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Voices from Academia

A Model of AT and AAC Service for Adults with Developmental Disabilities

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ABSTRACT

A group of 63 adults with intellectual and developmental disabilities, many of whom (75%) demonstrated complex communication needs, was provided with assistive technology that was selected based upon their personal goals. The aim was to discover whether assistive technology would improve quality of life for participants and allow them to do things they could not do previously. Performance gains were evident in every case that involved a performance goal. A quality of life survey indicated that many participants felt less lonely, saw themselves as more helpful, and were more inclined to be involved in self-advocacy following the intervention. While AT services were provided for 62 of the 63 adults in the project, 35 participated in the research and completed the survey. A multi-disciplinary model for service delivery of assistive technology and augmentative and alternative communication emerged from this project that focused on improving performance on skills important to each individual and enhancing quality of life.

Keywords: assistive technology, complex communication needs, intellectual disability, developmental disability

INTRODUCTION

Adults with intellectual and developmental disabilities are an underserved group in our society. When dismissed from the public school system at age 22, these individuals generally experience difficulty transitioning to the larger community and to the world of work. Unemployment and inactivity are often exacerbated by coexisting health issues including communication disorders (Mirenda, 2014; Taylor & Hodapp, 2012). Largely dependent upon family for support, their isolation takes a toll on their families as well. Most wait for some time to receive state funding (often Medicaid waivers) to enable their participation in a day program or for other support for their daily care (Braddock et al., 2008). Fuhrmann et al. (2018) and Young (1990) suggest that there are barriers and hindrances in the form of social conditions in the environment that obstruct and prevent individuals with developmental disabilities from full participation in the communities around them. These obstacles inhibit their full participation and the development of relationships.

The majority of individuals with intellectual and developmental disabilities also have challenges with verbal communication (Mirenda, 2014). This means that they do not have functional speech sufficient to engage in everyday communication activities (Stancliffe et al., 2010). Difficulty with communication limits individual choice and self-determination and defines educational opportunities (Brault, 2012). It also inhibits social connections with individuals in their communities and undercuts prospects for obtaining meaningful employment (Butterworth et al., 2012; Davies et al., 2002). Kozma et al. (2009) reported that, overall, the quality of life for individuals with developmental disabilities appears to be inferior to that of people in the general population.

Recognizing these factors, the Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD) and Georgia Tools for Life (TFL) at Georgia Tech sought to explore how assistive technology (AT) might be applied in the lives of individuals with intellectual and developmental disabilities to foster a measure of independence and self-reliance. These two organizations embarked on a three-year effort to identify and work with individuals who might benefit from using AT. The presence of a large proportion of individuals with Complex Communication Needs (CCN) required the integration of augmentative and alternative communication (AAC) systems and strategies to meet the needs of these individuals. A multi-disciplinary team which included AT specialists, speech language pathologists (SLPs), an occupational therapist (OTs) and rehabilitation counselors met with individuals with intellectual and developmental disabilities and their families to discover what skill or goal they personally wanted to achieve. The team worked with the individuals to select AT and AAC tools and strategies that would help them progress toward their goals and provided training, modeling and support.

TARGET AUDIENCE AND RELEVANCE

The target audience for this paper includes individuals with intellectual and developmental disabilities themselves, their families and friends, and all who serve them. It also includes the teachers and administrators, transition coordinators, vocational rehabilitation counselors, and support coordinators

who work with them. Those who shape or influence public policy would find this paper useful as well. The hopeful vision espoused by home and community-based care (HCBC) advocates would be reinforced by the identification of tools that foster individual independence, self-reliance, and connection to the community, and that are focused on the goals of the individual.

LITERATURE REVIEW

While progress has been made over the past three decades to move individuals with intellectual and developmental disabilities from institutional settings into the community (Mirenda, 2014), integrating these individuals into their communities remains a challenge (Chowdhury & Benson, 2011). People with developmental disabilities are often unemployed or underemployed (Hirst, 1987; Howlin, 2005; Kuh et al., 1988). A 2015–2016 survey indicated that only 19% of individuals with developmental disabilities were employed (National Core Indicators, 2019). The majority of adults with developmental disabilities are idle and live at home in the care of their parents (Braddock et al., 2008; Taylor & Hodapp, 2012). Research suggests that people with intellectual and developmental disabilities experience adverse health outcomes more frequently than typical peers (Helmsley & Balandin, 2014; Lipscomb et al., 2017). Because they generally have low incomes, most receive medical care under the state Medicaid program rather than through private insurance (Reichard et al., 2011). We observed that many of the participants in our study demonstrated a sedentary lifestyle, which may contribute to poor health conditions. The communication challenges that many in this group face complicate what is often an already daunting set of medical problems. An individual's inability to tell caregivers what is wrong or where it hurts, or to share with medical providers the nature of the problems they experience, often results in inadequate health outcomes (Rose et al., 2005; Taylor & Hodapp, 2012).

As many as 81% of people with developmental disabilities are considered to be living below the poverty line (Butterworth et al., 2012). They are generally living at home, where family members serve as care providers. These care providers are generally unpaid. Many people with intellectual and developmental disabilities in our study were on a *planning list*, waiting for Medicaid waiver funding. Without this waiver funding they are unlikely to be able to afford any sort of independent living arrangement or participation in a day program. Many have been waiting for a decade or more.

The use of AT for persons with intellectual and developmental disabilities has been shown to promote independence and enhance the quality of performance on daily tasks (Davies et al., 2002; Gilson et al., 2017; Wehmeyer et al., 2006). Cell phones, tablets and other portable and wearable devices have been used to demonstrate that individuals with intellectual and developmental disabilities can do tasks more independently, reinforcing the autonomy of the individual and reducing the level of required supervision (Cihak et al., 2008; Ferguson et al., 2005; Furniss et al., 2002; Mechling, 2011; Riffel et al., 2005). Apps and systems have been developed that provide prompting for such tasks as taking medication, and performance of daily tasks by providing step-by-step visual and auditory support for successful task completion (Cannella-Malone et al., 2006; Davies et al., 2002; Riffel et al., 2005; Van Laarhoven, et al., 2007). Further, there is an emerging body of research supporting the use of AT to successfully support these individuals in the workplace (Morash-Macneil et al., 2017). However, care must be given to carefully

considering the needs of the individual, and identifying AT approaches that will provide support for personally selected goals (Scherer, 2005).

