Perspectives of Parents of Children with Cerebral Palsy on the Supports, Challenges, and Realities of Integrating AAC into Everyday Life

TARA O'NEILL, PH.D., CCC-SLP
KRISTA WILKINSON, PH.D.
11-17-18

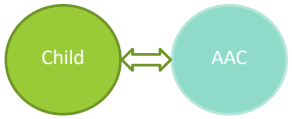
PennState

Disclosures and Acknowledgements

- Hintz Family Endowment for Children's Communicative Competence
- Penn State AAC Leadership Project, U.S. Department of Education grant #H325D110008
- ASHA Student Research Travel Award
- HUGE thanks to:
  - Doctoral adviser: Krista Wilkinson
  - Doctoral committee: Janice Light, Carol Miller, Rick Gillmore
  - Undergraduate research assistants: Brittany Boardley, Caroline Fehr, Erin Franey, and Alicia Hart
  - Parents who participated

Background

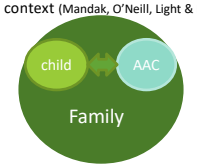
- AAC technologies should be designed to align with the **unique needs and skills** of children with complex communication needs (Blackstone, Williams, & Wilkins, 2007; O'Neill & Wilkinson, 2017)



- The design of AAC technologies can be modified to **achieve a better fit** between the technology and the needs and skills of the child (e.g., Drager et al., 2003; Fallon, Light & Achenbach, 2003; Light, Drager & Nemser, 2004; McCarthy et al., 2006; Wilkinson, O'Neill & McIlvane, 2014; Worah, Light, McNaughton, & Benedek-Wood, 2015)

Background

- Children who use AAC exist as part of a **family system**, whose strengths, needs, and skills cannot be fully understood outside of the family context (Mandak, O'Neill, Light & Fosco, 2017; Minuchin, 1985)



- AAC technologies introduce **additional demands** on family members that may make them resistant to the integration of AAC technologies
- In order to ensure long-term adoption and use of AAC technologies:
  - Technologies must support children in working **towards family-identified goals** (Calculator, 2014)
  - Family members must be able to **support their child** in using AAC technologies (Anderson, Balandin & Stancliffe, 2014)

Previous research: Parent perspectives on AAC

Priorities:

Parents want to be involved in supporting their children's use of AAC and they value AAC to enhance their children's participation and communication

Challenges:

Parents have experienced challenges in learning and programming technologies and working effectively with professionals

Anderson, Balandin & Stancliffe, 2014; Bailey et al., 2006; Calculator & Black, 2010; Calculator, 2013; Calculator, 2014; Goldbart & Marshall, 2004; McCord & Soto, 2004; McNaughton et al., 2008; Parette et al., 2001

Previous research: Parent perspectives on AAC

Priorities:

Parents want to be involved in supporting their children's use of AAC and they value AAC to enhance their children's participation and communication

Challe

Parent
effecti

Little is known about the specific AAC technology features that parents perceive to meet these priorities and address these challenges so that AAC technologies can be integrated into everyday life

Anderson, Balandin & Stancliffe, 2014; Bailey et al., 2006; Calculator & Black, 2010; Calculator, 2013; Calculator, 2014; Goldbart & Marshall, 2004; McCord & Soto, 2004; McNaughton et al., 2008; Parette et al., 2001

Questions

- (1) What are parents' perceptions of how AAC technologies support their child's **participation in family goals and the functional contexts of everyday life**?
- (2) What **features of AAC technologies present challenges or supports to participation** and integration of technologies into the functional contexts of everyday life?

Method: Design

Qualitative research design using **semi-structured interviews**

- **Why qualitative?**
  - Effective to describe and explain experiences from the perspective of participants (Bogdan & Bilken, 2007; Denzin & Lincoln, 2005)
- **Why semi-structured interviews?**
  - Ensures systematic data collection across participants
  - Additional questions can emerge from dialogue (Patton, 2015)

