

Ensuring Communication Access for All: Towards Challenging Ableism and Unlocking Possibilities



Kickoff Webinar, Communicative Competence Initiative,

April 11th, 2024

Yoosun Chung, PhD

Associate Professor, Division of Special Education and
disAbility Research in College of Education and Human
Development, George Mason University

Co-chair of the DEIA Committee, United States Society for
Augmentative and Alternative Communication (USSAAC)

Profession



Associate professor at George Mason University

Assistive Technology Program, Division of Special Education and disAbility research, in the College of Education and Human Development

❖ *Teach several graduate Special Education as well as Assistive Technology courses.*

❖ Research

Co-chair of the DEIA Committee at the United States Society for Augmentative and Alternative Communication (USSAAC)

Various volunteer work in the AAC field

Guest speeches



Personal Life

- Mother of two children (almost 26 year-old-son and almost 22 year-old-daughter)
- I am a college+ mom!
- Trying to be a good wife

Cerebral Palsy

Cerebral Palsy is caused by damage to the brain, especially affecting someone's ability to control their body movement

My cerebral palsy affects my speech and my body movement.

My Physical disAbilities

- I can do everything, except the things I can't do.
 - Computer, Cooking, Driving, and so on, and so forth
- Difficult things to do
 - Hold a fully filled cup/mug/glass
 - I can drink well regardless of the kind of drink
 - Peel a fruit
 - I can eat peeled fruit well

My Speech disAbilities

- Korean vs. English
- When I find myself in stressful situations, it becomes difficult for me to speak to others whether in Korean or English
- Thinking ahead process impedes my brain function somehow so it results in my experiencing more speech difficulties in English
- Pronounce difficulties – [r], [v], [f], [br-], [bl-], [dr-], [gr-]. etc.

Assistive Technology

- Assistive Technology is any tool that makes “it” easier for a person to
 - Get dressed, eat, or bathe
 - Read/Write
 - See
 - Get around, or move
 - Communicate
 - Play
- **Assistive technology** is “any item, piece of equipment, or product whether acquired **commercially off the shelf, modified, or customized to increase, maintain, and improve** the functional capabilities of individuals with disabilities.” (*Technology Related Assistance Act*)

Augmentative and Alternative Communication (AAC)

- Approaches, strategies, and methods used to enhance the communication for people facing communicative challenges.
- Augmentative – enhances or supplements a person’s existing communication abilities, typically when their oral speech is limited/unclear.
- Alternative – provides a variety of means of communication for people who do not rely on oral speech alone.

Significance of AAC

- Many people who face communication challenges **cannot consistently use speech** as their primary means of communication.
- Every person has the right to express their needs and interact with others, regardless of their disability and its severity. When people encounter communication challenges and are unable to communicate through speech, it should not mean that they are not entitled to communicate at all.
- Is Silence Golden?

Silence is GOLDEN???



- **Silence is UNNECESSARY!!!**
- While speech is one of many communication methods, using AAC is an important communication way for those who may need it.

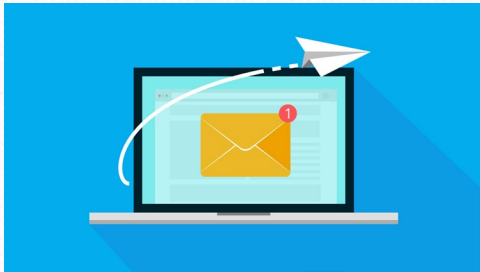
AAC Spectrum

- Using a broad definition, an AAC system is defined as all communication methods other than speech.
- This ranges from unaided methods such as the use of gestures, sign language, and facial expression to aided methods such as the use of alphabet or picture symbol boards and sophisticated voice output devices (Glennen & DeCoste, 1997)
- *No tech → Low Tech → High Tech*

My Augmentative and Alternative Communication (AAC)

- My dilemma before using AAC
- After using AAC
 - Gained self-esteem --- “I can do anything!”
 - My life has become more professional – teaching students at a university, presenting at conferences, being a keynote speaker, and so on.

