

Fabric not Fringe

Weaving Family Involvement
throughout Training and
Practice for Professionals
and Advocates Working
with Individuals with
Disabilities and Special
Health Care Needs



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES

THE LEADERSHIP, EDUCATION, ADVOCACY & RESEARCH NETWORK

Fabric not Fringe: Weaving Family Involvement throughout Training and Practice for Professionals and Advocates Working with Individuals with Disabilities and Special Health Care Needs

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*Dedicated in Memory of
Ruth Roberts*

Family Involvement in Healthcare

Families of children with developmental disabilities and special health care needs have typically increased positive outcomes in the care of their children by partnering with health providers in family-centered, provider-directed collaborations; King et al. (2004) offers a definition of family-centered care which is in line with this traditional perspective:

“Family-centered service is made up of a set of values, attitudes, and approaches to services for children with special needs and their families. Family-centered service recognizes that each family is unique; that the family is the constant in the child’s life; and that they are the experts on the child’s abilities and needs. The family works together with service providers to make informed decisions about the services and supports the child and family receive. In family-centered service, the strengths and needs of all family members are considered.” (p.79).

The evidence for various levels of outcome measures of family-centered care is assessed from the perspective of the health provider delivering the care. However, in recent years, families have increasingly been organizing themselves into family-directed initiatives to effect systems changes in service delivery (Osher & Osher, 2002). Families have built productive partnerships with health providers in the disability and health-related fields, who have in turn learned about the challenges, successes and benefits of family involvement in caring for children and families, and in shaping effective systems of care (Osher & Osher, 2002). Strong family leadership and substantial family involvement on the interdisciplinary team - based on mutual respect of knowledge, skills, and values – are vital to transforming discussion of theories for family-centered care into family-driven action.

This white paper approaches family involvement from the perspective of the family discipline itself, and the ongoing paradigm shift in family-centered care—from fringe to fabric. This shift demands a new focus from a peripheral family involvement to a substantial family partnership and is driven by workforce leadership development among family leaders (Reynolds et al., 2015; Schuh et al., 2015). We present readers with examples of family involvement in Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs, from both the programmatic perspective and that of trainees from diverse disciplines. We apply concepts from research studies on family-centered care (King et al., 2004) to understand the full potential of the family discipline in developing substantial family involvement partnerships and shaping family-directed systems of care for children with developmental disabilities and special health care needs.

The varying levels of family involvement visible at specific LEND, Maternal and Child Health (MCH) Title V, and Pediatric Pulmonary Center (PPC) programs around the country demonstrate both the commonly reported obstacles to achieving substantial family involvement and the opportunities for involving family leaders as substantial program partners. Family leaders could perform as faculty, peer mentors, advisors, service planners, providers and evaluators within programs and organizations. After grounding our discussion in the history of LEND Family Discipline Network and its leadership in this area of cultivating family leadership and family involvement, we will discuss how a program can evaluate its readiness for various types of family involvement. A family discipline perspective on family involvement uses both individual practitioner and organizational self-assessment to identify key priority areas an organization might need to address in enhancing or increasing family involvement. This perspective offers solutions for those provider organizations committed to the development of substantial family involvement partnerships in the areas of developmental disabilities and special health care needs. Finally, one-page practical guides will review the essential obstacles and opportunities associated with each of these types of family involvement.

Family-centered care has shifted in scope and focal point across two distinct paradigms (Osher & Osher, 2002). In scope, family-centered care practices have shifted from providers caring for one individual family at a time to family leaders sitting at the decision-making table, setting the direction of entire

systems of care, and evaluating agreed outcomes as peer members of the interdisciplinary team. In focal point, family-centered care has evolved from provider-driven to family-driven interactions between provider and family, organizational structures, and entire systems of care. In this white paper, this paradigm shift is described from the family leader perspective; we argue in favor of those family involvement roles and activities performed as part of a substantial partnership between families and providers, organizations, and systems of care.