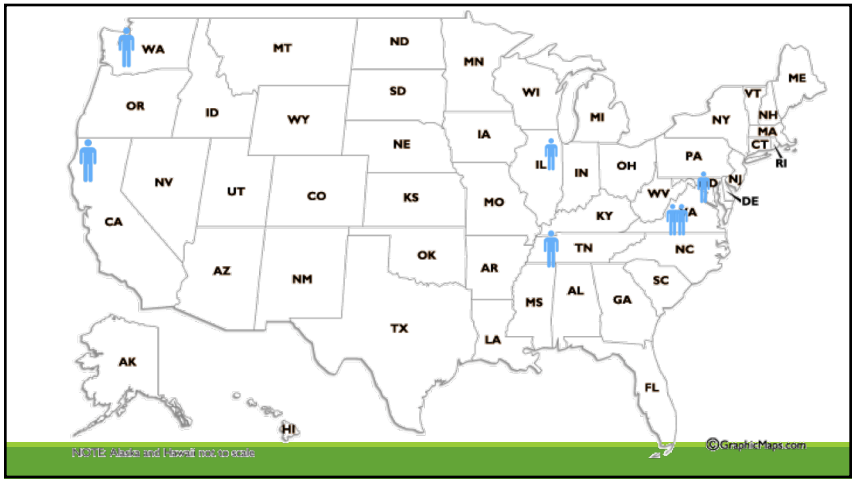
Method: Participants

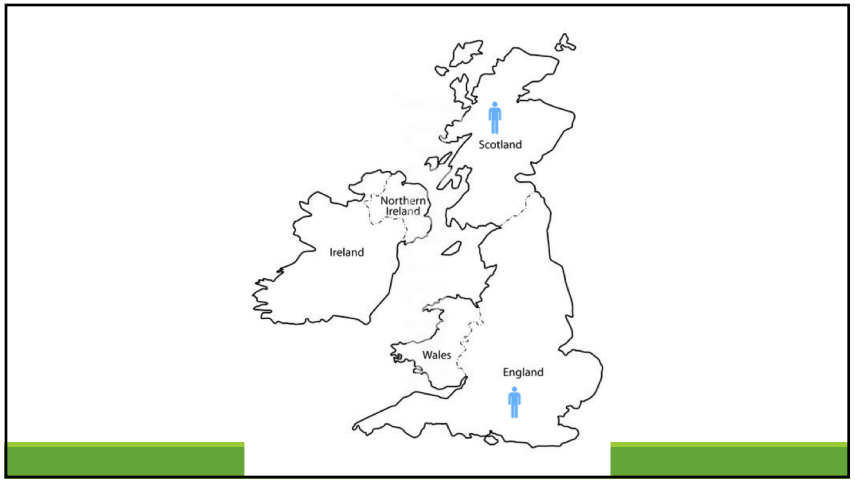
9 parents (8 mothers, 1 father) of 8 children who:

- Had cerebral palsy
- Were between 6-14
- Used AAC technologies

Method: Participants

Parents								
Pseudonym(s)	Allison & Jacob	Amelia	Lucy	Bailey	Jackie	Kelli	Emily	Shannon
Parent age	40 to 54	25 to 39	25 to 39	25 to 39	25 to 39	40 to 54	40 to 54	40 to 54
Parent education	4-year degree	4-year degree	4-year degree	Professional degree	4-year degree	Some college	Professional degree	4-year degree
Children at home	2	1	3	1 (+2 step-siblings)	4	3	1	3
Children								
Pseudonym	Zane	Julia	Jackson	Felix	Hayden	Taylor	Sadie	Luke
Child age	9	7	8	11	6	14	12	10
School setting	Inclusive	Home-schooled	Inclusive	Segregated	Segregated	Inclusive	Inclusive	Inclusive
AAC device	Proloquo2go app on iPad	Proloquo2go app on iPad	PRC accent 1400	NOVA Chat 10	NOVA chat 12	Tobii i15	PRC accent 1400	Tobii i12
Time using device	6 years	2+ years	2 years	2;8	2;6	3 years	10 months	5;6
Selection technique	Direct selection-finger	Direct selection-whole hand	Direct selection- eye gaze	Direct selection-finger	Direct selection-finger	Direct selection- eye gaze	Direct selection-eye gaze	Direct selection-eye gaze

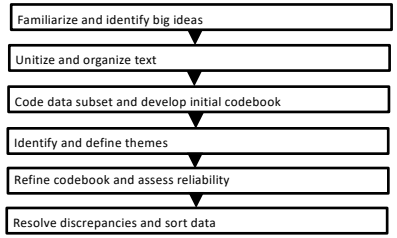




Method: Procedures

- Parents completed a background questionnaire
- PI conducted the interviews via video conference (7 parents) or phone (2 parents)
- 45-80 minutes in length
- Recorded and transcribed verbatim

Data Analysis: Thematic Analysis



Braun & Clarke, 2006; Campbell, Quincy, Osserman & Pedersen, 2013; Creswell, 2012; MacQueen, McLellan, Kay, & Milstein, 1998; Miles, Huberman & Saldana, 2014; Vaughn, Schumm, & Sinagub, 1996

Method: Research Quality Indicators

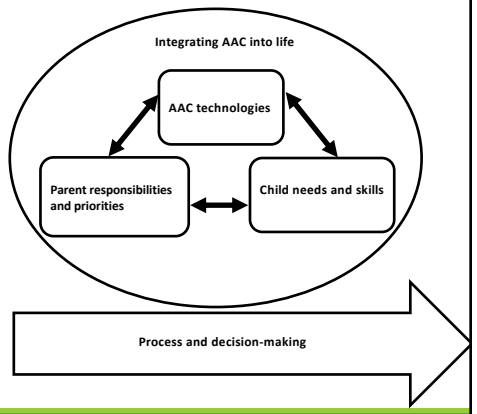
Credibility (believability)	Transferability	Reliability	Confirmability
• Triangulation of investigators	• Thick description	• Intercoder agreement	• Member check

