

A Model for Serving Adults with Complex Communication Needs

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CREATING THE NEXT®



Learning Objectives:

- Describe the conditions in which many individuals with developmental disabilities find themselves once they turn 22 years old and age out of the school system.
- List 3 reasons why individuals who have complex communication needs are at risk without an effective means of communication once they reach age 22.
- Identify at least one implication from this discussion that informs what might be done in K-12 and the Transition process to better serve individuals with developmental disabilities.

Timeline:

- Project conceptualized - June 2016
- GIT Institutional review Board – Aug. 2016
- Natl. Core Indicators Survey – Oct. 2016
- Referral Portal created – Mar. 2017
- Contract signed – Apr. 2017
- Natl. Core Indicators Survey App – Aug. 2017
- First Referrals - May 2017
- First DBHDD Staff Training – Aug. 2017
- No cost extension of contract – July 2018
- Contract was discontinued due to state budget cuts – November 2019

Who Were We Serving? ⁽¹⁾

Adults with developmental disabilities:

- Age 18 or older (out of school)
- Not employed
- Typically no individual resources
- Living with non-paid supports
- Limited family resources
- On the planning list (no waiver as yet)
- Eligible for basic GA Medicaid
- Possibly receiving SSI
- Possibly connected to Family Support
- Few have any AT

What Do We Know About Individuals with CCN? ⁽²⁾

75% of referrals are people with complex communication needs (CCN).

- 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.
- Extremely low rate of employment (McNaughton & Bryen, 2002; 2007)
- Poorer health care outcomes (Helmsley & Balandin, 2014).

Individuals with CCN:

- Require communication system + additional supports in order to be successful.
 - Require multiple visits/ support phone calls
 - Require additional training & support
 - Strategies for implementation
 - Create customized materials
- Individuals have no effective financial means by which they could access these speech services and supports until they are granted a waiver.

What Was Accomplished?

Accomplishments:

- 180 Individuals contacted
- 130 Interviews
- 270 Face-to-face visits
- 126 AT and AAC consults
- 62 have received AT and been trained
- 83 Individuals completed

Model for Service Delivery

Person Centered

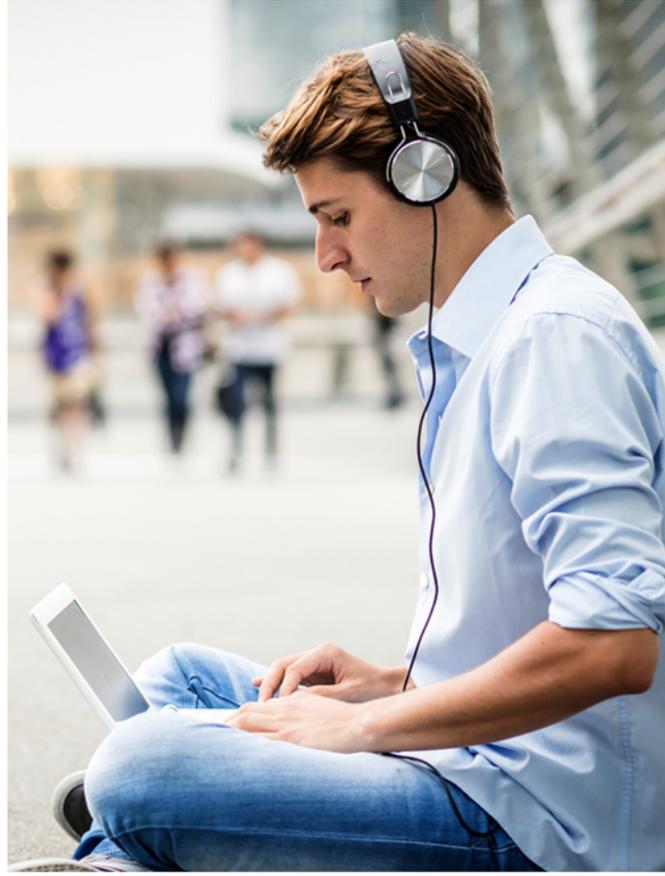
- Goal- directed

Multi-Disciplinary

- SLP
- OT
- AT Specialists
- Rehab

Evidence-Based/ Reality Grounded

- Focused on individuals with disability & families/ care providers
- Drew from a team with wide ranging skills within AT and beyond. Team was appropriate for each individual
- Project did not replace or supplant other services or funding
- No cost to participants



WHAT KINDS OF AAC/ASSISTIVE TECHNOLOGY?

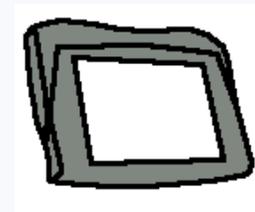
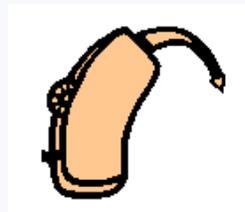
Assistive Technology Defined

“Any item, piece of equipment or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.”

(Code of Federal Regulations [CFR], 34 CFR § 300.5)

To facilitate: mobility, play, environmental control, access, communication, participation, etc...

» Ronski, et al. (2000)



Assistive Technology Services



Any service that directly assists a child with a disability in the selection, acquisition, or use of an assistive technology device....

(Code of Federal Regulations [CFR], 34 CFR § 300.6)

Includes evaluation in customary environment, coordinating services such as those associated with existing education plans and programs, training and technical assistance for professionals.

Why Assistive Technology?

“For a person without a disability, technology makes things easier.

