maybe, don't know). Josh accessed his communication board via direct selection using his left thumb. Josh lived at home with his parents and 16 year-old brother in a large metropolitan area. Josh was an academically competitive high school student. At the time of the study, he was about to begin his final year of high school.

Participant #5, Carson, was a 22 year-old man who had cerebral palsy. Carson was referred to as Participant #3 in Light, Collier, and Parnes (1985a). Carson had good head control, but no functional use of his hands or legs. His arms were typically strapped to the laptray of his wheelchair. Carson used a power wheelchair for mobility which he controlled through an array of switches embedded in his headrest. His hearing and vision were reported to be within normal limits.

Carson had received AAC services since the age of three. These services were delivered through a consultative model. Appendix A presents a summary of Carson's communication intervention. At the time of the study, Carson communicated using eye pointing, speech approximations (e.g., yeah, names of friends and family members), head nods/shakes, and an

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[8] WiVox is a voice output program designed to send text from a computer to an external speech synthesizer. Additional information is available from Bloorview MacMillan Centre, 350 Rumsey Road, Toronto, ONT M4G 1R8, CANADA or Prentke Romich Company, 1022 Heyl Road, Wooster, OH 44691, (800) 262-1984, and at www.wivik.com

IBM compatible laptop computer with WiVik and WiVox software and speech synthesizer. He accessed his computer-based system using a quartering system with four head switches. The quartering system worked in the following manner. An on-screen keyboard with letters, numbers, and punctuation was divided into four quadrants each containing sixteen items. Each of Carson's head switches represented one quadrant. To access a desired letter, Carson activated the corresponding switch. The selected quadrant was then enlarged and divided into four quadrants of four items each. This process continued until the desired letter was selected. Carson was so proficient with the system that he knew the correct sequence of switch activations for each letter by memory and did not need to look at the keyboard. To reduce the number of keystrokes necessary to type a message, his system also employed linguistic prediction. Carson lived at home with his mother, father, and 16 year-old brother in a small, tourist-oriented community.

Participant #6, Bradley, was a 23 year-old man who had severe quadriplegia due to cerebral palsy. Bradley was referred to as participant #4 in Light, Collier, and Parnes (1985a). Bradley had no functional use of his arms or legs, he had moderately good head control. He was typically seated in a manual wheelchair and had no independent means of mobility. Bradley's hearing and vision were reported to be within normal limits.

Bradley had received AAC services since the age of four. These services were delivered through a consultative model. See Appendix A for a summary of Bradley's communication intervention. At the time of the study, Bradley primarily communicated through eye pointing, and gestures for yes (turning his head up and to the right/looking up) and no (lowering his head and looking down). He also had a communication book made up of words and phrases represented by traditional orthography which was organized taxonomically (e.g., people, feelings) and schematically (e.g., eating out, personal care). He selected vocabulary in his communication book using partner-assisted scanning. That is, his communication partner read a list of the categories of vocabulary and Bradley indicated "yes" by looking up to select the item he wanted. Bradley's parents were so proficient with this system that they did not require the communication book to complete this process. Bradley's mother recited the categories and subsequent vocabulary items from memory, rather than using the book. Bradley also had a computer-based system consisting of a Freestyle notebook computer[9] with Speaking Dynamically Pro[10] software which he accessed through single-switch automatic scanning. Vocabulary was stored in single words or pre-stored phrases and represented with traditional orthography. Bradley did not use his computer-based system very often. Bradley's family did not like him to take the system out of the home, for fear it would be damaged. Also, Bradley reported that he preferred to use the partner-assisted scanning procedure with familiar partners because of its ease and speed. Bradley lived in a small city with his mother and father who were retired. Bradley had attended public schools until he was 21, at which time he completed school with a special education certificate. At the time of the study, he attended a day activity program for adults with disabilities aimed at teaching independent living skills.

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[9] The Freestyle is a Macintosh based notebook/laptop computer. The Freestyle can be accessed via a built-in touch screen, an on-screen keyboard, or through scanning. Additional information is available from Assistive Technology Inc., 7 Wells Avenue, Newton, MA, 02459 and at www.assistivetech.com

[10] Speaking Dynamically Pro is a software program that allows one to create customized, dynamic display communication boards with speech output via recorded speech or a speech synthesizer. Additional information is available from Mayer-Johnson Company, PO Box 1579, Solana Beach, CA, 92075-1579 and at www.mayer-johnson.com

Participant #7, Douglas, was a 23 year-old man with cerebral palsy. Douglas was referred to as Participant #1 in Light, Collier, and Parnes (1985a). He had moderately good head control, but no functional use of his hands or legs. He was typically seated in a manual wheelchair and had no means of independent mobility. Previously, he had used a power wheelchair controlled with a head switch array. However at the time of this study he was not using a power chair due to limited space in his home and issues regarding his judgment while driving. Douglas had a moderate high frequency (above 8000 Hz) sensorineural hearing loss in both ears. It was reported that his hearing loss did not affect his ability to understand speech. His vision was within normal limits. He had severe oral-motor problems and was fed by a G-tube.

Douglas had received AAC services since the age of six. These services were delivered through a consultative model. A summary of Douglas' intervention is presented in Appendix A. At the time of the study, he communicated using eye pointing, and a DynaVox 3100[11], a computerized voice-output communication system. He accessed the words and phrases stored in the DynaVox using directed scanning with a head switch array. He communicated primarily using pre-stored words and phrases. At the time of the study, his system contained 1216 pre-programmed words and phrases. Vocabulary was represented in the system with traditional

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[11] The DynaVox 3100 is a dynamic display, computer-based voice output communication aid. Additional information is available from DynaVox Systems Inc., 2100 Wharton Street, Suite 630, Pittsburgh, PA 15203 and at www.dynovoxsys.com

orthography and DynaSyms[12]. He had beginning spelling skills and occasionally attempted to spell words not stored in his system. He relied primarily on eye pointing and yes/no questions for the majority of his communication. At the time of the study, Douglas was living with a foster family with two other foster siblings. He had lived in this foster home for two months. Previously, he had lived with another foster family from age 6-23. For the first six years of his life, Douglas lived on a Native American reservation. At the age of six, he was placed in foster care because he had not received any special services for his physical, communication, and developmental needs. His foster family lived in a rural area but they were close to a city that could provide the services Douglas needed. Douglas spent weekends and summers on the reservation until he was approximately 11 years old. After that, visits to the reservation were less frequent and not regularly scheduled. His natural family spoke Ojibwa and it was reported that Douglas understood Ojibwa at that time. At the time of the study, it was unclear whether Douglas had retained his understanding of Ojibwa, as it had been approximately eight years since he last visited the reservation. When asked, Douglas reported that he could still understand some Ojibwa, however he was not sure how much.

Douglas completed high school in a special education program. At the time of the study, he spent his weekdays at two different day activity programs. One program was designed to teach skills necessary for independent or supported living. The other program provided recreational activities for a group of adults with severe developmental disabilities.

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[12] DynaSyms are line drawing symbols used to represent language concepts on DynaVox products. Additional information is available from DynaVox Systems Inc., 2100 Wharton Street, Suite 630, Pittsburgh, PA 15203 and at www.dynovoxsys.com

In addition to the individuals who used AAC, three communication partners for each participant were also invited to participate in the study. The partners included a caregiver, a familiar peer of approximately the same age (e.g., sibling or friend), and an unfamiliar adult partner (i.e., the student investigator). Table 3 lists the conversational partners for the language samples gathered with each participant. In most cases, the caregiver partner was the same person who had participated in the Light, Collier, and Parnes (1985 a,b,c) study with the exception of Douglas. Douglas' original foster mother participated in the Light, Collier and Parnes (1985 a,b,c) study, however she declined to participate in the present study, so Douglas' original foster father participated instead. Douglas had lived with these foster parents for 17 years, from age six until two months prior to the study.

Table 3
Conversational partners for language samples

Participant	Caregiver	Familiar Peer
Anthony	Mother	Younger brother, 14 years old
Leo	Older sister, 32 years old	Younger sister, 20 years old
Chad	Mother	Director of disabled student services at Chad's college, adult
Josh	Mother	Friend, 18 years old
Carson	Mother	Friend , 21 years old
Bradley	Mother	Volunteer at weekend activity program, 20 years old
Douglas	Original foster father	Original foster sister, 24 years old

Professionals (e.g., AAC specialists, speech/language pathologists, occupational therapists) who worked with the participants were also interviewed to discuss factors surrounding the participants' AAC instruction and outcomes. The professionals interviewed for each participant are listed in Table 4. The participants' clinical files were reviewed to identify professionals who had had ongoing clinical relationships with the participants. Two professionals were interviewed for each participant.

Table 4
Professionals interviewed for each participant

Participant	Professional Role	Time involved with participant	
Anthony	AAC Specialist	3 years	(ages 9-11)
	Occupational Therapist	4 years	(ages 17-20)
Leo	Speech-Language Pathologist	2 years	(ages 3-4)
	Occupational Therapist	6 months	(age 22)
Chad	Speech-Language Pathologist	6 years	(ages 3-8)
	AAC Specialist	4 years	(ages 8-11)
Josh	Speech-Language Pathologist	8 years	(ages 4-11)
	Occupational Therapist	12 years	(ages 8-19)
Carson	Speech-Language Pathologist	11 years	(ages 3-13)
	Occupational Therapist	11 years	(ages 12-22)
Bradley	AAC Specialist	4 years	(ages 10-13)
	Speech-Language Pathologist	4 years	(ages 20-23)
Douglas	Speech-Language Pathologist	9 years	(ages 6-14)
	Speech-Language Pathologist	5 years	(ages 19-23)

Procedures

Data collection for each participant occurred over a series of 3 – 6 days. The student investigator met with the participants and their families at their homes. Sessions were scheduled at the participants' convenience. Breaks were taken as needed. The participants selected the order in which they preferred to complete the tasks. Communicatively demanding tasks (e.g., interviews, language samples) were interspersed between less demanding tasks (e.g., questionnaires with rating scale responses). The amount of time for each participant to complete all tasks varied from 10 – 13 hours over an average of 4 sessions (range 3-6).

Due to scheduling limitations, two measures were collected by individuals other than the student investigator. The reading comprehension measures for Leo were administered by a speech-language pathologist who had many years of experience working with individuals who use AAC. Also, one of the language samples was not directly collected by the student investigator. Chad enlisted the help of his peer to videotape their conversation.

Each measure was administered according to established procedures unless adaptation of response mode was required to meet the participants' physical and/or speech needs (e.g., picture items on a response plate were separated and placed further apart to accommodate an individual's motor impairment). Specific adaptations for each instrument are described in each of the following sections. Unless otherwise noted no adaptations were made other than access accommodations.

Measures and Analysis

Outcomes were evaluated at the activity and participation levels of the ICIDH-2 (WHO, 2001). The measurement approaches used for each domain are presented in Table 5 and described in the following sections. This study focused on measuring outcomes at the activity and participation level. Specific details regarding each measure are presented in the following sections.

Table 5
Measurement approaches based on the ICIDH-2

Domain	Areas of Measurement	Method of Measurement
Body Function and Structures	• Motor function • Sensory functions (vision, hearing)	• From medical and therapeutic reports • From medical and therapeutic reports
Activities & Participation	• Receptive language skills	• Peabody Picture Vocabulary Test, Revised (Dunn & Dunn, 1981) • Test of Auditory Comprehension of Language, Revised (Carrow-Woolfolk, 1985)
	• Reading comprehension	• Gray Silent Reading Test (Wiederholt & Blalock, 2000)
	• Discourse skills, communicative functions, modes of communication	• Conversational samples with caregiver, peer, student investigator
	• Functional communication	• Functional Assessment of Communication Skills for Adults (ASHA FACS) (Frattali, et al., 1995)
	• Educational/vocational achievement	• Interviews with participants • From therapeutic reports
	• Self-determination	• The Arc's Self-Determination Scale (Wehmeyer & Kelchner, 1995)
	• Quality of life	• Quality of Life Profile (Renwick, et al., 1998)
Contextual Factors	• Products and technology	• Interviews with participants & professionals
	• Support and relationships	• Interviews with participants & professionals
	• Services	• Interviews with participants & professionals

Receptive Language

Receptive language skills were measured using the Peabody Picture Vocabulary Test, Revised (PPVT-R) (Dunn & Dunn, 1981) and the Test of Auditory Comprehension of Language, Revised (TACL-R) (Carrow-Woofolk, 1985). The PPVT-R measured comprehension of single word vocabulary. Scoring of The PPVT-R resulted in a standard score for each participant. The examiner presented a word orally and the participants were asked to select the drawing (from a field of four) that best represented the meaning of the word. Participants responded by either pointing to the appropriate picture or by indicating the number corresponding to the appropriate picture with their AAC system. Three participants (i.e., Anthony, Leo, and Bradley) responded via partner-assisted scanning. In these cases, the examiner called out the numbers corresponding to the pictures and the participants responded with their "yes" signals to indicate their desired response. The PPVT-R was selected because it was possible to modify its administration for individuals with significant speech and physical impairments, and it had adequate reliability and validity (Salvia & Ysseldyke, 1988).

The TACL-R measured comprehension of semantics (i.e., word meanings), morphology (i.e., grammatical markers of language), and syntax (i.e., sentence structure). Two of the three subtests were used, Grammatical Morphemes and Elaborated Sentences. The Word Classes and Relations subtest was not administered because the PPVT-R provided a more extensive measure of vocabulary comprehension. For both of the subtests administered, the examiner read a sentence aloud and the participant selected the drawing (from a field of three choices) that best represented the meaning of the sentence. The participants used the same response modes for the TACL-R as for the PPVT-R. From data presented in the administration manual, the TACL-R had adequate reliability and validity for the purposes of this study. Although the norms for the TACL-R are for younger children (3;0 – 9;11) this measure was selected because it provided a means for systematically measuring comprehension of syntax and morphology. According to the author of the test, the TACL-R can provide useful information for observing language comprehension of adults, particularly those with suspected comprehension limitations (Carrow-

Woolfolk, 1985). Due to the unavailability of appropriate age-based norms, the test was not scored according to standardized procedures. Rather, all 40 items in each subtest were administered and raw scores were calculated. Error analyses were conducted to determine areas of competence and areas of difficulty for each participant.

Reading Comprehension

Paragraph-length reading comprehension was measured using the Gray Silent Reading Test (GSRT) (Wiederholt & Blalock, 2000). The GSRT is a norm-referenced test of silent reading comprehension. Norms are reported for individuals from 7 years to 25 years, 11 months. There are two parallel forms of the measure, Form A and Form B. Form A was used for this study. Each form consisted of 13 separate paragraph-length stories followed by five multiple-choice comprehension questions. The questions were passage dependent, that is, they could only be answered correctly based on information presented in the passage, not based on general knowledge. The comprehension questions were comprised of a mixture of literal, inferential, critical, and affective questions. Literal questions measured comprehension of material explicitly stated in the passage (e.g., What color was the bird?). Inferential questions required the reader to infer meanings beyond what was stated in the passage (e.g., What kind of party do you think this was?). Critical questions required the reader to analyze, evaluate or make judgments about the text (e.g., Which sentence does not go in the story?). Affective questions involved emotional responses to the text, including determining the emotional states of characters in the text (e.g, How do you think the boy felt?).