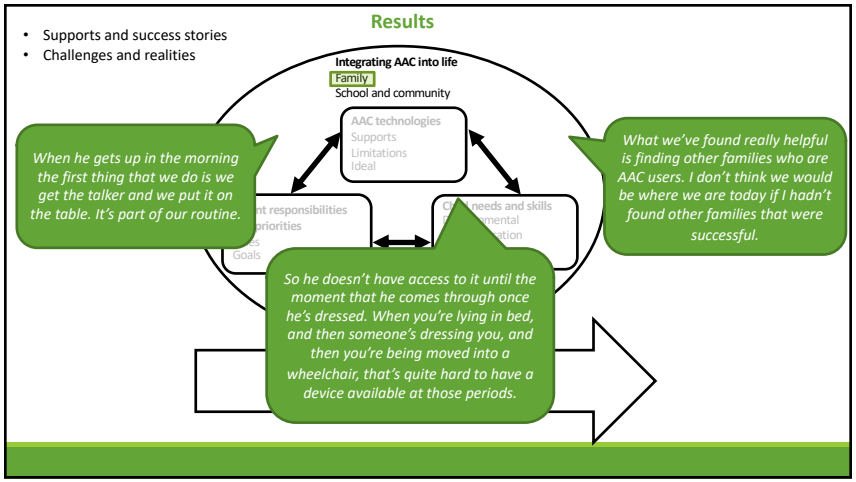
Campbell, Quincy, Osserman & Pedersen, 2013; Creswell, 2012; Geertz, 1983; Given, 2008; Hays & Singh, 2014; Lincoln & Guba, 1985; Tracy, 2014

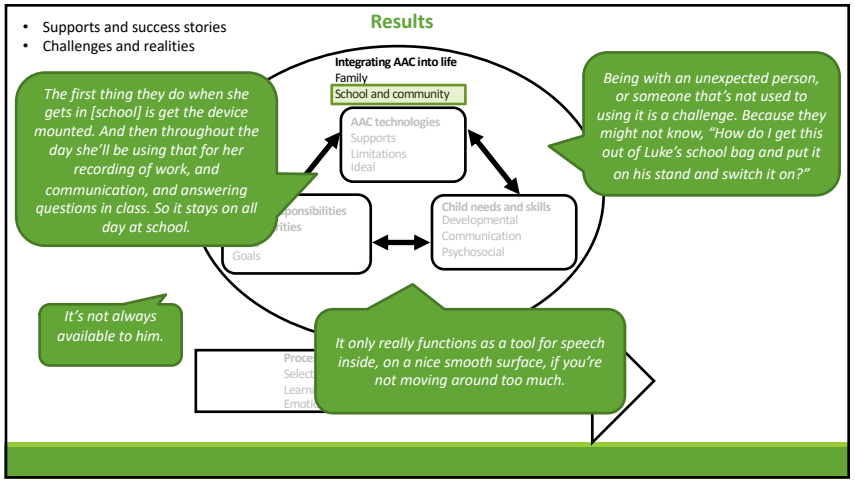
Results

Themes

- Integrating AAC into life
- AAC technologies
- Child needs and skills
- Parent responsibilities and priorities
- Process and decision-making







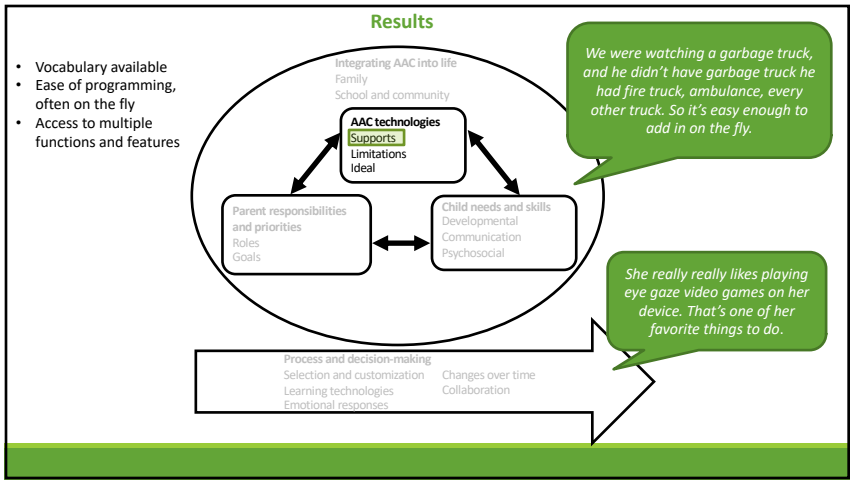
Integrating AAC Theme: Summary and Implications