For a person with a disability, technology makes things possible....”



Modified from: Mary Pat Radabaugh, *Director of IBM National Support Center for Persons with Disabilities*, 1988

Assistive Technology Device

...any item, piece of equipment or product that is used to increase, maintain or improve functional capabilities of individuals with disabilities.

- Public Law 105-394 [29 USC 2201]

Low/No-tech

- pencil grip
- adapted books
- slant board
- highlighters, tape
- magnifiers
- color coding
- read to out loud
- picture schedule
- strategies for memory
- colored transparencies
- Proof readers
- note taker

Mid-Tech

- word prediction
- text to speech
- speech to text
- spell checkers
- talking calculators
- digital recorders
- organizers
- e-books
- adapted keyboard
- adapted mouse
- adapted toys
- CCTV
- apps under \$100

High-Tech

- computer/laptops
- tablets/phablets
- smartphones,
- smart pens
- OCR scanner/software
- magnification software
- speech output devices
- switch, joystick access
- scanning access
- voice recognition
- environmental control devices
- apps over \$100

Types of Communication Systems Considered

Communication Systems

Low Tech:

Symbols

Communication boards, wallets, rings etc.

Mid Tech:

Single Message

Static Display Devices

Multi-Level/Configuration Devices

High Tech:

Communication Apps on Tablet



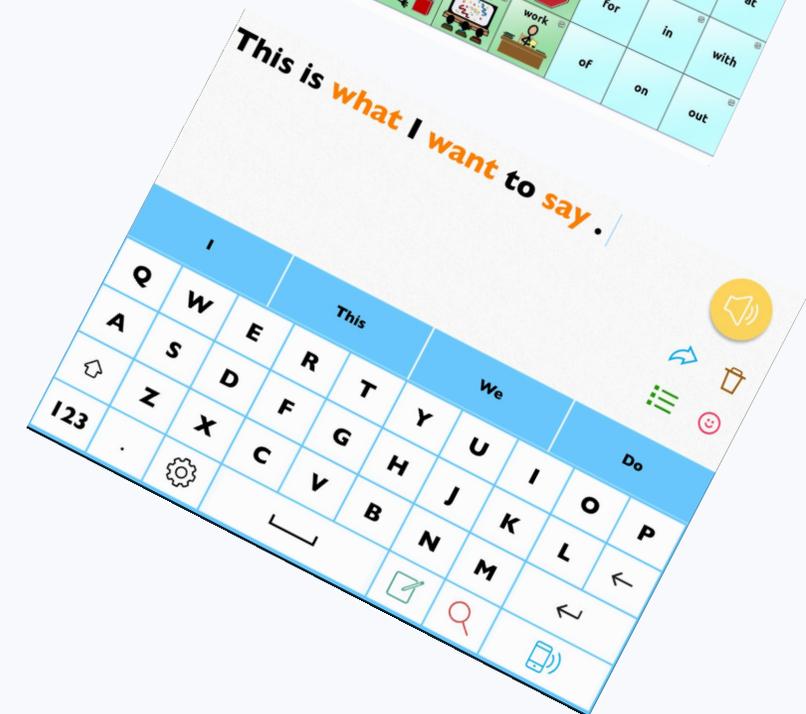
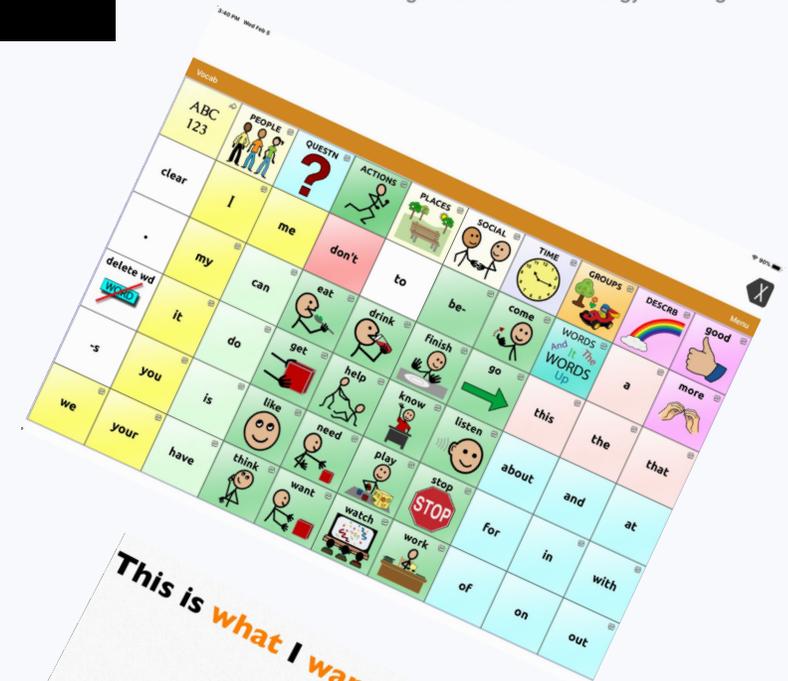
Communication Everywhere: Low Tech