The paragraphs and questions were re-typed in Arial 20 point font. Participants were asked if they would prefer to read the enlarged font or standard font in the test booklet. All selected the enlarged font. The GSRT was administered individually. Standard procedures for individual administration required the use of basal and ceiling rules. A ceiling was achieved and testing discontinued when three of five comprehension questions at a given level were answered incorrectly. All questions required the participants to select an answer from four multiple choice options. The participants used their communication systems or partner-assisted scanning to communicate their selection. The GSRT was selected because it did not require oral reading and was easily adaptable for individuals with physical disabilities who use AAC. The GSRT had satisfactory reliability and validity according to the data provided in the examiner's manual.

Three participants (Anthony, Leo, Bradley) indicated that the paragraphs presented in the GSRT were too difficult for them to read. All three participants achieved ceiling scores on the first item. For these participants, an informal measure of single word recognition was used (Erickson, 1995). Words from graded reading lists at the pre-primer, primer, and first grade levels (e.g., dog, baby, turtle) were presented on index cards to the participants. The participants were also presented with four black and white photocopies of colored drawings. They were asked to read the word presented and select the picture that represented the word. All participants made their selections via partner-assisted scanning.

Communicative Interaction

The participants' communication skills and interaction patterns were evaluated by collecting and analyzing conversational samples with three different partners: (1) a primary caregiver (2) a familiar, similar age peer (e.g., friend or sibling); and (3) an unfamiliar adult partner (i.e., the student investigator). The participants and each partner were videotaped in their natural environments (e.g., home, school). For the samples with the caregivers and peers, the participants and their partners were given examples of possible conversation topics such as discussing plans for the weekend or upcoming vacations, school, or "catching up" on the latest news. Two dyads elected to start the interaction by reminiscing while looking at photographs in a family album. This activity led naturally to additional topics of conversation. The other dyads selected topics from those suggested to start the interaction. The interactions with the unfamiliar adult were sampled as she became acquainted with each participant. The student investigator suggested that they "spend some time chatting, so we can get to know each other". All conversational samples were video taped for data analysis. In order to minimize any observer effects (i.e., the effect of the presence of recording equipment on observed behavior), observers were not present during videotaping. The video equipment was set up as unobtrusively as possible while still capturing adequate audio and video. The participants were videotaped for at least 30 minutes. Twenty minutes of each tape was used for analysis. Some dyads required a "warm-up" time to get comfortable, but all quickly became accustomed to the presence of the video equipment in the room. All participants and partners reported that they thought the samples collected were representative of typical daily interaction.

The videotaped interactions were transcribed in their entirety including documentation of vocalizations or speech, eye pointing, facial expression, gestures, actions, and communication system output. The coding of all videotapes was completed through a detailed analysis of the written transcripts along with repeated viewing of the videotapes. Due to the poor sound quality of the sample between Bradley and his peer, only 10 minutes of the sample was coded. For comparison with the other participants, the data were extrapolated to estimate the results for a 20-minute sample. The coding procedures used followed those used by Light (1985) and Light, et al. (1985a, b, c). The discourse status (e.g., initiation or response) of each act was analyzed as well as the communicative function it fulfilled, and the mode of transmission.

Discourse status. Discourse was analyzed on four levels. First, was a communicative act present (i.e., communicative turn) or absent (i.e., turn opportunity)? Turn boundaries were determined by the other speaker taking the floor, or a marked pause (i.e., turn opportunity). A turn opportunity was defined as a marked pause in which a participant could take a turn (Light, et al., 1985a). A pause greater than one second was determined to be sufficient time for a participant to begin to claim a turn. On some occasions, a participant began to claim a turn (e.g., started typing, directed focus to communication board and began to point), however the partner did not allow the participant to complete his message - either by interrupting and "stealing" the turn or by failing to acknowledge the participant's attempt to start his turn. These turns were coded as interrupted turns.

The second level of analysis determined whether the purpose of the turn was to contribute to the conversation (i.e., communicative turn) or to help co-construct the message of the participant using AAC (i.e., procedural play). Participants using non-electronic communication systems require the active participation of their partners to co-construct, or build their messages (Light, 1988). For example, the participant points to letters on his alphabet board and the partner “calls out” each letter as it is selected. All turns that contributed to the construction of a message were coded as procedural plays.

The third level of analysis addressed whether the turn shared the focus of the previous turn (i.e., response) or established a new topic (i.e., initiation). Turns were coded as initiations if they introduced a new topic or shifted the focus within a previously established topic. For example during a discussion of summer plans, an initiation was recorded when the topic shifted from discussing summer school to discussing leisure activities. Finally, turns were coded with regard to their summoning power. Did the turn require a response from the partner (i.e., oblige) or did it invite but not require a response (i.e., comment)?

To evaluate turn taking, frequency count and proportional distributions were calculated for each participant regarding the total turns fulfilled, procedural plays, and initiations. The distribution of turns between the partners was also calculated. Means and standard deviations were calculated across participants.

Communicative function. The following categories were used to code communicative functions: request for object/action, request for information, request for clarification, request for attention, confirmation/denials, provision of information, provision of clarification, expression of self, imitation/compliance, conversational fill, incomplete/unintelligible. These categories were used in the original study (Light, et al., 1985 b) and proved to capture the communicative functions used in the samples. The coding definitions of the communicative functions are presented in Appendix B. Frequency counts and proportional distributions were tabulated for the range and frequency of communicative functions used.

Mode of communication. The mode of transmission for each communicative turn was coded as communication board, voice output communication aid (VOCA), speech or vocalizations, eye pointing, and gestures. The categories of communication board and VOCA were then collapsed to one category represented aided means of communication. Speech or vocalizations included intelligible speech, word approximations, and vocalizations. Turns using eye pointing were determined to be communicative if the partner inferred meaning from the eye pointing and the participant used a three-point gaze, that is he looked at his partner, to the referent, and back to his partner. Gestures were defined as symbolic movements expressed with either the body or eyes. Gestures included head nods, shakes, formal signs, and trained eye gaze such as looking up to indicate "yes". During analysis, it was noted that some participants combined modes within a single turn. These turns were coded for each mode used. Frequency counts and proportional distributions were calculated for the range and frequency of modes used.

Coding reliability. Reliability of the coding procedures was determined through calculation of inter-judge reliability coefficients. Two volunteers with experience in AAC were trained in the coding procedures by the student investigator. At least 20% of each conversational sample was selected randomly and coded independently by one of the judges. Inter-judge reliability was calculated by dividing the number of agreements by the total number of agreements and disagreements. The reliability coefficients for discourse status, communicative function, and mode of communication for the participants and their partners is presented in Table 6.

Table 6
Inter-judge Reliability Coefficients for Coding of Conversational Samples

	Discourse Status	Communicative Function	Mode of Communication
Participants	.98	.97	.98
Partners	.89	.80	N/A

Functional Communication

Functional communication refers to a person's ability to meet the communication demands of his/her daily life (Frattali, 1998b). For the purposes of this study, functional communication was measured using the Functional Assessment of Communication Skills for Adults (ASHA-FACS) (Frattali, et al., 1995). The areas assessed included social communication (21 items); communication of basic needs (7 items); reading, writing, and number concepts (10 items); and daily planning (5 items). Each section contained items describing different communication behaviors related to the area being assessed. For example, the social communication section included items such as requesting information, participating in conversations, and understanding conversations. Items in the communication of basic needs section included requesting help, expressing needs or wants, and expressing feelings. The reading, writing, and number concepts section contained items such as understanding simple signs and writing/typing one's name. The section on daily planning addressed situations such as telling time and keeping a schedule.

Items in each section were scored on a 7-point rating scale with regard to how much assistance was required for the participant to complete the stated activity. The rating categories were as follows: (1) does not do, (2) does with maximal assistance, (3) does with moderate to maximal assistance, (4) does with moderate assistance, (5) does with minimal to moderate assistance, (6) does with minimal assistance, and (7) does independently. Within each section, ratings were averaged to determine scores for the area. Scores in each of these areas were averaged to calculate an overall communication independence score.

Qualitative aspects of communication were also rated in the areas of adequacy, appropriateness, promptness, and communicative sharing. Adequacy addressed whether the participant understood the gist of message and was able to get his/her point across. Appropriateness assessed whether messages were relevant and completed under the right circumstances. Promptness judged whether responses were made without delay and in an efficient manner. Finally, communication sharing evaluated how much burden was placed on the communication partner to complete the interaction. These aspects were each rated on a 5-point Likert-type scale. The scales for adequacy, appropriateness, and promptness of communication ranged from 1 = never (e.g., communication is never adequate) to 5 = always (e.g., communication is always adequate). Communication sharing was rated on how equally the individual and partner shared the communication burden. The scale ranged from 1 = partner carries all of the communication burden to 5 = individual and partner share equally in communication.

The ASHA FACS was used because it was designed to be a general measure of functional communication, applicable to use with a range of clinical populations. Although it was designed to use with individuals with a variety of communication disorders, reliability and validity statistics were only presented for individuals with traumatic brain injury and left hemisphere stroke (Frattali, 1995).

The ASHA FACS was completed by the student investigator based upon her behavioral observations of the participants during their interactions over the course of data collection. If there was no opportunity to observe a particular behavior during the previous assessment and interaction situations, the student investigator sought out the information by asking the participant and/or caregivers as recommended in the ASHA FACS procedural manual.

Educational and Vocational Achievement

Educational and vocational outcomes were measured through interviews with the participants and their caregivers. The interview questions are presented in Appendix C. Questions addressed current educational placement and educational history including schools and grades attended and types of special education services received. Vocational questions addressed previous and current employment history as well as plans and goals for future employment. The interviews were recorded through video or audio tape. The student investigator also took notes during the interviews to record the participants' responses. Information regarding educational and vocational placements were also collected through review of the participants' clinical files. The data were analyzed by tabulating the types of educational placements attended by the participants.

Self-Determination

Self-Determination was measured using The Arc's Self-Determination Scale (Wehmeyer & Kelchner, 1995). This scale is a 72-item self-report measure of self-determination. The scale is divided into four sections, each section assessing a different characteristic of self-determination as defined by Wehmeyer (1996): autonomy, self-regulation, psychological empowerment, and self-realization. Examples of items and the scoring procedures for each section are presented in Table 7. The autonomy section measured the participants' abilities to make choices based on their own preferences. The participants were asked to rate 32 situations regarding their independence and choice making. Participants were presented with a statement and asked to rate how often they took part in the activity listed.

The section of the scale addressing self-regulation contained two sub-sections, problem solving and goal setting. The sub-section on problem solving contained 6 items. The participants were presented with the beginning and ending of a story and asked to tell what happened in the middle to cause the outcome. Answers were scored on the effectiveness of the response to achieve the outcome stated. The situations presented were common situations that were familiar to most of the participants.

The sub-section on goal setting contained three items. The participants were presented with a situation and asked if they had made plans or had a goal for that outcome. If they had a goal, they were asked what the goal was and to identify four things they should do to meet their goal. The three items presented were vocational plans, plans for future living arrangements, and

Table 7,

Sample items and scoring criteria for The Arc's Self-Determination Scale (Wehmeyer & Kelchner, 1995)

Domain	Area assessed	Examples of Items	Scoring
Autonomy	Making choices based on one's own preferences	I keep good personal care and grooming I do free time activities based on my interests	0 = I do not even if I have the chance 1 = I do sometimes when I have the chance 2 = I do most of the time I have the chance 3 = I do every time I have the chance
Self Regulation	Problem Solving	You are sitting in a planning meeting with your parents and teachers. You want to take a class where you can learn to work as a cashier in a store. Your parents want you to take the Family and Child Care class. You can only take one of the classes. The story ends with you taking the vocational class where you will learn to be a cashier.	0 = answer did not address problem, or would fail to solve problem 1 = answer had limited utility to achieve ending 2 = answer was acceptable, adequate way to achieve ending
	Goal Setting	Where do you want to work in the future? Where do you want to live in the future?	0 = had not planned for that outcome yet 1 = identified goal but no steps to achieve goal 2 = identified goal and 1 or 2 steps to achieve goal 3 = identified goal and 3 or 4 steps to achieve goal
Psychological Empowerment	Locus of control Outcome efficacy	Select the statement that best describes you: • I usually do what my friends want • I tell my friends if they are doing something I don't want to do	0 = answers did not reflect psychological empowerment (e.g., beliefs in ability, perceptions of control, and expectations of success) 1 = answers reflected psychological empowerment
Self-realization	Self-knowledge Self-awareness	Do you agree or disagree with the following statements? • I know what I do best • I am not an important person	0 = answers that did not reflect a positive self-awareness and self-knowledge 1 = answers reflecting a positive self-awareness and self-knowledge

plans for future transportation arrangements. Responses were scored on the effectiveness of the plan to achieve the goal.

The section addressing psychological empowerment assessed the participants' locus of control and their perceived power over their environment. This section contained 16 items. For each item the participants were presented with two statements and asked to determine which statement described them best. For each pair of statements presented, one statement reflected a psychologically empowered viewpoint (e.g., beliefs in ability, perception of control, and expectations of success) and the other statement did not.

The section addressing self-realization assessed whether the participants' had realistic perception of their strengths and limitations. This section contained 15 items. The participants were presented with a statement and asked if they agreed or disagreed with the statement. Half of the statements presented reflected positive self-awareness and half did not. For example a statement reflecting positive self-awareness was "I know what I do best." A statement that did not reflect positive self-awareness was "I am not an important person."

The Arc's Self-Determination Scale was administered according to the procedures outlined in the manual. The student investigator read each item to the participants. Participants indicated their responses to the problem solving and goal setting sections through their AAC systems. For the sections which required multiple-choice responses, the participants responded through their AAC systems or partner assisted scanning. Responses were recorded in the test administration booklet and scored according to the procedures described in the manual.

Quality of Life

Quality of life was measured using The Quality of Life Profile for People with Physical and Sensory Disabilities (Renwick, Brown, & Raphael, 1998). The fundamental components of quality of life are the same for all people (Renwick & Brown, 1996). However, the importance attached to each component varies from person to person. Therefore it is critical that any evaluation of quality of life is based on the individual's perceptions of what is important. The Quality of Life Profile for People with Physical and Sensory Disabilities (Renwick, Brown, & Raphael, 1998) is based on an individual concept of quality of life, which allows individuals to weight items based on personal importance. The Quality of Life Profile was developed using a holistic view of quality of life. That is, it takes into account the physical, psychological, spiritual, and social aspects of an individual's life (Renwick & Brown, 1996). The measure was designed for individuals with physical disabilities and has adequate reliability and validity.

The Quality of Life Profile is a self-report rating scale consisting of 102 items in nine categories: my body and health, my thoughts and feelings, my beliefs, attitudes and values, where I live and spend my time, the people around me, my access to resources, the daily things I do, the things I do for enjoyment, and the things I do to improve myself. Participants rated each item on a 5-point rating scale. Each item was rated for both importance and satisfaction. Scores were derived from a combination of the importance and satisfaction scores. Items with high importance ratings were weighted more heavily than those with low importance ratings.

Contextual Factors

Contextual factors contributing to outcomes were assessed using semi-structured, open-ended interviews with the participants, their families, and professionals (e.g., AAC consultants, speech/language pathologists, occupational therapists) who had worked with the participants and their families. Two professionals were interviewed for each participant. The professionals were identified through a review of the participants' records at the Communication and Writing Aids clinic at Bloorview MacMillan Centre.

