

Effective Educational Approaches to Forging Family-Professional Partnerships

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**Abstract**

Respectful and trusting family-professional partnerships can positively influence the health care of children with intellectual and developmental disability. This manuscript describes a creative interdisciplinary educational approach that includes family members and pre-service professionals as partners and evaluates the perceived impact of this approach on the learners. The majority of survey respondents rated the impact of including family members in a nine-month interdisciplinary training program as co-learners, educators, and mentors as having a very high impact. Including family members in interdisciplinary educational activities, provides pre-service learners invaluable opportunity to experience true family-professional partnerships. Recommendations are provided for education of pre-service learners through a partnering process that fully includes family, self-advocacy, and professional disciplines, and targets family-centered inclusive services as an outcome.

*Key words: Family-professional partnerships, parent learner-educator-mentor, pre-service learners, family/families, inclusion*

### **Effective Educational Approaches to Forging Family-Professional Partnerships**

Health, educational and behavioral care complexities are numerous for children with an intellectual and developmental disability and their parents. Respectful and trusting family-professional partnerships are vital for genuine family-centered services for these individuals and families (Maternal Child Health, 2015). In their systematic review, Kuhlthau and colleagues (2011) observed family-professional partnerships were associated with improved outcomes for children with special health care needs. Development of the competencies necessary in authentic family-professional partnerships begins with an understanding of family-centered care. The concept and movement toward family-centered care emerged from the grass roots effort of individuals who were receiving care and their families, and has ultimately lead to the pursuit of improved services (Goldfarb et al., 2010; American Academy of Pediatrics, 2003). The Maternal and Child Health Bureau (MCHB) and the Institute for Patient- and Family- Centered Care (IPFCC) both recognize expertise of the patient and family viewed as a discipline to provide interdisciplinary teams with an invaluable perspective essential in the provision of family-centered care and inclusive services in the community (Johnson & Abraham, 2012; Maternal Child Health, 2015). Ahmann and Dokken (2012) reveal family-professional partnerships can be encouraged in clinical settings by establishing policies and practices that are welcoming to families and acknowledge their central role in the care process. Family-professional partnerships can be fostered in health professions education by using intentionally-designed educational strategies that include family members and pre-service learners.

Key components of family-professional partnerships for parents and providers include: trust, shared decision making and a willingness to negotiate, mutual respect, and open communication (National Center for Family-Professional Partnerships, June, 2018; U.S.

Department of Health and Human Services, May, 2018). Additional components of family-professional partnerships include professionals' tailoring of recommendations to address family-identified preferences, recognition of the impact a child with special health care needs has on a family, and acknowledgement of the family as a potential source of strength and support in the individual's care (National Center for Family-Professional Partnerships, June, 2018; U.S. Department of Health and Human Services, May, 2018). Pre-service learning provides a forum to provide meaningful experiences for students to gain knowledge and to practice some of the components necessary to forge family-professional partnerships. Some strategies used by academic programs in preparing health professionals to practice partnering with families are varied in process and in outcomes. Parents-as-Teachers, Families as Faculty, Project DOCC<sup>SM</sup> (Delivery of Chronic Care) are examples of programs designed for pediatric residents to gain knowledge and skills around family-centered practice (Blasco, Kohen, & Shapland, 1999; Kube, Bishop, Roth & Palmer, 2012; Rossingol, 2015). The purpose of this manuscript is to describe a creative interdisciplinary educational approach that includes family members and pre-service professionals as genuine partners and to evaluate the perceived impact of this approach on the learners. This educational approach has been implemented by the Oklahoma Leadership Education in Neurodevelopmental and Related Disabilities (OKLEND) program which strives to prepare pre-service professionals to develop meaningful family-professional partnerships as a core component of their future practice.

