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“All Children Can and Should Have the Opportunity to Learn”: General Education Teachers’ Perspectives on Including Children with ASD who Require AAC

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Abstract

A qualitative online focus group methodology was used to investigate the experiences of five elementary school teachers (grades K-5) who had included children with autism spectrum disorders (ASD) who required augmentative and alternative communication (AAC) in their general education classrooms. Information was obtained from the participants in the following areas: (a) the benefits of educational inclusion, (b) the negative impacts of educational inclusion, (c) the challenges of educational inclusion, (d) the supports for educational inclusion, and (e) recommendations for other teachers and individuals involved in the inclusion process. Participants primarily chose to focus on inclusion as a beneficial practice for all involved, but did describe a few barriers and challenges of inclusion. These results are discussed as they relate to these themes and with reference to published literature. Recommendations for future directions are also presented.

1. Introduction

During the past 10 years there has been a dramatic increase in the number of children with autism spectrum disorders (ASD; Center for Disease Control, <http://www.cdc.gov/ncbddd/autism>; retrieved December 14, 2007), and in the number of children with ASD who participate in general education classrooms. In 2005, approximately 120,000 students received special education services because of a diagnosis of autism (Government

Accountability Office, <http://www.gao.gov/htext/d05220.html>; retrieved December 20, 2007). It has been estimated that 14-20% of these children will not develop functional speech, and will require augmentative and alternative communication (AAC) to assist in meeting their communication needs (Lord, Risi & Pickles, 2004). Over the past few years, there has been an increasing emphasis on the inclusion of all children with disabilities, including children with ASD, in general education classrooms (McDonnell, 1998). At present, 88.4% of children with ASD spend some portion of their school day included in a general education classroom (2005 Annual Report to Congress on the Implementation of the IDEA).

While there are clear benefits to the inclusion of children who require AAC in general education classrooms (Kent-Walsh & Light, 2003; Soto, et al., 2001a; Soto et al., 2001b), there are also a number of challenges that have been identified in the literature, including a need for additional training for professionals, support for collaborative teaming, and a clear understanding of professional roles and responsibilities (Hunt, et al., 2002; Kent-Walsh & Light, 2003; Soto, et al., 2001a; Soto et al., 2001b). Additionally, inclusion of children with ASD in general education classrooms has also been shown to present additional challenges as a result of difficulties inherently present due to the characteristics of ASD (Simpson, Boer-Ott & Smith-Myles, 2003).

At present we have only a limited understanding of the potential benefits and unique challenges of supporting children with ASD who also require AAC in general education classrooms. One important source of information regarding these benefits and challenges may be general education teachers who have successfully supported the inclusion of children with ASD who require AAC in general education classrooms. Kent-Walsh and Light (2003) reported on the experiences of general education teachers who had worked with students who required AAC, however only 1 of the 11 teachers reported working with a child with ASD. For this reason, the current investigation sought to engage regular education teachers who had experience including children with ASD who required AAC in general education classrooms in an online focus group discussion. Our goal was to identify and understand the strategies that these teachers have used to support and facilitate the inclusion of children with ASD who use AAC. Specifically, information was gathered from general education teachers in the following areas: (a) the supports needed for successful inclusion (for the purposes of this paper, the term *inclusion* refers to the participation of children with ASD who require AAC in general education classrooms for any portion of the school day); (b) the benefits of inclusion; (c) the adaptations required to support inclusion; (d) the negative impacts of inclusion; (e) the barriers to successful inclusion; and (f) recommendations for other teachers, professionals, and school administrators who are involved in the inclusion of children with ASD who require AAC.

2. Method

Design

The current study employed a qualitative focus group methodology to investigate the experiences of general education teachers who had worked with children with ASD who require AAC in general education classrooms. Focus groups are a form of interview that focuses on the communication between the participants as an important source of data. A qualitative focus group methodology was chosen for this investigation for

several reasons. First, there has been limited research examining the experiences of general education teachers who have included children with ASD who require AAC, and qualitative research designs are appropriate for exploration of new areas of research (Patton, 1990). Second, focus groups are appropriate for use when investigating the opinions and experiences of a group of participants. Attitudes and perceptions are not developed in isolation, but through interaction with other people, therefore, a focus group methodology allowed the participants in the current investigation to explore and clarify their views in ways that are not as accessible in traditional one-on-one interview formats. Third, the data obtained in focus groups, although reflecting the views of the individual participants, are very different from individual narratives obtained through interview or questionnaire methodologies because the results reflect the nature of the interaction between the group and not solely the perceptions of an individual (Kitzinger, 1995; Morse & Field, 1995).

Traditionally focus groups have been conducted with all of the participants in a common physical environment (e.g., a meeting or conference room) for a certain period of time (e.g., 1 to 3 hours) to discuss questions and topics presented by a moderator (Vaughn, Schumm & Sinagub, 1996). The focus group used in this study, however, was slightly different from the traditional focus group in that it was conducted over the Internet over a period of weeks instead of in one physical location over a period of hours. There are only a few general education teachers with experience including children with ASD who require AAC into general education classrooms. In addition, we wanted to include educators from across the United States. For these reasons, the focus group in the current investigation was conducted via the Internet.

Participants

Criteria for Participation. To be considered for inclusion in the current online focus group each: each participant had to meet four criteria: (a) be a general education teacher; (b) have included at least one child with ASD who requires AAC in their general

education classroom; (c) work in a school district within the United States; and (d) have access to the Internet.