Various Methods of AAC



- No tech – gesture/spell out/write a note
- High tech – EZKeys, iPad apps
- Socially welcomed tech - instant messenger or email

Abilities Beyond disAbilities

- Disabilities are **NOT** Inabilities.
- People with various disabilities can do almost everything you can do, when they utilize useful tools such as Assistive Technology.
- For example, Dr. Stephen Hawking used a switch to operate his AAC.



Definition of Ableism

“Ableism is the **discrimination or prejudice against people who have disabilities**. Ableism can take the form of *ideas and assumptions, stereotypes, attitudes and practices, physical barriers in the environment, or larger scale oppression*.

It is oftentimes unintentional, and most people are completely unaware of the impact of their words or actions”

(<https://www.urbandictionary.com/>).

Timeline (Important Legislation)

1948 Communication Right

UN Declaration of Human Rights Article 19 - everyone has the right to freedom of opinion and expression; freedom to hold opinions without interference; to seek, receive and impart information and ideas through any media regardless of frontiers

1973 Section 504 of the Rehabilitation Act

First piece of civil rights legislation to specifically address the rights of people with disabilities

1990 ADA

Americans with Disabilities Act of 1990: Prohibits discrimination against people with disabilities in many different settings

Ensuring that African Americans and women could not be discriminated against in the workplace. It does not make any provision for people with disabilities

1964 Civil Rights Act

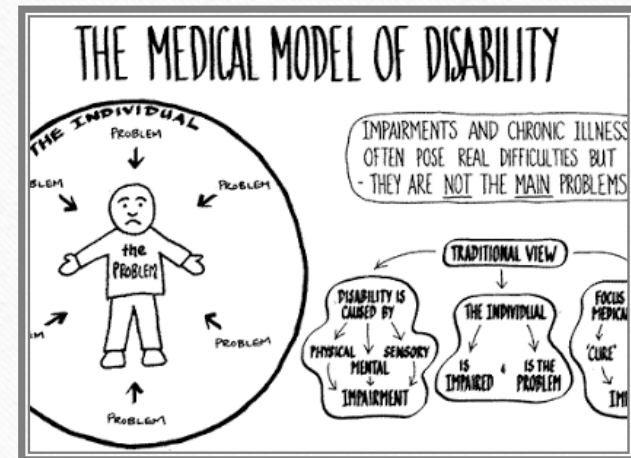
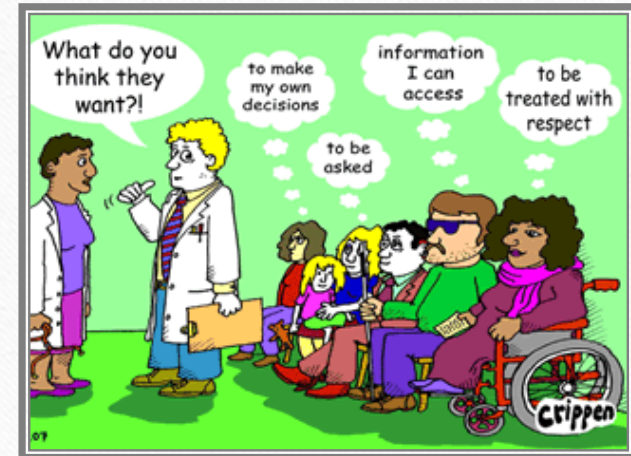
Individuals with Disabilities Education Act: This law mandates that children with disabilities must receive a free and appropriate education (FAPE) in the least restrictive environment (LRE)

1975 and 1990 IDEA

Ideas, Assumptions, Stereotypes

Medical View - assumes people with disabilities want or need to be 'fixed'/'cured'

- Talking to a person with a disability **like they are a child**, talking **about them** instead of directly to them, or speaking **for them**
- Asking **invasive questions** about medical history or personal life
- Assuming people must have a **visible** disability to be disabled