### **Educational Framework**

LEND programs are interdisciplinary workforce training programs of Maternal and Child Health Bureau (MCHB) that aim to enhance expertise and leadership skills in professionals who care for children with intellectual and developmental disabilities. Learners, classified as long-

term LEND trainees, perform a minimum of 300 hours in didactic, practicum and research activities within an academic year that are designed to advance their knowledge and skills in twelve leadership competency areas. The aim of the training program is to develop leaders in the field who will work to improve health care systems for children with neurodevelopmental and related disabilities and their families. LEND programs strive to provide interdisciplinary education stressing the importance of integrated services, community-based partnerships, cultural competence, and family-centered care (Association of University Centers on Disability, 2011). One of the twelve specifically targeted Maternal and Child Health competency areas is *Family-Professional Partnerships*. LEND programs are required to have Core Faculty in the family discipline, but educational methods for involving family vary across programs. Some programs include family as interdisciplinary team members in clinical settings (e.g., family support coordinators), while others may invite family members as guest presenters or panelists. Some programs may have family members from the community serving as program advisors, or consultants. LEND trainees have been shown to rate themselves higher on self-assessment scales of family-centered leadership competencies after engaging in a series of family led curricula (Keisling, Bishop, & Roth, 2017). The national network of LEND programs, through the Association of University Centers on Disability (AUCD), has been working toward increasing the capacity of LEND programs to include family members and self-advocates as representing their unique disciplines in their pre-service training programs. This manuscript describes and evaluates a LEND program that has been a pioneer in including the family members and self-advocates as faculty, trainees, and mentors as an integral part of the program.

## **Methods**

### **Educational Methods**

The OKLEND long-term training program uses a multi-faceted educational approach that includes family members and self-advocates alongside professionals as learners, educators and mentors. The OKLEND program, in partnership with the Oklahoma University Center of Excellence in Developmental Disability (UCEDD), has been at the forefront of a movement to include family members as equal partners in interdisciplinary education. In 1995, through a collaborative arrangement with the Oklahoma UCEDD, OKLEND hired a parent as an instructor to share family stories with the trainees. OKLEND petitioned the MCHB to recognize the expertise of parent/family as a discipline and asked for permission to include a Core Faculty position in the family discipline. Faculty in self-advocacy, represented by a person who has a developmental disability, was included in the program beginning in 1997. In 2004, OKLEND integrated learners as long-term trainees from the disciplines of family and self-advocacy into the program. Nationally, recognition of self-advocacy as a discipline in LEND programs has only recently emerged. We feel it is important to consider the role of the self-advocacy discipline in pre-service training, however the survey developed by the LEND Family Workgroup does not include any questions about the role of, importance of, or impact of the self-advocacy discipline. We will focus on the family discipline in this manuscript with the understanding that inclusion of self-advocates in equal roles is an emerging practice that deserves further study.

The educational approach developed by the OKLEND program requires interaction across professionals and family members in three different roles as: 1) *co-learners*, 2) *educators*, and 3) *mentors*. In the role of *co-learners*, family members participate in learning experiences alongside pre-service professionals. Trainees from all disciplines, including the discipline of family, are situated as equal members of the interdisciplinary team where they participate in all aspects of the training program, including didactic, practicum, and research activities. The

OKLEND program uses a method of interactive discussions in large and small groups, team-building activities, and experiential learning. Trainees prepare for classes by engaging with required content materials and preparing reflective papers or questions for discussion. The program requirements are identical for trainees from all disciplines. Accommodations, support, and guidance are provided for each trainee as needed by the core faculty in their discipline and the training director.

In the role of *educators*, family members serve as core faculty, in paid positions with job descriptions equivalent to faculty from all other health professions disciplines. The core faculty role involves advising trainees from the faculty educator's own discipline and facilitating discussion with trainees from all disciplines during class sessions. Family discipline educators apply their unique knowledge and experiences to guide trainees through the process of discovery and learning about interdisciplinary teaming, developmental disability services, and a myriad of issues related to care systems. All trainees have at least six required meetings with the core faculty in their discipline and two with core faculty in a discipline other than their own. Many of the trainees in health/medical disciplines choose to meet with the family faculty.

Each trainee spends time with families in the community who are intentionally assigned as family *mentors* for these practicum experiences. Trainees attend two structured experiences with the mentors, one focused on their mentor's family life and the other on the mentor's role in advocacy. Family mentors are considered experts in disability, acknowledged through a printed guide given to all of the trainees. The guide includes a professionally presented photograph, and a brief yet thorough biography outlining their life experience with disabilities, and their advocacy work. These three separate yet interconnected roles for the family discipline in our program provide the trainees with unique opportunities to have experiences that are integral to developing

genuine family-professional partnerships. Family trainees also learn from this unique opportunity to experience true partnership as equal members of the interdisciplinary team. This educational approach is expected to impact trainees by providing a foundation for forging family-professional partnerships as the trainees move on to their roles as service providers, community leaders and advocates.