The topics addressed during the interviews included the nature of communicative intervention over the past 15 years, satisfaction with intervention and service delivery, and factors each individual identified as contributing to the participants' communicative abilities. Questions were designed to elicit information regarding products and technology, services, and support provided. The topics addressed in the interviews were identified through a review of the literature and with feedback from an advisory team including an individual who uses AAC and his parent. Guide questions were used to elicit information. However, as needed, additional questions were asked to elicit more detailed responses. The interview guide questions used are included in Appendix D.

The interviews were tape recorded and transcribed in their entirety. Qualitative coding procedures were used to analyze the interview transcripts. The coding procedures used were adapted from Strauss (1987), Yin (1994), and Vaughn et al. (1996). The first step to coding was to divide the interview transcripts into "meaningful units". These units were the "smallest amount of information that was informative by itself" (Vaughn et al. p.106). Each unit was typically a single phrase or sentence. The second step was to code the data. The units were first organized into broad themes based on their general content. Next, within each theme the units were narrowly coded (Strauss, 1987) with regard to their specific content. These content codes were then reviewed and organized into sub-themes for each of the major themes.

SECTION 3: RESULTS

The results of the study are organized according to the domains of the ICIDH-2 model (WHO, 2001): activities and participation (i.e., receptive language skills, reading comprehension skills, communicative interaction skills, functional communication, educational/vocational achievement, self-determination, quality of life), and contextual factors (i.e., products and technology, support and relationships, services).

Receptive Language

The first area assessed in the activity and participation domain was understanding of spoken language, that is, receptive language skills. The results of the PPVT- are presented in Table 8. The participant's standard scores on the PPVT-R ranged from 44 to 77, where the standardized mean was 100 with a standard deviation of 15. The average standard score for the participants was 66. The group as a whole scored significantly below their same-aged non-disabled peers. The highest participant score (77) was more than 1½ standard deviations below the standardized mean. This indicates that the participants had significant difficulty with

Table 8
Participant scores for the PPVT-R

Participant	Raw Score	Standard Score
Andrew	126	75
Leo	122	72
Chad	116	67
Josh	128	77
Carson	113	65
Bradley	86	44
Douglas	106	59
mean	113.9	65.6
SD	14.5	11.3

comprehension of single-word vocabulary compared to their same aged peers. Error analyses indicated that most errors occurred on words relating to educational content areas such as math and geography (e.g., perpendicular, rhombus, peninsula). The participants also had difficulty with low frequency words (e.g., tranquil, slumbering). The participants were successful on items measuring vocabulary items that were more common, especially words they were likely to encounter in their daily lives (e.g., communication, vehicle, exhausted).

The participant's scores for the TACL-R are presented in Table 9. Because the age range for standard scores did not extend beyond 9 years, 11 months, only raw scores are presented. Adults without language impairments would be expected to respond with close to 100% accuracy (Carrow-Woolfolk, 1985). No participant answered all items correctly. The participants exhibited similar error patterns, however Bradley and Douglas made more errors than the other participants. All of the participants had difficulty with possessive forms and all

Table 9
Participant scores for the TACL-R

Participant	Grammatical Morphemes Raw Score (40 max)	Elaborated Sentences Raw Score (40 max)
Anthony	36	34
Leo	37	33
Chad	36	37
Josh	35	33
Carson	36	34
Bradley	30	28
Douglas	34	31
Average	34.9	32.9
SD	2.3	2.8

but Chad had difficulty with embedded clauses. In addition, Bradley and Douglas had difficulty with subordinate clauses. Bradley also had difficulty with verb tenses. All of the participants were successful on items measuring comprehension of prepositions, negatives, interrogatives, and coordinating conjunctions.

Reading Comprehension

The second area evaluated at the activity and participation level was reading comprehension. The participants' performances on the Gray Silent Reading Test (GSRT) are presented in Table 10. The passages in the GSRT ranged from a 1.4 to 12.0 reading level based on the Flesch-Kincaid Readability formula (Wiederholt & Blalock, 2000). Four of the seven participants (i.e., Andrew, Leo, Bradley, Douglas) were unable to complete the test because they achieved ceiling scores on the first story presented. Scores for two of the remaining three participants (i.e., Chad and Carson) were below the range of standard scores given for their age range. Only one participant, Josh achieved a score that could be converted to a standard score. His score of 79 was still more than one standard deviation below the average performance for his age (mean = 100, SD = 15).

Table 10
Participants' performance on the Gray Silent Reading Test

Participant	Raw Score	Standard Score	Percentile Score
Anthony	Unable to complete test		
Leo	Unable to complete test		
Chad	12	<55	<1st
Josh	37	79	8th
Carson	16	<55	<1st
Bradley	Unable to complete test		
Douglas	Unable to complete test		

Anthony, Leo, and Bradley indicated that the material on the GSRT was too difficult for them to read. They completed the single word reading assessment which measured word recognition at pre-primer, primer, and grade 1 levels. Their performance on this task is presented in Table 11. None of the participants read all of the words correctly, however Anthony only missed two of the words presented. Leo and Bradley demonstrated significant difficulty reading single words, performing with less than 70% accuracy.

Table 11
Participants' performance on the single word reading assessment

Participant	Pre-primer	Primer	Grade 1	Total
Anthony	6/7	8/8	9/10	23/25
Leo	6/7	4/8	5/10	15/25
Bradley	5/7	6/8	6/10	17/25

Communicative Interaction

The third area assessed at the activity and participation level was communicative interaction skills. Interactions between the individuals who used AAC and three different communication partners were analyzed with regard to discourse status (e.g., turn-taking patterns), communicative functions, and modes of communication used.

Discourse Status

Turns. Analyses of the participants' interactions with their caregivers, unfamiliar partners, and peers showed wide variation with regard to the number of turns taken by each dyad. The frequency of turns taken is presented in Table 12. Across all samples the total number of turns taken by the dyads ranged from 65-992 with a mean of 389. The participants who used AAC took a mean of 142 turns during interactions with their caregivers (range 33-328), a mean

Table 12

<u>Frequency of turns taken during 20 minute interactions</u>

	Light (1985)		Participant-Caregiver Interaction		Participant-Unfamiliar Partner Interaction		Participant-Peer Interaction	
	Participant	Caregiver	Participant	Caregiver	Participant	Unfamiliar partner	Participant	Peer
Anthony	100	241	316	456	268	470	372	620
Leo	168	309	101	116	45	52	243	299
Chad	105	233	131	161	78	98	54	56
Josh	N/A	N/A	328	346	434	433	478	496
Carson	111	256	47	62	74	97	175	199
Bradley	83	355	40	75	125	351	62*	126*
Douglas	121	280	33	50	20	45	56	87
Mean	115	337	142	181	149	221	206	269
SD	29	157	128	158	150	189	168	216

Note: N/A= data not available, *=data extrapolated from 10 minute sample

of 149 turns with the unfamiliar partner (range 20-434), and a mean of 206 turns with their peers (range 56-478). However, due to the large variation across dyads, the means were only representative for one dyad.

Part of the reason for the wide variation across samples was due to the large number of procedural plays taken by some dyads. Procedural plays are turns that are dedicated to the co-construction of the message of the participant using AAC (Light, Collier & Parnes, 1985a). For example, two participants (i.e., Anthony and Bradley) used partner-assisted scanning to access their communication systems and construct their messages. Each "offer" made by the communication partner to construct the message (e.g., "is it _____?) and the corresponding responses by the individuals using AAC (e.g., "yes") were coded as procedural plays. Josh and his partners also had a high number of procedural plays, however they were of a different nature than Anthony and Bradley. Josh used direct selection to access his communication board. He spelled his messages letter by letter and his communication partners "called out" his selections as he built his responses. Josh's selections of individual letters and his partner's voicing of these selections were coded as procedural plays.

Table 13 presents the frequency of turns taken without procedural plays. In other words, only turns that relayed communicative content related to the conversation were counted. When procedural plays were eliminated, there was still variation across the dyads, however it was not as large. The participants took a mean of 72 communicative turns during interactions with their caregivers (range 16-131), a mean of 57 communicative turns with the unfamiliar partner (range 20-78), and a mean of 109 communicative turns with their peers (range 46-243). Four of the seven participants took the most turns during interactions with their peers, two of the seven took the most turns during interactions with their caregivers, and only one participant took the most

Table 13

Frequency of turns taken during 20 minute interactions without procedural plays

	Light (1985)		Participant-Caregiver Interaction		Participant-Unfamiliar Partner Interaction		Participant-Peer Interaction	
	Participant	Caregiver	Participant	Caregiver	Participant	Unfamiliar partner	Participant	Peer
Anthony	93	207	75	110	54	63	99	113
Leo	144	268	101	116	45	52	243	299
Chad	105	228	131	144	78	98	54	57
Josh	N/A	N/A	102	117	71	74	91	107
Carson	111	249	47	62	74	95	175	199
Bradley	83	319	16	27	54	103	46*	68*
Douglas	121	273	33	50	20	45	56	87
Mean	111	257	72	89	57	76	109	133
SD	23	39	42	43	20	24	74	92

Note: N/A= data not available, *=data extrapolated from 10 minute sample

turns with the unfamiliar partner. All of the caregivers took fewer turns in the current interactions than they did when the participants were preschoolers. Similarly, most of the participants (i.e., all but Chad) took fewer turns during their interactions with their caregivers than they did as preschoolers.

Reciprocity. Table 14 presents the comparisons of the participant interactions from the current study with those 15 years earlier when the participants were preschoolers (data from Light, 1985). Analyses of the participants' interactions with their caregivers, unfamiliar partners and peers showed that in all interactions the participants who use AAC took fewer turns than their speaking partners. However, most of the participants were far from "passive" in their interactions. They fulfilled a mean of 43% of the turns in the interactions with their caregivers (range 37% - 48%), a mean of 42% of the turns in the interactions with the unfamiliar partners (range 31% - 49%), and a mean of 45% of the turns in the interactions with their peers (range 39%-49%). Four of the participants (i.e., Leo, Chad, Josh, and Carson) approached reciprocity across all communicative partners. Anthony approached reciprocity in his interactions with the unfamiliar partner and his peer. These data demonstrate that the participants were more reciprocal in their interactions as young adults than they were as preschoolers when the caregivers took more than twice as many turns as the participants.

Fulfilled turn opportunities. Table 15 presents the proportion of communicative turn opportunities that were fulfilled by the participants during interactions with their caregivers, the unfamiliar partner, and the peer. The participants fulfilled an average of 77% of their turn opportunities with their caregivers (range 62%-89%), 73% of their turn

Table 14

Distribution of communicative turns between augmented speakers and their partners

	Light (1985)		Participant-Caregiver Interaction		Participant-Unfamiliar Partner Interaction		Participant-Peer Interaction	
	Participant	Caregiver	Participant	Caregiver	Participant	Unfamiliar partner	Participant	Peer
Anthony	.31	.69	.41	.59	.46	.54	.47	.53
Leo	.35	.65	.47	.53	.46	.54	.45	.55
Chad	.31	.68	.48	.52	.44	.56	.49	.51
Josh	N/A	N/A	.47	.53	.49	.51	.46	.54
Carson	.31	.69	.43	.57	.44	.56	.47	.53
Bradley	.21	.79	.37	.63	.34	.66	.40*	.60*
Douglas	.32	.68	.40	.60	.31	.69	.39	.61
Mean	.30	.70	.43	.57	.42	.58	.45	.55
SD	.05	.05	.04	.04	.07	.07	.04	.04

Note: N/A= data not available, *=data based on 10 minute sample

Table 15
<u>Proportion of communicative turns fulfilled by the participants</u>

	Light (1985)	Participant-Caregiver Interaction	Participant-Unfamiliar Partner Interaction	Participant-Peer Interaction
Anthony	.61	.74	.83	.69
Leo	.53	.86	.82	.82
Chad	.49	.89	.76	.90
Josh	N/A	.86	.96	.84
Carson	.46	.76	.76	.88
Bradley	.29	.62	.52	.64*
Douglas	.51	.67	.44	.63
Mean	.48	.77	.73	.77
SD	.11	.10	.18	.12

Note: N/A= data not available, * based on 10 minute sample opportunities with the unfamiliar partner (range 44%-96%), and 77% of their turn opportunities with their peers (range 63%-90%). For the group, this is a significant increase in the rate of turn fulfillment from the original (Light, 1985) study when the participants fulfilled an average of 48% of their turn opportunities (range 29%-61%). These data suggest that even though the participants took fewer turns in the current study, they were more active in the conversation by fulfilling more of their opportunities to participate. The greatest variation regarding the proportion of turns fulfilled was with the unfamiliar partner. Two participants, Bradley and Douglas, struggled to fulfill their turn opportunities with the unfamiliar partner, forfeiting 48% and 56% of their communicative turn opportunities respectively. Both participants demonstrated higher rates of turn fulfillment with familiar partners, suggesting that the low rate of participation may have been due to a lack of social experience and difficulty interacting with unfamiliar people.

During interactions with their caregivers, the participants fulfilled an average of 86% of their obligatory turns (range 65%-95%) and an average of 61% of their non-obligatory turns (range 32% - 84%). This is a significant increase from when the participants were preschoolers when they fulfilled an average of 56% of their obligatory turns and 28% of their non-obligatory turns (data from Light, Collier, & Parnes, 1985 a). In the present study, the participants tended to fulfill most of their non-obligatory turns with "low cost" turns, such as nodding to indicate confirmation of the partner's message.

Initiations. Table 16 presents the comparisons of the participant initiations from the current study with those from when the participants were preschoolers (data from Light, 1985). In the current study, the rates of initiation were lower for both the participants as young adults and their partners. In the participant-caregiver dyads, the participants initiated a mean of 3.7

Table 16

Frequency of initiations for participants and their communication partners

	Light (1985)		Participant-Caregiver Interaction		Participant-Unfamiliar Partner Interaction		Participant-Peer Interaction	
	Participant	Caregiver	Participant	Caregiver	Participant	Unfamiliar Partner	Participant	Peer
Anthony	26	91	5	5	3	1	5	12
Leo	13	91	12	10	5	1	9	17
Chad	13	80	1	9	4	2	3	8
Josh	N/A	N/A	3	17	1	2	6	10
Carson	9	90	1	3	1	7	5	19
Bradley	1	166	1	1	2	3	2*	18*
Douglas	15	118	3	9	2	4	3	10
Mean	12.8	106.0	3.7	7.7	2.6	2.9	4.7	13.4
SD	8.2	32.0	4.0	5.3	1.5	2.1	2.4	4.5

Note: N/A= data not available, *=data extrapolated from 10 minute sample

topics (range 1-12) and the caregivers initiated a mean of 7.7 topics (range 1-17). During interactions with an unfamiliar partner, the participants initiated a mean of 2.6 topics (range 1-5) and the unfamiliar partner initiated a mean of 2.9 topics (range 1-7). In the interactions with a peer, the participants initiated a mean of 4.7 topics (range 2-9) and the peers initiated a mean of 13.4 topics (range 8-19). Overall, the rates of initiation for both the participants and their partners decreased significantly from the original study (Light, 1985) when the participants were preschoolers. During the current study, the dyads tended to establish a topic of conversation and they maintained that topic over a number of turns. The partners still initiated two to three times as often as the participants, however the disparity was not as large as in the original study. In the original study, the caregivers initiated more than 8 times as often as the participants.

