Building an important line of research to make a positive difference

Janice Light, Ph.D.
RERC on AAC Doctoral Student Think Tank
Penn State University, University Park, PA
May 10-12, 2022





Thank you!

Thank you for choosing to dedicate your careers to improving outcomes for individuals with complex communication needs and their families

1

Objectives for session

- To discuss what it means to build a line of research
 - Why it is important
- To provide some examples of lines of research
- To suggest some strategies for developing a research career
 - To share some lessons I learned during my research career



What is a line of research?

- A series of interrelated research studies designed to solve an important problem
- Your research plan
 - Driven by sound theory
 - Supported by empirical data
 - Fueled by vision of what could be



3

4

Why is it important to develop a line of research?

- Provides a road map to make a positive impact
 - Allows you to actually solve the problem & improve outcomes
- Provides a plan for your research career
 - Defines important steps and milestones along the way
- Brings recognition of your work
 - Allows you to be "known" for your work in a particular area

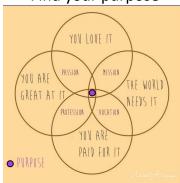
Getting started

- Start with a vision
- How do you want to make a difference?



6

Lesson #1 Find your purpose



Lesson #2 Focus on what is important

- A research program should have an important purpose
 - There are many questions but not all of them are worth answering
 - We have limited researchers and limited research funds
 - Don't waste time, money, & effort on trivial pursuits
 - Avoid research that is of limited consequence



7

RERC on AAC Think Tank, 2022

5

Lesson #2 Focus on what is important

- Engage in integrated knowledge translation
- Start by listening to stakeholders
 - Individuals who rely on AAC
 - Families
- What are the key challenges they face?
- Ask yourself:
 - "What difference will this research make?"





Lesson #2 Focus on what is important

- Don't ever stop asking questions
 - To advance knowledge
 - To improve practice
- Ask **beautiful** questions
 - Significant
 - Insightful
 - Unique
 - Potentially game-changing



9

10

Lesson #3 Tackle the problem step by step

- Important problems are not solved through a single study
 - Discovery is the result of the systematic accumulation of evidence across studies



Tackle the problem step by step:

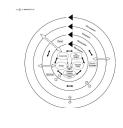
- 1. Describe the problem
- 2. Consider the solution
- 3. Figure out what needs to happen in between



11

Tackle problems step by step

- · AAC research is complex
- · Numerous variables to consider
 - Intrinsic variables related to the individual who requires AAC
 - Extrinsic variables related to the environment / communication partner
 - Variables related to AAC systems
 - Intervention/ instructional variables
- Systematically tease out these variables



Mandak, O'Neill, Light & Fosco, 2017

An example of building a line of research Identify an important problem

- Literacy skills are essential to all aspects of life
- More than 90% of individuals with complex communication needs enter adulthood without functional literacy skills
- As a result, they are severely restricted in
 - education, employment, healthcare & community living
 - access to generative language



13

14

The solution

 Effective, adapted, evidencebased intervention implemented across the nation so that individuals with complex communication needs develop functional literacy skills



Move from the problem to the solution NIDILRR's Stages of Research

| Exploration & discovery | Intervention development | Intervention efficacy | Scaled-up evaluation |

15

Exploration and discovery

- · Explores the problem in more detail to increase understanding
 - Factors that may limit successful outcomes
 - Factors that may support successful outcomes
- Generates hypotheses or theories
- Informs the development of intervention to address the problem
- Is not always necessary

17

- We may already know enough about the problem
- Research should never stop here

An example Exploration & Discovery

- Explore the early literacy experiences of children with complex communication needs
 - Survey methodology (Light & Kelford Smith)
 - Observational research (Light, Binger & Kelford Smith)
- Identify barriers

18

· Identify supports



Stages of research (NIDILRR) Exploration & Intervention discovery Intervention efficacy Scaled-up evaluation

Intervention development

- Focuses on development & initial testing of intervention to improve outcomes (solve the problem)
- Determines important components of intervention
- Defines important variables; develops measures
- Assesses the feasibility of the intervention

19

RERC on AAC Think Tank, 2022

-5

An example: Intervention development

- Development of training to teach partners to enhance storybook reading
 - Read
 - Model the use of AAC
 - Wait & allow child time to communicate
 - Ask appropriate questions
 - Respond to the child's communication
- Preliminary evaluation of this intervention (Kent Walsh, Light & McNaughton)



Stages of research (NIDILRR)

