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**REFLECTIONS OF NINE PARTICIPANTS REGARDING THEIR EXPERIENCES OF
BEING AFRICAN AMERICAN AND USING AUGMENTATIVE AND
ALTERNATIVE COMMUNICATION ACROSS THEIR LIFESPAN AT HOME,
SCHOOL, VOCATION, AND COMMUNITY**

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By

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Abstract

Individuals with complex communication needs that use augmentative and alternative communication (AAC) (e.g., letterboards, communication notebooks, computerized devices) have rich experiences regarding using AAC. However, individuals who use AAC are often not questioned about their personal experiences using AAC. In addition, individuals who are from diverse ethnic identities are often not included in research. For individuals from diverse ethnicities who also use AAC, their perspectives are virtually unknown. The lack of knowledge regarding individuals who are from diverse ethnicities and use AAC impacts the types and quality of service delivery to the population. The purpose of this study was to investigate the experiences of African American adults who used AAC in regards to barriers, supports, and recommendations for improving AAC services and systems for African Americans who use AAC. Phenomenology methods were utilized to explore nine participants' experiences using AAC across their life. A series of face-to-face, semi-structured interviews were conducted. After data collection was completed, participants read summaries about their personal experiences and answered questions about their personal data and questions about the themes that emerged from the data. From the data six themes emerged showing interrelationships between the themes. The six themes were the following: a) individuals, b) interventions, c) locations, d) barriers, e) supports, and f) recommendations for improving AAC services and systems. Based on the results of the study, many of the interventions were provided with the intent to improve the lives of African Americans who used AAC. Oftentimes however, the individuals and interventions were only minimally supportive or were barriers. Results of the study have clinical and social implications for African Americans who use AAC services and systems. Results, implications, and future research directions are discussed.

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“Talk to me. I talk back.”

--Hubert

CHAPTER ONE

Introduction and Review of Literature

Augmentative and Alternative Communication (AAC) is procedures and processes to provide communication modes for individuals with severe speech impairments by using light tech devices (i.e. communication books, picture boards), high tech devices (i.e. voice recordings, electronic device), and/or unaided systems (i.e. gestures, sign language, vocalizations) for comprehension and/or expression (ASHA, 2002). There are approximately two million Americans who use AAC when their speech does not meet their daily communication needs (ASHA, 2002; ASHA, 2004b). These individuals are from a variety of cultural identities. The use and acceptance of AAC is influenced by an individual's culture. Culture shapes how a person thinks, perceives, believes, evaluates, communicates, and acts based on shared elements passed from generation to generation (Hayes, 2001; Hetzroni & Harris, 1996). Every individual has multiple cultural identities (Hayes, 2001). Each identity impacts how an individual reacts to disabilities and the options available. Anecdotal reports in research indicate that some Non-European Americans (i.e., diverse) who could benefit from using AAC choose to not use AAC in any capacity or limit its use because of concerns that they (or their loved one) will experience more severe discrimination due to having a diverse ethnic identity and a disability identity (Huer, Parette, & Saenz, 2001; Parette, Huer, & Brotherson, 2001). Discrimination against diverse individuals or individuals with disabilities is often based on attitudes.

An attitude is a concept filled with emotion which causes an individual to favor a set of behaviors for specific situations (Triandis, Adamopoulos, & Brinberg, 1984). Because attitudes cannot be observed, attitudes cannot be directly measured (McCarthy & Light, 2005). Most attitudinal research is completed using self-reported measures. The problem with self-reported measures is that individuals tend to report information about themselves as being positive and may not report the full truth (McCarthy & Light, 2005).

Many researchers believe that attitudes and behaviors are connected. Behavior can be observed and may reflect attitudes (McCarthy & Light, 2005). It is possible, however, to produce a change in behavior but not have a change in attitude and vice versa. Attitudes and behaviors are impacted by a person's cultural identities and influence interactions between individuals from different identities which may lead to discrimination. Discrimination is behavior that denies people equal treatment (Blumenfeld & Raymond, 2000). Discrimination can occur in many forms due to misunderstanding, misinterpreting, or devaluing diverse behaviors, communication styles (Pincus, 2000), and communication modes.

The meaning of behavior and communication should be interpreted in the cultural context in which it occurred since communication occurs within a cultural framework (Agar, 1994; Heath, 1983; Hetzroni & Harris, 1996). Speech language pathologists (SLP) need to recognize that the acceptable level of social communicative competency (Light, 1989) is culturally influenced and determined by members of the same cultural identity (Hetzroni & Harris, 1996). SLPs also need to recognize that culture impacts the use and acceptance of AAC and thus AAC systems and services need to accommodate cultural needs unique to the diverse individual using the AAC system. It is critical that SLPs and other professionals gather information about the experiences of using AAC from diverse individuals who use AAC.

Currently, the experiences of diverse individuals who use AAC are unknown. Developing an understanding of the experiences of diverse individuals who use AAC is important because the information can be used to provide more appropriate AAC systems and services for diverse individuals who use AAC. Diverse individuals who use AAC are the experts on their life experiences and can provide insight for improving clinical practice (Creswell, 1998). The information gathered in the current study can also be used to identify future research

directions which were important to diverse individuals who use AAC (Schlosser, 2000). The purpose of the current research project was to develop an understanding of the experiences of several diverse individuals who used AAC. Phenomenological methodology was utilized for the purpose of better understanding the lived experiences of diverse individuals who used AAC (Denzin & Lincoln, 2000).

LITERATURE REVIEW

Every individual has multiple identities (Hayes, 2001). One identity model has identified ten identities which individuals possess (see Appendix A) (Hayes, 2001). Within each identity in the Hayes identity model, there is a dominant identity and one or more minority identities. A dominant identity is preferred by people with power (i.e., the ability to exert control over personal situations and situations of less powerful individuals) and privilege (i.e., advantages due to group membership) (Hayes, 2001). A minority identity is not favored by people with power. In different contexts, the same identity may be dominant or minority (Hayes, 2001). In relation to the present study, diverse individuals who use AAC have a minimum of two minority identities. Cultural identities however, are not mutually exclusive categorical variables because individuals vary in how much they adhere to a set of cultural practices (Ridley, Li, & Hill, 1998; Rodriguez & Olswang, 2003).

Identities develop from interactions within and between social groups (Tatum, 2000a). Social groups share histories, cultures, and traditions which are passed through generations (Portes & Rumbaut, 2001; Tatum, 2000a). Socialization is pervasive, consistent, self-supporting, self-perpetuating, and invisible (Harro, 2000). There are two types of socialization: enculturation and acculturation. Enculturation is the socialization which occurs by socializing a child within a family from birth (Harro, 2000). Acculturation is socialization which occurs from

contact between members of different cultural identities (Locke, 1998). Acculturation results in four types of adherence to cultural identities: bicultural, acculturated, traditional, and marginal (Locke, 1998). Bicultural acculturation means that the individual adapted to the new culture while retaining strong ties with original culture. Acculturated acculturation means that the individual adapted to the new culture yet lost portions of the original culture. Traditional acculturation means that the individual did not adapt to the new culture and continued adhering to original culture. Marginal acculturation means that the individual adhered minimally to both the new and original cultures. Interactions between individuals of the same identities and across identities impact the type of acculturation.

Cross-cultural interactions influence an individual's cultural identities. Interactions between cultures can be positive or negative and influence how one perceives himself or herself (Harro, 2000). Individuals may be unaware that they have a cultural identity until they interact with individuals from another culture (Agar, 1994). Cross-cultural interactions need to have less focus on simply identifying similarities and differences but instead focus on learning behavior patterns to develop communicative competence in the culture (Agar, 1994). By understanding other culture's behavior patterns (including communication patterns), a person can change his/her attitudes and behaviors toward various identities for better interactions between groups. For diverse individuals who use AAC it is unknown how the diversity and disability impact inculturation and acculturation.

The Ethnicity Identity

The concept of ethnicity is more than an individual's race. Race refers to a phenotype of physical features in an effort to group individuals by genetic similarities (Hayes, 2001). Yet, race does not provide information about a person's education, socioeconomic status (SES),

religion, or home environment. Individuals of the same race may have more in common with individuals of similar SES (Heath, 1983). Ethnicity may include a biological or geographical component but focuses mostly on beliefs, norms, and behaviors of group members (Hayes, 2001). Language may be a feature of ethnicity (Phinney, 1990; Portes & Rumbaut, 2001). However, language is too broad to be the primary issue in ethnicity. Ethnicity should be defined by the individual so that the individual defines his/her ethnicity in terms of norms, values, and level of acculturation (Hayes, 2001). Therefore, it is appropriate to ask individuals to identify their ethnicity rather than making assumptions based on phenotype or language. For individuals who use AAC and are from diverse backgrounds, it is unknown how the individuals perceive their ethnicity.

Incidentally, most European Americans do not identify ethnicity as a distinguishing issue in their identity like members of other ethnic identities (Omi, 2000). Some European Americans may describe 'ethnic' as anyone who is Non-European American. These European Americans do not believe they have an ethnic identity. For European Americans who recognize that all individuals have an ethnic identity, they may perceive ethnicity as being flexible, symbolic, and voluntary (Omi, 2000). Thus, European Americans can decide when to identify with a group.

Intercultural Sensitivity

When individuals of different cultures interact during acculturation, each individual may be interacting with different levels of intercultural sensitivity. Intercultural sensitivity is the cultural competence in intercultural interactions based on the individuals experiences (Bennett, 1986). Understanding the intercultural sensitivity of SLPs from the perspective of diverse individuals who use AAC is important because it may reveal appropriate methods of providing AAC services and systems. According to Bennett (1986) there are six levels of intercultural

sensitivity: a) denial, b) defense, c) minimization, d) acceptance, e) adaptation, and f) integration.

Denial is the belief that the individual's culture is the only culture and that other cultures do not exist. Defense is the belief that the individual's culture is the only valuable culture.

Minimization is the belief that the individual's experiences are universally experienced by other individuals and therefore differences in experiences are trivialized. Acceptance is the belief that the individual's experiences are only one set of experiences and therefore differences are acknowledged but the differences could be judged negatively. Adaptation is the belief that the individual can and does yield beliefs and own perceptions and adopts views appropriate within other cultures and will change behaviors and communication styles to match the perceptions and beliefs of individuals in different cultures. Integration is the movement from one belief set to another belief set often completed by individuals in diverse cultures for survival purposes.

Denial, defense, and minimization are grounded in the belief that the individual's culture is central to not only the individual's reality and life experiences but also to individuals from other cultural groups (Bennett, 1986). Acceptance, adaptation, and integration are grounded in the belief that the individual's culture is only one of many cultures experienced by a variety of individuals.

Individuals have the ability to move between awareness levels. The individual's cultural competence increases as the individual moves to different levels of recognizing other cultures and modifying individual behaviors when interacting with individuals from different cultures (Bennett, 1986). The first step to increasing intercultural sensitivity is to recognize that a culture identity exists. One identity often overlooked is the disability identity.

The Disability Identity

Unlike an ethnic identity, which is received at birth, the disability identity can be obtained at any point in life. Disabilities can be either developmental or acquired. A disability is a physical or mental impairment which restricts one or more life activities (e.g., communication) (Castaneda & Peters, 2000). In the U.S. 20% of the population reported a disability on the year 2000 census survey (U.S. Census Bureau, 2005a). On the same survey, Americans with disabilities earned on average between \$13,300 and 20,500 with nearly twice as many Americans with disabilities below the poverty level than Americans without disabilities (U.S. Census Bureau, 2005a). Individuals who use AAC are three times more likely to be unemployed as compared to other individuals with disabilities and tend to earn less money than other individuals with disabilities when they are employed (McNaughton & Bryen, 2002). Over one third of Americans with disabilities reported on the census survey that they were restricted in the types of work they were capable of completing and 20% of all Americans with disabilities reported having difficulty finding a job and/or staying employed (U.S. Census Bureau, 2005a). The disability identity was identified on the census survey by individuals from every ethnic identity (U.S. Census Bureau, 2005a).

The disability identity is often overlooked as a true identity with members who have the ability to advocate for themselves (Bryan, 2000). Most social-psychological research about disabilities equates all disabilities, ignores other identities, and ignores the interactions between disability and other identities (e.g., ethnicity) (Fine & Asch, 2000). Equating disabilities can lead to situations of not recognizing the severity of some disabilities. For example, an individuals with severe asthma may be legally disabled but able to work in some capacity and able to communicate with peers, family, and coworkers. Individuals with complex

communication needs with speech that does not meet their daily needs may be legally disabled but may have extreme difficulty finding employment due to the difficulty communicating with peers. Difficulty with communicating impacts every aspects of a persons life and may result in a lifetime of hardships with completing school work, finding employment, finding and making friends, maintaining family relationships, and interacting with individuals in the community which could result in emotional responses to using AAC and experiencing barriers on a daily basis. The barriers experienced by individuals who use AAC have even occurred with laws about disabilities. Most laws and policies about disabilities have excluded the voice/view of individuals with disabilities (Bryan, 2000). Typically developing peers tend to exclude individuals with disabilities in writing laws and have created handicapping conditions which individuals with disabilities must overcome.

Handicapping Conditions

A handicap is a barrier created by society which restricts an individual's opportunities when pursuing goals (Cartwright, Cartwright, & Ward, 1989). For example, not allowing an individual who uses AAC to work in any job or not allowing an individual to work to the individual's full potential is a handicap created by society. Most handicapping conditions created by society are based on false assumptions about disabilities. False assumptions about disabilities include the following: a) a disability is only biological in nature, b) the problems of an individual with disabilities are related to their impairment, c) the person is a victim, d) the disability is the center of the person's self-concept, and e) the disability is equated with being dependent on others and needing help (Fine & Asch, 2000).

Independence in all forms (e.g., democracy, physical ability) is valued in American society (Bryan, 2000). In contrast, dependence is coupled with negative concepts such as being

lazy or a burden on society. For individuals with disabilities, the level of achieved independence is partly due to attitudes and behaviors of families, teachers, doctors, and social systems (Bryan, 2000). If typically developing peers believe that individuals with disabilities cannot do an activity, they may restrict the opportunities of individuals with disabilities. Being a member of a diverse ethnic group and having a disability (e.g., communication disability requiring AAC) adds a layer of complexity to the situation.

Issues Specifically Related to Using AAC

Because individuals who use AAC are all very different (e.g., children, adults, developmental, acquired disorders, access issues) broadly describing characteristics of individuals who use AAC and broadly describing issues regarding the experiences of using AAC would be difficult. Limited data have been collected about the perceptions of individuals who use AAC about the experience of using AAC. Issues regarding the experience of using AAC are varied and range from topics such as access issues (e.g., Fried-Oken, Howard, & Stewart, 1991), limitations of AAC systems (e.g., Clarke, McConachie, Price, & Wood, 2001), and vocational opportunities (e.g., McNaughton, Light, & Arnold, 2002). From the research, two issues of interest to the current study have emerged frequently regarding the experience of using AAC but are unknown from the perspective of diverse individuals who use AAC: 1) emotional responses to having a communication impairment and/or using AAC and 2) barriers to opportunities to succeed with communication, employment, and other issues.

Emotional Issues

In regards to emotional responses, individuals in some studies have reported several negative emotions associated with their communication impairments. One negative emotion reported by some individuals who use AAC is frustration. Frustration may be experienced with

the inability to communicate what the person wants to say due to limitations of the AAC system (Clarke et al., 2001) or their own skills. Frustration may also be experienced with the type and quality of AAC services received (Smith-Lewis & Ford, 1987). For example, the individual who uses AAC may have a limited voice in decision-making so that the services provided do not meet the needs as identified by the individual who uses AAC.

A second emotional response individuals who use AAC have reported feeling is isolation (Clarke et al., 2001). Oftentimes individuals who use AAC are the only person using AAC in a classroom or work setting. Also, some individuals who use AAC may have limited peer interactions (Light, Binger, Agate, & Ramsay, 1999) which may cause feelings of isolation. When individuals who use AAC do interact with others, privacy may be an issue. Several individuals who use AAC have reported a lack of privacy and a need for privacy when communicating with others (e.g., Fox & Rau, 2001; Smith-Lewis & Ford, 1987).

A third emotion expressed by individuals who use AAC about having a communication impairment and/or using AAC has been depression. Recently on ACOLUG (a listserv for individuals who use AAC), depression was identified as an issue for several individuals who use AAC (personal correspondence, July 1-Sept. 9, 2004). Depression may occur in varying durations of time or be associated with grieving the loss of speech skills (Fox & Rau, 2001). Depression may also occur as an emotional response to barriers.

Barriers

Several barriers have been identified which limit opportunities for individuals who use AAC. Some barriers are similar to types of discrimination identified in disability literature. Discrimination can occur in three forms: Individual, Institutional, and Structural (Pincus, 2000). Individual discrimination is behaviors of individuals from one identity that are designed to

support differential treatment of individuals from another cultural identity (Pincus, 2000). Institutional discrimination are laws, customs, religion, or education that reinforces existing prejudice and discrimination (Blumenfeld & Raymond, 2000). Institutional discrimination occurs when dominant group policies—and the behaviors of individuals who control and implement the policies—are designed to have a differential effect towards another (often diverse) group (Pincus, 2000). Structural discrimination is policies of the dominant group institutions for the purpose of being group neutral in theory but actually have a differential or harmful effect on the minority group (Pincus, 2000). For example, a policy that reprimands schools for having a high number of diverse children receiving speech pathology services may result in Structural discrimination by not allowing diverse children to receive services even though they qualify the same as other children or demonstrate a significant need for services.

The relationship between barriers described in AAC literature and types of discrimination identified in disability literature can be seen in policy barriers. Policy barriers limit opportunities for individuals who use AAC (Light, Stoltz, & McNaughton, 1996) through legislative decisions and are similar to Structural discrimination described in disability literature (Blumenfeld & Raymond, 2000). Institutional discrimination in disability literature (Pincus, 2000) would encompass limited use barriers and practice barriers found in AAC literature. Limited use barriers are barriers in which agencies restrict the use of AAC systems bought with agency funds (Beukelman & Mirenda, 1998). Practice barriers are barriers in which routines become the expected method but are not actual policies (Beukelman & Mirenda, 1998). Limited use barriers and practice barriers are similar to institutional discrimination because an agency is completing the discrimination rather than specific individuals working on their own. Individual discrimination in disability literature (Pincus, 2000) would include attitude barriers identified in

AAC literature (Light et al., 1996). Attitude barriers occur when one individual restricts participation of an individual who uses AAC based on attitudes about AAC (Beukelman & Mirenda, 1998). Attitude barriers may be based on limited knowledge which results in limited opportunities for individuals who use AAC (Beukelman & Mirenda, 1998).

Four areas pertaining to AAC may impact the attitudes reflected toward the individual who uses AAC: 1) characteristics of the communication partner, 2) characteristics of the individual who uses AAC, 3) characteristics of the AAC device, and 4) characteristics of the AAC techniques (McCarthy & Light, 2005). Characteristics of communication partners which may influence attitudes towards individuals who use AAC include age (Beck, Kingsbury, Neff, & Dennis, 2000), gender (Gorenflo, Gorenflo, & Santer, 1994), and personal previous experience with individuals who use AAC (Beck et al., 2000). Characteristics of the individual who uses AAC which may influence attitudes towards themselves include the perceived communicative competency of individuals who use AAC (Beck et al., 2001) and message length (Beck et al., 2000). Characteristics of the AAC device which may influence attitudes towards individuals who use AAC include the perceived speech intelligibility of the voice synthesizer (Gorenflo et al., 1994). Finally, characteristics of AAC techniques may impact attitudes toward individuals who use AAC (Richter, Ball, Beukelman, Lasker, & Ullman, 2003). With attitudes literature, the concern is that the actual relationship between attitudes and behavior is unknown. Incidentally, none of the attitude studies reviewed by McCarthy and Light (2005) examined the impact of the ethnicity of the individual who use AAC on the attitudes toward individuals who use AAC. It is unknown how the attitudes reflected towards diverse individuals who use AAC are perceived. It is possible that the attitudes perceived may be different for diverse individuals who use AAC.

In addition to the external barriers created by individuals, institutions, and legislation, individuals who use AAC must also contend with barriers related to AAC systems and their own skills. All AAC systems have limitations in which individuals who use AAC must find ways to compensate (Mirenda & Bopp, 2003). For example, an AAC system may not have the vocabulary needed by the individual who uses AAC which limits the individual's ability to express thoughts. Another example is an individual who uses AAC may lack communication skills or the skills necessary to operate the AAC system (Beukelman & Mirenda, 1998).

External barriers, skill barriers, and AAC system limitations impact opportunities for individuals who use AAC and can result in emotional responses to AAC. Emotional response to having a communication disability and/or using AAC will impact the perceptions and use of AAC. Barriers and emotional responses to communication disabilities and/or AAC are challenges in the daily life experiences of many individuals who use AAC (e.g., Smith-Lewis & Ford, 1987). Some individuals who use AAC have the additional challenge of contending with issues associated with being a member of a diverse ethnicity as well.

Being a Member of a Diverse Ethnicity and Having a Disability

There are many multiple and unique needs of individuals from diverse populations when accommodating needs associated with disabilities. For example, diverse individuals with a disability may exhibit lower self-esteem than individuals with only one minority identity (Pape, Walker, & Quinn, 1983). An individual's ethnicity may influence his/her acceptance of and experiences with a disability (Ali, Fazil, Bywaters, Wallace, & Singh, 2001). Because each individual's experiences are unique, it is important to get the individual's perspective about his/her ethnicity and disability (Ali et al., 2001). It is important to address the individual's perception and goals of intervention and integrate them into therapy plans.

Not having needs addressed as perceived by the diverse family and individual with the disability may result in team conflicts (Zionts, Zionts, & Bellinger, 2003) and limited use of AAC systems and services. In regards to AAC, some diverse parents of children using AAC want their children to use AAC and succeed academically but are concerned about the additional social stigma (Parette, Chuang, & Huer, 2004). It is unknown if diverse individuals receive more discrimination or different types of discrimination than European American individuals using AAC. However, diverse individuals with disabilities are at risk for additional discrimination because they are a minority within a minority (Ali et al., 2001; Rogers-Dulan & Blacher, 1995; Vernon, 1999).

SLPs with limited skill with diverse populations (and may have decreased intercultural sensitivity) may be ill-prepared to value and accommodate ideals which conflict with the SLPs. SLPs are usually European Americans from middle SES with limited skill about working with diverse groups (Garcia, Perez, & Ortiz, 2000; Rosenfeld & Kocher, 1998). SLPs' views about cultural influences on language development, interaction patterns, and other topics affect their clinical decisions (Kritikos, 2003; van Kleeck, 1994). SLPs need to be aware of their culture and aware of cultural influences in clients' lives (Hayes, 2001; van Kleeck, 1994) since more than half of SLPs on two surveys work with diverse clients (Kritikos, 2003; Rosenfeld & Kocher, 1998). In one survey of SLPs who provided services to diverse clients, 95% of SLPs had clients who spoke more than one language on their caseload (Kritikos, 2003). The majority of the same SLPs reported that their knowledge and experience (or lack of knowledge and experience) with diverse cultures impacted clinical decisions. The lack of intercultural sensitivity by SLPs could complicate services provided to clients from diverse ethnic groups and also use AAC. At this time, the impact of the perceived intercultural sensitivity of SLPs by diverse clients is unknown.

AAC and Ethnicity Issues

Communication occurs within a cultural context (Hetzroni & Harris, 1996). Thus, at a minimum individuals need to be culturally competent communicators in interactions with individuals from the same cultural identities as themselves. The nature of AAC, however, requires that an individual who uses AAC be communicatively competent (Light, 1989) with using AAC systems and techniques and also with the communication styles of the communication partner. Some individuals who use AAC also need to be culturally competent in another language if family, friends, teachers, co-workers, and/or community members use a language other than their primary language. As a result, AAC systems may need to be adapted to meet linguistic and cultural needs (Huer et al., 2001; Parette, Huer, & Wyatt, 2002). For example, diverse children may communicate in Spanish at home and in English at school. Thus, AAC systems need to be designed to accommodate both languages for both the home and school environments.

Several studies have investigated cultural influences on AAC symbols, AAC system use, training expectations and decision-making. Research has demonstrated that the interpretation of AAC symbols is impacted by an individual's ethnicity to varying degrees (Huer, 2000, 2003; Stephenson & Linfoot, 1996b). An individual's cultural identities impact the level of acceptance and use of AAC (Parette, Huer, & Scherer, 2004). For example, SES has a strong impact on the acceptance and use of AAC due to experiences with technology or the lack of access to technology (Parette, Huer et al., 2004). Other families are concerned about the social stigma of using AAC and as a result may limit the use of AAC (Parette, Chuang et al., 2004).

For AAC training to be successful, SLPs need to be aware of 1) diverse families' and individuals' who use AAC perceptions about training and 2) linguistic needs (Parette et al.,

2001). In some diverse families, many individuals are involved in training and making decisions (e.g., community members, siblings, elders, etc.) (Parette, Brotherson, & Blake Huer, 2000).

Also, many families expect to build relationships with SLPs over time. Thus, socializing and sharing between the SLP and the client (and family) is expected and will impact how AAC training is perceived and accepted (Parette et al., 2000). Families need professionals to be aware of life demands and unique family experiences when providing intervention (Parette et al., 2000). For linguistic issues during training sessions, training in the families' native/primary language is recommended (Parette et al., 2001). Many diverse individuals living in the United States may have reduced reading/writing skills which may require bilingual materials for second language learners or orally provided information rather written material as part of accommodating cultural needs. Although research has identified the need to focus on diverse family and client needs when providing services to diverse clients who use AAC (Parette et al., 2000), it is unknown how diverse individuals who use AAC perceive the changes made to AAC services and systems.

