Communication is Job One:
Effective Communication and Employment

YES! Center Webinar Series:
Technology, Communication & Employment for Youth with Disabilities

Bob Williams, Policy Director
Tauna Szymanski, Executive Director

November 12, 2020

CommunicationFIRST
Because communication is a human right.

Who Am I?
Why Am I Here?

Who Am I?
Why Am I Here?

Job One

Enabling Youth to Excel and Succeed =

Assuring effective communication

CommunicationFIRST © 2020

Getting to YES!

Create high expectations

Encourage self efficacy

Provide opportunities and supports

Learn by doing

Sometimes fall down and get up again

Know what it is and feels like to succeed

CommunicationFIRST © 2020

How Did I Get Here?

I am a fluke and I am mad about it!

CommunicationFIRST © 2020

Progress?

I am glad that there are growing numbers of those using augmentative and alternative communication (AAC) going to college and pursuing careers.

Yet it angers me that the effective communication needs of these workers and professionals are often still ignored.

CommunicationFIRST © 2020

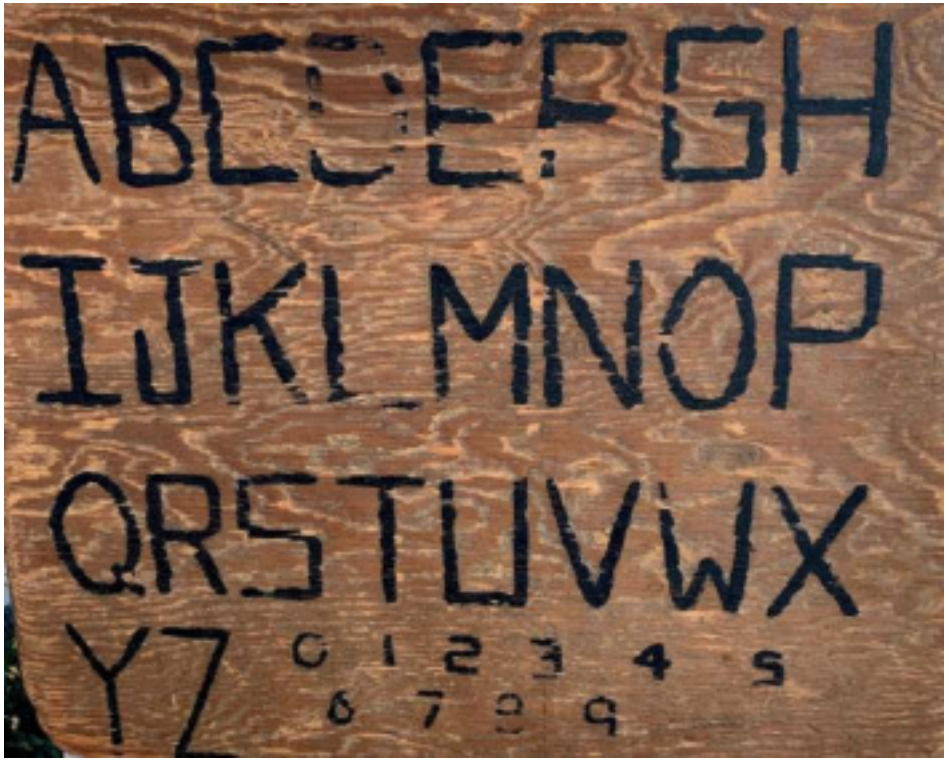
Expect and Nurture Early and Often

CommunicationFIRST © 2020

The Right to Optimal Literacy and Language Use is Key

