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Abstract

Background: *Experience in multidisciplinary collaboration among healthcare providers, leaders in public health, and educators is essential to effectively address the diverse needs of children with intellectual and developmental disabilities (I/DD) and their families.*

Purpose: *We describe three participatory action research (PAR) projects from an interdisciplinary training program, which used experiential learning to enhance leadership competencies and promote inclusive services. Trainees report their leadership growth as providers and advocates for children with I/DD using experiential learning through PAR.*

Approach: *Trainees discuss their engagement with organizations serving children with I/DD and ways that experiential learning supported leadership skill development, commitment to inclusive person- and family-centered practices, and contributions to disability advocacy and support programs.*

Conclusion: *PAR is a beneficial experiential learning approach to foster interdisciplinary collaboration through inclusive community engagement. Related training programs may adopt a similar approach to build leadership skills among professionals in health care, public health, and education, and promote optimal health outcomes for children with I/DD.*

Plain Language Summary

In this article, we describe three research projects that used a method called experiential learning to improve leadership skills and program care for children with intellectual and developmental

disabilities (I/DD) and their families. We find that when healthcare providers, public health leaders, and educators work together in this way, it can lead to positive health outcomes for children with I/DD.

Background

Children represent nearly one quarter of the U.S. population, and approximately one in six has an intellectual or developmental disability (I/DD) or developmental delays (Child and Adolescent Health Measurement Initiative, 2018; U.S. Department of Health and Human Services [HHS], 2015; Zablotsky et al., 2019). In accord with the joint position statement of the American Association on Intellectual and Developmental Disabilities (AAIDD) and the Arc, authors define I/DD as individuals with intellectual disabilities and/or developmental disabilities, which includes disabilities that may be intellectual, physical, or both (AAIDD, The Arc of the United States, 2016). Effective programming and evidence-informed advocacy are essential to promoting optimal health outcomes for children with I/DD who experience multiple challenges and persistent disparities in accessing quality healthcare and support services (Halfon et al., 2012). Community, state, and federal organizations exist to address the diverse needs of children with I/DD and their families, yet these organizations generally have specific foci and may not be designed to form the effective partnerships needed to optimally address needs (Margolis et al., 2013; McGrath et al., 2019). Training future care providers, public health leaders, and advocates could focus on essential interdisciplinary communication, negotiation, and conflict resolution skills, but seldom does (Clarke & Cilenti, 2018; Kavanagh et al., 2015). Likewise, training that includes collaborating with community stakeholders and working on interdisciplinary teams within various healthcare and government systems could be beneficial but is seldom provided (Margolis et al., 2013).

This article offers perspectives for educators to understand the benefits of participatory action research (PAR) in an interdisciplinary context and presents ways that PAR could be included in training programs to encourage future leaders and providers to understand the needs and barriers of populations from within the group itself and work collaboratively towards supporting inclusive services and positive change. We describe three PAR projects from an interdisciplinary training program, Leadership Education in Neurodevelopmental and Related Disabilities (LEND), at Georgia State University, which used experiential learning to enhance leadership competencies and advance local disability advocacy and support programs. Participating LEND trainees report the influence and perceived impact of experiential learning through PAR on supporting their leadership growth.

Participatory Action Research as Experiential Learning Tool

In order to prepare future professionals for effective interdisciplinary work, it is important for training programs to allow students to be active partners in the learning process through experiential learning. As a framework, experiential learning theory includes opportunities for experience and practice, reflection, conceptualization, and experimentation (Kolb, 1984). Experiential learning theory has been used as a framework within interdisciplinary training

programs to support activities such as simulation-based learning (Poore et al., 2014; Stocker et al., 2014). However, there is limited examination of ways in which community-engaged research projects can be included in an experiential learning theory framework for an interdisciplinary training program, such as through PAR.

PAR is a continuous and integrative set of processes and principles designed to foster meaningful collaboration between researchers, community members, and organizations as they address contextually relevant problems and provide support and advocacy for change (Greenwood et al., 1993; Kidd & Kral, 2005; McTaggart, 1997). PAR has been employed in the healthcare, public health, and education fields to engage stakeholders as they assess health-related needs and develop feasible, culturally relevant, and effective responses (Akintobi et al., 2014; Rodgers et al., 2014). In PAR projects, contextual relevance is enhanced by soliciting and valuing the views and experiences of all participants, especially community members, throughout the inclusive PAR knowledge acquisition, translation, and dissemination processes (Dudgeon et al., 2017). Although PAR is fundamentally centered around research, education, and action, it differs substantially from traditional research in the manner in which it facilitates action or change to address the identified needs, as continuous engagement and collaborative communication require additional expertise beyond traditional research skills (Dudgeon et al., 2017). Facilitating change requires future professionals to engage in both personal and professional self-reflection as they examine the interface of their chosen profession and community needs (Baum et al., 2006). This process is similar for researchers engaged in PAR. As such, PAR can be a way for future professionals to gain direct experience with community engagement, advocacy, and inclusive, person- and community-centered practice, while also allowing learners to reflect on their own experiences to foster professional growth.