Communicative Functions

Table 17 presents the proportion of communicative functions used by the participants during interactions with their caregivers. These data do not include turns coded as procedural plays. Overall, an average of 55% of the participants turns were spent issuing confirmations/denials (range 6%-75%). This is an increase from when the participants were preschoolers, when an average of 41% of their turns were confirmations or denials (range 19%-58%). However, as discussed earlier, it is suspected that the rise in confirmations and denials is related to the proportion of non-obligatory turns fulfilled, however additional analysis is required to confirm this hypothesis.

On average 30% of the participants' turns were provisions of information (range 12%-75%). This is similar to the data gathered when they were preschoolers at which time 23% of their turns were provisions of information (range 1%-40%). As in the original study, the participants rarely requested information from their caregivers (mean=1%, range 0%-6%), while their caregivers requested information from the participants on an average of 43% of their turns. The participants' low rate of requesting information from their partners, was not unique to the interactions with their caregivers.

The participants requested information from the unfamiliar partner on an average of 4% of their turns (range 0-10%) and from their peers on an average of 1% of their turns (range 0%-3%). Given that the purpose of the interaction with the unfamiliar partner was to "get to know each other", the low rate of requesting information is noteworthy. During interactions of this type it would be expected that a number of requests for information would be issued. All of the participants demonstrated the ability to request information in at least one of their interactions. However, they did not use the function frequently.

Mode of Communication

Data of the current study as well as the original study when the participants were preschoolers (Light, et al., 1985c) indicate that communication for individuals who use AAC is a multi-modal process. The proportion of modes used by the participants during interactions with their caregivers is presented in Table 18. In the current study, the participants used aided AAC techniques (i.e., communication board or VOCA) for a mean of 35% of their turns (range 4%-88%). This was an increase in frequency from when the participants were preschoolers and used aided AAC (i.e., communication board) for an average of 23% of their turns (range 8%-33%) (data from Light, 1985). The participants' use of gesture and eye pointing in the current study was similar to that when they were preschoolers. In the current study, they used gestures for a mean of 45% of their turns (range 6%-64%) and eye pointing for a mean of 5% of their turns (range 0%-19%). As preschoolers, the participants used gestures for an average of 48% percent of their turns (range 41%-61%) and eye pointing for an average of 6% of their turns (range 0%-18%) (data from Light, 1985). The participants decreased in their use of vocalizations from when they were preschoolers. All of the participants, for whom preschool data is available, decreased in their frequency of vocalizations. The group mean decreased as well. The participants used vocalizations for a mean of 20% of their turns (range 3%-61%) in the current study, and for a mean of 35% of their turns (range 18%-48%) as preschoolers (data from Light, 1985).

Table 18
Proportion of modes used by participants during interaction with their caregivers

	Aided AAC*	Gesture	Eye pointing	Vocalization
Anthony	.37	.45	.19	.29
Leo	.04	.81	.13	.03
Chad	.36	.64	.00	.03
Josh	.25	.14	.01	.61
Carson	.32	.43	.02	.26
Bradley	.88	.06	.00	.06
Douglas	.24	.61	.03	.12
Mean	.35	.45	.05	.20
SD	.26	.27	.07	.21

Note: Proportions will not total 1.00 since some turns utilized more than one mode
* Communication board for Anthony and Josh, all others used voice output communication aids

The frequency of communication mode used varied somewhat across partners for the participants. On average, the group used aided means less often during interactions with their peers (mean 21%, range 2%-66%) and the unfamiliar partner (mean 24%, range 11%-35%) than they did during interactions with their caregivers (mean 35%, range 4%-88%). However, the group increased their use of gestures during interactions with their peers (mean 62%, range 24%-82%) and the unfamiliar partner (mean 60%, range 10%-83%) from the interactions with their caregivers (mean 45%, range 6%-81%). These group trends are representative of most of the participants except Leo whose frequency of mode use was consistent across all three partners.

Functional Communication

The next area assessed at the activities and participation level was functional communication. The communicative independence scores from the ASHA-FACS are presented Table 19. Communication independence was defined as the need for prompting and/or assistance to effectively communicate in the situations presented for each domain (Frattali, et al., 1995). The participants' scores of communication independence for social communication ranged from 5.1 to 7.0 on a 7-point scale. Two participants (i.e., Leo, Douglas) scored in the 5 point range which indicated that they needed minimal to moderate assistance. The other 5 participants scored between 6 and 7 which indicated that they required minimal (rating of 6) to no assistance (rating of 7). Scores for communication of basic needs ranged from 6.1-7.0, again indicating that the participants required little, if any assistance to communicate messages to convey their basic needs. The section of reading, writing, and number concepts measured items

Table 19
Communication independence scores on the ASHA FACS

	Social Communication	Communication of Basic Needs	Reading, Writing, & Number Concepts	Daily Planning
Anthony	6.2	6.1	4.1	5.3
Leo	5.3	6.1	3.8	N/A
Chad	7.0	7.0	7.0	7.0
Josh	6.9	6.1	7.0	5.5
Carson	6.7	6.1	6.3	6.8
Bradley	6.0	6.1	5.2	5.8
Douglas	5.1	6.1	6.8	N/A

such as understanding basic signs (e.g., stop sign), typing one's name, and understanding basic money concepts. The participants' scores in this domain ranged from 3.8 (requiring moderate assistance) to 7.0 (does independently). The area of daily planning measured items including telling time, using a calendar, and reading a map. Leo and Douglas did not partake in enough of these activities to be able to score this domain for them. For the other participants, their scores ranged from 5.3 (does with minimal to moderate assistance) to 7.0 (does independently).

The results of the qualitative aspects of communication as measured by the ASHA-FACS are presented in Table 20. These areas were scored on a 5-point scale. The scales for adequacy, appropriateness, and promptness of communication ranged from 1 = never (e.g., communication is never adequate) to 5 = always (e.g., communication is always adequate). Communication sharing was rated on how equally the individual and partner shared the communication burden during interactions. The scale ranged from 1 = partner carries all of the communication burden to 5 = individual and partner share equally in communication.

Table 20
Qualitative dimension of communication scores on the ASHA FACS

Participant	Adequacy	Appropriateness	Promptness	Communication Sharing
Anthony	3.5	4.3	1.0	3.8
Leo	4.0	4.8	1.8	2.5
Chad	5.0	5.0	4.3	5.0
Josh	5.0	5.0	3.3	5.0
Carson	4.6	4.4	3.3	4.0
Bradley	3.5	3.0	1.3	2.0
Douglas	4.3	4.0	2.4	2.0

The adequacy domain measured the participants' ability to understand and convey the gist of messages. The participants' scores ranged from 3.5 to 5.0. Scores of 5 indicated that interaction (communication sharing). In other words, communication sharing measures how demanding it is for a partner to communicate with the participant. Scores for communication sharing ranged from 2 (i.e., partner carries almost all of the communication burden) to 5 (i.e., individual and partner share equally in communication). This was an area of difficulty for three of the participants (i.e., Leo, Bradley, Douglas). These participants often relied on their partners to determine the course of the interaction. They also were more limited in the generative capacity of their AAC systems, thus often relying on their partners to guess what they were trying to communicate.

Educational and Vocational Achievement

The next area assessed at the activity and participation level was educational and vocational achievement. The educational placement of the participants at the time of the study was as follows: 2 participants were in high school, 2 attended college, 2 attended adult day programs with a life-skills focus, and 1 did not attend any educational or vocational training. The latter participant had attended high school until he dropped out in the tenth grade. He reported that he had been frustrated and bored with his educational program and elected to stop attending school. Table 21 illustrates the academic placements for the participants throughout their lives.

Chad and Carson had graduated from high school and both attended college programs. At the time of the study, Chad was studying business and Carson was taking computer courses and courses to upgrade his literacy skills. Bradley and Douglas both completed high school in special education programs and were attending life skills classes at day activity programs. Josh and Anthony each had one year left of high school. Josh was an academically competitive student. Anthony completed courses in the regular curriculum with modifications (i.e., reduced work load) and accommodations for his literacy level (e.g., aide read class material aloud to him).

Table 21
Academic placements of participants

	Elementary (Kindergarten –grade 8)	Secondary (grades 9-12)
Separate special education class	Anthony, Leo, Douglas	Bradley, Douglas
Mainstreamed part-time		Anthony, Leo*
Full Inclusion	Chad, Carson, Josh, Bradley	Chad, Carson, Josh

* until 10th grade

None of the participants had yet begun to seek full-time employment. Three participants (i.e., Chad, Josh, and Carson) had goals of obtaining future employment. The other four participants had no plans for future employment or vocational training. Two participants were not interested in obtaining jobs (i.e., Bradley and Douglas) and two participants (i.e., Anthony and Leo) wanted jobs, but did not think that obtaining employment was attainable.

The participants who had vocational goals also had had previous employment experience through part-time and volunteer jobs. Carson did computer work on a volunteer basis during his summer vacations. He entered data into databases and updated the web pages for his town's web site. Chad had held a summer job delivering newspapers in his neighborhood when he was in high school.

When he was seventeen, Josh had a summer internship through a competitive program for high school students to gain experience in the business world. Josh was the only student with a disability of the twelve students selected for the program. During his internship, Josh worked for 20 hours per week in the corporate communications group of a large metropolitan bank. He was paid to write and edit articles for the staff newsletter. In addition to his internship, Josh had also worked as a speaker. Josh gave presentations to groups (e.g., teachers, students, therapists) about inclusion and his experiences as an individual with significant speech and physical disabilities. Josh reported that he gave approximately three lectures per year and was paid for his speaking engagements.

Self-Determination

The sixth area evaluated in the activities and participation domain was self-determination. Self-determination refers to the amount of control individuals have over their lives. This is important to measure when assessing individuals participation in society. The participants' raw scores, percentile scores and percent positive responses on The Arc's Self-determination Scale are presented in Table 22. Percentile scores are presented as a guideline for comparison with other students with disabilities, however the authors of the scale do not make any assumptions about the "normal" or "expected" amount of self-determination (Wehmeyer & Kelchner, 1995, p. 5). The participants' scores ranged from the 9th percentile to the 92nd percentile when compared to the norms of adolescents receiving special education services. The "percent

Table 22
Participants' overall scores on the Arc's Self-determination Scale

	Raw Score	Percentile Score	Percent positive responses
Anthony	92	35th	62
Leo	101	53rd	68
Chad	122	92nd	82
Josh	116	84th	78
Carson	113	79th	76
Bradley	97	44th	66
Douglas	70	9th	47

positive responses" score indicates how many of the participants' responses promoted self-determined behavior. The percent positive responses ranged from 47% to 82%.

Three of the participants (i.e., Chad, Josh, Carson) scored above the 50th percentile and over 75% positive responses indicating strengths in self-determination. Evaluation of the participants' scores by domain revealed individual areas of strength and challenge. The participants' scores on the autonomy domain ranged from 47%-80% positive responses. These results indicate that choice making was an area of moderate strengths for all of the participants. Psychological empowerment and self-realization were areas of strength for three participants (i.e., Chad, Josh, Carson) who all scored above 93% positive responses. The other participants' scores in these areas were more moderate, ranging from 60%-87%. Four participants (i.e., Andrew, Chad, Josh, Carson) demonstrated strengths in problem solving, all scoring 83% positive responses. However, the area of problem solving was a significant challenge for Bradley and Douglas who scored 33% and 22% respectively. The area of goal setting was a strength for Josh, who scored 100% on this section. However, the other participants struggled in this area with scores ranging from 22%-67%.

Quality of Life

The final area assessed at the activity and participation level was quality of life. The result of AAC interventions should be an improved quality of life (Blackstone & Pressman, 1995). Therefore, quality of life is an important area to measure when evaluating outcomes. Scores on the Quality of Life Profile were derived from a combination of importance and satisfaction scores. The possible range of scores was from –10 to +10. Scores of 5 or higher were described as contributing positively to quality of life. Scores between 0 and 5 were described as areas that contributed some quality, but might be enhanced. Negative scores reflected areas that detracted from quality of life. Scores for each section were averaged to calculate the overall quality of life score. The participants' scores on the quality of life measure are presented in Table 23. The table lists the scores for each section as well as the overall quality of life score for each participant. The overall quality of life scores for the participants ranged from 1.8 – 8.0. All participants scored positively on the measure, which indicated positive aspects to their quality of life. However, there was variation across participants as to how each section contributed to their overall score. For example, the section that evaluated "the daily things I do" contributed positively to quality of life (i.e., yielded scores above 5) for 3 participants (i.e., Leo, Chad, Carson), however this section also detracted from quality of life (i.e., yielded scores at or below 0) for 3 other participants (i.e., Josh, Bradley, Douglas) and was their lowest scoring section. The other participants differed with regard to which sections yielded their lowest scores. Two participants (i.e., Anthony, Carson) scored lowest on the section measuring "the things I do to improve myself", Chad scored lowest on the section measuring "my access to resources", and Leo scored lowest on the section measuring "my thoughts and feelings".

The participants also differed with regard to which sections yielded the highest scores, and therefore contributed the most to their quality of life. Three participants (i.e., Anthony, Josh, Carson) scored highest on the section measuring "where I live and spend my time", two participants (i.e., Leo, Chad) scored highest on the section measuring "the things I do to improve myself", Bradley scored highest on the section measuring "my beliefs and values", and Douglas scored highest on the "people around me" section.

Table 23
Participants' scores for the Quality of Life Profile

	Anthony	Leo	Chad	Josh	Carson	Bradley	Douglas
My body and health	4.0	4.4	7.5	4.1	9.4	3.9	-0.8
My thoughts and feelings	4.8	1.6	10.0	5.4	6.8	3.2	-0.4
My beliefs attitudes and values	3.9	6.4	5.4	6.6	8.0	6.7	1.7
Where I live and spend my time	8.6	2.9	6.4	8.1	10.0	6.5	1.1
The people around me	5.1	4.7	7.5	5.8	8.9	2.8	7.7
My access to resources	2.0	4.3	0.1	4.4	9.1	2.1	2.2
The daily things I do	1.3	5.7	8.0	-0.3	7.2	0.0	-2.5
The things I do for enjoyment	1.4	7.3	9.3	2.5	8.9	2.7	3.3
The things I do to improve myself	0.8	8.6	10.0	4.4	3.5	3.4	3.6
Overall Quality of Life Score	3.5	5.1	7.1	4.5	8.0	3.5	1.8

Contextual Factors

The second domain assessed was the contextual factors that may have contributed to the outcomes measured. Qualitative interviews were conducted with the participants, families, and professionals. The transcripts from the interviews were analyzed for themes and sub-themes. The final coding themes included: barriers to positive outcomes, supports to positive outcomes, and recommendations to professionals. Table 24 presents a summary of the sub-themes and examples of issues discussed by the participants for the first two themes: barriers to positive outcomes and supports to positive outcomes.

Barriers to Positive Outcomes

Five sub-themes were identified for the theme addressing barriers to positive outcomes: attitude barriers, cultural barriers, technological barriers, and service delivery limitations.