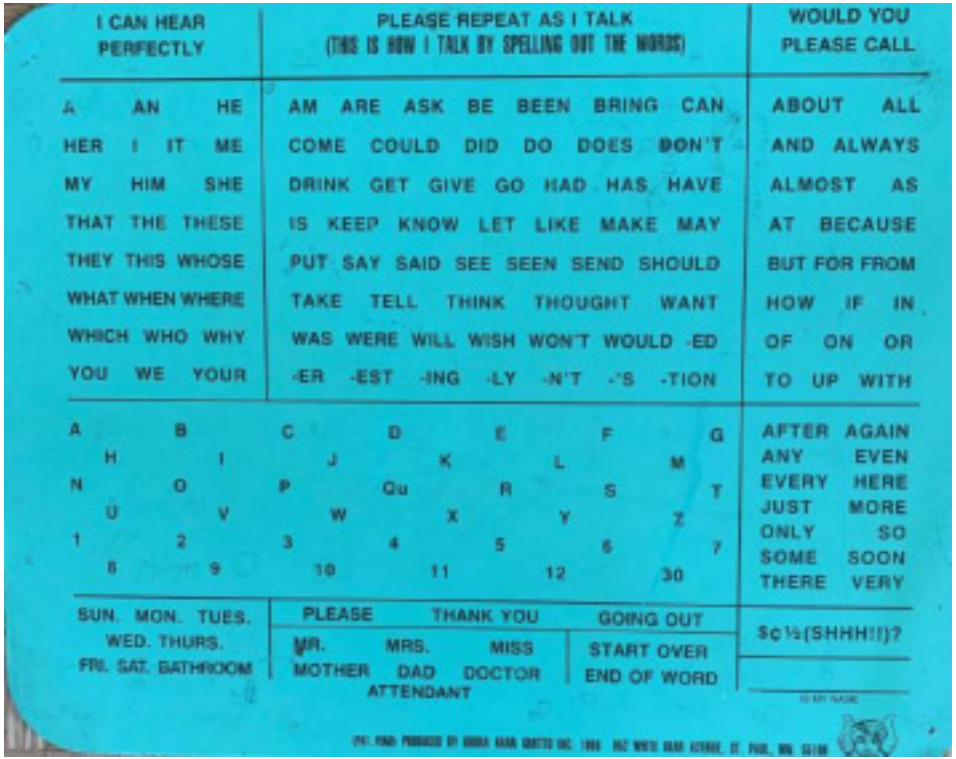
CommunicationFIRST © 2020

High School and College



CommunicationFIRST © 2020

High School and College



I CAN HEAR PERFECTLY	PLEASE REPEAT AS I TALK (THIS IS HOW I TALK BY SPELLING OUT THE WORDS)	WOULD YOU PLEASE CALL
A AN HE	AM ARE ASK BE BEEN BRING CAN	ABOUT ALL
HER I IT ME	COME COULD DID DO DOES DON'T	AND ALWAYS
MY HIM SHE	DRINK GET GIVE GO HAD HAS HAVE	ALMOST AS
THAT THE THESE	IS KEEP KNOW LET LIKE MAKE MAY	AT BECAUSE
THEY THIS WHOSE	PUT SAY SAID SEE SEEN SEND SHOULD	BUT FOR FROM
WHAT WHEN WHERE	TAKE TELL THINK THOUGHT WANT	HOW IF IN
WHICH WHO WHY	WAS WERE WILL WISH WON'T WOULD -ED	OF ON OR
YOU WE YOUR	-ER -EST -ING -LY -N'T -'S -TION	TO UP WITH

A	B	C	D	E	F	G
H	I	J	K	L	M	
N	O	P	Qu	R	S	T
U	V	W	X	Y	Z	
1	2	3	4	5	6	7
8	9	10	11	12	30	

AFTER AGAIN
ANY EVEN
EVERY HERE
JUST MORE
ONLY SO
SOME SOON
THERE VERY

SUN. MON. TUES. WED. THURS. FRI. SAT. BATHROOM	PLEASE THANK YOU GOING OUT	$¢½(SHHH!!)?
	MR. MRS. MISS MOTHER DAD DOCTOR ATTENDANT	START OVER END OF WORD

CommunicationFIRST © 2020

High School and College

CommunicationFIRST © 2020

Off the Cuff Remarks

CommunicationFIRST © 2020

Communication is a basic human need, a basic human right. And more than this, it is a basic human power.