Many individuals with developmental disabilities also have difficulty with communication (Mirenda, 2014). Only about 10% of those with CCN use AAC systems or sign language to communicate, leaving the remaining individuals with CCN with only gestures, behaviors and unintelligible utterances (Kozma et al., 2009; Lakin et al., 2011; Stancliffe et al., 2010). Many have transitioned out of the school system without the communication tools they need (Light & McNaughton, 2015).

AAC systems and supports have been found to enhance engagement and participation in learning as well as to foster social engagement with peers (Mirenda, 2014). Properly selected, implemented, and supported AAC systems can lead to significantly enhanced communication ability (Gustavsson et al., 2005; Näslund & Gardelli, 2013; Moser, 2003; Shakespeare, 2006).

There is an ever-increasing corpus of literature that suggests that AAC tools and strategies can make a difference in the lives of people with developmental disabilities (Light & McNaughton, 2015; Lund & Light, 2007; Mirenda, 2014; Roche et al., 2015; Snell et al., 2010). Selection and implementation of an AAC system is an individualized process (McNaughton et al., 2019). Successful implementation of AAC necessitates a team approach to insure an all-inclusive consideration of the individual's needs, interests and concerns. In addition to the SLP, this includes family members and care providers, and others in the individual's circle of care (e.g., other therapists, medical professionals, educators, etc.; Beukelman & Mirenda, 2013; DePaepe & Wood, 2001). Properly selected, implemented, and supported AAC systems can lead to significantly enhanced communication ability (Gustavsson et al., 2005; Moser, 2003; Näslund & Gardelli, 2013; Shakespeare, 2006).

There have been a number of obstacles to AT and AAC use among people with intellectual and developmental disabilities. First, many people with intellectual and developmental disabilities are not familiar with AT or AAC and are not aware that these tools could help them (Light & McNaughton, 2013). Second, the cost of systems and access to funding have been major factors that have limited acquisition of these tools. Third, a lack of support and training has resulted in the abandonment of many AT devices and AAC systems. The impact of these factors is compounded by difficulties in communication and a general lack of advocacy in making their needs known.

METHOD

Measuring AT Outcomes from a Person-Centered Approach

Georgia Tech and DBHDD approved the details of a contract in April of 2017. Shortly thereafter, a "referral portal" was launched through which the agency's Program List Administrators (PLAs) could refer individuals to the program. The first referrals appeared in May of 2017.

The project was designed to take a person-centered approach. Once an individual was referred, the team at TFL would conduct an interview to learn more about the individual. This included a discussion with the

family or care providers. On the initial visit, the team, individual, and family came together to explore the individual's personal dreams and desires, abilities, and challenges. They sought to identify some skill or goal that would be meaningful to the individual. These goals focused on independence and varied from engaging in a preferred activity in their free time, to tracking their blood pressure, to communicating regularly with family or friends. At this point, pre-intervention data was collected about performance and satisfaction. The team then met with the individual at least twice more to provide and implement AT that would address the skill or goal. The second visit focused on the provision of AT that addressed the skill or goal on which the individual wanted to focus. Examples of AT items provided are listed in Table 1. Demonstration and training were important parts of this visit. The third and final session was used to explore how the AT had addressed this goal or skill. Data were collected on performance and satisfaction. Visits with individuals were conducted in their homes to provide a natural setting that would be comfortable for the individual and instructive to the team.

Table 1: Examples of Technologies Provided by Area of Need

Area of Disability	Examples of AT Provided
Communication	<ul style="list-style-type: none"> • Tablet with communication app • Static display AAC devices • Communication wallets with communication symbols • Plexiglas eye-gaze board • Emergency ID bracelet
Mobility	<ul style="list-style-type: none"> • Adapted can opener • Modular hose for mounting devices and controls • Digital home assistant and smart plugs for voice activation of appliances • Switches and switch interfaces
Vision	<ul style="list-style-type: none"> • Currency reader • Voice labelling system • Picture phone with enlarged speed dial • Braille labeler • Enlarged keyboard
Hearing	<ul style="list-style-type: none"> • Pocket-sized sound amplifier • Doorbell that sends text message to resident • Flashing door- bell alarm • Bed-vibrating alarm clock
Activities of Daily Living	<ul style="list-style-type: none"> • Rocker knife Adaptive cutting board • Adaptive scissors • Weighted mug • Automatic toothpaste & soap dispensers • No-tie shoelaces • Long handle shower sponge
Cognition	<ul style="list-style-type: none"> • Cognitive prompting tools • Audio reminder devices • Personal schedule apps • Vibrating reminder watch • Automatic pill dispenser • Blood pressure tracker

Joe A. was one of the individuals served by this project. Joe was a 28-year-old man with partial paralysis. He wanted to gain more independence with his daily tasks and recreation. The project team provided and trained Joe with AT tools that included a soap dispenser, a toothpaste dispenser, and a long-handled bath brush, all of which he could operate with just one hand. Additionally, a cellphone mount attached to his wheelchair and a "smart speaker" enabled Joe to better access his world by using his voice. He was also able to play video games with greater independence and less frustration.

Sara L. was another individual who participated in this project. Sara lives at home and has limited mobility. Once in bed, she cannot turn lights on or off or control other appliances. The team equipped her with a smart home assistant device and smart plugs for her lighting fixtures and appliances. She was able to control her environment by herself, which she said gave her a greater sense of independence and security.