Attitudes & Practices

Refusing to provide reasonable accommodations

Using someone else's mobility device as a hand/ footrest

Using disability as a punchline, or mocking people with disabilities

Framing disability as either tragic or inspirational in news stories, movies, and other popular forms of media (also known as "inspiration porn")

Casting a non-disabled actor to play a disabled character in a play, movie, TV show, or commercial

Red tape (e.g., waitlists, endless paperwork)

Physical Barriers In the Environment



Failing to incorporate accessibility into building design plans

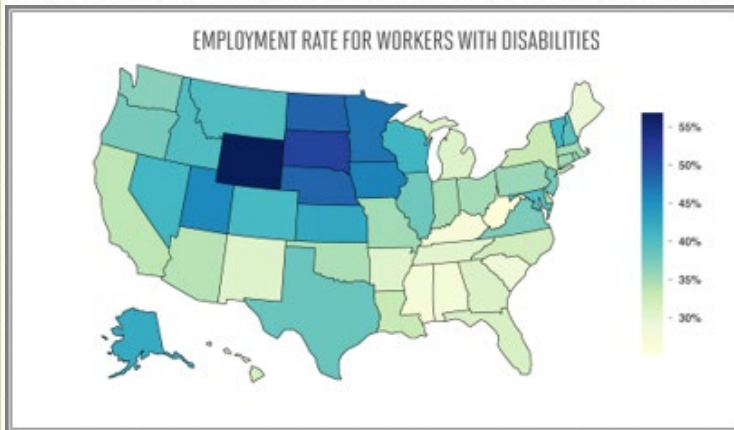
Inaccessible websites

Choosing an inaccessible venue for a meeting or event, therefore excluding some participants

Making a movie that doesn't have audio description or closed captioning

Using the accessible bathroom stall when you are able to use the non-accessible stall without pain or risk of injury

Larger Scale Oppression



* Lack of compliance with disability rights laws like the ADA

* Segregating students with disabilities into separate schools

* The use of restraint or seclusion as a means of controlling students with disabilities

* Segregating adults and children with disabilities in institutions

* High unemployment rate, underpaid, underemployed

* Healthcare access

Importance of Firsthand Perspectives

Real people, real stories

Direct viewpoint

Better understanding

Self determination

Medical vs. Independent Living



**Examples
of Ableism I
have
encountered
in my
everyday life**

- People talking to person(s) with me instead of talking directly to me (e.g., restaurant)
- People surprised when they realize my kids are my own kids
- People in the U.S. thinking that I can't speak English vs. Korean people in the U.S. thinking that I can't speak Korean
- You are an inspiration!

Importance of Language Use

- Kellar Institute for Human disAbilities - Official name for the center where I work at.
- **In common sense**, people usually represent the first letter of words in capital letters (e.g. Kellar Institute for **H**uman **D**isabilities)
 - However, our center uses the letter “**A**” in the word, disabilities, with a capital letter.
 - What does this imply?
 - From our perspective, we are giving more value to “Abilities” in a positive word than valuing “dis” which is a negative prefix.
 - As our official center name means, people in the world perceive people with disabilities as “people who can do anything in different ways”.

**Do's and
 Don'ts of
 AAC
 Terminology
 by
 AssistiveWare**

USE	THINK BEFORE USING	AVOID USING
AAC users, people who use AAC	Part-time AAC users, people with complex communication needs, multimodal communicators	People who rely on/require AAC, people with CCN, PWCCN, PWUAAC
People	Individuals, users	Consumers, support recipients, patients
(AAC) device, tablet	AAC system, AAC tool, speech-generating device	Talker, voice output communication aid, VOCA, SGD
Nonspeaking	Nonverbal	Functionally nonverbal, preverbal, prevocal
Communication disability, speech disability	Speech impairment	Speech deficit, communication deficit
Spoken language, spoken words	Speech, language, mouth words (referring to spoken language)	Natural language, natural speech (referring to spoken language)

Words We Currently Avoid by CommunicationFirst

Nonverbal From the root *verbum*, or “language,” the word **nonverbal** assumes that someone cannot understand or use *language* (as opposed to speech). These ideas are untrue and, for many, lead to the denial of AAC.