Recruitment of Participants. Participants in this online focus group were recruited by sending recruitment messages and material to five groups: (a) online support group sites for parents of children with ASD, (b) e-mail listservs for individuals and professionals in the field of AAC (ASHA Division 12 listserv and ACOUG listserv), (c) researchers in the field of AAC (i.e., members of the International Society of Augmentative and Alternative Communication (ISAAC)), (d) researchers who have recently (within the last 10 years) published articles related to the inclusion of children with ASD in general education classrooms, and (e) directors of ASD support programs in the state of Pennsylvania (i.e., Pennsylvania Training and Technical Assistance Network (PaTTAN)) requesting nominations of general education teachers.

Description of Participants. A total of five elementary school level general education teachers (grades K-5) who have included children with ASD who require AAC in general education classrooms volunteered for participation in the group and all were assessed as meeting the minimum criteria for inclusion in the study. All five of these participants were female, and ranged in age from 26 to 35 years. Their highest level of education obtained ranged from a bachelor's degree to a master's degree, and their training in special education ranged from no training to a master's degree in special education. The teachers had participated in various levels and types of training in ASD, ranging from no training in ASD to completion of a university course in ASD. Training and experience with AAC tools and strategies varied widely. The teachers reported levels of inclusion that ranged from inclusion for specials only (i.e., the child with ASD who required AAC was included for physical education, music, art, etc) to full day inclusion (i.e., the child with ASD who required AAC did not leave the classroom except for related services, if a pull-out model of service delivery was in place). See Table 1, for the participants' demographic information.

Materials

Phorum, a "guestbook" software program, was used for this Internet based focus group discussion. Phorum is a password-protected program that allows for text-based discussions of multiple topics. The program allows the participants to read the information that has been posted by other participants as well as contribute their own comments and ideas. The topics and questions that were posted to the discussion site were developed by the investigators based on a review of the literature related to including children with ASD and children who require AAC in general education classrooms (e.g., Hunt et al., 2001; Kent-Walsh & Light, 2003; Simpson et al, 2003) prior to the initiation of the focus group. Additionally, a parent of a child with ASD who is included in an elementary level general education class also reviewed the questions to further ensure that the topics covered were meaningful, comprehensive, and appropriate from a parent perspective. Though this review was not required based on qualitative research methodology, the researchers felt it was important to get a non-professional perspective on the questions prior to their use within the investigation. The posted questions reflected minor wording changes to incorporate the comments and feedback of this parent. See Appendix A (http://mcn.ed.psu.edu/dbm/Finke08/AppA_AppB.pdf) for a listing of the questions.

Throughout this focus group, all of the general education teachers posted comments to all of the topics posted on the Internet discussion site. None of the participants added new topics of discussion, however 32% of the responses posted contained comments that recasted, expanded or confirmed the experience of another general education teacher. The general education teachers also requested or provided more information or clarification in 8% of the responses.

Procedures

After the participants provided informed consent they were sent a brief questionnaire to describe their experience working with children with ASD, their experience in general education, and their

preservice and in-service training and experience working with children with ASD and AAC. This questionnaire was returned via e-mail or fax. The focus group discussion was initiated after all participants had returned their informed consents and their demographic questionnaires. To initiate the study, an e-mail was sent to all of the participants providing them with the information needed to create a pseudonym and log on to the focus group discussion website. With this information the participants were encouraged to post a message on the discussion site to ensure they knew how to post a message to respond to a topic. The procedures for this focus group discussion followed the adaptations made by McNaughton, Light and Groszyk (2001) of the best practices recommended by Vaughn, Schumm and Sinagub (1996). These adaptations were made to meet the unique needs of an online focus group discussion format. For a complete list of the adaptations made for this investigation and their correspondence to best practices refer to McNaughton et al., (2001).

The first author served as the moderator of the focus group, and was responsible for presenting the discussion topics, encouraging discussion, facilitating the discussion as needed by encouraging participation, and redirecting participants to relevant topics of discussion. On a weekly basis the moderator posted new topics to the focus group discussion site.

The participants were asked to visit the focus group discussion website at least one time per week and respond to the question posted by the moderator. The participants were also encouraged to visit past topics and comment on or respond to the ideas and information expressed by other participants. The discussion group continued for a 15-week period. During this time the participants posted 47 comments, a total of 14,618 words, to the 7 topics.

Data Analysis

Prior to the data analysis process, the data were saved from the focus group discussion website to a word-processing document. The 5-step analysis procedures adapted by McNaughton, et al., (2001)

were utilized to analyze the data in this investigation.

In Step 1, "Unitizing the Data," the information from the focus group discussion was broken into the smallest amounts of meaningful information that express a complete idea or thought (McNaughton, et al., 2001; Vaughn, et al., 1996). These units were typically no shorter than one sentence in length.

In Step 2, "Coding the Data," the units of thought were reviewed and organized into themes based on the topic or content of the thought. During this process, operational definitions were created for determining how to sort each thought unit into a theme. These operational definitions were created by the first author. After the thought units were sorted into themes, the themes were reviewed for the existence of sub-themes.

In Step 3, "Negotiating Agreement," the first author used the operational definitions to code the data for samples of text drawn from the participants. Then the researchers met to review areas of agreement and disagreement, to create new themes and sub-themes, and to adjust themes and operational definitions as necessary. Please see Appendix B (http://mcn.ed.psu.edu/dbm/Finke08/AppA_AppB.pdf) for the final operational definitions of the coding themes.

In Step 4, "Calculating Agreement," the researchers used the operational definitions for identified themes and sub-themes to code 20% of the data. The researchers then met as a group to compare their individual codings of the thought units into themes. If a disagreement was identified in how to code a particular thought unit the group discussed the disparate codings and came to an agreement as a group for how to code the thought unit. Cohen's Kappa was calculated based on agreement of the first two authors for the coding of 20% of the total data, and resulted in an agreement of .83.