This project incorporated a research component that measured two elements: (a) the performance changes in an individual with regard to the skill or goal, and (b) the satisfaction and quality of life of the individual and the engagement of the family/support person. In order to operationalize the changes in performance, the team adapted the Student Performance Profile (SPP; see Appendix A) developed by Watson et al. (2010) for use with an adult population. In order to collect data on quality of life and satisfaction, the research team was asked to develop a survey based upon the National Core Indicators (<https://www.nationalcoreindicators.org/>). This survey became known as the *Foundational Measures Survey* (Satterfield, et al., 2017; see Appendix B). The paper form of the survey was available in May of 2017. An accessible iPad app version of the survey was released for use in August of 2017.

Adapted Student Performance Profile

The team adapted the SPP (Watson et al., 2010) as a protocol for collecting pre- and post-intervention performance on skills important to the individual. This instrument was selected because it permitted the collection of outcomes data on performance changes across a range of different AT devices. Progress in the use of an adapted can opener and progress using a tablet with a communication app would appear to be very different things. However, the SPP allows the researcher to identify a task-related goal and measure the degree to which the individual can perform the task independently before, and then after, the implementation of the AT. The SPP also aids the team in examining other possible influences other than AT that may have influenced the evident progress.

Individual goals involving targeted skills or tasks were identified using a user-centered approach. A baseline measurement of an individual's ability to perform a task was taken before the AT intervention was presented. The scale was a simple 5-point Likert scale where 1 represented "not able" (successful on less than 10% of attempts), 2 represented "seldom able" (successful on between 10% and 40% of attempts), 3 represented "sometimes able" (successful on between 40% and 60% of attempts), 4 meant "often able" (successful on between 60% and 90% of attempts), and 5 represented "fully able" (successful on between 90% and 100% of attempts). The team included data collection about care provider engagement as well.

Foundational Measures Survey/National Core Indicators Survey App

The research team was charged with measuring the quality of life and satisfaction of individuals and their families in the context of the National Core Indicators (NCI; <https://www.nationalcoreindicators.org/>). Finding no NCI-based instrument designed specifically for sampling the perceptions and responses of individuals with intellectual and developmental disabilities, the team set about to design a survey that addressed the anticipated outcomes of the project via elements of the NCI. With the help of AbleLink Technologies, an accessible iPad app was created for the participants to use. The app was designed to present questions with auditory and visual support with limited text. Each of the 35 questions provided a 5-point Likert scale, where 1 was “strongly disagree” and 5 was “strongly agree”. The measure has five sub-scales representing key theoretical constructs: Relationships, Satisfaction, Self-Determination, Community Inclusion, and Health, Wellness and Human Rights. The FMS was presented twice, once pre-intervention and once post-intervention. To differentiate this instrument from the original NCI measure, it was named the Foundational Measures Survey (FMS; see Appendix B).

The app was designed to accommodate the individual participants to the greatest degree possible. If the individual could complete the survey for themselves, the team would facilitate their use of the app. If the individual was unable to complete the survey, a paper version was provided for the care provider to complete. The survey was presented at the outset of an individual's participation in the project and again at the end, providing a pre- and post-intervention view of the individual's perceptions on each of the relevant foundational measures.

Participants

The original target population was that of adults with intellectual and developmental disabilities who were on the *planning list* in Georgia and awaiting the Medicaid waiver. Participants had to be at least 18 years old and out of school, since public education is also a source for AT devices and services. The project sought to avoid any duplication of services.

Partway into the project, a subset emerged from among the target individuals. This group of individuals was comprised largely of adults with CCN. These adults were in a particularly awkward position because of their inability to address their daily communication needs effectively by speech alone. It was unclear whether participants left high school without an effective communication strategy in their transition plan, but it was evident that each one was now without a satisfactory solution for their communication challenges. At this point in their lives, there are no longer systems of support in place to pay for AAC evaluations or devices, or to provide ongoing therapy support. It is widely known that these communication challenges negatively impact multiple domains, resulting in extremely low rates of employment (McNaughton & Nelson-Bryen, 2002; 2007) and poorer health care outcomes (Helmsley & Balandin, 2014). Most significant of all is the fact that the challenges preclude access to the foundational right to communicate their hopes, dreams, needs, and wants, as well as their ability to connect with their family, friends, and community (McEwin & Santow, 2018; McLoud, 2018).

There were 180 individuals who were referred by the agency with a variety of needs (see Table 2). The team was able to reach and conduct intake interviews with 130 of the referred individuals. In all, the team

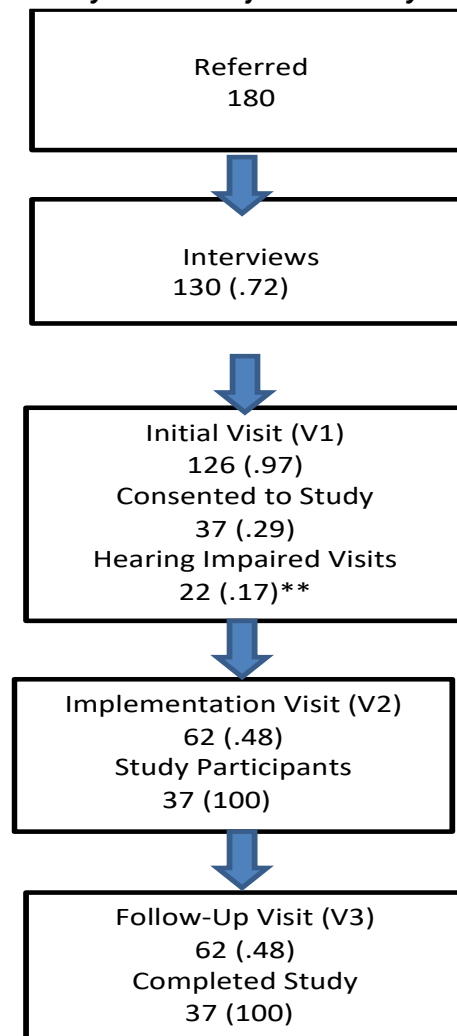
made 270 face-to-face visits, each involving two team members for a total of 440 member contacts. These visits included 126 AT consults, 62 implementation of AT visits, and 83 follow-up visits and final visits to collect endpoint data. Orders for AT products were placed for 62 participants.