▶ *Instead, use:* **AAC user** or **person who needs AAC** or **nonspeaking** (for autistic people)

Severe or **profound** They invoke feelings of fear and pity, not common humanity. Nor do they communicate what the person actually needs.

▶ *Instead:* Describe the person’s specific access needs

Words We Currently Avoid by CommunicationFirst

Disorders, impairments, or deficits Disability is a natural part of human diversity. No form of communication is wrong. Plus, all communication is two-way: it's an act we do together, not something we have.

▶ *Instead, use:* **condition** or **disability**

Complex communication needs We view this as similar to the term **special needs**. We have the same needs as everyone else to be heard and understood. That need is neither complex nor special.

▶ *Instead:* Describe our access needs directly and avoid euphemisms

Words We Currently Avoid by CommunicationFirst

Non-communicative Everyone communicates. It is impossible to know whether someone “has no language.”

► *Instead:* Describe and respect the ways we already communicate

Clients, consumers, or patients CommunicationFIRST, a disability-led organization, does not generally use these terms because they can be “othering” and dehumanizing.

Internalized Ableism that I had

In the past, I would not be able to be

- a mom!
- a college professor!

In the present, I AM

- an AWESOME mom!
- a WONDERFUL professor!





A Pictorial Representation of Yoosun Chung, Myself

In order to blossom into a beautiful flower, seeds are first planted into the ground where they sprout **roots**. Next, buds begin to sprout. The **stem** stretches high into the sky. From the stem, many **leaves** emerge. Finally, a **flower** blooms. However, none of this can happen without **water**.

My Own Suggestions



Encourage people with communication disabilities to talk.



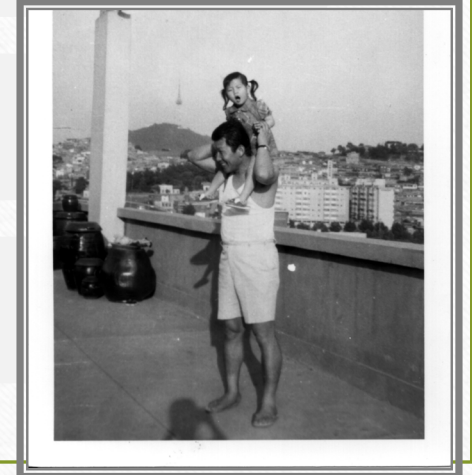
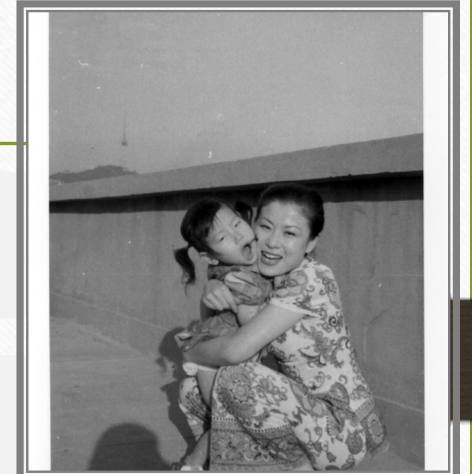
Talk directly to them, not a person with them.



Eye contact is important.



