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Factors related to the rejection and/or abandonment of AAC devices

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FACTORS RELATED TO THE REJECTION AND/OR
ABANDONMENT OF AAC DEVICES

BY

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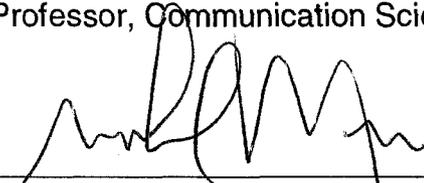
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ABSTRACT

FACTORS RELATED TO THE REJECTION AND/OR ABANDONMENT OF AAC DEVICES

by

Alla A. Johnson

University of New Hampshire, September, 2008

More than 3.5 million Americans have such significant communication disability that they cannot rely on their natural speech to meet their communication needs. As a result, these individuals are severely restricted in their participation in all aspects of life, including their education, employment, family, and community. Augmentative and alternative communication strategies offer great potential to enhance the communication of individuals with complex communication needs, and therefore improve their quality of life.

Even though the intent of an AAC intervention is to enhance an individual's quality of life, research provides evidence that the AAC acceptance does not occur routinely. In an effort to understand this phenomenon, this study was designed to explore factors that contribute to the rejection and/or abandonment of AAC systems. Factors were explored in relation to individuals who use AAC devices, their communication partners, settings, and the technology itself.

Fifty-two ISAAC members that responded to the online survey utilized a 5 point Likert-type scale (strongly agree to strongly disagree) to rate the importance of factors as they relate to the rejection and/or abandonment. The mean values of ratings were calculated to determine which factors were cited as relevant in predicting AAC device rejection and abandonment. Additionally, an independent T-test was utilized to determine if the factors cited varied depending on the role of the person completing the survey.

The results of this investigation indicate that it is imperative to consider a complex interaction of factors pertaining to the individuals who use AAC, their conversational partners, settings in which interactions occur, and devices used to interact, when designing an AAC intervention. The statistical analysis revealed no significance difference in how the respondents rated the factors based on their occupation. Based on the results of the study, a checklist of factors that an AAC practitioner might consider addressing in order to foster acceptance of AAC systems initially and later on was constructed.

FACTORS RELATED TO THE REJECTION/ABANDONMENT OF AAC DEVICES: INTRODUCTION

Approximately 1.3 % of all individuals (i.e., more than 3.5 million Americans) have such significant communication disabilities that they cannot rely on their natural speech to meet their daily communication needs (Beukelman & Mirenda, 2005). Without access to speech, these individuals are severely restricted in their communication and participation in all aspects of life, including their education, employment, family, and community. The development of augmentative and alternative communication strategies offers great potential to enhance the communication of individuals with complex communication needs, and therefore improve their quality of life.

Augmentative and Alternative Communication (AAC) refers "to an area of research, clinical, and educational practice. AAC involves attempts to study and when necessary compensate for temporary or permanent impairments, activity limitations, and participation restrictions of individuals with severe disorders of speech-language production and/or comprehension, including spoken and written modes of communication" (ASHA, 2005, p. 1). The term AAC *aid* refers to "a device , either electronic or non-elctronic, that is used to transmit or receive messages"(ASHA, 2004, pp. 1-2).

The ultimate goal of an AAC intervention is not only to find a technological solution to communication problems but to enable individuals with complex communication needs to efficiently and effectivly engage in a variety of

interactions and participate in activities of their choice. To achieve this goal, the AAC specialist needs to design an intervention that provides a person with a real meaningful change and opportunities to become a competent communicator. The American Speech-Language-Hearing Association (ASHA, 2002) has emphasized the need for speech-language pathologists (SLPs) to be proficient in evaluating functional outcomes of AAC, and in particular "... the overall effectiveness and usefulness of current AAC systems". ASHA further recognized the need for SLPs to understand "situations in which AAC systems are abandoned by individuals and their conversational partners" (ASHA, 2002, p. 104).

Scherer (1993) outlined the "Matching Person and Technology (MPT)" model, which includes the following components: (1) the characteristics of the milieu (environment) in which the assistive technology is used, (2) pertinent features of the person and their treatment, and (3) the salient characteristics of the assistive technology itself. Lasker and Bedrosian (2000) applied the MPT model specifically to AAC and proposed an AAC Acceptance Model. In the milieu portion of the model, factors related to the communication partners (including attitude), the environment of the communication, and the funding options are considered. The person branch of the AAC Acceptance Model describes factors that relate directly to the user, including features of the disease, attitude, personality, age, skills, needs, and intervention history. Finally, technology-related factors refer to features such as durability, ease of use, size/weight, voice

quality, and cost that should be considered when determining the appropriateness of an AAC system.

To be able to predict acceptance or abandonment of an AAC system, SLPs need to consider a complex interaction among all those factors pertaining to the user, the device, and the environment. In an effort to understand the phenomena of success and abandonment of AAC systems, researchers have asked individuals who rely on AAC, their communication partners, and SLPs to identify reasons for successful versus unsuccessful outcomes based on their experiences.

Ball, Beukelman & Patte (2004) studied the use of AAC technology by 50 persons with amyotrophic lateral sclerosis (ALS) over a period of four years. Ninety-six percent of the participants in this study accepted AAC technology, either immediately (90%) or after some delay (6%), and 4% rejected AAC technology. Analysis of interviews with participants and their families revealed three primary reasons for immediate acceptance: (1) desire to communicate with family, friends, caregivers, and medical professionals; (2) community involvement; and (3) desire to continue employment. Reasons regarding delayed acceptance were family members' resistance due to their beliefs that they: (1) could understand communication sufficiently to meet a person's need; and (2) were providing adequate care without assistive technology. Cognitive limitations were identified as the primary reason for rejection of AAC technology. Both individuals who rejected all low/no-technology attempts at AAC intervention exhibited symptoms of prefrontal-type dementia.

A study by Fager, Hux, Beukelman, & Karantounis (2006) described AAC acceptance and use patterns of 25 individuals with traumatic brain injuries (TBI) who used high- or low-tech AAC devices or strategies at some point during their recovery. The speech-language pathologists provided information about individuals with TBI from their clinics for whom they had recommended AAC. Results revealed that these adults generally accepted both high- and low-tech AAC recommendations (94.4 % and 100% respectively). When AAC technology was abandoned, it was usually attributed by the SLPs who completed the questionnaire to a loss of facilitator support rather than a rejection of the technology. The importance of ongoing support was evident as it impacted continued use of AAC strategies and technology. These results suggest that AAC acceptance among individuals with TBI is similar to that reported for people with ALS.

However, AAC acceptance does not occur routinely. For example, Lasker , Ball, Richter, Straebel, & Beukelman, (2000) reported family members of people with aphasia may reject AAC strategies and devices because of a strong preference for natural speech. They also noted that the individual using AAC's perception of the attitudes of their communication partners and actual partner attitudes may also influence how AAC is used in real life. Lasker & Bedrosian (2001) in their case study presented an individual with aphasia who accepted AAC initially but was unwilling to use it in public settings after acquisition of the device. The individual communicated that the device was "for the clinic" and "for

practicing speech" but was not for "talking with friends" and for "strangers". He also admitted that he was ashamed of using the machine in public.

Rackensperger, Krezman, McNaughton, Williams, & D'Silva (2005) studied the competency of AAC use among seven individuals, aged 21-41, with cerebral palsy who used speech generating devices. The selected individuals participated in a focus group discussion on the benefits and challenges of learning AAC technologies. As a result of this focus group discussion, one of the recommendations to other individuals about acquiring and learning AAC technology was to use the technology in the real world. However, it was reported that issues of self-image, identity and lack of perceived benefit may interact and interfere with individuals' successful use of AAC technology in real environments (Clarke, McConachie, Price &Wood, 2001).

There is no doubt that the opinions of those who use AAC systems should carry the most weight if we are to identify the factors that influence success versus abandonment of AAC systems. Soliciting perspectives from persons who use AAC and those who facilitate communication with them is not only useful in the research context, but also represents another approach to identify broader needs that could be considered important at a clinical level during service delivery.

Weitzner-Lin, Casarella, & Guerand (2005) studied AAC users' perspectives about their devices, their preferences concerning specific components of their devices, and use/nonuse of their devices. The findings revealed that AAC acceptance and successful integration of the technology were

due to factors such as: ease of transporting, learning how to use the device in a reasonable amount of time, involvement in the selection of the device, and ability to use their device independently.

In 1994 a group of AAC researches sponsored by the National Institute of Deafness and Other Communication Disorders (NIDCD) compiled a number of research priorities in the field of AAC. O'Keefe, Kozak, & Schuller (2007) utilized a focus group methodology and Likert-type scale to determine the level of agreement of individuals who use AAC systems and their communication partners with the research priorities set by the NIDCD. They found that AAC users and their communication partners provided high levels of agreement with the priorities identified by the NIDCD in 1994. However, participants expressed the need to see more research and service delivery designed specifically to provide key skills that result in greater functional success and AAC acceptance in those situations that are of importance to individuals using AAC and those with whom they interact.

Johnson, Inglebret, & Ray (2006) targeted SLPs' opinions specifically. A three-phase investigation that included focus groups and completion of a survey was used to identify factors SLPs perceived were related to long-term success versus abandonment of AAC systems. The long term success was defined as a continued use of an AAC system or a series of systems over a period of years. Inappropriate abandonment referred to the situation in which a person stopped using an AAC system, yet still needed one. Results showed that when a person who used AAC experienced success with the system, and when

that user and his/her communication partner highly valued the system, this resulted in success more than 90% of the time. The authors suggest that this aspect could be partially manipulated via intervention programs, especially if an ecological approach is employed and more naturalistic opportunities for communication are facilitated.

Other factors in the Johnson et al. investigation (2006) that were rated highly as they related to individuals' acceptance of their AAC systems included: the match between the user and the system, support from various stakeholders, ability to use the system in multiple settings, sufficient training, appropriate system characteristics, and positive attitudes of the individuals who use AAC systems and their communication partners. The respondents of this study indicated that when partners feel that they can understand the user without the system and/or do not provide sufficient opportunities for communication, the system is often abandoned. Lack of motivation on the part of the partner and the user's preference to use other, simpler means of communication also received high ratings for abandonment. A factor analysis revealed that the constructs of Support, Attitude, System Characteristics and Fit were the four most important components of long-term AAC acceptance. The two primary factors underlying abandonment were Not Maintaining/Adjusting the System and Lack of Training for individuals who use AAC devices and their communication partners.

The literature review above underscores the fact that the categories of milieu (environment), person, and technology are interactive. In most studies researchers attempted to investigate factors pertaining to one or two categories.

The study by Johnson et al. (2006) looked at various factors that relate to AAC users, their communication partners, environment and the technology itself. However, they surveyed exclusively SLPs' opinions about the factors that relate to the long-term use versus inappropriate abandonment of an AAC system. Additionally, the populations of the studies discussed earlier were limited to the USA. The investigators did not address whether the factors being researched are universally applicable or specific to US practices.