In Step 5, "Confirming the Summary with the Participants," each participant was e-mailed a copy of the summarized results for review and consideration as a member check step (Vaughn et

al., 1996). Participants were asked to comment on the accuracy and presentation of the findings as they related to their experiences and the information they contributed to the focus group discussion. All five of the participants replied to the result summaries and verified that the summaries accurately reflected their contributions to the focus group discussion.

Results

The results are presented as they relate to the four main coding themes that emerged from the five participants' varying experiences. Please see Table 2 (<http://mcn.ed.psu.edu/dbm/Finke08/Table2.pdf>) for a summary of the themes, sub-themes and examples of the specific issues discussed. Unless otherwise noted, all comments or quotations included in this section were initial posts to a topic, or the teacher quoted was the first to mention that specific topic in the focus group discussion.

Benefits of Educational Inclusion

The general education teachers reported benefits for students with ASD who require AAC and their parents, their classmates, the general education teacher, special education personnel as well as for the entire school.

Benefits for Students with ASD who Required AAC and Their Parents

First, three of the teachers indicated that the children with ASD who required AAC and their parents were satisfied with the level of inclusion of the child with ASD within the classroom and with his/her classmates. In response to a post by Mary, Helen explained,

the other students will often work together and include the child with autism; they may share ideas, or sometimes even discuss things off topic as they are working. I find this allows the students with autism to build friendships and relationships in the classroom and not only out on the yard.

Second, three of the teachers felt that increased opportunities for social interactions with typically developing peers helped the children with ASD who required AAC to see positive role models and appropriate classroom behaviors. Olivia stated in that inclusion provides the child with ASD with same age role models, social interactions, access to kid thinking and speaking that can at times be more clear to other kids than when said by an adult, it can lead to a person that's a buddy in the future, it can act as a visual story of cause and effect relationships and it can increase/improve communication as the child with autism makes an effort to communicate with those around and tries to be understood.

Olivia further cited the child's use of an AAC system as benefit in increasing social interactions with other students within the class. She specifically recalled an instance in her classroom when "my student who is non-speaking was given a Dynavox™ as a trial and the other students in my class helped him program it".

Further, four of the participants commented on the benefits of inclusion for skill development. They mentioned that the children with ASD who required AAC gained skills in many areas during the time they were in their classes. Mary summed this line of commenting up well when she stated: "The child gains academically, socially and in language skills. They are given the opportunity to perform to their ability level." This point was echoed in posts by Joann, Helen and Olivia.

Two of the teachers reported that inclusion benefits the parents of the child with ASD who requires AAC by providing access to a new social network. Olivia stated that parents "can get a break, access to other parents and a chance to interact socially in a situation where they already know their child is accepted." This experience was also echoed by Kate.

Benefits for Classmates

Four of the teachers reported that the typically developing students increased their

awareness and acceptance of children with ASD, as well as diversity in general. Kate reported that “inclusion has also helped my other students develop a sense of individual differences, compassion and understanding of individual needs”. The second benefit for the typically developing classmates was the development of academic and leadership skills through their interactions with the children with ASD. As Olivia commented: “the typically developing kids learn to act as a role model, they learn alongside the student with autism and at times are able to be the “expert” which kids do not often get the chance to be”.

Benefits for Teachers

The general education teachers described two ways in which they benefited from inclusion. The first benefit was their enjoyment at seeing the progress of students with ASD in the classroom. Kate expanded on a comment by Mary when she expressed that “working with autistic children...made me realize that everyone needs a chance to succeed”. Teachers also noted becoming more effective in their roles for all of their students. Helen summarized the sentiments expressed by the group when she said:

as a general education teacher, I have been changed greatly by teaching at a full-inclusion school. I am more aware of all of my students needs. I am more patient and understanding and develop lessons with so much more thought about each student.

Olivia echoed these thoughts when she expressed: “A child with autism can be a mirror to show you what you look like and are perceived by others to be doing”.

Negative Impacts of Educational Inclusion

Negative impacts were discussed for several groups including: (a) students with ASD who require AAC, (b) classmates, (c) teachers, (d) special education personnel, and (e) parents.

Negative Impacts for Students with ASD who Require AAC

Three participants reported an increase in stress as a result of irregular routines. Olivia summarized this negative impact: “The classroom can be an overwhelming place to be with many things going on...Having to explain yourself to people who don't already understand you is hard”. Three of the general education teachers also expressed concern about the impact of increased noise and activity within the included classroom. They reported that children with ASD who require AAC could become over-stimulated when the noise in the classroom increased. Joann's description of her student Joe exemplifies this:

When the children are reading aloud, working at their desk, etc... there is always some noise. Noise really affects Joe. He is very sensitive to what is going on around him. Most often he wants to remain at the computer table with headphones on to block a lot of the noise out.

Negative Impacts for Classmates

Four of the five participants also expressed concern about increased noise and disruptions for the other students in the classroom. Helen expressed this concern when she stated: “for the other students in the class ... the classroom can become very noisy with students of all abilities and my typically developing students have at times told me they were having a hard time hearing me or concentrating”. Mary, Kate and Joann echoed the impact of noise in later posts. Other negative impacts on the other students in the classroom included increased distraction, feelings of frustration, and fear secondary to the challenging behaviors exhibited by the child with ASD. In an expansion of a comment posted by Mary, Kate stated:

I think that the frustrations that surround the other children in the classroom are the behavioral outbursts from the autistic students. These verbal/behavioral outbursts sometimes cause fear in my kindergarten students. We address these issues with the students in the class, but that lack of

understanding and fear in a five year old is noticeable.

Finally, two of the teachers described negative impacts as a result of the frequent interruptions in the classroom for related service provision for the child with ASD who requires AAC. Mary restated a comment from Helen when she expressed that: “the other children can be impacted by frequent class interruptions; for example the psychologist comes in to observe the autistic student weekly, the teacher must stop and refocus the class”.