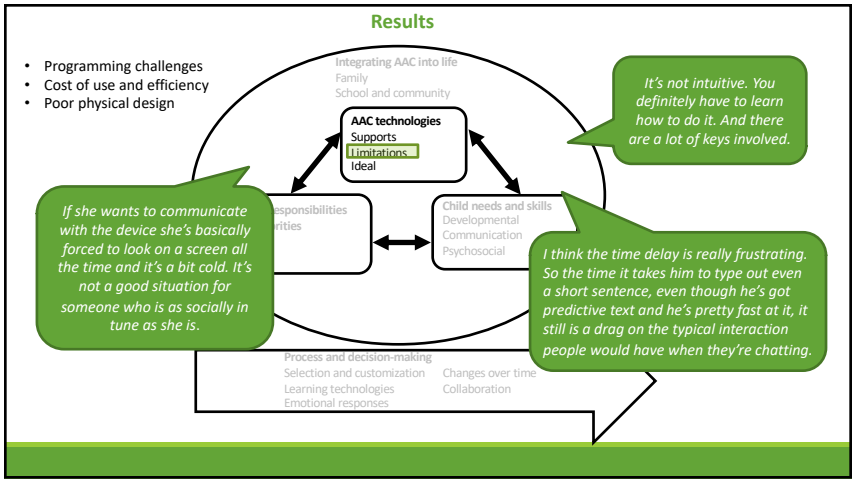
SUMMARY

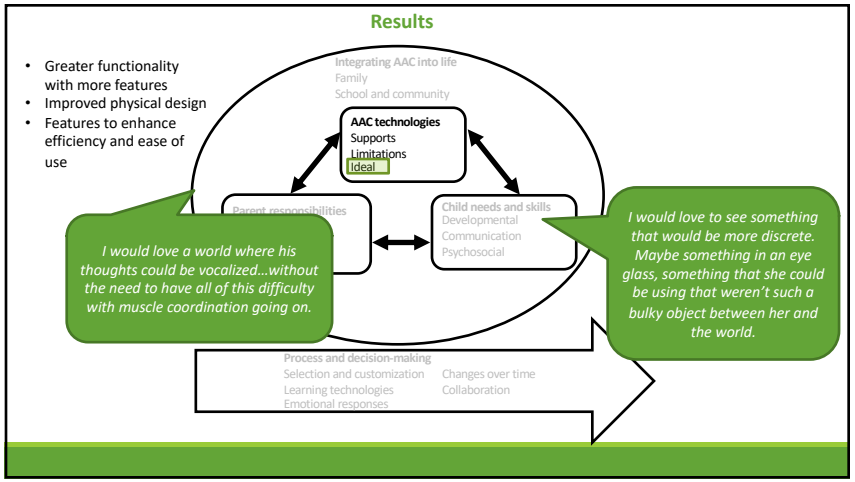
- Children used AAC technologies with various partners and in various everyday contexts
- However, AAC technologies were not always available

IMPLICATIONS FOR PRACTICE AND THE DESIGN OF TECHNOLOGIES

- Professionals should ask families about **contexts in which they value the use of AAC technologies**, and brainstorm ways for families to integrate AAC into those contexts
- Manufacturers should continue to develop technologies that can be more easily integrated into life (e.g., durable, lightweight, greater accessibility in rain and sunlight, augmented reality features)







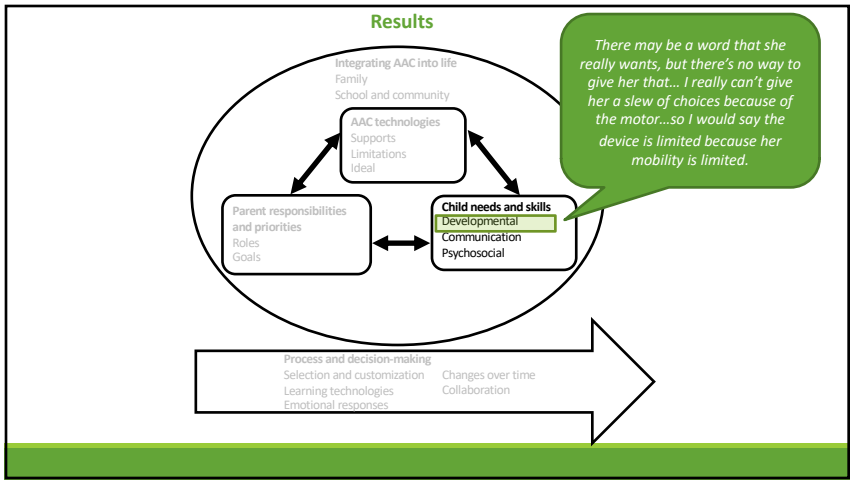
AAC Technologies Theme: Summary and Implications