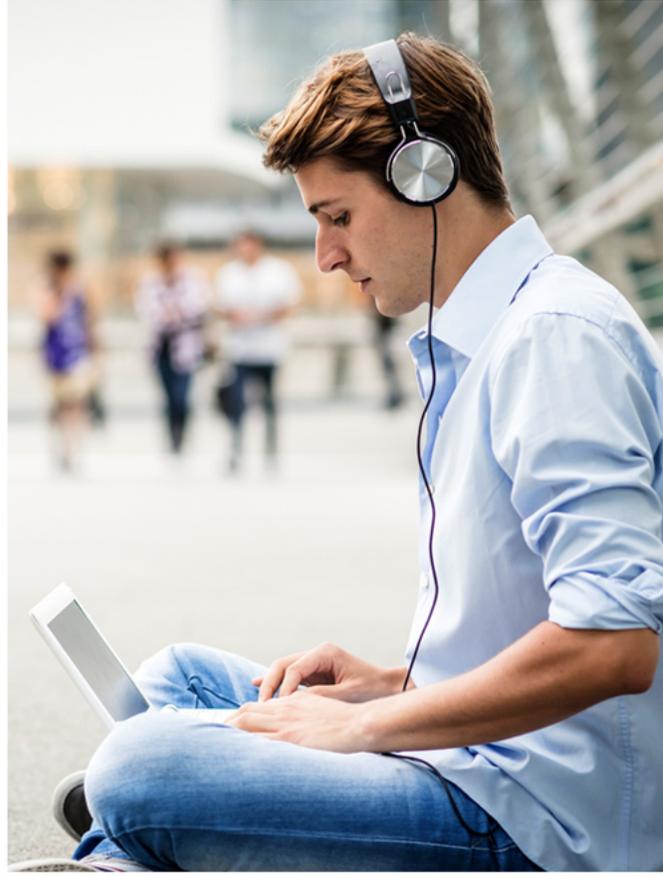
- **Low-Tech Options:**



Communication Everywhere: Hi-Tech

- **Communication Apps:**





AUGMENTATIVE COMMUNICATION CONSULTATIONS

Individuals were referred by DBHDD Planning List Administrators

- Referrals were checked for eligibility
- Initial contact was made with family/caregivers
- Number of visits varied

Visits were conducted to:

- Determine assistive technology/AAC needed
- Identify focused goal for use of AT/AAC
- Train individual/family/caregiver on AT/AAC selected
- Review individual's progress in using AT/AAC
- Transfer ownership of AT/AAC successfully used to individual

Challenges for Successful AAC Implementation:

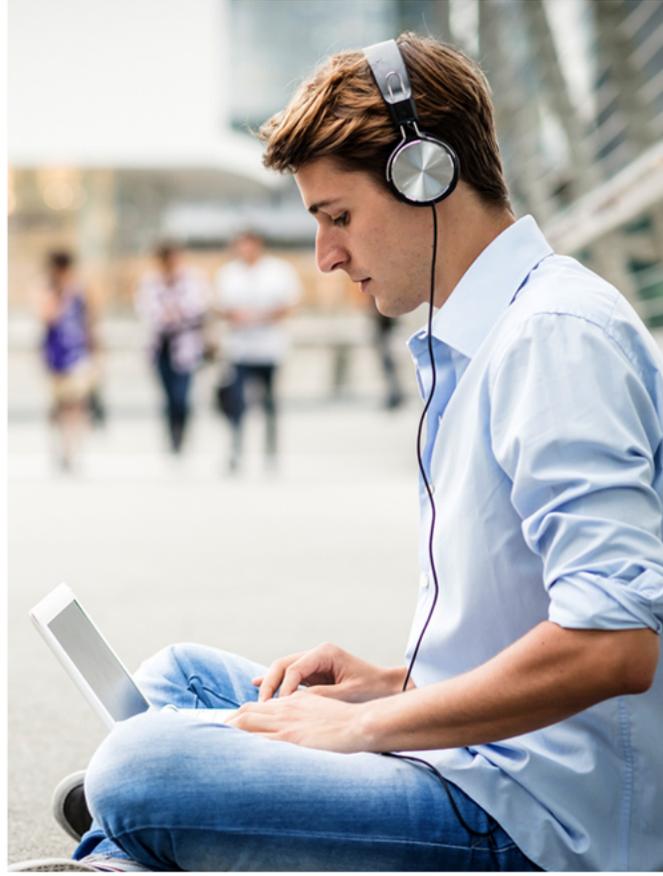
- Individuals needing AAC often required additional visits to train and support implementation of systems
- Limited ability for long-term follow-up
- Limited professional resources/support for adults
- Ability of family/caregivers to support AAC user in implementation

Strategies to Address Challenges:

- Select a focused goal that was highly desired by individual to help ensure initial success with system
- Train family and caregivers in modeling AAC use
- Provide online resources for programming/strategies
- Utilize AAC systems that can be supported by family/caregiver

Questions for Further Research

- Are there other models of AAC implementation for adults?
- Research support networks for individuals with CCN and their families/caregivers.
- Research the effectiveness of the transition process from secondary schools to communities/home environments.
- How can we ensure that individuals with CCN transition into the community of their choice with needed AAC equipment, supports and/or resources?
- What are the long term impacts of this program?