Attitude barriers. The first sub-theme addressed the attitudinal barriers encountered by the participants, including attitudes of teachers, professionals, peers, family members, and society in general. Participants encountered professionals who had negative attitudes toward AAC and toward the individuals themselves. For example, Josh's mother commented, "We've encountered a lot of speech paths [speech-language pathologists] along the way who have thought that augmentative communication is not part of their profession." Carson's mother also commented, "We had one teacher that openly said he didn't want him [Carson] in his class." Participants also discussed the difficulties encountered making friends due to the attitudes of peers. Bradley's mother stated, "When you hit high school, they're [students] not very compassionate." One of the speech-language pathologists currently working with Bradley discussed how family attitudes impacted expectations of Bradley, thus limiting his opportunities: "He [Bradley's father] sees Bradley as a very disabled individual and I think it's okay with him

Table 24
Coding themes, sub-themes, and examples of issues discussed by participants and facilitators

Themes	Sub-Themes	Examples of issues discussed by participants
Barriers to positive outcomes	Attitude barriers	- negative attitudes of professionals - negative attitudes of non-disabled peers - low expectations of family members
	Cultural barriers	- difficulties creating communication systems for multiple languages - lack of understanding of cultural issues by professionals
	Technological barriers	- limitations of technology - difficulty accessing technology - technical breakdowns
	Service delivery limitations	- lack of availability of services - limited knowledge of professionals - lack of collaboration between professionals - limited focus of goals
Supports to positive outcomes	Community support	- supportive, inclusive community
	Parent & family support	- strong parental advocacy - expectations of success - involvement in intervention
	Personal characteristics	- patience - persistence/determination - social nature
	Services	- competent and knowledgeable professionals - training for families, facilitators, and teachers - effective communication between professionals, family, school

that he's with individuals who are maybe a little bit lower functioning than Bradley". Societal attitudes were discussed as a barrier to interacting with individuals in the community. Josh's mother summed up some of the societal attitude barriers saying, "When you're a cute disabled kid, the world stops and listens more. As you become an adult, they're not as patient."

Cultural Barriers. Cultural issues were identified as barriers by Leo's and Chad's families. Two areas addressing cultural issues were identified: the difficulty of having an AAC system that addressed two languages and the lack of cultural empathy from professionals. Leo's parents spoke Portuguese and very little English. This posed many difficulties when developing a communication system for Leo as evidenced by the following quote from Leo's sister.

> The hardest thing for us has been my parents, the language barrier. They're [parents] still not able to read an English word.... they [professionals] got rid of that [Bliss board] and they started introducing him to words, but the thing is my parents didn't understand what the word meant because it was in English – so that was it.

Chad and his mother described their frustration regarding the difficulty they had finding a VOCA that could switch easily between two languages. Chad's family was French-Canadian and spoke French in the home. He also attended French schools through high school. He lived in a bilingual community and needed to be able to switch easily between French and English. His mother stated, "We had to wait a long, long time before we got a machine." Chad's first VOCA (i.e., the PolyCom PolyTalk) allowed him to have voice output in both English and French. However, the device was not reliable, it needed frequent repairs, and it finally stopped working altogether. The PolyTalk is no longer manufactured and none of Chad's VOCAs since have allowed him to switch easily between French and English voice output.

The other area impacted by culture was the relationship between the families and professionals. Chad's mother expressed frustrations regarding a lack of cultural awareness from professionals stating, "[services] were geared toward English-speaking people a lot more...I don't know if it's the fact that we were French, but to me that's how I projected it." She also reported that the family's needs were not addressed and that she thought the professionals did not fully understand Chad's needs as a bilingual person.

> They kept telling us that they could give us an English one [VOCA], but it wasn't giving us what Chad needed...when you go to French school here, you're not even supposed to speak English except for English classes...It's the same as if you were going to an English school. It wouldn't be proper to speak French when most people speak English, right? Well, it's the same with French.

Technological barriers. The sub-theme of technological barriers included technological limitations, difficulties accessing technology, and technical breakdowns. Many participants discussed their frustrations regarding the slow rate of communicating using AAC and expressed the need for technology that was faster and easier to access. Carson and his mother discussed the limitations of the computer software that he used and stated that it "doesn't go as fast as his thoughts are going." Access to technology was also discussed by many participants, families, and professionals. For example, Anthony's family discussed the difficulties Anthony has had trying to access communication and computer systems. His father commented, "It was extremely hard work [accessing the computer-based system]. The return on the investment, it just wasn't worth it."

The reliability of technology was also discussed. For example, Chad's mother talked about the frustration of frequent technological breakdowns.

> The only problem with it was that it was always breaking, [you] send it away to be fixed and you are without the machine for six to seven months..... The most frustrating part was not having a piece of equipment that you had had before. It was like taking a step back.

Service Delivery Limitations. The most frequently discussed area regarding barriers to successful outcomes were limitations of the services provided. Four areas within this sub-theme were discussed: lack of availability of services, limited knowledge of professionals, lack of collaboration among professionals, and limited focus of goals.

The discussions surrounding the lack of services reflected two areas of concern: the lack of services due to geographic location and the lack of services for adults. For example, Douglas' foster mother said, "Douglas lost out because we were in a small service community." Bradley's mother discussed the lack of adult services saying: "when they're younger there's a lot of services and then as they get older it just drops off."

The limited expertise of local (i.e., school-based) personnel was discussed by many participants. For example, when discussing Leo's transition to high school, his sister stated, "I don't think the teachers were prepared [to have Leo in their classes]." The limited knowledge and lack of preparation discussed is related, in part, to the next area discussed, the lack of collaboration between professionals because effective collaboration can be a method to promote the sharing of expertise among professionals. The lack of collaboration between professionals was the most frequently discussed barrier to positive outcomes and was mentioned by all of the families. The following comments by Josh's mother summarize the points raised by the families.

> ... a very negative experience is the lack of collaboration....each sector of professionals believes they can do it on their own....In the early years we had about 40 people involved with Josh from physicians to school personnel and they wouldn't talk to each other....There are lots of good skills around the table and lots of good problem solving skills, but because of professional ideology and people not knowing how to work together, the whole process is diminished.

Another frequently discussed area within the sub-theme of service limitations was the limited focus of intervention. The participants and their families commented that, at times, intervention was focused too specifically on technology or face-to-face communication, to the exclusion of other goals. For example, Josh's mother discussed his difficulties with writing by saying, "I think there has been not enough attention paid by the teachers along the way so now we are in the dilemma where it's a real nightmare to kind of flush everything out." Similarly, Leo's sister mentioned the areas of grammar and spelling, "his grammar and spelling would've been better today if they had worked on that." Andrew's mother discussed the importance of striking a balance between teaching operational skills and teaching other language and academic skills.

> I think a number of years of actual school learning was lost at the sake of them saying, "we have to find the proper communication system for him." These teachers, their whole focus was on communication. My feeling was, "well he could be learning as he's communicating as well." I understand that communication is a big part of it, but it shouldn't be at the expense of other things.

Josh's mother also warned about focusing too much on technology. "Others, like teachers and other professionals, thought it [technology] was sort of the answer to all of Josh's problems in terms of communication. And it really is a distracter that way." Josh summed up the issue with the following statement, "Technology is awesome, but it doesn't solve everything."

Supports to Positive Outcomes

In addition to the barriers discussed, many supports to positive outcomes were identified by the participants and their facilitators. The sub-themes identified for supports to positive outcomes included: environmental supports, parent and family supports, personal attributes, and AAC services.

Community supports. The first sub-theme addressed the supports provided by friends and communities. For example, Carson's mother described how their town facilitated Carson's inclusion in the community, "Everyone looks out for him. It's a small town,.... it's more of an inclusion." When asked what factors contributed to his communication skills, Josh reported that his friends contributed to his positive outcomes by facilitating his inclusion and social participation. A similar sentiment was shared by Dallas' former foster mother: "He's with people that want to talk to him, that accept him for where he's at."

Parent and family supports. The second sub-theme of factors that contributed to positive outcomes related to parent and family supports. The supports identified included strong parental advocacy, expectations of success, and family involvement in intervention. Many families related stories that indicated the participants' parents acted as strong advocates for their children. Parents advocated for services, educational inclusion, and equal participation for their children. For example Chad's mother described how she lobbied the local school board to make Chad's school accessible. She remarked that the school board thought if they ignored her long enough that she would drop the issue. However, she continued to advocate for her son and was eventually successful.

Another way in which families supported the participants was with their expectations of success. Josh's, Chad's, and Carson's mothers discussed how they had high expectations that their children would become competent communicators and competitive students. These families also described how their support and involvement helped their children develop their communication skills. For example, Chad credited much of his success to his mother. He stated, "She teached [sic] me to use my voice [VOCA]." His mother added, "I pushed him to use it [VOCA] more and more...I pushed him to be more independent." An occupational therapist who had worked with Josh attributed Josh's positive outcomes to his family who provided many opportunities for him to communicate and to participate in the same activities as his typically developing peers.

The final way in which families supported the participants was through their involvement in intervention. Many parents took an active role in coordinating and implementing services for their children. A professional who has worked with Josh stated, "His parents have coordinated the team and that's great because they know the players more than anybody. They have been able to help us understand that we needed to be part of that big team." The same professional commented on his mother's implementation of services: "way back, his mother was already making his communication displays." This same "ownership" of intervention was reflected in the following quote from Douglas' former foster mother: "I realized there were things I could be doing that [the professionals] hadn't suggested and I didn't call and ask permission. I did it because I knew it was best for him."

Personal characteristics. Personal characteristics of the participants were identified as the third sub-theme contributing to positive outcomes. The characteristics mentioned by the participants, their families, and professionals that contributed to the participants' success included determination, high expectations, patience, flexibility, a sense of humor, sociability, hard work, and intelligence.

Services. The final sub-theme that was identified to contribute to positive outcomes was the services that the participants' received. Specific topics within this sub-theme included competent and knowledgeable professionals; training for families and teachers; and effective communication between professionals, family, and school.

The participants and their families had positive things to say about most of the augmentative communication professionals who had worked with them throughout the years. For example, Bradley's mother said, "He's always had really good teams working with him." Douglas' former foster mother commented: "They've [augmentative communication professionals] always listened to what we've said" Josh's mother also described their positive experiences with professionals: "[We've had] some very dedicated augmentative communication professionals that had a vision and then had incredible dedication and commitment to finding how he was going to communicate"

Training for families and teachers was also identified as a positive aspect of the AAC services the participants received. Bradley's mother stated, "We've had a lot of training." One of the speech-language pathologists who worked with Bradley remarked further, "Training, lot's of training. We've spend hours and hours with that family making sure that they felt comfortable with the technology." Carson's mother described how training led to improved communication between AAC specialists and the teachers at Carson's school.

> [The AAC specialists] would come out about every year to meet and talk to his new teachers and try to explain what they were trying to do...and then that kind of opened a door so that there could be a direct communication between someone at the center and the teachers.

The supports and barriers identified addressed issues regarding communities and families, however issues surrounding intervention and service delivery were the most frequently discussed. As a result, the participants and their facilitators had many recommendations for professionals working with individuals with severe speech and physical disabilities.

Recommendations to Professionals

The third theme of the data was recommendations to professionals. The sub-themes of these recommendations were attitudes, services, and technology. The coding themes and examples of recommendations are presented in Table 25.

Attitudes. The first sub-theme of recommendations addressed professionals' attitudes. The participants and their families stressed that professionals needed to be patient, open-minded, and willing to try new things. For example Josh stated, "The most important qualities are easy-going and open minded." Families also discussed the importance of respect and empathy for the individual and their family. Douglas' former foster mother commented, "I deal better if people treat me like I'm not an idiot. Parents aren't stupid on the whole." The importance of taking the perspective of the individual who uses AAC was stressed by Anthony's father. He stated: "You've really got to put yourself in the individual's [who uses AAC] position."

Table 25
Summary of recommendations to professionals to facilitate positive outcomes for individuals who use AAC

Sub-Theme	Recommendations
Attitudes	- Have an open mind - Be patient - Show respect for individuals and their families
Technology	- Remember technology is a tool
Services	- Make collaborative teams work - Understand the individual's family and school environment - Start planning for the future early

Technology. As discussed earlier, the participants and families warned of becoming over-involved with the technology and losing sight of the goal of communication. Andrew's father captured the issue with the following statement, "I understand the technology and I understand how you can get enamored with it but I understand that it's really of no use unless it's functional."

Services. The recommendations to professionals regarding services focused on issues of working in collaborative teams, understanding the individual's environment, and planning for the future. As discussed previously, the inability of teams to work collaboratively was cited as a barrier to positive outcomes. The following comment by Josh's mother stressed the importance of collaboration:

> I think there had to be some better professional respect for each other's opinions. And just to sit down at the table as equals – and we don't play the game of, "You're on my turf." or "Don't tell me how to educate him."

The participants also discussed that professionals needed to understand the individual's environment and remember that every moment of the day can not be dedicated to therapy. Josh's mother stated that in order for AAC professionals to make appropriate recommendations they need to have "a better understanding of the environment where the kids are." Carson's mother stated, "you need to remember that these kids belong to a family...and you can't spend 24 hours a day with one person, it just doesn't work." She also stated that professionals need to make sure that "there's time in there that he just needs to be a kid."

The need to plan for the future was also discussed. Participants discussed that professionals needed to adopt a vision of the future for the individual who uses AAC, plan interventions to achieve that vision, and facilitate the transition for the individual and their family. The following comments by Josh's mother illustrated this issue:

> I think that right from the time that a young person is about 12...we need to start thinking about where they're going to be. Not only is it important for the individual in terms of

their goals but it's also important for the family. To start taking those steps to letting go and starting to take those steps to have a different kind of relationship in terms of being supportive. My relationship with Josh up until the last couple of years is I've been a strong advocate, a coordinator, the person who learns all the information, the person who goes to all of the meetings. My role is changing, and some of it I don't give up as easily and I have to learn to do that....I think that's something that you can bring in - in not a frightening way with families by saying, "Yeah, you know when Josh becomes an adult and lives in the community." You need to start having those discussions earlier rather than later because the actual transition is stressful enough, but if it's done with some certainty and some natural expectations it's a much easier step to take.

Summary of Results

This study has assessed outcomes for a group of individuals who use AAC in a wide range of areas. The main findings from the current study in each of the domains assessed are presented in Table 26.

Table 26
Summary of results

Area	Main Findings
Receptive language	• Participants understood basic vocabulary and many morphological and syntactic structures • Participants had difficulty with comprehension of vocabulary related to specialized educational content and low frequency vocabulary • All participants had difficulty with comprehension of embedded clauses and possessives • Some participants had difficulty with comprehension of subordinate clauses
Reading	• All participants had significant difficulties with reading comprehension • 4/7 participants were unable to independently read and answer questions of paragraph length material written at a 1st grade level

Area	Main Findings
Communicative Interaction Patterns	• There was individual variation across dyads regarding the number of turns taken during communicative interactions • Turn distribution between partners was more equitable than it had been when the participants were preschoolers • During interactions with their caregivers, participants fulfilled most of their obligatory turns and more than 50% of their non-obligatory turns • On average, participants fulfilled 75% of their turn opportunities, however two participants forfeited approximately half of their turn opportunities with the unfamiliar partner • Dyads sustained topics over numerous turn exchanges • On average, 55% of the participants' turns were confirmations or denials and 30% were provisions of information • Participants rarely requested information from partners; partners requested information often • Communication was multi-modal for all participants
Functional Communication	• The participants required minimal to no prompting to communicate in functional situations as measured by the ASHA FACS in the areas of social communication; communication of basic needs; • Communication for 5 participants was determined to be adequate (i.e., they were able to understand and express the gist of messages) and appropriate most of the time • For three participants, a large part of the burden for sustaining interactions was placed on their communication partners
Educational and Vocational Achievement	• 2 participants were attending high school; one was academically competitive and the other was partially included with modifications to the curriculum • 2 participants were attending college • 2 participants were enrolled in adult life skills training programs • 1 participant had dropped out of high school in 10th grade; was not employed or involved in a day program
Self-Determination	• There was individual variation across participants in their levels of self-determination • 3 participants had high levels of self-determination (>75% positive scores) • Problem solving was an area of strength for 4 participants; an area of weakness for 2 • Goal setting was an area of strength for 1 participant; an area of weakness for all others
Quality of Life	• All participants demonstrated a "positive" quality of life (scores ranged from 1.8-8.0) • The participants differed with regard to how the domains evaluated contributed to their quality of life

Area	Main Findings
Contextual factors	• Factors that posed barriers to positive outcomes included: - Attitude barriers - Cultural barriers - Technological barriers - Service delivery limitations (e.g., lack of effective collaboration) • Supports that contributed to positive outcomes included: - Supportive community - Parent and family support - Personal characteristics - Appropriate and high-quality AAC services

SECTION 4: DISCUSSION

This section discusses the results of the study with regard to the literature, suggests the implications of this study to improve practice, and provides directions for future research. In interpreting the results of this study it is important to consider the historical context. The field of AAC is young: it did not begin to emerge as an area of specialization until the 1970s and it was not until the 1980s that a research base was begun (Zangari, Lloyd, & Vicker, 1994). Prior to the emergence of AAC, individuals with severe communication disabilities who were unable to speak were usually institutionalized (Mirenda, 1993; c.f. Sienkiewicz-Mercer & Kaplan, 1989). The participants in this study were born between 1976 and 1980. They were the first generation of individuals to have grown up with AAC services, however the field of AAC was still in its infancy. Since that time, the knowledge base, quality of services, and AAC technologies have developed dramatically (c.f. Zangari, Lloyd & Vicker, 1994).