Table 2: Referrals by Region by Identified Area of Need*

Referred	Communication	Mobility	Vision	Hearing	Activities of Daily Living	Cognition	None
180	135	48	24	32	54	39	15
Percent of those referred	75.0%	26.67%	14.20%	17.77%	30.00%	21.66%	8.87%

*A number of individuals were referred as having multiple areas of need.

Figure 1: DBHDD Study Flow – Project Visits* by Tools for Life Team



*Each visit involved two (2) members of the TFL team.

**Consult only, AT provided by another entity.

Of the 126 individuals the team was able to visit, there were 83 who completed the project. Of this number, 37 agreed to be research participants. Participation in the research was optional. The team provided the AT consultation, goal identification, implementation of the identified AT, and the support and training to all individuals, whether they took part in the research or not. As shown in Figure 1, 22 individuals were hearing impaired and by contract received consultations only with AT provided by another entity.

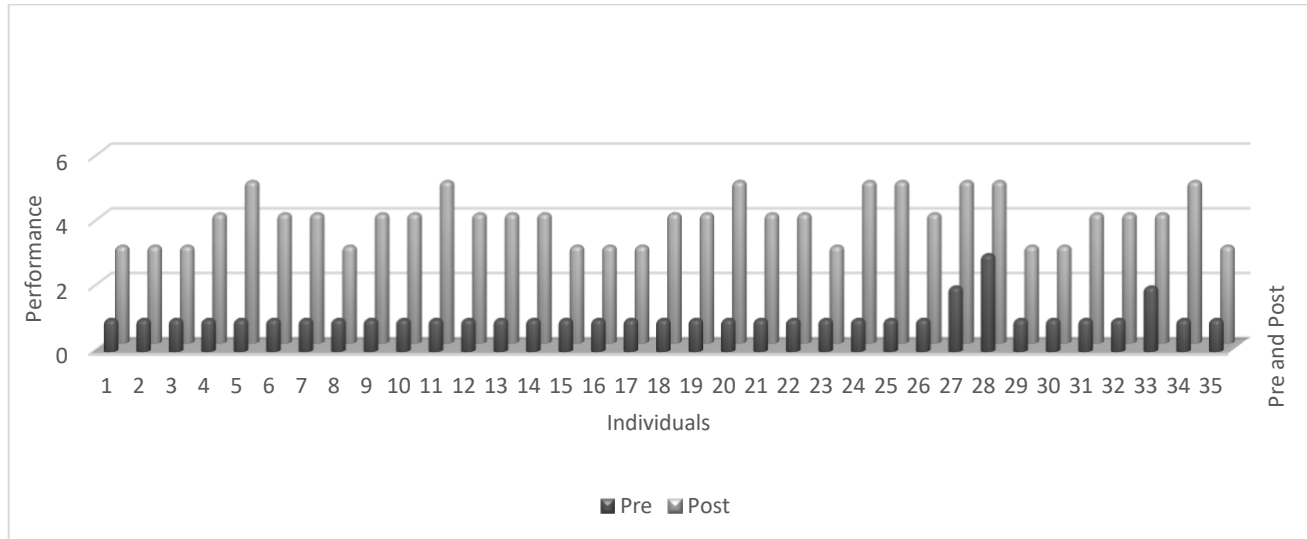
Analysis and Results

There were two research questions being explored in this project. These related to performance and satisfaction or quality of life.

Performance

The first research question asked whether the introduction of AT could help adults with developmental disabilities acquire skills or enhance the performance of tasks that were important to them. A total of 35 participants in this project had performance goals. To measure progress, the adapted SPP was administered during the initial visit and again during a follow-up visit after the AT was implemented. Every one of the 35 individuals demonstrated improved performance over the course of the project. Figure 2 presents a view of progress made by individual participants as measured by the 5-point scale provided by the SPP framework described above.

Figure 2: Performance Before and After Introduction of AT by Individual



Based upon this scale, the mean improvement for all participants was 2.83. The performance gains by disability area by the end of the project are shown in Table 3. Individuals with CCN demonstrated improved performance at slightly less than the mean (2.69) for the group.

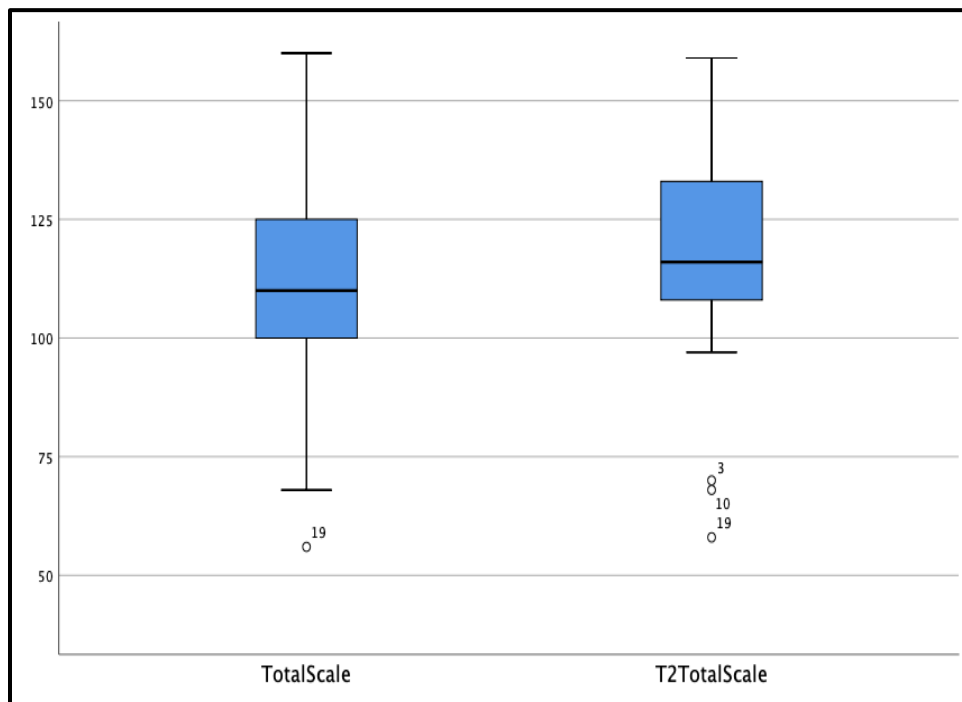
Table 3: Performance Gains by Disability Area by End of Project (scale of 1 to 5)