Beukelman (2002) presented data from several studies (Ball, Beukelman, Fager, Hanson, Hux, Pattee, Thomsen, & Ullman, 2002) in which the terms *rejection* and *abandonment* were used differentially. Rejection was used to refer to situations in which clients were shown AAC options but chose to pursue different options from the outset. Abandonment included situations when individuals accepted AAC systems initially but later chose not to use them. It was not clear, however, whether the clients had regained speech, thus obviating the need for further AAC use.

Further research is needed to identify the information required for predicting AAC rejection or abandonment. A key element in the research should include examination of all three aspects of the AAC Acceptance Model (Lasker & Bedrosian, 2001). In addition, it is imperative to expand the pool of participants including not only persons who use AAC, but also their communication partners, professionals involved in providing AAC services, teachers, researches and others.

In order to better understand the factors that relate to the success of an AAC intervention, the terms *rejection* and *abandonment* should be differentiated. The definitions of *rejection* and *abandonment* are adopted from the study by Ball et al. (2002) for the purpose of this present study. Once again, *rejection* refers to situations in which clients are presented AAC options but choose not to pursue them from the outset. *Abandonment*, on the other hand, refers to situations in which clients accept AAC systems initially but later choose not to use them. This may occur despite their ongoing inability to use speech as a primary method of communication.

SLPs play a central role in the coordination, assessment, selection, customization and ongoing interventions with AAC systems. Given the emphasized need for SLPs to be proficient in evaluating functional outcomes of AAC, and to understand "situations in which AAC systems are abandoned by individuals and their conversational partners" (ASHA, 2002, p. 104), it is imperative to create a tool that would help them to assess and avoid factors related to device abandonment and rejection. These factors may include the role of a person who uses AAC, the milieu in which interactions occur, attributes of communication partners with whom they interact, and the technology itself.

CHAPTER I

PROCEDURES

<u>Purpose</u>

The purpose of this study was to better understand reasons individuals reject or abandon their devices. It was felt this might be useful to clinicians, educators, families and others in taking steps to avoid such outcomes. Specific research objectives were:

- To determine, factors (i.e. the role of AAC users, the milieu in which interactions occur, attributes of partners with whom AAC users interact, and the technology itself) that are most strongly related to the likelihood AAC users may (1) *reject,* or, (2) later *abandon* their devices.

- To determine if the factors cited vary depending on the role of the person completing the survey (e.g., AAC user, parent, speech-language pathologist, physical therapist, occupational therapist, teacher, manufacturer, etc).

- To develop a tool that AAC practitioners may find useful in predicting whether or not an AAC system will be rejected or later abandoned.

- To help AAC practitioners take measures to better ensure the likelihood their clients will accept and continue to use their AAC systems.

Methods

An on-line questionnaire was utilized in this study to survey ISAAC (International Society for Augmentative and Alternative Communication) members' opinions about factors contributing to rejection and abandonment of AAC systems. Possible factors were extracted from the previously described review of the literature. All articles came from peer-reviewed journals and included empirical as well as non-empirical investigations. Moore, McQuay & Gray's (1995) taxonomy was used to assign a level of evidence to each study. This hierarchy is extensively used in evidence based practice to evaluate experimental and non-experimental studies. It consists of five levels, with Level I indicating the strongest evidence and Level 5 the weakest evidence. Level I includes evidence from at least one systematic literature review of multiple well-designed randomized controlled clinical trials; Level II includes evidence from at least one well-designed randomized controlled trial; Level III includes evidence from non-randomized clinical trials, and studies involving pretest and post-test of a single group, a cohort, time series, or case-controls; Level IV includes evidence from non-experimental studies enrolling subjects from more than one center or group of investigators; and Level V includes expert opinion based on clinical evidence, descriptive studies and expert panels. Practices chosen for this study were explicitly cited with rationale and in most cases included empirical data.

The first sample of subjects was selected from the 2007 ISAAC directory by randomly drawing 300 names from the subject pool of 3,119 international members. The members of ISAAC were chosen for this study (1) on the

assumption that they would be more likely to have experience in the area of AAC, and (2) the fact that the membership is multidisciplinary and includes AAC users compared to a sample drawn from the general public.

An invitation to participate in the survey was sent via email along with informed consent information and a link to the actual survey. The ISAAC members that were randomly identified for this study were from Australia, Austria, Belgium, Brazil, Canada, Denmark, England, Finland, Germany, Hungary, Israel, Italy, Japan, Norway, Peru, Scotland, Spain, Sweden, Switzerland, the Netherlands, the USA and UAE. A second invitation to participate in the survey was sent one week later. The response rate was 9% (27 participants responded). The low response rate may be related to the fact that the survey was formulated in English which might have posed a language barrier for some potential participants. Therefore, it was decided to randomly draw an additional 150 names from the 2007 ISAAC directory, USA chapter that consisted of 281 members. The email with the survey was also sent twice with the one week interval between emails. The response rate was 16.6% (25 participants responded). The total number of respondents was 52.

Subject Description

The subjects were asked to provide the following demographic information. Their responses are summarized in the sequence of figures that follow.

Total Number of Clients
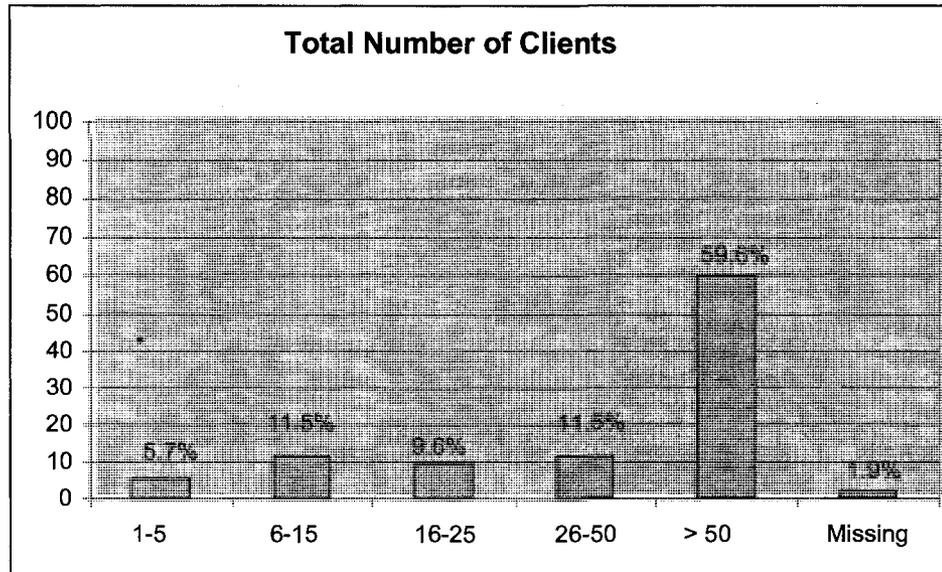
Figure 1. Approximate total number of AAC clients with whom the respondents

have worked over the course of their professional career.

As can been seen in Figure 1, the majority of participants (59.6%) had

more than 50 AAC clients over the course of their career. The same percentage

of respondents (11.5%) had 6-15 and 26-50 clients. The percentages of

participants who had 1-5 AAC clients and 16-25 AAC clients were 5.7% and

9.6% respectively. One response was missing (1.9%). Therefore, it can be

concluded that the majority of the respondents had a sufficient number of clients

to rely on their experience for the purpose of the present study.

Years of Experience in the Field of AAC
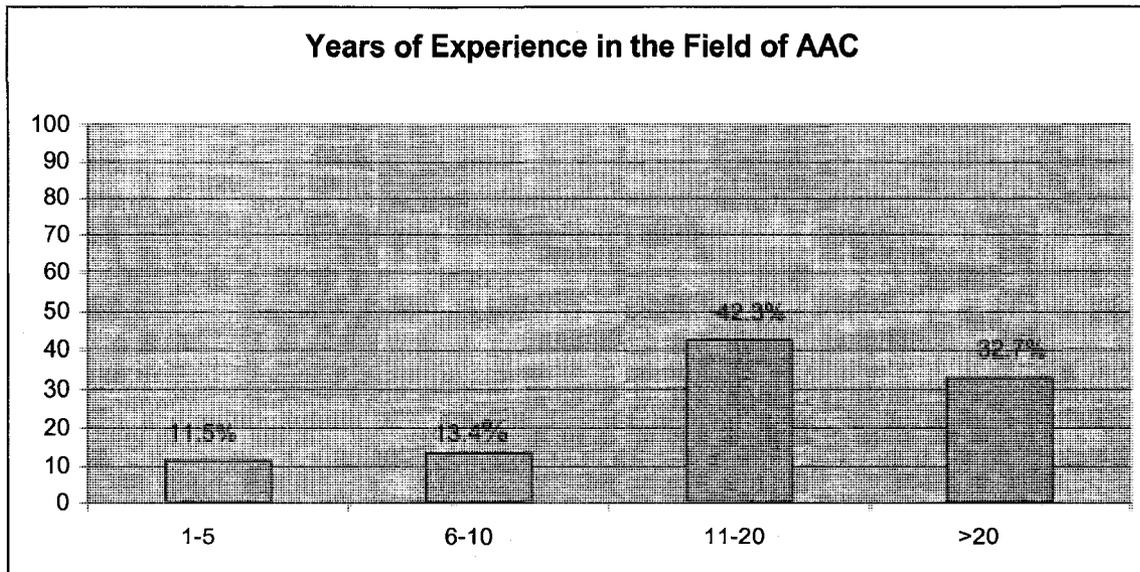
Figure 2. Years of experience in the field of AAC.

As shown in the Figure 2 the majority of the participants (42.3%) had 11-20 years of experience, and 32.7% had more than 20 years of experience in the field of AAC. The percentage of subjects who had 1-5 and 6-10 years of experience were 11.5% and 13.4% respectively. These data also support the assumption that the majority of the participants had extensive experience in the field of AAC.

As indicated previously there were 52 respondents to the survey. Occupations were varied and included administrators (4%), AAC specialists (17%), consultants (4%), family members/ caregivers (4%), professors (6%), psychologists (4%), researcher (2%), special educators (6%), individuals who use AAC (4%), SLPs (47%), and vendor (2%).

Respective percentages of subjects from each occupation are depicted in Figure 3. As can be seen speech-language pathologists accounted for the

highest percentage (47%) of respondents. The next most prevalent group of

respondents consisted of AAC specialists (17%).