ASSISTIVE TECHNOLOGY CONSULTATIONS

Smart Home Technology



Amazon Echo

- Speech-controlled speaker system
- Voice recognition - further distances
- Controls systems and appliances around home
- Set up reminders for daily "routines"
- Can be operated via AAC devices

Cognitive Support

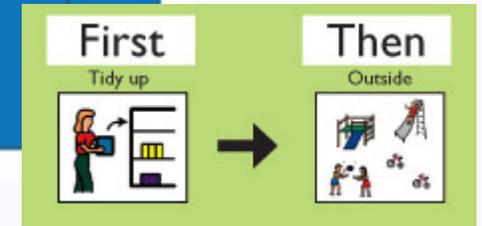
Helping to Build Independence for :

- Individuals with Intellectual and Developmental Disabilities
- Individuals with Traumatic Brain Injury
- Individuals experiencing problems with memory
- Anyone learning a complex or difficult task

Functions of Cognitive Support

- Alert a person
- Give information in manageable increments
- Give personalized directions
- Give feedback about performance

Cognitive Support – AT Examples



- 5 **I can't stand this and ready to explode.**
I want to hit someone, something, or throw something. I need an adult to help me go to a safe place so I can calm down.
- 4 **I am getting too angry.**
My brain isn't working clearly. I might say or do something I will be sorry for later. I need to go to my safe place to calm down.
- 3 **I am getting really irritated.**
I need to walk away from a bad situation. I will tell my teacher that I need a break.
- 2 **I am doing OK.**
I'm not pleased, but I'm not upset. I can stay where I am and keep working. I can control my anger by myself.
- 1 **I am doing great.**
I feel good about myself and about what is going on around me.



Low Tech Cognitive Support

Low Tech Cognitive Support: for grocery store clerk with developmental disabilities (DD)



Good



Reduce Price



Remove

Take proactive steps BEFORE incidents occur:

- Awareness of safety needs is key
- Home modifications or adaptations can reduce the amount of care required
- Protection in place for individual and caregiver to avoid injury, burn-out
- Increase independence of individual is empowering and a “win-win”!

Non-Slip Placemat

- Keep plates and other items from moving
- Use on roller walkers
- Cut to fit



Freedom wand

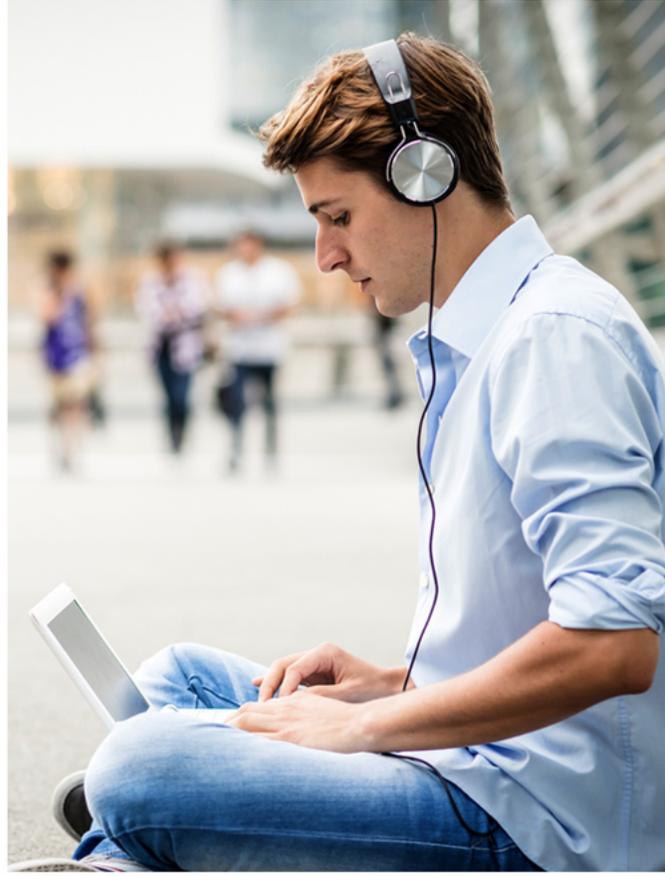
- toilet aid



Freedom Dinnerware

- Low vision, Alzheimer's, Arthritis, stroke
- Suction keeps plate from moving
- Helps with getting food on utensils