Area of Disability	Communication	Mobility	Vision	Hearing	ADLs	Cognition	Not Identified
Change from Baseline to Final	2.6897	2.7273	3.0000	3.0000	2.6364	3.0000	2.0000

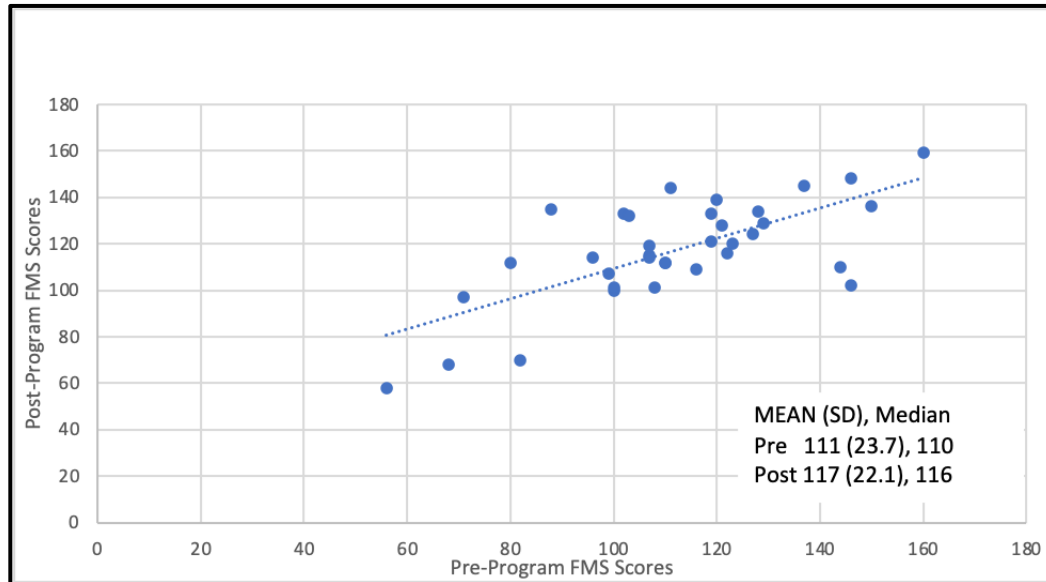
Quality of Life/Satisfaction

The second research question sought to discover whether the introduction of AT would make a difference in the individual (and family's) level of satisfaction and quality of life as reflected in the National Core Indicators (NCI). There were 35 individuals (or their care providers) who completed both pre- and post-surveys. Scores for the FMS total composite scale were computed, and the distributional properties examined suggesting non-normality and the subsequent use of non-parametric statistics. FMS scores ranged from a low of 56 to a high of 160 before the program and a low of 58 to a high of 159 after. The boxplots in Figure 3 highlight the change in the distributions of pre-post FMS scores.

Figure 3: Box Chart Comparing Pre and Post Responses to Foundation Measures Survey



A Wilcoxon Signed Rank Test (the NPar approximation of a paired *t*-test) revealed a statistically significant increase in total FMS scores following participation in the program, $z=1.98$, $p < .05$, with a medium effect size ($r = .40$). The median score on the FMS scale increased from pre-program ($Mdn = 110$) to post-program ($Mdn = 116$). Sixty-five percent of participants increased their scores following participation in the program (see Figure 4). All data analyses were performed using IBM SPSS Statistics for Macintosh (Version 27).

Figure 4: Scatterplot of Pre and Post Program Foundational Measures Survey Scores (n = 35)

Descriptive In-Depth Analysis of Individual Survey Items

We calculated change scores to further descriptively examine some of the individual survey items that changed following the introduction of AT. As shown in Figure 3, the survey items that presented perhaps the most intriguing changes were: the drop in average response to the statement “I feel lonely” and increases in the average response to the statements about helping others, liking technology, having choices regarding social media and the community, participation in self advocacy, and feeling safe at home.

Taken together, these responses indicate an elevated sense of agency and personal empowerment. The concepts of helpfulness, self-care, and self-determination are also reflected in these responses. While the individual items do not stand on their own, they do shed light on and support the significant finding of change in the FMS composite scores.

Two Items of Note. First, there were several individuals who received AT that addressed self-care (e.g., blood pressure tracker, automatic pill dispensers, etc.) that allowed or influenced individuals to monitor health conditions and to take their medications independently and appropriately. As such, the increase in the average responses to this question tends to confirm the success and the usefulness of this intervention. They also confirm the team’s recorded observations of individuals’ successes at using these tools. As this was a subset of the full group of survey respondents, the relative impact of this intervention upon the total survey result is noteworthy.

Second, our team made notes in our data collection that some individuals had difficulty with some of the vocabulary we used in specific survey questions. Some of the individuals did not appear to understand the concept of self-advocacy. Our team took time to explain this, as it is such a fundamental concept. It is possible that the fact that we emphasized this by spending extra time on it may have influenced the

result in this survey. But the relatively sizeable increase in the responses following the AT interventions is intriguing, and suggests this be studied further.

We also observed some other curious trends at the individual item level: decreases in average response to the statements regarding feeling connected with families and friends, satisfaction with the support received, and feeling respected in the day programs and at home.

The decrease in levels of satisfaction in these areas is interesting. Perhaps they are indicative of increased expectations in light of greater independence. The team came away with the sense that some individuals appeared empowered by the AT that they had been provided. We wondered if this sense of empowerment led them to recognize that something was missing in the area of self-determination. It is possible that the lower ratings on these items reflect an expression of frustration and the desire for greater autonomy. Given that care providers had now experienced the difference that the AT could make, we wonder if their eyes had been opened to greater possibilities. It is also possible that caregivers viewed the individuals in a different light, having observed their success and witnessed their expression of preferences not previously anticipated. These areas all warrant further study.