Ask which communication ways work for them



My Own Suggestions

Educate

Educate yourself

Patient

Be patient

Ask

Ask them if you do not understand what they mean

Smile

Don't forget to smile :)

Conversation between me
and my kids

Habeen is talking to me



I am talking



Yebeen is talking to me



Yebeen's Note

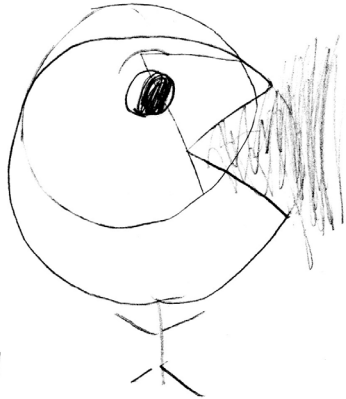
1 what ?

eye 

Should

a

y



2

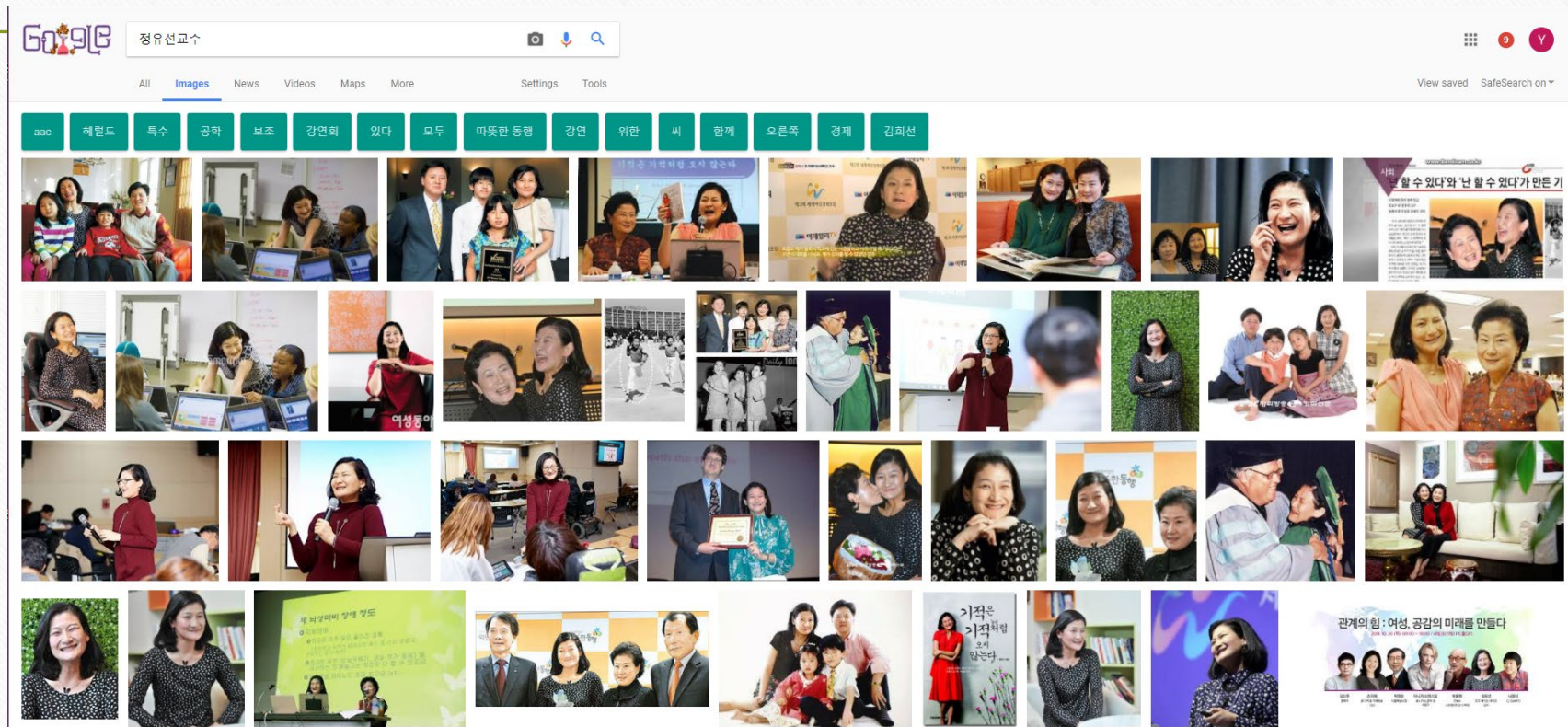
answer

1 a question

My mom is twitching her eyes
because when ^{high} she was young she
~~she~~ had a bad fever but ~~she~~ now
her fever lowered down.
So she's fine but she
is kinda speechless however
she works hard and now
she turned to be a
professor.