Negative Impacts for Teachers

One of the negative impacts related to feelings of frustration as a result of the increased time required for lesson planning and preparation. Joann echoed comments in posts by Helen, Olivia and Mary when she reported:

It's hard to plan and create these lessons as well as create modifications needed to make the lesson successful for children needing additional assistance. Teachers work so hard as it is and so much time is put into one work day.

Some of the teachers also reported concerns regarding the increased noise level in the classroom and the effects of this added noise on their ability to teach and conduct lessons. In illustrating this point, Helen said: “many of my students with autism often shouted out, talked to themselves, repeated sounds, etc. during my lessons, and I found it hard to teach over”. Finally, the general education teachers expressed concern regarding increased pressure from parents of the child with ASD who requires AAC as well as the parents of the other typically developing children in the classroom. Kate expressed her frustrations with these pressures when she stated: “I have encountered some very demanding parents - whether they are demanding with their communication log expectations or services their child is/isn't receiving”. However, she went on to soften this statement when she added: “I do realize

[however] that they are fighting for their children who cannot fight for themselves”. Further in an expansion on a post by Kate, Mary expressed the pressure she has received from parents of typically developing students when she stated: “a great deal of pressure is enhanced by the fact that teachers are confronted with the reactions of parents of “normal” children who are afraid that their child will get less attention”.

Negative Impacts for Parents

The first negative impact identified for parents was the dissatisfaction experienced with the amount of teacher time and attention given to all of the students in the classroom. This negative impact was illustrated by Helen when she said: “At times I have heard ... that parents feel students with special needs are given more support and attention during the day”. This experience was also echoed in a post by Olivia. The second issue was related to the frustration parents feel when their hopes for the child with ASD remain unmet even when included. Echoing a point made by Kate in a previous post, Joann commented:

If we are having a class performance, the chances are slim that Joe will participate. I know this is at times difficult for his parents. They want to see their child fully included and it's not that we aren't trying.

Challenges to Educational Inclusion

All of the teachers who participated in this investigation encountered challenges. It is important to mention however, that the participants preferred to view the process of inclusion in terms of “the glass being half full rather than half empty”(Mary).

Parent-related Challenges

Participants discussed two different types of parent-related challenges. The first related to having to advocate to get the child with ASD included in general education. In illustrating this point, Mary stated: “the biggest negative for parents is when they have to advocate to get inclusion recognized. They can

easily become frustrated by what they perceive as an uncaring school that lacks knowledge of the law". The second challenge related to having to take on the pressure and responsibility for finding a good academic match for the child with ASD. Again Mary was able to sum up this challenge when she stated: "parents also have to find the best curricular match for their child that is supportive, nurturing, caring and challenging because it serves as a foundation for the procurement of skills for the rest of their lives". This is vastly different than the experience of parents of typically developing children who do not often have to consider this aspect of their child's education.

Team-related Challenges

All of the general education teachers indicated that it was challenging when multiple members of the team need to coordinate their schedules to ensure the child with ASD receives all of the required services while still being in the classroom for important instruction and content area. Olivia commented that the related-service providers find "it hard to connect schedules so that they work for everyone". She further stated that they "find it hard to pull the student from 'positive' social experiences to work in isolation and then return to class not knowing what is going on". Four of the five general education teachers also found the team challenged by the need to clearly understand the roles and responsibilities of all of the professionals involved with the child with ASD. Kate expressed this challenge well when she stated: "a huge piece of this puzzle is managing each other as well. Knowing our boundaries and expectations of the specialists jobs, regular educators jobs and responsibilities, and the special educators piece - is difficult to establish at times". This challenge was echoed in posts by Helen, Olivia and Mary. Four of the five teachers further expressed that it is challenging to include a child with ASD who requires AAC when the team is not able to collaborate and consult on a regular basis. Mary stated that: "finding time during the day to brainstorm and collaborate with the appropriate staff can be difficult due to

schedules and case load", a sentiment which was further echoed by Helen, Joann and Kate in subsequent posts.

Teacher-related Challenges

All of the general education teachers discussed the need for more time to complete multiple aspects of their jobs. Among the tasks that required more time with inclusion were lesson planning and lesson modification. Helen stated:

I find it difficult at times completing all of the specific modifications and adaptations that need to be completed for each lesson. Instead of preparing one lesson for a class of 20, I am often preparing up to 3 or more different versions of the lesson.

This idea was also echoed in posts by Mary, Olivia and Joann. Four of the five teachers also commented on the time required to address the concerns of parents. Olivia illustrated this when she said: "parents feel their child is missing opportunities because the teacher is focusing on the child with autism. Some parents may feel that the child [with ASD] shouldn't be there because she's not performing at grade level". Kate further added regarding the challenge of needing more time: "as a regular education teacher, I find that my frustrations lie with the amount of meetings, with the class size, and (sometimes) parents of the autistic student". Finally, the challenge of time was also addressed with respect to the length of time needed for the children with ASD who required AAC to complete their class assignments. Joann expressed this challenge when talking about a particular student, "Joe", when she stated: "he would get a sentence or two typed into his system and then take a break ... at times it takes him a lot longer to complete an assignment".

All of the teachers also discussed the need for additional supports in the classroom as a challenge to inclusion. The supports needed by teachers varied from additional classroom professionals (e.g., educational assistants), to support from the administration in terms of reduced

class size. Kate summarized these challenges when she stated in a response to a post by Mary:

I think that class size has a huge impact on participation versus presence for all children, especially students with special needs. Twenty-five 5 year olds in a class, even with a half day educational assistant, is crazy (with or without the inclusion of special needs children and their personal educational assistant).