Care Provider Satisfaction and Engagement

Care providers for the individuals in this study were important stakeholders in this process. Most were family members providing unpaid support. With very few exceptions, these were very selfless and committed people. In this project, the response of the care providers was enthusiastic. Most pitched in and supported the intervention. When asked about their level of satisfaction with the AT introduced, 60% stated that they were highly satisfied, 40% reported that they were satisfied, and none reported being unsatisfied. As for the services provided by the research team, 68.57% reported being highly satisfied and 31.43% said they were satisfied. Again, none reported being unsatisfied. Results of the care provider survey are displayed in Table 4.

Table 4: Care Provider Satisfaction with Project

	Care Provider Device Satisfaction		Care Provider Satisfaction with Services	
Highly Satisfied	21	56.57%	24	64.86%
Satisfied	14	37.84%	11	29.73%
Unsatisfied	0	0.00%	0	0.00%
No Response	2	5.41%	2	5.41%

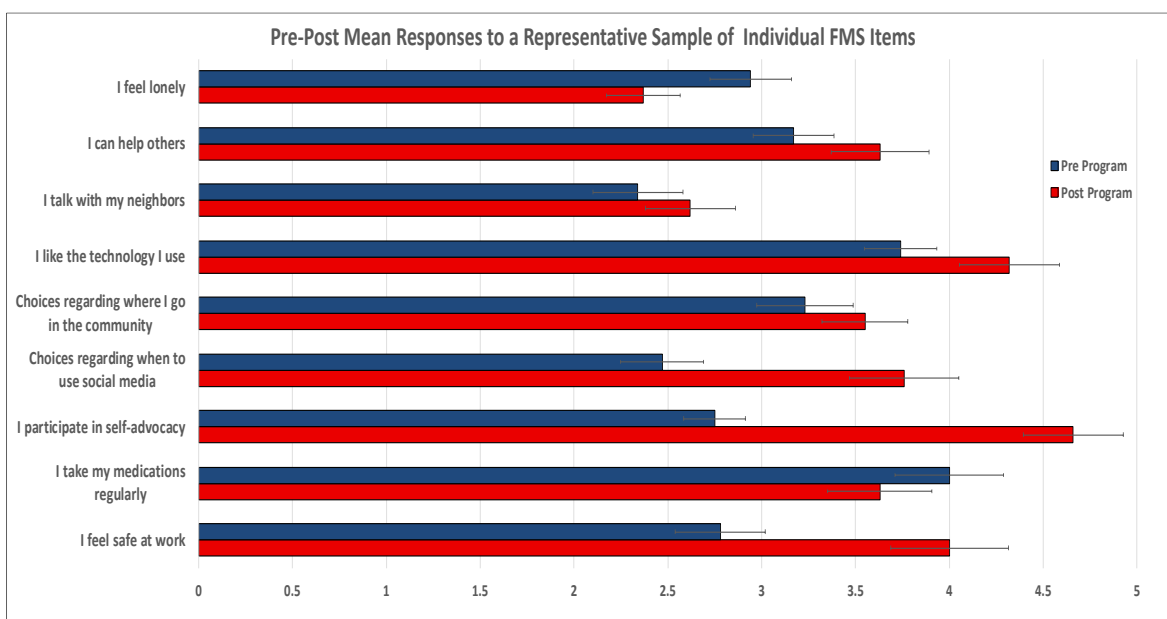
Discussion

Our study found that the individuals in our project were reflective of the profile of people with intellectual and developmental disabilities depicted in the research literature. Most were not working or attending a day program. Many were cared for by family members. Most lacked the resources to enable them to live in a more independent setting or the support to engage with their community more regularly. The majority were sitting at home and not physically active. A large proportion of them were persons with CCN who did not express their preferences and needs effectively. Because these individuals were waiting for Medicaid waiver funding to expand their options, the concept of providing AT made sense as a way to

help these individuals achieve some measure of greater independence, self-determination, or connection to their community.

The project was conducted on a person-centered basis. The focus of the AT provided and the research data collected was based upon skills and goals important to each participant. The team sought to collect data that could be gathered in such a way as to measure individual progress in terms of performance as well as to measure satisfaction and quality of life. The results from the performance data collected indicate a high degree of initial success. Every individual who had a performance goal demonstrated progress. There were several items from the Foundational Measures Survey that were found to be worthy of notice (see Figure 5). These findings indicate that participants: 1) felt less lonely, 2) felt that they were more helpful, 3) liked the technology they were using, 4) were making choices with their technology (use of social media), and 5) felt they were advocating for themselves. Other results of the Foundational Measures Survey suggest that participants felt a greater sense of independence and empowerment as well as an emerging desire to experience independence and express preferences in new areas.

Figure 5: Comparison of Pre and Post Responses to FMS for Selected Questions



CONCLUSIONS AND FUTURE STUDY

The Emergence of a Model for Serving Adults with DD

What has emerged from this project is a model for addressing the needs of adults with intellectual and developmental disabilities through the use of AT. First, the model is person-centered, in that it is built around an intervention that supports a goal of importance to the individual. Second, the model is interdisciplinary, in that it involved a team of experts across multiple domains. The TFL team consisted

of SLPs, OTs, AT practitioners, and rehabilitation counselors. The ability of the Tools for Life team to call upon experts from these different disciplines to shape a team around the needs of each individual proved invaluable and contributed to the progress observed in the individuals served.

The model suggests that an expert team working over the course of several visits to fashion and implement a customized solution and train the individual and the team to support the implementation can be effective. Such an approach can result in enhanced quality of life for the individual and their care providers. The length of the study provides no insight into long-term impacts, however. This should be examined in future studies of this model.

This study did not delve into the reasons why, out of the original 126 individuals, only 83 completed the project, or why only 37 agreed to take part in the research. Questions about what was common among those who participated, and among those who did not, could be explored and discussed as a direction for future research.