Receptive Language

The participants' raw scores on the PPVT-R (range 86-128) were similar to those reported for other young adults with cerebral palsy who used AAC (Sutton, 1989). In her study, Sutton (1989) evaluated the expressive language skills of four young adults between the ages of 18 and 29. The PPVT-R scores for those participants ranged from 96-120. In the present study, error analyses indicated that most of the participants' errors occurred on words relating to educational content areas such as math and geography (e.g., perpendicular, rhombus, peninsula). Participants also had difficulty with low frequency words (e.g., tranquil, slumbering). These are the types of vocabulary words that are typically learned in the later stages of language development (i.e., adolescence and beyond) (Paul, 1995). These words are not usually encountered in day-to-day conversation, rather they are more typically learned through academic coursework or through reading material written at middle or high school reading levels (Paul, 1995). The participants' difficulty with these types of vocabulary may be due to a lack of exposure to such vocabulary in academic courses or limited independent reading skills.

Learning new vocabulary is dependent upon experience and input (Blockberger, 1995). Therefore the limitations in receptive vocabulary may be due to limited exposure to such words. As mentioned previously, the items that were missed most frequently were highly specialized vocabulary and low frequency words. These types of vocabulary are more frequently used in written language than face-to-face communication (Westby, 1991). Such words are more likely to be encountered in specific academic courses or through reading. Therefore the difficulties observed may reflect limited literacy skills or lack of exposure to such vocabulary in academic courses. Vocabulary development benefits from reading (Smith, 1992). It has been suggested that the relationship between reading and vocabulary development is reciprocal (Stanovich, 1986). That is, vocabulary development both supports and develops from reading. As a result, individuals with limited vocabularies are in a "Catch-22" situation – experience in reading will help develop vocabulary skills, however advanced vocabulary skills are needed to facilitate independent reading (Stanovich, 1986). Therefore, it is important for individuals who use AAC to have exposure to such language through activities such as shared and supported reading (Cunningham & Allington, 1994). Shared reading is a process in which the individual and a more proficient reader (e.g., teacher, peer tutor) read a text together. The teacher initially takes the responsibility for reading the text, however students take on more of the reading as they becomes more familiar with the text (Cunningham & Allington, 1994). In supported reading, students read as much independently as they can and the teacher provides support when needed (Cunningham & Allington, 1994).

The participants' performance on the TACL-R indicated that they had difficulty understanding sentences containing possession and embedded clauses, and some participants had difficulty understanding subordinate clauses. Studies have shown that some individuals who use AAC have difficulty comprehending syntactic and morphological forms (e.g., Berninger & Gans1986; Blockberger and Johnston, 1998). The relationship between comprehension and production of grammatical forms is unclear (Sutton, 1999). However, difficulty with comprehension may be related to the same factors believed to influence the use of grammatical forms by individuals who use AAC. Many individuals who use AAC do not have means to mark morphological or syntactic structures through their AAC systems. In addition, many individuals use telegraphic messages to increase their rate of communication (Kelford Smith, et al., 1989). These production limitations may influence the development of comprehension skills.

In spite of their below average performance when compared to individuals without disabilities, all participants demonstrated at least basic receptive language skills. This is important to note given the significant speech impairments of all participants. The all developed comprehension skills in light of significant production limitations. These results are also important in light of the fact that languages other than English were primarily spoken in the homes of two participants (i.e., Leo and Chad). These participants had the added challenge of acquiring receptive and expressive skills in the language spoken in their homes as well as in the language spoken in the community in addition to learning to communicate via their AAC systems (Light, 1997).

The receptive language results stress the importance of focusing on comprehension as well as expressive language throughout development. Later developments of language are specific and subtle and not always evident in day-to-day interactions (Paul, 1995). As students progress through the secondary grades, the language demands of the school curriculum increase dramatically (Paul, 1995). Many students who had been "getting by" before, may now require support to perform at the same level. In addition, it has been suggested that receptive language skills contribute to success in reading (Smith, 1992). Therefore, it is important that receptive language skills are evaluated in a comprehensive manner including comprehension of single word vocabulary, morphologic and syntactic structures, and connected language (e.g., paragraph length material) (Roth & Cassatt-James, 1989) and that areas of need are addressed through intervention.

Reading Comprehension

The results of the GSRT and the single word reading assessment indicate that the participants had significant difficulties reading, especially understanding paragraph length written material. These results are similar to those reports in the literature that individuals with cerebral palsy who use AAC underachieve in reading (e.g., Berninger & Gans, 1986).

The participants may have had difficulty with reading for a number of reasons. Becoming a successful reader requires the integration of language and perceptual skills coupled with regular and frequent reading practice (Smith, 1992). The difficulties observed by the participants in this study may be due to problems with the underlying perceptual and language skills required for reading or due to a lack of appropriate practice and instruction.

The participants may have had limitations in the constituent skills of reading such as phonological processing (i.e., using information about the sounds of one's language in processing oral and written language) and underlying language and vocabulary deficits (Smith, 1992). Research has shown that individuals with severe speech and physical impairments often have difficulty with phonological processing (Vandervelden & Siegel, 1999) and phonological processing skills are related to early reading development (Smith, 1992). The participants' vocabulary skills may also have affected their reading ability. As discussed in the section on receptive language, vocabulary limitations are likely to have a detrimental effect on reading comprehension (Smith, 1992).

The difficulties observed may also have been due to a lack of appropriate instruction. Many individuals who use AAC have qualitatively and quantitatively early literacy experiences than their non-disabled peers (Light & Kelford Smith, 1993). Individuals with severe physical disabilities are often unable to manipulate books independently (Light & Kelford Smith, 1993; Smith, 1992) which may result in fewer opportunities to interact with books. In addition, children who use AAC have been observed to be less active than their nondisabled peers during reading activities both at home (Light, Binger & Kelford Smith, 1994) and school (Koppenhaver & Yoder, 1993). It has also been reported that school-aged children with severe disabilities to receive less literacy instruction that their nondisabled peers do (Koppenhaver & Yoder, 1993).

For most of the participants, literacy was not stressed at an early age (see Appendix A). Only one participant, Josh, had literacy goals for intervention prior to entering school. For some participants, independent reading was never an intervention goal. Their literacy goals did not extend beyond training in reading sight words. It is important to note that literacy was not identified as an intervention objective until late elementary school for some participants.

These results have serious implications for the participants' academic achievement. It is clear from these results that the participants were not independently reading at a level sufficient for high school and college material. In order to compensate for their difficulties with reading, the participants who were attending school (i.e., Chad, Josh, and Carson) often had material read aloud to them. The participants reported that they used this strategy mainly to compensate for issues of reading speed and their inability to manipulate books independently. However, it is apparent that this strategy also provides support for their difficulties with reading comprehension.

The results of this study highlight the difficulties that many individuals who use AAC have with reading. The significance of literacy for individuals who use AAC has been recognized in recent years and has initiated research in this area (Koppenhaver, 2000). It is of critical importance to stress the importance of literacy and foster appropriate expectations for individuals who use AAC to become literate (Light & McNaughton, 1993). Researchers and clinicians have identified and developed materials to help promote emergent literacy skills for children who use AAC (e.g., Musselwhite & King-DeBaun, 1997). However emergent skills are only the beginning. Intervention is needed to facilitate the transition from emergent to conventional literacy and developing reading comprehension skills for individuals who use AAC (Koppenhaver, 2000).

Communicative Interaction

Discourse Status

Turn taking. Analysis of the participants' interactions with their caregivers, unfamiliar partners, and peers indicated that most of the participants took fewer turns in their interactions as young men than they did in the 20 minute interactions when they were preschoolers (Light, 1985). This is an interesting result since an increase in the number of turns may have been expected. It is important to note that many of the turns taken in the Light (1985) study were yes/no or telegraphic one concept messages. Although many of the turns in the present study were yes/no responses as well, there were also many turns in the present study that conveyed complex linguistic content and structure, especially by Chad, Josh, and Carson (e.g., "Mark and I went to his house to get on his computer last night.", "I think college is looking good but I don't know if it will help me in the future"). The lack of increase in turn taking observed in the present study may be due to the participants spending greater amounts of time composing their messages. Further analyses of the data are warranted to determine the cause for this change.

When procedural plays were omitted, the caregivers took less than half of the number of turns that they did in the original (Light, 1985) study. The decrease observed in caregiver turns is similar to that reported by Light, Dattilo, English, Gutierrez, and Hartz (1992). In their study, Light, et al. (1992) taught strategies to partners of individuals who use AAC in order to decrease the speaking partners' conversational control and provide greater opportunities for the individuals who used AAC to participate in the interaction. All of the caregivers in the current study received training in strategies to promote interaction with the participants who used AAC. The decrease observed in the number of turns taken by the caregivers allowed the participants using AAC to occupy more conversational space, thus making the distribution of turns across partners more equitable.

Reciprocity. Many studies of interactions between individuals who use AAC and communication partners who use natural speech reported that the interactions were dominated by the partner using natural speech (e.g., Harris, 1982; Müller & Soto, 2000). However, the results from the current study showed that the interactions between the individuals who used AAC and their partners approached reciprocity. These results are similar to those of Light, et. al. (1992) who found that interactions between individuals who used AAC and their partners were more reciprocal after the partners received training in interaction strategies. As discussed earlier, all of the caregivers in the current study received training in strategies to promote interaction with the participants who used AAC and significantly reduced the number of turns that they took. The improved reciprocity of the interactions may also have been due to the participants occupying greater "conversational space" with their turns. As discussed in the previous section, although the participants took fewer turns than they did as preschoolers, many of their turns conveyed complex content. Therefore, the participants occupied more conversations space than if they communicated simple, one-concept messages, thus resulting in more reciprocal interactions.

Fulfilled turn opportunities. The participants fulfilled most of their obligatory turns and over half of their non-obligatory turns. This is a significant increase from when the participants were preschoolers. The participants fulfilled many of their non-obligatory turns by using "low cost" turns such as nodding to confirm their partners' message. These results are similar to the strategies employed in an instructional program designed to teach individuals who used AAC how to take non-obligatory turns (Light, Binger, Bailey & Millar, 1997). In their study, Light et. al. (1997) taught individuals who used AAC to fulfill non-obligatory turn opportunities by using turns that were minimally demanding but communicated to the partner that the AAC user was actively involved and interested in the conversation (e.g., social interjections such as "cool", "yeah", "all right"). The use of these quick, "low cost", social interjections was found to positively influence the communicative competence of the individuals in their study.

Initiations. There are many reports in the literature describing the low rate of initiations issued by individuals who use AAC (e.g., Dalton & Bedrosian, 1989; Müller & Soto, 2000). In these studies, the participants who used AAC demonstrated the ability to initiate topics, however they did not initiate often. Communication partners who used natural speech were observed to initiate up to 97% of the topics during interaction (Müller & Soto, 2000).

During the current study, the participants and their partners shared a communicative focus most of the time. The dyads established a topic and maintained that topic over a number of turns. This is evident by the significant decrease in the number of initiations by the dyads from when the participants were preschoolers. In the original study the dyads initiated over 100 times on average. The caregivers were responsible for most of those initiations. In the current study, the partners only initiated two-three time as often as the participants.

Summary. The results of this study indicate that discourse skills can improve for individuals who use AAC. The participants who used AAC participated more actively during interactions by fulfilling more of their turn opportunities than when they were preschoolers. The interactions were also more reciprocal than when the participants were preschoolers. This improvement seemed to be due to changes in the behavior of both partners: the individuals using AAC fulfilled more of their turn opportunities and their communication partners took fewer turns.

While there was no experimental control to determine what caused these changes, review of the participants clinical files revealed that interaction skills had been intervention goals for the participants and their caregivers (see Appendix A). All of the caregivers, the unfamiliar partner, and most of the peers had been trained in appropriate interaction strategies (e.g., decreasing directiveness, providing opportunities). These strategies have been shown to be effective in changing interaction patterns between individuals who use AAC and their partners (Light, Dattilo, English, Gutierrez & Hartz, 1992). Most of the participants received instruction to provide feedback to their partners, initiate topics of conversation, and develop topics of conversation. These interventions seemed to have contributed to the positive changes observed in the participants' interaction skills.

Communicative Functions

The results of the current study are similar to other research indicating that individuals who use AAC show a restricted range of communicative functions (Light, Collier & Parnes, 1985b; Udwin & Yule, 1991), issue a high number of confirmations and denials (Clarke & Tarplee, 2000), and ask questions infrequently (Dalton & Bedrosian, 1989; Müller & Soto, 2000). The range of communicative functions used by the participants in the current study was similar to that when they were preschoolers. The frequency was also similar, however there was an increase in the number of confirmations and denials issued. As discussed previously, the participants used confirmations and denials to fulfill their non-obligatory turns. Many participants used confirmations as quick, "low cost" turns indicate their interest in their partner and mark their participation in the interaction.

All of the participants demonstrated the ability to request information during at least one of the samples. All of the participants were able to ask questions of their partners, they just did so infrequently. Other studies have also found that individuals who use AAC rarely request information (Müller & Soto, 2000, Udwin & Yule, 1991).

Mode of Communication

The results of the current study as well as when the participants were preschoolers (Light, et al., 1985c) indicate that communicating using AAC is a multi-modal process. Other studies have highlighted the multi-modal nature of communicating via AAC as well (e.g., Smith, 1994). When evaluating the frequency of aided system use, it is important to remember the multi-modal nature of communication for individuals who use AAC. While 35% of turns may seem to be a low rate of device use, it is important to bear in mind that the mode of communication used is usually related to the communicative function expressed (Light, Collier & Parnes, 1985c; Smith, 1994). The principle of response effectiveness states that "people will communicate in the most efficient and effective manner available to them at any given point in time" (Mirenda, 1993, p. 8). Unaided means of communication are more efficient and often the most effective means to convey certain communicative functions such as confirmation/denials (Smith, 1994). However, the range of ideas that many individuals who use aided AAC can communicate by unaided means are often limited. Therefore, aided systems play an important role in the repertoire of modes for individuals who use AAC. Without access to symbolic language, individuals are severely restricted in their ability to participate in interactions (Smith, 1994).