The final challenge was the need to accept the child with ASD as part of the class. Olivia illustrated this when she stated: "one challenge I have found with making inclusion successful is the teacher's presentation/reception of the student to the classroom". This challenge was also evident for Kate when children with ASD who required AAC did not have their AAC system in school. She stated that on these days inclusion is challenging because: "I am constantly wondering what these non-verbal children must be thinking or fearing or dreading, or hopefully the majority of the time, enjoying".

Classmate-related Challenges

The first challenge for classmates is the need to have answers to their questions about their new classmate. Mary reported that: "the other children may be confused and afraid to ask questions about why the autistic child does certain behaviors or has an adult working with him/her all the time". This challenge was echoed by both Kate and Joann. The second challenge related to the classmates need for equal time and attention, as Olivia suggested: "with a larger class size the students may feel that they don't get enough attention while the student with autism has an adult with her at all times".

Student with ASD who Requires AAC-related Challenges

Two main challenges to inclusion were associated with the students with ASD who require AAC themselves. These challenges included the need to deal with increased environmental activity and noise as well as the need for increased

communication and social skills. Kate illustrated the challenge of increasing communication and social skills when she stated: "autistic children sometimes have frustrations or negative reactions to the social piece and not knowing how to communicate that ... not having the social skills to interact with their peers" can also be challenging in an inclusive classroom. This experience was echoed by Helen and Joann in later posts.

3.5.1 Personal characteristics

The participants reported that they were realistic about their personal strengths and abilities. As Phil commented: "I feel I can do a job just as good as the next person, but I have to work a lot harder at it." Sam described how he managed his tasks: "I know what my abilities are, and I never take on more than I can handle."

Some group members noted a combination of realistic attitude, drive, and confidence as important personal characteristics to succeed at a job. Carl described his desire to be a manager and his plan to get there:

I realize that you are not going to start out on the top of the ladder, but I feel I am qualified to start at a low management level and then work my way up... I was taught that you need to work hard to get where you want, yet you must be careful that you don't step on other people's toes.

Sam described the challenge of maintaining a positive attitude in the face of a poor reaction from others: "All we can do is have enough faith in ourselves so that the opinions of others don't matter. That's not easy."

Other participants described techniques to impress potential employers. Carl shared his technique: "I know I need to plan ahead and get accommodations ready before hand. I even negotiate pay for my helpers when I go speak at a retreat or convention." Sam described how he displayed initiative: "In the interview, I take control. I don't just pretend to be sure of myself, but I never act like I know it all."

3.5.2 Education and experience

The group emphasized education and job experiences as important supports to employment. Carl commented on the importance of formal education: "I feel I have been prepared to be self-employed by my college education."

For others "on the job" learning was seen as valuable but hard to obtain. One of Sam's current employers, for whom he did contract work, took the time to provide the feedback Sam needed to learn new skills. Sam wrote, "My boss 'kicks my butt' a lot, and sometimes I hate it. Yet because of how far I am now I wouldn't want it any other way".

3.5.3 Technology

Participants in the study identified their communication devices and systems as important supports to employment. Ron described the confidence that an effective AAC system gave him: "Once having a voice, I found out that I was unlimited and slowly things started to snowball". Bob also described the importance of his device, saying: "My Liberator is a part of me." Participants described how thoughtful use of a variety of communication techniques could help overcome communication obstacles. For example, email allowed for an individualized pace in the creation of messages, and this could sometimes be used in place of more demanding face-to-face communication. Bob wrote, "I use email a lot because it is easy... The person has my thoughts in front of him or her instantly."

3.6 Recommendations for Improved Employment Outcomes

Four major subcategories were identified following discussion of recommendations for improved employment outcomes: recommendations for individuals who use AAC, recommendations for educational institutions and schools, recommendations for AAC device manufacturers, and recommendations for government. (See Table 4 for a *Summary of Recommendations to Facilitate Self-Employment for Individuals who use AAC*).

3.6.1 Recommendations for individuals who use AAC

Recommendations for individuals who use AAC included both ideas for self-employment as well as strategies to improve access to the traditional job market. Sam suggested that individuals take "practice" jobs – that is jobs that are not necessarily a good fit for their long term goals but which can be used as learning opportunities. Sam suggested that workers "pick a skill that you want to work on, knowing that you might eventually get fired, even if it does not fit you. A variety of work experiences also helps with making contacts for future employment opportunities." Carl outlined the benefits he had experienced from efforts to network with potential employers: "Hopefully by networking I will have several offers on the table, so I can choose. It is all about networking and working hard. I have networked and it is paying off."

Being able to quickly demonstrate competence in the workplace was seen as a highly valued skill. John suggested how to establish this impression and why: "They [AAC users] must start a conversation with the interviewer right from the beginning.... you might be the first AAC user the interviewer ever saw. By starting a conversation, you will make the interviewer comfortable and show them how intelligent you are."

3.5.2 Recommendations for educational institutions and schools

The participants had experienced first hand the positive impact of education, and had numerous recommendations for teachers. Sam wrote: "Always expect the best from your students and you will never be disappointed." Carl also recommended having faith in student's ability to perform: "My message to schools is do not underestimate a child." Bob also emphasized that it is important to have high expectations, recommending to teachers "Do not cop out by saying 'oh this student will never do that, so we don't have to teach him this'".

Jim spoke of the valuable role that experienced individuals who use AAC can play for novices. He recommended a mentor program in which individuals who use AAC and have accomplished significant life goals could work and

problem-solve with younger individuals who use AAC.