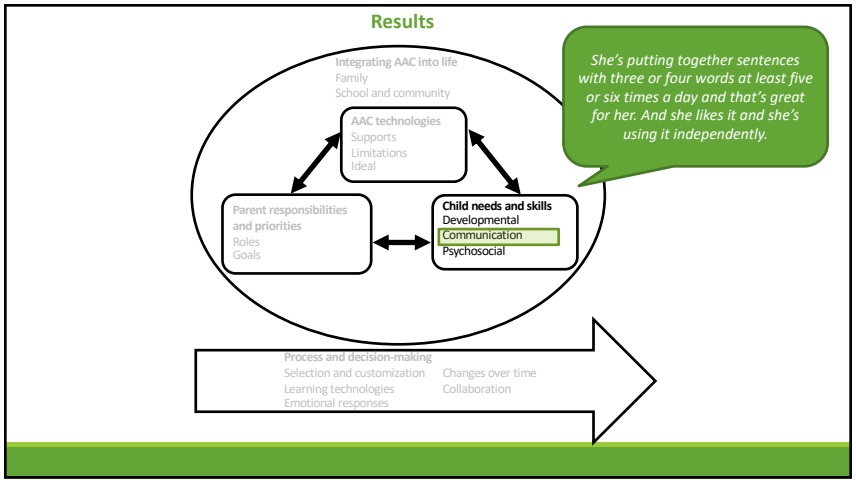
SUMMARY

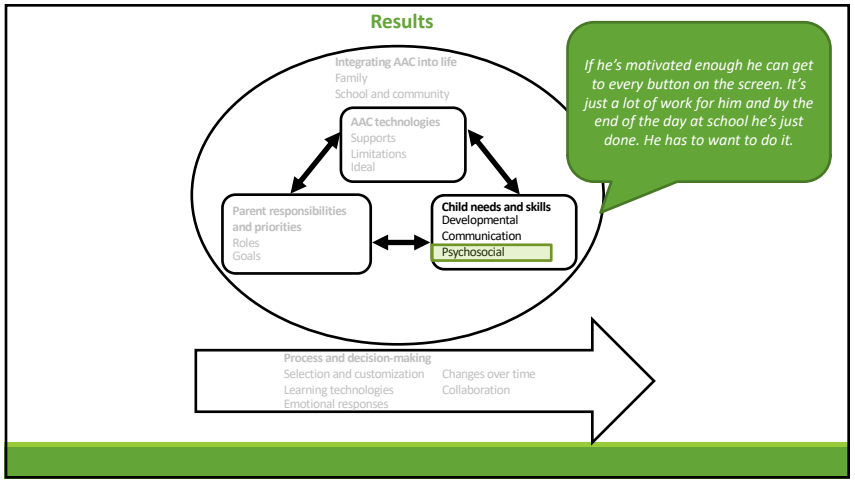
- Current AAC technologies had features that supported participation and also features that presented barriers for participation
- Parents had unique ideas for improving the design of technologies

IMPLICATIONS FOR THE DESIGN OF TECHNOLOGIES

- AAC technology development must take a **multi-disciplinary approach** that includes children who use AAC and their families, clinicians, AAC researchers, rehabilitation engineers, and mainstream technology developers







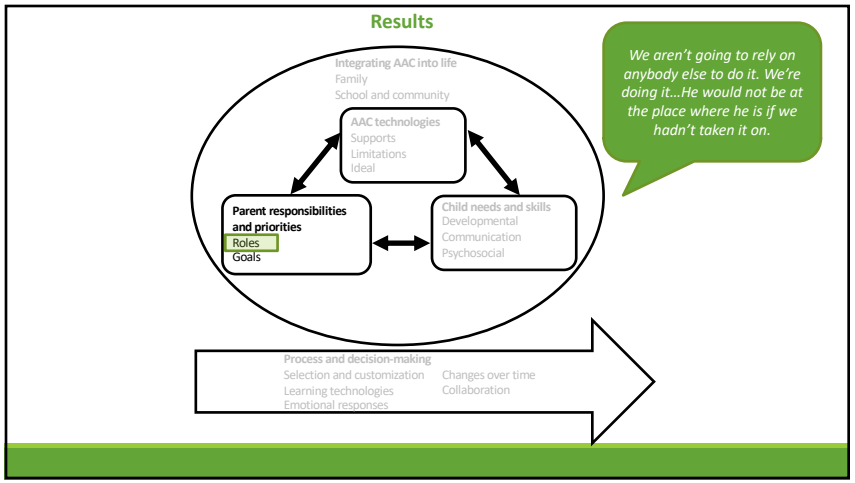
Child Needs and Skills Theme: Summary and Implications