Primary Occupation

Occupation	Percentage
Vendor	2%
Special Educator	6%
SLP	47%
Researcher	2%
Pscychologist	4%
Professor	6%
Family Member/Care Giver	4%
Consultant	4%
Administrator	4%
AAC Specialist	17%
AAC User	4%
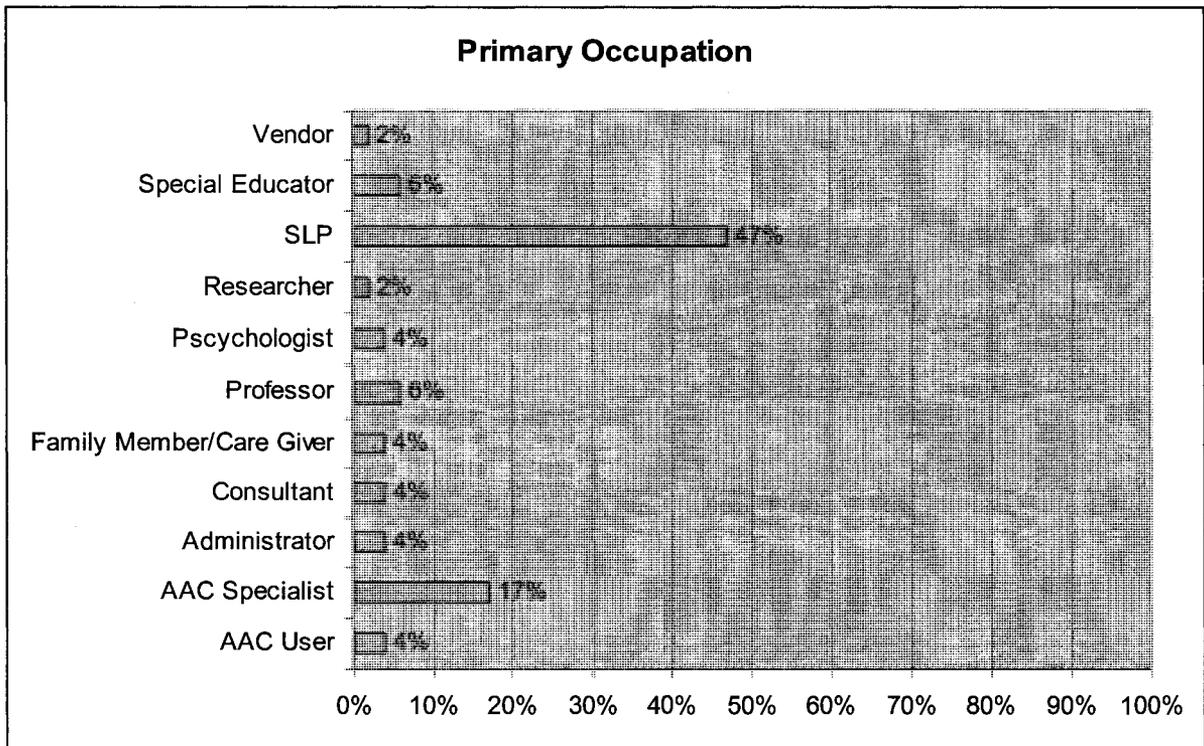
Figure 3. Respondents' primary occupation or role in the area of AAC.
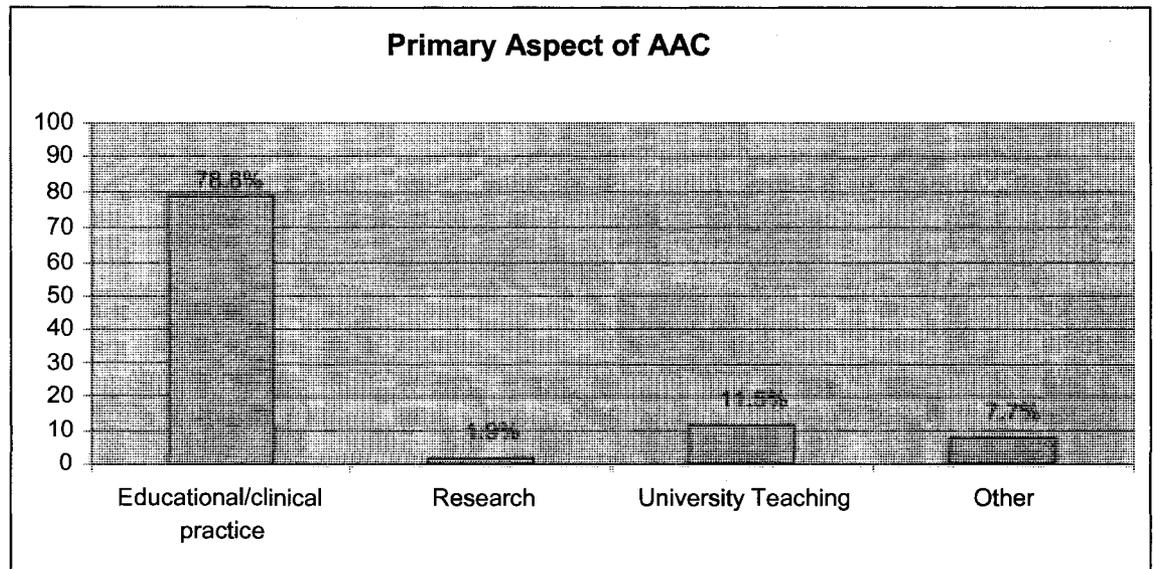
Figure 4. The primary aspect of AAC in which the respondents have been engaged.

The primary aspect of AAC with which the majority of respondents have been involved was educational and clinical practice (78.8%). Additionally, participants have been engaged in research (1.9%), university teaching (11.5%) and other aspects of AAC practice (7.7%).
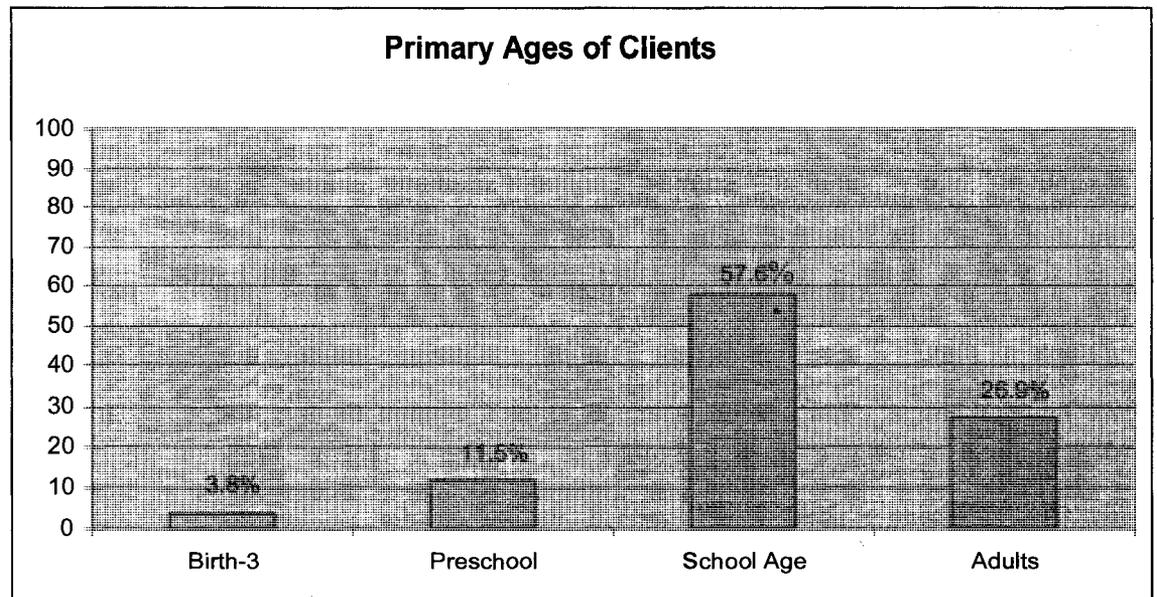
Figure 5. The primary ages of clients for whom the respondents are currently

providing AAC service.

School age (57.6%) was the primary age of clients for whom the majority

of respondents were providing AAC service at the time of the survey completion.

The percentage of adult clients was 26.9%. The respondents were also providing

AAC services to infants (3.8%) and preschool children (11.5%).
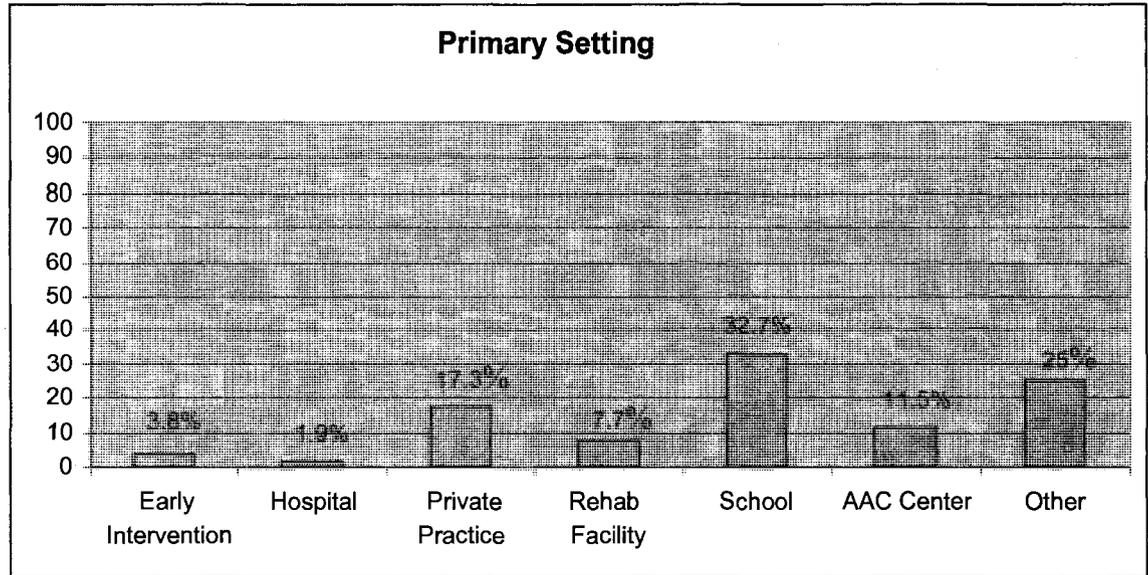
Figure 6. The primary settings in which the respondents provide or receive AAC

services.

The participants who responded to the survey were from a variety of

settings. Schools were the primary settings for most respondents. The

percentages of respondents from private practices and AAC centers were 17.3%

and 11.5% respectively. In addition, the participants provided AAC services in

rehabilitation facilities (7.7%), early intervention settings (3.8%), hospitals (1.9%),

and elsewhere.

Procedures

The on-line survey was posted on Survey Cat (UNH online survey system http://survey.unh.edu/). Contributing factors were examined in relation to the role of persons who use AAC, the milieu in which interactions occur, attributes of partners with whom AAC users interact, and the technology itself.

A 5 point Likert-type scale was used in this study (Strongly Disagree, Mildly Disagree, Neither Agree nor Disagree, Mildly Agree, and Strongly Agree). The ISAAC members were asked to assess the relative importance of the factors that may contribute to rejection and/or abandonment of AAC systems based on their experience.

The survey consisted of two parts. The first part was devoted to the factors that relate to the *rejection* of AAC systems. In the second part the same factors were listed as they relate to the subsequent *abandonment* of AAC systems. Each part was comprised of four sections: Factors Related to the AAC User, Factors Related to Conversational Partners, Factors Related to Settings in Which Interactions Occur, and Factors Related to the Device Itself.