In combination with the experiential learning theory framework, PAR can be employed as an experiential learning tool to develop leadership skills using the mechanisms of self-determination theory (SDT), which is a well-developed approach for the study of the relationships between intrinsic/extrinsic motivation and cognitive/social development (Niemiec & Ryan, 2009; Ryan & Deci, 2000). Essentially, SDT seeks to enhance intrinsic motivation by facilitating human interactions that meet the core psychological needs of competence, relatedness, and autonomy (Ryan & Deci, 2000). In SDT, people are at their most satisfied, productive, and intrinsically motivated when they engage in tasks that are challenging but achievable (competence), work with others toward a valued goal (relatedness), and have the agency to make meaningful choices (autonomy). PAR projects can provide the means to both engage interdisciplinary leaders in such activities themselves and learn to lead others using the principles of SDT. Consequently, SDT builds upon individual competencies and expertise to support leadership growth (Truscott et al., 2012), which is similar to what McTaggart (1997) called the "self-reflective spiral," wherein PAR requires sequences of reflecting, planning, engaging, and observing leading to personal and organizational growth. As such, including PAR projects in healthcare, public health, and education leadership training programs can provide an evidence-based method to engage trainees in processes that support change by considering the needs, barriers, and contexts of children with I/DD and their families.

Participatory Action Research and Georgia LEND

To promote optimal health outcomes for children with I/DD and their families, the Maternal and Child Health Bureau funds programs that provide developing leaders with tools and training to strengthen infrastructure and effectively address systemic challenges of children and families (Clarke & Cilenti, 2018). LEND programs are one example. LEND is an interdisciplinary, graduate-level leadership training program designed to develop future leaders with the skills to improve systems of care for children and adolescents with, or at risk for, neurodevelopmental and related disorders (Health Resources and Services Administration, n.d.). There are currently 52 LEND programs across the country, each using a unique approach to develop clinical competence and leadership skills in research, teaching/training, and policy/advocacy (Association of University Centers on Disabilities, 2011; Leff et al., 2014). LEND programs encompass faculty members and trainees from a range of health and disability-serving disciplines, and often include individuals who identify as having a disability and/or their family members.

Like most LEND programs, Georgia LEND (GaLEND) trainees participate in didactic and experiential coursework on neurodevelopmental disabilities, systems of care, and leadership. They also participate in a longitudinal, team-based PAR project. This PAR component was developed to provide trainees with hands-on experience in identified maternal and child health leadership competencies of communication, negotiation and conflict resolution, interdisciplinary/interprofessional team building, and working in and promoting inclusive systems and communities (HHS, 2018). Following the highly collaborative nature of GaLEND and the PAR approach, 2016-2017 PAR project participants also included post-doctoral fellows from the Morehouse School of Medicine's Satcher Health Leadership Institute and public health students from Emory University's Rollins School of Public Health in addition to LEND trainees. Consistent with experiential learning theory and SDT, the PAR component of GaLEND training provided opportunities for trainees to work collaboratively. Trainees worked within their competency range but also practiced skills that enhanced their capabilities. By forming interdisciplinary teams of professionals, self-advocates, and family advocates, GaLEND trainees were able to integrate more meaningfully into partnerships with each organization. This unique aspect was built into the GaLEND projects, which added value to trainees' experiential learning and enabled them to operationalize SDT more thoroughly throughout the PAR process. SDT's intrinsically motivated outcomes provide a critical platform for learning (Niemiec & Ryan, 2009). Accordingly, trainees predominantly focused on the educational outcomes of the process (i.e., maternal child health leadership competencies and PAR as a process for growth) alongside the research and action components of PAR.

GaLEND faculty aimed to create opportunities for trainees to contribute to broader PAR initiatives through time-limited participatory projects designed to be completed within the LEND training cycle. As such, trainees engaged in a streamlined PAR adaptation (as full PAR projects are often multi-year initiatives). Trainees exercised some autonomy in deciding which project to join and in using their unique interests and skills on the team project. Although the PAR projects were consistent with SDT, trainees were initially unaware of the intended theory of change. The

core value of the PAR process lies less in a theory of change, and more in the opportunities for real-time experience working with community partners, which ultimately required trainees to improve their skills in communication, negotiation and conflict resolution, interdisciplinary/ interprofessional team building, and working in systems and communities.