Exploration & Intervention discovery

Intervention efficacy

Scaled-up evaluation

21

Intervention efficacy

- Evaluates the efficacy of the intervention
- Assesses the strength of the relationship between the intervention and the outcomes
- May identify intrinsic or extrinsic factors that may impact outcomes
 - What intervention is effective with whom under what conditions
- Determines whether there is sufficient evidence to support "scaling up" intervention

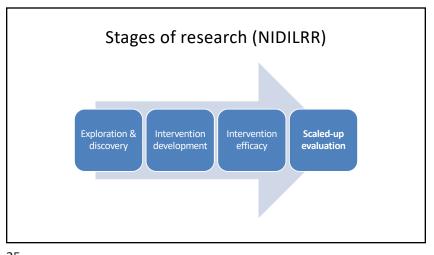
An example: Intervention efficacy

- Series of studies to investigate the effects of partner training program on the participation of children who require AAC during storybook reading
 - parents, paraprofessionals, teachers
 - children of different ages with different disabilities
 - Kent Walsh, Binger & colleagues



23

RERC on AAC Think Tank, 2022



Scaled-up intervention

- Provides larger scale evaluation of the intervention in the real world
- Tests the outcomes of an evidence-based intervention in a range of real world settings
- Investigates the challenges of real world adoption

25

26

Scaled-up intervention

- Broad-based dissemination of the parent training program
 - imPAACT program (Kent Walsh, Binger &
- Evaluation of real world uptake and application
 - Web-based training
- Evaluation of real world outcomes

ImPAACT Program: Purpose of Targeted Skills (Kent-Walsh, Binger & colleagues, 2012)	
Aided AAC Modeling	To provide functional models of effective AAC use
Expectant Delay	 To provide communication opportunities, additional processing time, and an expectation for communication.
WH-Question Asking	To prompt higher-level content expression
Verbal Prompts	To provide client with direct indication of what s/he is supposed to do
Increased Responsivity	To reinforce communicative attempts and expanded utterances.

We were making progress by increasing partner knowledge & skills

BUT....

There were significant technology barriers that also had to be addressed to improve emergent literacy outcomes

27

The problem

- AAC technologies were
 - Difficult to integrate with book reading activities
 - Difficult for young children to learn and use
 - Time consuming to program with new vocabulary
 - Not responsive to child interests in the moment
- The solution

29

31

 Improved AAC technologies that are quick & easy to program & use and that appeal to children

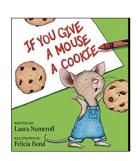


Proof of concept
To determine if idea is feasible

Proof of product
Trials to determine if technology is beneficial; evaluate uptake

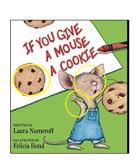
An example: Proof of concept

- Easy VSD app (Jakobs & Jakobs)
 - Allows quick & easy capture of meaningful activities as visual scene displays (VSDs)
 - Integrates books & AAC supports
 - Infuses language concepts into context
 - Supports quick & easy "just in time" (JIT) programming of new vocabulary
 - Allows parents to respond to child interests & needs on the fly
 - Supports language & emergent literacy development



An example: Proof of concept

- Easy VSD app (Jakobs & Jakobs)
 - Allows quick & easy capture of meaningful events
 - Integrates books & AAC supports
 - Infuses language concepts into context
 - Supports quick & easy "just in time" (JIT) programming of new vocabulary
 - Allows parents to respond to child interests & needs on the fly
 - Supports language & emergent literacy development



RERC on AAC Think Tank, 2022

32

An example: Proof of product

- Series of studies to investigate effects of AAC VSD app that supports JIT programming
 - young children who require AAC (Light, Drager, et al., 2012)
 - older beginning communicators (Holyfield et al., 2019; Drager et al., 2019)
 - young children who require AAC with typical peers (Therrien & Light, 2016; 2018)
 - young children with ASD with their parents (Laubscher et al. 2022)

33



An example: Proof of adoption

- Successful tech transfer to AAC manufacturers
- Next step Scaled up evaluation of adoption, uptake, & effects

34





We had made progress

Young children who required AAC had the opportunity, supports, & tools to develop emergent literacy skills

But we still had not solved the problem

They were not yet reading!

35

RERC on AAC Think Tank, 2022

So......

