

Designing AAC interventions & research to improve outcomes for individuals with complex communication needs

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<http://aac.psu.edu> for handouts



I want her to be happy. I want her to love and to be loved. I want her to be safe and secure. I want her to be accepted for who she is. I want her to dream big and know the thrill and the satisfaction of accomplishments that come from hard work. I want her to have the courage to try and sometimes fail. At the end of the day, I want her to know that she left the world a little bit better than when she started out.

A parent talking about her goals for her child, a preschooler who uses AAC.

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Adjusting focus

- Are AAC research & intervention truly aligned with the goals of individuals who require AAC and their families?
- As researchers & clinicians, we tend to focus on our own disciplinary domains
 - Target specific motor, sensory perceptual, speech, language, and/or cognitive skills
 - Often in isolated settings
 - Without natural communication partners
 - Assume that somehow these interventions will lead to positive overall outcomes



We need to re-think AAC research & intervention to improve outcomes.



Positive effects of AAC

- There is no question that **AAC positively impacts the communication** of
 - Young children with CCN (e.g., Branson & Demchak, 2009; Ronski, Sevcik, Barton-Husley, & Whitmore, 2015)
 - Individuals with ASD (e.g., Ganz, 2015; Ganz et al., 2011; Schlosser & , 2015)
 - Individuals with severe or profound IDD (e.g., Mirenda, 2014; Roche et al., 2015; Snell et al., 2010)
 - Individuals with challenging behaviors (e.g., Walker & Snell, 2013)
 - Individuals with severe chronic aphasia (e.g., Beukelman, Hux, Dietz, McKelvey, & Weissling, 2015)
 - Individuals with ALS (e.g., Ball, Beukelman, & bardach, 2007; Beukelman, Fager, & Nordness, 2011)
 - Individuals with motor speech disorders (e.g., Hanson, Beukelman & Yorkston, 2013).

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Challenges to participation

- Despite these gains, **many individuals with CCN face substantial challenges**
 - Many children with CCN are still denied the opportunity to participate in appropriate general education (e.g., National Center for Education Statistics, 2013)
 - Up to 90% of individuals with CCN enter adulthood without functional literacy skills (e.g., Foley & Wolter, 2010)
 - Less than 5% of individuals with CCN are employed even part-time (e.g., McNaughton & Beukelman, 2009; McNaughton & Bryen, 2002; 2007)
 - 91% of adults with severe IDD do not have access to AAC & have no means to participate in activities of daily living (Stancliffe et al., 2010)

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Re-thinking AAC intervention & research to improve outcomes

- Build on the individual's strengths
- Support the individual's participation in real world contexts
 - Focus on the integration of skills to maximize communication
- Build positive psychosocial factors
- Address environmental barriers



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Build on the individual's strengths



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Build on the individual's strengths

- Most AAC research focuses on the deficits experienced by individuals with CCN
 - These studies cloud recognition of the unique characteristics & strengths of the individual
 - Perhaps these studies reflect a Type III error
 - Asking the wrong question (Mawn & Goldberg, 2012).
- Focus on the individual's strengths
 - Build on these strengths to address challenges

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Anna

- 3 years 10 months old
- autism spectrum disorder
- severe challenging behaviors
- limited access to communication
 - no spoken words
 - <10 PECS used to request objects & activities
 - preliterate
- interest in books and magnetic letters

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Build on Anna's strengths

- Harness her interest in letters & books
- Teach literacy skills
 - Letter-sound correspondences
 - Phonological awareness skills
 - Decoding skills
 - Shared reading
 - Sight word recognition skills
 - Reading and understanding books / other texts
 - Early writing skills

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Build on Anna's strengths

- Used written language to
 - Support speech development
 - Letters as visual supports
 - Letter sound knowledge
 - Support language development
 - Build more complex communication
 - Expand semantic, syntactic, morphological, discourse dev't
 - Foster social interaction
 - Shared reading, texting, social media

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Anna: Build on strengths

- After 15 months /60 hours of instruction
 - 5 years 2 months old
- Mastered basic literacy skills
 - Letter sound correspondences
 - Reads simple books independently
 - Responds to factual wh-questions with >80% accuracy; learning to respond to inference questions
 - Types simple stories
- Enters Kindergarten as a reader and writer
 - Literacy skills exceed those of peers
 - Included in regular education class

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Email from Anna (Grade 3)

Hi Miss Janice .

It's Anna. I miss you. Im a good reader. Thank you for making me happy with with reading. Where are your Janice books? I loved reading them. Im in third grade at grays'woods. I watch my old Janice movies. Do you watch Janice movies? Where are you working?