Approach

This paper illustrates the impact of selected PAR projects implemented by GaLEND trainees and describes trainees' perceptions of how participation on those projects promoted growth in specific maternal child health leadership competencies. Each case presentation describes the process of community engagement, highlights trainee experiences, and reflects on PAR as a process for promoting inclusion and integrating the vision of community organizations in the context of limited resources. Perceived trainee leadership growth will be discussed in light of experiential learning theory and SDT and provide preliminary information of perceived competencies for future investigations and future leaders.

Case Presentations

The three projects described below are representative, but not exhaustive, examples of GaLEND PAR projects. Each was implemented in collaboration with either a nonprofit healthcare organization serving individuals with I/DD (Projects 1 and 2) or a state health department (Project 3). Each project resulted in improved skills in leadership, conflict and resolution, interdisciplinary team building, and communication among trainees, as well as positive outcomes for community members. Throughout each project, trainees were required to think critically about the needs of families, consider cultural responsiveness, and focus on the intentional and inclusive nature of family-professional partnerships required for successful implementation. These projects engaged in preliminary work with community partners and as such, did not include any research activities with human subjects and did not require an Institutional Review Board approval.

Project 1

Trainees collaborated with a healthcare organization that served the medical needs of individuals with I/DD and aimed to (1) evaluate the evidence for fitness and nutrition interventions to reduce obesity in adults with I/DD, and (2) implement and evaluate the impact of three pilot workshops developed by trainees and organizational staff. Project outcomes featured reproducible workshops that resulted in 100% attendance by agency patients and their caregivers. Post-workshop outcomes indicated that attendees increased knowledge and skills to make responsible health and wellness decisions and planned to continue making healthy decisions in the future. Anecdotal reports from patients, staff, and patients' caregivers indicated that attendees were more aware of their food and beverage choices. The facilitation of the workshops encouraged internal coordination among the trainee group, as well as external collaboration with the healthcare organization. Implementing the workshops in an inclusive and culturally appropriate manner enabled the trainees to meaningfully engage the community members and offered opportunities to reflect on their experience between each workshop.

Project 2

Trainees collaborated with a healthcare organization to assess the broad network of services provided to individuals with I/DD transitioning from pediatric to adult care, and identify improvement areas in their direct healthcare provision. Over the course of the project, trainees communicated with the organization's leadership and stakeholders to (1) evaluate literature on the current state of practice for adults with I/DD, (2) participate in clinical observations, (3) develop and pilot a protocol for stakeholder focus groups, and (4) develop a client satisfaction survey. This work highlighted the importance of inclusive, person-centered care and identified challenges experienced by individuals with I/DD and families. Trainees observed evidence-based practices to support inclusive, person-centered health care delivery (e.g., fluid communication among providers, patients, and parents; transparent billing practices; and comprehensive care plans established in real time), and identified needs to improve access to quality care for individuals with I/DD, include the patient in care planning, and enhance patient and family autonomy while administering care tailored to the patient's needs (i.e., supported decision making). The activities involved in this PAR project provided a comprehensive experience for trainees to practice and advance their communication and advocacy skills and reflect on their experiences at different points throughout the project timeline.

Project 3

Trainees worked directly with a state health department to conduct a needs assessment for the implementation of audiology telehealth services (i.e., tele-audiology) for children with hearing loss living in rural areas. To conduct their research, trainees (1) conducted a comprehensive literature review of implementation barriers and successful practices for telehealth and tele-audiology in rural areas; (2) interviewed stakeholders from an early childhood hearing screening program, statewide telehealth program, nonprofit rural emergency medical technician program, and newborn hearing screening services to gather information about program experiences, barriers and successes, current project status, previous evaluations, and lessons learned about implementing telehealth protocols; and (3) created educational materials and surveys for medical and public health facilities. Project outcomes included a presentation of telehealth best practices to the state health department to inform next steps and connect with additional community stakeholders. Additionally, trainees created educational fliers describing the tele-audiology process to present to families, and created family and provider surveys to collect feedback on future tele-audiology services. In working collaboratively with the state health department, trainees were able to practice communication skills by directly interacting with community stakeholders and reflecting on community needs. The creation of materials also allowed trainees to participate in the process of survey creation and practice inclusive, person- and community-centered engagement.