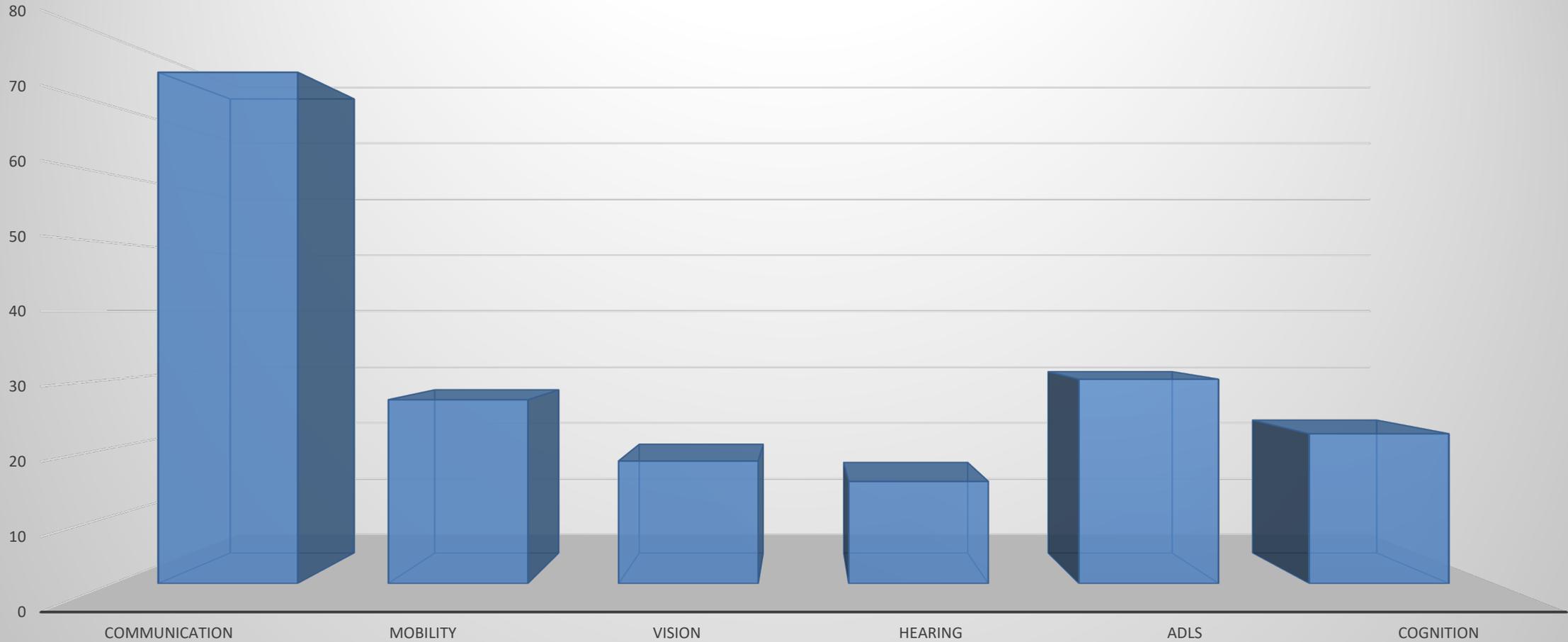




RESEARCH: OVERVIEW

Participants by Area of Need

Participants by Area of Need

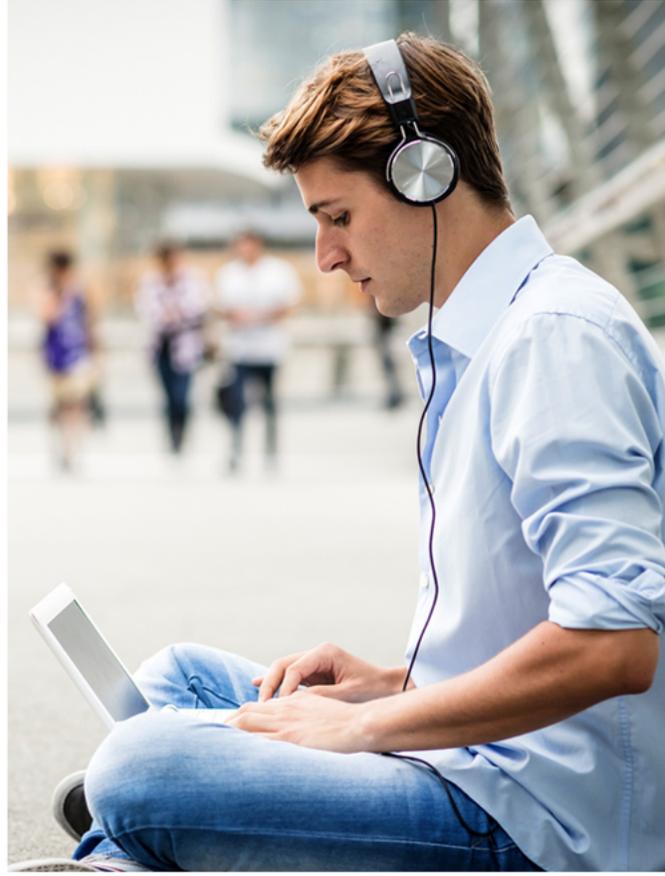


	Communication	Mobility	Vision	Hearing	ADLS	Cognition
Series1	75	27	18	15	30	22

Research: Complete

Referred	Communic.	Mobility	Vision	Hearing	ADLs	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%

Note: Some participants were identified with more than one issue.



RESEARCH: PERFORMANCE

Performance Measures –

- 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.
- Measurement of the individual's ability to perform that task was taken before the AT intervention and again afterwards.
- The scale was a simple 5 point Likert scale.

Outcomes Questionnaire (pre & post)

Goal:

Current ability level (%)

Not able	Seldom able	Sometimes able	Often able	Fully able
1	2	3	4	5

Adapted the Student Performance Profile (Watson, Ito, Smith, & Andersen, 2010)