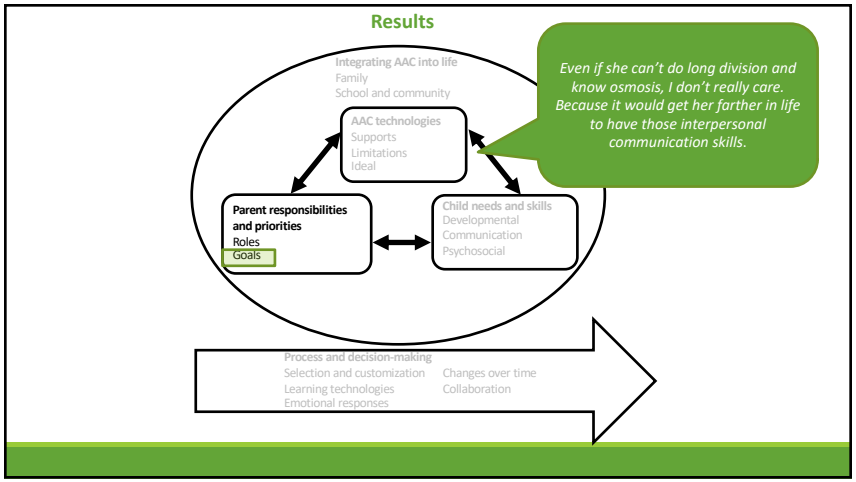
SUMMARY

- Children developed communicative competence using AAC technologies
- Developmental needs and skills and psychosocial factors contributed (positively or negatively) to their ability to effectively use AAC

IMPLICATIONS FOR PRACTICE

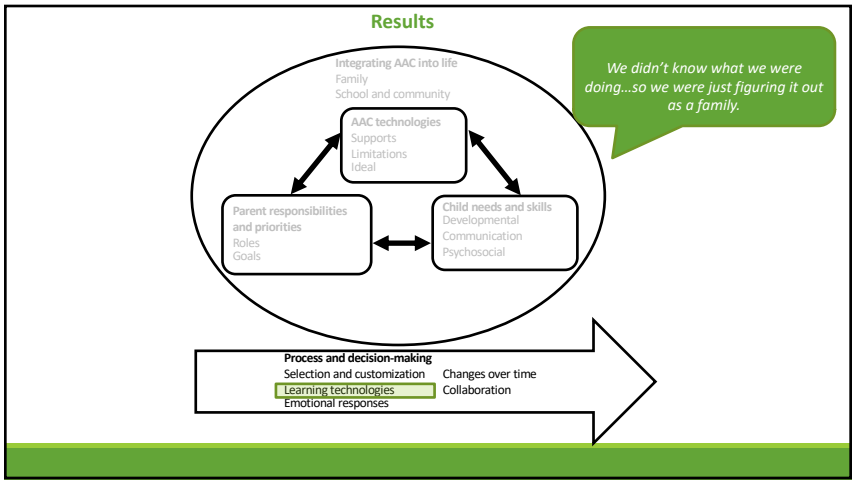
- **Seek parents' expert input** on their child's needs and skills
- Use this expert knowledge to **customize technologies**

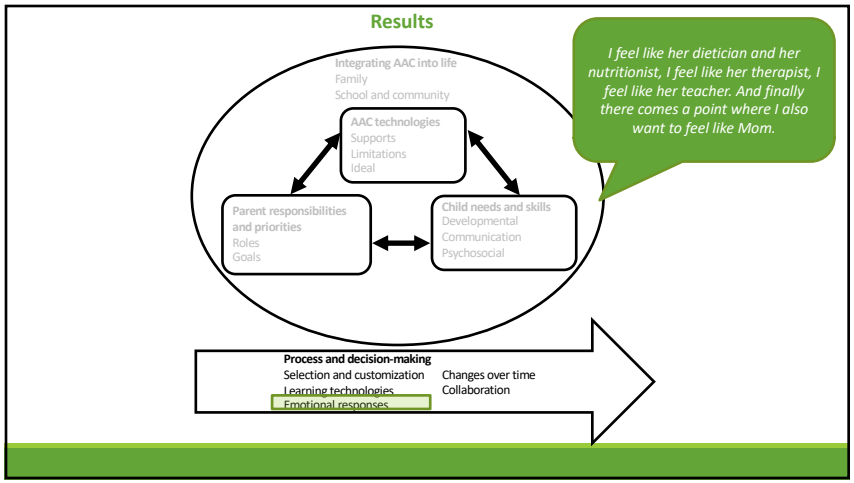




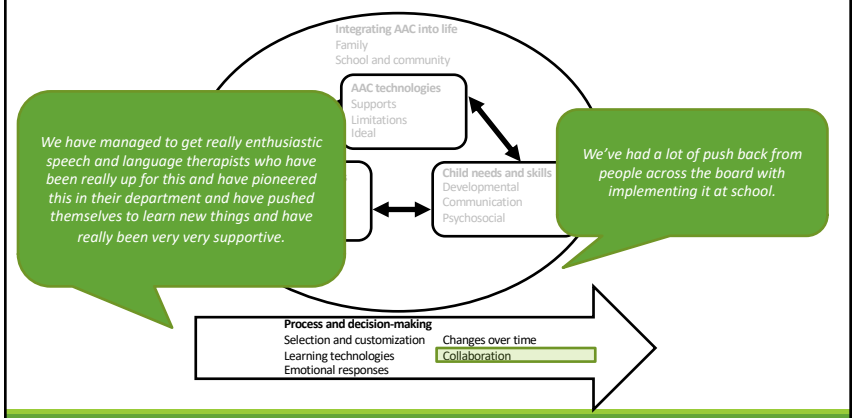
Parent Responsibilities and Priorities Theme: Summary and Implications