BOB WILLIAMS

CommunicationFIRST

What Is AAC and Who Needs It?

What Is AAC?

AAC (augmentative and alternative communication) is **anything other than speech that can help a person be understood**, including (most use **many** of these!):

- Gestures, eye gaze, pointing, facial expressions, sounds, body positioning
- Pointing or looking at pictures, icons (low tech, high tech)
- Robust, language-based AAC (no, low, high tech)
  - Writing, signing, typing, pointing to letters and words that can be combined to communicate anything
  - Someone familiar with a person's speech repeating what they are saying

CommunicationFIRST © 2020

I H G
K J 7
F E D
6 5 4
C B A
3 2 1
Space
W V U
T Y X
0 9 8
Z S R
N M L
Qu P O

Alphabet Board
No
Yes
1 2 3 4 5 6 7 8 9 0
Q W E R T Y U I O P
A S D F G H J K L
Z X C V B N M ?

Who Needs AAC?

Anyone who cannot rely on speech to be understood

- **Congenital and Developmental** Disabilities
  - Apraxia, autism, cerebral palsy, Down syndrome, rare genetic syndromes, Tourette syndrome
- **Acquired** Health Conditions and Disabilities
  - ALS, aphasia, dementia, locked-in syndrome, multiple sclerosis, muscular dystrophies, Parkinson's disease, traumatic brain injuries

CommunicationFIRST © 2020

Who We Are

Over 5 million in US with speech-related disabilities

- Very diverse community in terms of lived experience, disability/condition, type of AAC, etc.
- MOST don't have access to robust, language-based AAC!

CommunicationFIRST © 2020

Importance of Effective Communication

- Hard to overstate
  - **Necessary** for education, emotional well-being, citizenship, social relationships, self-determination, employment
- Civil and human rights issue
  - Key part of the ADA
  - Universal Declaration of Human Rights: "Everyone has the right to **freedom of opinion and expression**; this right includes freedom to hold opinions without interference and to seek, **receive and impart information and ideas through any media and regardless of frontiers**." (Article 19)

CommunicationFIRST © 2020

Importance of Effective Communication

- Effective communication strategies are often denied when the person is presumed to lack "communicative intent" or the capacity to understand language

  → vicious cycle (how can you prove otherwise without effective communication tools?)

- The costs: years of missed education, isolation, depression, acting out in frustration, opportunities foreclosed, trauma

CommunicationFIRST © 2020

Research: People Who Need AAC

- Have poorer education, employment, and health outcomes
- Experience more abuse
- And those who belong to racial, ethnic, and linguistic minorities **fare worse***

* Meryl Alper (2017), Giving Voice: Mobile Communication, Disability, and Inequality (MIT Press); Saili S. Kulkarni & Jessica Parmar (2017), Culturally and linguistically diverse student and family perspectives of AAC, Augmentative and Alternative Communication, 33:3, 170-180

CommunicationFIRST © 2020

Multiply Marginalized

We **need** to eliminate widespread disparities in access to AAC based on race, ethnicity, primary language, and other SES characteristics