### **Evaluation of Educational Methods**

As part of a national research project initiated in 2013 by the national LEND Family Workgroup led by Fran Goldfarb to assess the value of family participation in LEND programs, LEND trainees complete the LEND Family Discipline Network LEND Family Involvement Survey at the end of each program year (Goldfarb, et al. unpublished data). Participation in the annual survey is offered to trainees from 52 LEND programs in 44 states (AUCD, 2018). For the focus of this study that is specific to the OKLEND program, we present only the responses from OKLEND program trainees as an assessment of the trainees' perception of the impact of family involvement in this program. Aggregated data from the nationwide survey is in progress for a future publication. The Children's Hospital of Los Angeles Committee on Clinical Investigations and the University of Oklahoma Institutional Review Boards reviewed and determined the study was exempt from human subjects research.

### **Analysis**

The analysis of the LEND Family Discipline Network LEND Family Involvement Survey consists of a quantitative and a qualitative analysis. Data from the surveys completed in 2014, 2015, 2016, and 2017 pertaining to the OKLEND program were analyzed for this study and a summary of those results are provided. The 2014 survey included 20 questions and over the years expanded to 30 questions that ask trainees to rate the importance of family

involvement, the impact of family involvement, and the types of family involvement they experienced in their training.

For the purposes of assessing the perceived impact by our trainees of including the family discipline in our program, we selected questions that were asked consistently in every survey year and specifically related to the three facets of family involvement used in the Oklahoma program. Three questions ask participants to rate the impact of family participation in the LEND program as trainees (i.e. *co-learners*), faculty (i.e. *educators*), and *mentors*. These questions are: 1) “What is the likely impact of family members participating as LEND trainees from the family discipline?” 2) “What is the likely impact of family members serving in the professional role of LEND or university faculty and staff?” and 3) “What is the likely impact of families from the community serving as mentors to host LEND trainees for home or community visits?”

Participants rated each question using a five-item Likert scale with response options of: Very Low Impact; Low Impact; Some Impact; High Impact; Very High Impact; and Not Applicable.

Two open-ended questions asked participants to describe how they were influenced by family participation in the program and how family participation in LEND might impact their future work. These questions are: 1) “In what ways did the experience of having family participation in the LEND training program influence or change your views of family and disability?” and 2) “How do you think your experiences of having family participation in the LEND program will impact your work with individuals with disabilities of all ages and their families?”

**Quantitative analysis.** A descriptive analysis was conducted using the survey responses obtained from graduates of the OKLEND program to the three Likert-type questions analyzed. Measures of central tendency were not calculated due to small sample size, categories with no

responses and data skewed to the Very High Impact and High Impact responses. For this reason, percentages of responses were calculated. Responses from graduates of the OKLEND program were entered into an Excel spread sheet for each year of the survey by question and response category. The response rates for each year were calculated using the number graduate trainees that year divided by the number of survey responses, multiplied by 100%. A cumulative response rate was calculated summing the total number of completed surveys divided by the total number of survey responses, multiplied by 100%. Due to the small number of responses per year, the responses for each question from each of the four years were aggregated. For each question the total number of responses was divided by the number of responses for each rating (Very High Impact, High Impact, Some Impact, Low Impact and Very Low Impact) and multiplied by 100% to determine the percentage per response.

**Qualitative analysis.** Responses from OKLEND participants to the open-ended questions were analyzed using thematic analysis of open-ended questions. The primary author has experience in qualitative analysis through previous qualitative research studies using in-depth interviews. The analysis process involved reading through all written responses for both of the open-ended questions and highlighting the main ideas line-by-line. The highlighted words were then reviewed to identify commonalities across ideas and grouped into initial thematic concepts. The number of responses for each concept were counted by survey year and in total across all four years. Themes were maintained when statements within the group were found to be iterated with high frequency across participants and across all four survey years, these were then named using in vivo codes derived from the quotes. Thematic concepts that were not strongly iterated across participants were eliminated. Significant statements that conveyed the overall sense of each of the themes were selected for presentation in this manuscript. The codes

generated and associated statements were reviewed by all authors to ensure credibility of the analysis process.