Functional Communication

The ratings of communicative independence on the ASHA FACS indicated that the participants demonstrated functional communication skills in most of the domains measured. Three participants (i.e., Chad, Josh, Carson) showed strengths across all of the domains measured. Two participants (i.e., Anthony, Bradley) showed strengths in communication of basic needs and social communication, however had weaknesses in the reading, writing, and number concepts and daily planning domains. Two participants (i.e., Leo, Douglas) showed strengths in communication of basic needs, yet required more assistance in the other domains.

In the qualitative domains measured all participants showed strengths in regard to the adequacy and appropriateness of their communication. Scores in the promptness domain ranged from 1 (never without delay) to 4.2 (often without delay). Most of the participants scored at the level of 3 (without delay about half of the time). These scores reflect the nature of communicating via AAC. As discussed previously, the participants used a variety of modes during their communicative interactions. When using unaided modes (e.g., gestures, vocalizations), their communication was often prompt. As a result, the ratings reflect the efficiency of the individuals using all of their modes combined.

Educational and Vocational Achievement

The participants who were fully included from elementary school through high school were those who had the most positive educational outcomes. That is, they were academically competitive students. However, it is impossible to determine what was the cause and the effect. Were these students academically competitive because they were successfully included, or were they included successfully because they had strong academic skills? Interviews with the parents and participants (see section on contextual factors) revealed that the parents of these three participants (i.e., Chad, Josh, Carson) had strong beliefs in inclusion. They advocated to have their children fully included in regular education classes and all felt that this was a very important part of their success. These three participants were fully included as evidenced by their social and academic participation (Beukelman & Mirenda, 1998).

The participants who were physically integrated into mainstream classes, but were not actively engaged (as reported by the participants and their families) (i.e., Leo, Bradley) had far less positive academic outcomes. This point is illustrated by Leo's case. He had attended separate schools for children with disabilities from preschool through eighth grade. In this setting, the curriculum was designed to meet his needs. He was academically challenged and enjoyed school. When it was time for him to attend high school, he was integrated into his community school. He physically attended some classes with his typical peers, however there were limited expectations for him to participate academically. Leo reported that he hated high school because he was bored and not challenged. As a result, he dropped out during the tenth grade.

The participants in this study had not yet begun to seek full-time employment. However, four of the seven participants had no plans to seek employment. One of the reasons cited for not pursuing employment was that they did not think it was a realistic goal for them. Obtaining competitive employment is a challenge for individuals with disabilities, especially those who require AAC. Individuals who use AAC need to believe that employment can happen for them (Estrella, 2000). It is important for individuals who use AAC to have role models who have successfully obtained and maintained employment. It is imperative that education prepare students for employment by teaching necessary communication and work skills (Light, Stoltz & McNaughton, 1996). This preparation needs to start early and not just at the time of the transition plan. This fact was stressed by two of the parents in this study who emphasized the importance of having a vision for the future, while planning for and striving toward that future.

Self-Determination

One cannot become self-determined without the opportunity to do so. Self-determination is not a skill acquired only at adolescence, rather it is something that develops throughout childhood and adolescence and into adulthood as individuals have opportunities to make choices, set goals, and solve problems (Doll et al., 1996). The participants in this study demonstrated varying levels of self-determination. All of the participants demonstrated moderate strengths in the area of choice making. Four participants demonstrated strengths in problem solving, however it was also an area of challenge for two participants. Goal setting was an area of challenge for all participants but Josh. Josh's strengths in goal setting are likely due to the fact that his family included him as an active participant in his goal setting and intervention planning from an early age. The literature on self-determination stresses the importance of providing opportunities for individuals to participate in choice making, problems solving, and goal setting from an early age (Doll, et al., 1996; Doss & Hatcher, 1996). It is also important to help individuals set goals and recognize the process of completing steps to reaching their goals (Doll, et al., 1996) while providing support and scaffolding where needed as they are developing these skills (Light & Gulens, 2000).

For individuals who have had difficulty developing goal setting and problems solving skills, they may need to be explicitly taught. The Penn State Mentor Project has been successful teaching individuals who use AAC collaborative problem solving and goal setting skills (Light, et al., 2000). Using the acronym DO IT!, 30 adults who used AAC were taught the steps of effective problem solving and goal setting;

D – Describe the specific problem or goal
O – Outline lots of ways to solve the problem or meet the goal
I – Identify the consequences of each plan and choose the best plan
T – Take action
! – Celebrate success.

Individuals completed a web-based lesson that (a) presented the problem solving strategy, (b) demonstrated the benefits of strategy use, (c) modeled strategy use, (d) checked the learner's knowledge of the strategy steps, (e) provided opportunities for the learner to practice recognizing effective problems solving, (f) provided role play situations in which learners had the opportunity to apply the strategy, and (g) provided feedback regarding their performance. The individuals practiced a variety of role plays until they were proficient at applying the steps. These participants were then assigned as mentors to adolescents and young adults who use AAC. Through this program, adolescents and young adults who use AAC were matched via e-mail with mentors who could provide role models of competent, self-determined adults who can help facilitate the development of problem-solving skills for the protégés.

The area of self-determination is a new area of research. This study is the first to evaluate the self-determination of individuals who use AAC. Self-determination is a critical outcome of education and it is important that it be addressed throughout children's development. Being communicatively competent does not guarantee that one will be self-determined, yet one will not be self-determined unless he/she is communicatively competent (Light & Gulens, 2000). Therefore, it is important to provide opportunities for individuals to develop the skills of self-determination such as problem solving and goal setting from an early age. Future research needs to identify the effectiveness of interventions and strategies to develop self-determination for individuals who use AAC.

Quality of Life

The participants' overall quality of life scores ranged from 1.8 to 8.0 on a scale of –10 to +10. All participants demonstrated a positive quality of life, however there was variation across participants with regard to how each area measured contributed to their score. The variability of scores observed reflects the individual nature of quality of life. Quality of life is a multi-dimensional construct that encompasses the physical, psychological, spiritual, and social aspects of one's life (Renwick & Brown, 1996). All of these aspects contribute to quality of life, however the influence of each area is unique for each person (Brown, Renwick & Nagler, 1996).

Quality of life is an individually defined construct. Therefore the variability observed across the participants is not unusual, and should be expected. Ratings of quality of life reflect individual values, priorities, and expectations (Brown, Renwick & Nagler, 1996). What may appear to outside evaluators as a high quality life, may be rated lower by an individual with high personal expectations. Conversely, an individual with different priorities may be perfectly content with a lifestyle that appears to others as one of lower quality.

One factor that may have contributed to the participants' quality of life scores was their environment and community. Some of the sections that demonstrated the greatest variability across participants were "my access to resources", "where I live and spend my time", and "the daily things I do". All of these sections were highly influenced by the physical environments of the participants. For example, Chad's low score on the section "my access to resources" was influenced by the town he lived in. However for Carson, his community and environment contributed positively to many of his scores including "where I live and spend my time", "the people around me", "my access to resources", and "the things I do for enjoyment".

Quality of life measures provide insight into an individual's priorities and values and can help identify areas that can be improved by intervention, thus contributing significantly to one's quality of life. Communication can affect the physical, psychological, spiritual, and social aspects of one's life (e.g., directing one's personal care, expressing feelings, establishing and maintaining friendships, participating in religious services and rituals). Therefore evaluating of quality of life can be an important part of planning communication interventions. For example, an individual may identify having friends as an area of high importance, but low satisfaction. Interventions can then be designed to teach social communication skills or help develop a social network (e.g., Circle of Friends [O'Brien, Forest, Snow & Hasbury, 1989]) as needed.

Contextual Factors

When planning interventions for individuals who use AAC, it is important to consider the contextual factors described. These factors were identified by the participants as important appear to outside evaluators as a high quality life, may be rated lower by an individual with high personal expectations. Conversely, an individual with different priorities may be perfectly content with a lifestyle that appears to others as one of lower quality.

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Contextual Factors

When planning interventions for individuals who use AAC, it is important to consider the contextual factors described. These factors were identified by the participants as important supports and barriers to positive outcomes. Interventions should seek to develop and encourage the areas of support and minimize the barriers that were identified (Beukelman & Mirenda, 1998).

The first sub-theme identified was attitude barriers. Attitude barriers are one of the five types of opportunity barriers identified by Beukelman and Mirenda (1998). Negative attitudes of family members, professionals, peers and the general public were identified by the participants and their facilitators as barriers to positive outcomes. Negative attitudes often create reduced expectations of the individual who use AAC, which subsequently lead to limited participation opportunities (Beukelman & Mirenda, 1998). There has been much research investigating the attitudes of different groups toward individuals who use AAC (e.g., Gorenflo & Gorenflo, 1991; Blockberger, Armstrong, O'Connor & Freemen, 1993). However, this body of research has measured how people's attitudes differ based on characteristics of the individual who uses AAC (e.g., type of communication system used). These studies have only measured attitudes at a single point in time and have not investigated ways to change attitudes. Research is needed to identify effective and efficient ways to improve attitudes of individuals and society towards individuals who use AAC.

The second barrier identified addressed the issue of culture. Culture plays an important role in communication (Hetzroni & Harris, 1996). It is important that professionals are culturally aware in order to meet the needs of the individuals they serve (Taylor & Clarke, 1994). Traditional assessment and intervention approaches often do take into account cultural issues (Hammer, 1998). To date, the subject of cultural and linguistic diversity has been neglected in the AAC field (Light, 1997). Research is needed to develop technology that can meet the needs of multi-lingual persons as well as investigate the impact and affect of culture on the assessment and intervention process for individuals who use AAC.

The third area identified as a barrier to positive outcomes was technological barriers. Technological limitations have also been identified as barriers to successful outcomes in two studies of employment for individuals who use AAC (McNaughton, et al., 2000; McNaughton, Light & Groszyk, in press). One of the technological barriers identified in the present study was difficulty accessing technology. Operational demands refer to the skills required to technically operate an AAC system (Light, 1989). For many individuals with severe physical disabilities, the operational demands of AAC systems are substantial (Light, 1993). Research and development are needed to improve the technology available to individuals who use AAC and design communication systems with reduced operational demands (Light, 1997).

The final barrier identified addressed limitations of service delivery. Due to the complexity of issues involved, it is critical that a team approach is used for AAC assessment and intervention planning (Beukelman & Mirenda, 1998). Given the comments from the participants and their families, effective teamwork is a critical component for successful outcomes. It is often assumed that effective collaboration will happen simply by bringing a group of people (i.e., professionals and families) together (Beukelman & Mirenda, 1998). Efficient and effective teamwork is not something that "just happens", rather, it is something that needs to be developed.

Effective teams have regular, face-to-face interactions, equal value for each member, positive interdependence between members, positive interpersonal skills, and individual accountability (Thousand & Villa, 1992). Positive interdependence refers to the spirit captured by the phrase "all for one and one for all" (Thousand & Villa, 1992). In order to develop positive interdependence, team members must identify their learning and work styles and agree on mutual team goals (Givner & Haager, 1995; Thousand & Villa, 1992). Interdependent teams share or exchange roles and tasks when needed in order to ensure the workload is equally shared across team members. To facilitate successful interdependence, professionals must give up individual "possession" of tasks and roles; rather the tasks and roles belong to the team. When teams fail to work together effectively, it is often because they have failed to develop positive interdependence (Givner & Haager, 1995; Thousand & Villa, 1992).

There are multiple and complex interpersonal skills required for effective team interaction. Some of the interpersonal skills required include being considerate of each other (e.g., arriving to meetings on time, respecting all team members' opinions), communicating effectively, solving problems collaboratively, and managing controversy and conflict appropriately (Johnson, et al., 1984). The interpersonal skills required for teams to function effectively often do not come naturally, however they are skills that can be learned (Thousand & Villa, 1992).

Finally, individual accountability is critical for the team to function effectively. Each team member must take responsibility for his/her contribution to the group. This happens when members believe that their work is worthwhile and valued by the group (Givner & Haager, 1995; Thousand & Villa, 1992). The team can only succeed as a whole when each member has fulfilled his or her roles. In sum, positive interdependence, strong interpersonal skills, and individual accountability are critical for teams to collaborate effectively. Effective collaboration requires effort, however it has been identified by the participants of this study as a critical piece contributing to positive outcomes.

Another service delivery limitation discussed by the participants and their families was the limited focus of goals and the over-emphasis on technology. Often it is easy to become enamored with the incredible feats of technology. However it is critical to remember that "AAC – and communication in general – is a means to and end; it is not the end in itself" (Mirenda, 1993, p. 5). Communication is a tool that allows people to participate in the activities of life. If learning to communicate using an AAC system is the ultimate goal of intervention, it becomes more important than the participation it is meant to facilitate (Mirenda, 1993). Therefore it is critical that interventions are developed that teach individuals to use AAC as the tool that it is, a tool to achieve active participation in life.

Implications to Improve Practice

The results of this study have important implications to improve services for individuals with severe communication disorders who use AAC (see Table 27 for a summary).

Table 27
Summary of the implications to improve practice

Area	Implications
Receptive language	• Evaluate receptive language throughout development • Provide intervention to teach higher-level language (e.g., syntax and vocabulary) as needed
Reading	• Foster appropriate expectations for individuals who use AAC to become literate (Light & McNaughton, 1993). • Develop interventions to facilitate the transition from emergent to conventional literacy • Develop interventions to teach reading comprehension and writing
Communicative Interaction Patterns	• Provide interventions to teach active participation in interactions (e.g., non-obligatory turn taking) • Provide instruction in social strategies to extend interactions (e.g., asking partner-focused questions) • Provide intervention to communication partners to teach strategies to promote interaction ? • Develop interventions to teach use of a variety of communicative functions

Area	Implications
Educational and Vocational Achievement	• Provide role models to foster expectations that employment is attainable for individuals who use AAC • Prepare students for employment by teaching necessary communication and work skills
Self-Determination	• Address self-determination throughout development • Teach the skills of self-determination (e.g., choice making, problem solving, goal setting) as needed
Quality of Life	• Use quality of life indicators to help guide intervention by identifying individuals' priorities and needs
Contextual Factors	• Need to collaborate for teams to function effectively • Develop interventions to reduce barriers and facilitate supports (e.g., reduce attitude barrier, facilitate family support)

Limitations of the Study

This study provided much needed information on outcomes for individuals who use AAC. However, there are some limitations to the study. This study evaluated outcomes in a variety of areas, however some domains were not addressed. The domains omitted included speech and cognitive function at the body level; spelling and written expression at the activity level; and societal attitudes and friendships/social contacts at the participation level.

The conclusions of this study are based on one small sample of seven young men with cerebral palsy who use AAC. As a result, the generality of the study is limited. One of the unique things about AAC is that it is not a specific intervention, but rather a range of technologies and interventions for individuals with a variety of disabilities whose speech is inadequate to meet their daily communication needs. Therefore, it is important to evaluate outcomes further, for individuals with other disabilities who use AAC and have received different interventions.

This study described outcomes for a group of young men who have used AAC systems since preschool. However, this study is descriptive; there was no experimental control. As a result, there can be no claim that the outcomes observed were caused by the AAC interventions provided. The outcomes reported were the outcomes for this group of individuals who have used AAC systems and received AAC services. However, no cause and effect relationship can be claimed.

