

Project Summary

**Tools for Life Assistive Technology (AT)
Services for Georgia DBHDD
April 2017 – November 2019**

Origins of the Project

In June of 2016 Carolyn Phillips, Director of Tools for Life (TFL) and Nicki Wilson Cline, the Family Support Manager for the Georgia Department of Behavioral Health and Developmental Disabilities (DBHDD) began to explore a potential collaboration to test the efficacy of assistive technology (AT) as a way to address specific needs of adults with developmental disabilities. Specifically, DBHDD manages a Planning list of Georgians with Developmental Disabilities who are waiting for access to the Medicaid Waiver Program. Tools for Life, as the Tech Act Agency for the state of Georgia, serves all Georgians, all ages and all disabilities with information and guidance with regard to AT that can help them live, learn, work and recreate in the community of their choice.

As the project was originally envisioned, DBHDD Plan List Administrators and Navigators would make referrals to TFL of individuals who might benefit from AT. TFL would provide training to assist the DBHDD staff as to how to identify and refer such individuals. The original plan anticipated 325 individuals being referred.

Person Centered Approach

The project was conceptualized as taking a person centered approach. Once an individual was referred, the team at TFL would then conduct an interview to learn more about the individual and then meet with the individual at least twice with the intent to focus upon a goal and skill that was very important to them. The first visit would be to conduct an AT consult and determine a skill or goal that they wanted to work upon that AT could address. The second session was to deliver and implement the AT that would help address this goal or skill. Visits with individuals were to be conducted in their homes to provide a natural setting that would be comfortable for the individual and instructive to the team.

It was decided that this project should incorporate a research component that would measure two elements: 1) the performance changes in the individual with regard to the skill or goal, and 2) the satisfaction of the individual and family/support person as reflected in the National Core Indicators (NCI). The research team developed a survey based upon the NCI which became known as the *Foundational Measures Survey*. The paper form of the survey was available in May of 2017. The iPad app version of the survey was released for use in August of 2017.

Georgia Tech and DBHDD approved the details of a contract in April of 2017. Shortly thereafter Tools for Life launched a “referral portal” through which PLAs could refer individuals to the program. The first referrals appeared in May of 2017.

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). Finding no NCI-based instrument designed specifically for sampling the perceptions and responses of individuals with 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, a survey consisting of 35 questions was framed and an app designed to present questions with auditory and visual support and

limited text. To differentiate this instrument from the original NCI we called it the “Foundational Measures Survey”. The contents of the survey are presented in appendix A.

The app was designed to accommodate the individual participants to the greatest degree possible. If the individual could complete the survey for themselves, we sought to 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.

DBHDD Staff Training

As part of this project, a series of six training and public awareness events were planned with the goal of reaching 600 individuals and DBHDD staff. The focus of the training events was about the nature of the project as well as the potential value of AT. Several events were scheduled specifically for the DBHDD plan administrators (PLAs) and navigators of the projects features, and to inform and encourage them with regard to referring individuals on the planning list to Tools for Life as candidates for the project. A set of trainings were provided that were open to all PLA’s. Other sessions were to smaller groups at the local region level.

As part of the training and awareness aspect of the project a number of other events were scheduled to help to promote awareness of the project among individuals and their families and to broaden the understanding of assistive technology (AT). In all a total of 14 events were held and 952 individuals were presented with the information about the project.

Target population

The original target population was that of adults with Developmental Disabilities who are on the planning list in Georgia and awaiting the Medicaid waiver. Participants would be at least 18 years old and out of school – since public education is also a source for AT items and the project sought to avoid any duplication of services.

Part way into the project, a second group of target individuals was presented. This group (referred to as the “Belton Group”) consisted of individuals who were deaf or hard of hearing. Some of these individuals also presented with other disabilities as well. Once again, these individuals were over 18. But many of this group would require sign interpreters. Twenty of these individuals were referred as part of a pilot sub-project to see how AT recommendations might benefit these individuals. Reports on the AT Consults were provided for these individuals, but the recommended AT for these individuals was to be provided elsewhere.

Table 1 presents a breakout of the referrals by type of disability. Of the 180 individuals referred to Tools for Life, the vast majority were identified as having complex communication needs (CCN). This consisted of two groups of referrals: (1) those with communication needs (135 / 75%) and those with a hearing challenge (32/ 17.77%). There were 54 individuals (30%) whose greatest need was deemed to be activities of daily living, 48 individuals (26.67%) with mobility issues, 39 individuals (21.66%) with

cognitive challenges, and 24 referred (14.20%) with vision issues. There were 15 (8.87%) who were referred without any identified area of need.