SUMMARY	IMPLICATIONS FOR PRACTICE
•Parents took a leadership role and managed multiple responsibilities	•Demonstrate sensitivity to the **competing demands of everyday family life**
•Parents prioritized their children's development of communicative competence and their independence and inclusion	•Engage in **collaborative goal-setting** with families to ensure that AAC technologies are responsive to family-identified priorities (King & Chiarello, 2014)





Results



Process and Decision-making Theme: Summary and Implications

SUMMARY

- Acquiring and learning to use AAC technologies was an ongoing process that required decision- making and collaboration with professionals

IMPLICATIONS FOR PRACTICE

- Form **collaborative relationships** with parents that are characterized by mutual trust and information sharing
- **Improve training** for professionals in the knowledge and skills needed for **AAC** assessment and intervention *and* **working effectively with families**

Limitations → Future Research

- Results reflect the perspectives of a small group of **well-educated, highly involved parents**, with little diversity → Seek perspectives of a **larger, more diverse group** of individuals
  - Various ages, diagnoses, and cultural and linguistic backgrounds
- Data were collected at **one point** in time → Conduct **longitudinal research** to capture how experiences change over time
- Results reflect only the experience of parents and not **other important stakeholders** (e.g., siblings, extended family, child using technology, care aids, school professionals, etc.) → Gain input from multiple stakeholders using an **in-depth case-study approach**

Key take-aways

- AAC technologies support children's participation in **family goals** and **everyday life**!
  - When family priorities, preferences, and routines are considered
- We still have **"work to do"** to improve the technology design and collaboration with families.

"Hopefully in the future we [are] able to achieve much more"

Thank you!

Tara O'Neill, PhD, CCC-SLP

toneill1@misericordia.edu

MISERICORDIA UNIVERSITY

References

Anderson, K. L., Balandin, S., & Stancliffe, R. J. (2015). Alternative service delivery models for families with a new speech generating device: Perspectives of parents and therapists. *International Journal of Speech-Language Pathology, 17*, 185-195. doi:10.3109/17549507.2014.979876

Bailey, R. L., Parette, H. P., Stoner, J. B., Angell, M. E., & Carroll, K. (2006). Family members' perceptions of augmentative and alternative communication device use. *Language, Speech, and Hearing Services in Schools, 37*, 50-60. doi:10.1044/0161-1461(2006/006)

Blackstone, S. W., Williams, M. B., & Wilkins, D. P. (2007). Key principles underlying research and practice in AAC. *Augmentative and Alternative Communication, 23*, 191-203. doi:10.1080/07434610701553684

Bogdan, R. C. & Biklen, S. K. (2007). *Qualitative research for education: An introduction to theory and methods* (5th Ed.). Needham Heights, MA: Allyn & Bacon.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*, 77-101. doi:10.1191/1478088706qp063oa

Calculator, S. N., & Black, T. (2010). Parents' priorities for AAC and related instruction for their children with Angelman syndrome. *Augmentative and Alternative Communication, 26*, 30-40. doi:10.3109/07434610903585406

Calculator, S. N. (2014). Parents' perceptions of communication patterns and effectiveness of use of augmentative and alternative communication systems by their children with Angelman syndrome. *American Journal of Speech-Language Pathology, 23*, 562-573. doi:10.1044/2014_AJSLP-13-0140

Campbell, J. L., Quincy, C., Osserman, J., & Pedersen, O. K. (2013). Coding in-depth semi-structured interviews: Problems of unitization and intercoder reliability and agreement. *Sociological Methods & Research, 42*, 294-320. doi:10.1177/0049124113500475

Creswell, J. W. (2012). *Qualitative inquiry and research design: Choosing among five approaches*. Thousands Oak, CA: SAGE Publications.

Denzin, N., & Lincoln, Y. (2005). *Handbook of qualitative research* (3rd ed.). Thousand Oaks, CA: Sage.

Drager, K. D. R., Light, J. C., Speltz, J. C., Fallon, K. A., & Jeffries, L. Z. (2003). The performance of typically developing 2½-year-olds on dynamic display AAC technologies with different system layouts and language organizations. *Journal of Speech Language and Hearing Research, 46*, 298. doi:10.1044/1092-4388(2003/024)

Fallon, K., Light, J., & Achenbach, A. (2003). The semantic organization patterns of young children: Implications for augmentative and alternative communication. *Augmentative and Alternative Communication, 19*, 74-85. doi:10.1080/0743461031000112061

Geertz, C. (1983). Thick description: Toward an interpretive theory of culture. *The interpretation of cultures* (pp. 3–30). New York: Basic Books.

Given, L. M. (Ed.). (2008). *The SAGE encyclopaedia of qualitative research methods* (Vols. & 2). London, UK: Sage Publications.