Upon receipt of responses, obtained data were transferred to SPSS for statistical analysis. The SPSS program was utilized for descriptive statistics corresponding to ratings of the importance of individual items overall and in relation to types of respondents (e.g. speech-language pathologists, persons who use AAC, researchers and etc.).

CHAPTER II

RESULTS

Rejection

a. Factors Related to AAC Users

As can be seen in figure 7, the majority of respondents (the combined percentage of "strongly agree" and "mildly agree" answers) expressed their agreement that the following AAC user-related factors relate to the *rejection* of AAC systems:

Figure 7. Factors related to AAC users that raters agreed were important in explaining AAC users' rejection of their AAC devices.

(1) The individual fails to perceive the benefits of the AAC system relative to other methods of communication he/she is already using.

(2) The individual fails to see a relationship between use of the AAC device and the attainment of life goals.

(3) Although unintelligible at times, the individual is still able to use speech to communicate with moderate success.

(4) The individual is able to communicate with moderate success using gestures.

(5) The individual does not foresee a significant difference in how often conversational breakdowns will occur with or without the AAC system.

The majority of respondents (the combined percentage of "strongly disagree" and "mildly disagree") indicated their disagreement that the following factors relate to the rejection of AAC devices:

Figure 8. Factors related to AAC users that raters disagreed were important in explaining AAC users' rejection of their AAC devices.

(1) The individual lacks the cognitive/intellectual skills necessary to use the device effectively.

(2) The individual lacks physical abilities necessary to access and use the device independently.

(3) The individual's understanding of language is impaired significantly.

b. Factors Related to Conversational Partners

The factors related to conversational partners were highly rated as they pertain to the rejection of AAC systems. All factors in this section received "strongly agree" and "mildly agree" responses from the majority of the participants (more than 50% of respondents).

Figure 9. Factors related to conversational partners that raters agreed were important in explaining AAC users' rejection of their AAC devices.

(1) Family members and others have unrealistic expectations regarding the impact the device will have on the individual's life.

(2) Others reject the device.

(3) Others refuse to use the device with the individual.

(4) Others do not do their part in making the device available to the individual at all possible times.

(5) Others refuse to follow through with AAC objectives.

(6) There are too few individuals who communicate with the individual voluntarily.

(7) Others feel they do not need to use the device in order to communicate effectively with the individual.

(8) Partners have not been taught how to interact effectively with the individual when using the device, resulting in inadequate conversational support.

(9) Others provide insufficient emotional support for the individual to use the device.

(10) There are not enough opportunities for the individual to observe and/or interact with role models and mentors who are competent users of the same or similar AAC devices.

c. Factors Related to Settings

There were four factors in the survey that related to the settings in which interactions occur. The statistical analysis revealed that the majority of respondents indicated their agreement with three of these factors after "strongly agree" and "mildly agree" responses were combined. There were no factors in which the majority of respondents indicated their disagreement.
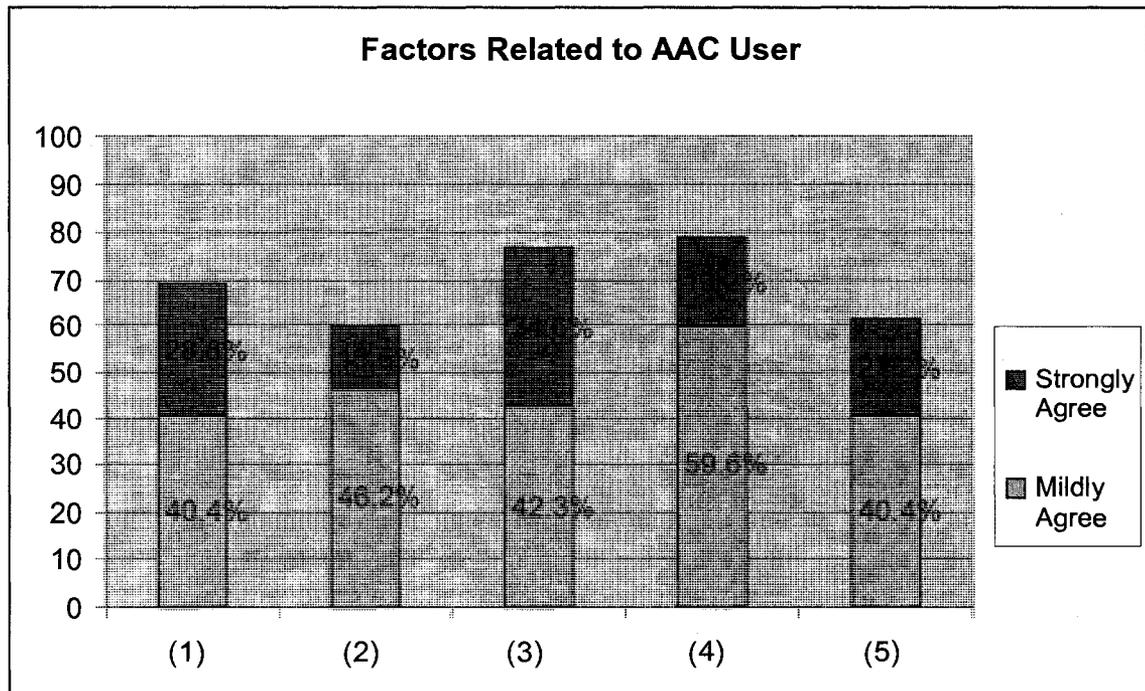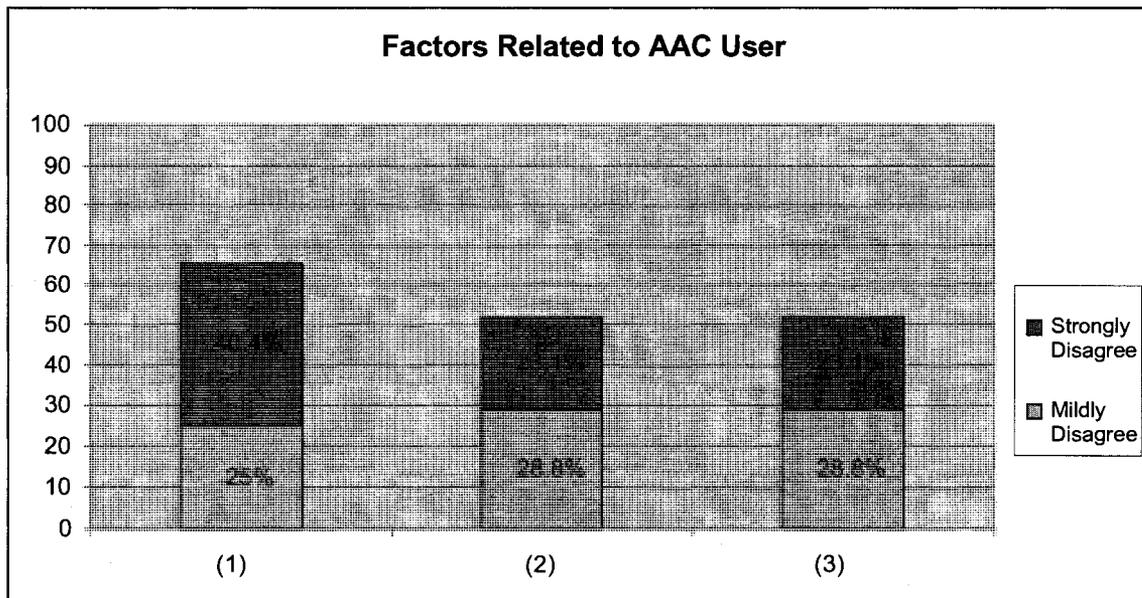
Figure 10. Factors related to settings that raters agreed were important in

explaining AAC users' rejection of their AAC devices.

   (1) There is an insufficient number and quality of settings in which the

      individual can use the device functionally throughout the day.

   (2) There are not enough reasons to use the device over the course of the

      day.

   (3) There are not enough opportunities for the individual to use the AAC

      system throughout the day.

d. Factors Related to Device

There were eleven factors in the survey that related to the device itself.

Figure 11 depicts the eight factors the majority of respondents expressed
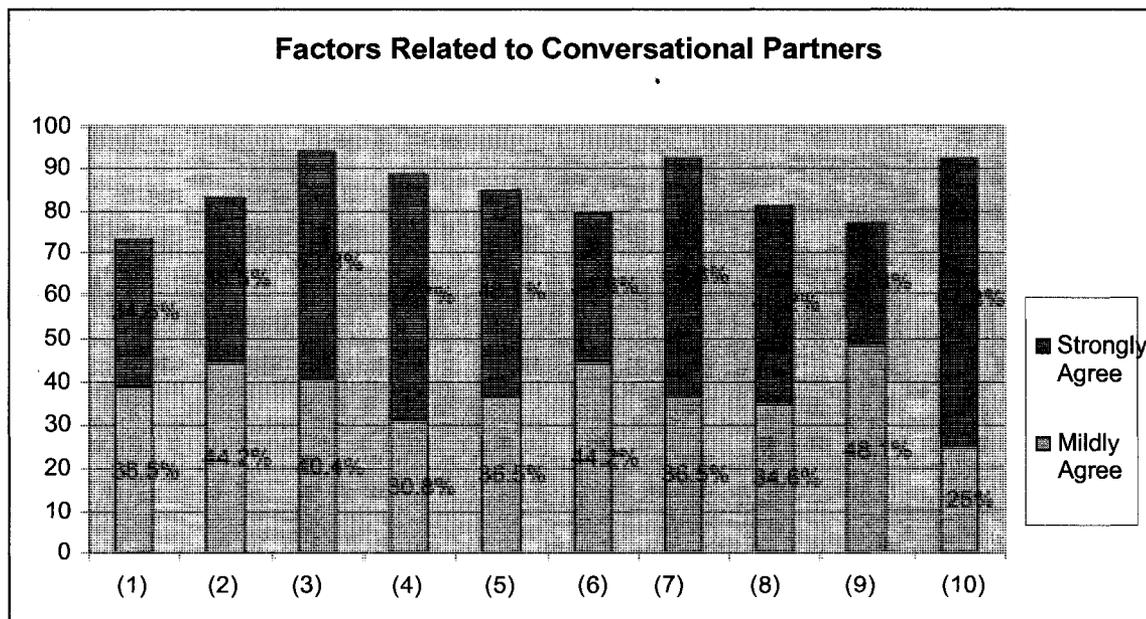
agreement with as they relate to the rejection of AAC devices.

Figure 11. Factors related to devices that raters agreed were important in explaining AAC users' rejection of their AAC devices.

(1) The device is too expensive to purchase, with or without insurance.

(2) Vocabulary available on the device is insufficient to meet the individual's short and/ or long term needs.

(3) The device is difficult to program.

(4) It is difficult to transport the device from one location to another.

(5) Too much time and effort is required for the individual and others to learn to use the system as intended.

(6) Rate of communication is too slow.

(7) The individual does not have enough time to get familiar with the device before it is purchased.

(8) The device requires levels of technological support for maintenance and repair which exceed resources that are readily available.