3.6.3 Recommendations for manufacturers

The group also made recommendations to improve technology in the workplace for individuals who use AAC. Many of the participants wanted AAC devices that would allow them to communicate more easily with others at a distance by incorporating cell-phone or email technologies. Participants also wanted business applications such as calendars and contact lists available in their AAC devices. Sam presented a suggestion for a new approach to AAC technology, suggesting the development of a device that could recognize an individual's dysarthric speech and repeat the statement using synthesized speech. Suggestions to make AAC devices more usable in a wide variety of environments included suggestions for devices that would automatically adjust their volume level and screen brightness depending on the surrounding conditions, and devices that would be waterproof. Finally, individuals wanted devices that would better help them communicate their personality. For example, Bob wanted an easy way for the voice in his device to reflect different emotions: "the serious mode, the sarcastic mode, the funny mode, etc."

3.6.4 Recommendations for government

Some participants recommended new and stronger laws preventing discrimination and promoting education. Ron recognized the need for new programs but also the limitations: "Unfortunately, the government can do little to control morals, but it can [educate] society with public awareness programs." Sam suggested a more proactive solution: "No matter how hard we try to prove ourselves, we will only be what the Laws say we are until we change them. If we change the Laws, we change the world."

The complexity of dealing with government benefits was a frequently mentioned topic, and many participants wanted universal health care, both so that their medical costs would not serve as a deterrent to a potential employer and so that they would not have to worry about the impact of earned

income on government benefits. Sam wanted more financial control over the funds used for attendant care, and the right to personally hire and fire attendants:

It would be much better if we could just all deal directly with the State...if we got rid of all of these "do nothing" agencies, the pay (for care providers) would go up. We would get much better help, and maybe it would effect our ability to work...

4. Discussion

For the individuals in this study, self-employment provided a measure of income, the knowledge that they were active participants in society, and, for many, a chance to help others. Four of the seven were involved in "community building" activities (e.g. advocacy work, youth ministry). For all of the participants, their self-employment activities were valued not only for the benefits that they brought the individual worker, but for their potential impact on society and societal attitudes.

Self-employment brings its own challenges, including the potential of social isolation [5] and the challenges of managing personal finances and coordinating government benefits [7]. There also are benefits to employment in community based settings (e.g., social interaction, public recognition) that may be more difficult to obtain while working from a home-based office [13].

These challenges notwithstanding, self-employment allowed these individuals to demonstrate skills and talents that often were not valued in traditional office-based competitive employment situations. The participants in this study frequently described the discrimination they faced in their efforts to be employed in "mainstream" society. Self-employment provided these individuals with an opportunity to set their own rules and standards, and to be able to work to meet their own goals.

Despite considerable effort to be self-supporting, all of these individuals received some type of financial assistance from the government. The fact that these businesses were typically not the primary means of financial support should not result in the interpretation that they were not successful.

As reported by Hagner and Davies [5] these small businesses provided a sense of identity for individuals with severe disabilities, and a supplemental income that enabled them to participate in important life events like getting married or obtaining their own apartment.

For individuals with severe disabilities, the option of self-employment may become even more important during the coming years. The Federal Government, traditionally a good employment opportunity for individuals facing discrimination in the private sector [17], reduced its workforce by 19% between 1985 and 2000 [3]. At the same time, the percentage of temporary (i.e., nonpermanent or less than fulltime) jobs grew to make up approximately 30% of the US workforce [23]. For individuals with severe disabilities, the compensation package offered in their part-time or temporary positions is rarely sufficient to meet the living needs of individuals with significant medical or care expenses [7]. The model of self-employment activities as a supplement to government assistance may be a useful option for individuals who use AAC.

While many services and supports need to be in place in order for employment to be a success, the vocational rehabilitation counselor can provide support in three key areas to individuals who use AAC and are considering self-employment as a long-term goal. First, while the individual is in school, the counselor should advocate for an appropriately challenging educational program. While educational goals need to be set on an individual basis, many of the participants spoke of the importance of strong reading and writing skills. Many of the individuals were involved in jobs that required the use of computer technology, and strong literacy skills were key. Second, vocational rehabilitation personnel can offer an important work-place perspective on the individual's communication skills and priorities for intervention. Different job activities will require different communication skills, however past research has documented the importance of being able to communicate as clearly and as quickly as possible, and to make use of appropriate workplace social skills [13]. Third, the vocational rehabilitation counselor should help identify a wide variety of part-

time or "work-experience" jobs while the individual who uses AAC is still in school. The work experiences will help the individual to develop both "formal" job skills (e.g., working with a database) as well as "informal" skills (e.g., learning to manage personal care services in the workplace). Work-experience activities also give direction to the educational program by helping to identify individual areas of strength and of concern, and assist individuals in developing a network of potential employers that may be helpful when the individual is seeking long-term employment.

5. Conclusion

While self-employment may only be able to provide full financial support for a small number of individuals, it can play an important role in augmenting government support for many others. Like the individuals described here, self-employment may be just one part of a constellation of activities, including traditional work activities and community-building volunteer activities. These employment activities allow people who use AAC to feel both some measure of financial independence as well as additional pride in their employment activities. As one of the participants commented, in describing his emotions when he received his first pay, "I feel human for the first time in my life".

Society should recognize a wide variety of achievements, not just those that result in the generation of income [17]. At the same time, as a society, we need to work to ensure that individuals with severe disabilities have access to the supports and services they need to pursue desired outcomes such as self-employment. As Rizzo [18] noted, the capacity of an individual to sustain employment is often more a factor of the supports provided rather than the disability. Given the importance of self-employment in the lives of the people described here, the need for the appropriate provision of supports is clear.