The History of Family as a Discipline within LEND Programs

LEND programs provide training to cohorts of graduate student from diverse disciplines with a focus on improving the health of infants, children, and adolescents with disabilities. They accomplish this by preparing trainees to assume leadership roles in their respective fields and by ensuring high levels of interdisciplinary clinical competence. There are 52 LEND programs located in 44 US states, with an additional six states and three territories reached through program partnerships. Each LEND program is a member of the Association of University Centers on Disabilities (AUCD), and collectively they form a national network that shares information and resources and maximizes their impact. They work together to address national issues of importance to children with special health care needs and their families, exchange best practices, and develop shared products. While each LEND program is unique, with its own focus and area or areas of expertise, they all provide interdisciplinary training with faculty and trainees in a wide range of disciplines with the core disciplines of Audiology, Family, Genetics, Health Administration, Medicine/Pediatrics, Nursing, Nutrition, Occupational therapy, Pediatric Dentistry, Physical Therapy, Psychology, Public Health Policy, Social Work, Speech-Language Pathology, and Special Education. Family is the only required discipline for all programs. The LENDs grew from the 1950s efforts of the Children's Bureau (now the Maternal and Child Health Bureau or MCHB) to identify children with disabilities as a Title V program priority. They are funded under the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act, and are administered by the Health Resources and Service's Administration (HRSA).

This network of training programs led the field in elevating the voices of family members as "a discipline" with a specific and valuable expertise as equal members on interdisciplinary teams providing services and supports to people with disabilities. The Family "Discipline" can be defined as that body of knowledge about the child/family member with a disability, that is inherent to the family, acquired by life experience and affected by culture and community. LEND programs have involved families in different ways and for varying amounts of time. As early as 1992, the LEND program at the Westchester Institute for Human Development had hired a family member to represent the discipline on their faculty. By 1995, The CA-LEND at the University of Southern California began including family members as trainees. Since family involvement was initially limited to a few isolated programs, family faculty sought each other out at AUCD meetings and workgroups.

The intermittent nature of these LEND family connections became more consistent and focused in 2004 with the following two events: 1) Elaine Ogburn, family faculty from Virginia, suggested for family faculty to meet face-to-face at the AUCD annual meeting and 2) MCHB identified "Family" as the Discipline of the Year for the 2004-2005 training year, which encouraged collaboration among family faculty and culminated in a meeting of the designated discipline faculty scheduled for February 2005. The 2004 AUCD annual meeting resulted in a network survey that revealed that family faculty engaged in a wide variety of roles including supervising family trainees, teaching in the LEND program (with or without family trainees), organizing the parent mentor program, and helping to develop curriculum. The roles for family faculty within LEND programs were further illuminated during the meeting in February 2005 where clear consensus emerged about the importance of LEND family faculty and the need to devote conscious effort to developing and expanding the role of the family discipline in other

interdisciplinary, clinical and leadership settings. Over the course of the following year, family faculty developed two resources toward that end: [Promising Practices in Family Mentorship: A Guidebook for MCHB-LEND Training Programs](#)¹ and the [LEND Family Discipline Competencies](#)².

In 2006, the LEND family faculty working on these resources formalized their relationship by forming a workgroup, the LEND Family Discipline Network. The goal of the Network is to support the successful integration and growth of the family discipline in the LEND and other MCHB-funded training programs, with an initial focus on supporting family faculty and trainees. In this workgroup, family discipline faculty worked together to address issues unique to the inclusion of families in the LEND programs and beyond. Members of this network represent LEND programs across the country and bring their experience in academic and advisory capacities. They have provided consultation and mentorship to new faculty and to LENDs aiming to add or expand the family discipline as a component of their LEND programs. Additionally, they have worked on a number of projects and publications including “[Partnering with Professionals: Family Centered Care from the Family Perspective](#),” published in the March-April 2010 *Journal of Family Social Work*.

In 2012, the Network expanded its focus beyond the role of family faculty in LENDs to the role that families play in educating all LEND trainees and strengthening all LEND programs. The Network partnered with AUCD and MCHB to systematically survey all LEND trainees—as part of the end of the year evaluation process—on 1) components of inclusion of “family” in their respective training programs, and 2) the impact/importance of these components of family involvement for their training. Nine LENDs participated in the survey pilot. Based on the results of the pilot, the survey was revised and was approved by the Children’s Hospital Los Angeles IRB. In 2013, the first national survey was launched. The survey was endorsed by both AUCD and MCHB. Since 2013, the survey has been administered annually. The results of the survey are being analyzed for publication.