My mom's
brain hurt
and speech.

Believe It Or Not



Miracles do
not come
miraculously.



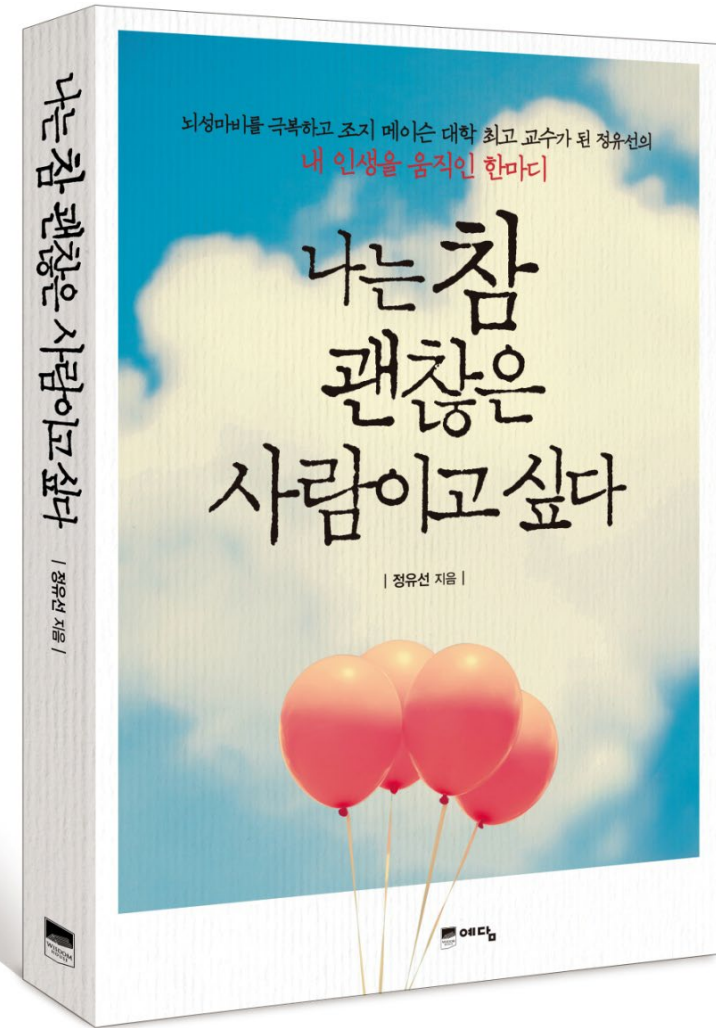
기적은
기적처럼
오지
않는다 | 정유선 지음 |

뇌성마비 장애인 정유선 박사의 희망찬가,
긍정의 눈으로 세상을 보라!

대교북스권

The image shows a woman with dark hair, wearing a bright red, short-sleeved, button-down dress, standing with her arms crossed against a light grey wall. To her right, there is a cluster of pink carnations. The background is a plain, light-colored wall. The text is written in a clean, modern Korean font.

I want to
be a
decent
person



Socrates

Women are weak,

but

mothers are strong!