CommunicationFIRST © 2020

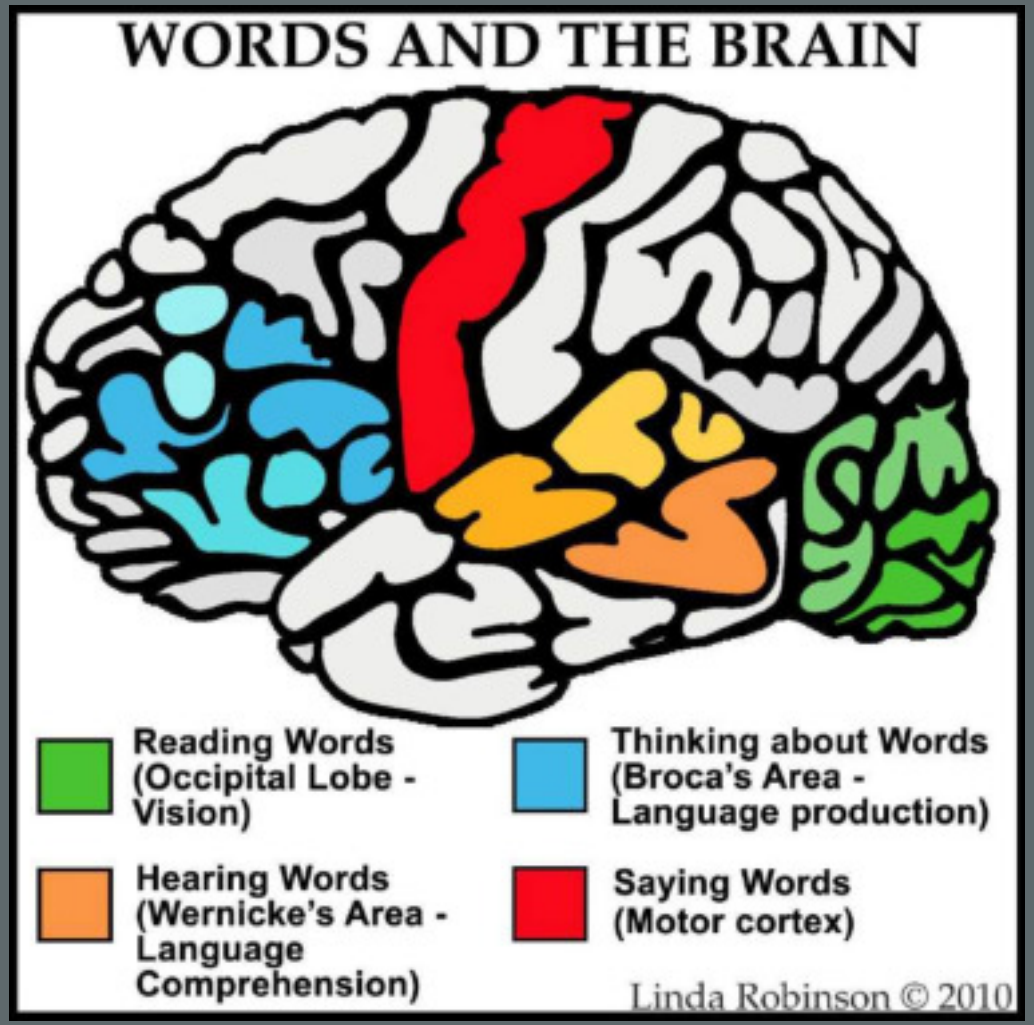
True or False?

True or False?

1. Speech and language are generated and processed in the same part of the brain

CommunicationFIRST © 2020

FALSE!


WORDS AND THE BRAIN
Reading Words (Occipital Lobe - Vision)
Thinking about Words (Broca's Area - Language production)
Hearing Words (Wernicke's Area - Language Comprehension)
Saying Words (Motor cortex)
Linda Robinson © 2010

True or False?

2. It’s safe to assume that someone who can’t speak can’t understand what you are saying

CommunicationFIRST © 2020

FALSE!

True or False?

3. IQ tests accurately measure the intelligence, cognitive abilities, and potential of a person who cannot speak and who cannot move their body in controlled and intentional ways

CommunicationFIRST © 2020

FALSE AGAIN!

Assumptions?