Love,
Anna

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Focus on successful participation in real world contexts

Focus on the integration of skills to
build communicative competence



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Focus on participation in real world

- Traditionally AAC interventions have targeted
 - small measurable goals
 - often isolated skills
 - Requests for preferred items
 - within restricted settings
- These studies & interventions are important but they are not enough
 - Should not limit intervention goals to those which are easiest to measure

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Focus on the integration of skills to build communicative competence

- Communicative competence rests on the dynamic integration of knowledge, judgment, & skills to attain goals
 - Linguistic domain
 - Operational domain
 - Social domain
 - Strategic domain (Light, 1989; Light & McNaughton, 2014)

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Focus on successful participation in real world contexts

- Communication is not an end goal in and of itself
 - It is a tool to allow individuals to participate in society and attain life goals
 - Education
 - Employment
 - Healthcare
 - Community and family living
- AAC intervention /research must also focus on participation in real world environments

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Focus on participation in real world contexts

- Challenges
 - AAC research
 - Approximately 40-60% of studies are conducted in isolated settings
 - Majority of studies address interventions implemented by researchers (not clinicians or natural partners)
 - Many service delivery models are set up so that AAC intervention with individuals with CCN occurs
 - Away from their natural environments
 - Without many of their key communication partners

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If we want more evidence-based practice, we need more practice-based evidence (Green, 2008).

Research that investigates AAC intervention to build participation in the real world.

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Focus on participation in real world Lena (O'Neill & Light, 2016)

- 16 year old with autism
- Uses some speech to communicate, but fulfills very few communication opportunities
 - especially during independent living activities & vocational tasks
- Highly dependent on prompting to complete vocational and community tasks



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Focus on participation in the real world

- Goal
 - To increase independent participation in community & vocational activities
 - E.g., using public transportation
 - working at the print shop
 - Requires integration of knowledge, judgment & skills across domains



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Task analysis Using public transportation

- | | |
|-------------------------------------------------------|-------------------------------------|
| 1. Walk to the bus stop. | 7. Walk to seat, sit down, and wait |
| 2. Look at the schedule for the time of the next bus. | 8. Pull cord when stop is next. |
| 3. Wait for the bus to arrive. | 9. Get up and walk to exit. |
| 4. Get on the bus | 10. Thank the driver. |
| 5. Greet driver. | 11. Exit the bus. |
| 6. Give bus pass to driver. | |

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AAC video VSD app

- AAC video VSD app
 - Initial prototype developed by InvoTek as part of RERC on AAC
 - Capture video of daily routines
 - Via built in cameras & wireless import
 - Allow pause of video
 - Create VSDs at these junctures
 - Create hotspots with speech output to support communication



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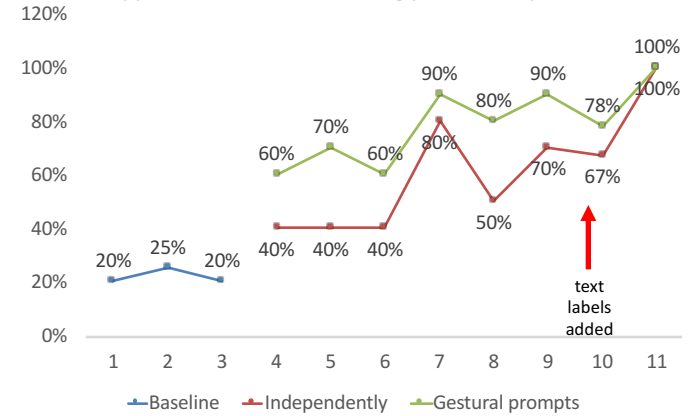
Intervention to increase participation in the real world

- Implementation of AAC video VSD app
 - Provides integrated dynamic visual schedule of routine & VSDs to support communication within routine
 - Play video of each step of activity
 - Video automatically stops at end of step
 - Functions as VSD with hotspots providing communication supports as required



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Percent of steps completed and communication opportunities fulfilled – using public transportation



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Build positive psychosocial factors



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Build positive psychosocial factors

- Communication & participation are impacted
 - Not just by individual's skills
 - But also by personal psychosocial factors (Light, 2003; Light & McNaughton, 2014).
- Most AAC research & intervention focuses on isolated skills alone
 - Only a very small percentage of studies have focused on the development of positive psychosocial factors

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Build positive psychosocial factors

- Psychosocial factors are critical to successful outcomes
 - Motivation – drive to communicate & participate
 - Attitude – willingness to do so
 - Confidence – propensity to act
 - Resilience – persistence in the face of adversity (Light, 2003; Light & McNaughton, 2014)

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Build positive psychosocial factors

- Mentor project (Light, McNaughton, Williams & Krezman, 2007)
 - Provided training for mentors who used AAC in active listening and collaborative problem solving skills
 - Linked adolescents and young adults who used AAC with mentors who also used AAC
 - Access to role models
 - Encouragement and social support
 - Collaborative problem solving and goal setting
 - Access to relevant resources

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Topics / Problems discussed

- Attitude barriers
- AAC systems
- Funding delays
- Lack of knowledgeable service providers
- Low expectations /lack of meaningful roles
- Family stresses / supports
- Challenges developing friendships / relationships
- Feelings about disability, etc.

