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OREGON HEALTH & SCIENCE UNIVERSITY
OHSU

Supporting the Meaningful Participation of Persons with Disabilities in Research
Melanie Fried-Oken, PhD, CCC-Sp
RERC on AAC partner

Slide 2

Participatory Research: A basic value

Individuals with disabilities are members of the research team

Slide 3

DEFINING TERMS:

"Work from strong models." - McNaughton

Slide 4

Community-based research Continuum (USA)

Types of Participatory Research
(University of Kansas, 2018)

Traditional Research	Community-Placed Research	Community-Based Research	Community-Based Participatory Research
Completely driven by the researcher; problem identified by researcher who plans and conducts the research and then analyzes, interprets, and disseminates the results to academic audiences	Happens *in* the community setting but is still researcher driven. Community members are not active participants	Conducted **with** the community where the community members are participating **to some degree** in the research process	Conducted **with** the community where the community members are **equal partners in all research phases**
What words are common to 2-year-old twins, one with CCN and one with age appropriate development?	*What types of questions are asked by teachers during individual reading time to children with CCN compared to their speaking peers?*	*Teacher: "There's a student coming to my class with an expensive eye gaze system. What should I do?"* *Student: "I want to tell people you can or can't pet my service dog."*	*What are the satisfaction ratings of the community members to the first show in the Disabilities Art Gallery?*

CBPR: Community-based participatory research

AHRQ defined CBPR as "a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change."

Agency for Healthcare Research and Quality. Community-based participatory research: assessing the evidence. Rockville. 2004. Evidence Report/Technology Assessment No. 99.

CBPR involves:

(1) Co-learning and reciprocal transfer of expertise by researchers and consumers alike;

(2) Shared decision making power;

(3) Mutual ownership of the processes and products resulting from the research collaboration

Methodologies used: participant observation, individual interviews, field notes, photos and video footage analysis.

White GW, Suchowierska M, Campbell M. Developing and system-atically implementing participatory action research. *Arch Phys Med Rehabil 2004;85*(4 Suppl 2):S3-12.

PAR: Participatory Action Research

"People with disabilities (should) be allowed a more prominent and influential role in research at every stage of the process, but most especially, in determining the questions worth asking."

Olkin R. What psychotherapists should know about disability. New York: Guilford Pr; 1999.

The goal is to give groups previously excluded from research and policy decisions a "voice" in these processes and to recognize the formerly invisible contributions of these groups to the success of research and policy endeavors.

PAR History: 1920s agriculture

- Researchers developed and disseminated an efficient variety of hybrid corn seed that increased corn yield.
- It was tested in the SW USA
- **REJECTED BY FARMERS**
- The processed corn meal could not be used to make suitable corn tortillas
- End game: A more efficient variety, but the product had limited value to the consumer.

Why include participants in research?

- Improve researchers' awareness of and sensitivity to the questions, needs, and priorities of consumers
- Help researchers pursue a more relevant consumer-driven agenda
- Increase potential for research relevance
- Successfully recruit and complete clinical research
- Socially validate knowledge translation
- Adopt effective interventions at the community level

Seekins, T., & White, G. W. (2013). Participatory action research designs in applied disability and rehabilitation science: protecting against threats to social validity. Archives of Physical Medicine and Rehabilitation, 94(1), S20-S29.

Increasing social validity of our work

- Social validity: The extent to which potential adopters of research results and products judge them as useful and actually use them.

- Threats to social validity:
  - Irrelevant goals (school: 2 choices; home: self determination with choices)
  - Consider an innovation that is not acceptable to the consumer (making a grid for home activity vs. JIT scene)