The fact that the team included speech-language pathologists was vital to the success experienced with individuals with CCN. That their communication difficulties were a central barrier to achieving their personal goals required skilled and experienced support. Some of these participants required additional visits beyond the three that were contemplated. Nevertheless, these individuals experienced similarly successful performance outcomes.

This article describes one model for delivering services to individuals with intellectual and developmental disabilities. There may be other methods of service for this group emerging. Future studies might look at what other approaches to support for this group might exist. Perhaps a hybrid method could be developed.

Limitations of This Study

This research was constrained by the resources of the sponsoring agency. The project was halted in response to mandated statewide budget cuts. As such, there was no provision for long-term follow up to see how participants' lives had evolved following the introduction of AT. It would be valuable to determine whether there was a need for follow-up support and training, whether there was continued use of the AT, and to what degree the indicators of satisfaction and quality of life in the Foundational Measures Survey were impacted.

The results of this project appear very positive. This study explored performance gains and customer satisfaction/quality of life. Gains were evident in both areas. However, the size of the sample was limited for such a diverse set of represented disabilities. A larger study, which included larger numbers of participants in each of the disability groups, or a focused study on individual disability groups, might produce more targeted insights.

The Foundational Measures Survey was developed by the research team in response to a requirement of the sponsoring agency. As the development of a tool for sampling of quality of life for people with

intellectual and developmental disabilities is an involved process (Claes et al., 2010), the use of a survey created specifically for this study should be noted as a limitation. The Foundational Measures Survey was used by many, but not all, of the participants in this study. The team suggested that a review of the survey language, looking for even more simple phrases, might be helpful in engaging more individuals in the survey app.

The research framework for this study was laid out at the start of the project before the proportion of participants with CCN was evident. The study had set out to examine the impact of AT upon the lives of the participants. While AAC is a subset of AT, there were missed opportunities to gather data regarding the specific impact of the tools provided upon the communication capabilities of these participants. Future studies might seek to gather more specific relevant impacts of AT and AAC systems provided.

It would also be valuable to do a more definitive analysis of return on investment (ROI) from this project. The cost of providing AT services and devices under this model averaged \$3464 per individual (which included travel, staff time for the interview and three visits, time for researching and costs associated with ordering the AT devices, and the AT itself—capped at \$3000 per individual). However, if future studies can explore how the individual gains impact an individual's independence and the support systems around them in the longer-term, then perhaps a means of ascribing a financial benefit can be derived. In this way, benefits can be analyzed from a financial perspective as well.

OUTCOMES AND BENEFITS

There are several outcomes and benefits from this study. This article describes a model for service delivery for adults with intellectual and developmental disabilities. These individuals have not been well served in the past. This study suggests that AT may provide a path to some measure of greater independence and self-determination.

This study points to measurable outcomes of use of AT and AAC systems with adults with intellectual and developmental disabilities that indicate improvements in individual performance and personal satisfaction. These findings should encourage families and providers to seek AT solutions that could enhance self-determination and encourage independence in the individuals they serve. These results should lead to opportunities for individuals with intellectual and developmental disabilities for growth and self-actualization.

This study revealed the significant involvement of communication in the challenges people with intellectual and developmental disabilities face. While more remains to be discovered, these results indicate that people with intellectual and developmental disabilities and CCN were able to accomplish goals that were important to them with the AT and AAC tools they received. The facilitation of generative speech and enhanced engagement with family and community are concrete first steps toward the ideal of successful and fulfilling community-based living. These outcomes should encourage the exploration of policy implications regarding broader access to AAC solutions for these adults with CCN.

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APPENDIX A. ADAPTED STUDENT PERFORMANCE PROFILE

First Visit Outcomes Questionnaire

During the initial home visit, individual goals will be explored.

Foundational Measures (FMS) Indicators

CIRCLE FMS AREA:

- | | |
|---------------------------|--------------|
| Relationships | Satisfaction |
| Self-Determination | Work |
| Community/Inclusion | Family |
| Privacy | Safety |
| Health, Welfare, & Rights | |

FMS – specific indicator/area in which individual would like to make progress

AT Objective or Goal (which addresses core indicator above):

Goal:				
Current (baseline) ability level (%)				
Not able	Seldom able	Sometimes able	Often able	Fully able
1	2	3	4	5

Legend:

- 1 **Not able** (successful on less than 10% of attempts)
- 2 **Seldom able** (successful on between 10% and 40% of attempts)
- 3 **Sometimes able** (successful on between 40% and 60% of attempts)
- 4 **Often able** (successful on between 60% and 90% of attempts)
- 5 **Fully able** (successful on between 90% and 100% of attempts)

Final Visit Outcomes Questionnaire

During the final home visit, individual goals will be evaluated.

Performance (with AT)

Goal:				
Current ability level (%)				
Not able	Seldom able	Sometimes able	Often able	Fully able
1	2	3	4	5

Legend:

- 1 **Not able** (successful on less than 10% of attempts)
- 2 **Seldom able** (successful on between 10% and 40% of attempts)
- 3 **Sometimes able** (successful on between 40% and 60% of attempts)
- 4 **Often able** (successful on between 60% and 90% of attempts)
- 5 **Fully able** (successful on between 90% and 100% of attempts)

If you feel your individual has made progress in this objective, please indicate (circle) the contribution each of these possible influences/intervention strategies may have made to that progress:

1. Assistive Technology (AT) provided by the AT team

No contribution	Some contribution	Great contribution			
1 2 3	4 5 6	7 8 9	10		

2. AT other than that provided by the AT team

No contribution	Some contribution	Great contribution			
1 2 3	4 5 6	7 8 9	10		

3. Personal assistance (e.g. aide, helper, interpreter, family member)

No contribution	Some contribution	Great contribution			
1 2 3	4 5 6	7 8 9	10		

4. Related and support services (e.g. OT, PT, SLP, etc.)

No contribution	Some contribution	Great contribution			
1 2 3	4 5 6	7 8 9	10		

5. Performance expectations changed (e.g. greater expectations to obtain success)

No contribution			Some contribution			Great contribution			
1	2	3	4	5	6	7	8	9	10

6. Natural development

No contribution			Some contribution			Great contribution			
1	2	3	4	5	6	7	8	9	10

7. Compensation for impairment by the student (e.g. use other hand if one hand is impaired)

No contribution			Some contribution			Great contribution			
1	2	3	4	5	6	7	8	9	10

8. Other: _____

No contribution			Some contribution			Great contribution			
1	2	3	4	5	6	7	8	9	10

9. Other: _____

No contribution			Some contribution			Great contribution			
1	2	3	4	5	6	7	8	9	10

Level of care provider/family member support:				
Current ability level (%)				
None	Hesitant	Willing	Engaged	Effective
1	2	3	4	5

APPENDIX B. FOUNDATIONAL MEASURES SURVEY

Relationships	Strongly Disagree	Somewhat Disagree	Sometimes	Somewhat Agree	Strongly Agree
I can visit or talk with my family and friends when I want.	1	2	3	4	5
I feel lonely.	1	2	3	4	5
I have friends.	1	2	3	4	5
I can help others.	1	2	3	4	5
I talk with my neighbors.	1	2	3	4	5

Satisfaction	Strongly Disagree	Somewhat Disagree	Sometimes	Somewhat Agree	Strongly Agree
I like my daily program/activities I do each day.	1	2	3	4	5
I like the technology I use.	1	2	3	4	5
I like where I live.	1	2	3	4	5
I am satisfied with the support I have received.	1	2	3	4	5
The technology I use helps make my life better.	1	2	3	4	5

Self-Determination	Strongly Disagree	Somewhat Disagree	Sometimes	Somewhat Agree	Strongly Agree
I make (have made) choices regarding					
• My daily schedule	1	2	3	4	5
• How I spend my free time	1	2	3	4	5
• What to buy with my money	1	2	3	4	5
• The technology I use	1	2	3	4	5
• Where I go in the community	1	2	3	4	5
• When to use the internet	1	2	3	4	5
• When to use social media	1	2	3	4	5

Community/Inclusion	Strongly Disagree	Somewhat Disagree	Sometimes	Somewhat Agree	Strongly Agree
I go out for entertainment (movies, concerts, theatre).	1	2	3	4	5
I go out for exercise or recreation.	1	2	3	4	5
I go out to dinner/for coffee.	1	2	3	4	5
I go shopping.	1	2	3	4	5

Community/Inclusion	Strongly Disagree	Somewhat Disagree	Sometimes	Somewhat Agree	Strongly Agree
I am connected to/involved as much as I want it:					
• Family	1	2	3	4	5
• Friends	1	2	3	4	5
• Neighborhood	1	2	3	4	5
• Church	1	2	3	4	5
• Recreational services	1	2	3	4	5

Health, Welfare, & Rights	Strongly Disagree	Somewhat Disagree	Sometimes	Somewhat Agree	Strongly Agree
Health					
• I engage in activity/exercise regularly.	1	2	3	4	5
• I take my medications regularly.	1	2	3	4	5
I am treated with respect					
• Day program	1	2	3	4	5
• Home	1	2	3	4	5
• In the community	1	2	3	4	5
I participate in self-advocacy	1	2	3	4	5
I feel safe:					
• At home	1	2	3	4	5
• At work	1	2	3	4	5
• At my day program/activity	1	2	3	4	5

APPENDIX C. FOUNDATIONAL MEASURES SURVEY RESULTS

Item #	Survey Item	Pre	Post	Change
1	I can visit or talk to my family and friends when I want	3.67	3.89	0.23
2	I feel lonely	2.97	2.46	-0.51
3	I have friends	3.24	3.59	0.36
4	I can help others	3.14	3.59	0.46
5	I talk with my neighbors	2.31	2.62	0.32
6	I like my daily program and the activities I do each day	4.38	4.11	-0.27
7	I like the technology I use	3.85	4.19	0.34
8	I like where I live	4.40	4.19	-0.21
9	I am satisfied with the support I have received	4.62	4.32	-0.30
10	The technology I use helps make my life better	3.94	4.14	0.20
11	I make or have made choices regarding my daily schedule	3.61	3.68	0.06
12	I make or have made choices regarding how I spend my free time	4.00	3.81	-0.19
13	I make or have made choices regarding what to buy with my money	3.20	3.24	0.04
14	I make or have made choices regarding the technology I use	3.69	3.70	0.01
15	I make or have made choices regarding where I go in the community	3.22	3.49	0.26
16	I make or have made choices regarding when to use the internet	3.36	3.59	0.23
17	I make or have made choices regarding when to use social media	2.45	3.06	0.61
18	I go out for Entertainment (movies, concerts, theatre)	3.53	3.54	0.01
19	I go out for exercise or recreation	3.86	3.68	-0.19
20	I go out to dinner or for coffee	3.63	3.92	0.29
21	I go shopping	4.00	3.78	-0.22
22	I am connected to my family	4.67	4.38	-0.29
23	I am connected to my friends	3.80	3.70	-0.10
24	I am involved as much as I want in my neighborhood	2.97	3.08	0.11
25	I am involved as much as I want in my church, synagogue or mosque	3.19	3.47	0.28
26	I am involved as much as I want in recreational services	3.26	3.32	0.07
27	I engage in activity/exercise regularly	3.46	3.68	0.22
28	I take my medications regularly	4.00	4.29	0.29
29	I am treated with respect at my Day Program	3.58	3.52	-0.07
30	I am treated with respect at my Home	4.72	4.57	-0.15
31	I am treated with respect in the community	4.23	4.42	0.19
32	I participate in self-advocacy	2.79	3.29	0.51
33	I feel safe at home	4.65	4.73	0.08
34	I feel safe at work	2.71	3.04	0.32
35	I feel safe at my day program/activity	3.84	3.73	-0.12

N=37; two (2) failed to complete second survey.