There was only one device-related factor that 50% of respondents indicated their disagreement with as it pertains to the rejection of AAC systems: *the device can not accommodate to changes in the person's communicative skills over time.*

The factors listed for *rejection* of AAC devices were also analyzed as they relate to *abandonment.* Abandonment refers to situations in which clients accept AAC systems initially but later choose not to use them. This may occur despite their ongoing inability to use speech as a primary method of communication. Results of ratings of the factors concerning abandonment of AAC devices are discussed below.

Abandonment

a. Factors Related to AAC User

The statistical analysis revealed that the majority of respondents rated as "strongly agree" and "mildly agree" six out of sixteen factors that relate to device abandonment linked to the persons who use AAC systems.
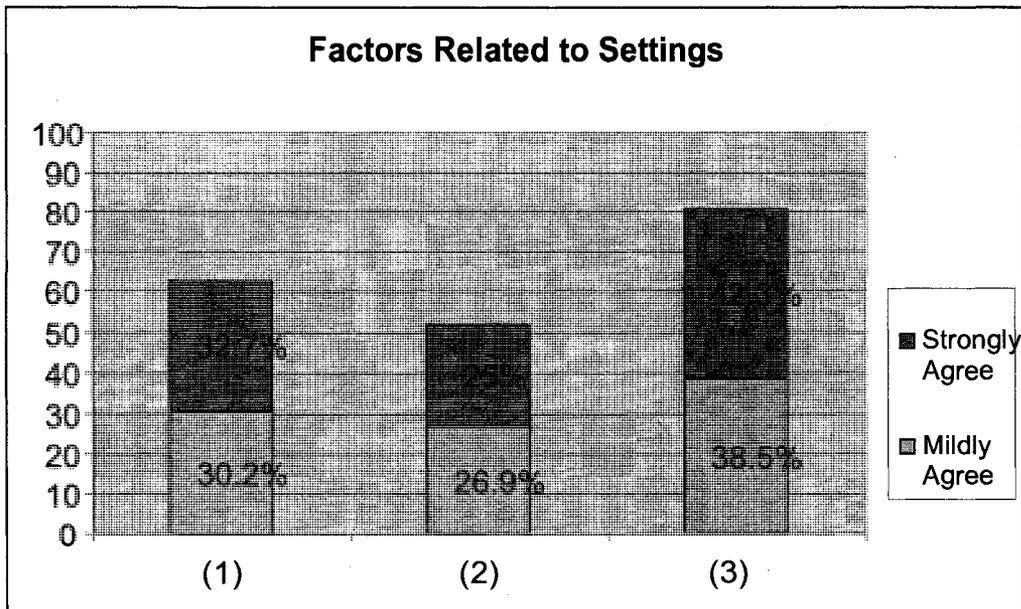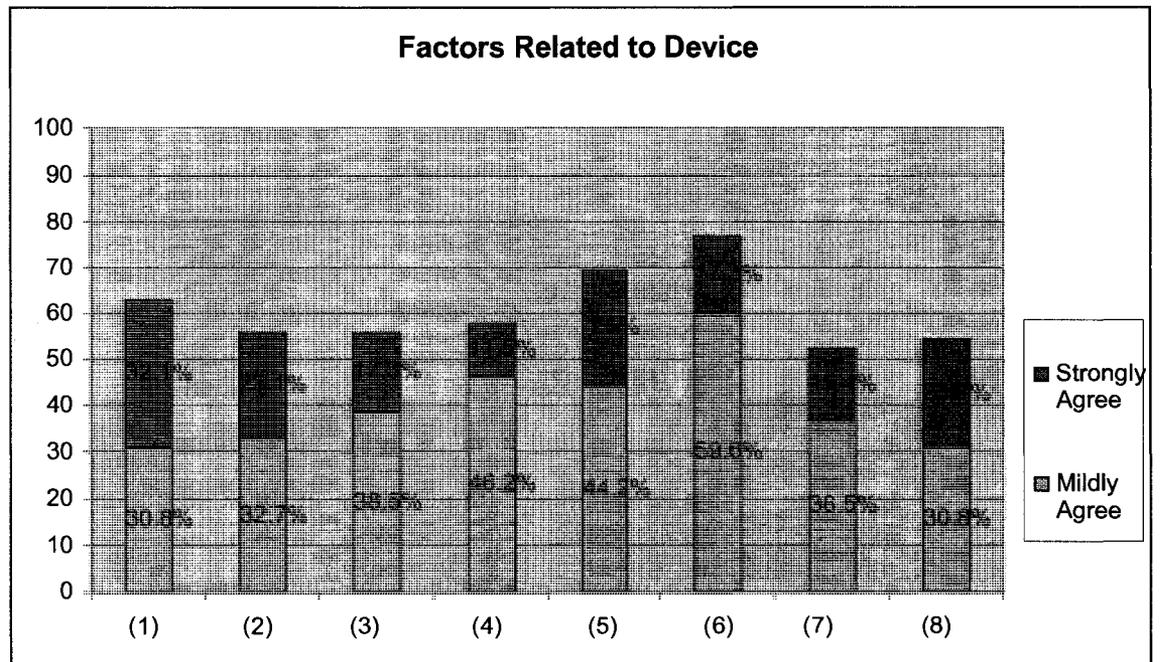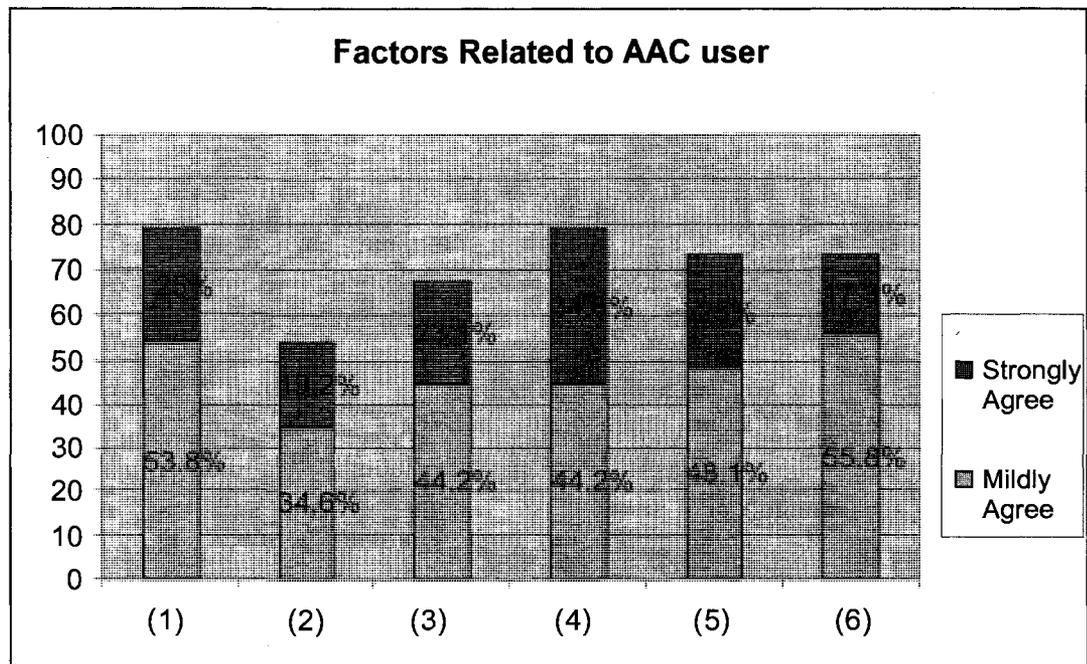
Figure 12. Factors related to AAC users that raters agreed were important in explaining AAC users' abandonment of their AAC devices.

(1) The individual fails to perceive the benefits of the AAC system relative to other methods of communication he or she is already using.

(2) The AAC system does not foster the individual's achieving personal communicative goals that he or she values.

(3) The individual fails to see a relationship between use of the AAC device and the attainment of life goals

(4) Although unintelligible at times, the individual is still able to use speech to communicate with moderate success.

(5) The individual is able to communicate with moderate success using gestures.

(6) The individual does not foresee a significant difference in how often conversational breakdowns will occur with or without the AAC system.

The only factor that the majority of respondents rated as "strongly disagree"

(23.1%) and "mildly disagree" (36.5%) was: *the individual lacks the*

cognitive/intellectual skills necessary to use the device effectively.

b. Factors Related to Conversational Partners

The factors concerning abandonment that relate to conversational

partners were rated similarly to the factors in the *Rejection* part of the survey. All

ten factors received "strongly agree" and "mildly agree" answers from the

majority of respondents.

Figure 13. Factors related to conversational partners that raters agreed were

important in explaining AAC users' abandonment of their AAC devices.

> *(1) Family members and others have unrealistic expectations regarding*
>
> *the impact the device will have on the individual's life.*
>
> *(2) Others reject the device.*
>
> *(3) Others refuse to use the device with the individual.*

(4) Others do not do their part in making the device available to the individual at all possible times.

(5) Others refuse to follow through with AAC objectives.

(6) There are too few individuals who communicate with the individual voluntarily.

(7) Others feel they do not need to use the device in order to communicate effectively with the individual.

(8) Partners have not been taught how to interact effectively with the individual when using the device, resulting in inadequate conversational support.

(9) Others provide insufficient emotional support for the individual to use the device.

(10)   There are not enough opportunities for the individual to observe and/or interact with role models and mentors who are competent users of the same or similar AAC devices.

c. Factors Related to Settings

The statistical analysis revealed that the setting-related factors pertaining to abandonment were the same factors the respondents identified as relevant for rejection. The majority of participants rated the following three factors as "strongly agree" and "mildly agree":

Factors Related to Settings
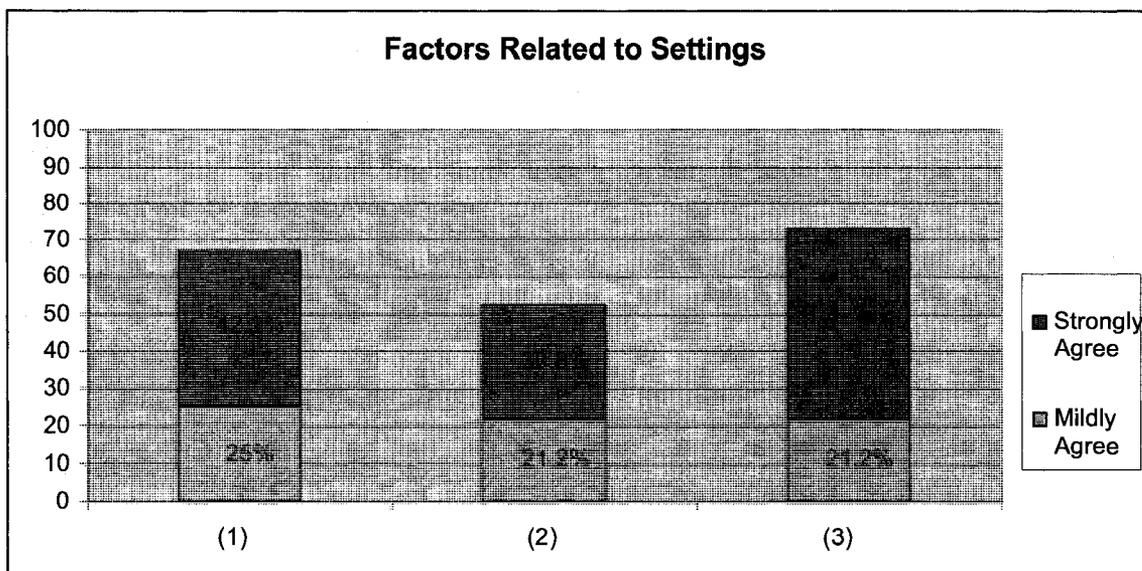
Figure 14. Factors related to settings that raters agreed were important in explaining AAC users' abandonment of their AAC devices.

