Collaborations with Community Organizations and Participatory Action Research Methods: Lessons Learned from 3 GaLEND Projects

2016-2017 GaLEND Trainee Panel & Mark Crenshaw, MTS
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Panel Speakers

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Photos courtesy of The People of GaLEND, Ryan Johnson (photographer)
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Acknowledgements

The 2016-2017 Trainees of Georgia LEND (GaLEND Program) wish to share their gratitude for the Leadership and Faculty, especially:

● Dan Crimmins

● Mark Crenshaw

● Stephen Truscott

● Community Partners including the:
  ○ Adult Disability Medical Home
  ○ Georgia Department of Public Health
Abbreviations & Terms Used Frequently

- LEND: Leadership and Education in Neurodevelopmental Disabilities
- Interdisciplinary: Involving 2 or more disciplines in a single project
- PAR: Participatory Action Research
- Ga: Georgia
- MCH: Maternal and Child Health
Objectives of this Presentation:

At the conclusion of this presentation, you will be able to:

1. **Identify** and **describe** Participatory Action Research (PAR) used in GaLEND;
2. **Discuss** process and product outcomes of PAR projects;
3. **Discuss** the successes and barriers experienced by GaLEND trainees;
4. **Explain** how PAR impacted MCH Leadership Competencies
3 Take Home Messages

Participatory Action Research (PAR) projects resulted in:

1. Developing Leadership Skills in LEND Trainees

2. Positive outcomes for Community Partners

3. Expanding Conflict and Resolution Skills, Interdisciplinary Team Building Skills, and Communication Skills
What is Participatory Action Research?

● “PAR seeks to understand and improve the world by changing it” (Baum, MacDougall, & Smith, 2006)

● Stakeholders and community partners drive the work & are involved at every point of project

● Terms & phrases associated with PAR include:
  ○ “Messy”
  ○ “Pluralism”
  ○ Reconsideration of power and authority
  ○ Management of competing agendas
GaLEND: Training and Mentorship in PAR

PAR was included in GaLEND based on the Exceptional Professional Learning Model (Truscott et al., 2011)

A framework to promote learning and change, which includes:

- Trainees need opportunities to work together (Relatedness)

- Trainees need to contribute toward solving actual challenges faced by communities (Authenticity)

- Trainees need to have some choice in what they work on and the ways they engage with the challenge presented (Autonomy)

- Solutions to challenges need to be shaped by the trainees experience and real-world context of the project (Responsiveness)
GaLEND: Training and Mentorship in PAR

- Trainees selected their top 3 choices for a PAR project
- Decisions about placement were made by a team of GaLEND faculty
- Teams included non-GaLEND members from Emory
- Contact information for the organization and a general statement of what was desired by the community organization was provided to the group
- Time in GaLEND coursework was dedicated to meeting (approximately 1 hour a month)
PAR 1
PAR Project 1: Get Fit & Be Healthy

Community Partner: Adult Disability Medical Home of Atlanta, GA

- Patient Centered Medical Home model
- Teens and adults with Down syndrome and other developmental disabilities
- ADMH partners: 2 Physicians, Executive Director, Nutritionist
- GaLEND trainees: Self-advocate, 1 School Psychologist, 1 Developmental Psychologist, Occupational Therapist
PAR Project 1: Get Fit & Be Healthy

Objectives of Collaboration:

- **Learn** about the research on programs to improve healthy eating and exercise in adults with developmental disability.

- **Develop** a series of health and wellness workshops for adults with Down syndrome and other developmental disabilities.

- **Deliver** 3 pilot workshops and **evaluate** the impact.
PAR Project 1: Get Fit & Be Healthy

Process:

- GaLEND group received Objectives of project
- Roles were discussed and some roles clearly defined and assigned to members
- Literature Review conducted specific to interventions and outcomes to improve health of adults with Down syndrome
- Continued Consultation and Communication between GaLEND trainees, PAR project mentors, & Community Partner
- Created, Reviewed, and Implemented workshop content and delivery
- Concluded Project and established Closure with Community Partner
Lessons Learned:

- Time consuming process to involve all members effectively
- Need for better communication processes
- Establishing expectations was helpful early on
- GaLEND input did not necessarily result in Community Partner’s implementation or use of the recommendation

Barriers:

- Timeframe to complete Community partner’s goals
- Resources to implement program effectively
- Differences of opinion as to how to implement project goals
- Differences in understanding of how evidence should or shouldn’t be used
PAR 2
PAR Project 2: Addressing Health Disparities in Adults with Developmental Disabilities

Community Partner: Adult Disability Medical Home of Atlanta, GA

- Focus: Transitioning to adult care
- ADMH partners: 2 Physicians, Executive Director, Nutritionist

GaLEND trainees:
  - public health professionals
  - speech language pathologist
  - nurse navigator
  - developmental psychologist
  - public health graduate students
PAR Project 2: Addressing Health Disparities in Adults with Developmental Disabilities

- Forming the partnership
- Learning the culture
- Determining scope and planning
- Conducting formative research
- Initiating 2nd phase of research
- Building capacity
PAR Project 2: Addressing Health Disparities in Adults with Developmental Disabilities

Lessons Learned

Communication
- Ongoing
- Internal and external

Combined Experiences
- Individual member skills
- Collective experiences of group

Stakeholder Perspectives
- Access to care
- Person-centered, interdisciplinary
PAR Project 2: Addressing Health Disparities in Adults with Developmental Disabilities

What does the ideal care team look like?
PAR Project 2: Addressing Health Disparities in Adults with Developmental Disabilities

Graphic Description:

The graphic in the previous slide illustrates an ideal care team for a person with a disability. The example includes the caregiver, primary care physician, nutritionist, specialist, advocate, medical home, support staff, and mental health provider, with the patient at the center of that team as the key decision maker in his or her care.
PAR 3
PAR Project 3: Teleaudiology in Rural Georgia

Community Partner:

Project 3 worked directly with the Georgia Department of Public Health (DPH) to research the implementation of telemedicine services, particularly teleaudiology services, for children with special health care needs in rural Georgia.