We cycled back to tackle the problem of learning conventional literacy skills

Need for adapted literacy instruction Need for AAC technologies to support the transition to literacy

Build lines of research & development

New line of research

- Develop and evaluate the effects of adapted literacy instruction (ALL curriculum) (Light & McNaughton, 2009)
 - Intervention development
 - Intervention efficacy
- Scaled-up intervention (implementation science) to investigate uptake & adoption (Caron, 2022)



37

38

Build lines of research & development

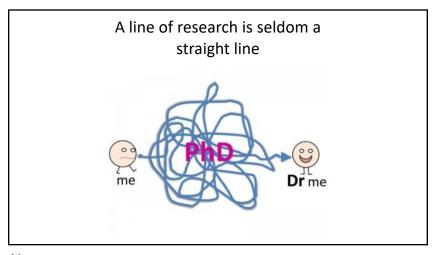
New line of technology development



- Develop & evaluate AAC technologies to support the transition from picture symbols to literacy
 - Transition to literacy (T2L) sight word technology
 - T2L decoding technology

Start to plan your line of research now!

39



But it should not be a smattering of unrelated studies

41

43

Lesson #4
Build your arsenal of research tools

- Learn everything that you can about research methods & data analysis
 - Qualitative & quantitative methods
 - Observational & experimental
 - Tools to answer any question
 - · From basic research to
 - · Applied clinical research to
 - Implementation science
- Hone your science
 - It doesn't take any more time to do good research than it does to do bad research



RERC on AAC Think Tank, 2022

44

Lesson #5 Work hard

- · Work hard
 - One of the greatest predictors of achievement is time on task
- · Never stop learning
 - Read & learn as much as possible
 - in AAC
 - · in other domains
 - Synthesize & integrate across domains
- Persevere



Lesson #6 **Build an AAC community**

- "One is never enough"
 - Discovering solutions requires the input of many
 - Reach out to others /collaborate
- Build an AAC community
 - Individuals who use AAC, families, undergraduate & graduate students, faculty, clinicians, engineers, technology developers, AT manufacturers
 - Other researchers
 - Those in AAC
 - Those in other disciplines



45

Many thanks to my AAC community

- · Jane Cale
- · Barbara Collier
- Penny Parnes
- · Nora Rothschild
- Lynnette Norris
- Arlene Kraat
- Sarah Blackstone
- Margret Beesley
- · David McNaughton
- Peter Lindsav
- Rosemary Tannock

- David Beukelman
- · Pat Mirenda
- Alison Kelford Smith
- Susan Thurston
- Steve Calculator
- Luigi Girolametto
- Karen Yanak
- Barbara Roberts
- John Dattilo
- Jane English
- Lisa Gutierrez

Many thanks to my AAC community

Jane Hartz

46

- · Rosemarie DiMarco
- · Nina Greiner
- · Tracy Agate
- · Karen Ramsay
- Betty Stoltz
- · Kevin Cohen
- Karen Fallon
- · Tara Kramer-Page

- Michael Williams
- · Carole Krezman
- · Cathy Binger

- Eva Björck-Åkesson
- · Mats Granlund
- · Kathy Drager
- · John McCarthy
- · Linda Groszyk
- Kara Arnold
- Liz Clark
- Maija Gulens
- Arielle Parsons
- · Joe Reichle
- · Jennifer Kent Walsh
- · Amy Achenbach

47 48

RERC on AAC Think Tank, 2022

Many thanks to my AAC community

- · Shelley Lund
- · Stephanie Gulla
- · Diane Millar
- · Craig Parrish
- Jessica Currall
- Suzanne Mellott
- · Stacy Rhoads
- Marika Ward
- Michelle Welliver
- Jessie Nemser
- Rhonda Carlson
- Karen D'Silva

- · Brittany Larsson
- · Gini Stopper
- Gus Estrella
- · Laura Estrella
- Megan Seabury
- Rebecca Page
- Jen Curran
- Laura Pitkin
- · Tracy Rackensperger
- · Elizabeth Benedek-Wood
- Lauren Jeffries
- · Laura Grodzicki

Many thanks to my AAC community

- Elizabeth Panek
- Elizabeth Parkin
- Ralf Schlosser
- · Erinn Finke
- · Line Kristiansen
- · Marissa Weyer
- Lauren Karg
- Jeff Higginbotham
- Diane Bryen
- Kevin Caves
- Frank DeRuyter
- Tom Jakobs

50

- Erik Jakobs
- · Howard Shane
- Alix Galskoy
- Marleah Umpleby
- · Melanie Fried-Oken
- · Susan Fager
- Krista Wilkinson
- · Aileen Costigan
- Karl Newell
- Kelly Chew
- · Sarah Guthrie
- · Lisa Mellman