### **Results**

Survey responses from participants who graduated from the OKLEND program in 2014, 2015, 2016, and 2017 are included in the analysis. Survey participants are adults who are completing a graduate program, residency, or fellowship in a health/medical or social service profession in the field of developmental disability, or are non-student learners in the disciplines of family and self-advocacy. The disciplines represented by survey participants include: audiology, autism spectrum disorders, family, genetic counseling, developmental-behavioral pediatrics, nursing, nutrition, occupational therapy, physical therapy, psychology, psychiatry, public health, self-advocacy, social work, and speech-language pathology. Forty-seven (47) surveys were completed by graduates of the OKLEND program over the four year period. Survey participants represented eighty-nine percent (89%) of the fifty-three (53) trainees who graduated from the OKLEND program in the years 2014-2017 (Table 1).

Results from the three Likert-type questions addressing the impact of including family members in the pre-service training program as trainees (co-learners), professionals (educators), and community mentors received from graduates of the OKLEND program are presented. Table 2 presents responses from each survey year on the likely impact of including trainees (learners) from the family discipline. In total over four years, ninety-two percent (92%) of the participants rated the likely impact of including family members as trainees (learners) as very high (43/47), six percent (6%) as high (3/47), and two percent (2%) as some (1/47). Table 3 shows the responses from each year on the likely impact of family members serving in the professional role of LEND as university faculty and staff. In total over four years, eighty-three percent (83%) of

participants rated the likely impact of including family members in a professional role (educators) in the program as very high (39/47), fifteen percent (15%) as high (7/47), and two percent (2%) as some (1/47). Table 4 presents responses from each survey year on the likely impact of family members from the community serving as mentors. In total over four years, eighty-three percent (83%) of participants rated the likely impact of families serving as mentors as very high (39/47), thirteen percent (13%) as high (6/47), and four percent (4%) as some (2/47). None of the participants from the OKLEND program in any of the survey years rated the likely impact of family in the roles of trainee (co-learner), professional (educator), or mentor as low or very low.

Forty-six out of forty-seven participants (98%) responded to the two open-ended survey questions on the influence of family involvement in the program and its impact on their future work. Forty-five out of forty-six responses described the positive influence of family involvement in broadening their perspectives and preparing them for participating as partners through a family-centered approach. One respondent noted that due to their previous experience with families they did not experience a change in views or impact on future practices resulting from family involvement in LEND. The themes generated from the analysis do not represent each individual's unique experience. Four in vivo codes, named using words stated by respondents, emerged from the review and categorizing of the responses to represent the main themes found in the responses. These codes were: unique and invaluable perspective; true member on the interdisciplinary team; partnership; and better understanding. The statements quoted are those that convey the essence of the themes elicited from the responses.

Question one - "In what ways did the experience of having family participation in the LEND training program influence or change your views of family and disability?" Twenty-nine

statements in response to this question referred to the importance of learning from the unique and invaluable perspective of the family. A sample response representing this theme was, “Involving families served as an opportunity to learn about the needs of the family directly from the source. The experience has made me more acutely aware for the need to include the family in the team.” Another respondent stated, “Having a LEND trainee representing family issues on our team was greatly influential in shifting the way the entire team viewed the role of the family. It really helped us to strive for person-centered/family-centered services.” Twenty-four statements referred to learning the value of including family as a true member on the interdisciplinary team. A sample response in this theme stated, “It helped me learn how to better serve families and to make them equal partners in their care.” Another respondent wrote, “It was very important to have a constant reminder that to be TRULY interdisciplinary, the family must be an active and engaged team member at all stages.”

Question two - “How do you think your experiences of having family participation in the LEND program will impact your work with individuals with disabilities of all ages and their families?” Twenty-three statements identified an impact on practices that described their intent to work in partnership. The theme of partnership was represented in this sample statement:

“It has altered everything I do as a professional. Instead of remaining focused on working with other professionals, I have realized that the Discipline of Patient-Parent-Family must be a part of ALL interdisciplinary teams I am a part of clinically and in the community.”

