

# AAC and Transition: Life Starts at Twenty-one

Kathryn Helland, M.S., CCC-SLP  
TechOWL PA  
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## Financial Disclosure

**Kathryn Helland works for Temple University, and they pay her salary. The Institute on Disabilities receives a stipend for this presentation.**



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## Kathryn Helland Speech-Language Pathologist

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## During the Presentation

- Microphones off
- Please complete the survey at the end
- Type questions in the chat or raise your hand
  - There will be additional time at the end for more questions



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# Learning Objectives

**At the end of today's session, attendees will be able to...**

- List three considerations impacting vocabulary selection for adults who use AAC.
- Discuss three critical elements to a successful transition.
- Describe a template transition plan for AAC Users in high school.

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**“You can't really know where you are going until you know where you have been.”**

-Maya Angelou

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## The History of Incarceration of People with Disabilities

### The Twentieth Century: Eugenics, Disability, and Activism

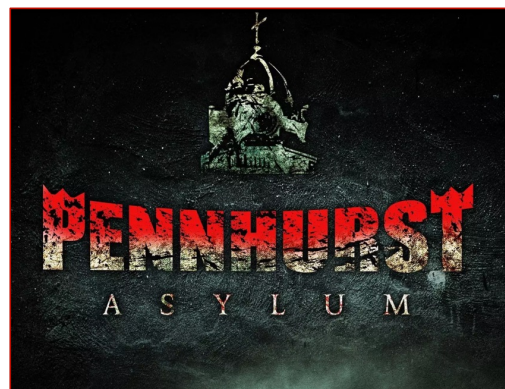
- People with disabilities were locked up in large state hospitals. They had no control over their lives.
  - People who did not match societal “norms” were incarcerated
  - Institutionalization peaked in the 60s and 70s
    - 180,000 + people with ID/DD resided in large state facilities
  - The Disability Rights Movement grew in tandem with the Civil Rights movement in the 1960s

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## Pennhurst: Now a “Halloween Attraction”

- The building is being used as a Halloween haunted house.
- Self advocates suspect that hundreds of bodies are buried there
- The suffering of thousands is turned into a spectacle
- THIS IS NOT OKAY
- The fact that this is seen as acceptable is a reflection of ableism and the devaluation of the lives of people with disabilities



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## A Fierce Kind of Love

- This is a play about the rights of people with disabilities
- A Fierce Kind of Love is about closing the Pennhurst state hospital and fighting for disability rights.
- Produced in conjunction with the Institute on Disabilities at Temple University
- Disabled Actors tell the story of deinstitutionalization



[Link to the Play on Vimeo](#)

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## Legislation and Court Cases Impacting Rights for People with Disabilities

### **Laws leading to greater rights, access to AT, and deinstitutionalization**

- The Rehabilitation Act of 1973 – leads to changes in work, housing, and transportation
- Education for All Handicapped Children Act – 1975 (now IDEA) - leads rights in public education
- Americans with Disabilities Act – 1990 – Leads to rights in access to public spaces, telecommunication services, employment, access to assistive technology, and rights in higher education
- Olmstead Decision – 1999 – Segregation of people with disabilities is a form of unlawful discrimination under the ADA



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## Home and Community Based Services (HCBS)

### HCBS helps people live at home in the community

- A tool for deinstitutionalization: HCBS allows people to opt to live in the community as part of their Medicaid waiver services.
  - HCBS added to Social Security Act – 1983
  - Became a formal state Medicaid option in 2005
  - It is not implemented by all states
  - It is an eligibility-based program and there may be waiting lists and annual budget limitations.



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## Getting Ready for Life After School-Aged Services

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## Consider the Goals for 21+

### It is important to plan for life as an adult!

- Does the student want to work?
- Will they need supported employment?
- Will they continue to live at home?
- Will they pursue vocational training or higher education?

Preparation for a self determined life begins the moment we assess for AAC!



[Presentation Powerpoint by Dr. McNaughton on transition & AAC](#)

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## Do We Take Away Someone's Voice?

### When someone graduates, the school may take back their AAC.

- If owned by the district, start discussing whether they will prorate the cost of the device and sell it to the family
  - Be aware that you cannot transfer an app from one Apple ID to another
- As needed, plan for an AAC evaluation and insurance report before their last semester!
- If the goal is post-secondary education, the family can request a reevaluation the final year of school This can be used to document disability to higher education institutions.