Cultural Accommodations and AAC

AAC systems and services need to be tailored to the unique needs of diverse families and also build on family members' strengths while recognizing the limitations of circumstances and resources to support the use of AAC systems. Currently, some SLPs may be making cultural accommodations in AAC systems and services. Yet, it is unknown how diverse individuals who use AAC perceive the accommodations. It is unknown if the cultural accommodations are valued by diverse individuals who use AAC. It is also unknown if cultural accommodations which were made were functional as perceived by the diverse individual using AAC (Huer & Saenz, 2002). To explore the experience of being diverse and using AAC and the perceptions of

diverse individuals who use AAC regarding cultural accommodations in AAC systems, services, and related issues, phenomenology research methods were implemented in the current study.

Current Research Project

Currently, there is a limited perspective of individuals who use AAC (Bedrosian, 2000). Based on the research reviewed for the current study, several issues related to diverse individuals who use AAC are unknown. There is a lack of perspective from diverse individuals with communication disabilities who use AAC about their experiences using AAC. Little is known about ethnicity and AAC issues from the view of diverse individuals who use AAC. The impact of discrimination and other barriers as perceived by diverse individuals who use AAC is unknown. Likewise, the impact of support services as perceived by diverse individuals who use AAC is unknown. Also, recommendations for designing culturally sensitive AAC systems and services from the perspective of diverse individuals who use AAC are unknown. The following research objectives were designed to address these unknown issues regarding diverse individuals who use AAC.

Research Objectives

The overall objective of this project was to describe and develop an understanding about the experience of being Non-European American (i.e., diverse) and using AAC. In order to accomplish the overall objective, the following three sub-objectives were identified: a) to describe barriers and the impact of barriers on a person's life who is diverse and using AAC as perceived by the diverse individual who uses AAC, b) to describe support services and systems for diverse individuals who use AAC, and c) to describe cultural accommodations and recommendations that diverse individuals using AAC have had or would like to have in regards to AAC services and systems.

CHAPTER TWO
METHODOLOGY

Research Design

The research design for the current study was based primarily on phenomenology procedures with slight variations necessary for the research questions and the target population. Phenomenology research focuses on a concept or phenomenon to understand the meaning of the experience (Creswell, 1998; van Manen, 1997) from a post-positivist perspective (see Appendix B for a more extensive discussion of qualitative research and phenomenology) (Creswell, 1998; Denzin & Lincoln, 2000). In phenomenology, researchers explore the meaning of the experience by encouraging individuals to describe their everyday life experiences for data collection (Creswell, 1998). Phenomenology data analysis is a cyclical reflection of collecting, analyzing, and writing about the essence of the data (Creswell, 1998). Data are organized into categories of similar meaning and concepts (Lincoln & Guba, 1985) from which themes develop explaining essential aspects of a phenomenon or lived experiences (van Manen, 1997). The phenomenology product is a text such that the reader should be moved to better understand what it means to experience the individual's reality (Creswell, 1998; Rudestam & Newton, 2001).

Recruitment Procedures

Language and cultural barriers may exist which could impact the ability of diverse individuals to participate in research due to not being aware of the study (Shavers-Hornaday, Lynch, Burmeister, & Torner, 1997). To accommodate the needs of diverse participants, a variety of recruitment procedures were utilized since some diverse participants may have poor access to healthcare which limits their opportunities to learn about studies and participate in studies (Duncan, Strycker, Duncan, He, & Stark, 2002; Skaff, Chesla, Mycude, & Fisher, 2002). The following recruitment practices for contacting individuals who use AAC and/or diverse participants were utilized in this project (Creswell, 1998; Schiavetti & Metz, 2002): a) snowball

sampling, b) contacting SLPs via list-serve email in Special Interest Division 12 (AAC) in the American Speech-Language-Hearing Association (ASHA), c) placing advertisements in augmentative communication publications, d) contacting SLPs working at hospitals, clinics, and schools located in large, metropolitan areas with diverse populations, and e) contacting previous researchers who have published research with similar participants (Creswell, 1998; Duncan et al., 2002; Shavers-Hornaday et al., 1997). In addition, the following recruitment procedures were used: a) requesting participation on ACOLUG@LISTSERV.TEMPLE.EDU (list serve used by individuals who use AAC), b) conducting web searches for personal web pages of individuals who use AAC and c) contact company vendors. Participants in the project received an honorarium for participation.

Participant Selection Criteria

The targeted sample size was 6-10 participants within the continental United States (Creswell, 1998; Denzin & Lincoln, 2000; Lincoln, personal correspondence, 10/11/04). Participants were individuals who met the following criteria: a) individuals who were Non-European American but from the same ethnic populations as other participants, b) individuals who were 18 years of age or older, c) individuals who had the same diagnosis resulting in the need for AAC, d) individuals who used one or more aided AAC communication modes (light tech or high tech devices) for at least one year, e) individuals who had experiences interacting with people of their same culture and with people from a different culture, f) individuals who had the willingness and ability to discuss their life experiences in face to face interviews and through written correspondence, g) individuals who had the language skills to produce multiple symbol/word messages that relayed relevant information in response to screening questions on the Participant Information Form (Appendix C), and h) individuals who gave/signed a consent

form to participate in research. For the Participant Information Form, several of the participants had nondisabled peers complete the form for the participants because the participants had difficulty writing (others used an email version and typed their responses into the emailed version). For participants who had assistance with completing the form, the nondisabled peer was instructed by the researcher to write exactly the words, phrases, and messages that the participant produced. The nondisabled peer was instructed to not correct grammar or spelling nor was the nondisabled peer to embellish the statements.

In regards to cognitive ability to participate in the study, the participants needed to be able to recall and express past events. The participants needed to be able to explain possible reasons why events occurred in the individual's life. The participants also needed to demonstrate self-awareness. Several diagnostic tests used with teenagers and adults were reviewed in an attempt to find a suitable test item(s) to use for determining the participants' ability to participate in the study. No items were identified that could be used appropriately for the current study. Thus, as part of the Participant Information Form which was sent to potential participants with information about the study, two questions were asked: 1) what is a favorite memory of yours when growing up? and 2) why is this memory your favorite memory? The first question allowed the participant to demonstrate displaced talk, recalling events, and self-awareness. The second question allowed the participant to demonstrate abstract reasoning. Simultaneously, the participant's answers to the questions provided a forum for examining the expressive language skills of the participants. The responses were evaluated for clarity of the response, relatedness to the question, and rational reasoning of responses.

To be considered a potential participant in the study, the individual's answers to the questions must have demonstrated displaced talk, event recall, self-awareness, and abstract

reasoning. Also, the responses must have been multiple words expressing a coherent thought relevant to the question.

Potential participants who met the criteria were scheduled an interview. During the first few minutes of the interview the participant was asked screening questions which required the participant to demonstrate the following skills: a) displaced talk, b) abstract reasoning, c) multiple word/symbol messages, d) short term recall, and e) long term recall. The potential participant had to adequately answer all five screening questions for the interview to continue and participate in the study. All participants' responses on the Participant Information Form and the screening questions were reviewed by Rhonda Davis and Kathryn Drager, Ph.D. to determine if the candidate had adequately answered the questions for the study.

Selected Participants

After an extensive search for participants, nine individuals met the criteria for the study. The participants were matched as closely as possible in a variety of characteristics. Participants were African American adults who had Cerebral Palsy (CP). The participants had used aided AAC for 1-49 years (see Table 1). All the participants used at least one high tech aided AAC device and a few participants also used light tech devices such as notebooks and letterboards. Most of the participants also used unaided communication modes such as gestures and residual speech skills. Educational attainments ranged from finishing the 10th grade in high school to graduating from high school and beginning college (See Table 2). The participants ranged in age from 26-54 years of age (see Table 3). Within each decade (e.g., 20-29), there were at least two participants. Seven of the nine participants were employed in a variety of part-time employment. One participant had a paid position which was eliminated just prior to the interviews. As a result, the participant was retraining for a new job. The other participant who was not working

was also participating in vocational training. All of the participants indicated they were in a low SES. In regards to the participants' social life, three participants were married or dating, three were actively looking for a partner, and three were not interested in pursuing a relationship at the time. All participants had contact with community members from a variety of ethnicities including African American and European American. Community activities varied and ranged from shopping field trips from a disability service center to sports, church activities, and nationwide travel. Below is a description of participants with thick descriptions in Appendix D. The communication mode was designated by established standards in AAC texts (see Table 6) (von Tetzchner & Jensen, 1996).

Andy

Andy was 54 years old and had been using various AAC systems for 45 years. His vision was corrected to within normal limits with bifocal glasses. His hearing was within normal limits. Andy drove his electric wheelchair with his right hand and direct selected on his Dynavox with knuckles on his right hand. He could move objects with his right "pinky" finger such as a plate. Andy used his Dynavox to spell out complex sentences (e.g., "*It was hard, but I managed to communicate to the best of my abilities.*") with word prediction throughout most of his interview time. He rarely used residual speech and when he spoke it was single word messages. Andy did not have a light tech system. Andy graduated from high school with a regular diploma (see School for discussion regarding diplomas). He worked as a part-time receptionist at a disability center. He was married for 22 years. He was active in church and enjoyed being with family.

Brittany

Brittany was 54 years old and had been using AAC for 49 years. Brittany's vision was within normal limit. Her hearing was mildly impaired and she used a hearing amplification

system in one ear and to correct her hearing within functional limits. Brittany operated her electric wheelchair, Gemini, and other equipment with her toes on both feet. Brittany communicated primarily by producing sentences on her Gemini supplemented with her residual speech (e.g., “*I had hard time with the spell word.*”) Brittany did not have a light tech system but did have her previous device, a Dynavox. Brittany completed a special education diploma in school. She rented a room in a private home in which the owner provided assistance for her at home. Brittany’s job was recently eliminated and she was retraining for a new position. She had limited contact with the community. She enjoyed being on the computer.

Dedric

Dedric was 39 years old and had used AAC for 26 years. His unaided hearing and vision were within normal limits. Dedric operated his electric wheelchair with his right arm and his Liberator/Pathfinder with his left hand. He was swapping from his Liberator to a Pathfinder at the time of the study. His SLP took both high tech devices back to the clinic during the switch. Dedric used a light tech letterboard as a back up device where he spelled sentences most of his interview time (e.g., I d-i-d n-o-t g-e-t t-o t-a-l-k). Dedric rarely used his residual speech. Dedric completed a special education diploma. He lived in a group home/ institution with one roommate and 16 housemates. Dedric worked as an artist and painted art that was sold at his sheltered workshop. He also trained staff about AAC issues. Dedric had limited contact with the community. His favorite activities were painting and cooking.

Donald

Donald was 50 years old and had been using AAC for one year. Donald’s hearing and vision were within normal limits. Donald operated his electric wheelchair with his left forearm and used a headmouse to control his Vanguard II. Donald relied primarily on his residual speech

and supplemented with his Vanguard II and a list of messages on a light tech board throughout his day to produce sentences for communication (e.g., *everything cost a dollar*). Donald completed the 10th grade. Donald had a private apartment with aides for support. He was self-employed and sold snack food throughout his city similar to a street vendor. Donald enjoyed his work and contact with the people in his city.

Hubert

Hubert was 28 years old and had been using AAC for 15 years. Hubert's vision and hearing were within normal limits. Hubert operated his electric wheelchair with his right hand and used both index fingers to access his Dynamyte to produce sentences for the majority of his messages (e.g., "*when I was 1 3 I stopped talk*"). Hubert used his Dynamyte and light tech notebook throughout the day to talk to coworkers and friends. Hubert never used his residual speech throughout the interviews. Hubert completed a vocational diploma. Hubert lived in a private apartment with aides for support. Hubert worked in a sheltered workshop and a second part-time job as a grounds keeper. Hubert enjoyed going to the movies, eating at restaurants, and spending time with his girlfriend.

Jimmy

Jimmy was 48 years old and had been using AAC for 10 years. He wore glasses which corrected his vision to within normal limits. His hearing was within normal limits. Jimmy was ambulatory with an unsteady gait and used his right hand for direct selection on his Dynamyte. Jimmy could produce grammatically correct sentences on his Dynamyte but preferred to use multiple communication modes within a single sentence so that he might start with the Dynamyte, supplement with his backpack of props, and end with sign language (e.g., examiner: So who do you like to email? Jimmy: GROUP AROUND HERE friends (after completing

manual signs for 'group' and 'around here' the word 'friends' written as a whole word and the paper was turned to examiner to read). Jimmy used his residual speech for single word messages. Jimmy completed a vocational diploma. Jimmy lived in a private apartment with aides that helped with cleaning, cooking, and financial issues. Jimmy worked part-time as a janitor. He enjoyed being involved in a variety of sporting activities and traveling nationwide.

Keith

Keith was 26 years old and had used AAC for 21 years. His hearing was within normal limits. His vision was corrected to within normal limits with glasses. Keith was ambulatory for short distances in his home but in the community he used an electric wheelchair. Keith produced sentences on his Pathfinder for communication (e.g., "*I had a shirt that I made that says to be a gimp is to be myself and GIMP to our inner circle means gaining independence through motivated persistence*"). He occasionally used his residual speech or fingerspelling. When working as a self-employed part-time web designer, Keith used instant messaging (IM) to talk with customers and friends in his internet community. At home with his mother and brother, he would use the Pathfinder only on the main level of the house because it was too heavy to carry. His mother and brother provided minimal assistance with clothes fasteners and food preparation. Keith had some contact with the community primarily when he was with his brother or his girlfriend. Keith enjoyed his work and chatting with a multitude of friends online.

Loleeta

Loleeta was 46 years old and had been using AAC for 36 years. Loleeta's hearing was within normal limits. Her vision was corrected to normal limit with bifocal glasses. Loleeta controlled her electric wheelchair with her left forearm and used a switch which she activated with the back of head to scan on her Dynavox. Loleeta produced sentences on her Dynamyte for

most of her communication needs throughout the day (e.g., *I went to store get something to eat.*”). Loleeta worked part-time as a bus ticket manager at a disability center. She rarely used residual speech. She used a light tech letterboard when her Dynavox was not available. She rarely used either device when communicating with her mother or brother at home. Loleeta graduated with a regular diploma and was the only person in her family to complete high school. Loleeta went shopping and to restaurants routinely by herself or with friends. She enjoyed being in the community and was looking forward to trying to move to her own apartment.

Mac

Mac was 39 years old and had been using AAC for two years. His hearing and vision were within normal limits. Mac controlled his manual wheelchair with his feet and used a switch positioned near his right temple to scan on his Vanguard II. Mac produced simple sentences on his Vanguard II but preferred to use his residual speech whenever possible (e.g., *I can talk.*) Mac did not use his Vanguard II at home nor did he have a light tech system. Mac obtained a certificate of attendance from high school. Mac lived at home with a variety of relatives but his mother was his primary caregiver. Except for field trips from the disability center where he did vocational training, Mac had limited contact with the community. Mac’s favorite activity was watching baseball games.

Census Information about African Americans

Describing the population of African Americans would be nearly impossible with the many different sub-groups. The purpose of the comments below is to provide a brief overview of the ethnic identity selected for the study and how the data compared to the current participants. In the 2000 U.S. census, African Americans (non-Hispanic) comprised 13 percent of the total population (U.S. Census Bureau, 2005c). The majority of African Americans lived in

the South followed by equal numbers of African American percentages in the Northeast and Midwest, with the smallest percentage of African Americans living in the West (study participants were from the South, Northeast, and Midwest) (U.S. Census Bureau, 2005c). In a survey examining several components of African American life in the U.S., researchers identified that over one third of respondents were involved in their community as evidenced by participation in neighborhood organizations (including churches) (over half of study participants participated in neighborhood organizations) (Milburn & Bowman, 1991). On the same survey participants also reported that over 22% of African American households included a female head of household with children, other relatives, and non-related individuals (six study participants' households had female household heads with other relatives or non-related individuals) (Hatchett, Cochran, & Jackson, 1991). According to the U.S. Census Bureau (2005b) 26% of all households headed by a female were below the poverty level (all study participants indicated they were from below the poverty level or below \$25,000 for a household income for four) (Hatchett et al., 1991). Finally, African Americans (along with American Indian and Alaska Natives) had the highest disability rate reported in the U.S. at 24% (U.S. Census Bureau, 2005a).

Materials

Interview Question Construction

Semi-structured interview questions were developed to collect data regarding the individual's experiences using AAC. A review of literature was completed prior to the development of questions to ensure that key issues were included (Babbie, 1998; Fowler, 1993; Higginbotham, 2000). The interview questions were reviewed by experts in AAC, race/ethnicity/culture, and qualitative research (Babbie, 1998; Skaff et al., 2002). Based on feedback from the research panel, the interview questions were revised. Specifically, topic

changes included adding a focus about barriers to success when using AAC and being a diverse American. Also, changes were made to the interview questions to make the questions more concrete. After revisions were made, the interview questions were reviewed by an individual from a diverse ethnic group and an individual who used AAC. Both individuals indicated that they felt comfortable answering the questions and felt that the questions addressed key issues relevant to the topic (Babbie, 1998; Skaff et al., 2002).

Equipment

All of the initial interviews were videotaped using a Sony Digital Video Camera. All videotapes were copied onto VHS tapes for safe use during analysis. All videotapes used in analysis were kept in a locked file cabinet and coded for confidentiality. Codes for tapes were stored separately.

NVivo Qualitative Research Computer Program

Qualitative computer programs assist researchers in consolidating and establishing consistent patterns in the data (Denzin & Lincoln, 2000). NVivo 2.0 software is a qualitative analysis and data management system (Creswell, 1998). The program helps manage the volumes of text associated with qualitative research (Lincoln, personal correspondence, 10/11/04). Data analysis via coding of text across multiple participants is possible. Theme development is also possible by showing visual links between sets of data. NVivo is also designed for memos, multiple versions of category and theme rules for an audit trail, as well as documents from other sources such as Microsoft word, photographs, and audio-video clips. Qualitative software (e.g., NVivo) has been used for data analysis in previous research (Creswell, 1998; Loxley, 2001). In the current study, NVivo was used to manage the data from the transcripts. During the analysis

phase of the study, the coding feature was used to code the data. A data trail was utilized to identify if and when changes were made to category definitions.

Data Collection

Data were collected primarily through multiple face to face interviews (Creswell, 1998; Seidman, 1998). Face to face interviews were chosen because they provide a mechanism for developing personal contact with participants which is important when working with diverse participants (Skaff et al., 2002). The interviews were semi-structured with prepared questions to guide the interview according to the purpose of the interview (see Appendix E) (Rudestam & Newton, 2001). The interview is the most appropriate data collection technique for obtaining in-depth information regarding a phenomenon from participants because the researcher and participants can explore topics at length as appropriate (Creswell, 1998; Rudestam & Newton, 2001; Seidman, 1998). Interviews allow the researcher to understand how a person's experiences interacts with social and organizational forces (Seidman, 1998). Semi-structured interviews provide the guidance to keep the interview focused while allowing the researcher and the participant to jointly explore a topic as appropriate (Creswell, 1998; Rudestam & Newton, 2001; Seidman, 1998). Interviews were conducted in environments which were comfortable for participants (Parette, Chuang et al., 2004). The participants chose a variety of environments such as where they worked, where they lived, and where they received speech therapy services. All of the participants were observed interacting with individuals in their environment. Over half of the participants were observed in multiple locations.

A series of three interviews were conducted over a 7-14 day period (Seidman, 1998). An issue with using individuals who use AAC as participants may be that the individuals who use AAC may be limited in their ability to fully express themselves. Because of the concern with

not fully understanding the message, the researcher backchanneled (i.e., repeated the message 'received' to insure that the participants' views were understood) as appropriate (Buzolich & Wiemann, 1988). Each interview took 1-2 sessions. A session was approximately 1-2 hours in length. For the 3 interviews the participants were involved 6-12 hours. Participants reviewed a summary of his/her interview and completed written follow-up (i.e., member checks as defined in verification strategies below) (approximately 1-2 hours). Thus, the total participant time was approximately 7-14 hours. The three interview series helped manage some of the cross-cultural interactions between the researcher and participant by helping to develop a relationship and trust over time (Seidman, 1998). The first interview focused primarily on the participant's school age years in regards to issues related to his/her race/ethnicity/culture and AAC (Seidman, 1998). The second interview focused primarily on his/her current life in regards to issues related to his/her race/ethnicity/culture and AAC (Seidman, 1998). The third interview focused on recommendations to professionals regarding improving AAC services and systems to better meet his/her race/ethnicity/cultural needs (Seidman, 1998). Using multiple interviews allowed for the opportunity to observe internal consistency of responses from the participant (Seidman, 1998).

Two communication techniques with individuals who use AAC are backchanneling and coconstruction. Throughout the interviews the researcher completed numerous backchanneling episodes which consisted of repeating the message understood to the speaker (Buzolich & Wiemann, 1988). Backchanneling was necessary due to the type of interactive communication between individuals who use AAC and typically developing communication partners. Backchanneling provided both communicators an opportunity to ensure that the message sent was the message received. Coconstruction occurred when both communication partners participated in the construction of the message being created by the individual who used AAC

(Buzolich & Wiemann, 1988). In some situations the coconstruction was speaking the written letters/words or messages. In other situations the examiner may have engaged in a rate enhancement technique while reading the letters for a message and guess the final word. Finally, coconstruction occurred when the participant used unaided communication modes to relay part or all of a message and the researcher spoke words that may have represented the originally intended message. In each form of coconstruction the possibility existed that the participant's true message may have been altered or changed due to the nature of coconstruction. To ensure that the message was accurate and true to the intended words of the participant, the researcher completed numerous backchannels to verify the message received. The researcher also provided numerous options for words to be used to interpret gestures, facial expressions, and partially spoken messages to allow the participant to choose the words which reflected the message most accurately from the participant's perspective. For example, the participant might frown and the researcher would provide a series of words with numbers (e.g., 1=unhappy), visual spaces (e.g., if you look at my left hand you mean unhappy) or other coding systems which the participant could engage to indicate a message. After the message had been verified via backchanneling by the participant, the researcher would move to the next question. All interviews were completed with meticulous attention to understanding the message being sent by the participant to insure the highest possibility of accuracy while collecting data during the face to face interviews. The same meticulous attention was given to written follow-up after the interviews.

Follow-up (i.e., member check) with participants after their interviews was completed via email/postal mail to address any questions that needed further clarification and to allow participants to respond to the themes which emerged from the entire data set (Creswell, 1998). Procedurally, the participants were mailed summaries of the information obtained from the

interviews. Participants were asked to comment on the summary information as it pertains to their personal life (Creswell, 1998; Rudestam & Newton, 2001). Also, participants were asked to clarify statements they made during the interviews or answer additional questions about the interview topics. If participants used typically developing peers to assist with writing responses, the typically developing peers were instructed to not add words, correct spelling or grammar, and write the exact message produced. The participants mailed his/her responses back to the researcher.

Transcriptions

The videotaped interviews were transcribed prior to data analysis. The videotapes were viewed and the message in any communication mode was transcribed (e.g., gestures such as sign language or mimicking actions and objects; pointing at objects, people, and places). Speech and other communication modes were identified in the transcripts as part of the message so that the message and the communication mode were recorded. Backchanneling to make sure the message sent was the message received (Buzolich & Wiemann, 1988) between the interviewer and the participants was also noted in the transcripts. Reliability checks of the transcripts were completed (see Reliability).

Data Analysis

Qualitative research moves from an inductive paradigm of sources of data to develop an explanation of the experience (Creswell, 1998). Several steps to data analysis were completed. First, the entire transcripts for all data sources were read (Creswell, 1998). There was a constant movement between describing, classifying, and summarizing data (Creswell, 1998; Lincoln & Guba, 1985). Descriptions were designed to explain the phenomenon in context (Creswell, 1998). Classifying data meant that data were grouped into categories of similar statements and

similar categories were grouped into themes (Creswell, 1998). Themes are constructs derived from the data such that without the themes—the experiential structures of the experiences—the phenomenon would not exist (Denzin & Lincoln, 2000; van Manen, 1997). Common themes across participants were organized and presented to summarize data (Creswell, 1998).

There were several steps to classifying data (Lincoln & Guba, 1985). First, data were unitized which means that data was sectioned into the smallest set of text that could stand alone (Denzin & Lincoln, 2000; Lincoln & Guba, 1985). The units were categorized (classified). A tentative category rule was written for each category that explained the essence of inclusion into the category after approximately 50 units were categorized. The units placed together in a category were reassessed by the tentative category rule. Constant comparative analysis was completed by comparing each new unit to the tentative rules and units that had already been put in that category. After examining all of the raw data, all categories were reviewed for consistency (Lincoln & Guba, 1985). The tentative category rules were modified as appropriate. All data were examined by the new rule or rule adjustments. Final versions of the category rules clearly stated inclusion and exclusion properties of the category so that units in categories were similar (Lincoln & Guba, 1985).

After the data were categorized, the categories were examined to determine the quality of categories. Weak or not clearly established categories were used for follow-up with participants. Categories were also examined to determine if they were related (i.e., had similar concepts in the categories) to other categories and could be combined into themes (Lincoln & Guba, 1985). All data were examined by the new rule or rule adjustments for combining categories into themes. Final versions of themes clearly indicated inclusion and exclusion of categories so that units in the theme were similar (Lincoln & Guba, 1985). At the completion of data collection, the entire

data set was reviewed to determine if any units had been missed prior to the researcher writing summaries of the data. NVivo was utilized throughout data analysis to manage categories and themes developed by the researcher by color coding units across all interviews of all participants.