Self-Assessment of Family Involvement

Although a family involvement self-assessment tool is not currently available, the LEND Family Discipline Network is developing a self-assessment tool that specifically addresses the issues described in this white paper. The purpose and value of conducting a self-assessment is to provide a program with useful information about the ways and degrees to which its policies, practices, and staffing promote family involvement. Additionally, this process can identify areas to increase family engagement thus enhancing overall program improvements. In response to the increasing recognition of the importance of family involvement, the following examples are provided as a guide to assist programs interested in undertaking an informal self-assessment process. The following series of questions are designed to elicit baseline information and to identify and implement action steps to enhance family involvement. Naturally, programs should consider how to best use or modify the example questions as well as add or remove items to address their own needs and individuality. Additionally, programs should be sure that their discussion process among stakeholders includes families. The following material was excerpted with adaptations to better align with family involvement from a publication by the National Gateway to Self-Determination Initiative (Schwartz et al., 2011).

1 Authored by Becky Adelman, Barbara Levitz, Jan Moss, Elaine Ogburn, Crystal Pariseau, Ruth Roberts and Barb Wagner

2 Authored by Darla Cohen, Sheryl Feuer, Fran Goldfarb, Paula LaLinde, Mark Smith and Jackie Yingling

A Framework for Implementing an Informal Family Involvement Self-Assessment Discussion

1. To what extent does our program include family members as lead instructors, co-instructors, and curriculum developers in pre-service preparation and continuing education programs?

Discussion Questions

- How are families involved by our program in providing community training and technical assistance?
- How are families involved in our program's training of its students and professionals?

2. To what extent are family members involved in the planning, implementation, and evaluation of model and/or demonstration programs?

Discussion Question

- How does our program encourage family members to become leaders and strong advocates?

3. To what extent are families involved in participatory research conducted by our program?

Discussion Question

- How are families involved in our program's research projects? Do they help to design and conduct research projects, collect information, and present the findings at conferences? Do they co-author publications?

4. To what extent does our program make it a priority to employ, and advance in employment, qualified family members?

Discussion Question

- How does our program make sure that family members of individuals with disabilities have a chance to work for the organization?

5. To what extent does our program include family members as full participants on the organization's committees, task forces, and work groups?

Discussion Question

- How does our program assist and support family members to participate fully in our organization's activities?

After exploring your program's strengths and gaps in including family members, the following summaries of types of family involvement will help you to prioritize areas for change and determine your programs readiness to implement change. To offer programs a thorough understanding of each type of involvement, the following information sheets all include a definition of a specific type of involvement, the context for implementation, a discussion of the need, and the potential benefits. This is followed by specific strategies for implementation including existing resources, ideas for overcoming potential barriers, and a process for evaluating success. We hope that these one-pagers can be used by programs interested in increasing family involvement through:

1. Family members serving in the professional role of faculty and staff;
2. Family members serving as interdisciplinary team members in clinical settings (e.g., family support coordinators);
3. Families from the community serving as mentors to host trainees for home or community visits;
4. Families sharing their personal stories as guest presenters or panelists;
5. Family members from the community serving as program advisors, as advisory board members, research participants, or consultants for clinical issues or thesis preparation;
6. Training curricula that incorporate topics specifically focused on family and disabilities;
7. Family members participating as trainees from the family discipline; and
8. Family members participating in program planning, implementation, and evaluation.

Family Members Serving as Faculty or Staff

Definition

Family members of individuals with disabilities and special health care needs who are specifically recruited for employment; and who typically hold appointment positions designated as “family faculty” and/or other similar titles. Parents have largely assumed these roles, but siblings and other family members have also fulfilled the responsibilities that include activities of curriculum coordination, mentoring family discipline trainees and other aspects of family involvement.

Best for Programs That

- ...are newly funded programs requiring the addition of family discipline as faculty of MCH training programs
- ...demonstrate an interest in initiating, increasing or enhancing the roles of families as faculty and University staff
- ...currently employ family members as staff in other programs and are seeking guidance to expand their roles in training as faculty

Discussion of Need

A 2017 MCH Journal article by Kleisling, Bishop and Roth states, “Alongside the 14 academic disciplines, parents and family members of children with neurodevelopmental disabilities have been included as members of the interdisciplinary faculty team. MCHB mandated the inclusion of family as a formal discipline in 2005...This was, in part, in response to the lack of emphasis on family-centered care across many medical and allied health education programs (Crais et al.2006; Strickland et al. 2009)”. Qualified families may potentially be effective as faculty in content area competencies that are critical for professionals working with individuals with disabilities and special health care needs. Trainees report that gaining knowledge about family issues is best achieved through first hand, real-life experiences as provided by family members themselves. Additionally, family faculty members are also likely to be experienced in directly navigating service systems; and skillful in identifying resources and community supports. Family members, as disability leaders, typically have engaged in advocacy activities and have connections to a network of other families available to also contribute.