[Erin Sheldon's presentation on transition and AAC](#)

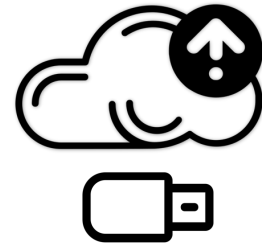
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## Can We Make Sure Someone's Voice is Preserved?

### SAVE the AAC vocabulary to a flash drive or computer

- Given appropriate safeguards for student information, save backups to a Cloud folder that the parents will be able to access after graduation
- Even better, train the individual and/or family to maintain backups in their own folder
- This should be a part of the transition of knowledge and skills that allow the person or family to maintain the device. They need to be the experts!
- Information on app backups: [Backing UP AAC Apps on the iPad](#)



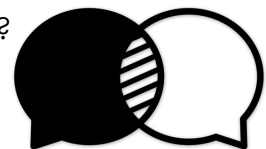
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## Can We Make Sure Someone's Voice is Preserved?

### We need to teach the AAC user to take care of their AAC device

- Train the individual and/or family to maintain backups in their own folder
- This should be a part of the transition of knowledge and skills that allow the person or family to maintain the device. They need to be the experts!
- Does the individual or family know how to edit buttons?
- Do they know how and why the app is organized the way it is?
- It can be incredibly hard to find SLPs who know AAC to work with adults
- [A reference for family-centered AAC service](#)



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## “TOMORROW” - POST-SECONDARY ENVIRONMENTS



- People who use AAC do many things with their lives
- Employment (competitive, supported; entrepreneurial; telework; etc.)
- Residential (dorm; with parents/family; independent; independent with support; full agency support)
- Education (2-year, 4-year, vo-tech/trade; adult ed)
- Community participation (specialized with supports, etc.)

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## What Does Eligibility Entail for Adults Who Need AAC?

### **It is much harder to find help as an adult**

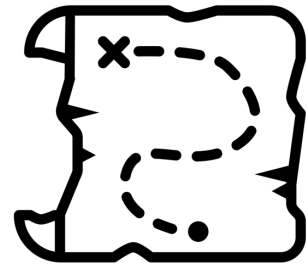
- You have to be aware of services and seek them out
- So, for students with ID/DD, help families be aware of their options prior to their last year!
  - Especially in under resourced communities!
- For Medicaid waiver programs (HCBS), there may be a waitlist of several years, dependent on the type of waiver coverage needed
- Options for employment include the state office of vocational rehabilitation
- There are also options within vocational rehabilitation for supports for continuing education

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## Where to Look for Support

- Speech therapists are hard to find for adults
- It can be incredibly hard to find SLPs who know AAC *and* work with adults
  - Services are not mandated and reimbursement rates are low
  - CMS reimbursement in 2020: \$36 per hour
  - Too frequently, adults with complex communication needs who receive speech services, are working on /b/, /p/, & /m/ sounds!
  - Contact your state's AT Act Program for resources – [AT3Center.org Website](https://www.at3center.org)
  - The Job Accommodation Network: <https://askjan.org>



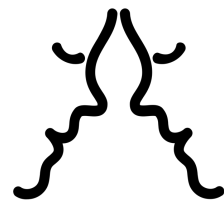
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## Vocabulary for Adulthood – ALL THE WORDS!

### Vocabulary for relationships is important

- AAC users date, have sex, get married, and have children.
- Research shows that only 55% of words needed for six adult roles were found on participants device (Bryen, 2008)
- If we don't have the words to talk about our bodies, how can we report abuse?
- Don't forget orientation and gender identity
- Blog post by AAC user Donnie Denome: [How do you symbolize intimacy blog?](#)
- [Denome & Cooper Presentation on Autonomy and Dignity of Risk](#)



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# Talking About Our Bodies

## Kids with AAC need the same words as other kids

- Can we teach words for “forbidden topics”?
- This is a difficult topic in schools and needs attention!
- WHAT IF AN AAC USER CURSES IN SCHOOL?
- If we teach body parts in a matter-of-fact way, we empower the adults they become!
- They will be better able to report their physical needs and prevent unwanted touch
- We also need to empower people to say NO. And we need to listen.