Table 1. 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
% 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.

While the presence of individuals with CCN was not unexpected, the preponderance of individuals with CCN was surprising. After accounting for the number of referrals with multiple areas of need, the total number referred with CCN was 135 (75%). There were others who presented with CCN despite being referred as having a greater need in another area.

Unforeseen challenges

The project encountered a number of unforeseen challenges.

Preponderance of referrals with CCN. The fact that 135 out of 180 referrals (75%) were individuals with CCN had a marked impact upon this project. This forced a realignment of staffing which would allow TFL to bring expertise in the area of communication to bear upon the communication challenges these individuals faced. A second Speech Language Pathologist (SLP) was added to the team to help address the number of individuals with CCN. This may also be indicative of a perception of AT by the PLAs and Navigators, who were making referrals, that AT consists primarily of Augmentative Communication solutions.

Limited referrals. In all, 180 individuals were referred to TFL by DBHDD – well short of the anticipated 325. Of those who were referred, there were many who were not actionable. There were 19 referrals that were ineligible due to age or waiver status. Another 18 were unreachable (contact information was not current or incomplete) and 21 declined our services.

Three visits instead of two - The combination of research requirements and the complexity of the needs of the individuals being served made it clear almost immediately that at least 3 visits would be required rather than 2. For those participating in the research 2 visits provided inadequate spacing for the collection of baseline data, implementation of an intervention, and then collection of data post intervention. There were some individuals who could only tolerate short periods of time working with a team member. This forced the team to make as many as 5 trips to see some individuals.

Two team members per visit - The necessity to provide services in the home elicited concerns about the appropriateness of in-home visits by a single team member. The University advised Tools for Life to send two team members on in-home visits. In fact, the team quickly discovered that many situations required a combination of skill sets which spanned multiple domains. This further obviated the need for two

team members to make a visit. For instance, there were some individuals with mobility challenges and CCN that required the collaboration of an OT and an SLP. Further as the team analyzed the breadth of things to accomplish on each visit, they determined that having two team members working with the participant and the care provider simultaneously allowed them to complete their work in about two hours per visit. Sending a single team member would have likely resulted in more visits of longer duration.

Complexities of scheduling visits – The team also discovered that there were many challenges to scheduling visits with the individuals referred. Families of individuals with developmental disabilities often have many things going on and challenges that hamper scheduling. The team had an overall goal to maximize the value of visits and to try to be good stewards of the travel funds. The team tried to insure that they could schedule visits with multiple participants on each trip. Thus it took time to catch up with folks and work out schedules that suited everyone. It was understandable that unforeseen situations would arise that would force rescheduling of trips. Notably several individuals or family members experienced hospitalizations, causing some extended delays of visits. Also there were at least 2 weather events that caused extended postponements of planned visits.

Interesting discoveries

This target population (adults with developmental disabilities) is a particularly underserved population. They possess few resources: most do not work and while they may be eligible for SSI funds and Georgia Medicaid, they typically do not have the resources to afford to live in a group home setting or to attend a day program on a regular basis. Most are living with family members who, themselves are not paid for providing support.

This set of referred individuals was comprised largely (75%) of adults with CCN. Adults with CCN find themselves in a particularly awkward position. These individuals are unable to communicate their needs, wants, and preferences effectively. Almost all left high school without an effective communication strategy in their transition plan or without a satisfactory solution for their speech challenges. At this point in their lives, there are no longer any systems set up to pay to obtain AAC or to provide therapy support. Their communication challenges impact them in very negative ways, especially in regards to extremely low rate of employment (McNaughton & Bryen, 2002; 2007) and poorer health care outcomes (Helmsley & Balandin, 2014).

Accomplishments:

The TFL team attempted to contact all of the 180 individuals who were referred. However, many were discovered to be ineligible or proved to be unreachable. The team did conduct 130 intake interviews with 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, 22 of which were consults for individuals with hearing impairments, 62 implementation of AT visits, and 83 follow up visits and final visits to collect endpoint data. Orders for AT product were placed for 62 participants. This activity is presented in Table 2.

Table 2. DBHDD Project Visits* by Tools for Life Team

Referred	Interviews	Initial Visit	2nd Visit Implementation	3rd Visit & Follow up	Hearing Impaired visits**
180	130	126	62	61	22

* Each visit involved 2 members of the TFL Team.

** By contract, hearing impaired individuals received consult only, AT to be provided by another entity.

Research

Of the 126 individuals TFL visited, there were 63 individuals who agreed to take part in the research and who remained in the project. Of the 83 that completed the project, 35 were research participants. It should be noted that the 22 deaf/hard-of-hearing group (those who were complete) were not research participants.