Photo Credit: The Times of London

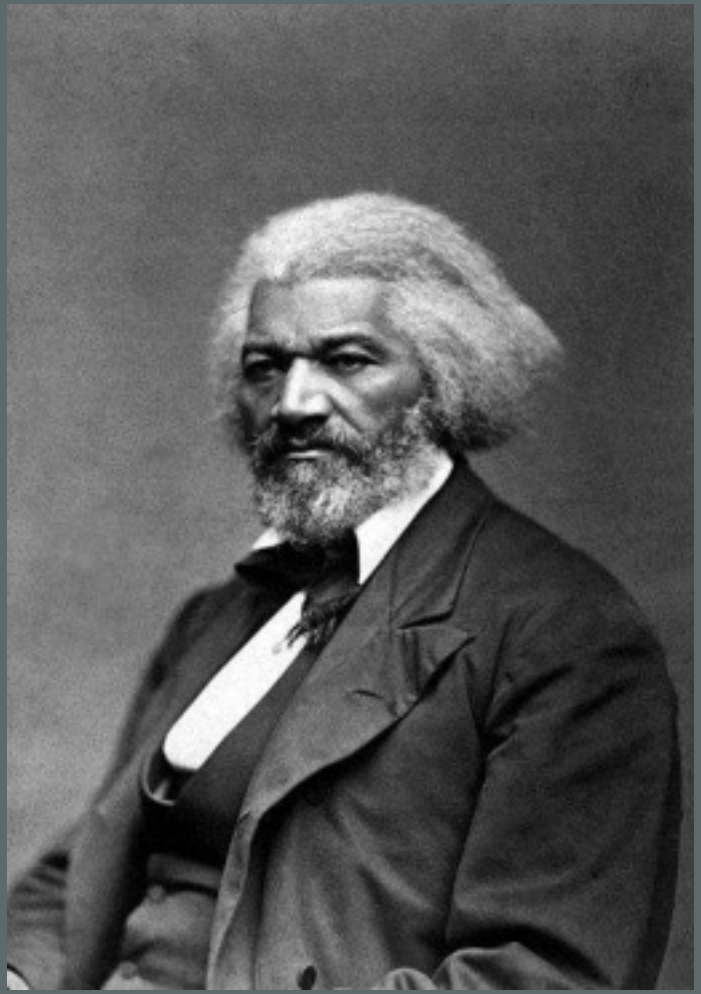
CommunicationFIRST © 2020

Assumptions?

If Stephen Hawking hadn't already established he could contribute, would companies like Intel have bent over backwards to invent new communication systems for him? Why is communication more highly prioritized for some?

CommunicationFIRST © 2020

Why CommunicationFIRST?



“If there is no struggle, there is no progress. Power concedes nothing without a demand. It never did and it never will.”

– Frederick Douglass

A Human and Civil Rights Organization

Cross-disability, disability-led civil rights organization

Making language-based communication access for **all** a national **priority**

Elevating understanding of **vital importance** of communication

CommunicationFIRST © 2020

A Human and Civil Rights Organization

Fighting common prejudices and discrimination

Fighting racial and linguistic disparities in accessing AAC

Fighting institutionalization, isolation & segregation

- We are the last to get out of institutions and be integrated in the community
- Even if we do get out, there is no meaningful integration if we cannot express our thoughts, ideas, knowledge, and desires about who to be with, where to live, where to work
- Are communication barriers (e.g., a lack of meaningful access to robust AAC) a form of institutionalization?

CommunicationFIRST © 2020

“
Unjustified isolation ... is properly regarded as discrimination based on disability.
”
Justice Ruth Bader Ginsburg
Olmstead v. LC,
527 U.S. 581, 597 (1999)
(majority opinion)
CommunicationFIRST
Because communication is a human right.