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APPENDIX A Topics and Questions Posted to the Discussion by the Moderator

Topic	Question
Welcome! Please click here and say "Hi!"	<p>Welcome! Thank you for joining our discussion! Before proceeding to our first topic, could you please post a message saying "Hello" and, for the fun of it, please tell us something about local news that is important to you. It could be something about a recent holiday or local events, or even just the weather. This will give you a chance to practice using this Discussion Site (and help us imagine where you are when you post to this Site!)</p>
Benefits	<p>What are some of the good things about having a job? Clearly having a job involves a lot of hard work, and not everyone makes the same decision. If someone were to ask why you have chosen to work so hard to have a job (or, for some of you, a number of jobs), what would you say?</p>
Finding a job	<p>As some of you may have guessed, you are a unique group! You are all individuals who, in one way or another, are self-employed. You are writers, musicians, artists, ministers. You are not working 9-5 jobs in an office.</p> <p>I am interested in how you made the decision to be self-employed.</p> <p>Did you try the "9-5" world and decide it wasn't for you?</p> <p>Do you think you faced special challenges in finding a "conventional" job because you are an AAC user, and being self-employed was your best way to make an income?</p> <p>Did you decide to be self-employed because the activity you love most (e.g., art) is not something that most businesses want to hire?</p>
What the government should do	<p>In a nutshell, how did you come to be self-employed?</p> <p>A number of you have mentioned problems you have faced in seeking employment: Bob mentioned the concern of some employers about health insurance rates, others have mentioned that some employers do not see beyond the disability.</p> <p>What do you think the government's role should be in addressing these problems?</p> <p>Are these "people" problems that government cannot change, or is there legislation that could improve the job prospects of people with disabilities?</p> <p>If you could "run Washington for a day" (or a year), what would you do?</p>
Communication and AAC Technology	<p>A number of you have talked about the importance of AAC technology, and a number of you have also mentioned that you</p>

Supports	<p>are sometimes frustrated with this technology (e.g., problems with the telephone, problems connecting up to computers). One of the groups that is interested in what you have to say is Rehab Engineers who are involved in designing the "next generation of AAC" devices. What have been your experiences with AAC technology in working with other people? What has been positive about the AAC technology that you use? What has been a problem with the AAC technology that you use?</p> <p>Other individuals who use AAC and their family members will read about the results of this research, and many will be interested in starting businesses from home and becoming self-employed. I am interested in what is needed to make that happen. A number of important supports have been mentioned so far - the support of family members, the use of assistive technology, and reliable personal care attendants</p>
Message to schools	<p>What have been your experiences? What are the supports that have been important to you in being self-employed?</p> <p>One of the goals of this project is to provide individuals who use AAC, their parents, and teachers, with information on how individuals who use AAC can prepare for employment while they are still in school. Already, some of you (Carl and Sam) have mentioned that your schools routed you into boring data-entry jobs, and failed to offer programs that were academically challenging.</p> <p>I am hoping that at least some of the time there was a mix of the "good" with the "bad". Looking back, what were some of the things that happened in school that helped you get ready for the "world of work"? Was there anything or anyone in your school years that was particularly helpful?</p> <p>Also, was there something that you wanted at school but did not get? Looking back now, was there a way that school could have better prepared you to find and keep a job, and/or to pursue your current self-employment projects? What would you like the teachers of tomorrow to know or do? While clearly there are a lot of attitudes that need to change, I am also interested in specific strategies that you think might be useful (.e.g., providing individuals who use AAC with legal training so they can advocate for their rights in the special education system).</p>
Message to technology developers	<p>As you have discussed augmentative communication technologies you have referred to features that you like in augmentative communication technologies (e.g., fast, large digital memories) , and features that you do not like (slow, short battery life).</p> <p>What would be the features of an ideal augmentative communication device? Another part of this research project is a group of engineers who want to hear from technology users what</p>

the next generation of technology should include. We would all be sincerely interested in your ideas on this topic. Again, please don't be shy about coming up with "far-fetched" ideas, 5 years ago no-one knew the WWW would look like this.

Also, don't think you have to figure out HOW to do it, just say WHAT YOU WANT. For example, if what you want is a device that can work for 24 hours at a time, you don't need to say "I want a device that can plug into an electric wheelchair battery", just say you want a device that can work for 24 hours at a time!

Many of you were at the Pittsburgh Employment conference last summer and you heard the ideas of individuals who use AAC there: daily calendars, cell phones, pagers, WWW link-ups, and (I think this was a joke) a home entertainment system. I would encourage you to "think big", as Bob did when he said he wanted a "mind meld". What is on your "wish list"?

Barriers to developing your business

What are some of the things that make it hard to get a job or develop your business?

We have spoken extensively about the problem of people's attitudes, are there other factors that also provide challenges? Are there government programs that have made it hard for you to get a job or develop your business?? transportation? Computer breakdowns? Problems with OVR? I would be interested in hearing about some of the reasons that it is sometimes hard to get a job or develop your business.

APPENDIX B: Operational Definitions of Coding Themes

1. *Description of Employment Activities* - Comment that provides information about employment activities, but does not include benefits/ reasons for employment, negative impacts, barriers, or supports related to employment (e.g., "my duties included").
2. *Benefits of Self-Employment* - Positive outcomes resulting from engagement in employment activities, including social, financial, familial, personal, psychological, or physical gains. Motivational factors or reasons for participating in employment activities, including negative effects of unemployment.
3. *Negative Impact of Self-Employment* - Negative experiences (including social, financial, familial, personal, psychological, or physical) resulting from engagement in employment.
4. *Barriers to Employment* - Any person, organization, situation, action, or device that impedes an individual's ability to obtain and maintain a job. Barriers can include policies, practices, attitudes, knowledge, skill, education, preparation, information dissemination, access, or physical/medical conditions.
5. *Supports to Self-Employment* - Any person, organization, situation, action, or device (including educational) that enables or assists an individual to obtain and maintain a job.
6. *Recommendations* - Suggestions regarding ways of overcoming barriers to employment based upon the participants' personal experiences and ideas. Includes recommendations to persons with cerebral palsy and their families, employers, co-workers, policy makers, service providers, rehabilitation professionals, and technology developers.
7. *Unrelated Statement* - Comment or question that is unrelated to cerebral palsy and not directly related to employment (e.g., "Go Nittany Lions!").