There were two research questions being explored in this project:

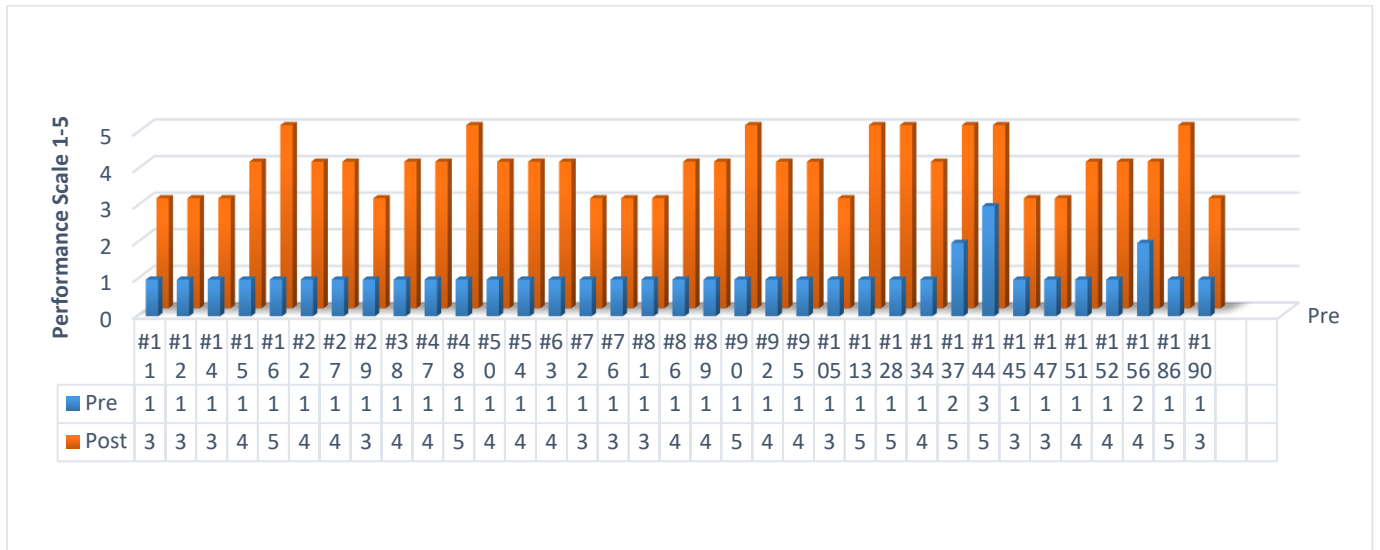
Performance -The first research question asked whether the introduction of AT could help adults with developmental disabilities acquire skills or enhance the performance of tasks that were important to them. In order to operationalize this the team adapted the Student Performance Profile (SPP) developed by Watson, Ito, Andersen, & Smith (2006). This framework allowed for the selection and measurement of goals that might be very different among participants. A goal involving some targeted skill or task was identified using a user-centered approach. A baseline measurement of the individual’s ability to perform that 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). After the AT was implemented a follow up visit was made to assess the participant’s ability and was rated upon the same scale.

Quality of Life/Satisfaction -The second 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). A Foundational Measures Survey consisting of 35 questions that were based upon the NCI was developed. Each question provided a 5 point Likert Scale where 1 was “strongly disagree” and 5 was “strongly agree”. The same survey was presented twice, once pre-intervention and once post-intervention. An accessible iPad app was created for the individuals with developmental disabilities to use. This app provided visual and auditory supports and employed very limited text to present the questions. If the individual could not complete the survey, a printed version of the survey was used with the care provider.

Research Results and Analysis

Performance data – The performance data collected during this project indicated that every individual whose goal had to do with a skill or task demonstrated gains when performance following the introduction of AT was compared to performance prior to receiving AT. Chart 1 presents a view of progress made by participants as measured by the 5-point scale provided by the SPP framework described above.

Chart 1. Performance before and after introduction of AT



When we examine the progress demonstrated by area of disability, it appears that those identified as having Vision, hearing and cognitive challenges demonstrated the most progress: 3.0 points in each case. Individuals with mobility challenges improved by an average of 2.73 points, and those with communication challenges improved an average of 2.69 points. Those who were referred without an area of disability identified improved at an average rate of 2.0 points. These results are presented in Table 3.