Findings

After completion of the PAR projects, the authors invited GaLEND trainees to reflect on

their experiential learning in both group discussions and an individual survey of their perceptions of the PAR project's impact on their leadership competencies. In combination with a greater overall understanding of inclusive, patient-centered approaches for individuals with I/DD, trainees reflected on the influence of their PAR project involvement on specific leadership competencies, including communication, negotiation and conflict resolution, and interdisciplinary team building (Maternal and Child Health Leadership Competencies, HHS, 2018). The leadership competencies commonly mentioned by trainees as areas where they experienced personal and professional growth included skills in negotiation and conflict resolution, interdisciplinary team building, communication, and family-centered care. Respondents commented that although developing leadership competencies was not an explicit PAR project goal, the skills were required indirectly and supported by the GaLEND faculty through reflective discussions. Trainees also reported perceived growth and increased competence in areas of professionalism, cultural responsiveness, interdisciplinary team building, and working with communities and systems. Overall, trainees reported greater awareness and value of patient inclusion in all aspects of healthcare planning and inclusive decision-making as an outcome of participation in the PAR projects.

Discussion

Although the PAR projects presented many opportunities to learn, they also presented challenges. Implementation challenges arose in areas such as establishing and maintaining communication with multiple and varied stakeholders, differences in timeline expectations between community partner and trainees, and decision-making related to focus groups implementation. Meeting the challenges required trainees to develop problem-solving, negotiation and conflict resolution, and priority-setting skills as they resolved differences with stakeholders, which also attributed to PAR as a positive experiential learning tool. GaLEND faculty mentors supported trainee skill-building via coaching and guidance on communication and negotiation, resulting in improved engagement with stakeholders and interdisciplinary collaboration among trainees.

Findings from the case studies presented herein complement and extend knowledge gained from previous studies on PAR efforts within healthcare, public health, and education leadership training programs. Vargas et al. (2012) indicated the value of community engagement processes that foster leadership skills for clinicians in training and advocacy skills for families. Recent evaluations of similar leadership training programming indicate that participants continue to demonstrate interdisciplinary leadership in settings serving communities that have been marginalized following their training (Kavanagh et al., 2015), and that LEND participants develop inclusive, family-centered care attitudes, skills, and principles (Keisling et al., 2017). Similarly, findings from the survey indicated that trainees reported growth in the areas of negotiation and conflict resolution, interdisciplinary team building, communication, and family-centered care—skills directly related to the core psychological needs described in SDT. PAR supported leadership growth in trainees by building skills, knowledge, and relatedness while working in interdisciplinary teams, as well as practicing autonomy in their work as leaders. The collaborative

work environment provided a valuable opportunity for trainees to gain experience implementing inclusive leadership practices, expanding advocacy skills, and highlighting the impact of the I/DD network in community-based settings.

Implications for Practice

Consistent with a growing consensus on the need for inclusive, family-centered systems to serve children with I/DD and their families, future professionals require knowledge and experience in leadership qualities that enhance such systems. PAR's guiding principles and collaborative nature offer a promising approach to teach professional skills and promote inclusion in professional and community-based settings. Trainees perceived that participation in PAR projects contributed to the overall effectiveness of the GaLEND experience. GaLEND faculty members facilitated that effectiveness by defining, discussing, and reflecting on individual and collective leadership development during the process. The PAR projects supported GaLEND program goals by ensuring their relevance to participant needs (i.e., patients and caregivers, organizational staff, community partners). Each PAR group had opportunities to build leadership competencies through the experiential process, including negation and conflict resolution skills, interdisciplinary team-building skills, communication skills, and family-centered care skills.

These results parallel evaluations of other LEND and healthcare, public health, and education leadership programs with similar projects for trainees (Humphreys et al., 2015). Likewise, application of SDT in leadership training enhanced trainee opportunities for leadership growth specific to the needs of each individual via self-direction and self-reflection inherent in the PAR process. Self-assessment of growth in domains of leadership competency strengthened the reflective process. Collectively, the PAR experience will extend the reach of the LEND experience and trainee interactions with future communities of practice, public health systems, and policies.

Conclusion

Future health and human service professionals play a critical role in supporting the health and well-being of children with I/DD and their families. Collective efforts, as expressed in PAR, offer the best opportunities for individual providers and organizations to identify needs, perspectives, models of service delivery, and best practices that foster inclusion of individuals with I/DD within their communities. PAR offers applied research opportunities to develop trainee leadership competencies while also providing rich and meaningful experiences from inclusive, person- and family-centered approaches to care provision and research. The GaLEND case examples highlight the importance of mentored experiences with community organizations and the value of integrating individuals with I/DD and family advocates into the interdisciplinary teams. PAR can serve as a model for similar LEND programs to develop future leaders who are able to work collaboratively and inclusively with individuals with I/DD and community stakeholders.

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