Goldbart, J., & Marshall, J. (2004). "Pushes and Pulls" on the Parents of Children who use AAC. *Augmentative and Alternative Communication, 20*, 194-208. doi:10.1080/07434610400010960

Hays, D. G. & Singh, A. A. (2014*). Qualitative inquiry in clinical and educational settings*. New York: Guilford Press.

References

King, G., & Chiarello, L. (2014). Family-centered care for children with cerebral palsy: Conceptual and practical considerations to advance care and practice. *Journal of Child Neurology, 29*, 1046-105. doi:10.1177/0883073814533009

Light, J., Drager, K., McCarthy, J., Mellott, S., Millar, D., Parrish, C., . . . Welliver, M. (2004). Performance of typically developing four- and five-year-old children with AAC systems using different language organization techniques. *Augmentative and Alternative Communication, 20*, 63-88. doi:10.1080/07434610410001655553

Light, J. C., Drager, K. D., & Nemser, J. G. (2004). Enhancing the appeal of AAC technologies for young children: Lessons from the toy manufacturers. *Augmentative and Alternative Communication, 20*, 137-149. doi:10.1080/07434610410001699735

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry* (Vol. 75). Sage.

MacQueen, K. M., McLellan, E., Kay, K., & Milstein, B. (1998). Codebook development for team-based qualitative analysis. *Field Methods, 10*, 31. doi:10.1177/1525822X980100020301

Mandak, K., O'Neill, T., Light, J., & Fosco, G. M. (2017). Bridging the gap from values to actions: a family systems framework for family-centered AAC services. *Augmentative and Alternative Communication, 33*, 32-41. doi:10.1080/07434618.2016.1271453

McCarthy, J., Light, J., Drager, K., McNaughton, D., Grodzicki, L., ... & Parkin, E. (2006). Re-designing scanning to reduce learning demands: The performance of typically developing 2-year-olds. *Augmentative and Alternative Communication, 22*, 269-283. doi:10.1080/00498250600718621

McCarthy, J. W. & Boster, J. B. (2017). A comparison of the performance of 2.5 to 3.5-year-old children without disabilities using animated and cursor-based scanning in a contextual scene, *Assistive Technology,* 1-8. doi: 10.1080/10400435.2017.1307883

McCord, M. S., & Soto, G. (2004). Perceptions of AAC: An ethnographic investigation of Mexican-American families. *Augmentative and Alternative Communication, 20,* 209-227. doi:10.1080/07434610400005648

McNaughton, D., Rackensperger, T., Benedek-Wood, E., Krezman, C., Williams, M. B., & Light, J. (2008). "A child needs to be given a chance to succeed": Parents of individuals who use AAC describe the benefits and challenges of learning AAC technologies. *Augmentative and Alternative Communication, 24*, 43-55. doi:10.1080/07434610701421007

Miles, M. B., Huberman, A. M., & Saldaña, J. (2014). *Qualitative data analysis: A methods sourcebook* (Third ed.). Thousand Oaks, California: SAGE Publications, Inc.

Minuchin, P. (1985). Families and individual development: Provocations from the field of family therapy. *Child Development*, *56*, 289-302. doi:10.1111/j.1467-8624.1985.tb00106.x

O'Neill, T. & Wilkinson, K M. (2017, November). *"Valuable," though not "prerequisite": Designing AAC systems that respond to and promote early developmental skills*. Poster session presented at the annual conference of the American Speech-Language-Hearing Association, Los Angeles, CA.

References

Parette Jr, H. P., Brotherson, M. J., & Huer, M. B. (2000). Giving families a voice in augmentative and alternative communication decision-making. *Education and Training in Mental Retardation and Developmental Disabilities, 35*, 177-190.

Patton, M. Q. (2015). *Qualitative research & evaluation methods: Integrating theory and practice* (Fourth ed.). Thousand Oaks, California: SAGE Publications, Inc.

Thistle, J. J., & Wilkinson, K. M. (2015). Building evidence-based practice in AAC display design for young children: Current practices and future directions. *Augmentative and Alternative Communication, 31*, 124-136. doi:10.3109/07434618.2015.1035798

Tracy, S. J. (2013). *Qualitative research methods: Collecting evidence, crafting analysis, communicating impact*. John Wiley & Sons.

Vaughn, S., Schumm, J. S., & Sinagub, J. M. (1996). *Focus group interviews in education and psychology*. Thousand Oaks: Sage Publications.

Wilkinson, K., O'Neill, T., & McIlvane, W. (2014). Eye-tracking measures reveal how changes in the design of aided AAC displays influence the efficiency of locating symbols by school-age children without disabilities. *Journal of Speech Language and Hearing Research, 57*, 455-466. doi:10.1044/2013_JSLHR-L-12-0159

Worah, S., McNaughton, D., Light, J., & Benedek-Wood, E. (2015). A comparison of two approaches for representing AAC vocabulary for young children. *International Journal of Speech-Language Pathology, 17*, 460-469. doi:10.3109/17549507.2014.987817