Verification Procedures

Verification is the process of confirming the truth/accuracy of data collection, analysis, and/or report writing (i.e., summary) throughout the study (Creswell, 1998). It is recommended that qualitative research projects include at least two verification strategies (Creswell, 1998). A variety of verification strategies was used in this project during the data collection, analysis, and report writing phases of the study. Bracketing (i.e., written statement clarifying the primary researcher's view and potential bias so that it is clearly identified for the reader) was completed to reduce its potential influence on the data analysis and report writing (Appendix F) (Creswell, 1998). Multiple interviews with multiple participants were completed to help establish credibility (i.e., believability) of the data collection and analysis (Lincoln & Guba, 1985; Rudestam & Newton, 2001). Throughout the duration of the project peer reviews were conducted (i.e., regular meetings with a researcher not directly involved in the research process) for the purpose of questioning the data collection, analysis, and report writing to ensure it was a true/accurate representation of the participants' meaning (Creswell, 1998). A summary of the peer review meeting was written to provide a data trail.

After the interviews were completed, other verification strategies were implemented. Member checks were completed (i.e., obtaining the participant's perspective of the data collection and analysis) to verify the accuracy of his/her own data and the credibility of the data analysis (Lincoln & Guba, 1985; Rudestam & Newton, 2001). To ensure that the participants' voice/perspective was heard in the final report writing, quotes were included as appropriate

(Creswell, 1998). The verification strategy of thick descriptions (i.e., detailed descriptions of participants, settings, and situations) were completed so that readers can apply the findings to other situations (Lincoln & Guba, 1985; Rudestam & Newton, 2001).

Research Assistant Training

Research assistants (RA) (undergraduate student volunteers) were involved in the reliability procedures (see reliability procedures below). All RAs completed the IRB training program at Pennsylvania State University. All RAs completed training regarding their role in reliability measures. RAs completed training and practice regarding transcribing and classifying data with supervision and guidance from the primary researcher. In addition to training by the researcher about the categories and themes, the RAs were required to produce the category definitions in their own words as well as create examples explaining the categories and themes to ensure that the categories and themes were be applied uniformly across RA and the researcher. When the RA achieved 90% accuracy or better as compared to the primary researcher, the RA was involved in reliability measures by checking randomly selected material which was assigned by the primary researcher.

Reliability Procedures

Reliability is the “consistency among repeated observations of the same phenomenon” (Hegde, 1994 p. 129). Two reliability measures were completed with the current study: a) intraobserver reliability measures, and b) interobserver reliability measures. Intraobserver reliability is the measurement for the same phenomenon for the same observer (Hegde, 1994; Kazdin, 1982). Intraobserver reliability measures were completed for 20% of data transcript pages (Neuman & McCormick, 1995). The primary investigator completed each task (i.e., transcriptions, units, categories, and themes) two times and compared the two versions to

determine if both tasks were consistently completed. The data compared for reliability measures was the messages produced by the participants and the researcher. The formula for both intraobserver and interobserver reliability checks was the sample size (e.g., for transcriptions the number of words in the transcript) minus the number of differences divided by the sample size. The intraobserver reliability was 98% for transcriptions, 99% for units, 98% for categories and 98% for themes. Interobserver reliability is the measurement for the same phenomenon for different observers (Hegde, 1994; Kazdin, 1982). Interobserver reliability measures were completed on 20% of transcriptions, units, categories, and themes across for each participant's data (Neuman & McCormick, 1995). The researcher and research assistant completed the same task (i.e., transcriptions, units, categories, and themes) and compared the two versions at each stage of analysis to determine if both tasks were consistently completed. Discrepancies were addressed and resolved prior to moving to the next task.

Reliability checks (intraobserver and interobserver) of 80% or better agreement between intra- and inter-observer measures indicates good reliability (Krippendorff, 2004). If interobserver reliability checks had fallen below 80%, disagreements would have been discussed with the RA. If the RA misinterpreted or misunderstood the concept, the issue would be discussed with the RA to resolve the discrepancy. If the RA did not understand procedures, the RA would be retrained. If the RA and the primary investigator identify a discrepancy in the categories or themes, the categories or themes would have been re-examined. If categories and themes had needed to be adjusted by the primary investigator, the entire data set would have been reviewed for any changes to the category or themes. Interobserver reliability was 90% for transcriptions, 95% for units, 85% for categories, and 87% for themes.

CHAPTER THREE

Results

Twenty-seven categories emerged from the data analysis and were organized into six themes: a) location, b) barriers, c) supports, d) individuals (subdivided into people and people characteristics), e) interventions, and f) recommendations (see Table 4). Based on the data, the impact of the individuals and interventions themes on the participants varied according to places within the location theme. Individuals and interventions which were identified as supportive in one location may have been a barrier in a different location. Within a location, an individual or intervention could be a barrier, support, or neutral (i.e., the participants did not report an individual or intervention as helpful or a hindrance). As a result, the individuals and interventions were discussed in relation to the barrier and support themes according to the location theme. Also within a location, the participants made recommendations about individuals and interventions. The results of the study were organized according to locations while addressing barriers, supports, and recommendations for improving AAC systems and services. Issues identified as Barriers, a Barrier as well as a Support, Supports, and Recommendations by participants were summarized in Table 5. To be true to the participants' original messages, quotes utilized commas in the text to represent pauses during message construction and delivery to the listener (the researcher in most situations). The communication mode was designated by established standards in AAC texts (see Table 6 for samples and descriptions of communication mode designations) (von Tetzchner & Jensen, 1996).

Home

The majority of the data about home referred to housing, individuals in the home, and equipment. Participants discussed housing arrangements as a child and in their current lives. The individuals who lived in the same home were also discussed. Participants also discussed services and equipment they received or desired in their homes.

Home Prior to Adulthood

As children, seven of the nine participants lived in traditional homes with one or more family members. For the seven participants who lived in traditional homes, most of the participants had a variety of family members in the home such as parents, siblings, uncles, and grandparents. Two participants (i.e., Andy, Hubert) moved to larger cities to receive services for individuals with disabilities. For Andy, the move meant splitting his family so that he was raised by his mother and his sister was raised by his grandmother in another city.

Two participants, Dedric and Jimmy, lived in state operated institutions for children with disabilities. Jimmy met his mother twice. Dedric never met his family members. Dedric's first Home was an institution created to simulate small homes with staff providing services for activities of daily living (ADLs). When he was a teenager he was moved to a housing complex and school for children with CP. Dedric reported that both of his housing situations provided services which were relatively supportive/adequate for his needs but that he missed not knowing his family.

For Jimmy, his housing situation as a young child was unique. He lived in a barrack style institution with approximately 50 children with disabilities in one barrack. Several of the children were placed in straight jackets. The staff provided minimal care for Jimmy and the other children. Jimmy recalled several instances of abuse including beatings with belts. Overall, the services provided were barriers to care. The institution was closed by state authorities when he was approximately 13-14 years old and he was sent to live in a small town group home. There were six adult men with disabilities in the group home. The group home had "parents" that lived on site and provided services which were supportive. However, Jimmy reported there was no privacy and no parental love displayed to Jimmy in the group home.

Barriers

Although most of the participants reported that they were cared for well as children, the participants identified several barriers. Most of the barriers were due to the lack of interventions such as services and equipment. Some of the participants who could not walk did not receive wheelchairs to use at home or school until they were school-age. Andy said about his mobility equipment, “*At first I had wooden chairs and later on they [PT at school] gave me a walker.*” None of the participants recalled any adaptive equipment for activities of daily living (ADLs) in the home.

AAC. The intervention of AAC light tech devices was not received by participants until school-age. For Donald, Jimmy, and Mac, AAC devices were not received until adulthood. For the six participants who had AAC devices as children, only Keith reported using his AAC device at home with family. Keith reported being frustrated with his light tech AAC device because the communication speed was too slow and family could not keep pace with his message construction. Keith said, “*I was, pointing, as fast, as, I was thinking . . . I had to repeat myself.*”

All of the participants received the intervention of care for their daily needs in the home as children. However, not all of the participants considered the care supportive. Detric indicated that the intervention services he received in two different institutions were adequate but the care he received was not always the same as the services received by European American children with CP. For example, Detric described a few incidences when European American staff (i.e., theme of individuals) called him derogatory names because of his ethnicity while providing services. Jimmy reported that abuse and neglect were common behaviors of the staff at his first institution. In regard to intervention therapy services, all of the participants indicated

that they did not receive therapy services such as physical therapy (PT), occupational therapy, (OT), or speech therapy (SLP) in the home.

Supports

The participants only identified a few supports in the home environment. The identified supports however, were considered very helpful. A few had the intervention of equipment such as manual wheelchairs when they were young and as teenagers a few had switched to electric wheelchairs. The wheelchairs were strongly considered supportive by the participants.

The only intervention service provided in the home for participants was assistance with ADLs. As children, none of the seven participants living with family identified any disability services provided for them in the home by service personnel. The mother was the primary caregiver for seven of the participants and helped the participants with ADLs. The seven participants indicated that the care provided by their mothers during childhood was supportive.

Recommendations

Across participants, there were very few recommendations for improving life as a child. All the participants recommended having the intervention of equipment including AAC systems in the homes. All of the participants indicated a desire to use AAC systems with family and friends in the home when they were children. Some of the participants believed having individuals such as aides in the home for help with ADLs would have been beneficial. Most of the participants indicated a strong desire for intervention services of PT, OT, and SLP to be provided in the home because they wanted their families to be included.

Home in Current Life

As adults, eight participants lived in houses or apartments alone or with family members. Dedric lived in a group home. Approximately half of the participants wanted to change housing

arrangements. For example, Keith was planning to move to a new state and live in his first private apartment. Loleeta wanted to move back to a private apartment and by the time of follow-up questions of the study, she was working to get an apartment and schedule aides to help her in her new home. Andy, Donald, and Dedric wanted their own houses. When asked about the house, Donald wanted *to own a real nice house where everything [equipment] is in it.*

Barriers

Most of the participants identified several barriers within their current life pertaining to intervention such as equipment and services in the home. One equipment concern was the lack of adaptive equipment available in the home. Most of the participants had limited access to environmental control units to open doors, turn on lights, and complete other household activities. Some participants, like Loleeta, did not have environmental controls.

Some of the participants reported that individuals in their homes restricted their life. For example, Loleeta said that her mother did not respect her wishes and requests. Dedric reported that staff and administrators restricted his activities in the Home and in the Community.

Many participants found scheduling individuals such as aides to help with ADLs in the home difficult. Most participants only had two aides so gaps in the schedule existed when aides were busy. For other participants, scheduling intervention services was hard because aides had to work a minimum of four hours when the participant only needed 15 minutes to an hour of assistance.

Keith: "I use them [aides] to travel, putting on my shoes, cutting up food, buttons. But I haven't used them at home because it's a different mindset then how I and we use them in [name of his college] at my college because the county requires 4 hours straight and I had to say this is what I'm doing before they come."

AAC. Most of the participants reported that intervention equipment such as AAC high and light devices in the home were supportive. However, Loleeta's and Mac's experiences using AAC with individuals such as family in the home was a barrier. The family of Loleeta and Mac would not use any high tech or light tech devices. Both Loleeta and Mac's family preferred for Loleeta and Mac to use gestures and residual speech. Loleeta and Mac indicated they were frustrated by their limited communication abilities at home. Loleeta was especially frustrated because her mother, her primary caregiver, was hearing and vision impaired which complicated communication even further.

Loleeta: "*She can't hear*"

Researcher: she told me she has a hard time hearing in her left ear. Do you think it's in both ears?

Loleeta: 'yes' (headnod)

Researcher: . . . Wow. That just makes it even harder. Does she have a hard time understanding the words on the device?

Loleeta: 'yes' (headnod)

Researcher: yeah. But she also has a hard time when you try to talk to her. 'Cause I saw you using your speech on Saturday and she didn't understand what you were saying. And that happens a lot?

Loleeta: 'yes' (headnod)

Supports

A variety of supportive intervention equipment used in the Home was recalled by all the participants. Some of the more frequently identified equipment were wheelchairs, hospital beds, speaker phones, and adapted toilets. Less frequently mentioned equipment items were environmental control units, computers, and adapted handles on doorknobs and refrigerators.

The participants received a variety of intervention services in their homes including individuals such as aides to help them with ADLs, housekeeping services, and wheelchair services. Only Dedric received SLP in his home and reported that the SLP was supportive. If the other participants received therapy services, the services were provided at clinics in the

community. All the participants reported that the services they received in the home were supportive to varying degrees.

AAC. A variety of communication modes were used in the home including intervention equipment. Seven of the nine participants used either a high tech or light tech device to communicate with aides, family, and friends in their homes. For the participants who used AAC in the home, the participants indicated that the devices were helpful (supportive) for general communication. As Andy said, *“The [name of device] is a part of my life and I wouldn’t be myself without it.”* However, most participants indicated they were frustrated by the lack of vocabulary available for communication in the home. The participants said that the vocabulary available to them was helpful for daily needs but did not reflect the vocabulary and slang they used when communicating with African American individuals such as aides, friends, and family. All of the participants indicated that device changes such as adding vocabulary and changing access methods were helpful. However, when asked if any device changes had been made to their devices to add African American vocabulary and slang, most participants simply responded “no”. If they had the ability to program their devices themselves, they reported they added words/slang to use with African American communication partners.

Andy: *“My friend, [friend’s name], and I joke around with each other and I say ‘Oh shut-up jive turkey’.”*

Brittany: (in response to who added a page in her Gemini called ‘soul food’) *I did!*

Keith: *“Slang,”*

Researcher: Yeah,

Keith: *“is, time, sensitive.”*

Researcher: uhuh,

Keith: *“so, I, program, it, on, the, fly.”*

Researcher: You do—you, you type it out when you want to do it right then but you don’t have it preprogrammed.

Keith: *“I, save, it, on, the, fly, too.”*

Researcher: Okay can you give me an example of something you've saved—that's G rated.

Keith: "*When, I, first, got, this, the, bud, weiser, commercial, was, hot, so, I, program, this,*" ((plays pre-stored message)) What's uup!

Recommendations

Several recommendations were made for intervention services and equipment. For services, participants wanted more aides for scheduling flexibility. For equipment, participants suggested that homes be equipped with environmental controls or be wired so that environmental controls could be added. Most equipment recommendations pertained to improving AAC devices.

AAC. The participants provided numerous suggestions for improving AAC devices via the intervention of device changes so that the devices could be used with African American communication partners in the home. One of the most frequent recommendations for improving AAC devices was to add more vocabulary. Specifically, *more words that we always use* as Donald explained because he wanted more vocabulary/slang used by African Americans when speaking to other African Americans. Donald, who preferred to sing in church with his device, also wanted his device to sing *more spirituals*. Donald showed his song page to emphasize his point. On the device song page, the songs listed were traditional hymns. For the participants who had the ability to program their devices, they appeared to be somewhat less concerned about adding vocabulary to meet their needs. Only five of the nine however, programmed their devices. For the five participants who could program their devices, the programming often required enormous time investments because of the individuals' physical limitations. Even with the ability to program, participants wanted devices to be pre-programmed with African American vocabulary and slang.

Researcher: Do you wish you had some of these [African American foods]?

Andy: “*I sp—((device stops and Andy hits button again)) I spell it out*”

Researcher: . . . Would you like it to be preprogrammed?

Andy: “*Yes*”

A second device change intervention for improving AAC devices was to make the devices more representative of the person who used AAC. Keith articulated the representation concept when he said, “*because it’s my device and a device is just an extension of myself.*” The need for AAC devices to better represent the individual who used AAC was manifested in requests for changing the icons on AAC devices and changing the voice output options. For the icons that represented words and concepts, most of the participants preferred the icons to have different skin tones.

Dedric: I w-o-u-l-d l-i-k-e t-o c-h-a-n-g-e t-h-e p-i-c-t-u-r-e-s

Researcher: ok. And what would you like the pictures to look like?

Dedric: A-f-r-i-c-a-n A-m-e-r-i-c-a-n-s

In regards to changing the voice output on high tech devices, participants wanted the option to have an African American accent so that participants pronounced words the same way they heard other African American pronounce words. As Andy said in his second interview, “*Pronouncing words correctly.*” In his third interview, Andy expanded his thought on African American accents being in AAC devices when he stated, “*Making it more suitable and add more pronouncing words because of us speaking like we’re from the South.*”

Overall, AAC devices were considered supportive rather than as a barrier to communication in the home for the participants who used AAC devices in the Home. For Mac and Loleeta, not using AAC devices in the home was a tremendous barrier to communication with the individuals in their Homes. For the participants who used AAC devices in the home,

the vocabulary was helpful for communication with European Americans and basic communication but the vocabulary was not very conducive for interactions between the African American using AAC and African American individuals. The AAC devices limited the participants' ability to interact socially with other African Americans.

School

The participants described a variety of school experiences across elementary school, high school, and college. Although each participant's experiences were unique, similarities were observed across participants in regards to individuals and interventions. All of the participants spent part of their elementary and/or high school years in classes in which the majority of the individuals were peers with disabilities. Only Keith experienced full inclusion into classes with typically developing peers. Of the other eight participants, four were mainstreamed for class time with typically developing peers and the class time was usually non-academic courses such as art and playtime on the playground. Five of the participants' school experiences were further segregated from typically developing individuals because their classes were held in separate schools for children with disabilities.

Educational achievements were varied. Participants either reported the type of high school degree obtained or described the coursework completed in high school which provided some indication of the type of diploma obtained. For example, Hubert discussed his vocational training classes whereas Andy mentioned English, history, and math. Three participants described graduating from high school or coursework often associated with graduating from high school. Keith graduated from high school and had attended two years of college. Two participants completed vocational diplomas. Two participants completed special education

diplomas. Mac recalled being in special education classes through the age of 22 but could not recall academic coursework or graduating from school. Donald left school after the 10th grade.

In the school location, the lines between barriers and supports were blurred. Most of the interventions (i.e., services, equipment, and device changes) and individuals in the participants' lives were frequently a barrier and a support. In general, interventions were somewhat supportive but the participants indicated that the supports did not fully meet their needs or help them to progress in their lives. The individuals discussed by the participants were in general helpful but nearly all of the participants recounted instances in which the individuals would be considered barriers. The primary barrier associated with individuals was discrimination in a variety of forms such as name calling, reduced services as compared to European Americans with disabilities, and restricted access to academic coursework.

Barriers

The barriers identified by the participants at school were primarily related to AAC issues (i.e., intervention equipment) rather than general service and equipment issues. Most of the participants reported not having equipment to help them with academic work. Discussions about barriers tended to focus mostly on the individuals who provided services that the participants received.

The individuals identified as barriers in school were therapists and aides in the classroom. Seven of the participants reported receiving two or less hours of intervention for each of PT, OT, and SLP. All seven of the participants did not believe they received enough therapy to meet their needs. Donald emphatically reported that "*They [European American children with disabilities] had more services*" and that the reason he received less therapy service time than European Americans with disabilities was due to his ethnicity. Even though all the participants reported

that individuals such as aides were helpful, most of the participants recounted instances in which intervention services provided by aides were obstacles, even discriminatory. Donald recalled several instances in which European American aides refused to provide services for him. In the incident below, Donald recalled an incident between himself and a European American aide whose job at school was to help children with disabilities in the restroom.

Donald: *well, I remember ((struggles)) XXX [unintelligible speech] bathroom*

Aide: you remember one time you had to go to the bathroom

Donald: *XXX [unintelligible speech]*

Aide: where were you when you had to go to the bathroom?

Donald: *at school*

Aide: ok

Donald: *he didn't want to help XXX [unintelligible speech]*

Researcher: so you were at school and you needed to go to the bathroom. And this was a White guy who was supposed to help people in the bathroom with disabilities, but he didn't want to help you. Is that what I am hearing?

Donald: *yeah*

Researcher: So what happened? Did he do his job or did he just refuse?

Donald: *Someone else helped me*

Researcher: How did you feel about that?

Donald: *got mad*

Aide: you got mad

Donald: *I curse*

Researcher: you started cursing at him. So you told him what you thought of him. ((everyone laughing))

Donald: *yeah*

Researcher: so the other people that finally came and helped you, were they a White person or were they African American?

Donald: *they were African*

AAC

Six participants had AAC devices (i.e., intervention equipment) provided for them at school. When asked about their AAC devices in school, the participants reported that the AAC devices were helpful but did not fully meet their communication needs. Slow communication rate, poor access methods, and limited vocabulary were frequently mentioned barriers. Another

barrier participants reported was that the AAC devices did not have African American vocabulary which they wanted to use when talking to African Americans in their environment. The majority of participants indicated that The SLP was the individuals who added vocabulary (i.e., device change intervention) to their AAC devices.

Speech language therapy intervention was considered helpful for developing general communication skills but not helpful with AAC or African American issues. Keith reported that his SLP after he changed schools did not know about AAC and as a result “*I, dislike, speech language pathologists.*” When participants were asked about how their cultural identity was accommodated (i.e., intervention) in speech therapy, all of the participants reported no cultural accommodations were made. Specifically, none of the participants reported intervention such as any vocabulary or slang being added that would be more commonly used in the African American community. None of the participants indicated that African American holidays or heroes were utilized in therapy sessions as language material. None of the participants reported SLPs discussing African American interaction styles or asking about African American preferences. None of the participants recalled SLPs trying to include their families in therapy plans or sessions. During interactions with the SLP during therapy sessions, the participants said that the SLPs were friendly but were not very social in their interactions. As Keith stated, “*I think it’s the culture on a whole, they need to loosen their scarves.*”

Supports

The participants identified a variety of supportive intervention such as equipment and services. The participants used many of the same equipment at school as they used at home. Wheelchairs were the most commonly mentioned equipment. Andy used a typewriter and Keith

used a computer to complete academic assignments. No other equipment was identified to help participants with academic work.

The services provided in the classroom across participants were very similar. In general, individuals such as teachers and other authorities were not primary caregivers as evidenced by helping with ADLs. Individuals such as teacher aides helped the participants with activities of daily living. Many of the participants had similar statements as Donald when he said that aides *help me with my work*. Many of the participants indicated that teachers and aides were a support. However, some participants preferred services provided by friends. Hubert said when asked if he had a teacher's aide in class, *"I use my friends more."*

All of the participants reported they had received intervention services such as PT, OT, and SLP at school. Only Brittany and Keith recalled receiving three or more hours of PT, OT, and SLP each. In the early grades, Keith received therapy daily. Brittany and Keith said the therapy services were adequate. All of the participants indicated that PT, OT, and SLP were somewhat helpful or helpful.

AAC

For the participants who had AAC devices, the intervention equipment was identified as supportive for basic communication. Participants indicated that AAC devices were helpful with communicating with individuals such as teachers and aides. Only a few recalled using AAC devices with friends. Most participants indicated that AAC devices were helpful during academic activities in class.

Recommendations

Recommendations for improving school focused primarily on AAC devices and services. For school in general, all of the participants wanted full inclusion with typically developing peers

not only for academic opportunities but also for social interactions with typically developing peers. Keith cautioned that full inclusion without contact with peers with disabilities caused him to be isolated. Rather, he preferred to have a mix of students with or without disabilities so that students with disabilities did not have to choose between academic stimulation and social connectedness with peers with disabilities.

Keith: *“Being or having a disability is a dichotomy of being socially stimulated and academically stimulated when you are in primary and secondary school. So the transition [from special education class to full inclusion] was rough on both aspects due to me gaining more challenges academically but being more isolated due to not having the disability. That is like you [the researcher] being a female and going to an all boy school just because you are that smart.”*

AAC

The participants had numerous recommendations for improving AAC devices and intervention services when they thought about the AAC devices and services they received in school. Loleeta said when asked what she wished she had had in school, *“I wish I had a [device name].”* Every participant wanted high tech devices in school to be used throughout their school careers. All of the participants believed that having a high tech AAC device would have helped them academically and socially by improving their communication with peers.

All of the participants but Keith and Brittany (who had three or more speech therapy hours) wanted more time in speech language therapy. As Donald stated, *treat all kids equal* at school for intervention services whether the children were African American or had disabilities. Most of the participants wanted their families involved in speech therapy. Most of the participants were very concerned that the desires of the individual who used AAC were incorporated into therapy plans. For example, Dedric said that SLPs should a-s-k t-h-e-m [African Americans who use AAC] w-h-a-t t-h-e-y w-a-n-t t-o u-s-e for communication.

The participants also mentioned several recommendations for improving ST services which pertained to SLPs (i.e., individuals) rather than the types of intervention services provided. Most participants wanted SLPs to be more social with them. For example, Hubert wanted, “*Be more friends. Get close and talk more.*” All of the participants wanted the SLPs to know more about African Americans. There was some concern voiced that European American SLPs did not understand African American clients. Dedric felt so strongly about the lack of understanding of African Americans he said, I t-h-i-n-k A-f-r-i-c-a-n A-m-e-r-i-c-a-n-s t-h-a-t a-r-e s-p-e-c-h p-a-t-h-o-l-o-g-i-s-t-s c-a-n d-o b-e-t-t-e-r for providing intervention services to African Americans who use AAC.

When asked how the SLPs should learn about African Americans, all the participants wanted SLPs to learn about African Americans in college. As Hubert said when told that not all SLPs have studied cultural issues, “*go back to school.*” Dedric had a different recommendation for SLPs to learn about African Americans and AAC.

Dedric: I w-o-u-l-d d-o a w-o-r-k-s-h-o-p f-o-r t-w-o w-e-e-k-s t-o s-h-o-w e-v-e-r-y-b-o-d-y t-h-a-t B-l-a-c-k A-m-e-r-i-c-a-n-s c-a-n u-s-e d-e-v-i-c-e-s

Researcher: What else do you want people like me, speech pathologists, to learn?