49

Many thanks to my AAC community

- · Katie Riley
- · Sarah Douglas
- Smita Worah
- Nimisha Muttiah
- Jessica Caron
- Michelle Therrien
- April Yorke
- Beth Davidoff
- Caitlin Brown
- Megan DoorisGina Pecile
- Carly Staffin

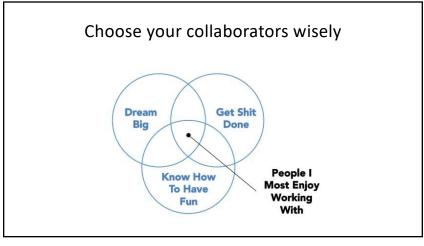
- Julia Karnezos
- Merissa Ekman
- Shelley Chapin
- Suz Boyle
- Lauramarie Pope
- Clark Knudtson
- · Hannah Young
- Megan Hoorn
- · Ethan Richtsmeier
- Maggie Lamb
- Crystal Bluto
- · Mari Therrien

- Christine Holyfield
- Kelsey Mandak
- · Tara O'Neill Zimmerman
- · Jessica Gormley
- Salena Babb
- Naima Bhana
- Sojung Jung
- Emily Laubscher
- Kaitlyn Clarke
- Amanda Slowey
- · Tara Tedesco
- Savanna Brittlebank-Douglas
- Dana Nieder
- Chris Klein

52

- Many thanks to my AAC community
 - Godfrey NazarethDave Chapple
 - Tracy Rackensperger
 - Heidi Koester
 - Dawn Sowers
 - Tara McCarty
 - Kasie Galley
 - Sharon Sternfeld
 - Jessica Fantasia
 - Olivia Pfaff
 - · Courtney Dobrzynski
 - · Hailey Atiyeh
 - And many many more

51



Lesson #7 Be generous

- Support others
 - Share your ideas with others
 - Provide feedback to others
 - Offer encouragement to others
 - Become a mentor
- Foster the next generation
 - Encourage and inspire others



53

54

A mentor provides a brain to pick a shoulder to cry on and a kick in the pants



Role of mentors

When you teach someone what you know, there are now two of you blazing the trail rather than you by yourself.



· Michael Williams

55 56

Lesson #8 Take time to think

- · Reflect on problems
 - Slow down /step back
 - Think
 - Record your ideas
 - Write to develop your thinking
- Being paid to wonder is a heavy responsibility



Lesson #9 Be courageous

Embrace the "aha moments"

- · Challenge yourself
 - Keep raising the bar
- Ask questions
 - Challenge others' ideas
- Put your ideas out there
 - Spend time with others who will challenge you
 - Don't be afraid to make mistakes
- Fear complacency



57

58

Lesson #10 Don't be afraid to change directions

- As you investigate new areas & unearth new discoveries, be ready to shift directions to accommodate new findings
 - Be flexible
- Be open to serendipitous discoveries
 - Observe, analyze, reflect
 - Embrace the "aha moment"



Don't be afraid to change directions

59

RERC on AAC Think Tank, 2022 15

Birth of a new line of research

- How do we re-design AAC systems so that they are
 - Developmentally appropriate?
 - Support language development?
 - Dynamic?
 - Easy to learn & use?
 - Appealing?

61



61

62

researchers, administrators, policy makers, etc.

• Think about what content should be disseminated to whom

• Think about how it should be delivered to each stakeholder group

Lesson #11

It's not over until it is successfully adopted

• Disseminate results to all stakeholders to ensure uptake and use

- Individuals with complex communication needs, families, clinicians,

- Peer-reviewed publications, conference presentations
- Websites, visual abstracts, webcasts /podcasts
- Social media, Facebook, Twitter, blogs
- Success stories, etc.



Choose the best approach for each stakeholder group



Building a line of research is a process Which step have you reached?



63

Lesson #12

Celebrate your contributions!
Discover joy in your work!



rerc-aac.org

- The contents of this presentation were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number #90REGE0014) to the Rehabilitation Engineering Research Center on Augmentative and Alternative Communication (RERC on AAC). 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.
- We are also grateful to the Hintz Family for their support of the AAC Doctoral Student Think Tank through the Hintz Family Endowed Chair in Children's Communicative Competence.





65

RERC on AAC Think Tank, 2022