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# Poop (Talk) Happens

I love this video!  
[Link to Small Talk video](#)



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## We Really Need ALL the Words

### Rates of abuse

- People who can't speak are often treated badly
- Individuals with ID are SEVEN TIMES MORE LIKELY to be abused.
- NPR's Joe Shapiro covered this in 2018: [NPR Report on Abuse and Semi-Speaking and Non-speaking Adults](#)
- Introducing vocabulary for a court proceeding is going to be disputed by the defense (leading the witness)



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## Adult Roles, Rights, and Responsibilities

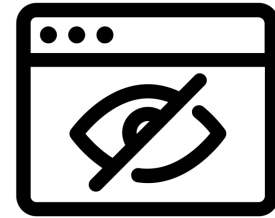
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# Privacy and Data Tracking

## People need to respect the privacy of AAC users

- Have you been tracking vocabulary type, use, and location?
- Is the student now a teenager?
- Consider privacy rights and data ownership
- The original iPad AAC users are growing up and they have a lot to say!
- Transition goals and therapy should maximize autonomy
- Resources:
  - ISAAC webinar: [Data Privacy and AAC Webinar](#)
  - AAC in the Cloud presentation: [Webinar on Autonomy, Self-determination, Dignity of Risk, and Harm Reduction](#)



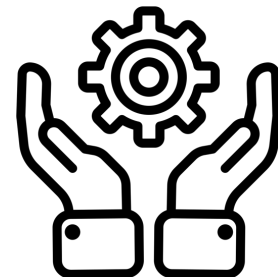
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# Vocabulary for Work and Higher Education

## AAC users get jobs and go to college

- What vocabulary considerations are there for higher education and work?
- Some adults I know use both symbol-based and text to speech. They depend on hybrid systems
- A key school-aged consideration is access to literacy skills!



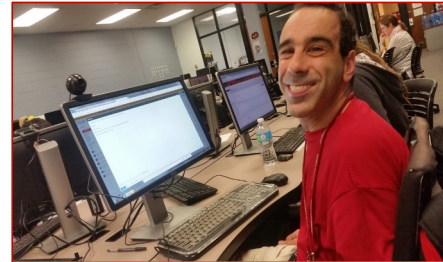
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# Getting Accommodations for Work

## You can get help with finding and keeping work

- Varies from state to state
- Will sometimes pay for an assessment?
- The ADA only requires employers to provide those good old “reasonable accommodations”
- In Pennsylvania, OVR has sometimes contracted with the Institute on Disabilities for assistive technology services, including AAC



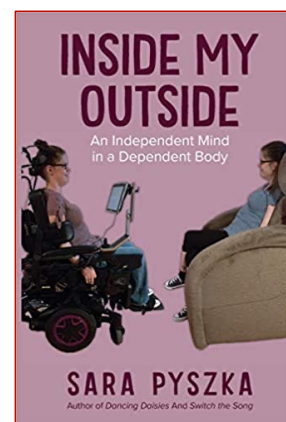
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# Accommodations for Higher Education

## People who use AAC can get some help in college Is compliance with the ADA enough?

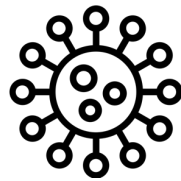
- The ADA still requires the student to request accommodations
- Universally Designed environments would alleviate most of that need
- The ADA does not require provision of highly customized assistive technology
- Some universities may go above and beyond....
- Wright State University
- The system of having to disclose and request accommodations is, in essence, ableist and othering



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# Covid-19



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## The Impact of Covid-19 and Remote Learning

### **Covid 19 changed how people go to school**

- Remote learning does not work for all, but it may work for some AAC users....
  - Asynchronous interactions remove the time barrier present in F2F communication
  - Studying online, we are all using AAC!
  - Learning Management Systems are not perfect, but professors can use these tools to intentionally design a course with access and UDL principles in mind
  - Will this level of access be maintained with a "return to normal"?
- Pros and Cons: Increased access but Is social capital lost when we do not interact F2F?
  - AAC in Higher Education will be the focal point of my doctoral research (fingers crossed!)

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**Thank you for attending!**

**Kathryn.Helland@Temple.edu**



**Feel free to contact me for a list of references used in this presentation**

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## **AAC Essentials**

- Free, online, asynchronous learning strands
- Learn about AAC at a time that works for you
- Take a course that fits your role
- Upon completion, print out a certificate to use for CEUs
  - Check if these are accepted by your employer to meet annual training requirements
- Share this resource with your networks!
- <https://aaccommunity.net/aac-essentials/>



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[Bit.ly/TechOWLsurvey](https://bit.ly/TechOWLsurvey)

Presenter: Kathryn Helland

Topic: Life Begins at Twenty-One - Transition

## Questions & Survey

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