Other examples from responses that represent this theme were, “I realized that I have to include the family as a full member of the team to work together toward meaningful goals of the family.” And “I don’t think there is a way to have person-centered, family-centered practices without

having that voice in the conversation.” Twenty statements described an expected impact that trainees would make use of the better understanding they gained through the program in their interactions with families. Sample statements from respondents that represent the theme, understanding included: “I will be sure to listen to and include families and children in every aspect of my professional duties.” And, “I think having worked so closely with a LEND trainee representing family issues will forever change the way I approach my role as an interdisciplinary team member.”

### **Discussion**

The survey results provide evidence to support the positive impact of including family members and professionals as side-by-side as learners, educators, and mentors in pre-service training programs. This educational approach sets the foundation for establishing relationships and developing future inclusive family-professional partnerships. In practice, evidence shows that strong relationships between health care professionals and the patient/family lead to better patient and family health outcomes (American Academy of Pediatrics, 2003). Inclusion of family members in pre-service education establishes family-professional relationships as the norm. Responses to the open-ended survey questions demonstrated the effectiveness of family involvement in the OKLEND in influencing pre-service professionals and preparing them to value inclusion and seek out partnerships with families.

Situating parents as teachers to share their stories and experiences has been shown to be effective in building an understanding of family perspectives and increasing competency in family-centered practices (Blasco et al., 1999; Kiesling et al., 2017; Kube et al., 2012). The importance of bringing the family perspective was recognized early in the development of the

OKLEND program, leading to the UCEDD-LEND cooperative arrangement to provide family members as instructors. The addition of family mentors in the educational program created a tangible opportunity for pre-service professionals to experience a day in the life of individuals with disabilities and their families. OKLEND's educational approach of including family members and in the program partners family and professional disciplines at all levels of the educational process, intentionally building respectful working relationships and partnerships that are key to developing family-centered care (Kuo et al., 2012).

The multi-faceted approach to family involvement in the OKLEND program begins with the concept of recognizing the unique knowledge and experiences of family as a discipline. Clear demonstration of equal membership on the interdisciplinary team establishes mutual respect across all disciplines. Pre-service professionals and family members realize that they each have expertise to add to the team from their discipline. In the faculty role, family members bring a unique perspective that is not available in typical university coursework (Cohen et al., 2006). Family mentors share a view of their family life and their role as advocates, demonstrating the critical function of families in creating change at individual, organizational, and systems levels.

Through the multi-faceted educational approach described, that includes family members as faculty, mentors, and side-by-side learners, trainees learn to value family-professional partnerships. They discover how their participation in these partnerships maximizes the effectiveness and relevance of services, programs, and research activities that aim to support individuals with disabilities and their families in the community. Highlighting the expertise of families not only influences the way these pre-service professionals view the role of family on a team but also encourages trainees from the family discipline to discover the importance of their voice in these partnerships. Inclusion as an equal member in the training program encourages all

individuals to recognize the knowledge they bring to the collaborative team process and to expect this level of inclusion in future team interactions. It is notable that 100% of program graduates responded to the 2017 survey. Trainees from family discipline were among these survey participants, and 100% of the 2017 survey participants rated the likely impact of including trainees from the discipline of family as very high. We conclude from this that the family trainees feel their involvement as co-learners is a valuable aspect of the program. Learners from all disciplines build the skills necessary for forging family-professional partnerships and come to expect these partnerships as the norm in their interactions as future professionals, leaders, and advocates.

### **Recommendations for Educational Practices**

Pre-service education, training programs, and continuing education events for professionals in disability related fields can promote inclusive family-centered practices by including family as an integral part of their educational activities. Further, although not specifically addressed in the results of this survey, we recommend recognizing and including the unique expertise of the emerging discipline of self-advocacy. Self-advocates are individuals with lived experience with disability and they bring a unique perspective to educational programs. Strategies for improving health/medical education include including family members and self-advocates fully in curricular planning and delivery, and intentionally designing interactive experiential educational activities with individuals and families in the community. The OKLEND program has learned that including family and self-advocacy faculty in collaboration on the curriculum ensures relevance of the information conveyed to the lives of individuals with intellectual and developmental disability and their families. During the delivery of the curriculum, inclusion of family members and self-advocates as educators, speakers and panelists

highlights the unique expertise that they bring from their experiences. For interactive learning, partnering professionals with family members and self-advocates during experiential learning activities facilitates relationship building at a personal level, and promotes discussion about the experience from the professional, family, and individual perspectives. By leveraging these strategies in the design of educational activities, the likelihood of forging stronger family-professional partnerships increases, leading to more family-centered and inclusive practices.