Dedric: W-e a-r-e v-e-r-y s-m-a-r-t

All of the participants wanted SLPs to develop their knowledge and skills regarding AAC issues as well. Jimmy wanted all college students to study all issues pertaining to AAC. One AAC issue, self-programming, was an issue participants believed SLPs should consider. Keith, felt strongly that SLPs should teach individuals who use AAC to program their own devices.

Keith: “*I think that speech language pathologist should teach people how to program their own devices and let them experiment while they [SLPs] are experimenting themselves. But I think speech language pathologists are control freaks. They have to know everything before they can teach.*”

A final recommendation pertained to intervention services and was to start working with AAC as soon as possible. All of the participants felt strongly that AAC should be implemented as soon as possible in the early grades in School. Keith and other participants realized that many SLPs are inexperienced with AAC. His suggestion for solving the problem of an inexperienced SLP and providing services to individuals who needed AAC was for SLPs to learn with the client.

Keith: "This is for aug. comm. users on the whole. That it is ok to be dumb. I know you [SLPs] all have or had 3.6 or whatever in college and have at least a master degree but it's ok not to know everything and look at teaching the device like you are a sergeant in World War I and don't know what the hell you are doing yourself. But teach the user how to fight the war on self communication."

Overall, participants indicated that interventions such as AAC devices and services that were provided assisted the participants in school. All of the participants, however, indicated that AAC devices and services were not accommodating of cultural differences and the needs of African Americans who used AAC when communicating with other African Americans. Participants identified that individuals including SLPs lacked knowledge about AAC devices and African American culture. Participants desired for SLPs to develop their knowledge about AAC issues and African American culture while students in college and additional workshops. Participants also identified a desire for SLPs to be more social and engaging while providing therapy.

Vocation

The participants worked in a variety of employment opportunities completing a wide array of tasks. Despite the differences in individual tasks, there were similarities across participants regarding vocational issues. One similarity across participants was the amount of

time worked on an average basis. Seven participants worked part-time. Jimmy worked 25-30 hours a week which was the most average weekly hours spent on job related tasks. Brittany and Mac were not working at the time of the study and were completing vocational training. Brittany had worked until a few weeks prior to data collection but her subsidized position was eliminated. All of the participants wanted to work part-time or full-time with typically developing peers.

The second similarity between participants regarding vocational issues was the types of employment. Eight participants worked in positions which did not require college coursework. For example, Andy worked as a receptionist. Loleeta worked as a bus ticket manager. Jimmy worked as a janitor. A few participants worked additional jobs to supplement their income. For example, Andy taught classes on money management and legal rights. Hubert worked seasonally as a grounds keeper. Finally, Dedric taught staff about AAC and devices.

The third similarity between participants in regards to vocational issues was that the concept of vocation was intertwined with financial constraints and financial freedom. The participants who worked enjoyed their jobs. The participants liked having earned income separate from the funds they received from the government. Most of the participants indicated they wanted to be financially independent and not need governmental support. As Keith said, *“Isn’t that the goal of everyone?”*

A fourth similarity between participants in regards to vocational issues was that all of the participants interacted with a variety of individuals with disabilities and typically developing peers while working. During the course of the interviews, the participants chose to focus more on their interactions with typically developing peers. Most participants did not distinguish between issues related to general disabilities versus speech disabilities when discussing interactions with typically developing peers. Only Keith commented on the differences between

individuals with disabilities who could use natural speech and individuals who used AAC when interacting with typically developing peers. Keith said, *“I think it’s a total difference between non-verbal and verbal people with disabilities because non-verbal pick their spots to say something and verbal can integrate themselves more to be more social.”* Keith shared a poignant example of individuals with disabilities trying to interact with typically developing peers. Keith said, *“Like lunch or dinner I could be more interacting- because you saw me yesterday, I have a hard time speaking and eating but that is where most people talk. . . . It makes me stand out if I take forever but isolates me if I don’t speak.”* The researcher observed this phenomenon occur while eating meals with three participants on three different occasions.

Barriers

Most participants discussed very few barriers in their jobs because their jobs had been adapted to their abilities. One barrier identified was the intervention services provided by individuals such as staff and aides. Although the participants who used aides at work reported that aides were supportive, the majority of comments about aides were negative. For example, Brittany reported that aides did not take the time to make sure they understood her message. Jimmy had staff ignore him. In one instance, Dedric was told by his aide that Dedric was the equivalent of what was in the diaper.

A second barrier regarding vocational issues was not being hired or allowed to work with typically developing peers or European Americans. A few participants believed that being African American made it hard to find employment and to work. Donald for example, was told not to sell on certain streets while street vending by European American store workers but not by African American store workers. Donald said, *Sometimes they [European store workers] different. Sometimes they ask me XXX [unintelligible speech] move on.* While a few provided

instances of discrimination due to ethnicity, all of the participants indicated that being disabled with a speech disability negatively impacted their ability to obtain employment or to work. For example, Keith applied online where employers did not know his ethnicity but did know about his speech disability. Keith said, "*It [AAC device] stigmatizes me.*"

AAC

The one consistent barrier related to AAC devices (i.e., intervention equipment) was the lack of durability. Keith indicated that his AAC device was not water resistant. Because he drooled, he had to be careful to keep moisture off his device. Keith also bought a waterproof case for his device to help with moisture control so the device had to stay in the case at all times making it more difficult to carry. Mac was particularly frustrated with his device. His device was broken so often he could hardly use it. When asked if AAC had improved his life, Mac said that AAC made his life *harder*. Donald and his customers enjoyed his device for communication but his battery would not last throughout his work day. When his device stopped working, Donald had to rely on his residual speech and eye gaze with customers which was much more difficult. However, Donald's speech skills were not dependable. As Donald stated, *Sometimes I have good day sometimes I don't . . . sometimes I be tired*. With her toes, Brittany reattached the device's power cord to her electric wheelchair battery constantly throughout the interviews conducted at work. She was very agitated and frustrated (as evidenced by Brittany throwing herself into her wheelchair and vocally exclaiming at her device repeatedly throughout her interviews) because she had to start her message over from the beginning because the device did not auto-save work.

Supports

The participants identified a variety of intervention equipment designed to support them while working. For example, Andy worked as a receptionist and needed to be able to answer phones. His employer supplied him with a speaker phone he could access with his right “pinky” finger. Hubert worked as a groundskeeper at a baseball field and needed to be able to pick up trash. Hubert’s employer supplied him with a reacher so that Hubert could collect trash off the ground while in his wheelchair.

AAC

All of the participants strongly indicated that their AAC devices and other intervention equipment for communication used at their jobs with individuals such as peers, aides, and employers were extremely helpful. *I like to talk* replied Mac when discussing using his AAC device at his vocational training. The AAC devices were the primary communication equipment used at work but other equipment was identified as well. For example, Jim said, I use sign language, the computer, a voice machine [AAC device] that I can use to talk on the phone and a TTY machine. The computer was used by several participants to talk to peers at work, aides, and friends in the community with email and instant messaging (IM). Keith said that using email and IM equalized the communication interaction. Keith stated, *“I like the equality it gives me.”*

AAC devices were used by participants virtually every time they advocated (i.e., individual: people characteristics) for themselves when individuals discriminated against them in their vocational settings. Jim recalled a situation in which his AAC device was not available so he was unable to explain his side of a fight with another employee to his employer. As a result, Jim was sent to the district manager and received a warning whereas the other employee did not

receive a formal warning. However, when AAC devices were available, the participants used the devices to defend themselves or explain their points of view.

Andy: *“One time ((device stops and Andy fixes problem)) One time I was really upset at the Head Director because he wouldn’t take time to listen when I wanted to say”*

Researcher: Whoa! What did you do about it?

+Andy thinks for a moment before beginning to respond

Andy: *“I still kept bugging him until I got my point across”*

Researcher: Ahh. You were persistent. Yeah, good for you! How did you think that umm, your speech disability or using that [name of device] impacted that situation?

Andy: *“The [name of device] is a big help”*

Recommendations

There were several recommendations for vocational issues. The first recommendation was for individuals such as employers to hire not only African Americans, but African Americans with disabilities. Brittany stated simply, *“I want to have more money”* when discussing her current lack of employment. A second recommendation for employers was for employers to be more accommodating (i.e., interventions) for such issues as scheduled times. Keith discussed that African Americans do not view time and appointments the same as European Americans. He also said that individuals with disabilities tended to need more time to complete tasks so they were often late for activities. Keith said that because he was African American and had disabilities *“I’m really, late, because, I have, the, two.”* For Jimmy the problem was more serious. His disabilities prevented him from driving a car so Jimmy was dependent on the disability bus system. Jimmy was often late for work because of his disabilities and needing more time to get ready in the morning plus using the disability bus system. Jimmy said, *“I may be late for work. 15 extra minutes would make a big difference. I can work 15 minutes longer everyday.”*

AAC

The only recommendations for AAC issues and vocation pertained to the intervention of AAC devices. All of the participants reported that AAC devices were supportive and useful at work. Most of the improvements suggested were to add features to the AAC device so that the device was more interactive with other equipment. Andy wanted “*A built in computer on my [name of device].*” Hubert wanted “*make small . . . [name of device].*” When he was asked why he wanted the device smaller he replied, “*Put in pack [his fanny pack] . . . I can call people*” because he wanted AAC devices to have built in cell phones. Donald was creative when he indicated that he wanted his device to *drive a car*. The second most frequent suggestion for improving AAC devices in the workplace was to increase the durability of the devices and improve device batteries so the batteries lasted longer.

Overall, AAC devices were reported by participants to assist the participants communicate with a variety of individuals including employers, peers, and aides. Although participants mentioned a lack of vocabulary and slang they preferred when communicating with other African Americans, the most frequently mentioned barrier associated with AAC devices was the poor durability. Participants wanted a variety of device changes (i.e., interventions) such as features added to AAC devices so that the devices served as a primary control point for accessing equipment in the workplace, face to face communication, communication on landline and cell phones, and environmental controls.

Community

All of the participants enjoyed being in the community alone or with friends and/or family. The participants reported a variety of recreational activities they enjoyed in their communities. For example, Jimmy reported, I bowl on 3 leagues and play on the Special

Olympics volleyball and bowling teams. We play in [three large cities] and have won many championships. Loleeta said that her favorite community activities were shopping and going to the movies. Dedric said that art shows inspired him. The participants reported that they interacted with a variety of European Americans, African Americans, Mexican Americans, and other individuals in the community. Interactions occurred at stores, restaurants, bus stations, and rehabilitation clinics. Brittany and Dedric were the only participants who did not interact often with people in the community. Brittany however, did not report her lack of community contact as a barrier. She only wanted to travel to see her family.

Barriers

The most frequently mentioned barrier in the community mentioned by all of the participants was nondisabled peers. The typically developing peers could have been individuals in the general population (e.g., customers, people on the street) or employees at stores and restaurants. Individuals in the general population sometimes behaved in a manner that was not accepting of the participants. The participants were asked to describe what nondisabled peers were doing that made the participants feel unaccepted. The vast majority of the examples provided were due to the participants' disabilities rather than their ethnicity. Hubert said that typically developing peers "*don't look at me.*" Andy said, "*I said hello and they just walked right past me without responding.*" Although Jimmy said, "*I was called bad names*" on a routine basis (including racial slurs), he felt that the name calling was due to his disability rather than his ethnicity. Dedric said when customers stared at him and avoided him he thought they were thinking, w-h-a-t a-r-e y-o-u d-o-i-n-g o-u-t of the institution. Hubert said that when individuals ignored him he thought that people thought he was stupid because he used a device

and how he phrased his messages. *“Some stuff I say ((retypes answer into device again)) Some stuff I say I think people think I stupid.”*

Many of the comments about customer service workers indicated that customer service workers did provide some assistance to the participants. However, fast food workers were frequently mentioned by a variety of participants as providing poor service or being openly discriminatory in their practices. Loleeta and Andy both described separate instances at fast food restaurants in which Mexican American and African American fast food workers refused to let them order food even when using their AAC devices. Andy’s situation was also striking because not only was he ignored when speaking with his device, but also his wife with CP using natural speech was ignored, and other customers were ignored.

Andy: *“My wife and I went into a [name of fast food chain] and the people just looked over us and ignored us”*

Researcher: Umm, were the people that were ignoring you, were they workers at [name of fast food chain]?

Andy: *“Yes”*

Researcher: Were they European Americans or African Americans?

Andy: *“Mexican and African American”*

Researcher: Do you think that you being African American impacted the situation?

Andy: *“Probably our disability”*

Researcher: Yeah. Were you and your, were you using AAC that day? Were you using your [name of device] that day?

Andy: *“Yes”*

Researcher: And your wife was using speech—

Andy: *“Yes”*

Researcher: Yeah, ‘cause she talks with her mouth, and they were still giving you a hard time? Was there anything else you think that might have been impacting that situation?

Andy: *“The other customers got angry too because they told the person off”*

Researcher: They stood up for you! Yeah! That’s neat! That’s really cool that they did that. What did you do?

Andy: *“We left and went into [different fast food chain]”*

A second community barrier identified by all the participants was the intervention service of public transportation. Only Mac and Keith owned vehicles. Both vehicles were vans adapted for wheelchairs but the wheelchair lift on Mac's van was broken. None of the participants could drive vehicles so they were dependent on public transportation or rides from friends and family. The participants' various cities provided transportation for individuals with disabilities but in different ways. In Donald's city, the public buses used by typically developing peers were adapted with lifts. The rest of the participants' cities used specially designed wheelchair buses with wheelchair lifts or vans that were not part of the public transportation system. All of the participants reported the buses/van were often late.

Donald was the only participant whose public transportation intervention service was integrated for people with disabilities to be with typically developing peers. However, Donald reported that the lifts were sometimes broken and he would have to wait for another bus. Donald reported that waiting on the bus with a working lift for sometimes an hour was a barrier. Donald avoided using the buses because the buses were *not very good . . . they never on time.*"

The other eight participants used segregated public transportation. The other eight participants had to call and make reservations for a bus to pick them up. The other participants indicated that arranging for transportation was restrictive upon their lives. Jimmy for example, could only work until 3:00 p.m. because his city only ran the buses for individuals with disabilities until 3:00. Reservations for a bus/van pick-up were supposed to be made the day prior to being picked up. The participants had to be ready and waiting on the bus at specified times even if the bus was late or they would miss their ride and have to call for another bus/van.

AAC

Most of the participants were still receiving SLP services from clinics in the community. Although the participants reported that AAC devices assisted them with communication in the community, most of the participants had less than favorable comments about SLP intervention services. Many of the participants believed they needed more SLP services. Most of the participants were either receiving consultative services (i.e., once or twice a year) or weekly therapy sessions for less than an hour. Even though the participants could get their individuals to understand most of their messages, they wanted to improve the communication skill and specifically their skills with using high tech devices. As Brittany said, "*I want know about this [name of device] help me to do talk better.*" None of the participants recalled their SLP services they received as an adult targeting communication skills to be used at their jobs or in the community.

Participants were questioned about their interactions with SLPs (i.e., individuals) and the types of intervention services provided. The participants reported that the SLPs were friendly and said greetings. The participants did not report that their SLPs were social. Participants reported that their families were not included in their sessions. Loleeta was having problems getting her hearing impaired mother to let her use her AAC device when she communicated at home. She reported that she discussed the problem with her SLP. Loleeta's SLP did not invite her mother to a therapy session and her SLP did not complete a home visit. Loleeta reported that her SLP's solution to her problem was for Loleeta to use her device more often.

In regards to intervention accommodations for ethnicity, participants reported that their SLPs had provided few (if any) accommodations. Most participants identified one or two device changes made by SLPs to add vocabulary/slang that participants might want to use when

communicating with African American individuals. Most participants did not indicate any device changes (i.e., intervention) to the skin tones on their picture symbols. None of the participants recalled their SLP discussing African American communication styles or asking them about their communication with African Americans.

Supports

The participants only identified a few intervention services which were somewhat supportive. Despite the problems with the participants' transportation systems the participants remarked that the bus systems intervention was somewhat helpful in helping the participants go to different locations. Individuals such as customer service workers in stores were often reported to be helpful and as Dedric said T-h-e-y h-e-l-p m-e o-u-t o-f k-i-n-d-n-e-s-s. Intervention equipment such as wheelchairs and AAC devices were the primary supportive equipment.

AAC

All of the participants reported that their AAC devices were very helpful when interacting with individuals in the community—provided that community members would acknowledge them. AAC high tech and light tech devices were used for shopping and going to restaurants. The participants used their intervention AAC devices with friends in the community as well. Even though AAC devices overall provided assistance, participants indicated that the devices were not very accommodating to communicating with other African Americans in regards to vocabulary and the voice output accent.

Recommendations

The recommendations for the community primarily pertained to educating typically developing individuals such as customers and customer service personnel about AAC.

Participants wanted typically developing peers in the community to learn more about individuals

with disabilities. They also wanted individuals to ask about AAC devices instead of stare at them. Andy also wanted to be treated the same by customer service personnel when shopping. Andy stated, *“They could be understandable and look at us as another customer because we’re just like everybody else.”*

Overall, AAC devices provided valuable assistance to the participants in most community locations such as stores. Some participants expressed difficulty obtaining services at fast food restaurants even while using AAC devices. However, most participants indicated that AAC high tech or light tech devices (intervention equipment) were helpful when interacting with customer service workers in stores and other types of restaurants. Participants indicated that typically developing peers that were customers were typically less than accepting of individuals with disabilities. Participants said that typically developing peers needed to know more about AAC and were encouraged to ask questions rather than stare at participants. In regards to SLP intervention services provided in the community, participants reported that most SLP services did not meet the participants’ needs for communication with individuals in their environments, African Americans, or in the workplace.

Participants’ Views of Their Identities and Discrimination Associated with Using AAC in Addition to being African American

The participants were asked questions about discrimination, their ethnic identity, their disability identity as it pertained to AAC, and how they viewed their different identities. All of the participants were asked a series of questions regarding discrimination related to being African American and discrimination related to having a speech disability. All of the participants reported experiencing discrimination for either being African American or having disabilities. As Keith said, *“Discrimination is a part of life.”*

Some participants reported some discrimination due to being African American. For example, Donald recalled receiving less therapy services and equipment than the European American children with disabilities. Donald said, *When I went to school back then I didn't have nothing XXX [unintelligible speech]. It was not equal back then.* Loleeta and Dedric recalled not being allowed to go on field trips with the European American children with disabilities. Dedric stated that he knew his discrimination at his CP school was due to him being African American because I w-a-s t-h-e o-n-l-y B-l-a-c-k A-m-e-r-i-c-a-n.

Most of the participants recalled instances of discrimination due to having disabilities. The disability discrimination experiences most participants chose to discuss were not due to having a speech disability but rather disabilities in general. Dedric's vocation discrimination, for example, was not being paid at a sheltered workshop for individuals with disabilities in which he painted pictures which were sold to the community. At the time of the study, Dedric was only paid for training staff about AAC and running errands on campus rather than his paintings. Dedric said that previously, I w-a-s m-a-k-i-n-g 1 c-e-n-t an hour for his paintings but that salary had been stopped. Many participants indicated that discrimination due to disabilities was not related to just European Americans discriminating against African Americans with disabilities. Rather, some of the incidences of discrimination shared with this researcher were between Mexican Americans or African Americans against the African American participants who used AAC. As Keith stated, *"I have, been, discriminated, against, for, race, but, it's, in, the, disability, community."*

After each incident of discrimination was discussed by participants, participants were asked how they advocated for themselves to stop discrimination. Some participants were physically aggressive. For example, Donald said, *I'll run over them sometimes* with his electric

wheelchair. Other participants try to educate the person who is discriminating against them.

Keith stated that he adapts his advocacy efforts according to his environment.

Keith: *“Because, at, camp, I’m, known, as, a, hell, raiser. . . . People, hate, speaking to me, because, I’m, so, adamant about, things, but at home, I, switch, gear, because, my, mom, is, ((K pumps fists)). I have to be, relaxed to, compensate her ((K pumps fist)) energy, or I would be, crazy.”*

Most participants chose to ignore the discriminatory acts. The reasons provided for not engaging the person being discriminatory were varied. Loleeta said that confronting discrimination took too much energy. Dedric said, I-f I s-a-y s-o-m-e-t-h-i-n-g i-t w-o-u-l-d b-e r-u-d-e. Hubert and Andy believed that people would act how they wanted and they could do nothing to stop them. As Andy stated, *“God says love them anyway. . . . I just kept going and kept smiling.”*

Participants were asked if being African American and having disabilities placed them in a situation of receiving increased/more discrimination as compared to having only one minority identity. Keith stated, *“I think it’s possible but I try not to think about that because it’s discouraging to me and will just make me not them frustrated.”* Most of the participants did not believe that they had personally experienced additional or more severe discrimination because they were African American and had disabilities yet the participants believed it was possible. Most of the participants did not believe that having a speech disability made them experience more discrimination than they would have experienced if they had only had other disabilities. Rather, the participants tended to report that the speech disability made the situation worse in which the discrimination occurred. The participants were asked whether they received more discrimination due to being African American or if they received more discrimination for having a speech disability. All of the participants reported receiving more discrimination because of the

speech disability rather than being African American. Keith stated, *“I feel my ethnicity is more overshadowed by my disability as far as putting me separate from other people.”*

All the participants were presented with a situation in which Non-European American family members were concerned about allowing loved ones to use AAC devices because the family believed there would be increased/additional discrimination. Participants voiced a variety of concerns about making sure the African American with a speech disability had the opportunity to use AAC devices. Dedric said, I-f I w-a-s t-h-e-m I w-o-u-l-d l-e-t t-h-e-m t-r-y d-e-v-i-c-e. Donald was concerned that the individuals with speech disabilities made the decision whether to use AAC devices. Donald stated, *Well do what you want if that’s what you want. . . . depends on what the patient want.* Andy indicated that AAC devices were designed to assist individuals with AAC when he said, *“It would help him [individual with speech disability], not hurt him.”* Keith wanted the individuals with speech disabilities to have AAC devices so that they could defend themselves against discrimination. Keith stated, *“Can they speak without it is the first question I would ask the family and how can they defend themselves against discrimination without a mean to speak.”* Incidentally, while discussing the scenario the majority of participants suddenly volunteered to help children or adults who needed AAC either design their systems or mentor the individuals and their families. As Hubert said, *“I be happy to help.”*

After discussing the scenario of potentially not allowing an individual with a speech disability to obtain an AAC device, the participants were asked if they would want an AAC device if they knew they would receive additional discrimination because they used an AAC device. All of the participants emphatically stated they would still want AAC devices even if it meant having to experience more discrimination than discrimination experienced due to being African American and discrimination due to having other disabilities.

Finally, participants were asked how they viewed their ethnic identity and their disability identity. The participants chose what they wanted to call their ethnicity. Some chose African American while other chose Black. Dedric used the terms Black American and African American interchangeably. Keith preferred the term African American but chose to use the term Black because African American was too time consuming on his AAC device. Although the concept 'ethnicity' was not discussed at length with the participants, most of the participants indicated that they believed ethnicity was the same concept as race and color. Furthermore, the participants alluded to discrimination being due primarily to their color rather than behavioral norm. All of the participants indicated that their disability identity and ethnic identity were important to them. However, the aspect of their identity and self-perception most important to the participants varied considerably between participants. Many of the participants indicated that their disability identity had a greater impact on their daily lives but several of the participants indicated they viewed the two identities of equal value for themselves. For these same participants, their ethnic identity and disability identities were not as important to them as unique aspects of their personalities and goals they had achieved. Dedric's comments on the discussion of his ethnic identity and disability identity revealed a more important issue to him; he wanted individuals to focus more on him as a person than his identities which made him different.

Researcher: When you look at the aspects of your identity, I want you to explain how being African American and using AAC fits in your view of yourself.

Dedric: U-s-i-n-g a d-e-v-i-c-e i-s v-e-r-y i-m-p-o-r-t-a-n-t.

Researcher: What's the most important thing about how you view yourself that you want the world to know?

Dedric: H-o-w I f-e-e-l.

Recommendations

The participants identified a variety of suggestions for reducing and/or eliminating discrimination against African Americans who used AAC. The recommendations pertained primarily to three groups of typically developing peers: teachers and SLPs, employers and coworkers, and typically developing peers in the general population. The recommendations for teachers and SLPs were primarily for teachers and SLPs to develop their own awareness about African Americans, individuals with disabilities, and AAC. Andy wanted teachers and SLPs in general to *“Have more knowledge and research about our history and how we started to gain freedom and respect as we are Americans.”* Keith wanted teachers to incorporate AAC into the class better by sharing fun examples of using AAC and being an example for students. Andy specifically wanted SLPs to learn *“about our culture and language . . . by doing some research.”* According to Andy, SLPs could improve the services provided to African Americans who used AAC if they would *“Learn about what we do in everyday life.”* Keith wanted SLPs to remember when providing services for individuals who used AAC, *“It’s [ST] a service and a science. But it’s a service first.”*

In the workplace, education was also a recommendation for employers and coworkers. Besides having employers hire more African Americans who used AAC, participants wanted employers to educate coworkers about AAC. Andy said employers should *“teach the other coworkers about people with disabilities using the [name of device] to communicate.”* Dedric was concerned that employers allow individuals who needed AAC devices be allowed to use the devices at work. In regards to coworkers, Andy stated that coworkers should *“Help to get other people to realize [name of device] is a part of our lives.”* Keith wanted coworkers to *“Just be*

truthful and if they don't understand say it and more most like likely we will find a way to make you understand."