Our Work

- Changing the **social narrative and public understanding** about our community
- **Ensuring access** to robust expressive communication tools and supports
  - Full lifespan approach: IT'S NEVER TOO LATE OR TOO SOON to introduce language-based communication tools
- Reducing barriers and **ensuring equal opportunity to meaningfully participate in all aspects of life and community**
  - Communication is about ACCESS and OPPORTUNITY and JUSTICE

CommunicationFIRST © 2020

The Right to Communicate in Integrated Employment

Americans with Disabilities Act

Congress in 1990 recognized **discrimination** against people with disabilities (PWD) includes:

- failure to provide **equal access** to opportunities, programs, activities, and services
- "failure to make **modifications** to existing practices"
- "**communication barriers**"

42 U.S.C. § 12101(a)(5)

CommunicationFIRST © 2020

Americans with Disabilities Act

Four Key Principles

1. Integration Not Isolation

PWD cannot "by reason of such disability, be **excluded from participation in** … the services, programs, or activities of a public entity" 42 U.S.C. § 12132

Public entities must "administer services, programs, and activities in the **most integrated setting** appropriate to the needs of" PWD. The "most integrated setting" is one that "**enables** [PWD] **to interact with** nondisabled persons **to the fullest extent possible** …." 28 C.F.R. § 35.130(d) (the "integration mandate" and preamble)

CommunicationFIRST © 2020

Americans with Disabilities Act

Four Key Principles

2. Effective Communication

- "**ensure** that communications" with PWD "**are as effective as** communications with others" 28 C.F.R. § 35.160(a)(1)
- "furnish appropriate **auxiliary aids and services** to afford individuals with disabilities … **an equal opportunity to participate in**, and enjoy the benefits of, a service, program, or activity of a public entity" 28 C.F.R. § 35.160(b)(1)

CommunicationFIRST © 2020

Americans with Disabilities Act

Four Key Principles

3. Equal Employment Opportunity

- Prohibits discrimination in hiring
- Requires employers to provide reasonable accommodations, including communication-related supports
- 42 U.S.C. § 12112