Table 3. Performance gains by disability area by end of project (scale of 1 – 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

Survey Insights - To measure participant satisfaction and the project’s impact upon quality of life in the context of the National Core Indicators, a Foundational Measures Survey was created and administered to research participants. There were 30 individuals (or their care providers) who fully completed both pre and post surveys. The mean (average) of the pre-intervention surveys results were compared with that of the post-intervention survey results. A single tailed T-Test was conducted to determine the significance of each set of responses. Results of the comparisons for each question are presented in Appendix B.

The survey results which presented the greatest statistical significance were:

- 1) the drop (-0.5128 points) in the average response to the statement "I feel lonely."
- 2) The increase (0.4557 points) in the average responses to the statement "I can help others"
- 3) The increase (0.3415 points) in the average responses to the statement "I like the technology I use"
- 4) The increase (0.6100 points) in the average responses to the statement "I make or have made choices regarding when to use social media"
- 5) The increase (0.5062 points) in the average responses to the statement "I participate in self advocacy"

These responses suggest a greater sense of independence among participants reflected in certain choices they are able to make. These results further suggest a greater sense of freedom to access their community, and a reduced sense of isolation.

There were other survey results which, while not reaching the level of significance suggest some other possible impacts of AT.

- The increase (0.2643 points) in the average responses to the statement, "I make choices regarding where I go in the community".
- The increase (0.3362 points) in the average responses to the statement, "I talk with my neighbors".
- The increase (0.3843 points) in the average responses to the statement, "I take my medications regularly."
- The increase (0.3228 points) in the average responses to the statement, "I feel safe at work."

These responses indicate an elevated sense of agency and personal empowerment. The concepts of helpfulness, self-care, and self-determination are reflected in these responses. While these results do not stand on their own they do support the more significant findings mentioned above.

Two items of note. First, there were several individuals who received AT that addressed self-care (blood pressure tracker, automatic pill dispensers) that allowed or influenced individuals 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 and confirm the team's recorded observations of the individual's success 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 curious trends:

- The drop (-0.1008) and (-0.2278) respectively in the average response to the statements regarding being connected with families and friends.
- The drop (-0.3448) in the average response to the statement “I am satisfied with the support I have received.”
- The decrease (-0.2037) and (-0.0924) respectively in the average response to the statement that Individuals feel respected in the day programs and at home.

The decrease in levels of satisfaction in these areas, while not statistically significant, is interesting. Are we seeing Increased expectations in light of greater independence? The team came away with the sense that some individuals appeared empowered by the AT they have been provided. We wondered if some individuals perhaps realize something of what they have been missing in the area of self-determination and are expressing frustration and the desire for greater autonomy? With regard to care providers, having now seen the difference that the AT provided has made, we wonder if their eyes have been opened to greater possibilities? As they observe these individuals expressing preferences not previously anticipated, do the care providers see their individuals in a different light? These are questions for further study.

Care provider satisfaction

Care providers for the individuals in this study were important stakeholders in this process. Most are 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. None reported being unsatisfied. With regard to the services provided by our team, 68.57% reported being highly satisfied and 31.43% said they were satisfied. Again, none reported being unsatisfied.

Table 4. Care provider satisfaction with project

	Care provider Device Satisfaction		Care provider satisfaction with services	
Highly Satisfied	21	60.00%	24	68.57%
Satisfied	14	40.00%	11	31.43%
Unsatisfied	0	0.00%	0	0.00%

The Emergence of a Model for Serving Adults with Developmental Disabilities

What has emerged from this project is a model for addressing the needs of adults with developmental disabilities employing AT. Specifically, the model is built around an intervention which supports the identification of a person-centered goal and engages a team of AT experts from a range of disciplines. The TFL team consisted of Speech Language Pathologists, Occupational Therapists, AT Practitioners, and

Rehabilitation Counsellors. The ability of the team to draw from these different disciplines to shape a team around the needs of the 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 a solution and train the individual and the team to support the implementation can be effective. The length of the study provides no long term data however. This should be examined in future studies of this model.

The results appear very positive. This study explored performance gains and customer satisfaction/ quality of life. Gains were evident in both areas. What is lacking is a more definitive analysis of return on investment (ROI) from this project. The cost of providing AT services under this model (average \$3464/ individual) is somewhat expensive. However, if future studies can explore how the individual gains impact the support systems around them, then perhaps a means of ascribing a financial benefit can be derived. In this way the short and long term benefits can be analyzed from a financial perspective as well.

Appendices

Appendix A. Foundational Measures Survey

	Strongly Disagree	Somewhat Disagree	Sometimes	Somewhat Agree	Strongly Agree
Relationships					
I can visit or talk with my family & 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					
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					
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					
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
I am connected to/ involved as much as I want in:					
• 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					
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