Discussion of Benefits

The LEND Family Discipline Network, comprised of Family Faculty representing LEND programs across the country, continues to have an increasing membership due to the MCH requirement that all LEND programs include faculty representing the “family discipline”. Such family members are most likely, based on first-hand experiences, to provide a family perspective that ensures that family-centered practices are a component of the training program. The Family Involvement Surveys reported that trainees highly rate the impact and importance of having family as faculty. An additional benefit is that family faculty can effectively coordinate an array of family-related components of the training, in addition to family-centered practices, such as family-professional collaboration; family support; family quality of life; and family involvement in program planning, implementation and evaluation. In implementing the family mentorship home and community visiting experiences, family faculty often have access to other family members available to participate, enhancing the diverse scope of the training program.

Resources for Implementation

- ITAC Training Toolbox: www.aucd.org/itac
- AUCD/LEND Family Discipline Network
- Family Voices www.familyvoices.org
- “Integrating Family as a Discipline by Providing Parent Led Curricula: Impact on LEND Trainees’ Leadership Competency” <https://www.ncbi.nlm.nih.gov/labs/articles/28108835/>

Strategies for Implementation

An initial step in creating an employment position for families as professional faculty/staff may be to delineate the objectives of this type of leadership position. Types of responsibilities and activities could include, but are not limited to: 1) developing and implementing curriculum, resources and training materials in teaching and training students and fellows, medical students and residents, professionals, adults with disabilities and families, and community members; 2) recruiting, supervising and coordinating training of family discipline trainees, family interns, and a network of volunteer families serving as presenters/trainers and mentors; 3) serving as a team member on various grant-funded initiatives related to the development of training programs and materials including a focus on family leadership and partnerships in advocacy; 4) serving in a family support capacity in clinical settings and practicum experiences; 5) collaborating on projects with and serving as a liaison to local, state, and national disability networks and organizations; 6) assisting in participatory research; and 7) promoting family and person-directed approaches to training, policy and systems change on a local, state and national level. Another key preliminary strategy is to identify potential obstacles such as credentialing and budgeting; and to assemble a development team to address such organizational issues and to research examples, including through networking, of how other institutions have overcome similar barriers. Some programs have generated practical strategies in which other funding streams have been identified to support related roles that are compatible with family faculty/staff responsibilities that also may enhance their training activities. For example, the Mailman Center (Miami, FL) has grant-funding for a Family Navigator Program and, through IT consultation, built a resource portal for families (a practical resource for trainees and professionals to share with families). The Family Navigators will also work with LEND trainees and family faculty. In the Minot State North Dakota LEND program, a family member of the UCEDD Parent Advisory Panel serves as co-faculty for the disabilities studies course at the University. With family faculty leadership, the Alaska LEND program leverages connections with networks to involve diverse families. At the Westchester Institute for Human Development (Valhalla NY), LEND family faculty reach out to family members employed as service coordinators, as well as staff of the Special Education Parent Center and other grant-funded programs, to participate as co-trainers and mentor families. At the USC/ Children’s Hospital of Los Angeles, Family Faculty members have a key role in a network of Family Resource Centers across the state of California.

Addressing Barriers

The recruitment of qualified candidates as faculty or university staff is a process that involves targeted outreach that may be through new and different channels. This may require alternative approaches such as working with family support services networks, parent groups, Parent Training and Information Centers, Parent-to-Parent and FTFHICs, Family Advisory Councils and disability organizations. Such recruitment may benefit from both working with current community partners or forming new alliances. Salary may also be an issue if there is not a good comparison for this staffing position, and particularly if the candidate does not hold the same educational degrees as other faculty in this level of leadership. A written position description highlighting life experience may provide guidance as well as outreach to Human Resource personnel at similar training programs while factoring regional cost-of-living comparisons. Credentialing may also be an issue when a university faculty appointment is the criteria for employment.