Seekins, T., & White, G. W. (2013). Participatory action research designs in applied disability and rehabilitation science: protecting against threats to social validity. Archives of Physical Medicine and Rehabilitation, 94(1), S20-S29.
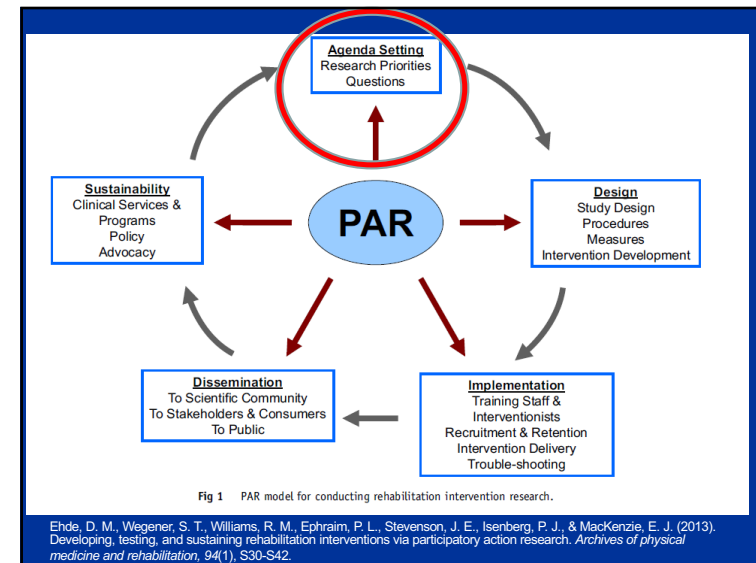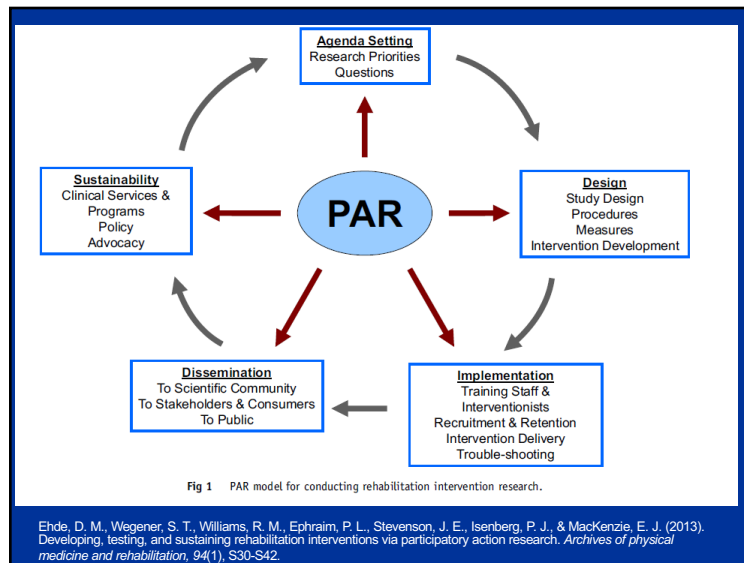
"Create a knowledge base." - Beukleman

- Consider the stages of research:
  - Application
  - Integration
  - Advancement
  - Dissemination

Fig 1   PAR model for conducting rehabilitation intervention research.

Ehde, D. M., Wegener, S. T., Williams, R. M., Ephraim, P. L., Stevenson, J. E., Isenberg, P. J., & MacKenzie, E. J. (2013). Developing, testing, and sustaining rehabilitation interventions via participatory action research. *Archives of physical medicine and rehabilitation, 94*(1), S30-S42.

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Research studies are based on the needs of people with disabilities

" I can understand what my husband is saying when I start the conversation. But when Jim comes up to me and wants to tell me something, and I don't know the topic, I have no idea what he is talking about!"

Mobile technology and AAC research at Oregon Health & Science University

- Can people with progressive aphasia use computer tablets with specialized software (apps) to help their conversations?
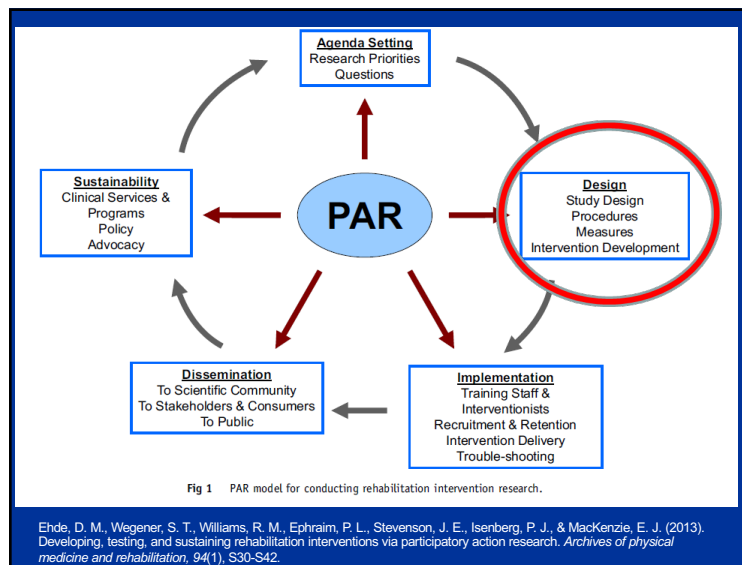
Slide 1