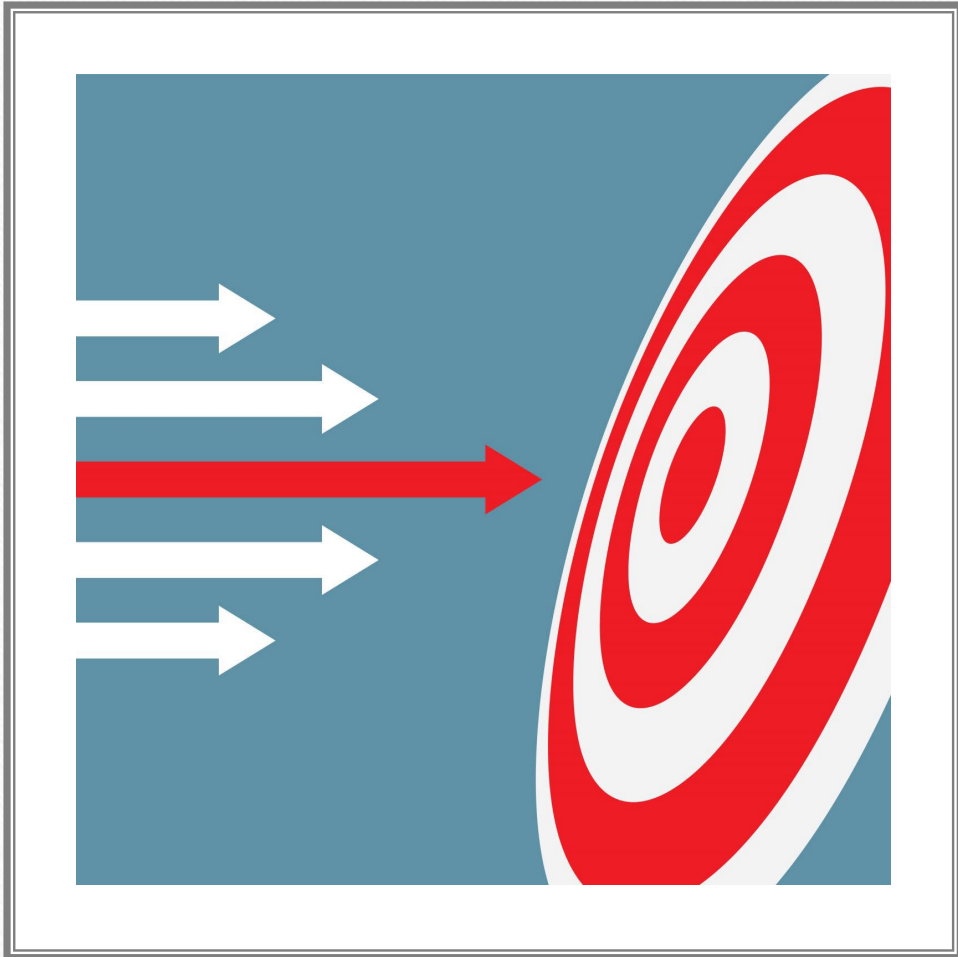
How I Got Into This Current Position?

My Mottos:

Heaven helps those who help themselves

Where there's a will,
there's a way





My Own Strategies

- Set a short term goal and a long term goal
- Do your best to meet your goals
- Remember!!!
 - Your goals can be always altered and/or postponed
 - There can be many alternative ways
 - We all learn from our mistakes.

```
graph LR; A["Promoting Assistive Technology, including AAC"] --- B["Finding Voices of AAC Users"]; B --- C["Advocacy"]
```

Promoting
Assistive
Technology,
including AAC

Finding Voices of
AAC Users

Advocacy

My Goals for the Future and Beyond



Concluding Remarks

- Ableism **still exists today**, some experience it firsthand at school, work, home, or in the larger community.
 - Others may see it happening in the media through movies, books, magazines, social media and the news.
- Some might be unaware or misinformed of Ableism
 - **What happens after, is what matters.** We have come far considering our past, but there is still work left to be done.

Miracles do not come miraculously!!!

Love



A little
Miracle



-
- Life is worth the struggle!
 - As we dream, one step after another!

Thank you very much



USSAAC
THE VOICE OF AAC