### **Limitations**

The survey did not specifically ask about the impact of including individuals with intellectual and developmental disability representing the discipline of self-advocacy in the program. We hypothesize that including the discipline of self-advocacy in the roles of learner, educator and mentor has a similar impact on pre-service learners, but further investigation is necessary to determine if this is the case. In addition, the survey responses could not be tied to specific disciplines so the impact of this educational approach on trainees from the disciplines of family and self-advocacy could not be individually analyzed. Another limitation was the brevity of the responses to the open-ended questions, limiting insight into the underlying meaning of the statements. Despite these limitations, the survey results demonstrate a positive impact of including the discipline of family in all aspects of the program as perceived by OKLEND graduates. However, without pre-test or retrospective data it is unclear if the educational methods of the program are responsible or if the trainee's attitudes were pre-framed toward viewing family involvement as impactful. Participant responses to the open-ended question, "In what ways did the experience of having family participation in the LEND training program influence or change your views of family and disability?" describe learning that occurred over the program year, but further investigation is necessary to understand any lasting changes that occurred. In-

depth interviews would provide greater insight into the long-term impact of family involvement in the program on the trainees.

### **Recommendations for Future Research**

Future research is recommended to specifically investigate the impact of including individuals who represent the self-advocate perspective as learners, teachers, and mentors on pre-service professionals. Use of pre- and post- measures will expand our knowledge around the impact of including family members and self-advocates in pre-service health education. In addition, research is needed to explore the impact of partnering of family and professionals on the leadership development of the family members and self-advocates included in the educational experience. Finally, studies should investigate the similarities, differences and outcomes of educational approaches that include family members and self-advocates as partners compared to other interdisciplinary education programs that do not include family members and self-advocates in the educational process. Pre- and post- measures of interdisciplinary attitudes and family-centered practices will help us understand the impact of differing educational methods. Interviews and focus groups could provide further insights into the educational methods that contribute to fostering future family-professional partnerships.

### **Conclusions**

The innovative educational approach developed in the OKLEND program to forge family-professional partnerships in pre-service training influences graduates of the program and impacts their future work. The deliberately designed inclusion of family members as learners, teachers, and mentors, highlights the family voice as an equal and important partner on the interdisciplinary team. In the movement toward improved family-centered care in health services, and inclusive communities, family-professional partnerships must be fostered during

the pre-service educational process. Intentionally including the voice of family members in a multi-faceted way in health professions education positively impacts educational outcomes that promote inclusive attitudes and practices.

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Table 1

*Survey Participants as Percent of Program Graduates*

Survey year	Program Graduates	Completed Surveys	Survey Completion %
2014	13	13	100%
2015	13	9	69%
2016	11	9	82%
2017	16	16	100%
Total	53	47	89%

Table 2

*Impact of Family: Participating as LEND Trainees*

Survey year	Completed Survey	Very High Impact	High Impact	Some Impact	Low Impact	Very Low Impact
2014	13	12	0	1	0	0
2015	9	8	1	0	0	0
2016	9	9	0	0	0	0
2017	16	14	2	0	0	0
Total	47	43	3	1	0	0
Percent		92%	6%	2%	<i>n/a</i>	<i>n/a</i>

Table 3

*Impact of Family: Professional Roles as Faculty and Staff*

Survey year	Completed Survey	Very High Impact	High Impact	Some Impact	Low Impact	Very Low Impact
2014	13	11	1	1	0	0
2015	9	8	1	0	0	0
2016	9	8	1	0	0	0
2017	16	12	4	0	0	0
Total	47	39	7	1	0	0
Percent		83%	15%	2%	<i>n/a</i>	<i>n/a</i>

Table 4

*Impact of Family: Serving as Mentors*

Survey year	Completed Survey	Very High Impact	High Impact	Some Impact	Low Impact	Very Low Impact
2014	13	11	1	1	0	0
2015	9	8	1	0	0	0
2016	9	9	0	0	0	0
2017	16	11	4	1	0	0
Total	47	39	6	2	0	0
Percent		83%	13%	4%	<i>n/a</i>	<i>n/a</i>