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Attitude barriers

“Do people ever treat you like you are 2 years old? In my school, some of the kids talk to me like I am 2 years old and can’t hear. It really makes me crazy. I know they are trying to be nice, but I go nuts sometimes. I am 14. Not 2. What should I do to handle this?”

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Challenges promoting friendships

- “I know what you’re going through. When I was in high school I was called names and made fun of. And all I had was a letter board to communicate with. So you think you don’t have any friends in school... Do you ask other students questions about themselves, about the homework assignments, and school activities?? Sometimes you need to focus on them first before they will focus on you.”

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Role of mentors

- Falling in love, starting a new school, starting a new job, changing communities or homes, mastering a skill, learning a new piece of assistive technology - all are easier and more fun if the experience can be shared with and guided by someone who has “been there”

- Michael Williams



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Address environmental barriers



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Address environmental factors

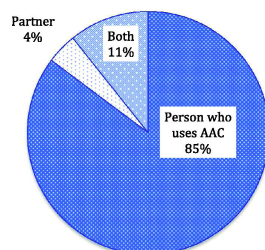
- It is critical to focus on the individual with CCN
 - Skills
 - Psychosocial factors
- But it is not sufficient to do so
- Also critical to address environmental barriers
 - Policy & practice barriers
 - Attitude barriers
 - Knowledge & skills barriers



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Address environmental barriers

- Majority of intervention studies do not address environmental barriers
 - Only a tiny percentage address policy, practice, or attitudinal barriers
 - Only 15% taught partners strategies to support communication
- It is critical to address environmental barriers so that individuals who use AAC have **opportunities** to communicate & participate.



Focus of intervention in studies published between 1985-2015 (McNaughton & Light, 2015)

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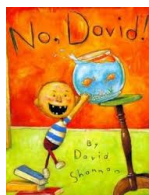
Impact of partner instruction

- Recent meta-analysis (Kent-Walsh, Murza, Malani, & Binger, 2015)
 - Partners learned to modify their interactions strategies successfully in a short amount of time
 - Increased opportunities for communication
 - Changes in partner strategies had positive effects on communication of individuals who use AAC
- Most research to date focused on effects
 - On instruction of educators & parents of children
 - In a limited range of contexts (e.g., book reading)

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Addressing environmental barriers Intervention to foster peer interactions

- Study (Therrien & Light, 2016)
 - Multiple baseline across partners
 - 2 children with CCN
 - Each with 3 peers without disabilities
- Intervention
 - Provision of iPad with AAC app (GoTalk Now)
 - Programmed with motivating books with hotspots of meaningful & fun vocabulary
 - Functioned as a shared context to support interaction between preschoolers who used AAC and peers without disabilities
 - Instruction in “sharing” for both participants
 - Wait for partner
 - Take a turn



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Intervention to foster peer interactions

- Results
 - 2 preschoolers who used AAC showed gains in symbolic communicative turns after intervention
 - Gains observed across different peers without disabilities.
 - Participant 1 demonstrated average gains of 30-46 symbolic communicative turns per 10-minute session
 - Participant 2 had average gains of 11-24 turns
 - Participant 1 maintained gains after three weeks without training
 - Participant 2 moved to new school; no maintenance data

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Just providing AAC systems is not enough! Address environmental barriers

Ensure individuals who require AAC
have **opportunities** to communicate
and participate



Conclusions

- AAC field has come a long way over the past 30 years
 - Research has established the positive effects of AAC on communication
 - Evidence-based AAC intervention has significantly enhanced communication for individuals with CCN and their families
- Now the challenge is to extend our work
 - Research that focuses on enhancing participation and real world outcomes for individuals who require AAC
- AAC intervention that ensures the possible becomes the probable in the daily lives of all individuals with CCN



Re-thinking AAC intervention & research

- We need to re-think AAC intervention & research to improve outcomes
 - Build on the individual's strengths
 - Support the individual's participation in real world contexts
 - Focus on the integration of skills to maximize communicative competence
 - Build positive psychosocial factors
 - Address environmental barriers to ensure opportunity



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A parent talking about her
goals for her child, a
preschooler who uses AAC.

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For further information

For handouts for this session, visit <http://aac.psu.edu>

For free access to Light & McNaughton (2015), visit <http://rerc-aac.org>



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Acknowledgements

- We are especially grateful to the individuals who participated in this project. Thank you for allowing us to be a part of your lives.
- The contents of this presentation were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number #90RE5017) to the Rehabilitation Engineering Research Center on Augmentative and Alternative Communication (RERC on AAC). <http://rerc-aac.org>
- NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this presentation do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