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: Other Influences

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

None	Low contribution				Some	Great contribution				
0	1	2	3	4	5	6	7	8	9	10

2. AT other than that provided by the AT team

None	Low contribution				Some	Great contribution				
0	1	2	3	4	5	6	7	8	9	10

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

None	Low contribution				Some	Great contribution				
0	1	2	3	4	5	6	7	8	9	10

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

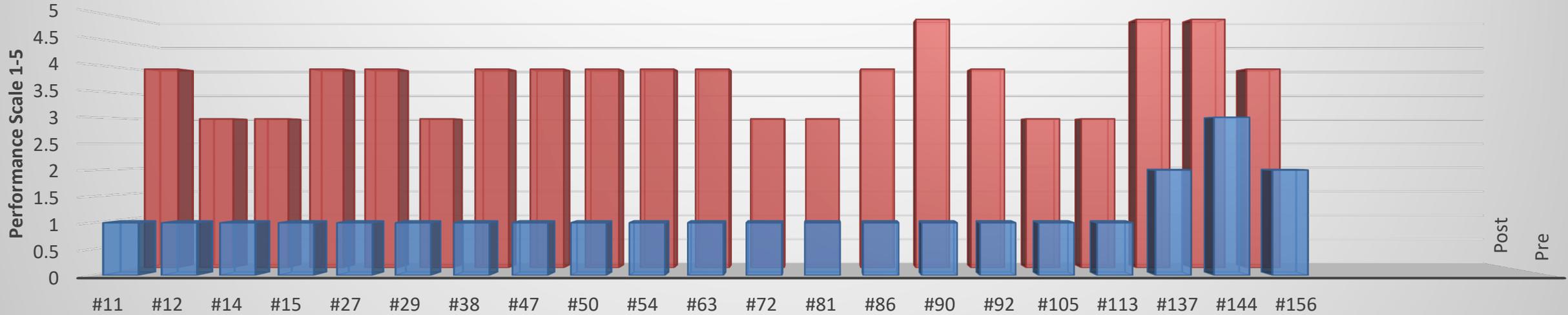
None	Low contribution				Some	Great contribution				
0	1	2	3	4	5	6	7	8	9	10

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

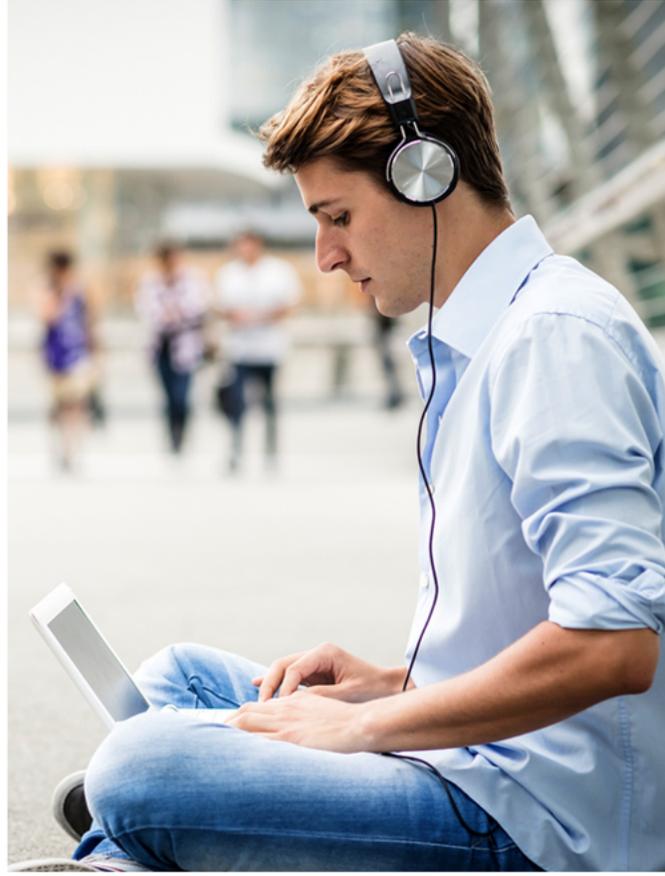
None	Low contribution				Some	Great contribution				
0	1	2	3	4	5	6	7	8	9	10

Research: Performance Results (3)

Performance Before and After Introduction of AT



	#11	#12	#14	#15	#27	#29	#38	#47	#50	#54	#63	#72	#81	#86	#90	#92	#105	#113	#137	#144	#156				
Pre	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	2	3	2				
Post	4	3	3	4	4	3	4	4	4	4	4	3	3	4	5	4	3	3	5	5	4				



RESEARCH: QUALITY OF LIFE/SATISFACTION

Survey to Measure Quality of Life & Satisfaction

Quality of Life Measures –

- A 35 question Foundational Measures Survey (FMS) was developed based upon the National Core Indicators.
- Survey was presented pre-intervention and once post-intervention.
- An accessible version of the survey (iPad app) was created for the individuals with developmental disabilities to use.
- If the individual could not complete the survey, a printed version of the survey was used with the care provider.

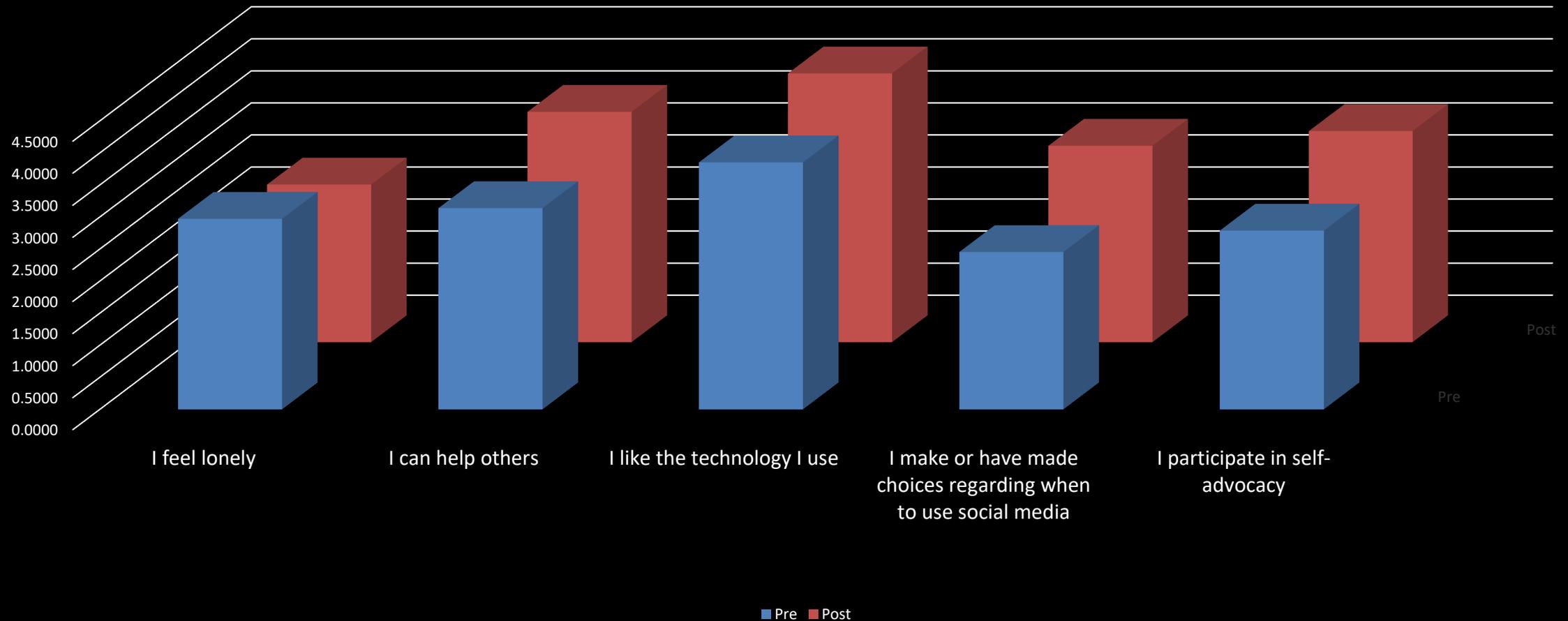
Survey Insights:

Analysis of surveys based upon National Core Indicators (pre and post) indicates:

- Individuals report feeling less lonely.
- Individuals see themselves as more helpful.
- Individuals are seen as (see themselves as) better at self-advocacy.
- Individuals like their AT and feel like it is helping them.

Change in Quality of Life / Satisfaction

Change in QoL/Satisfaction



Survey Insights (cont.)

Analysis of surveys based upon National Core Indicators (pre and post) also indicates:

- Individuals see themselves as empowered to make choices
 - Technology (how and when they use their AT)
 - Going out (i.e. for dinner or coffee)

Survey Insights: Participant Perspective

- Individuals appear to feel more involved in their communities.
- Individuals appear to feel more connected to friends and neighbors.
- Individuals who take meds appear to feel empowered to take them more independently.

Survey Insights: Participant Perspective ⁽²⁾

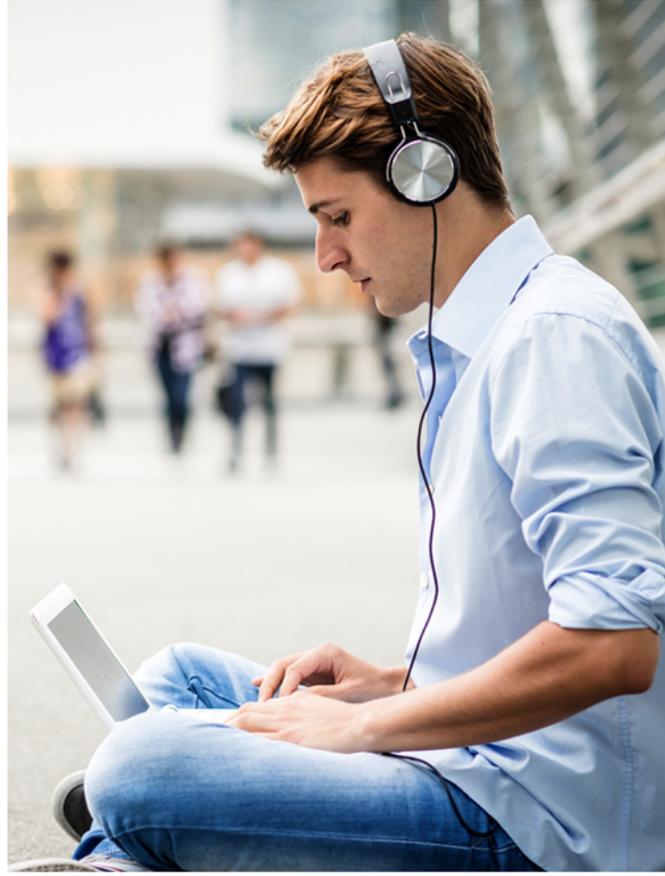
Some curious trends:

- Individuals report wanting to be more connected with families and friends.
- Individuals report that they are unsatisfied with their daily program and living arrangements.
- Individuals report less satisfaction with the support they have received.

Participants report wanting to be more connected with family and friends

Survey Insights: Observations from a Distance

- Increased expectations in light of greater independence?
- Some individuals appear empowered by AT they have been provided.
- Some individuals realize what they have been missing and express frustration, desire for greater autonomy.
- After AT provided, care providers:
 - eyes may have been opened to greater possibilities.
 - observe individuals expressing preferences not previously anticipated.



SUCCESS STORIES

J - Communication

J - male, 28 y.o., Autism

Issue:

- Verbal, majority of speech as unintelligible to listeners
- He makes sounds when he wants something, or he will say one word repeatedly like "mom mom mom." He stutters and has tick like motions when he is trying to say something.

Intervention:

- An iPad with TouchChat/Word Power 42 was introduced. J was able to find symbols and reproduce 3-4 word statement with model; however, did not attend to language system without maximum support.
- The text based app, Verbally, was introduced. He quickly engaged, typing 3-4 word sentences in response to questions independently. The iPad with Verbally was recommended.