The final recommendations were for nondisabled peers in the general population in the Community. The participants were primarily concerned that individuals in the Community accept African Americans who used AAC. Andy wanted fellow customers to treat him the same when shopping. Rather than stare at him, Dedric wanted people to a-s-k m-e h-o-w i-t [the device] w-o-r-k. Finally, Hubert stated, "*Talk to me. I talk back.*"

CHAPTER FOUR

Discussion

The purpose of the current study was to a) describe barriers and the impact of barriers on a person's life who was diverse and using AAC as perceived by the diverse individual who uses AAC, b) describe support services and systems for diverse individuals who use AAC, and c) describe cultural accommodations and recommendations that diverse individuals using AAC have had or would like to have regarding AAC services and systems. The participants provided a rich account of personal experiences regarding barriers and supports as well as numerous recommendations for interactions with typically developing peers and for improving AAC for African Americans.

Several patterns across locations emerged from the results. One pattern of results across locations suggest that many interventions which were implemented with well-meaning intentions for improving the lives of African Americans who used AAC, did not meet the participants' needs adequately. For example, AAC high and light tech devices were used by participants in all locations. The observed benefit from using AAC systems overall was helpful but in varying degrees. AAC systems at the vocation location were helpful in most work related scenarios. AAC systems in the home were minimally effective. The decrease in benefit of using AAC systems was partially related to the lack of cultural accommodations to AAC systems so that participants could use the AAC systems with African American communication partners and express vocabulary and messages the same as communication partners.

A second pattern across locations was related to the intervention services provided. Across locations, individuals who provided interventions were minimally supportive in their endeavors and often were barriers to progress. The participants repeatedly mentioned that intervention services such as assistance with ADLs was important and had some benefit. However, in every location, the aides completing the service of assistance with ADLs were

criticized for the quality of service provided. Another service, speech pathology services, were identified as a needed service for all locations. Participants wanted speech language pathology services provided in the home. The participants also wanted speech language services provided as adults which could help them with communication needs in the community and vocation. Participants reported that speech therapy services provided in all locations were appropriate for developing basic communication needs. Participants also reported that speech therapy services provided in all locations were not adequate at providing cultural accommodations to services and AAC systems. The discussion below focuses on the research questions by examining the study results in regards to barriers, supports, and recommendations for improving the AAC services and systems in relation to existing research. Barriers, supports, and recommendations are discussed across locations.

Barriers

All participants identified a variety of barriers. Most barriers were related to false beliefs about disabilities, problems with AAC devices, or discrimination. The discrimination identified by participants was often examples of individual discrimination, institutional discrimination, or structural discrimination. Within each form of discrimination, participants also identified issues pertaining to the favored status of dominant and diverse group members.

False Beliefs about Disabilities

Participants shared incidences in which barriers to interactions with typically developing peers were partially due to false beliefs about disabilities. One false belief held by some typically developing peers is that the disability is the most important aspect of life for individuals with disabilities (Fine & Asch, 2000). From the data gathered in the current study, the disability was important to the participants because it impacted their daily lives. However, personal,

unique aspects of their lives were often more important than their disabilities. Five of the nine participants considered their ethnic and disability identities equally important. Participants identified that some typically developing peers reacted to the participants as if the participants' disability was the most important part of their lives. As a result, the participants recalled that typically developing peers would ignore other important identities, abilities, and unique aspects about the participants.

A second false belief often held by nondisabled peers is that peers with disabilities were dependent on others and incapable of giving assistance (Bryan, 2000; Fine & Asch, 2000). In contrast, the participants enjoyed being as independent as possible. Although the participants utilized services for their ADLs and housekeeping, the participants strove to increase their independence through technology and employment. The participants also were currently providing assistance to others (e.g., Andy worked in outreach ministries to homeless people) or wanted to provide assistance to other individuals who used AAC. Some participants indicated that by completing the current study and identifying problems with AAC devices and services they were helping future individuals who used AAC.

Problems with AAC Devices

The problems with AAC devices were numerous but primarily pertained to durability. Device problems have been reported in other research as well (e.g., Clarke et al., 2001). One problem identified was poor power supplies such as faulty power cords and limited battery life. Many of the participants were limited in their ability to communicate effectively with communication partners because of poor power supplies for devices. The participants' AAC devices were often broken or would suddenly stop working while participants composed messages. Due to devices suddenly stopping, participants often lost part of the message they had

composed so that participants had to start composing the message again. For the participants, the impact of devices suddenly stopping was increased errors (Mirenda & Bopp, 2003), decreased communication rate (Treviranus & Roberts, 2003), and increased confusion of communication partners (Brady & Halle, 2002). The poor communicative competence displayed due to AAC device limitations (McCarthy & Light, 2005) could have impacted attitudes and potential discrimination exhibited by typically developing peers (Beck et al., 2001).

Discrimination

As observed in previous literature, the discrimination observed in the current study took a variety of forms (Pincus, 2000). Some participants experienced negative attitudes and behaviors (McCarthy & Light, 2005) from typically developing peers in the Community due to the participants having disabilities. Other participants received poor quality services or were denied services due to their ethnicity (Blumenfeld & Raymond, 2000). Similar to other research results, all of the participants in the current study experienced discrimination while trying to find employment with typically developing peers in the general workplace (McNaughton et al., 2002). All of the participants also experienced some form of individual discrimination.

Individual Discrimination

Individual discrimination are behaviors of individuals from one identity that are designed to support differential treatment of individuals from another cultural identity (Pincus, 2000). Discrimination can be exhibited in a variety of forms (Pincus, 2000). In the current study, participants identified a wide variety of individual discrimination incidences. Some discrimination such as calling participants names and staring at African Americans who used AAC resulted in the participants feeling as if their communication mode was not acceptable and that the individuals themselves were not accepted by typically developing peers. Not feeling

accepted has been identified in literature and research by other individuals with disabilities (Fine & Asch, 2000; Li & Moore, 1998). Several individuals indicated that they believed that typically developing peers did not accept the participants because the participants used AAC devices or the participants did not display communicative competence (Beck et al., 2001). The participants were frustrated by their communication abilities (Clarke et al., 2001; Smith-Lewis & Ford, 1987) and also frustrated by typically developing peers who isolated the participants because of their speech disability (Smith-Lewis & Ford, 1987). Frustration, anger, and feeling isolated were frequently mentioned by participants as emotional responses to having a speech disability and the barrier the speech disability created when interacting with typically developing peers.

Other individual discrimination resulted in services not being provided or the services were poorly provided. The participants' speech disability created situations in which individuals that were being discriminatory might not be confronted. Not confronting discrimination is a situation in which the individual is actually working against social justice (McClintock, 2000). Not confronting discrimination can occur for a variety of reasons including safety concerns, physical energy constraints, and ability levels. However, some participants chose to work towards social justice by either confronting the perpetrator or educating the perpetrator (McClintock, 2000). For example, during Detric's toileting incident, the individual discrimination of poor quality service occurred. Simultaneously, the caregiver tried to use Detric's speech disabilities to hide the discrimination because Detric was supposed to not be able to report the incident to authorities. Detric chose to wait until he felt safe and confronted the perpetrator in front of witnesses and supervisors.

Non-Favored Group Member Status. Some of the instances of individual discrimination were also examples of favored status for ethnicity or other identities (Hayes, 2001). Andy's

example of the fast food workers refusing services to Andy and his wife is an example of individual discrimination. In this situation, the favored dominant group members were typically developing peers rather than ethnicity because all partakers in the event were ethnically diverse African Americans and Mexican Americans. The non-favored identity in the incident was individuals with disabilities represented by Andy and his wife who both had CP.

Institutional Discrimination

Institutional discrimination occurs when dominant group policies—and the behaviors of individuals who control and implement the policies—are designed to have a differential effect towards another group (Pincus, 2000). The institutional discrimination identified by participants in the current study pertained primarily to School and Vocational locations. One institutional discrimination experienced by all the study participants while in School was segregation. All of the participants had classes and some contact with children from different ethnic identities (including European American) at some point in their School careers due to legal changes such as *Brown vs. the Board of Education* in 1954. However, all of the participants received institutional discrimination and segregation due to their disability identity while in School. In the Schools, all of the participants were segregated into classes in which the only peers were peers with disabilities. Keith recalled his mother having to fight the School system (e.g., fight a practice barrier) every year for him to participate in full inclusion with typically developing peers (Beukelman & Mirenda, 1998).

The lack of inclusion experienced by all of the participants (and the difficulty in obtaining inclusion for Keith) spanned over 40 years of educational experiences. The lack of inclusion for individuals with disabilities occurred despite numerous federal legislative changes mandating that children with disabilities only be removed from regular education classrooms if

the children's needs can not be met with a variety of supports including aides and assistive technology such as AAC systems (e.g., Education for All Handicapped Children Act, Individuals with Disabilities Education Act, Americans with Disabilities Act, Rehabilitation Act). All of the participants should have benefited from the legal changes at some point in their educational career (Hourcade, Pilotte, West, & Parette, 2004). While the problems with inclusion for children with disabilities have continued, there was some evidence in improvement across time when examining the experiences of participants. The three oldest participants (Andy, Brittany, and Donald) were in segregated classrooms for children with disabilities with limited or no contact with typically developing peers in School. The two youngest participants (Hubert and Keith), both had contact with typically developing peers in School. Keith was included in all classes with typically developing peers starting in the third grade. Even though problems continue to exist for including children who use AAC in the regular education classroom, some progress has been made.

A second school-based and community-based institutional discrimination identified by all the participants was the lack of contact between SLPs and family members. Lack of contact between family members and SLPs is a practice barrier because it is the accepted norm. Although limited contact between SLPs is common for clients of all ethnicities (Rosenfeld & Kocher, 1998) the lack of contact with diverse families may be interpreted by SLPs as a lack of interest or involvement by families (Brice, 2002; van Kleeck, 1994). In the current study, participants identified that their families were not included in therapy services. Families were also not included in the process of AAC device selection or implementation.

Best practices for providing ST services include the concept of families as team members in the therapeutic process (ASHA, 1997; Brice, 2002). Including families in all phases of

intervention has been identified by ASHA as a knowledge and skill that SLPs should be including in their service delivery (ASHA, 2003). For AAC intervention, research has recognized that family members are an integral part of improving the lives of individuals who use AAC (Kent-Walsh & Light, 2003). Families need to be involved at every phase of AAC intervention because the family knows the individual who uses AAC better and will be interacting with the individual who uses AAC well after the SLP who designed the AAC system and therapy goals is no longer available. Simultaneously, SLPs need to ensure they have an understanding of the life demands and communication preferences of families so that the AAC system is integrated into the family rather than forced on the family's already established communication system and lifestyle. As the participants stated in the current study, SLPs need to develop an understanding of the life experiences of the individuals who use AAC so that the AAC services and systems designed meet their communication needs at Home, in the Community, and at work.

Similar to other research, most of the participants also experienced institutional discrimination in the workplace (McNaughton et al., 2002). Participants identified extreme difficulty in finding employment in working with typically developing peers in the general workplace. Participants reported they felt stigmatized by using an AAC device. Feelings of being stigmatized by using assistive technology such as AAC devices has also been identified in research with other individuals from diverse groups (Kemp & Parette, 2000). Some of the participants stated that African Americans who used AAC were not hired because of preconceived ideas held by employers that African Americans who used AAC would not be able to complete job tasks adequately. The preconceived idea that African Americans who used AAC

were unable to complete job tasks could have been based on their lack of experience working with individuals who use AAC (Beck et al., 2001).

Another institutional discrimination all of the participants encountered were laws designed to limit financial earnings from employment for individuals receiving disability benefits and Medicaid for health benefits. All of the participants in the study required some type of assistance from aides or families for ADLs. Furthermore, participants had extensive healthcare needs that were costly. For example, equipment such as AAC devices and electric wheelchairs cost thousands of dollars. All of the participants in the study identified themselves as low SES and received from government agencies funding and services for daily care services and equipment. However, by accepting government funds for disability services and equipment, the participants were required not to earn more than standards set by the government. As a result, the laws restricted the participants' ability to work full-time at higher earning positions (Pincus, 2000). If the participants accepted higher paying jobs, then the participants would lose funding for medical care, assistance with ADLs, and home care services such as cooking, cleaning, and help with money management. Ironically, without the assistance with ADLs and home care services, the participants would have been unable to keep a full-time position paying higher wages.

Non-Favored Ethnic Group Member Status. Several participants recalled instances in which the institutional discrimination they experienced was also related to being a member of a diverse ethnic group. For several of the participants, School services and social activities were denied to the African American participants who used AAC (Tatum, 2000b). For example, Donald recalled receiving less therapy services than European American children with disabilities. Several participants were not allowed to participate in field trips and other School

activities while European American children with disabilities were included. The incidences in Schools were not necessarily written policies supporting the discrimination. Rather, the discrimination occurred because discriminating against African Americans was an accepted norm (Pincus, 2000).

Non-Favored Low SES Status. One of the underlying issues across participants was the issue of low SES. All of the participants in the study self-identified as being in a low SES group. The participants identifying as low SES was not too surprising since both African Americans and Americans with disabilities have high percentages of group members in low SES (U.S. Census Bureau, 2005a, 2005b, 2005c). Also, four of the seven participants who were raised with biological families were in female-headed households. There is a large percentage of female-headed households (across ethnic groups) classified as low SES (U.S. Census Bureau, 2005b).

Many of the barriers identified by the participants were similar to barriers associated with low SES across ethnic groups, nondisabled, and disabled peers (Lopez & Stack, 2001; Milburn & Bowman, 1991). For example, children living in low SES households (across racial groups) are more likely to achieve lower grade point averages in school and placed in educational tracks with less focus on academic achievement needed for higher education (Epps, 1995).

Employment barriers also exist for individuals from low SES. Individuals classified as low SES (across racial groups, nondisabled, or disabled) are more likely to hold non-standard jobs (i.e., part-time, temporary, independent contracting) (Schur, 2002). Non-standard jobs usually do not have health benefits or retirement saving plans (Schur, 2002). Most non-standard jobs also meet the Undo Hardship clause of the Americans with Disabilities Act which stipulates that disability accommodations are too difficult because of the economic hardship on employers of making permanent changes for temporary and part-time positions (Schur, 2002). As a result,

employers may not have to make accommodations for individuals with disabilities which in turn increases the difficulty of employing individuals with disabilities even in non-standard jobs.

Yet, within the barriers associated with low SES, discrimination continues to exist for African Americans, and for individuals with disabilities. In education for example, low SES African American students are disproportionately placed into lower academic tracks as compared to low SES European American students (Epps, 1995). In employment situations, low SES individuals with disabilities (across ethnic groups) are paid significantly less than low SES typically developing peers for non-standard jobs (Schur, 2002).

In the current study, similar results regarding Vocation were observed. For example, none of the participants had full-time work. As identified in research for non-standard jobs, none of the participants had health benefits which created a situation of dependency on federal funding. None of the participants had company sponsored savings plans to help with retirement.

During the course of the study, the exact hourly wage of participants was not directly questioned. However, many of the participants indicated their employment positions were subsidized and they did not earn the minimum wage (currently \$5.15 per hour). The lower salaries identified by participants (or alluded to by participants) were dramatically different from the current minimum wage standard of \$5.15 per hour. For example, Detric's wages (prior to his funding being stopped) were only one cent an hour which was lower than the hourly rate of free African Americans between the years of 1820 and 1850 (Pease & Pease, 1990). The low wages and limited number of working hours limited the participants ability to improve their economic outlook which was similar to other research results (Schur, 2002). For the participants, the barriers experienced associated with low SES may have been compounded by the additional minority identities of being African American and having disabilities (Ali et al.,

2001) as evidenced by limited educational opportunities, severely reduced wages, and difficulty obtaining standard and non-standard employment. However, the exact impact of having three minority identities (low SES, African American, having disabilities) or four minority identities (low SES, African American, having disabilities, female) was beyond the scope of this study.

Structural Discrimination

Structural discrimination are policies of the dominant group institutions for the purpose of being group neutral in theory but actually have a differential or harmful effect on the minority group (Pincus, 2000). For the participants in the current study, the structural discrimination was also related to being a member of the non-favored disability identity. For eight of the nine participants, transportation systems were a form of structural discrimination. While appearing to be a service to equalize and promote the opportunities of individuals with disabilities (Pincus, 2000), most of the transportation systems used by participants in the current study required the participants to use transportation segregated from typically developing peers. The disability transportation systems discussed in the current study required the participants to complete additional tasks to obtain transportation (e.g., making reservations a day ahead) as compared to typically developing peers (Pincus, 2000). Also, the transportation systems were restrictive on life activities. For example, participants had to designate a time to be picked up when shopping or seeing a doctor. If the shopping check-out line was slow, or the doctor was late, the participant would have to call for another bus. In contrast, typically developing peers could ride the cities' transportation system anywhere in the cities at anytime. The transportation system for Jimmy was exceptionally restrictive because it required him to only work a limited number of hours; otherwise Jimmy would not have transportation home. Despite the problems with transportation systems, participants identified transportation systems as somewhat supportive.

Supports

All the participants identified a variety of supports. The individuals and interventions identified as supports by the participants were either somewhat helpful or helpful. None of the individuals or interventions identified as supportive was considered supportive in all locations. Individuals such as authority figures, family, and service personnel were frequently discussed as generally supportive. Interventions such as services and equipment were also frequently discussed as generally supportive.

Individuals

Authority figures

Authority figures such as teachers and employers were frequently identified as helpful. Participants recalled teachers being somewhat helpful in classrooms as children with academic issues. Most participants were referring to teachers in special education classrooms rather than teachers in regular education classrooms. Over the several decades of education experienced by the study participants, improvements were observed in the type and quality of services in the classroom so that more acts of assistance were provided. The younger participants in the study shared more instances of help provided by classroom teachers for African Americans who used AAC than the older participants. The increased number of assisting instances provided by teachers identified by younger participants could have occurred for a variety of reasons including age and distance in time from remembering School events, comfort level with the researcher (Smith, Bradham, Chandler, & Wells, 2000), and/or more instances of support were actually provided for the younger participants as compared to the older participants. For the workplace, the types and number of supportive events identified were similar for the younger and older participants.

In the current study, employers were often described as individuals with whom participants could discuss discrimination issues and problems. Some employers helped the participants confront discrimination in the workplace and in the Community (Fine & Asch, 2000; McClintock, 2000). Most employers had made adaptations to equipment or job expectations to match the participants' abilities which the participants indicated was very supportive. The participants wanted more support from employers particularly during the hiring process. The employment desires voiced in the current study were similar to employment desires of other individuals with speech impairments (e.g., Light et al., 1996; McNaughton et al., 2002).

Family

Most of the participants had some contact with family at different points in their lives. Overall, families were identified by participants as supportive particularly when the participants were discussing their childhood. For many African Americans and the participants, families were an integral part of their lives and most support for African Americans was provided by family members and other members in the social network of the family (Hatchett et al., 1991).

In other research, African American families were not homogenous groups with stereotypical behavior patterns in response to having a family member with a disability (Rogers-Dulan & Blacher, 1995). Research examining the African American family unit identified that nucleus families (i.e., parents and children) of individuals with disabilities relied heavily on the support and acceptance of relatives and friends (Billingsley, 1992; Rogers-Dulan & Blacher, 1995). African American nucleus families often consider close friends the same as biological family (Rogers-Dulan & Blacher, 1995). Thus, the nucleus family, relatives, and close friends provide a network of social contacts, support, and unconditional acceptance for individuals with disabilities (Billingsley, 1992).

In the current study, the participants also displayed a social network and family structure consisting of family members and close friends similar to other research results. Individuals living in the participants' Homes were often the nucleus family (half of the participants households were headed by women), relatives, and non-related individuals considered close enough to be families. The family structure observed in the current study was similar to findings in which over 22% of the participants in the National Survey of Black Americans were female-headed households with children, relatives, and non-relatives (Hatchett et al., 1991).

The participants in the current study also displayed similar financial resources as observed in other research. In the same survey, over 85% of the female-headed households with children and other individuals had a household income of less than \$25,000 (Hatchett et al., 1991) which was commensurate with the data from the current study. In different research, families from diverse ethnic groups tended to have lower SES and the families from lower SES made assistive technology needs for children with disabilities a low priority (Parette, Brotherson, Hourcade, & Bradley, 1996). In the current study, all the participants indicated they or their families were from low SES. Only Keith remembered his mother being actively involved in obtaining AAC devices and services for Keith when he was a child.

Although the participants who had families identified their families as supportive, the participants reported that their families rarely used AAC in the Home as a child and/or in their adult life. Low SES and the decreased priority of assistive technology such as AAC devices may be one explanation for AAC devices rarely being used by some families in the current study (Parette et al., 1996). Many individuals from low SES have a decreased familiarity with technology and therefore AAC may appear to them to be too complicated for their lives when their lives are already financially strained (Parette et al., 1996). Another possible explanation for

AAC devices not being used in the Home could have been lack of training and education about AAC services and systems by SLPs (Angelo, Jones, & Kokoska, 1995; Angelo, Kokoska, & Jones, 1996; Culp, Ambrosi, Berniger, & Mitchell, 1986; Murphy, Markova, Collins, & Moodie, 1996). None of the participants recalled training about AAC devices being provided to their families (or institutional staff). A third possible explanation for AAC devices not being used in the Home was the family member's lack of experience with AAC. Individuals with previous experience with individuals who use AAC tended to be more positive about AAC than individuals without previous experience (McCarthy & Light, 2005). A final possible explanation to the lack of use of AAC in the Home with family may be that family members had already developed unaided communication systems and preferred the unaided systems and the higher level of intimacy unaided communication may possess for individuals from diverse ethnic groups (Huer et al., 2001; McCord & Soto, 2004).

Service personnel

SLPs were service personnel that the participants indicated were somewhat supportive. Participants indicated that SLPs were helpful for general communication but were not helpful for communication at the workplace or with other African Americans. The participants identified the SLPs' lack of knowledge about AAC services and systems as a significant barrier (Simpson, Beukelman, & Bird, 1998) even though the participants clearly identified SLPs as supportive in general. The participants also identified that SLPs lacked knowledge about African American culture and as a result provided virtually no cultural accommodations to AAC devices and services. Recently, the American Speech-Language-Hearing Association (ASHA) has also identified the lack of expertise by SLPs when addressing AAC issues (ASHA, 2002) and cultural issues (ASHA, 2004a). As a result, ASHA has revamped its certification program with new

emphasis on developing the knowledge and skills of future SLPs in the areas of AAC and culture (ASHA, 2003; Ratcliff, 2003).

Interventions

Services

A variety of services provided were identified as supportive or somewhat supportive. Assistance with ADLs was supportive. Wheelchair clinics to maintain and clean wheelchairs were identified as supportive. Transportation services were somewhat supportive. Therapy services such as physical therapy, occupational therapy, and speech therapy were considered somewhat supportive by participants. Speech therapy was identified as helpful for developing general communication skills. Results regarding speech therapy services were similar to other research with participants who were from diverse ethnic groups (Huer et al., 2001; Parette, Chuang et al., 2004; Parette et al., 2002).

Equipment

A variety of equipment was identified by participants. Wheelchairs and AAC devices were the most frequently mentioned supportive equipment. Results regarding the supportiveness of AAC devices and wheelchairs were similar to previous research (Angelo et al., 1996; Hutzler, Fliess, Anat, & Yves, 2002). Wheelchairs and AAC devices were identified as supportive in all environments. Most of the participants desired to use AAC devices more often with typically developing peers, in more environments, and more frequently with families in their current life and when they were children. For the participants to use the AAC devices more than current use, several changes may be required.

Recommendations

The recommendations provided by the participants were similar to recommendations identified in culture and disability literature and research. Most of the recommendations for individuals pertained to educating typically developing peers. Most of the recommendations for interventions pertained to improving accommodations made to AAC services and systems and modifying AAC devices to be integrated with a variety of equipment in the environment.

Individuals

The participants strongly desired for typically developing peers to learn more about AAC and African Americans. Education was the primary suggestion for improving the knowledge and skills of typically developing peers about AAC and African Americans. Research has also identified education and training as successful methods for developing knowledge and skills of individuals about AAC. Education can take many forms such as educational programs for typically developing school-age peers regarding AAC (e.g., Beck & Fritz-Verticchio, 2003). Another method of helping typically developing peers learn about AAC is through training programs such as developing aides' communicative turn-taking skills (e.g., Kent-Walsh, 2003) and family training strategies for implementing AAC in the Home (Berry, 1987).

Participants also wanted typically developing peers to develop an understanding about African American culture in a variety of locations. For typically developing peers to learn about culture, literature regarding culture sensitivity training has suggested providing opportunities for individuals to learn about themselves and identify similarities, differences, and ways of positively changing their behavior when interacting with individuals from other identities (Scheller, 2000). Cultural sensitivity literature has also suggested interactive training sessions to help typically developing peers move to acceptance and adaptation when reacting to individuals

from other identities (Bennett, 1986). Cultural sensitivity and accommodations were also a priority when providing AAC services to African Americans who used AAC.

Interventions

The participants in the current study repeatedly identified cultural accommodations as a recommendation for AAC services provided by SLPs. Participants wanted SLPs to recognize that the individuals who used AAC were African Americans and that as African Americans their life experiences were different from those of the European American SLPs. Recognizing differences in life experiences and modifying therapy services provided by SLPs has been identified in literature (ASHA, 2004a; van Kleeck, 1994). Research has reported that an SLPs' cultural awareness influences therapy decisions and interpretations of behavior (Kritikos, 2003; Parette, 2000). In the present study, the lack of cultural awareness exhibited by SLPs resulted in limited or no cultural accommodations being provided. Research has questioned if cultural accommodations provided by SLPs were considered functional when viewed by diverse individuals who use AAC (Huer & Saenz, 2002). In the present study, the rare cultural accommodations were appreciated but did not adequately meet the needs of the participants.