CommunicationFIRST © 2020

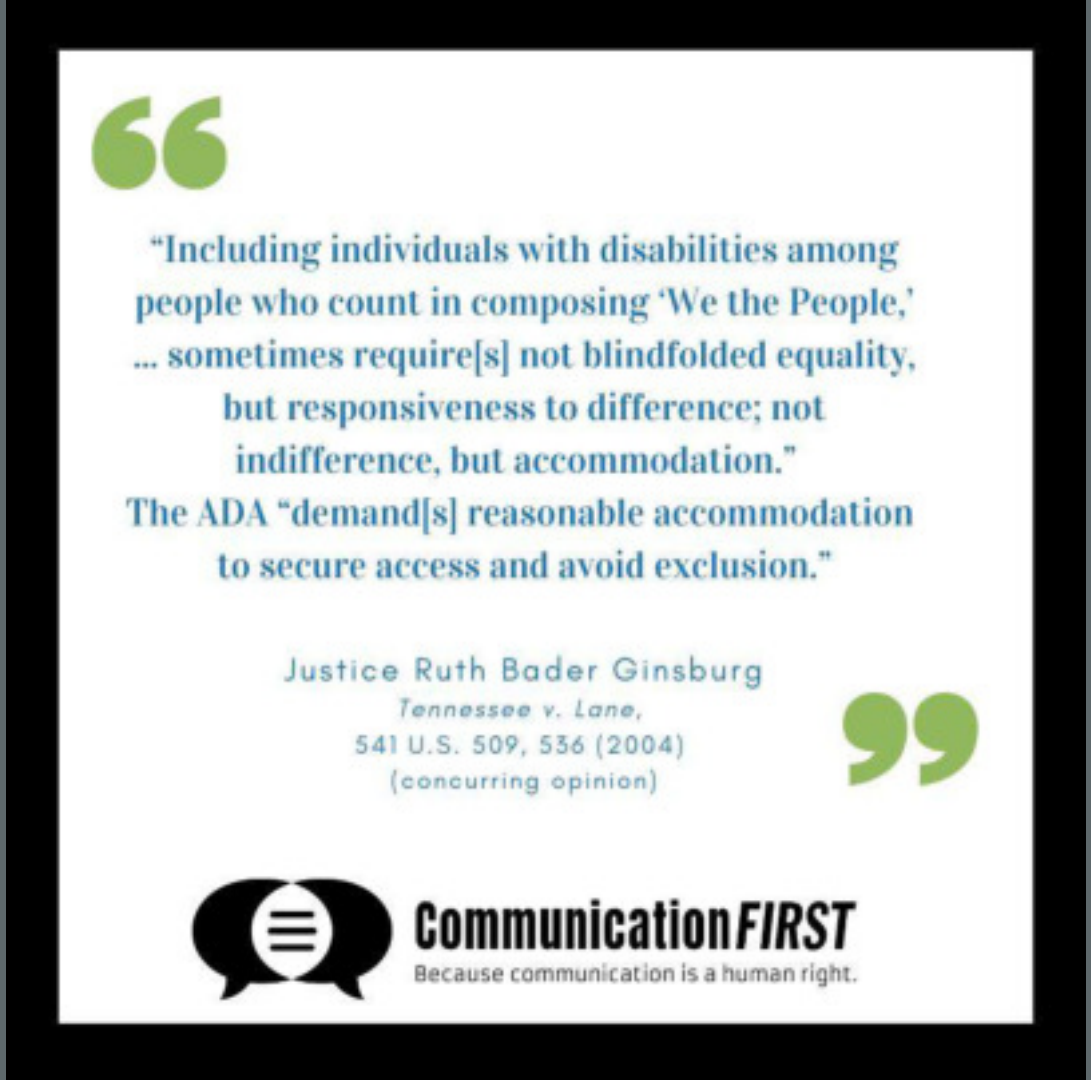
Americans with Disabilities Act

Four Key Principles

4. Reasonable Accommodations

- Must "make **reasonable modifications in policies, practices, or procedures** when … necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity." 28 C.F.R. § 35.130(b)(7)(i)

CommunicationFIRST © 2020


"Including individuals with disabilities among people who count in composing 'We the People,' ... sometimes require[s] not blindfolded equality, but responsiveness to difference; not indifference, but accommodation."
The ADA "demand[s] reasonable accommodation to secure access and avoid exclusion."
Justice Ruth Bader Ginsburg
Tennessee v. Lane,
541 U.S. 509, 536 (2004)
(concurring opinion)
CommunicationFIRST
Because communication is a human right.

AAC and Integrated Employment

AAC & Employment

About 20% of adults served by DD agencies do not rely on speech as their primary means of expression

There is an ethical duty and social justice responsibility to provide access to communication!

➔ **No free pass** to the DD, VR, Medicaid, and Work Force systems to continue to write us off if the educational system never gave us access to effective AAC

There is this habit to say we will do better by the next generation, but **we** can't wait!

CommunicationFIRST © 2020

Poll Question

What percentage of adults with I/DD who can rely on **augmentative communication** are employed in **individual jobs in community-based settings**?

A. 0-10%
B. 11-30%
C. 31-60%
D. 61-100%

CommunicationFIRST © 2020

Answer A (0-10%):

2.3%

Employment Data Summary

% of adults served by state DD systems who use:

Natural speech and spend their days in the following activities:

- Paid individual job in a community-based setting (17.3%)
- Paid group job in a community-based setting (6.8%)
- Paid job in a community business that primarily hires people with disabilities (2.6%)
- Paid facility-based work (16.6%)

Augmentative communication and spend their days in the following activities:

- Paid individual job in a community-based setting (2.3%)
- Paid group job in a community-based setting (1.4%)
- Paid job in a community business that primarily hires people with disabilities (0.8%)
- Paid facility-based work (7.7%)