Individuals with disabilities are the experts……

Slide 2

Individuals with disabilities are Advisory Board Members

They attend our annual meetings and provide input.

Slide 3

Agenda Setting
Research Priorities
Questions

Sustainability
Clinical Services &
Programs
Policy
Advocacy

PAR

Design
Study Design
Procedures
Measures
Intervention Development

Dissemination
To Scientific Community
To Stakeholders & Consumers
To Public

Implementation
Training Staff &
Interventionists
Recruitment & Retention
Intervention Delivery
Trouble-shooting

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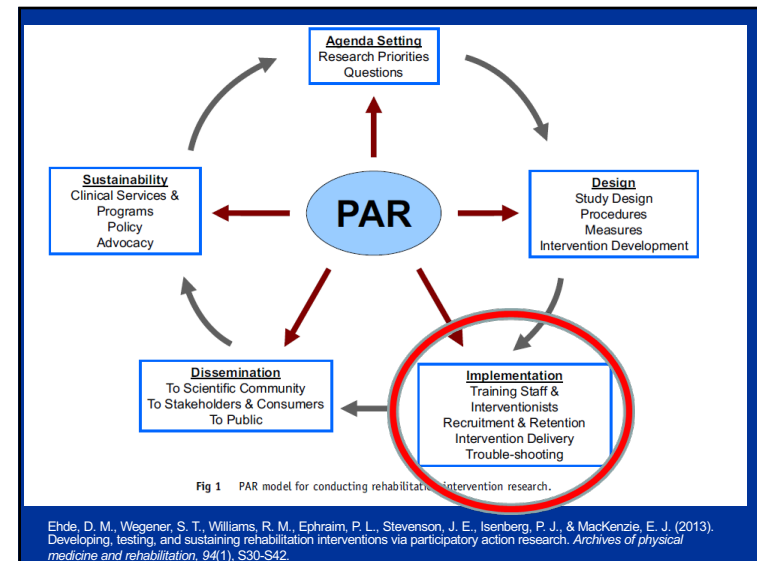
Slide 4

Design phase

Considerations that impact validity and sustainability of intervention being evaluated:
- Components of the intervention (DV, IV)
- Means of delivery (SCRD, group, in person, telehealth)
- Dose
- Inclusion/exclusion criteria
- Recruitment procedures
- Outcome measures

Inclusion of stakeholders in the decision-making may increase the ecological validity and acceptability of the intervention and significantly help with recruitment of the study population.

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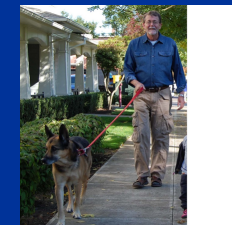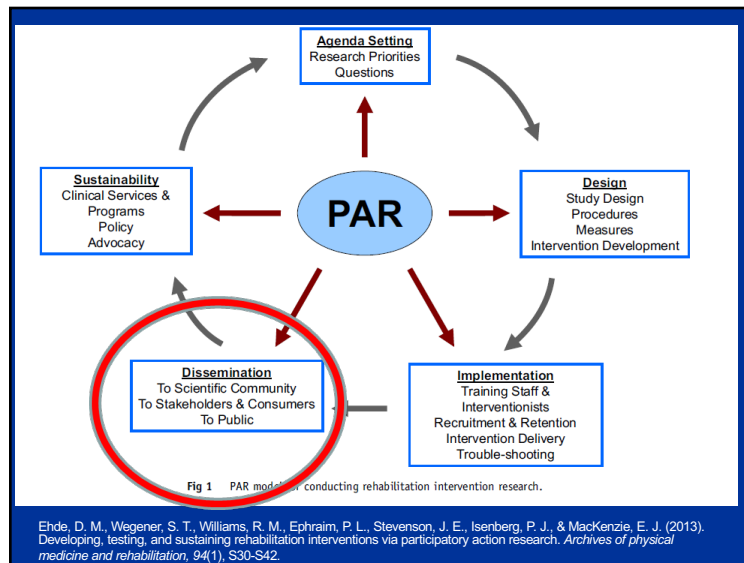**Research materials are customized to individuals with disabilities**