In regards to AAC devices and cultural accommodations, participants desired their AAC devices to reflect their ethnic identity. Participants wanted device changes made to their AAC devices to include vocabulary and slang used by African Americans. Participants wanted devices to have African American accents and skin tones. In research, some interpretation of AAC symbols was influenced by the ethnicity of typically developing peers (Huer, 2000, 2003; Stephenson & Linfoot, 1996a). In the present study, participants did not report a lack of understanding of symbols in their AAC systems. However, participants did report that AAC devices did not have symbols for concepts/words they used with African Americans.

Other device changes were identified by the participants to make AAC devices integrate into a variety of locations. Participants desired for AAC devices to have flexibility in communication styles when interacting with different individuals in a variety of locations (Higginbotham & Caves, 2002; McNaughton & Bryen, 2002). As part of integrating AAC devices into a variety of locations, the study participants desired for AAC devices to integrate with other technology so individuals could use the AAC devices as a method of accessing a variety of other equipment and environmental controls (Beukelman & Ball, 2002; Blackstone, Williams, & Joyce, 2002; Higginbotham & Caves, 2002; Light & Drager, 2002; McNaughton & Bryen, 2002; McNaughton, Light, & Gulla, 2003). Overall, participants' recommendations evolved from life experiences interacting with individuals in the general population or individuals who provided services.

Interrelationship of Themes

An interrelationship existed between the themes. In Appendix G is a visual representation of the interrelationships between the themes of the current study's data. View "a" is a top view showing the four locations, individuals, and interventions. Individuals and interventions were available in all four locations. The circle representing individuals was larger than the circle representing interventions because it was possible for the participants to interact with individuals without an intervention occurring. The interventions had the flexibility to be provided by a variety of individuals and therefore were represented as a dashed line. View "b" is a side view representing interactions. The vertical arrow represented the interaction. The interaction represented in the side view is between individuals while providing services for African Americans who used AAC. The interaction could occur in any location. The result from the interaction was usually a barrier or support and a recommendation. The diagram represents

continuous, fluid interactions which have barriers and supports occurring in a variety of locations depending on the individuals involved in the interaction and the type of intervention provided.

The recommendations from the interactions have important clinical implications.

Implications

Clinical implications

There were several clinical implications from the current study. One implication from the current study is cultural sensitivity education for SLPs. Another clinical implication from the current study is for SLPs to develop their knowledge and skills regarding AAC. Other clinical implications focus on service delivery. For example, the third implication of the current study is for families to be included in the therapeutic process. The fourth clinical implication of the current study is a need for individuals who use AAC to program their own devices.

Developing Cultural Sensitivity

The results of the current study indicate a need for SLPs to develop their cultural sensitivity knowledge and skills. Cultural sensitivity educational opportunities need to occur in college programs and continuing education for future and current SLPs. College programs for SLPs need to provide students with a variety of learning activities about different ethnicities (including their own) while being wary of promoting stereotypes. Cultural sensitivity training for SLPs is important because most SLPs are European American (Rosenfeld & Kocher, 1998) and European Americans tend to not realize/recognize they have a culture (Omi, 2000). As a result, European American SLPs may minimize cultural differences and needs. Cultural sensitivity training is more than recognizing differences. Rather, SLPs should learn about communication styles, social interactions, expectations of professionals, and other issues related to interactions between SLPs, clients, and families (ASHA, 2004a). SLP students should explore

what about implications for system design (e.g. symbols)

their own culture and the cultures of others through study and interactive experiences. The knowledge gained from the experiences can assist SLPs in providing services to diverse clients.

In regards to continuing education training after college, many SLPs are working with diverse clients with limited cultural sensitivity training. A brief review of continuing educational opportunities advertised in SLP trade magazine resulted in very few opportunities to develop cultural sensitivity. SLPs who have finished college need cultural sensitivity training to help SLPs better meet the needs of diverse clients. Several options are available for clinicians besides workshops/seminars. First, SLPs can join ASHA's special interest division for cultural issues. Within the culture special interest group are educational opportunities through readings. Some of the readings qualify for continuing education units (CEUs) which are required by most state licensing boards. Another option is for SLPs to attend a course at college about cultural issues. College courses would provide SLPs with a breadth of knowledge about a variety of topics. ASHA also allows many college courses to qualify as CEUs. Finally, SLPs could explore local cultural activities through festivals, special events such as guest speakers, and joining organizations. Each learning opportunity is available to SLPs and can be tailored to the needs of the SLPs. The same is true for developing knowledge and skills regarding AAC.

Developing Knowledge and Skills Regarding AAC

The results of the current study indicate a serious lack of knowledge and skills by SLPs about AAC. Because of the lack of knowledge and skills about AAC, participants received limited AAC services and systems they needed to improve their communication skills. For example, SLPs did not provide equipment to most participants until the participants were reading or completing pre-reading activities. Non-literate individuals can operate AAC devices for communication. Beginning communicators can utilize and benefit from AAC devices and

services to improve their communication (Kangas & Lloyd, 1988; Ronski, Sevcik, Hyatt, & Cheslock, 2002). Symbols such as line drawings and miniature objects provide the beginning communicator the power to develop communication with individuals in their environment (Bishop, Rankin, & Mirenda, 1994). By denying AAC services and systems, SLPs are limiting individuals' ability to communicate when the individuals' natural speech does not meet his/her needs. Best practices indicate that SLPs should support the development of all communication modes; not just natural speech for individuals with complex communication needs (ASHA, 2002). Another best practice for SLPs providing AAC services is to include the family in therapy services.

Improving Service Delivery

In the current study, participants reported that family members were not included in therapy services or during AAC device development and implementation. Families are an integral part of clients lives and need to be included in therapy services (Ratcliff, 2003). It is critical to include family members so that AAC systems are not only welcomed and utilized in the Home, but also to insure that communication goals, interaction styles, and expectations of family members are valued and included in AAC services and systems. Care should be taken to meet the family's needs and expectations of the therapy process so that the family is comfortable with the level of inclusion and the SLP does not stereotype family members for the amount or type of inclusion (van Kleeck, 1994). SLPs may need to find creative ways to include families in the therapy process. Some methods of involving families in AAC systems and services include the following: a) visiting client's home to become more familiar with the family and have the family share their lives, structure, and behaviors with the SLP, b) vocabulary lists which family members suggest words/concepts for devices, c) videotaping family interactions to demonstrate

family interaction patterns, d) loaning the family cameras to video or photograph family members and life experiences which could be included in therapy sessions and on AAC devices, e) communicating between the SLP and family via notebooks to increase family involvement and support of therapy activities, f) designing and programming AAC systems with family members, and g) celebrating birthdays, successes in life, and therapy goals to help merge therapy sessions with real life experiences of the individual who use AAC and the family members. Including family in therapy may also require SLPs to be more social during therapy sessions.

All of the participants in the study wanted SLPs to be more social and engaging with them during therapy sessions and out of therapy sessions. SLPs need to find a balance between social and professional relationships but small changes are possible. For example, sharing about one's family can be a rewarding experience for the SLP, the client, and family. SLPs could recognize holidays and special events in the family's life. SLPs could also invite families and clients to social events which may be less intimidating than formal settings.

One final clinical implication from the current study is to help clients learn how to program their own devices. Half of the participants in the current study had the skills to program their devices. The participants who could self-program reported an increased comfort level with their AAC devices as compared to other participants. The participants who could self-program could also address vocabulary and slang needs without having to wait for SLPs. The participants who could self-program identified the lack of vocabulary in devices as a barrier but participants clearly believed they had the ability to overcome the barrier. For the other participants, the dependence on SLPs and other knowledgeable individuals created situations in which participants had to wait to communicate concepts and messages until someone programmed the device. Even when someone programs a device, there is no guarantee the programmer will put

in the words and concepts the individual using AAC needs or desires. As a result, there was a distinct lack of freedom displayed by the participants who could not self-program.

Clinicians can address self-programming needs through a variety of methods. First, clinicians could teach individuals who use AAC the steps necessary to complete device programming. For individuals who lack the cognitive ability to complete multiple step directions, the individuals could keep word/concept lists to give to the SLP (or other knowledgeable individuals) for programming at a later date. For other individuals who use AAC who do not read/write, SLPs can regularly query the individual who uses AAC and family about words/concepts that should be added. Finally, clinicians should develop the strategic competence of individuals who use AAC for independently solving communication breakdowns (i.e., message sent is not received or understood) (Davis & Drager, 2005; Miranda & Bopp, 2003).

Improve AAC Systems

A final clinical implication is to improve AAC systems. Specifically, there is a need to address technology needs such as providing a variety of ethnic representations in symbols. For example, symbol systems need to have variation in skin color not only for individual people representing specific people in a participant's life. Rather, symbols should also have variation in skin tones for the predetermined vocabulary such as nouns, verbs, and pronouns so that an AAC system has the opportunity to fully represent an individual's ethnicity in all symbols used.

Another AAC cultural accommodation that is needed is for voice output to reflect the speech pronunciation of the individual. High tech devices should have African American influenced speech productions, Spanish speech productions and regionally influenced speech productions such as the Southern speech production. Participants identified that the voice output would be improved if it sounded like their communication partners in social settings.

Social Implications

There were social implications from the study pertaining to interacting with typically developing peers. Across locations, there is a strong need for typically developing peers to accept individuals who use AAC. One way to improve the acceptance of individuals who use AAC at school would be to have students included in regular educational classrooms. Being physically present, however, is not enough. Teachers and school administrators should foster an environment in which students learn together and from each other in the classroom and during recreational activities. Parents of typically developing peers could foster acceptance of individuals who use AAC by inviting the children to birthday parties and other events held outside of school.

In the workforce, employers could hire individuals who use AAC. Tax deductible adaptations to the work environment could be completed to foster independence and equality between individuals who use AAC and typically developing peers. Employers could also request guest lecturers from local universities to speak about AAC to employees and provide employees time to interact with AAC devices and perhaps individuals who use AAC.

In the community, stores could ensure that physical spaces meet ADA regulations and employees are trained about AAC issues. Recreational facilities such as stadiums could integrate disability seating throughout the stadium rather than isolating the individuals who use AAC and wheelchairs to a single row in one section. Stadiums could also provide light tech communication boards as marquee at vendor stalls to foster communication between individuals who use AAC and typically developing peers who provide vending services. Many changes to foster acceptance of individuals who use AAC are inexpensive. Other changes can be completed

through education and action demonstrated by actively using the information while interacting with individuals who use AAC.

Limitations

Despite the contributions of the current phenomenological study towards developing an understanding of the experience of being African American and using AAC, there are at least five limitations which should be considered. The first limitation of the study which needs to be acknowledged when interpreting the results was the small number of participants. There were only nine participants in the current study. Although the number of participants was appropriate for qualitative research and phenomenological methods (Creswell, 1998; Denzin & Lincoln, 2000), the number of participants would not lend itself to conclusions for larger groups of similar participants. Readers should focus on the thick descriptions about participants and the patterns and similarities across participants when interpreting the results (Denzin & Lincoln, 2000).

A second limitation of the current study was that only literate participants were included. The advantage of using literate participants who used AAC was that the participants had the ability to spell specific words and messages to ensure their exact message was relayed to the listener. The limitation of only using literate individuals who use AAC is that the experiences of the non-literate individuals who used AAC were not included and are unknown. Thus the results were limited to only literate African Americans who used AAC.

A third limitation of the current study was that the collected data was based on recalled events. Many of the individuals were recalling events across several decades of time. There was the potential for participants to not recall the data accurately or not remember relevant events for the current study. To address the limitation of recalled data, participants were asked repeatedly

about recalled events; probing the memory from different views, and probing memories during different interviews to observe consistency.

A fourth limitation of the current study was the incongruence of the ethnicity and physical ability of the participants and the researcher. The researcher for the current study was European American and the participants were African American. There was the potential that participants may not have felt comfortable sharing personal, private, life experiences with a European American. To address the situation, the researcher made a point of sharing about her life whenever appropriate with participants to increase the level of familiarity. The researcher engaged participants in humor at her own expense to help participants know that the researcher did not take herself or her ethnicity too seriously so that participants would not be uncomfortable criticizing European Americans during the interviews. The participants were also acutely aware of the temporary but visible physical limitations of the researcher due to her accident. The social engagement efforts and identifying personal weaknesses appeared to help participants feel relaxed and comfortable sharing about their positive and negative life experiences.

A fifth limitation of the current study was the researcher's participation in some of the messages produced by the participants. Due to the nature of co-construction, there was the possibility that the participant's exact words or phrases were not expressed due to reduced communication abilities. The researcher may not have expressed the specific word or meaning the participant was attempting to express. The researcher addressed the possibility of lack of authentic voice in the interviews by backchanneling, summarizing, and providing the participants with a variety of synonyms from which to choose while co-constructing the message. It is possible however, that the precise message may have still been misunderstood.

Future Research Directions

Based on the results of the current study, several future research directions have been identified. One research direction would be to replicate the current study with non-literate African Americans who use AAC. The participant and family could be sent the interview questions prior to the face-to-face interview so the participant would have time to prepare messages with the assistance of family. Obtaining the perspective of other individuals would provide the field with a more complete understanding of the experiences of using AAC. Research with non-literate participants would be difficult and the data would have to be interpreted cautiously due to the strong possibility that the messages produced were not the precise message intended by the participants.

Future studies could also replicate the current study with individuals from other ethnic identities. Perhaps on a larger scale several ethnic identities could be investigated to determine if patterns exist across ethnic groups which might be beneficial for clinical implications. It would also be worthwhile to explore some of the same issues addressed in the current study with SLPs and parents. Obtaining the perspective of parents across the lifetime may yield data which could be used for providing better services to families of diverse individuals who use AAC. Obtaining the perspectives and experiences of SLPs who work with diverse clients who use AAC may yield data regarding service delivery and cultural accommodations. The data could be used to shape SLP programs at colleges and continuing education activities to help clinicians improve the services provided to diverse individuals who use AAC.

A second future research direction could explore methods for improving cultural accommodations in speech language therapy services for diverse individuals. All of the participants indicated that culturally accommodating AAC services was important to them but

few individuals could identify how they wanted cultural accommodations provided. Granted, every individual is unique and stereotypes are inappropriate, yet qualitative research could be conducted to explore how cultural accommodations could be implemented during AAC services. Diverse individuals who use AAC and their families could be interviewed about cultural accommodations in AAC services. Observational studies could be completed by analyzing interactions between SLPs and clients to explore cultural accommodations. If a pattern of cultural accommodations was determined to be beneficial by diverse individuals, research could examine developing training modules for SLPs.

Conclusion

This study was emerging research examining issues related to diverse individuals who use AAC from the perspectives of the diverse individuals who use AAC. Based on the results of the current study, several significant results were identified. One significant finding was that the African Americans who used AAC in the current study had received a variety of services. The services that were provided over their lifetime had been minimally beneficial. The services provided rarely met their needs to the level which the participants would consider very beneficial. The second significant finding was that the benefit of the service provided depended on the individual who provided the service rather than on merely having the service available. Services were provided by individuals who were somewhat helpful to not helpful. In many situations, individuals (e.g., aides, SLPs) were considered helpful in one location but not helpful in another location. Lack of knowledge and skills about African Americans and about AAC thwarted the benefit of many well-intended services.

A third significant finding from the results of the current study was that participants did not believe they were receiving additional discrimination for using AAC when compared to the

discrimination they received for being African American or for the discrimination of having other disabilities. The participants believed that although the speech disabilities made discrimination worse, having AAC devices empowered the participants to choose how to address discrimination. Furthermore, all of the participants still wanted to have AAC devices even if they knew they would receive more discrimination.

Finally, despite the lack of knowledge and skills of SLPs regarding African Americans and AAC issues, the participants in the current study believed that SLP services were beneficial and could improve with increased education and training of current and future SLPs. Participants had hoped that AAC systems and services could improve if SLPs developed their knowledge and skills regarding African Americans and AAC issues. Likewise, participants had hope for the future that typically developing peers in the Community and workplace could improve their knowledge and skills about African Americans and about AAC so that the participants would be more accepted by typically developing peers.

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APPENDICES

Appendix A

ADDRESSING Model to Identify Aspects of an Individual's Cultural Identity

(adapted from Hayes, 2001)

	Defined aspects of an individual's cultural identity	Dominant identity in U.S.
A	Age	25-40 yrs. of age
D	Disability due to developmental disorders	Able-bodied
D	Disability due to acquired disorders	Able bodied
R	Religion	Christian
E	Ethnicity	European American
S	Socio-economic status	Middle-class
S	Sexual orientation	Heterosexual
I	Indigenous heritage	None
N	National origin	U.S. citizen
G	Gender	Male

Appendix B

Qualitative Research

There are several differences between quantitative and qualitative research. Quantitative research and qualitative research are conducted from different paradigms and thus explore different questions and use different methods. Quantitative research and hypothesis testing studies are built on a positivistic view. Positivism espouses that objectivity accounts for reality and research based on positivism ideas searches for a single truth (Creswell, 1998; Denzin & Lincoln, 2000; DePoy & Gitlin, 1998). Quantitative research is built on the premise that all knowledge can be derived from direct observation and logical inferences can be made from the direct observations (Rudestam & Newton, 2001). Quantitative researchers do not engage/interact with participants (Rudestam & Newton, 2001). Quantitative research tries to identify differences between group averages by isolating and manipulating variables (Rudestam & Newton, 2001). Thus, knowledge is separate from individuals and can be discovered and verified through observation and measurements designed to be unbiased and objectified. Quantitative research has precisely defined hypotheses developed on preconceived theoretical foundations (Creswell, 1998; DePoy & Gitlin, 1998). As a result, quantitative research derives from deductive reasoning by testing a theory.

In contrast, qualitative research can be based on post-positivism, constructivism, participatory-cooperative paradigms as well as other paradigms which focus on the perspective of the participants (Denzin & Lincoln, 2000). Post-positivism proposes that alternate voices provide a partial account of reality so that truth is probabilistic (Denzin & Lincoln, 2000). Constructivism proposes that reality is constructed based on actual occurrences by the actual participants so that truth is based on local events. Participatory-Cooperative proposes that the

researcher cannot do the data justice by observing from the outside (etic view) so the researcher becomes involved in what is being researched for a view from the inside (emic view) so that truth is co-created (Denzin & Lincoln, 2000).

A “Crisis of Representation” developed over time due to the concern of etic vs. emic view of data (Denzin & Lincoln, 2000; Patton & Westby, 1992). Qualitative research developed from a concern about the view taken in the research process (the ownership) (Rudestam & Newton, 2001). Qualitative research stipulates that no single research method can provide the ultimate, full truth (Denzin & Lincoln, 2000). According to qualitative research principles, truth comes from the individual and is relative to the individual who experiences the event (Denzin & Lincoln, 2000). Individuals live in subjective realities and knowledge and truth are based on how the individual perceives the world (DePoy & Gitlin, 1998). Therefore, individuals who experience being diverse and using AAC will be the most knowledgeable about the experience of being diverse and using AAC (Denzin & Lincoln, 2000; DePoy & Gitlin, 1998). To develop a more emic view, the researcher seeks information from individuals who have experienced the concept or reality and the researcher becomes involved with the participants to develop a knowledge base of the experience (DePoy & Gitlin, 1998). Qualitative methodology provides researchers with paradigms and procedures to explore issues from a participant-centered concept.

“Qualitative research is an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem. The researcher builds a complex, holistic picture, analyzes words, reports detailed views of informants, and conducts the study in a natural setting” (Creswell, 1998, p. 15). Qualitative research usually operates from the paradigm of inductive reasoning so that events lead toward a theory (Creswell, 1998; Patton & Westby, 1992; Rudestam & Newton, 2001). Typically, the researcher begins the

study with raw data without preconceived ideas by categorizing data into broader concepts derived from the original data (Creswell, 1998). Content analysis procedures are often used to analyze texts or interview transcripts for the purpose of determining categories (Morgan, 1993; Neale & Nichols, 2001). After categorizing the data, the researcher derives themes describing the essential aspects of the meaning of the experience from the categorized data.

The goal of qualitative research is to obtain meaning (not causality) and to understand processes (Denzin & Lincoln, 2000; Rudestam & Newton, 2001). As a result, qualitative research is descriptive-based and not focused on quantity, intensity, and/or frequency of behavior. Qualitative research tries to find patterns and/or interrelationships between variables that impact the meaning of the event as a whole (Patton & Westby, 1992; Rudestam & Newton, 2001). Qualitative research is not concerned with replication. Thus, qualitative research demonstrates validity of results by consistency of results across, participants, data sources, or methods (Morse, Swanson, & Kuzel, 2001). Because qualitative research is conducted in the natural environment (e.g., tries not to control or influence the environment or the data collected) and the researcher is trying to gain an emic view of the issues, the researcher must maintain a neutral position even if involved in the event or engaged/interacting with the participant (Patton & Westby, 1992). One qualitative research method which can be used when researchers are seeking an emic view is phenomenological research.

Phenomenology

Phenomenology research focuses on a concept or phenomenon in an attempt to understand the meaning of the experience (Creswell, 1998; van Manen, 1997) from a post-positivist perspective (Creswell, 1998; Denzin & Lincoln, 2000). Phenomenology research is retrospective because the participant is asked to reflect on personal experiences. Quality

phenomenological research describes an experience so that the reader develops an understanding of the lived experience of other individuals. In phenomenology, the researcher examines the everyday experiences of individuals who experience a concept, culture, or reality to understand how individuals create and work within their social world (Denzin & Lincoln, 2000).

Phenomenology research is based on the paradigmatic view that meaning is within the lived human experience without theoretical constructs (Rudestam & Newton, 2001). The phenomenological researcher does not have preconceived ideas for data analysis but focuses on discovering the essence of the experience (i.e., without the central structures, features, concepts, or experiences the phenomenon could not exist) (van Manen, 1997). For researchers to understand the life experiences of individuals without theoretical constructs, the researcher must bracket personal beliefs about the phenomena—set aside how the researcher views the phenomena (Denzin & Lincoln, 2000; van Manen, 1997). It is important for researchers to suspend preconceived ideas about the reality of the participants so that they do not influence the results (Creswell, 1998). By focusing on the individuals' experiences with a concept, universal themes across participants can be discovered from the individuals' perspectives which reflect the essence of the experience. In phenomenology, it is important for researchers to develop questions which explore the meaning of the experience and encourage the individuals to describe their everyday life experiences for data collection (Creswell, 1998).

Phenomenology data collection and analysis is based on first-hand accounts of the phenomenon such as interviews, participants' written documents (e.g., diaries), or observations (Creswell, 1998; van Manen, 1997). Phenomenology data analysis is a cyclical reflection of collecting, analyzing, and writing about the essence of the data (Creswell, 1998). Data are organized into categories of similar meaning and concepts (Lincoln & Guba, 1985). Statements

summarize what happens in the phenomena and how it was experienced by the individuals (Creswell, 1998). Themes developed from the categories explain the essential aspects of a phenomenon or lived experiences (van Manen, 1997). The product in phenomenology is a rich text such that the reader should be moved to better understand what it means to experience the concept and the reality of the individual (Creswell, 1998; Rudestam & Newton, 2001).

Appendix C

PARTICIPANT INFORMATION FORM

Please fill out all applicable sections

Participant Name: _____

Participant Address: _____ email _____

Participant Phone: _____

Participant DOB: _____ Age: _____

Participant's ethnicity: _____

Please list any diagnoses associated with using the AAC system: _____

Questions about your AAC system:

1. Describe your AAC system: _____

2. Please circle how you access the AAC system:

touches it with: a finger a fist a pointer What type of pointer: _____

scanning: linear row/column group Other: _____

encoding (please describe): _____

switch access (please describe): _____

3. How many years has the current AAC system been used? _____

4. Describe previous AAC systems that have been used: _____

5. Describe how the AAC system is used on a daily basis: _____
_____6. What issues related to AAC and your ethnicity do you think speech language pathologists
need to know about to provide better services? _____

7a. Tell me about your favorite memory as a child: _____

7b. Why is this your favorite memory as a child: _____

Appendix D

Participant Descriptions

Andy

Andy was a 54 year old African American male with Cerebral Palsy who lived in a large metropolitan city in the Midwest. His vision was corrected to within normal limits with bifocal glasses. His hearing was within normal limits. His muscle tone in all four extremities was spastic. Movement was observed in all four extremities. Andy had a limited range of motion in his arms. His hands were clenched but he used his pinky on his right hand to manipulate objects in his environment. He accessed his Dynavox by tapping the screen with his right index knuckle for direct selection. Andy used aides at work and at Home for his activities of daily living such as bathing, grooming, toileting, meal set-up, and transferring to and from his electric wheelchair. Andy controlled his electric wheelchair with his left forearm.

Andy used a variety of communication modes throughout his day. He primarily used his Dynavox at Home and at work. He quickly spelled grammatically correct messages while using word prediction. He would nod/shake his head for yes/no but usually used the Dynavox for yes/no. He rarely used his residual speech for single word messages. He used facial expressions to express emotions. Andy did not have a light tech system. Andy used a speaker phone with his Dynavox for work and at Home. Andy checked his email at work.

Andy lived at Home with his wife of 22 years. Andy said that his wife was “*Hispanic Black*,” had CP, and used natural speech for communication. Andy did not have children. They lived in a private apartment with aides for assistance for a specified number of hours per week.

Andy attended public schools as a child. His classes were with children with disabilities with limited contact with children without disabilities. His classmates were primarily African

American but mixed with European American and Hispanic American. Andy recalled learning to read in first grade. He got his first AAC light tech letterboard at 9 years of age. He graduated from high school when he was 19 years old. He attended day programs, workshops, and his current job at a center for individuals with Cerebral Palsy since finishing high school.