Evaluating Success

Success of family faculty/staff can be measured by assessing the degree to which identified goals and outcomes have been achieved, not only by the program's trainees but also in the areas of faculty/ staff development and achieving the organization's overarching objectives such as individual and family advocacy, capacity building and systems change. Goals may include professionals and family leaders who are competent in issues related to families of individuals with disabilities and special health care needs and act as professional leaders and advocates; the development and dissemination of training materials for individuals with disabilities and their families; providing continuing education and training for professionals; and faculty/staff members who are current on information, resources and best practices in training. An organizational outcome may be increased interagency collaboration on issues such as family support, and increased participation in policy leadership on family issues.

Family Members as Supports in Clinical Settings

Definition

Trained parents can combine professional expertise with their lived experience in supporting a wide range of clinical service delivery. They frequently serve in a care and service coordination role. Family members can serve as family navigators, clinic coordinators, support brokers, advocates, and benefit counselors. They assist in obtaining, coordinating, and monitoring the services that the individual with disabilities receives in addition to accessing community resources and supporting the individual's transition between services. At the systems level, they can represent the family system in clinical leadership and liaise with community agencies and partners.

Best for Programs That

- ...serve the medical needs of individuals with disabilities or chronic healthcare needs that are complex and require multiple service providers.
- ...lack identified staff or professional care coordinators.
- ...have access to a cadre of parents or caregivers who are trained or are willing to be trained in care coordination principles and medical and community resources.
- ...have funding to compensate parent resource coordinators.

Discussion of Need

The use of parents and caregivers of individuals with disabilities serving in clinical settings has increased in response to the implementation of Medical Home concept of Care Coordination. While much of the Medical Home model addresses pre-existing professional roles within primary health services, a specific role dedicated to the provision of care coordination services is new to most primary medical care settings. In many cases this specific role has been assigned to nurses or other support staff who a) may have no training in this area and b) likely have other, competing clinical duties. This has resulted in an uneven implementation of the Medical Home Care Model nationally with families of newly identified children with special needs being paired with "experienced" family members. This can result in an individual parent-to-parent mentoring arrangement, as a means to get critical information to the newly identified parents, or to offer options in terms of support organizations available to the family as a resource. There are numerous variations of these models, ranging up to and including national networks including as primary examples Parent to Parent USA (P2P) and Family Voices USA.

Discussion of Benefits

The use of family members and caregivers as care coordinators in clinical settings has been implemented now in several states (e.g. the Rhode Island Parent Information Network and the Hali Project in Texas). While this is a new role to medical settings, it is an approach firmly based in evidence-based practices as a means of support and education for families with children with disabilities and special healthcare needs. The practice of peer- to-peer mentoring for parents of children with special healthcare needs dates back to the parent to parent movement in the 1970s. Benefits emerging from programs using trained parents include increases in caregiver satisfaction; increases in the number of successful referrals; decreases in the number of missed follow-up appointments, and-in some cases-a reduction of per patient costs. Connecting caregivers of children with disabilities to peers enhances the effectiveness of communication and aides the prioritization of information critical to the well-being of the family and child. The "lived experience" of disability often can serve to more quickly establish rapport between individuals. This does not alleviate the need for training and competency of the professional parent, but it can and often does enhance the outcomes of the relationship.

Resources for Implementation

Three programs that have implemented parent resource coordinators in medical and other health-related clinics:

- The Family Care Enhancement Project, University of Nebraska Medical Center Munroe-Meyer Institute Sarah.Swanson@unmc.edu
- The Hali Project, Brad Thompson <https://www.thehaliproject.org/>
- The Rhode Island Parent Information Network, Practice Enhancement Project <http://www.ripin.org/>
- Institute for Patient and Family Centered Care Partnering to Design a Patient and Family-Centered Health System <http://www.ipfcc.org/resources/PartneringwithPatientsandFamilies.pdf>
- The [ITAC toolbox](#) contains information on additional implementation strategies: www.aucd.org/itac

Strategies for Implementation

First, identify the need and cultivate a motivation to implement a family-based care coordination service within the clinical space. This motivation may be drawn from the implementation of the Medical Home model broadly or it may be the result of advocacy efforts aligned with supporting data documenting a demonstrable need within a traditional medical system.

Enlist involvement on the part of a university or community disabilities program (for example a LEND or UCEDD, a parent training and information center, or Arc) for training and organizational support in designing a role that will meet the needs. Experience dictates that the use of a parent care coordinator is best served by insuring the coordinator is first well-trained in community resource options and furthermore presents as a professional member of the care team. This goes beyond the care coordinator themselves to the lead organization overseeing the development of the project. Typically, memoranda of understanding are required along with clinic-specific protocols meant, for example, to protect patient privacy and comply with the Health Information Portability and Accountability Act provisions. Often, this partnership moves from memoranda to contractual arrangements.