Slide 2

Agenda Setting — Research Priorities, Questions

Sustainability — Clinical Services & Programs, Policy, Advocacy

PAR

Design — Study Design, Procedures, Measures, Intervention Development

Dissemination — To Scientific Community, To Stakeholders & Consumers, To Public

Implementation — Training Staff & Interventionists, Recruitment & Retention, Intervention Delivery, Trouble-shooting

Fig 1   PAR model for conducting rehabilitation intervention research.

Ehde, D. M., Wegener, S. T., Williams, R. M., Ephraim, P. L., Stevenson, J. E., Isenberg, P. J., & MacKenzie, E. J. (2013). Developing, testing, and sustaining rehabilitation interventions via participatory action research. *Archives of physical medicine and rehabilitation, 94*(1), S30-S42.

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Implementation phase

Execution of procedures:

- Participant enrollment
- Intervention delivery
- Outcome assessment
- Data storage

Stakeholders may contribute advertising the study, recruiting participants, troubleshooting implementation problems, or delivering the intervention.

Slide 4

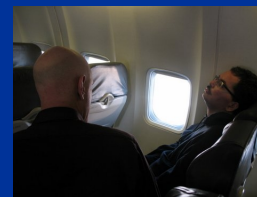**All research is conducted in the participant's residence or location of choice**

Fig 1 PAR model for conducting rehabilitation intervention research.

Ehde, D. M., Wegener, S. T., Williams, R. M., Ephraim, P. L., Stevenson, J. E., Isenberg, P. J., & MacKenzie, E. J. (2013). Developing, testing, and sustaining rehabilitation interventions via participatory action research. *Archives of physical medicine and rehabilitation, 94*(1), S30-S42.

Dissemination phase

- Conduct analyses
- Interpret findings
- Disseminate their findings (professional publications and scientific conferences)
- Plan for future research based on the findings

Participants can help disseminate results to other stakeholders, such as healthcare providers, consumers, and the public. Stakeholders can assist in identifying additional modes of dissemination results to the groups they represent (eg, newsletters, blogs, industry publications).

Individuals with CCN are presenters
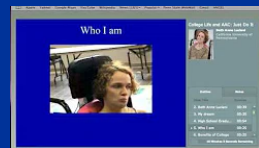
Individuals with disabilities have traveled to international conferences with us to present our recent research results

Individuals with disabilities are co-authors

Fig 1 PAR model for conducting rehabilitation intervention research.

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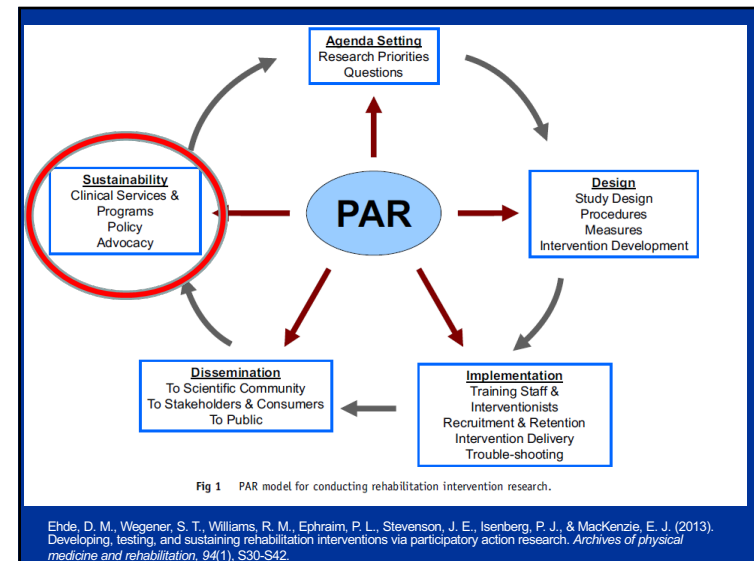
Sustainability phase