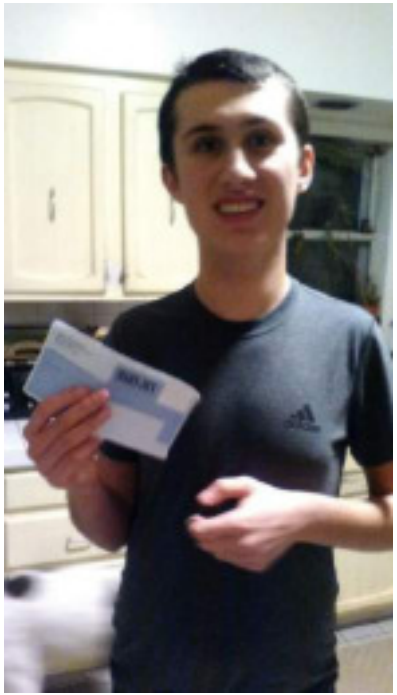
Source: National Core Indicators In-Person Survey (2018-2019)

CommunicationFIRST © 2020

Community Inclusion

"Having a real job is one of the **most important ways to include** people with disabilities in their **community**."

— Niko Boskovic, February 22, 2018
(AAC-using, autistic young adult employed at Trader Joe's in Portland, Oregon)



CommunicationFIRST © 2020

Community Inclusion

Source: Niko Boskovic's public blog on Facebook)

CommunicationFIRST © 2020

Community Inclusion

"Finding a way to communicate has made all the difference in the world. **It made it possible** for me to attend school and get a job. ... It takes some coordination and a lot of patience from everyone, but ultimately, it's so worth it. ... It is so important for us to be **visible in the community**. I like to think of being at work as **an act of rebellion**.…

"Just think about how many disabled people you see in your community – I mean, those of us who have **serious challenges** that impact our ability to be independent adults. I bet you don't see them very often, do you? I know I don't, and I look for them constantly because **I am a striped unicorn surrounded by horses.**"

— Niko Boskovic, September 18, 2018

CommunicationFIRST © 2020

Employer Assumptions?

Trader Joe's Interviewer: "We often have customers in the store who can be very rude or difficult to interact with. We're worried that would be hard for you."

Niko: "I have been sheltered all my life, and I am ready to get my hands dirty."

(Source: Niko Boskovic's public blog on Facebook)

CommunicationFIRST © 2020

Diversity and Strengths

"I believe I was hired because the company **respects the diversity of its employees**. They have taught me new skills while keeping in mind that **I may need more time and different roles** from other employees. The thing is, this approach works! After all, we are not robots, and possess different skills and interests. A business is smart if it recognizes that and **plays to people's strengths**. Trader Joe's definitely does that!"

— Niko Boskovic, September 18, 2018

CommunicationFIRST © 2020

Community Impacts

Email from a Trader Joe's customer:

> "I have always been a big fan of you guys, from upbeat friendly attitude of staff and fun atmosphere and great product. But today you took it to a new level. My stepson has autism, and see[ing] a young adult, who appeared to be autistic, stacking shelves, and the patience of your assisting staff, almost brought me to tears. Thank you for continuing to be awesome!"

(Source: Niko Boskovic Blogger FB page, July 10, 2018)

CommunicationFIRST © 2020

“It matters when those younger than we are see the possibility that they have a place in the world.”

– Cal Montgomery

(public comment on Niko’s public blog on Facebook)

"All of us might wish at times that we lived in a more tranquil world, but we don't. And if our times are difficult and perplexing, so are they challenging and **filled with opportunity**."

— Robert F. Kennedy

CommunicationFIRST © 2020

Seizing the Opportunity

Our times are not tranquil and they are certainly difficult and perplexing. And, so are they challenging and filled with opportunity.

The same is true with what we have discussed today.

The question is, **how do we grapple with the collective challenges and seize on the opportunity of these times?**

CommunicationFIRST © 2020

Bob Williams, Policy Director
bwilliams@communicationfirst.org

Tauna Szymanski, Executive Director
tszymanski@communicationfirst.org

Website
https://communicationfirst.org/