Andy worked part-time at a CP center as a receptionist. He answered the phone, redirected calls, and used the internal p.a. system to announce calls. He answered the caller's questions with his Dynavox. He took messages by memorizing the message and the phone number of the caller to relay to the recipient at a later time. Andy also taught classes about finances to the other individuals with CP at the center. He was paid for his receptionist work and his teaching duties but at wages below minimum wage because he job was considered subsidized employment (i.e., partial funds for employment provided through government programs, grants, or endowments). He was searching for a job (via the web and newspaper) so that he could work with typically developing peers and be paid a regular salary (i.e., not subsidized).

Andy led an active social life. Besides talking with staff and coworkers at work, he and his wife enjoyed socializing with family and friends who visited them. His wife spoke Spanish and English with her family when they visited. Andy said that he had learned a few Spanish words but because his Dynavox does not speak Spanish, he rarely used the words he knew. Andy was active in his church. He attended services weekly and enjoyed singing with his natural voice. He said that the people at his church were primarily African American and were very accepting of him and his wife. Andy was involved in outreach projects to the homeless.

Andy had several goals in life. He wanted to find a part time job with typically developing peers. He would like to have an office job but would be satisfied to work as a greeter

at Wal-Mart. Andy would like to have more money saved for emergencies and for his retirement.

Brittany

Brittany was a 54 year old African American female with Cerebral Palsy who lived in a large metropolitan city in the Midwest. Brittany's hearing was mildly impaired and she used a hearing amplification system in one ear and to correct her hearing within functional limits. Her muscle tone in all extremities was spastic. Her shoulders, elbows, wrists and fingers were contracted and minimal movement was observed. Brittany used her toes to operate her electric wheelchair and her Gemini. Brittany had an extra long seat so she could recline and readjust her seating at will. She used aides at work and her "house parent" at Home for her daily needs of dressing, grooming, and toileting. A house parent was an individual who provided a room and board plus physical assistance to someone with disabilities in his/her private home.

Brittany had a joystick mounted on her left foot pedal with two Jelly Bean switches mounted on the side of the joystick box and a flip switch (like a light switch) on the top of the joystick box. She used the joystick to drive her wheelchair and to move a cursor on the Gemini screen for direct selection. She used the Jelly Bean switches and the flip switch to make selections with the Gemini and to alternate controlling the device and wheelchair.

Brittany did everything with her toes. When she is outside buildings she wore shoes with thick, sturdy soles for traction to control the joystick but inside buildings she was barefoot. She primarily used her left foot to operate the joystick. Brittany fed herself "finger foods" and held her cup with her toes and drank with a straw. She also carried her lunch to the trash with her right toes as she drove her wheelchair with the left toes. Brittany accessed the device screen with the big toe on either foot for direct selection on buttons that were approximately ½ inch.

Brittany used a variety of communication modes throughout her day. Primarily she communicated with her Gemini. Brittany usually spelled her grammatically correct messages with word prediction. The Gemini had a series of topic pages. Some pages were single word messages but others were sentences set up for serial communication needs such as answering the phone. Brittany had programmed some of her own topic pages. One page of interest was a “soul food” page where she had added symbols and/or text buttons for foods she preferred. Besides using the Gemini for communication, Brittany often used her residual speech for short answers. She also pointed with her toes at objects in her environment and “nodded” with her toes for yes or shook her toes for no. Brittany used her facial expressions to communicate emotions and ask for clarification when she did not understand. Brittany used a computer at Home, at the center, and the computer feature on her Gemini. She did not use the phone or email.

Brittany went to a public school and attended classes with children with disabilities who were primarily African American. Her favorite subject in school was English because she loved to read. Brittany moved to several day centers and workshops after she finished School.

Currently, Brittany attended a CP vocational training center. She had a part-time job at the center but her subsidized position was eliminated. She was looking for a part-time job in the center or Community. She attended vocational classes and during breaks she surfed the internet.

Brittany’s social life was restricted. Brittany had six siblings. She said that her brother visited last year and implied that family visits were rare. Brittany said she did not have friends outside work or Home. Brittany only went on Community excursions with aides/coworkers.

Brittany lived in a private room in a Home of a house parent. Brittany had one roommate who had Down Syndrome in another private room. The house parent, her daughter, and two grandchildren lived in the house. Brittany was the only individual in the house who used AAC.

Brittany mentioned a few goals in life. She said she would like to have a job. She also would like to email friends. She greatly desired to be able to go and visit her family.

Dedric

Dedric was a 39 year old African American male with Cerebral Palsy who lived in a large metropolitan city in the Midwest. His unaided hearing and vision were within normal limits. His muscle tone in all four extremities was flaccid with no movement observed in his legs. Dedric had limited range of motion in his arms. He used his right forearm to control his electric wheelchair. He held a pen/pencil in his left hand with a modified grip and swept his hand across his communication device to direct select. His hand/arm was in contact with the device as it lay in his lap while he direct selected. Dedric's head laid on his headrest but he displayed good head control in the supported position. Dedric used an aide for all of his ADLs.

Dedric used several communication modes. Currently he was changing from a Liberator to a Vanguard II because he was starting to use a head mouse system to access his device quicker. He used semantic compaction with his high tech devices. Dedric said that his SLP took his Liberator and his Vanguard II during the device change so his only aided mode currently available to him was his letterboard. He had not had either high tech device for four weeks. He received his first light tech letterboard when he was a teenager and he used the same letterboard to spell his grammatically correct messages. Dedric would occasionally use his voice to say "yeah" but usually nodded/smiled for 'yes' and shook his head/frowned for 'no'. He used facial expressions to communicate emotions and sarcasm. Dedric rarely used the phone because as he explained he did not have anyone to call. Dedric owned a computer and had an email address.

Dedric lived in a group home setting on a campus designed for individuals with severe disabilities. Dedric said that he was placed at the group home by his family soon after he was

born. He lived in the group home and attended School locally until he was a teenager. At that time, he moved to an institution he called the “Cerebral Palsy School.” He stayed at the Cerebral Palsy School until his 22nd birthday when he finished his high school degree. The facility told him he could not live there anymore. He tried to tell them with his letterboard he wanted to come back to the group home campus. Instead, a grandmother he had never met placed him in a nursing home. He lived in the nursing home approximate 3-4 years. He convinced the nursing home staff that he did not belong there. The staff asked him where he wanted to live and he said that he wanted to return to the adult side of the group home campus where he had lived as a child. He moved back to the group home campus at that time and has continued to live there.

The group home campus had houses on several acres. Each house had a communal dining room, living room, and other spaces. Dedric shared a room with one person and a bathroom with four people. Each home had 8-16 residents with staff assigned to a single home.

Dedric worked at a sheltered workshop on campus. He painted pictures (individual creations or repetitive prints) which were sold locally. Dedric reported that he did not receive a paycheck for his artwork but he knew some individuals in other departments at the sheltered workshop did get paid. Dedric did get paid when he ran errands on campus for personnel and for training staff about his AAC device. Despite the lack of a paycheck, Dedric enjoyed his work.

Dedric’s social life was limited. He rarely went on Community outings to go shopping, eat at restaurants, or watch movies. He said that when he asked to go into the Community he was told there was not enough staff to spare. Although he never knew his family, Dedric indicated he felt he had a family in his group home. He talked about his four “sisters” two of which were residents and two were staff. Dedric had known all of his close friends for years.

Dedric had several goals in life. He wanted to live in his own apartment with aides to help with ADLs. Dedric indicated that he always wanted to go to college and study art history. He said that he would like to work at job away from the campus and to earn a paycheck.

Donald

Donald was a 50 year old African American male with Cerebral Palsy who lived in a metropolitan city in the South. Donald's hearing and vision were within normal limits. His muscle tone in all four extremities was spastic with minimal movement observed in his extremities throughout the interviews. Donald had a limited range of motion in his arms/hands in a six inch space in front of his chest. Donald leaned forward from the hips and used the side of his hand to press buttons on his cell phone and remote control. Donald exhibited contractions of elbows, hands, and fingers. Donald had excellent head control and accessed his Vanguard II with a headmouse to move the cursor on the screen for direct selection. Donald reported using a wheelchair throughout his life for mobility. Currently he used a power wheelchair for his daily needs and a manual chair for backup when his power wheelchair was broken. Donald used an aide for all of his ADLs. Donald reported using his residual speech skills throughout his life. He received his first AAC device approximately one year ago at the age of 49.

Donald uses a variety of communication modes throughout his day. On his Vanguard II, he used a spelling page to spell messages and semantic compaction. He preferred to use his speech even though he recognized that most people did not understand his speech. He used three-point-eye-gaze to identify objects and people for communication. He used facial expressions to communicate emotions, sarcasm, and yes/no responses. Donald used a light tech system at work which was a series of single sentence messages on a piece of paper (e.g., "Everything cost a dollar"). He did not have access to email.

Donald attended a public school in a class with peers with disabilities. Donald reported that he was the only child who had difficulty speaking. Donald could not write with a pencil so most of his school work was done with an aide. Donald reported that students did not like the fact that Donald was given personal attention and the tension between him and the other students made the process of making friends difficult. Donald quit School after 10th grade.

Donald was very focused on working and being in the Community. Donald was self-employed and sold snack foods throughout the metropolitan area. Donald's typical routine was to complete his ADLs in his private apartment with his aide by 10:00 a.m. Then he transferred into his power wheelchair and his aide loaded his snack foods onto his customized display rack, a sign advertising his business, a bucket for the cash, a large water bottle with a two foot long straw, his mounted Vanguard II, and his mounted cell phone. He sold snacks until after 6:00 p.m. Donald drove his wheelchair around town to a variety of locations and often traveled several miles in one direction. Donald worked without assistance. As a result, he often went 8-10 hours without food because there was no one to feed him. Donald preferred his job because he enjoyed the freedom of being self-employed and *being my own boss*.

Donald reported that his social life was primarily spent calling friends and family on the phone. He enjoyed going to a local mall and "*talking to the ladies*." Donald had limited contact with his five siblings. In 1980, Donald decided he wanted a "godmother" to help meet his needs in the Community and on personal issues. He interviewed several women and chose Hannah to be his godmother. Hannah bought his groceries, wrote his checks (Donald indicated that he was actively involved in his own finances) and essentially served the role of family by going to doctor's visits with him and other typical family responsibilities. Donald went to church and

enjoyed singing with his Vanguard II. However, he repeatedly mentioned that the Vanguard II did not have enough songs and did not have African American songs and spirituals.

Donald only shared one goal in life during the interview. Donald wanted to own a candy shop. He wanted to sell candy and other snack foods from a store that he was the sole proprietor.

Hubert

Hubert was a 28 year old African American male with Cerebral Palsy who lived in a large metropolitan city in the Northeast. Hubert's vision and hearing were within normal limits. He muscle tone in all four extremities was flaccid and no movement was observed in the lower extremities. He accessed his Dynamyte with incredibly precise movements with his left and right index fingers for direct selection. Hubert had been using some type of AAC system since he was approximately 12 years old. According to Hubert, he had the ability to use speech for communication when he was very young and gradually lost the ability to speak. He also indicated that he had been using a wheelchair all his life but when he was a child he could walk with assistance. Hubert currently drove an electric wheelchair which he controlled with his right hand. He fed himself but used a personal care assistant for all other daily needs.

Hubert used a variety of communication modes throughout his day. His primary mode of communication was a Dynamyte. He had several topic pages which he easily moved between for communication. Hubert's topic pages had approximately 50 symbols per page and were color-coded with the Fitzgerald Key (different categories of words were color coded such as green for verbs). He had text and symbols on the symbol buttons. However, Hubert primarily spelled his grammatically correct messages while using word prediction. Hubert also used a light tech paper notebook for communication. The 4 x 5" laminated notebook had an alphabet page and approximately ten topic pages. The notebook also had a few pages with short

paragraphs of text about him and his family. Hubert was born and raised in the United States. However, his mother and grandmother who raised him, as well as his maternal relatives and some neighbors, were from Haiti and spoke French. Hubert spelled his messages in French in his notebook to communicate with these family and friends. There was no French vocabulary in his Dynamyte. The Dynamyte and the notebook were the only aided communication modes Hubert used. Hubert produced a few gestures with his hands which this researcher was not able to understand. When asked about his gestures, Hubert reported that there were very few close friends or relatives that understood his gestures. Hubert used facial expressions primarily for yes/no communication. Hubert never attempted to speak in any of the interviews. He only vocalized once. Hubert did not have his own computer. However, Hubert reported that he had a friend who had a computer and that he was on the internet and emailed friends on a regular basis.

Hubert attended School when he was five with typically developing children. However, by kindergarten he was placed in a segregated classroom for children with disabilities. Hubert recalled being mainstreamed for math and playtime. Hubert indicated that the majority of his School years were spent with peers with disabilities. He completed a vocational diploma.

Hubert led a fairly active lifestyle. He had a private apartment. He shopped by himself or with an aide. Hubert had a standing arrangement with the bus system for individuals with disabilities for his job at the sheltered workshop which transported him to and from work five days a week. Hubert sorted and labeled products at the sheltered workshop. Hubert also worked as part of a grounds keeping crew at a local baseball field approximately eight months a year. At the baseball field, Hubert used a reacher to pick up trash off the ground and put it in a garbage bag attached to his wheelchair. He cleaned up the trash in areas which were frequented by the crowds of people attending the games. Hubert arranged his own transportation to this second job

as well as transportation to restaurants and the movies which he reported are his favorite things to do. Hubert was currently dating a European American woman without disabilities. Hubert mentioned that he would like to be a father some day as a goal in his life.

Jimmy

Jimmy was a 48 year old African American male with Cerebral Palsy who lived in a small city in the Northeast. He wore glasses which corrected his vision to within normal limits. His hearing was within normal limits. His muscle tone in all four extremities was flaccid. Jimmy was ambulatory with unsteady gait. He was able to pick up objects, turn doorknobs, write brief messages, and direct select on his Dynamyte with fair accuracy. Minimal movement for facial expressions was observed. He presented with open mouth posture, continuous drooling, and minimal tongue movement. Jimmy reported having dysphagia and had to be careful about how he ate his food. Jimmy completed all of his ADLs.

Jimmy used a variety of communication modes. He used his Dynamyte at work and for socializing with friends. He had numerous topic pages. He also used word prediction when he spelled words or messages. Jimmy was quick to let the listener know when the listener misunderstood. Although Jimmy demonstrated the ability to express complete, grammatical sentences on his Dynamyte, his preference was to use multiple modes to a single messages. For example, he might start responses by selecting a preprogrammed message on his device which had some of what he wanted to say. He finished his message by writing text and/or signing. Jimmy also carried communication props in his backpack such as a personal information notebook, pamphlets about his social activities, and souvenirs from his travels. He also used his t-shirts and many caps with souvenir pins attached to them for communication. Jimmy had a cell phone and used it with his Dynamyte. He did not have a computer or email.

Jimmy was placed in an institution for children with disabilities at birth. He met his mother twice. The institution had large barracks with 50 children per barrack with the beds along the walls. The children ate in their barracks at the other end of the hall. Jimmy recalled several children being kept in straight jackets. The staff at the institution rarely spoke to Jimmy or the other children. Jimmy recalled numerous instances in which the children were beaten severely with belts. Jimmy reported that he lived in Building 13 from birth until the state closed the institution for its abusive practices when he was a teenager.

After the institution, Jimmy was placed in a group home with 6-8 adult males until he was 26 years old. There were staff parents at the group home as well. After the group home Jimmy got his first apartment which he said was his first true Home and the first place he ever had any privacy. He recently moved from one apartment in a dangerous neighborhood to an apartment in an apartment complex. Jimmy lived alone with minimal assistance. Someone came to his apartment weekly to help with meal preparation, cleaning, and financial issues.

Jimmy worked as a janitor for a disability service center at the same location for 23 years. He enjoyed his work and considered several employees such close friends that he referred to them as his family. Jimmy worked part-time at the center. He wanted to work a few more hours but the disability public transportation did not have services after 3:00 p.m.

Jimmy had a very active social life. He was a member of a bowling league for men with disabilities. He proudly showed his certificates for winning the high score and another certificate for highest average score. He raised funds to help the league have practice sessions. Jimmy was a member of a coed volleyball team for individuals with disabilities. Jimmy liked to shop and go to movies. Jimmy has traveled throughout the continental United States and to Hawaii.

Jimmy had several goals in life. His most important goal in life was to meet a woman with or without disabilities and develop a relationship. Jimmy said he was lonely for companionship and this was an important goal for him. Jimmy would like to earn more money. Jimmy would also like to travel more.

Keith

Keith was a 26 year old African American male with Cerebral Palsy who lived in a large metropolitan city in the Midwest. His hearing was within normal limits. His vision was corrected to within normal limits with glasses. Keith's muscle tone in all four extremities was mixed. He was able to "walk" on his feet/ankles or his knees short distances in his Home. He used a chair lift on the stairs in his Home. He used an electric wheelchair outside the Home for mobility. He controlled the wheelchair with his left hand. He presented with a mild drooling problem and would periodically wear a sweatband on his wrist to wipe his mouth. Keith reported that he had surgery to reduce his drooling and now his drooling was much better. Keith fed, dressed, groomed, and toileted himself. He did require his food to be cut into bite size pieces. When Keith wore lace up shoes, jackets or shirts with zippers or buttons, his mother or younger brother would help him with the fasteners. He was able to move his left hand and fingers with fair range of motion and accuracy. His right hand range of motion was extremely limited and generally contracted. Keith accessed his Pathfinder with his left index finger.

Keith used a variety of communication modes. In face to face interactions, Keith primarily used semantic compaction with spelling unique words on his Pathfinder. Keith created grammatically correct, complex sentences and paragraphs. Keith used facial expressions for emotions. He would nod/shake his head or verbalize for yes/no responses. He would fingerspell short messages to family when his device was not available. Keith had a cell phone attached to

the side of his Pathfinder which he used with his speech or his Pathfinder when making phone calls. Keith used a speaker phone at the house primarily with his residual speech. Keith could not carry his Pathfinder downstairs to his computer (where he works) so when he was downstairs he would type messages on the computer; email someone, or his favorite communication mode, instant messaging. Keith said that instant messaging made everyone use AAC so it equalized the communication between him and his customers.

Keith was an independent contractor for designing websites. Keith primarily obtained new customers through referrals from previous customers. He would also surf the web and find poorly designed websites for private organizations such as churches, foundations, and activist causes. He would sometimes create an introductory web design for them and send it to them as part of marketing his business. Keith stated that he had to be careful to not work too much or he could lose his medical benefits through Medicaid and SSI. In his state, individuals who had disabilities are not allowed to get medical insurance policies or life insurance policies as well.

Keith led a relatively active social life. Keith was at Home all day primarily by himself working on the computer. However, he would email friends throughout the day. He would go out into the Community by himself or with friends and families several times a week. Keith, his brother, and his mother were very close and liked to spend time together even though they recognized they are often on different time schedules. Keith graduated from high school with his class and was currently taking a year off from college because he was “*getting stressed out.*” Keith was majoring in computer science with an emphasis in information technology. When in School, Keith lived on campus and socialized with friends. Keith was a junior in college.

Keith had several goals in life. He planned in the next year to move to another state. He was hoping to have his own apartment when he moved. Keith was planning on finishing his

college degree but recognized it would take some time because he got overwhelmed with a full load of classes. Keith also would like to work full-time as a computer programmer/web designer with full benefits like his typically developing peers.

Loleeta

Loleeta was a 46 year old African American female with Cerebral Palsy who lived in a large metropolitan city in the Midwest. Loleeta's hearing was within normal limits. Her vision was corrected to normal limit with bifocal glasses. Her muscle tone in all four extremities was mixed. Minimal movement was observed in her lower extremities. Loleeta controlled her electric wheelchair with her left forearm. She accessed her Dynavox with a switch mounted behind her head which she used to control row column scanning. Loleeta exhibited moderate drooling and wore a washcloth pinned to one shoulder so she could wipe her mouth as needed. She used aides at work for toileting and meal set-up. Her food was served on a paper plate placed on dycem (to decrease skidding) which was on a 12 inch high box. Loleeta fed herself by biting the plate to turn it so she could reach the food. She scraped the plate with her mouth to get the food. At Home, her mother fed her and helped her with ADLs. At one time, Loleeta had aides at Home to help with ADLs and cleaned her living spaces. However, her mother dismissed them and chose to do it herself since the aides did not clean the entire apartment.

Loleeta used a variety of communication modes. Primarily, she spelled grammatically correct sentences on her Dynavox with word prediction. Her communication rate was slow and occasionally required 30 minutes to write two sentences. She nodded/shook her head for yes/no responses. She vocalized for emphasis but rarely used her residual speech. At Home she used yes/no responses. If family didn't understand her they might use her light tech board while she pointed (with poor accuracy) at words and letters. She used facial expressions to communicate

emotion and occasionally for yes/no responses by smiling/frowning. Loleeta rarely used the phone but when she did use the phone she used a speaker phone. Loleeta used a computer at Home and work but did not use email because her friends and family did not use email.

Loleeta's education was first at a public school primarily designed for children with disabilities. Her classes were with mostly African American children all of which had disabilities. Later, she was moved to a School for individuals with CP. Loleeta graduated from high school. She was the only person in her entire family to graduate from high school. Her CP school had a day program which later transitioned into a day program/workshop/vocational training center. Thus, Loleeta had been at the same center since she was a teenager.

Loleeta worked a subsidized position at a disability center and received a paycheck. She organized bus tickets for the participants at the center. She was completing other vocational training for office equipment with adaptations. She attended classes about her legal rights. She would surf the internet on breaks.

Loleeta tried very hard to lead an active social life. She socialized with the staff and coworkers at the center where she worked. She saved her money and spent it shopping primarily for clothes. She arranged her own transportation for shopping excursions while at work so she could be more involved in the planning. She went into the Community nearly every weekend either with friends with disabilities, aides, or by herself. Loleeta did not socialize with neighbors in her apartment building. She lived with her mother who had a disability and her able-bodied brother who did not provide care for Loleeta.

Loleeta had a few goals in life. She would like to go to college but indicated that she did not think it would happen. She wanted to work a part time job with typically developing peers. Loleeta had a private apartment at one time for a few months but her mother insisted she move

back in with her mother and her brother. Loleeta wanted to live in her own apartment with aides and she was actively working towards getting her own apartment by the end of data collection. Loleeta also would like to date someone with or without disabilities.

Mac

Mac was a 39 year old African American with Cerebral Palsy who lived in a large metropolitan area in the Midwest. His hearing and vision were within normal limits. His muscle tone in all four extremities was spastic with some movement observed in all extremities. Mac had limited range of motion in his arms. He moved his manual wheelchair by pushing with his feet on the floor. He accessed his Vanguard II by hitting a switch with his right temple for scanning. Mac used aides at his day center and his mother at Home to attend to all of his ADLs. Mac was easily distracted but could also be easily redirected by repeating the last question or statement.

Mac used a variety of communication modes. He used facial expressions to signal emotions and provide feedback to his communication partner. He nodded and shook his head for yes/no responses. He occasionally pointed with his elbow at objects in the room that he wanted or was discussing. He used his residual speech at Home to create multi-word messages. His residual speech was essentially unintelligible even to familiar audiences such as his mother. He used his Vanguard II primarily at the day center. His Vanguard II was programmed for row/column scanning. He used semantic compaction to create messages on his Vanguard II. According to Mac and his work supervisor, Mac was able to read simple sentences and spell short messages. Mac was unable to demonstrate his spelling skills during the interviews because his mother took his device away from him during his interview. Mac talked on the phone on his

birthday but did not use the phone throughout the year. Mac did not send email but did use a computer at the center.

Mac has lived with his mother his entire life. His mother assisted Mac with his ADLs at Home and aides meet those needs at the day center. He lived with his mother, grandmother, sister, and a nephew. His room was on the main floor of the house and he did not go anywhere in the house but the main floor.

He attended the day center since he started School. The day center initially was a school for children with severe disabilities. His original classmates were primarily African American. He described his schooling as primarily entertainment with few academic classes. He started attending more academic classes when he was a teenager but did not graduate from high school. Later, the day center was bought by a disability group and changed into a workshop for individuals with disabilities. It currently provided part-time work for some individuals with disabilities. Mac was at the center taking classes about his legal rights and was in vocational training for working with office equipment.

Mac's social life was very limited. He attended the day center and enjoyed the staff and other individuals with disabilities at the center. The center took him on field trips a few times a month to go to the mall or to a restaurant for lunch. He rode the public bus used for individuals with disabilities to and from the center. He rarely went anywhere with the family. He had his own van but the lift does not work correctly so he was unable to use the van. He was waiting on someone to come fix the lift in his van. However, he lived in an extremely dangerous neighborhood so service companies refused to come to the van and fix it. Mac did not socialize with individuals in his Community.

Mac had a few goals in life. He would like to finish vocational training and start working a part-time job. He thought it would be nice to have his own apartment but indicated he did not believe it would happen. One goal he was very emphatic about was dating. Mac wanted to have a serious dating relationship with a woman without disabilities.

Appendix E

Semi-Structured Interview Question Guide

1. First interview (Seidman, 1998): Phenomenon during school years

- a. To help me get to know you better, please tell me about your family, neighbors, and friends

Follow up

1. what ethnicity/race/culture are your neighbors/friends/family
2. how do you interact with your neighbors/friends/family
 - a. phone/email/face to face
 - b. with your speech? Gestures?
 - c. with AAC device

- b. Tell me about your classes in school

Follow up

1. were you in a special class with only children with disabilities?
2. what were the opportunities like for you to interact with the other kids in school?
3. what ethnicity/race/culture were the other kids and teachers?