(1) There is an insufficient number and quality of settings in which the individual can use the device functionally throughout the day.

(2) There are not enough reasons to use the device over the course of the day.

(3) There are not enough opportunities for the individual to use the AAC system throughout the day.

d. Factors Related to Device

Percentages of respondents who expressed their agreement that the following device-related factors contribute to the abandonment of AAC systems are summarized in Figure 15.
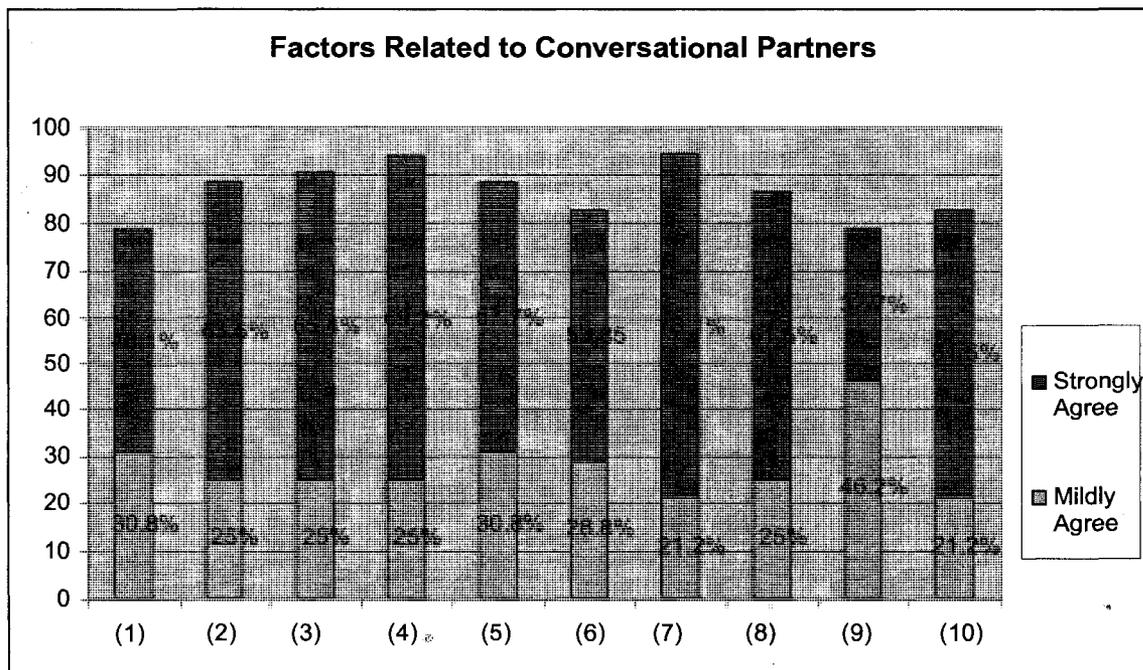
Factors Related to Device
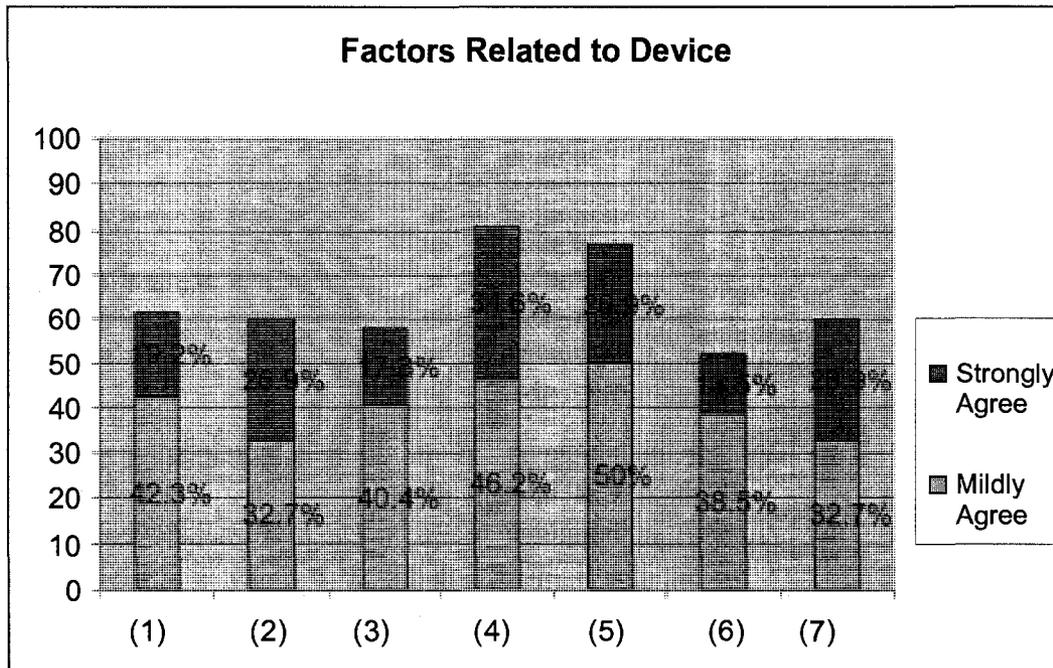
Figure 15. Factors related to AAC devices that raters agreed were important in explaining AAC users' abandonment of their AAC devices.

(1) Vocabulary available on the device is insufficient to meet the individual's short and/ or long term needs.

(2) The device is difficult to program.

(3) It is difficult to transport the device from one location to another.

(4) Too much time and effort is required for the individual and others to learn to use the system as intended.

(5) Rate of communication is too slow.

(6) The individual does not have enough time to get familiar with the device before it is purchased.

(7) The device requires levels of technological support for maintenance and repair which exceed resources that are readily available.

Mean values of assigned ratings and standard deviations were calculated in order to compare the ratings of factors as they relate to the rejection and/or abandonment of AAC devices. Table 1 provides the mean ratings and standard deviations for all factors surveyed in this study in relation to both, rejection and abandonment.

Table 1

Mean Ratings and Standard Deviation of Factors as They Relate to AAC

Rejection and/or Abandonment

Factors	Rejection Mean Rating (Std. Deviation)	Abandonment Mean Rating (Std. Deviation)
Related to AAC User		
The individual lacks the cognitive/intellectual skills necessary to use the device effectively.	2.2 (1.3)	2.5 (1.3)
The individual's emotional and behavioral problems interfere with his or her acceptance of the AAC system.	2.8 (1.2)	3.0 (1.1)
The individual fails to perceive the benefits of the AAC system relative to other methods of communication he or she is already using.	3.8 (1.0)	3.9 (1.0)
The individual has unrealistically high expectations of the impact the AAC will have on the quality of his or her life.	2.8 (1.0)	3.0 (1.2)
The individual perceives the AAC system will have little or no positive impact on finding or maintaining a job.	3 (0.8)	3.0 (0.8)
The AAC system does not foster the individual's achieving personal goals that he or she values.	3.1 (1.2)	3.5 (1.0)
The individual has little or no input, direct or indirect, in selecting the device.	2.9 (1.5)	3.0 (1.2)
The individual lacks physical abilities necessary to access and use the device independently.	2.8 (1.4)	3.0 (1.2)

The individual's lack of communication skills occurred suddenly (e.g. after some type of trauma).	2.7 (1.0)	2.7 (0.9)
There was a gradual loss of communication skill (e.g. amytrophic lateral sclerosis).	2.6 (1.1)	2.8 (1.0)
The individual does not accept the nature or extent of his or her disability.	3.0 (1.3)	3.3 (1.2)
The individual fails to see a relationship between use of the AAC device and the attainment of life goals.	3.5 (1.1)	3.7 (1.1)
Although unintelligible at times, the individual is still able to use speech to communicate with moderate success.	4.0 (1.1)	4.0 (1.0)
The individual is able to communicate with moderate success using gestures.	3.8 (0.9)	3.8 (1.0)
The individual does not foresee a significant difference in how often conversational will occur with or without the AAC system.	3.7 (1.0)	3.8 (0.9)
The individual's understanding of language is impaired significantly.	2.8 (1.5)	2.8 (1.2)
Related to Conversational Partners		
Family members and others have unrealistic expectations regarding the impact the device will have on the individual's life.	3.9 (1.1)	4.1 (1.0)
Others reject the device.	4.0 (1.0)	4.5 (0.8)
Others refuse to use the device with the individual.	4.4 (0.8)	4.5 (0.8)
Others do not do their part in making the device available to the individual at all possible times.	4.4 (0.9)	4.6 (0.6)
Others refuse to follow through with AAC objectives.	4.3 (0.9)	4.4 (0.8)

There are too few individuals who communicate with individual voluntarily.	4.0 (1.0)	4.3 (1.0)
Others feel they do need to use the device in order to communicate effectively with the individual.	4.5 (0.6)	4.7 (0.6)
Partners have not been taught how to interact effectively with the individual when using the device, resulting in inadequate conversational support.	4.0 (1.2)	4.4 (0.9)
Others provide insufficient emotional support for the individual to use the device.	4.0 (1.0)	4.0 (0.9)
There are not enough opportunities for the individual to observe and/or interact with role models and mentors who are competent users of the same or similar AAC devices.	4.6 (0.8)	4.3 (1.0)

Related to Settings

There is insufficient number and quality of settings in which the individual can use the device functionally throughout the day.	3.6 (1.4)	3.8 (1.4)
There are too many settings in which other methods of communication are more appropriate and useful than the AAC device.	3.1 (1.3)	3.3 (1.2)
There are not enough reasons to use the device over the course of the day.	3.2 (1.5)	3.3 (1.4)
There are not enough opportunities for the individual to use the AAC system throughout the day.	4.0 (1.2)	4.0 (1.3)

Related to Device

The device is not flexible enough to accommodate to changes in the individual's communicative needs over time.	3.0 (1.4)	3.0 (1.4)
The device can not accommodate to changes in the person's communicative skills over time.	2.6 (1.2)	2.8 (1.4)

The device is too expensive to purchase, with or without insurance.	3.3 (1.4)	2.6 (1.1)
Vocabulary available on the device is insufficient to meet the individual's short and/or long terms needs.	3.3 (1.4)	3.5 (1.3)
The device is difficult to program.	3.3 (1.2)	3.5 (1.3)
It is difficult to transport the device from one location to another.	3.3 (1.2)	3.4 (1.2)
Too much time and effort is required for the individual and others to learn to use the system as needed.	3.8 (1.1)	4.0 (1.0)
Rate of communication is too slow.	3.8 (1.0)	3.9 (1.0)
The individual doe not have enough time to get familiar with the device before it is purchased.	3.3 (1.2)	3.2 (1.2)
The design and physical appearance of the device are unappealing to the individual and/or conversational partners.	2.8 (1.1)	2.7 (1.0)
The device requires levels of technological support for maintenance and repair which exceed resources that are readily available.	3.3 (1.4)	3.5 (1.4)

Ratings Based on Occupation of Respondents

Given the fact that each of the following professions was represented by a small percentage of respondents (administrators, AAC specialists, consultants, family members/care givers, AAC users, professors, psychologists, researchers, special educators, and vendor), it was decided to combine them into one group, "Others". SLPs were represented by the largest group of respondents in this study (47%). As a result, an Independent T-test was utilized to compare the mean ratings of two groups, "SLPs" and "Others". There were 25 participants in

the "SLPs" group and 27 participants in the "Other" group. Further, the mean ratings for both parts of the survey (Rejection and Abandonment) were calculated to compare mean ratings across all survey items in relation to AAC users, conversational partners, settings and devices.