Table 1: Demographic Characteristics of the Participants

Variable	Participant						
	Andrew	John	Carl	Sam	Phil	Bob	Ron
Gender	<i>M</i>	<i>M</i>	<i>M</i>	<i>M</i>	<i>M</i>	<i>M</i>	<i>M</i>
Age	22	49	26	35	28	44	53
Disability	CP ⁸	CP	CP	CP, VI ⁹ corrected	CP	CP, VI, uses display magnifier	CP, VI corrected, HI ¹⁰ corrected
Mobility	Power wheelchair	Power wheelchair	Power wheelchair	Power wheelchair	Manual wheelchair	Power wheelchair	Power wheelchair
Education	Some college	Bachelor's degree	Bachelor's degree	High School (GED)	High school diploma	Bachelor's degree , some graduate coursework	Some college
Means of communication	Liberator	Liberator	Dynavox 3100, Speech,	Vanguard, speech	E-tran board with letters,	Liberator	Dynavox 3100
Length of use of current AAC system	8 years	12 years	2 months	2.5 years	25 years	8 years	10 years
Writing system	Standard keyboard	Standard keyboard	Adapted keyboard (Intellikeys)	Portable AAC device	On-screen keyboard	Standard keyboard	Portable AAC device
Access techniques	Finger	Finger	Left big toe to type and a trackball	Finger	Eyegaze, HeadMouse	Headstick	Headstick

⁸ Cerebral palsy

⁹ Vision impairment

¹⁰ Hearing impairment

Table 2

Coding Themes, Subthemes, and Examples of Issues Discussed by Participants

Coding Themes	Sub-themes	Examples of Issues discussed by Participants
Benefits of self-employment	Financial benefits	<ul style="list-style-type: none"> – Providing for others – Being financially independent
	Enjoyment of work activities	<ul style="list-style-type: none"> – Being with others – Being active – Flexibility of self-employment
	Fulfillment of personal expectations	<ul style="list-style-type: none"> – Contributing to society – Meeting job challenges – Exceeding expectations of others
	Societal change	<ul style="list-style-type: none"> – Demonstrating competence of individual who uses AAC
Negative impacts of self-employment	Financial impact	<ul style="list-style-type: none"> – Reductions in government benefits
	Societal prejudice	<ul style="list-style-type: none"> – Work is “under-valued” – Work is “over-valued”
Barriers to employment	Attitude barriers	<ul style="list-style-type: none"> – Being denied opportunities to participate
	Educational barriers	<ul style="list-style-type: none"> – Lack of instruction in use of AAC – Low expectations of teachers – Limited options considered in vocational planning
	Technological barriers	<ul style="list-style-type: none"> – Technology break-downs – Needing to be able to communicate quickly – Technology upgrades

	Policy and funding barriers	<ul style="list-style-type: none"> – Government support programs (e.g., SSI) complicated – Need to coordinate health insurance, home health care – Lack of medical benefits in entry-level positions
Supports to self-employment	Personal characteristics	<ul style="list-style-type: none"> – Knowledge of personal strengths and goals – Interest in demonstrating competence – Ability to plan for needs
	Education and experience	<ul style="list-style-type: none"> – Strong formal education – On the job learning
	Technology	<ul style="list-style-type: none"> – Competence in device use – Coordinated use of different communication technologies (e.g., email).

Table 3 Employment Characteristics of the Participants

Variable	Participant						
	Andrew	John	Carl	Sam	Phil	Bob	Ron
Job activities	Web site development, advocacy	Printing, office work, software consulting	Freelance speaker, Assistant Youth Pastor, Chairman of nonprofit organization	Musician, software consultant	Pottery maker	Freelance journalist, public speaker on disability rights	Artist, religious/motivational speaker, author, AAC Consultant
Time at job (yrs)	1.6	25	3	10	5	5	30
Prior employment	None	Copying services at a larger manufacturer	Data entry	Newspaper reporter, singer	Newsletter editor	Freelance magazine writer	None
Main Income/ Supplement. To SSI	Supplement	Supplement	Supplement	Supplement	Supplement	Supplement	Main
Work Hours/ Week	10-20	10	Youth pastor 7 hours; chairman 5-10; freelance speaker 5-10	35-40	10-20	10	20
PCA hrs/wk	15-22	Family provides care	28	35	Family provides care	3	70
Compensation ¹¹	Declined to respond	Minimum wage	More than minimum wage	More than minimum wage	Minimum wage or less	More than minimum wage	More than minimum wage

¹ Compensation received for total hours worked

Table 4

Summary of recommendations to facilitate self-employment for individuals who use AAC

Audience	Recommended Actions
1. Individuals who use AAC	<ul style="list-style-type: none"> – Take "practice" jobs – Network with co-workers and future employers – Demonstrate competence – Learn social interaction skills
2. Educators	<ul style="list-style-type: none"> – Communicate high expectations – Listen to students – Set up a mentor program
3. Technology developers	<ul style="list-style-type: none"> – Add cellphone capabilities to AAC devices – add business applications (e.g., calendars, contact databases) to AAC devices – Develop computer "translator" to interpret dysarthric speech – Add capability of automatic device adjustment to changing noise and lighting conditions to AAC device – Manufacture more durable, water-proof devices – Provide synthesized speech that communicates personality and emotion
4. Policy makers	<ul style="list-style-type: none"> – Create legislation to fight discrimination – Provide economic supports (e.g., universal health care, minimum annual income) to promote independence – Give individuals with disabilities control over personal care attendant funding