- c. Tell me what it was like to interact with/talk with people when in school. If helps,

remember a time when you wanted to share about something fun you did

Follow up

1. with teachers
2. with peers/classmates

- d. Think about a time when school was hard. Tell me about it. What made it hard?

Follow up

1. How did AAC or your difficulty with speaking impact doing well in school
2. How did your ethnicity/race/culture impact doing well in school
3. Were there other issues or problems that made it hard to do well in school
4. Can you remember a time in which someone discriminated against you (treated you differently because of something about you such as your ethnicity/race/culture or disability)? Please tell me about it.

Follow up

- a. How did your ethnicity/race/culture impact the situation
 - b. How did your difficulty with speaking impact the situation? Did you use AAC?
 - c. Were there other issues impacting the situation?
 - d. What did you do to stop discrimination against you?
- e. What kinds of things that helped you to succeed/do better in school?

Follow up

1. people
 2. equipment
 3. services
 4. What kinds of things did people do to help you in school
 - a. for your speech disability/using AAC?
 - b. for your ethnicity/race/culture?
 - c. were there other types of things that helped you succeed in school?
- f. Tell me about anything you wished you had had that might have helped you to do better in school?

Follow up

1. people
 2. equipment
 3. services
2. Second interview (Seidman, 1998): Phenomenon during current life
- a. This interview is focusing mostly on your current, every day life. To help me get to know you better, please tell me about you like to do for fun, your job, and/or what you do on a daily basis.
 - b. Tell me about your job duties (or daily activities if not employed?)
Follow up
 1. What duties are easy? What duties are hard?
 2. What are the opportunities like for you to interact your coworkers?
 3. What ethnicity/race/culture is your boss and coworkers?
 - c. Tell me what it is like to interact with/talk with people at work (or during your daily activities). If helps, remember a time when you wanted to share about something fun you did
Follow up
 1. with your boss
 2. with coworkers or friends
 - d. Think about a time when work was hard. Tell me about it. What made it hard?
Follow up
 1. How does AAC or your difficulty with speaking impact doing well at work
 2. How does your ethnicity/race/culture impact doing well at work
 3. Are there other issues or problems that make it hard to do well at work

4. Can you remember a time in which someone discriminated against you (treated you differently because of something about you such as your ethnicity/race/culture or disability)? Please tell me about it.

Follow up

- a. How was your ethnicity/race/culture impacting the situation
 - b. How was your difficulty with speaking impacting the situation? Did you use AAC?
 - c. Were there other issues impacting the situation?
 - d. What do you do to stop discrimination against you?
- e. Tell me about anything that helped you to succeed/do better at work?

Follow up

1. people
 2. equipment
 3. services
- e. Please tell me about anything done to help you at work
- a. for your speech disability/using AAC
 - b. for your ethnicity/race/culture
 - c. were there other types of accommodations made for you?
- g. Tell me about anything you wished you had had that might have helped you to do better at work?

Follow up

1. people
2. equipment

3. services

3. Third Interview (Seidman, 1998): Accommodations and Recommendations

This interview will be focusing on ethnicity/race/cultural accommodations for your AAC

services and systems. Also, we will be discussing recommendations for improving AAC services and systems.

a. What if any changes were made because of your race/ethnicity/culture to your AAC

1. System

- a. Symbols—specifically because of your race/ethnicity/culture
- b. Languages—languages besides English
- c. Vocabulary—wording or slang
- d. Techniques—how you use or operate your device
- e. Strategies—how you compensate when your device does not have the words you need

2. Services

- a. SLP interactions—changes made to make you and/or family more comfortable
 - b. Language differences—languages used besides English
 - c. Cultural expectations—changes to how AAC would be used due to your race/ethnicity/culture
 - d. Cultural needs—changes to tx plans and services due to your race/ethnicity/culture
 - e. Tx plans, goals, and methods
- b. If accommodations were made, which cultural accommodations were most beneficial
- c. If accommodations were made which cultural accommodations were least beneficial

- d. If you could tell professionals how to be better at meeting needs based on your race/ethnicity/culture, what changes do you want/suggest for AAC
 1. System
 - a. Symbols
 - b. Languages
 - c. Vocabulary
 - d. Techniques
 - e. Strategies
 2. Services
 - a. SLP interactions
 - b. Language differences
 - c. Cultural expectations
 - d. Cultural needs
 - e. Tx plans, goals, and methods
- e. Give examples or ideas that you think would bring positive change and reduce/eliminate discrimination against you due to your ethnicity and AAC use
 1. When you were in school
 2. For teachers
 3. For SLPs
 4. For peers/classmates
 5. For employers
 6. For others (e.g., store clerks)
- f. Give an example of how has discrimination impacted your life

1. Financially
 2. In relationships
 3. In opportunities in life
- g. Does ethnicity or AAC have more of an impact in different situations—give an example
- h. What events impacted how you view yourself today
- i. When you look at the aspects of your identities, explain how your ethnicity and AAC fit into your view of yourself—its significance or impact as compared to other aspects of your identity

Appendix F

Bracketing Statement

I have had many relationships with African Americans and with individuals who use AAC. In regards to African Americans, I was raised in the South in an environment which appeared to be accepting of African Americans. Like many Southerners, I was raised to believe that tolerance was the level of interaction expected from European Americans for African Americans. However, my life experiences outside my family and family friends developed my awareness of the difference between acceptance and tolerance. When I was a young adult, family and family friends considered me somewhat radical because my views about ethnic relationships were very different from their views of ethnic relationships.

As a young adult, I attended church of mixed ethnicity but mostly European Americans. There, I tried to shed beliefs and stereotypes about African Americans. Changing one's views and interaction styles can be very rewarding. Yet, growth can have a price. For me the price for breaking my silence was losing friends and a few strained family relationships.

Today, I tend to code switch with individuals from different ethnicities and SES. Even though I have learned to adapt (Bennett, 1986), it is sometimes a struggle to not make quick judgments of interactions and people based on ethnicity. Old behaviors and attitudes sometimes resurface and must be addressed again. The impact of my experiences with African Americans on the current study was that I am alert to innuendos, double-talk, and circular discussions in which the topic is indirectly addressed via stories and analogies. I strove to address the different communication styles by letting the interaction flow naturally. I asked direct questions after the exchange was finished to make sure I had the messages' meaning correct as possible while not destroying the discussion with my preferred, direct communication style.

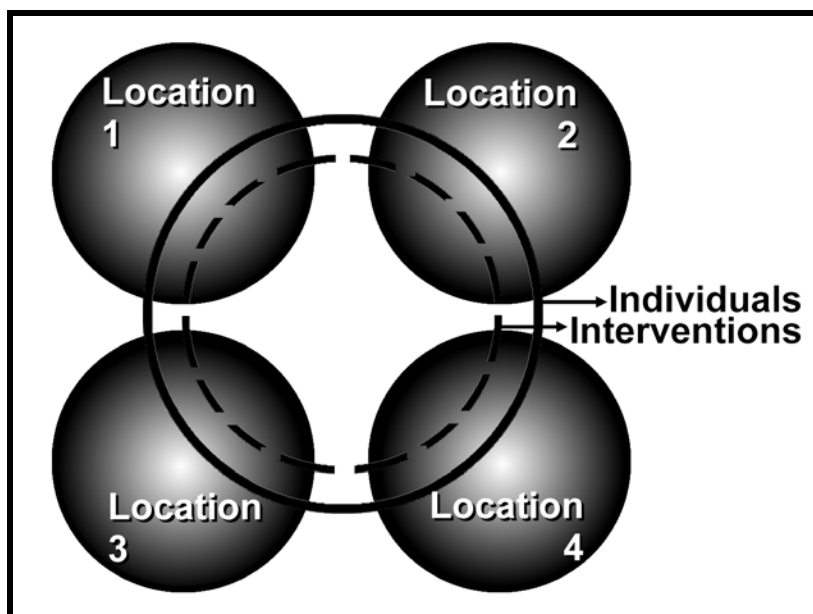
I have worked with individuals who use AAC for many years as an SLP. Recently, I have become friends with several individuals who use AAC. Communication speed, lack of words, and physical limitations were relationship roadblocks I understood cognitively but I had not understood personally. Being friends of someone with severe disabilities and who uses AAC is more work than friendships with typically developing peers. The impact on the study was that I allowed myself to be immersed in the shared emotions. The connection was important for the participants and me. I honestly shared myself while focusing on the task. Because I shared myself, I believe that participants were more willing to share private feelings/experiences than they would have if I had been more distant or had used different methodology such as a survey.

During data collection I experienced a serious injury. Most participants met me before and after the injury and all of the participants knew of my injury by follow-up questions. It was interesting to see the change in interactions when participants saw me struggling with a wheelchair or crutches. Many participants directly or indirectly indicated that I was “one of them” because I was experiencing their lives—even if only temporarily. Many participants used my injury to share experiences. There was a deeper camaraderie with the participants because of the injury which I believe enriched the interview experience for the participants and myself.

Overall, my life and injury experiences helped me during the study by allowing me to view the data from multiple perspectives. Thus, the text benefited by me being careful to focus on the participants’ perspective of their life events. My biases for looking for hidden meanings were tempered with numerous follow up questions during interviews to insure the participants’ meaning I recorded was accurate. My emotional connection with participants helped build trust. Simultaneously, I did not allow myself to become emotional engrossed so that the focus of the study was maintained.

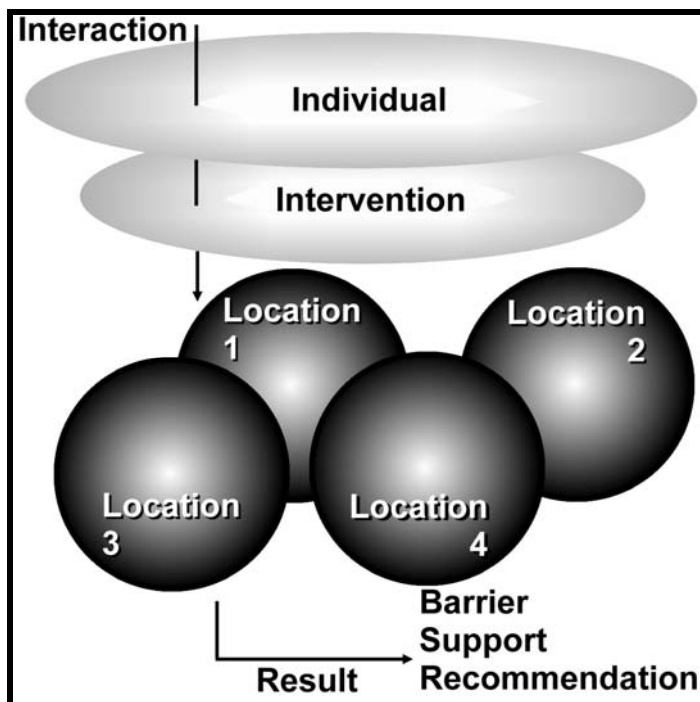
Appendix G

Model Visualizing the Relationships between the Themes



- Legend:
- Location 1: Home
 - Location 2: School
 - Location 3: Vocation
 - Location 4: Community

View a. Top view showing interrelationships between themes.



View b. Side view showing interactions between themes.

Table 1
Participants' AAC Systems

Participant	Age at first AAC device	First AAC Device	Current AAC System	Current access method	Device self-programmed
Andy	9	Light tech letterboard	Dynavox, gestures	Direct select, right hand	Yes
Brittany	5	Light tech letterboard	Gemini, Dynavox, residual speech	Foot controlled joystick; direct select, feet	Yes
Dedric	13	Light tech letterboard	Pathfinder, Liberator, light tech letterboard, facial expressions	Direct select, left hand	No
Donald	49	Vanguard II	Vanguard II, light tech message board, residual speech	Headmouse	No
Hubert	13	Light tech notebook	Dynamyte, light tech notebook, gestures	Direct select, both index fingers	Yes
Jimmy	38	Dynamyte	Dynamyte, light tech notebook, backpack props, residual speech, sign language	Direct select, right hand	Yes
Keith	5	Light tech Bliss-symbol board	Pathfinder, residual speech, fingerspelling	Direct select, left hand	Yes
Loleeta	10	Light tech letterboard	Dynavox, facial expression, gestures	Scanning with head switch	No
Mac	37	Pathfinder	Pathfinder, residual speech, gestures	Scanning with head switch	No

Table 2

Participants' Home and School Settings Prior to Adulthood

Participant	Caregivers			Reading	Education
	Home	School	Residents in the home	Age	Achieved
Andy	Mother	Aides	Mother (Grandmother and sister briefly)	9	Regular Diploma
Brittany	Mother	Aides	Parents, and 6 siblings	5	Special Ed. Diploma
Dedric	Staff	Aides	Peers with disabilities	13	Special Ed. Diploma
Donald	Mother	Aides	Parents, 5 siblings, and Grandmother	7	10 th grade
Hubert	Mother, Grandmother	Aides and peers	Parents, Uncle, 2 siblings, and Grandmother	13	Vocational Diploma
Jimmy	Staff	Aides	Peers with disabilities	15	Vocational Diploma
Keith	Mother	Aides	Mother, brother (1 cousin briefly)	6	Regular Diploma and some college
Loleeta	Mother	Aides	Mother, 3 siblings, and cousins	8	Regular Diploma
Mac	Mother	Aides	Mother, 2 siblings, and Grandmother	25	Certificate of Attendance

Table 3

Current Life Activities and Goals

Participant	Age	Home	Work	Community	Family Life	Goals
		setting	setting	involvement		
Andy	54	Private apt. with aides	Part-time receptionist at disability center	Church, restaurants, shopping	Lives with wife, family visits regularly	Part-time work in typical setting, better pay
Brittany	54	Private room with house parent	Vocational training at disability center	Occasional trips from disability center	Lives with 1 housemate, house parent, her daughter, and daughter's 2 children	Find a job, visit her family
Dedric	39	Semi-private room with aides	Sheltered workshop	Rare field trips from institution	1 roommate, 16 housemates, no family contact	Own apt., go to college
Donald	50	Private apt. with aides	Self-employed salesman	Church, shopping	Friends visit often, limited family contact	Own a candy store
Hubert	28	Private apt. with aides	Sheltered workshop, part-time grounds crew	Shopping, restaurants, movies	Close family contact, girlfriend	Be a father
Jimmy	48	Private apt. with aides	Part-time janitor at disability center	Several sport leagues, travels, shopping, restaurants, church	No family contact, numerous close friends	Work more hours, get married
Keith	26	Private home with family assistance	Self-employed web designer	Internet chatting, restaurants, shopping, clubs	Lives with mom and brother, girlfriend	Full-time work, financial independence

Loleeta	46	Private home with family assistance	Part-time bus ticket manager	Shopping, restaurants, church	Lives with mom and brother, visits sister	Own apt., get married
Mac	39	Private home with family assistance	Vocational training at disability center	Occasional trips from disability center	Lives with mom, Grandma, sister, and 1 nephew	Part-time job, date a girl without disabilities

Table 4

Coding Themes, Sub-themes, Categories, and Category Definitions

Themes	Sub-themes	Categories	Category Definitions
Individuals	People	Authority figures	Statements made about individuals with power over the participant. It could have been a formal relationship such as teachers, bosses, employers, guardians, or other individuals or informal or temporary.
		Family	Statements made about biological relatives. Statements made regarding close friends that felt like family would be classified as friends.
		Friends	Statements made about individuals who were not biologically related to the participant but who were emotionally close to the participant as identified by the participant.
		Peers with disabilities	Statements made about peers with disabilities.
		Peers without disabilities	Statements made about typically developing peers.
		Service Personnel	Specifically identified individuals whose job duties included providing services as defined below. These individuals' job titles included but were not limited to the following: staff, aids, therapists, customer service representative at stores, and waiters.
	People Characteristics	AAC Feelings	Positive, negative, or neutral emotional responses made about AAC services or systems.
		Ability	Positive or neutral statements made about the participant's ability or the participant's belief about his/her ability to complete tasks or goals with or without equipment for education, work, or activities of daily living. Statements might include a participant's ability to advocate for him/herself even if the participant decided to advocate for him/herself by ignoring other individual's comments/behaviors.
		Commun-	Statements made about different communication

	ication mode	modes. Modes included all aided/unaided modes.
	Disability	Statements made about limitations in activities of daily living including but not limited to communication, mobility, literacy, feeding, dressing, toileting, etc. Statements could also include references, attitudes and/or behaviors made by individuals in the participant's environment about the participant's limitations.
	Ethnicity	Statements made about ethnic/race/cultural relationships and issues with other individuals or AAC systems.
	Language	Statements made about vocabulary, slang, or languages other than English.
	Physical control	Statements made about mobility ability, mobility issues, hand ability, and access issues to devices.
	Recreation activities	Statements made about leisure activities which the participant enjoyed doing. Activities could have been solitary activities such as reading or social activities completed with other individuals.
Location	Community	Statements made about people and locations in the community. It did not include educational situations or work situations.
	Home	Statements made about living arrangements
	School	Statements made about school related activities. The statements could also have been about the location.
	Vocation	Statements made about work related activities. The statements could also have been about location. Work did not require a paycheck. It could have been job responsibilities or job training completed on a regular basis unrelated to activities of daily living.
Interventions	Services	Statements made about aid provided to and for the participant for help with educational activities, work activities, and/or and activities of daily living. Services could have been formal arrangements such as therapy services and personal care assistant (aide) services or informal arrangements such as pushing a

Barriers	Equipment	wheelchair by friends between classes. Statement made about any electronic or non-electronic device used by the participant to complete activities of daily living, educational activities, or work related activities.
	Device changes	Statements made about changes made to any part of AAC systems
	Obstacles	Any person, service, equipment, rule, environment, behavior presented by both other individuals, and/or inflexible systems/policies that inhibited progress or made it difficult for the participant to complete a task or make progress with tasks or goals. Not having personnel, services, or equipment that would help the participant was also an obstacle.
	Discrimination	Statements made about attitudes and behaviors of individuals which caused the participant to not receive the same services, education, acceptance, or participation in activities as other individuals.
Supports	Device problems	Statements made about any AAC concerns, issues, inconveniences, or aided communication mode not working properly (light tech or high tech).
	Accommodation	Statements made about actions taken by individuals to recognize or acknowledge individual differences related to ethnicity or disability. Statements were not types of assistance designed to help a person have a positive outcome on a specific task or goal.
	Assistance	Statements made about people, services, equipment or aid that resulted in a positive outcome by helping the participant succeed at a tasks or goal. Could have included help provided by equipment, strangers, peers, family, friends, or service personnel.
Recommendations	Wish list	Statements made about people, services, equipment, or changes made to society and/or policies desired by the participant. Statements could have been related to the participant's past, present, or future.

Table 5

Barriers, Supports, and Recommendations for Home, School, Vocation, and Community as
Identified by Participants

Location	Barrier and also			
	Barriers	Support	Supports	Recommendations
Home	<ul style="list-style-type: none"> •Minimal adaptive equipment or environmental controls available •At first no AAC device; later AAC device not used by family •No therapy services •Care provided by aides 	<ul style="list-style-type: none"> •AAC devices supportive for basic communication but did not meet vocabulary needs 	<ul style="list-style-type: none"> •Wheelchairs •Care provided by mothers when young 	<ul style="list-style-type: none"> •Place equipment and environmental controls in the home •Start AAC as soon as possible •Start high tech devices as a child •Add vocabulary for ethnicity needs •Develop self-programming skills •Make AAC devices more representative of individual's ethnicity •Provide therapy services in the home with family •Schedule more aides •Improve services provided by aides
School	<ul style="list-style-type: none"> •Segregated classrooms •Limited therapy services •Therapy services did not include families •SLPs did not recognize or accommodate diverse needs or issues •SLPs lacked skills and 	<ul style="list-style-type: none"> •Therapists provided minimal support which did not meet participant's needs •AAC devices helped with some communication needs yet device limitations and restricted vocabulary were barriers 	<ul style="list-style-type: none"> •Wheelchairs 	<ul style="list-style-type: none"> •Include individuals who use AAC in regular ed. classes •Increase therapy times to match individual needs •Include families in therapy plans and sessions •Increase knowledge about African Americans •Socialize with clients and families

	<p>knowledge about AAC</p> <ul style="list-style-type: none"> •Aides were often discriminatory •Limited equipment for academic needs 			<ul style="list-style-type: none"> •Increase knowledge about AAC •Implement high tech devices for school use in elementary grades •Add vocabulary for ethnicity needs
Vocation	<ul style="list-style-type: none"> •Limited hiring of African Americans •Limited hiring of individuals who used AAC to work in jobs with nondisabled peers •AAC devices lacked durability 	<ul style="list-style-type: none"> •Aides provided minimally helpful services; Most examples of services were barriers 	<ul style="list-style-type: none"> •Adaptive equipment for job tasks •AAC device helped with communication with employers, peers, and staff •AAC device helped individuals self-advocate •Other technologies and gestures helped communication 	<ul style="list-style-type: none"> •Hire African Americans •Hire individuals who use AAC •Increase flexibility with appointments and schedules •Improve device durability •Increase AAC device's network capabilities with other technologies
Community	<ul style="list-style-type: none"> •Nondisabled peers in general population were sometimes not accepting of individuals with disabilities •Fast food workers sometimes discriminated •SLP services were limited •SLPs were not social with clients •SLPs rarely included families 	<ul style="list-style-type: none"> •Transportation systems helped but often limited activities or were inoperable •Ethnic accommodations in therapy sessions or AAC devices were rare but helpful 	<ul style="list-style-type: none"> •Store workers often helped •AAC devices were helpful for basic communication 	<ul style="list-style-type: none"> •Educate nondisabled peers about disabilities and about AAC •Educate employees about AAC

Table 6

Sample Text Notations for Types of Communication Modes (adapted from Tetzchner and Jenson, 1996)

Communication Mode	Description and Sample of Communication Mode
Natural speech	<i>Messages are italicized without quotation marks</i>
Digitized or synthesized speech	“ <i>Messages are italicized with quotation marks</i> ”
Manual signs	MESSAGES ARE CAPITAL LETTERS WITHOUT QUOTATION MARKS
Graphic signs/pictures	<i>MESSAGES ARE CAPITAL LETTERS, ITALICIZED, WITHOUT QUOTATION MARKS</i>
Glossing signed messages	A SINGLE SIGN TRANSLATES/GLOSSES INTO ENGLISH AS TWO OR MORE WORDS: HYPHENATE-BETWEEN-WORDS WITHOUT ITALISIS OR QUOTATION MARKS
Pre-stored messages or words	<u>Messages are underlined without quotation marks</u>
Spelled messages	<u>M-e-s-s-a-g-e-s a-r-e h-y-p-h-e-n-e-d b-e-t-w-e-e-n l-e-t-t-e-r-s, u-n-d-e-r-l-i-n-e-d b-u-t n-o q-u-o-t-a-t-i-o-n m-a-r-k-s</u>

CURRICULUM VITAE

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Degrees Awarded:

M.Ed.	M.Ed. Speech Language Pathology. University of Montevallo	1995
B.S.	B.S. Speech Language Pathology. University of Montevallo	1993

Professional Experience:

Owner	Private Practice, Tampa FL	2000-2002
SLP	Pasco County School Board, New Port Richey, FL.	1999-2001
Program Mgr.	Prism Rehab Systems, Tampa, FL	1997-1999
Senior SLP	Genesis Eldercare Rehabilitation Services, Clearwater, FL	1995-1997

Awards:

ASHA ACE Award	2004
Genesis Eldercare Customer Service Award	1996
Omikron Delta Kappa Honors Society	1993
National Dean's List	1993
University of Montevallo Honors Society	1992
Who's Who Among Students in American Universities and Colleges	1992
Sigma Alpha Pi Honors Society	1990

Grants and Scholarships:

ASHA Student Research Travel Award \$500.00	2004
Small Project Grant: College of HHD Alumni Society (PSU) \$500.00	2003
Pennsylvania State University Graduate School Assistantship	2002-2005
Creative Teaching Award and Grant \$500.00	2000
Veteran's Administration Medical Center: Stipend Recipient	1994
Ancient Order of Scottish Rite Fellow	1993-1994
Ancient Order of Scottish Rite State Scholarship Winner	1989-1993

Research Projects:

Primary Investigator	Providing AAC Services to Culturally Diverse Clients from the Perspective of SLPs	2004-2005
Primary Investigator	Being Culturally Diverse and Parenting a Child who Uses AAC from the Perspective of Parents	2004-2005
Primary Investigator	Being Culturally Diverse and Using AAC from the Perspective of Individuals who use AAC	2004-2005
Primary Investigator	Communication Repair Strategies for Individuals who use AAC: An Intervention Study	2003-2005
Primary Investigator	Augmentative and Alternative Communication Service Delivery Survey	2002-2003
Investigator	Comparison of DECTalk Speech Intelligibility in a Typical AAC Device vs. Platform-Based System	2001

Manuscripts in Preparation:

- Davis, R. and Light, J. (2004). Augmentative and Alternative Communication Service Delivery in the U.S. and the Factors that Influence AAC Service Delivery.
- Davis, R. and Drager, K. (2004). Communication Repair Strategies for Individuals who use AAC.

Presentations at Scientific and Professional Meetings:

- Davis, R. and Drager, K. (November, 2005). Communication Repair Strategies for Individuals who use AAC. Poster presented at the Annual Conference of ASHA, San Diego, CA (accepted)
- Davis, R. and Light, J. (November, 2004). AAC Service Delivery Survey: SLPs Time Allotment for AAC Services. Paper presented at the Annual Conference of ASHA, Philadelphia, PA.