The statistical analysis revealed that there was no significant difference in how the two groups ("SLPs" and "Others") rated any of the factors based on whether or not they were speech-language pathologists. The mean ratings, standard deviation and p values (statistical significance) for each section of the survey can be seen in Table 2.

Table 2

Comparison of Mean Ratings

	SLPs N=25	Others N=27	*p*
Rejection	Mean (Std. Deviation)		
Related to AAC Users	3.04 (.51)	3.13 (.52)	t = -.58 (50); *p*=.57
Related to Conversational Partners	4.22 (.55)	4.20 (.57)	t = .10 (50); *p* =.92
Related to Settings	3.50 (1.0)	3.45 (.90)	t = .17 (50); *p* = .87
Related to Device	3.20 (.60)	3.27(.70)	t = -.38 (50); *p* =.70
Abandonment			
Related to AAC Users	3.24 (.46)	3.28 (.57)	t = -.30 (50); *p* = .77
Related to Conversational Partners	4.35 (.53)	4.44 (.50)	t = -.68 (50); *p* =.50
Related to Settings	3.57 (1.0)	3.64 (1.0)	t = -.22 (50); *p* =.83
Related to Device	3.21 (.57)	3.33 (.81)	t = -.59 (50); *p* =.56

CHAPTER III

DISCUSSION

As indicated earlier, the purposes of this investigation were to:

- determine factors (i.e. the role of AAC users, the milieu in which interactions occur, attributes of partners with whom AAC users interact, and the technology itself) that are most strongly related to the likelihood AAC users may (1) *reject*, or, (2) *abandon* their devices.

- determine if the factors cited vary depending on the role of the person completing the survey (e.g., AAC user, parent, speech-language pathologist, physical therapist, occupational therapist, teacher, manufacturer, etc).

- develop a tool that AAC practitioners may find useful in predicting whether or not an AAC system will be rejected or later abandoned.

- help AAC practitioners take measures to better ensure the likelihood their clients will accept and continue to use their AAC systems.

The part of this study aimed at *determining which factors are most strongly related to the likelihood AAC users may reject or later abandon their devices* revealed that the terms *rejection* and *abandonment* can not be used synonymously. Although the majority of factors were rated similarly as they relate to rejection and abandonment, there are a number of important differences that should be noted.

Specifically, in the section "Factors Related to AAC User" the factor "the AAC system does not foster the individual's achieving personal goals that he or she values" was only cited by the majority of respondents as it contributes to the abandonment of AAC systems. The respondents did not associate this factor with the rejection of AAC devices. Therefore, it is critical to address personal goals and needs of an individual during an AAC intervention to facilitate a successful outcome of the program.

In both sections of the survey, *Rejection* and *Abandonment*, the majority of respondents disagreed that the factor "the individual lacks the cognitive/intellectual skills necessary to use the device effectively" was a contributing factor. However, in the *Rejection* part, the participants expressed their disagreement with two additional factors: "the individual lacks physical abilities necessary to access and use the device independently" and "the individual's understanding of language is impaired significantly". These differences suggest that physical abilities and language comprehension might be especially crucial at the initial stage of an AAC intervention and highly indicative of whether an individual is going to be an effective and efficient AAC user.

In the section "Factors Related to Device", the factor "the device is too expensive to purchase, with or without insurance" was cited as it relates to the rejection and not to the abandonment of an AAC system. The difference in ratings of this factor reveals the importance of the device cost and funding options when presenting an AAC system initially.

It is noteworthy that all communication partner-related factors were rated highly as they contribute to both rejection and abandonment. These results indicate that communication partners are crucial for successful outcomes of an AAC intervention, and they should be involved in designing and planning of therapy programs.

The "Factors Related to Settings" were also rated similarly in both the Rejection and Abandonment sections of the survey. The majority of respondents agreed that the following factors related to unsuccessful outcomes: "there is insufficient number and quality of settings in which the individual can use the device functionally throughout the day", "there are not enough reasons to use the device over the course of the day", and "there are not enough opportunities for the individual to use the AAC system throughout the day". These results suggest that the respondents agreed that it is equally important to provide quality settings for new AAC users as well as individuals who have been using their devices for a period of time.

The second goal of this study was *to determine if the factors cited vary depending on the role of the person completing the survey.* The independent T-test analysis revealed no significant difference between "SLPs" and "Others". This finding is important in terms of understanding how the opinions of individuals who use AAC, their family members/caregivers, AAC specialist/providers, and others may vary or be similar when determining what factors are most important for a successful outcome. Since this study revealed no significant difference in the opinions of all respondents, this preliminary finding can be considered as a

positive result, implying that there was consensus among the participants as to what factors constitute successful versus unsuccessful outcomes.

To address the next two goals of this study: *to develop a tool that AAC practitioners may find useful in predicting whether or not an AAC system will be rejected or later abandoned*, and *to help AAC practitioners take measures to better ensure the likelihood their clients will accept and continue to use their AAC systems*, Table 3 was constructed. It compares factors cited for rejection vs. abandonment and provides AAC practitioners with a comprehensive overview of factors that are important to consider when planning an AAC intervention program, and subsequently aid them in avoiding unsuccessful outcomes. The factors marked with "X" are those that the majority of respondents expressed their agreement or disagreement with as they relate to AAC rejection and/or abandonment.

Table 3

Factors Deemed Important in Explaining and Predicting AAC users' Rejection

and Abandonment of Their AAC Devices

Factors	Rejection	Abandonment
	Agreement/ Disagreement	Agreement/Disagreement
Related to AAC User The individual lacks the cognitive/intellectual skills necessary to use the device effectively.	X	X
The individual's emotional and behavioral problems interfere with his or her acceptance of the AAC system.		
The individual fails to perceive the benefits of the AAC system relative to other methods of communication he/she is already using.	X	X
The individual has unrealistically high expectations of the impact the AAC will have on the quality of his or her life.		
The individual perceives The AAC system will have little or no positive impact on finding or maintaining a job.		
The AAC system does not foster the individual's achieving personal goals that he/she values.		X
The individual has little or No input, direct or indirect, in selecting the device.		
The individual lacks physical abilities necessary to access		

and use the device independently.		X	
The individual's lack of communication skills occurred suddenly (e.g. after some type of trauma).			
There was a gradual loss of communication skill (e.g. ALS)			
The individual does not accept the nature or extent of his/her disability.			
The individual fails to see a relationship between use of the AAC device and the attainment of life goals.	X		X
Although unintelligible at times, the individual is still able to use speech to communicate with moderate success.	X		X
The individual is able to communicate with moderate success using gestures.	X		X
The individual does not foresee a significant difference in how often conversational breakdowns will occur with or without the AAC system.	X		X
The individual's understanding of language is impaired significantly.		X	
Factors Related to Conversational Partners Family members and others Have unrealistic expectations regarding the impact the device will have on the individual's life.	X		X
Others reject the device.	X		X
Others refuse to use the device with the individual.	X		X
Others do not do their part			

in making the device available to the individual at all possible times.	X	X
Others refuse to follow through with AAC objectives.	X	X
There are too few individuals who communicate with individual voluntarily.	X	X
Others feel they do need to use The device in order to communicate effectively with the individual.	X	X
Partners have not been taught How to interact effectively with the individual when using the device, resulting in inadequate conversational support.	X	X
Others provide insufficient emotional support for the individual to use the device.	X	X
There are not enough opportunities for the individual to observe and/ or interact with role models and mentors who are competent users of the same or similar AAC devices.	X	X
Factors Related to Settings There is insufficient number and quality of settings in which the individual can use the device functionally throughout the day.	X	X
There are too many settings in which other methods of communication are more appropriate and useful than the AAC device.		
There are not enough reasons to use the device over the course of the day.	X	X
There are not enough opportunities for the		

individual to use the AAC system throughout the day.	X	X
Factors Related to Device The device is not flexible Enough to accommodate to changes in the individual's communicative needs over time.		X
The device can not Accommodate to changes in the person's communicative skills over time.		
The device is too expensive to purchase, with or without insurance.	X	
Vocabulary available on the Device is insufficient to meet the individual's short and/or long term needs.	X	X
The device is difficult to program.	X	X
It is difficult to transport the device from one location to another.	X	X
Too much time and effort is required for the individual and others to learn to use the system as needed.	X	X
Rate of communication is too slow.	X	X
The individual doe not have enough time to get familiar with the device before it is purchased.	X	X
The design and physical appearance of the device are unappealing to the individual and/or conversational partners.		
The device requires levels of technological support for		

maintenance and repair which exceed resources that are readily available.	X	X

Based on Table 3, we can create a checklist of factors that an AAC practitioner might consider addressing in order to foster acceptance of AAC systems initially and later on. The factors that are important to consider are summarized in the table below.