Another limitation to interpreting the outcomes for this group is the lack of information about the participants' cognitive abilities. The outcome areas measured in this study are likely to be affected by cognitive limitations. Some of the variability observed across participants may have been due to cognitive differences. However, no documentation regarding the cognitive skills of the participants was available. Given the severe speech and physical impairments of the participants, cognitive testing would have been difficult and was beyond the scope of this project. Therefore it is difficult to interpret some of the results without a cognitive context.

Outcomes measurement is challenging because of the interaction of the variables measured (Light, 1999). This study assessed outcomes is specific domains (i.e., receptive language, reading comprehension, communicative interaction, self-determination, and quality of life). However, these domains are interrelated. Because of this interrelationship, it is not clear how outcomes in one domain may have influenced outcomes in other domains.

Directions for Future Research

This study was the first to document long-term outcomes for individuals who use AAC. Outcomes were measured in a broad range of domains including receptive language, reading comprehension, communicative interaction, functional communication, educational and vocational achievement, self-determination and quality of life. In addition to measuring outcomes, this study has laid the groundwork for future outcomes research and identified important questions that require investigation in future studies.

Additional research is needed to investigate the receptive language skills of individuals who use AAC. Research needs to investigate the relationship between receptive and expressive skills for individuals who use AAC. It is important to understand how a constrained expressive system may impact receptive skills. Additionally, appropriate interventions to teach syntax (both expressive and receptive) and promote higher level language need to be investigated.

As discussed, the AAC field has recognized the importance of literacy for individuals who use AAC. However, the bulk of research has been devoted to investigating the earliest stages of literacy development (i.e., emergent literacy). Additional research is needed to understand the development of conventional literacy for individuals who use AAC. Specifically, studies need to research the efficacy of interventions to develop conventional literacy and reading comprehension.

Research has begun to identify factors that lead to successful employment for individuals who use AAC (e.g., McNaughton, et al., 2000). Additional research is needed to design interventions to develop these factors for individuals seeking employment. In addition, similar studies investigating the successful educational inclusion of individuals who use AAC are needed. It is critical to determine the factors that contribute to successful inclusion and learn how to foster successful inclusion for others.

Self-determination and quality of life are new areas to be addressed for individuals who use AAC. Research is needed to develop and evaluate the efficacy of interventions designed to teach the skills of self-determination to individuals who use AAC (e.g., problem solving, goal setting). Similarly, quality of life is not usually an area of assessment that guides intervention

DISSEMINATION

In addition to this report, the results from this study have been disseminated through the following presentations at national and international conferences:

- Lund, S., Light, J., & Schlosser, R. (2000, August). Fifteen years later: The long-term outcomes of AAC interventions. Miniseminar presented at the 9th biennial conference of the International Society for Augmentative and Alternative Communication, Washington, DC.
- Lund, S., & Light, J. (2000, November). Fifteen years later: A follow-up on AAC interaction patterns. Technical paper presented at the annual convention of the American Speech-Language-Hearing Association, Washington, DC.
- Lund, S., & Light, J. (2000, November). Self-determination and quality of life for individuals who use AAC. Technical paper presented at the annual convention of the American Speech-Language-Hearing Association, Washington, DC.

Five manuscripts are in preparation for publication in peer reviewed journals and other publications. Due to the breadth of the project, separate papers are being prepared addressing the communicative interaction, literacy, self-determination, quality of life, and contextual factors sections of the study.

Finally, information regarding the project is available for public view on the Penn State Augmentative and Alternative Communication website at the following web address: http://aac.hhdev.psu.edu/

CONCLUSION

This project provided greatly needed information regarding the long-term outcomes for a group of individuals who used AAC systems. This study was the first to measure outcomes for individuals who use AAC in a broad range of domains and the project has laid the groundwork for future outcomes research.

In considering the results it is important to remember that the field of AAC is young; it did not begin to emerge as an area of specialization until the 1970s and it was not until the 1980s that a research base was begun (Zangari, Lloyd, & Vicker, 1994). The outcomes for individuals who use AAC have improved with the advent of AAC systems, however the journey is not over. There is still room for further improvement. This study has provided an important first step to document outcomes for a group of individuals who use AAC, identify areas to improve practice, and identify areas for future research. This project provided data regarding the feasibility of the outcome measurement tools used, thus paving the way for their use in future prospective research studies measuring the outcomes of AAC interventions. The study identified factors that were believed to contribute to positive outcomes and communicative competence and identified important questions for future research. This study and future research will identify exemplary practices to improve the outcomes for individuals who use AAC. Improved outcomes will allow individuals who use AAC to attain their full potential at home, school, work, and in the broader social community.

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APPENDIX A:

Summary Of Intervention For Participants

	Communication Systems	Focus of Intervention	Facilitator Training	Other
Anthony Preschool (age 3-5)	• Growth from 30 to > 120 Blissymbols • Access: eye pointing and coding system	• Communicative functions	• Strategies to promote interaction	
Elementary (age 6-10)	• Communication display > 650 Blissymbols • Access changed to partner-assisted scanning • Trial evaluation with VOCAs – discontinued due to access problems	• Interaction with unfamiliar partners • Early reading skills		• Powered mobility introduced
Secondary (age 11-21)	• Growth to > 900 Blissymbols	• Operational skills for computer access	• Operation and maintenance of computer for family and school personnel	• Computer provided for written communication • Search for independent access to computer discontinued
Leo Preschool (age 3-5)	• Growth from 30 to > 250 Blissymbols • Access: partner-assisted scanning	• Vocabulary development • Increase symbol use	• Strategies to promote interaction	
Elementary (age 6-10)	• Replaced Blissymbols with English words on communication display • VOCA introduced at school (age 8)	• Communicative functions • Use of VOCA to facilitate peer interaction • Sight word recognition	• Strategies to promote interaction	• Power mobility introduced at school • Computer access with single switch introduced
Secondary (age 11-17)	• VOCA discontinued (age 11)	• Morse code and computer operation • Spelling	• Operation and maintenance of computer for school personnel	• Computer access with Morse Code introduced for writing (age 14)
*No intervention age 18-21				
Post – Secondary (age 22)				• Computer system upgraded

	Communication Systems	Focus of Intervention	Facilitator Training	Other
Chad Preschool (age 3-5)	• Growth from ~20 to >140 Blissymbols (labeled in both French and English)	• 2-3 symbol combinations • Negation, questions, and verb tenses	• Strategies to promote interaction	
Elementary (age 6-10)	• Communication display > 600 Blissymbols	• Strategies to provide feedback to listener • Repair of communication breakdowns • Reading and spelling		• Powered mobility introduced (age 6) • Computer provided for written communication
Secondary (age 11-21)	• Replaced Blissymbols with French words on communication display • VOCA introduced (age 13)	• Technical operation of VOCAs	• Operation and maintenance of computer and VOCAs for family and school personnel	
Josh Preschool (age 3-5)	• Growth from 20 to 450 Blissymbols	• Clarification strategies • Increase initiation and participation	• Strategies to promote interaction	• Power mobility introduced (age 4)
Elementary (age 6-10)	• Growth from 450 pictures & Blissymbols to using spelling as primary method of communication (age 7) • Trial evaluation with VOCA discontinued due to problems with access (age 6)	• Communicative functions • Topic introduction, expansion, maintenance • Peer interaction • Sentence structure, negation, possession, questions, conjunctions, verb tenses • Vocabulary development • Writing	• Strategies to promote interaction for school personnel • Operation and maintenance of computer	• Computer provided for written communication
Secondary (age 11-19)	• Alphabet board used for most face-to-face communication • Speech synthesizer added to laptop (age 15)	• Reading comprehension • Writing: structuring essays, editing and revising • Increase speed and accuracy of computer access • Take more active role in managing personal care	• Operation and maintenance of computer for family and school personnel	• Laptop computer provided for written communication

	Communication Systems	Focus of Intervention	Facilitator Training	Other
Carson Preschool (age 3-5)	• Growth from 30 to > 200 Blissymbols • Access: gross fist pointing and eye pointing with number coding	• Increase initiation and participation • Communicative functions • Use verbs, adjectives, • Clarification strategies	• Strategies to promote interaction for parents and school personnel	• Power mobility introduced (age 5) • Computer access with single switch introduced
Elementary (age 6-10)	• VOCA introduced with directed scanning using head switches (age 8) • Communication display ~150 words	• Conversational strategies • Communicating with unfamiliar partners • Vocabulary development • Spelling • Syntax and morphology in writing	• Strategies to promote interaction for parents and school personnel • Operation and maintenance of computer for family and school personnel	• Computer provided for written communication
Secondary (age 11-21)	• Discontinued use of VOCA (age 11) • Speech synthesizer added to writing system (age 15)	• Reading instruction • Vocabulary development • Peer relationships	• Strategies to promote interaction and operation and maintenance of computer for new school personnel	• Laptop computer provided for written communication

	Communication Systems	Focus of Intervention	Facilitator Training	Other
Bradley Preschool (age 3-5)	• Growth from 30 to > 80 Blissymbols	• Encourage symbol use	• Strategies to promote interaction for parents and school personnel	
Elementary (age 6-10)	• Growth from ~ 85 to > 150 Blissymbols • Some Blissymbols replaced with written words	• Increase initiation and participation • Communicative functions • Topic maintenance and development • Vocabulary expansion • Reading & writing activities	• Strategies to promote interaction for parents and school personnel	• Introduced to computer • Received computer for written communication
Secondary (age 11-21)	• Changed from Bliss to traditional orthography • Communication display with > 500 words and picture symbols • VOCA introduced (age 17)	• Reading and spelling familiar words • Direct personal care at home and school • Use VOCA for social communication	• Operation and maintenance of VOCA for family and school personnel	• Power mobility introduced (age 13)
Post-Secondary (age 22-23)	• New VOCA introduced (age 22)	• Send e-mail • Use clarification strategies • Initiate and maintain conversation • Use VOCA to complete phone conversation	• Operation and maintenance of VOCA for family	

	Communication Systems	Focus of Intervention	Facilitator Training	Other
Douglas Preschool (age 3-5)	• Picture board provided. Board was not functional and did not use it			
Elementary (age 6-10)	• Growth from 30 to ~150 Blissymbols • Access: direct selection using both hands • VOCA introduced as supplement to communication display (age 10)	• Increase initiation and participation • Negation, question forms, verb tenses • Sound-letter associations • Reading and spelling development • Strategies to provide feedback to listener • Use VOCA in specific contexts (e.g., initiate conversation, peer interaction)	• Strategies to promote interaction and operation and maintenance of VOCA for family and school personnel	• Powered mobility introduced (age 8) • Computer provided for written communication
Secondary (age 11-21)	• Communication display ~300 words/symbols • New VOCA introduced, used as primary aided mode (age 18)	• Asking questions • Peer interaction • Spelling • Phonological awareness • Reading familiar words • Vocabulary development • Direct personal care with familiar and unfamiliar people	• Operation and maintenance of computer and VOCA for family and school personnel	• Changed computer access to directed scanning with head switch array
Post-Secondary (age 22-23)	• VOCA access changed to directed scanning with head switch array	• Use of VOCA in functional contexts		

APPENDIX B

Coding Definitions for Communicative Functions (from Light, 1985)

Request for Object or Action

These turns direct the listener to provide an object or to perform an action.

Request for Information

These turns direct the partner to provide information about an object, action, person, location, or event. They serve:

- to request information by asking a yes/no question;
- to request information already known to the speaker;
- to request information unknown to the speaker.

Request for Confirmation/Clarification

These turns seek to verify the accuracy of the speaker's understanding of the partner's communicative turn or seek additional information regarding the previous turn. Repetitions of the previous utterance or reading the communication display without a rising intonation, are not coded as requests for confirmation. The category includes turns which serve:

- to express non-comprehension of the partner's communicative turn (i.e., a general request for clarification);
- to request specific information from the partner (i.e., specific request for clarification);
- to request confirmation that the listener understand the message correctly.

Confirmations/Denials

These turns serve:

- to confirm or deny partner's understanding of the message;
- to respond affirmatively or negatively to yes/no questions seeking information;
- to agree or disagree with partner's comments.

Provision of Information

These turns comment on objects, actions or persons or provide information requested by the partner. These turns serve:

- to comment on objects, events, persons in the here and now;
- to comment on objects, events, or persons removed in time or space.

Provision of Clarification

These turns provide clarification when a previous turn has not been understood by the partner. These turns serve:

- to provide clarification by repeating the message without modification;
- to provide clarification by changing the content of the message;
- to provide clarification by changing the mode of communication.

Expression of Self

These communicative turns express the participant's emotional state. These turns serve:

- to protest;
- to express a negative state (e.g., displeasure);
- to convey humor;
- to express a positive state (e.g., pleasure).

Conversational Fill

Some communicative turns, while clearly intelligible to the listener and coder, seem to carry no specific propositional content or illocutionary force. These turns serve as fillers in the interaction and include utterances such as "mm-hmm" and "okay" when used as fillers and not a confirmation.

Unintelligible/Incomplete

Some communicative turns, while clearly involving communicative behaviors are unintelligible as to their propositional content or illocutionary force. Other turns are interrupted in mid-turn so that the propositional content and illocutionary force of the turn are unknown. These turns are classified as unintelligible.

APPENDIX C:

Educational/Vocational Assessment

1. Are you currently in school?
2. What school do you attend?
3. What grade/year are you in?
4. What courses are you taking?
5. Do you receive any special education services? Modifications to the curriculum/course load?
6. What previous schools have you attended/completed? Any special education services?
    - Elementary
    - Middle School
    - High School
7. Do you have future educational plans? What are they?
8. Are you currently employed? Doing what? How many hours/week?
9. Have you ever had a job (including volunteer work)? Doing what? Where? How many hours/week? Were you paid?
10. Do you have future vocational plans? What are they?

APPENDIX D

Interview Guide Questions

Questions for Participants and Families

1. Tell me about how you communicate
    - What are your first memories of using AAC? What happened next? And then?
2. I'd like to know more about your experiences with AAC, overall have you been satisfied with the services you have received?
    - What approaches were most helpful? What worked well?
    - What things did not work as well?
    - What would you have liked to have happened differently?
3. What are your current concerns regarding your present communication intervention approaches?
    - Are you satisfied with your current "system(s)"?
    - Would you change anything?
4. Describe your experiences with the professionals dealing with AAC (and other disciplines).
    - What did you find helpful?
    - What would you like to have seen done differently?
    - What suggestions do you have for professionals working with individuals, especially children, who use AAC?
5. What do you think has contributed to your current communication abilities?
    - Both positive and negative influences
6. What are your hopes for the future?

Questions for Professionals

Note: ____ = insert participant who uses AAC's name

1. When did you first work with ___?
2. Tell me about ____'s communication.
3. I'd like to know more about your experiences with ___ and AAC.
   - What systems, programs have been used over the years?
   - What were your expectations/goals?
   - Has ___'s communication changed since introducing AAC? How?
   - What approaches were most helpful?
   - What approaches were not helpful? Knowing what you do now, what would you have done differently?
4. What are your current concerns regarding ___'s present communication intervention?
   - Are you satisfied with the current "system(s)"?
   - What would you change?
5. What do you think has contributed to ___'s current communication abilities?
   - Both positive and negative influences
6. What are your future expectations for ___'s communication?