- Translate and sustain intervention research
- Bring products to market
- Change educational or medical procedures based on findings
- Advocate for policy changes

Stakeholder involvement would lead to the generation of additional meaningful research agendas, priorities, and questions to tackle in the next phase of intervention research. Advocates move systems: Steve Gleason: the ice bucket challenge; the Steve Gleason Act; Microsoft entering the AT research arena.

The Steve Gleason Enduring Voices Act

The legislation permanently ensures people living with diseases such as ALS access to speech generating devices regardless of their setting, whether at home or a healthcare institution. The bill will provide a Medicare payment for communication devices and for the accessories needed to allow the devices to work effectively.

Products: Curricula
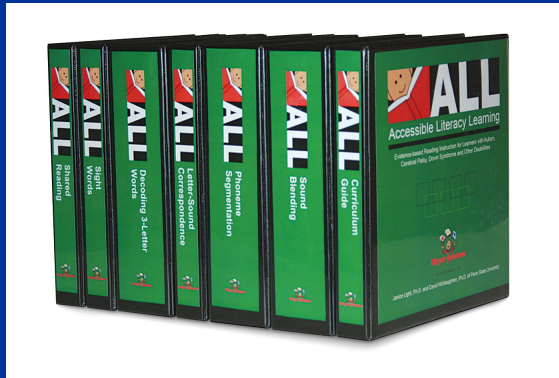
Devices and software: SNAP SCENE

Instant scene-based communication and language learning app for your child.

Snap Scene is a perfect app for in the moment learning opportunities. Take a photo and tag it with recordings to let your child communicate on the fly. Snap Scene turns everyday moments into chances to learn to communicate naturally. It's that simple!

Buy now or start with a free trial version.

Available for iOS (iPad) and Windows (I-Series+) from **tobii dynavox**

Invotek: SSR & MultiAccess

GET IT ON
Google play

An example of data collection:
Can people with progressive aphasia use an iPad app to share new information?

Participant input

- Asking the research question
- Selecting the dependent variables:
  - number of content words produced for sharing new information
  - Satisfaction measure for spouse
- Suggesting the activity (gardening)
- Choosing the location (home)
- Approving the data
- Presenting results to local providers

A speaking app to help Bob with conversation

003WMcA 3

Questions you should ask as you form your research plan

- *Will the design improve with input from the research cohort?*
- *What can I learn from beta testing my design with the research cohort before starting data collection?*
- *How can I involve parents, teachers, SLPs, people with CCN in the research question and design phase?*
- *How can I establish them within my research community from the start to facilitate participant recruitment?*

- *Can parents present the study in their children's school to help with recruitment?*
- *For qualitative research, can I ask parents to view the themes that I created from the interviews and confirm their relevance?*
- *For quantitative research, can I explain the results to the pALS and answer their questions clearly?*
- *Can I ask the SLPs and parents to disseminate the results at their local school meetings?*

- *Can I develop something that is useful to the constituents (pALS and cALS)? – Amanda*
- *Can I ask parents to suggest children's favorite books and use them as materials if they fit our inclusion criteria? – Emily*
- *For family centered services, can I ask parents to review the questions that form the survey to compare perceptions of parents and SLPs? -Elizabeth*
- *Can people with aphasia identify the meaningful roles that they want to participate in with SGDs? -Juhi*

"What difference will this make?" –Light

- Innovation is the hallmark of our research
- Consider not only the effectiveness of procedures and the acceptability of the methods and results
- Consider also whether the innovation itself will be acceptable to potential adopters.

Including participants in your research

People with CCN are the anchor of our field and all investigations

Your challenge:
Add Participatory Research to (at least) one phase of your project.