Outcome:

- J's mother reported that J is doing very well with the Verbally app. His SLP reported his verbal MLU has increased to 6 and his mother has observed that his speech has improved.

DJ - Communication

DJ – female, 25 y.o., ID

Issues:

- Verbal, but speech is largely unintelligible. If asked a question she will answer with a one-two word phrase. DJ is very hesitant to speak in front of anyone besides her parents. She usually takes her mother to what she wants or she will go and get it herself.
- No history of using an AAC system while in school.

Intervention:

- The NovaChat 10 with WordPower 25 was introduced . After minimal modeling, DJ was able to navigate through the language system, creating 5-7 word utterances, making repairs when a vocabulary word she did not want was selected, return to the main screen and clear the message display.
- An iPad with TouchChat with WordPower 45 was recommended. The family and DJ were trained on how to program and use the app. DJ was able to use system with minimal training.

Outcomes:

- Follow-up with the family indicated that AAC has been very successful, with DJ independently moving herself up to WordPower 80.

DJ - Communication (2)



BM – Medication Management

BM – male, 58 y.o., mild ID

Issues:

- regulating meds, taking BP, tracking glucose levels
- Unable to read pill bottles: names, directions
- Blood Pressure Monitor - not able to read the glucose monitor, but could use the color coding to determine if his levels are ok. His daughter wanted a way to monitor his glucose levels remotely.

Outcomes:

- He has been successfully using the blood pressure cuff.
- His daughter was able to install the app on his phone and he can use independently due to the visual cues of green and red.
- The app saves his data and his daughter and doctor check his history.
- Billy was also given a talking photo album that will be used to have photos of his medication, what it is for and how often to take.
- He will be able to take the photo album with him to doctors appointments and not have to carry all of his medications.

P – Activities of Daily Living

P – male, 30 y.o., Cerebral Palsy

Issue:

- Needs assistance with accessing keyboard at work
- Problems with balance at home
- Difficulties opening packages, dispensing soap and toothpaste in bathroom

Outcomes:

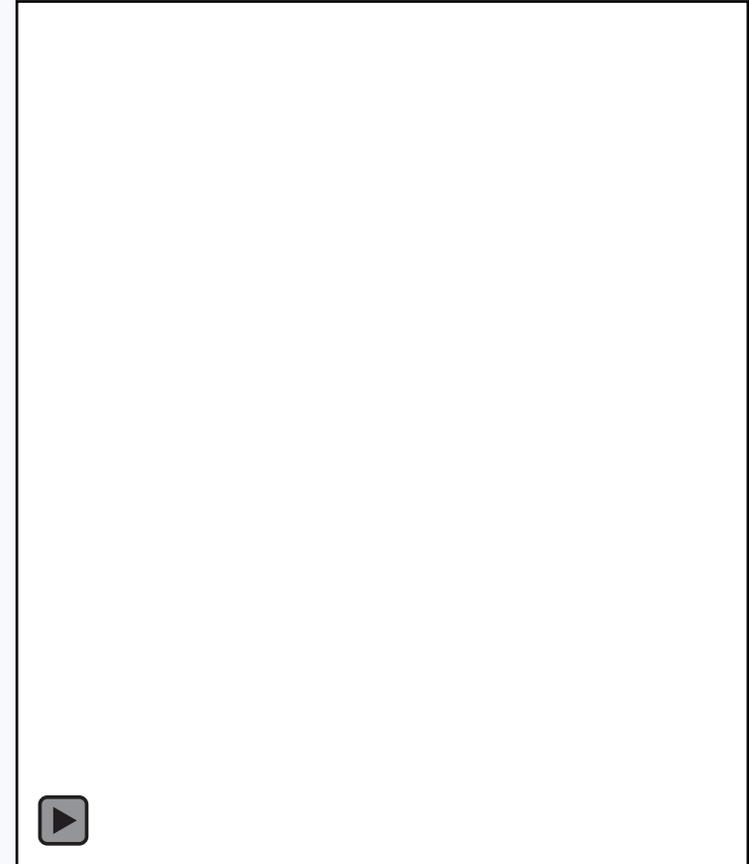
- Setup a smaller keyboard at work
- Recommended performing daily tasks from a seated position to minimize fall risks (Rollator walker with built in seat and shower chair)
- Provided easy access soap dispenser and toothpaste dispenser for bathroom to increase his independence
- Provided one-handed canisters to allow him to access snacks independently

P – Activities of Daily Living (2)



TFL team member:
“What do you think of the toothpaste dispenser?”

Mr. P:
“I think it’s Neato – Dorito!”



Ms. K – Activities of Daily Living

K – female, 30 y.o., Blind, TBI, limited mobility in upper extremities, memory/cognition challenges

Issues:

- Difficulties with Activities of Daily Living including self-care, eating & drinking, bathing, dressing
- Problems with memory related to medication reminders and steps involved in tasks

Outcomes:

- Provided a suction plate, adapted eating utensils and a mug with handles to increase independence with eating and drinking
- A liquid level provided so she could independently pour drinks
- Automatic soap, toothpaste dispensers and long handled sponge provided
- Recommended a bra with front closure to assist with dressing
- Safety scissors to assist with opening food packages
- Utilized Alexa to provide daily routine reminders for medication, toileting schedule and steps for daily tasks



Ms. K - Vision





QUESTIONS



Let's continue the discussion...



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