Table 4

Checklist of Important Factors

Factors	Rejection	Abandonment
Related to AAC User		
The individual fails to perceive the benefits of the AAC system relative to other methods of communication he or she is already using.	X	X
The AAC system does not foster the individual's achieving personal goals that he or she values.		X
The individual fails to see a relationship between use of the AAC device and the attainment of life goals.	X	X
Although unintelligible at times, the individual is still able to use speech to communicate with moderate success.	X	X
The individual is able to communicate with moderate success using gestures.	X	X
The individual does not foresee a significant difference in How often conversational breakdowns will occur with or Without the AAC system.	X	X
Related to Conversational Partners		
Family members and others have unrealistic expectations Regarding the impact the device will have on the individual's life.	X	X
Others reject the device.	X	X
Others refuse to use the device with the individual.	X	X
Others do not do their part in making the device available to the individual at all possible times.	X	X
Others refuse to follow through with AAC objectives.	X	X
There are too few individuals who communicate with individual voluntarily.	X	X
Others feel they do need to use the device in order to communicate effectively with the individual.	X	X
Partners have not been taught how to interact effectively with the individual when using the device, resulting in inadequate conversational support.	X	X
Others provide insufficient emotional support for the individual		

	X	X
to use the device.	X	X
There are not enough opportunities for the individual to observe and/or interact with role models and mentors who are competent users of the same or similar AAC devices.	X	X
Related to Settings There is insufficient number and quality of settings in which the individual can use the device functionally throughout the day.	X	X
There are not enough reasons to use the device over the course of the day.	X	X
There are not enough opportunities for the individual to use the AAC system throughout the day.	X	X
Related to Device The device is too expensive to purchase, with or without insurance.	X	
Vocabulary available on the device is insufficient to meet the individual's short and/or long terms needs.	X	X
The device is difficult to program.	X	X
It is difficult to transport the device from one location to another.	X	X
Too much time and effort is required for the individual and others to learn to use the system as needed.	X	X
Rate of communication is too slow.	X	X
The individual does not have enough time to get familiar with the device before it is purchased.	X	X
The device requires levels of technological support for maintenance and repair which exceed resources that are readily available.	X	X

In conclusion, the respondents in this study agreed that the majority of factors in the survey contributed to the rejection and/or abandonment of AAC systems. The factors cited by the respondents related to all components of the AAC Acceptance Model, therefore it is imperative to consider all of them when designing an AAC intervention. In other words, the pertinent characteristics of

individuals who use AAC, their conversational partners, settings in which interactions occur, and devices used to interact can not be ignored when designing an AAC intervention plan.

Limitations of Present Study and Implications for Future Research

The survey was sent to ISAAC members from twenty-two countries (see Introduction), however it was formulated in the English language only. This might have had a negative impact on the response rate when the survey was sent to the first 300 participants. It might be useful to translate this survey into multiple languages and replicate this study in order to increase the representativeness and response rate. The greater number of respondents from different parts of the world would also allow making universal inferences as opposed to more limited ones constrained by different cultural beliefs and practices.

Another potential limitation is that there are possibly other factors that were not included in this investigation. It would be important to provide spaces for comments where participants could write down the factors that in their opinion are important but not included in the survey.

Finally, although there is an agreement among the participants on what factors relate to the rejection and/or abandonment of AAC systems based on their role, the order of priority may be different for each group of respondents (e.g. individuals who use AAC vs. AAC specialists). Therefore, further research is needed in order to investigate the differences in priorities.

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APPENDICES

APPENDIX A

Submitted to IRB for Approval

Factors Related to the Rejection and/or Abandonment of AAC Devices

I. Introduction

Approximately 1.3 % of all individuals (i.e., more than 3.5 million Americans) have such significant communication disabilities that they cannot rely on their natural speech to meet their daily communication needs (Beukelman& Mirenda, 2005). Without access to speech, these individuals are severely restricted in their communication and participation in all aspects of life which include their education, employment, quality of time spent with their families, and level of participation in their communities. The development of augmentative and alternative communication (AAC) strategies offers great potential to enhance the communication of individuals with complex communication needs, and therefore improve their quality of life.

Unfortunately, AAC acceptance does not occur unanimously. While the intent of an AAC intervention is to enhance an individual's quality of life, some research (Ball et al., 2002; Beukelman, 2002) has indicated that people may reject/abandon even well-designed and functional AAC systems. *Rejection* refers to situations in which clients are shown AAC options but choose not to pursue them from the onset. *Abandonment* refers to situations in which clients accept AAC systems initially, but later discontinue using them despite ongoing inabilities to communicate orally.

In an effort to understand the phenomena of rejection and abandonment of AAC systems, it is important to consider a complex interaction of factors pertaining to the user, the device, and the environment. It is also critical to acknowledge the perspectives of all stakeholders in determining which factors are the most relevant. Therefore, subjects for this investigation will be selected randomly from the 2007 Directory of the International Society for Augmentative and Alternative Communication (ISAAC) The members of ISAAC represent people who use AAC, their families, therapists, teachers, doctors, researchers, and manufacturers

Speech-Language Pathologists (SLPs) play a central role in AAC coordination, assessment, selection, fitting and instruction of AAC users and their partners. Given the emphasized need for SLPs to be proficient in evaluating functional outcomes of AAC (ASHA, 2002, p. 104), it is very important to create a tool that would help them to predict and avoid factors related to device abandonment and rejection. These include the role of AAC users, the milieu in which interactions occur, attributes of partners with whom they interact, and the technology itself.

II. Specific Aims

A. To determine, factors (i.e. the role of AAC users, the milieu in which interactions occur, attributes of partners with whom AAC users interact, and the technology itself. that are most strongly related to the likelihood AAC users may (1) *reject*, or, (2) later *abandon* their devices.

B. To determine if the factors cited vary depending on the role of the person completing the survey (e.g., AAC user, parent, speech-language pathologist, physical therapist, occupational therapist, teacher, manufacturer, other)

C. To develop a tool that AAC practitioners may find useful in predicting whether or not an AAC system will be rejected or later abandoned.

D. To help AAC practitioners take measures to better ensure the likelihood their clients will accept and continue to use their AAC systems.

III. Research Protocol

A. <u>Settings:</u> The present study will be conducted at the Department of Communication Sciences and Disorders, UNH. The subjects will be selected from the 2007 ISAAC directory by randomly drawing 300 names. An invitation to participate in the survey will be sent via email along with informed consent information and a link to the actual survey. The on-line survey will be posted on SurveyCat (UNH's online survey system). Access to completed surveys will be restricted to the co-investigators, Stephen Calculator and Alla Johnson. Data shared with others will be in aggregated form with no information that would enable the reader to link a response to a particular respondent.

B. <u>Investigator Experience:</u> The letter is attached.

C. <u>Protocols:</u> The on-line questionnaire will be utilized in this study to survey ISAAC members' opinions about factors contributing to rejection and abandonment of AAC systems. The factors will be extracted from the previously conducted studies that were yielded by an exhaustive review of the literature review. Contributing factors will be examined in relation to the role of AAC users, the milieu in which interactions occur, attributes of partners with whom AAC users interact, and the technology itself. The members of ISAAC were chosen for this study (1) on the assumption that they would be more likely to have experience in the area of AAC, and (2) the fact that the membership in multidisciplinary and includes AAC users compared to a sample drawn from the general public.
A 5 point Likert-type scale will be used by ISAAC members to assess the relative importance (strongly disagree to strongly agree) of factors that may contribute to rejection and/or abandonment of AAC systems. There

also will be space for respondents to comment on items and cite other factors not included in the survey that they feel might also be relevant *The copy of the survey is attached.*

D. Procedures for obtaining consent: The participants will be required to click "I consent/agree to participate" if they accept the terms of the informed consent information. Participants will then proceed to the actual survey.
The copy of informed consent is attached.

IV. Data

The on-line survey will be utilized to collect the data. Upon receipt of responses, obtained data will be transferred to the SPSS program for statistical analysis. The computer, on which data will be stored and analyzed, will be password protected with the password known only to the principal investigators and kept in a locked office.

Data will be analyzed both qualitatively (primarily by examining respondents' comments) and quantitatively. The mean value of ratings will be used in order to determine the importance of each factor in predicting AAC device *rejection* and *abandonment.*. The SPSS program will be utilized for descriptive statistics corresponding to ratings of the importance of individual items overall and in relation to types of respondents (e.g. speech-language pathologists, teachers, AAC users, etc.). All other identifying information will be masked in order to maintain confidentiality.

V. Risks

Participants will be invited to participate in a research project that will *anonymously* study their perspectives on factors contributing to rejection and abandonment of AAC systems. Additionally, the results of the project will be stored on a password-protected computer to ensure confidentiality. Therefore, there are no foreseeable risks to subjects associated with the present study.

VI. Benefits

Results of the present study will be shared with participants, who may find them to be helpful in providing and/or using AAC systems themselves or with others. Findings will also be prepared for presentation at national conferences and publication consideration. As indicated earlier, the survey itself may prove to be a useful AAC assessment tool for practitioners, parents, and others.

APPENDIX B

Submitted to IRB for Approval

INFORMED CONSENT DOCUMENT

Dear ISAAC member,

I am directing a thesis being carried out by Ms. Alla Johnson, a graduate student at the University of New Hampshire (USA), that is exploring factors related to the rejection and/or abandonment of AAC systems by individuals for whom these devices are intended. We are trying to get a large and broad sample of respondents with expertise in the area of AAC. You were identified as a potential subject upon being randomly selected from the 2007 ISAAC Directory. Please consider completing the attached survey (see link at the bottom of this letter) as your cooperation will be integral to the validity of the research. By returning the survey you will convey informed consent to participate. The survey should not require more than 15-20 minutes to complete. Your participation is purely voluntary and you are free to withdraw your consent and discontinue participation at any time. You should understand that although your responses to the survey will be anonymous and kept confidential, any form of communication over the Internet does carry a minimal risk of loss of confidentiality. Results of this investigation may be presented at conferences and will likely be submitted for publication consideration.

Please feel free to contact me directly at the University of New Hampshire, Department of Communication Sciences and Disorders, Hewitt Hall, 4 Library Way, Durham, NH. 03824. You can also contact me by phone (603.862.3836) or email (Stephen.calculator@unh.edu). If you have any questions about your rights as a research subject please feel free to contact the University of New Hampshire's Office of Sponsored Research at 603.862.2003. Thank you so much for considering this request.

Stephen N. Calculator, Ph.D.
Professor and Chair
Department of Communication Sciences and Disorders
UNH –Durham

Please click on the link below in order to access the survey.

Link to survey:
http://survey.unh.edu/surveycat/surveys/survey383_AllaCalc08.htm

APPENDIX C

IRB APPROVAL LETTER

University *of* New Hampshire

Research Conduct and Compliance Services, Office of Sponsored Research
Service Building, 51 College Road, Durham, NH 03824-3585
Fax: 603-862-3564

14-Feb-2008

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IRB #: 4162
Study: Factors Related to the Rejection and/or Abandonment of AAC Device
Approval Date: 11-Feb-2008

The Institutional Review Board for the Protection of Human Subjects in Research (IRB) has reviewed and approved the protocol for your study as Exempt as described in Title 45, Code of Federal Regulations (CFR), Part 46, Subsection 101(b). Approval is granted to conduct your study as described in your protocol.

Researchers who conduct studies involving human subjects have responsibilities as outlined in the attached document, *Responsibilities of Directors of Research Studies Involving Human Subjects.* (This document is also available at http://www.unh.edu/osr/compliance/irb.html.) Please read this document carefully before commencing your work involving human subjects.

Upon completion of your study, please complete the enclosed pink Exempt Study Final Report form and return it to this office along with a report of your findings.

If you have questions or concerns about your study or this approval, please feel free to contact me at 603-862-2003 or Julie.simpson@unh.edu. Please refer to the IRB # above in all correspondence related to this study. The IRB wishes you success with your research.

For the IRB,

Julie F. Simpson