This partnership brought together statewide stakeholders, including representatives from the Early Hearing Detection and Intervention program, the statewide Telehealth program, a nonprofit rural EMT program, and newborn hearing screening services.
PAR Project 3: Teleaudiology in Rural Georgia

Objectives of collaboration:

- Write a comprehensive literature review regarding facilitators and barriers to successful implementation of a telemedicine program
- Conduct a community needs assessment
PAR Project 3: Teleaudiology in Rural Georgia

Process:

- Completed a literature review on telemedicine service delivery models
- Interviewed and connected with local stakeholders
- Created a summary of stakeholder goals, needs, and current projects related to telemedicine
- Created promotional materials based on summary that could be used to present information on teleaudiology services and process to families
- Designed family-centered surveys that could be used to evaluate family and provider satisfaction
PAR Project 3: Teleaudiology in Rural Georgia

Where do we go from HEAR?

1. Newborn Hearing Screening
   All newborns will undergo a hearing screening before leaving the hospital.

2. Referral
   If your child does not pass his/her initial screening, he/she will be referred to your district’s Early Hearing Detection and Intervention Coordinator (EHDI).

3. EHDI Coordinator
   Your district EHDI Coordinator will contact you about setting up an outpatient rescreening exam.

4. Rescreening
   Within 1 month of your child’s initial screening, he/she will have another hearing screening completed by a certified technician.

5. Secondary Referral
   If your child does not pass his/her rescreening exam, your EHDI Coordinator will refer you for a full hearing exam.

TELEAUDIOLOGY CLINIC
Ware County Health Department
604 Riverside Avenue • Waycross, GA 31501

Susan Greer
EHDI Coordinator
Southeast Health District
Susan. Greer@dph.ga.gov
912.654.5007 (Glenville)
912.338.5916 (Waycross)

Clinic Details
Open the last Wednesday of each month. The clinic is free of cost and offers diagnostic hearing exams. Exam is conducted by an audiologist housed at Children’s Healthcare Of Atlanta.
PAR Project 3: Teleaudiology in Rural Georgia

Lessons Learned:
- Working with community partners requires flexibility
- Participatory Action Research can be an evolving process
- Sometimes what is needed in a community is not straightforward - You don’t know what you don’t know

Barriers:
- Limited time frame of project does not always match with community partner timelines
- Location of community partner can make meeting and reviewing community needs more difficult
Lessons Learned & Recommendations
MCH Leadership Competencies Fostered

1. Negotiation and Conflict Resolution Skills (4.36)
2. Interdisciplinary Team Building Skills (4.27)
3. Communication Skills (4.09)
4. Family Centered Care Skills (4.09)

PAR was not felt to be helpful in accomplishing Policy & Advocacy Skills (2.73), the only average rating below the midpoint of the rating scale.
Lessons Learned from the PAR Process

- Having multiple actors/collaborators with a range of experiences is a positive (although results in disagreement)
  - Communication is essential-- setting expectations early about who, what, when, and how
  - Openness to learning from others

- Establishing trust is essential

- Trainees sometimes felt frustrated that organizations were not flexible enough to create changes, but these changes often take time

- A short timeframe can be difficult, but forces action & learning to occur
Lessons Learned - PAR & Community Partnerships

- PAR takes time, and sometimes multiple years with long-term engagement;
- Trainees may not see change in the time they are engaged with community partners;
- Reflection with others about the process is essential
Feedback from Community Partners

- GaLEND trainees were “thorough in their assessment and approach” & “high energy and eager to learn”
- “The tools developed for outreach and education were most useful.”
- Product “provided useful and important feedback…for improving our clinical process”
- “Working with GaLEND Fellows has been a real strength over the past year”
- “The overall experience with GaLEND was a win”
Recommendations for LEND Training Programs

- **Recruit and intentionally** include trainees with varied experience and diversity to expand perspectives;
- **Recruit** partner agencies who will commit the resources to supporting successful outcomes;
- **Obtain** buy-in of the trainees—providing opportunities for selection of project was important;
Recommendations for LEND Training Programs

- Work with trainees, mentoring faculty and partnering organizations to keep project scope achievable within allotted timeframe.
- Provide reflection time on the process at multiple points of the project;
- Provide feedback to trainees about impact, even after the training interaction ends.
3 Take Home Messages

Participatory Action Research (PAR) projects resulted in:

1. Developing Leadership Skills in LEND Trainees

2. Positive outcomes for Community Partners

3. Expanding Conflict and Resolution Skills, Interdisciplinary Team Building Skills, and Communication Skills
Image Caption:

“Success: What people think it looks like” with a straight line picture.

“Success: What it really looks like” with a line that goes in many circles and curlicues before heading in a direction.
Questions?