The family role may be a “Start-Up and Support” broker, designed to give people with disabilities and their advocates the most freedom to make choices that are right for them. The Start-Up/support broker assists the individual and their family and other supports to develop a comprehensive Consolidated Support Services plan and budget, establish and maintain cooperative relationships, and foster open communication with all support personnel, connect with their community, and recruit and hire staff that will support their goals and desires. Parents and family members can also serve in the role of benefit navigators, trained and qualified work incentive practitioners who can work with people with disabilities and their families to insure they are able to get access to benefits that they are entitled to depending on disability and individual needs.

Resources related to the startup of the program are also prerequisite. While in rare cases medical clinics have been willing to fund care coordination projects, often grant or state funds are necessary to establish data-collection and prepare the first cohort of coordinators and placements. Over time, the goal is that medical providers assume more of the costs as benefits to their practices become apparent. Where these resources are not currently available, it is often best to start slowly, implementing pilot projects before attempting wider dissemination. This provides data and also allows the provider of the service to streamline their practices.

Addressing Barriers

There are a number of sources for misunderstandings and other problems that deserve consideration to ensure smooth and successful implementation. It is important to have a plan in advance for 1. Training of family care coordinators; 2. Communication with medical providers to ensure that they understand the role of coordinators, and 3. Planning for the sustainable funding, specifically the expectation of eventually moving the financial responsibility for the coordinator to the clinic. Furthermore, data from the perspective of a sound quality improvement process is critical to insuring success. If project leadership is not utilizing data to determine program efficacy, problems will likely arise. There are numerous CQI methodologies available. It is also notable that accessing technical assistance in the initial stages can be a necessary precursor to success (and without it, problems may arise.) The programs listed as resources have successfully implemented parents as care coordinators programs at the systems level and are available to serve in technical assistance roles.

Evaluating Success

Data are critical in promoting these processes. Often, university or public health programs can provide the means to efficiently collect data to show benchmarks for success are being met. These can include:

- The number of coordinators in place per the number of potential clinical placements.
- The rate of expansion of clinics being served.
- The number of contacts the coordinators are making, particularly from a qualitative standpoint successful contacts.
- Other activities the Coordinators may be implementing to support families, for example support groups.
- The degree to which the funding of coordinators moves from grant or government funding to clinic funding to support the coordinators.

Families as Mentors

Definition

Families of children with special health care needs are matched with trainees in the institution's training program. By sharing their experiences and perspectives with the trainees, families help them develop important leadership competencies, such as family-centered care skills. Trainees learn the positive and negative experiences families have encountered within health care systems. In this capacity, the families are the teachers, and the trainees are their students.

Best for Programs That

- ...provide training to present and/or future medical providers and allied health professionals.
- ...wish to improve health care by developing trainees' family-centered care skills.
- ...wish to demonstrate a commitment to including the family voice in their grant-funded training program.
- ...wish to increase their trainees' cultural and linguistic competence.
- ...wish to increase their trainees' capacity for self-reflection and perspective-taking.

Discussion of Need

Medical care in the U.S. has traditionally been systems-centered, providing patients and families little opportunity to contribute to the development of programs and policies. While medical and allied health students obtain the highest level of training within their respective disciplines, the benefits of including families as educators within health care training programs has largely gone unrecognized. As a result, trainees do not hear what does and does not work for families within organizations and systems. By excluding the consumer from the education of present and future providers, meaningful improvements can go unidentified, leaving health care provision less effective in improving patient outcomes and decreasing costs.

Discussion of Benefits

Hearing directly from families ensures students and trainees are better prepared to meet the needs of the families they serve. Mentoring projects offer trainees the unique opportunity of spending one-on-one time with a family of a child with a disability, helping the trainee develop an understanding of the unique challenges the family faces and acknowledge the similarities between families with and without children with special health care needs. It also allows for more in depth discussion and sharing of concepts and perspectives. The trainee learns firsthand how a child's disability can impact, not only the family as a unit, but also individual family members.

By increasing professionals' knowledge and awareness of families' needs, mentoring projects help lead to better health care provision, which results in better outcomes for both the patient and the family. In addition, consumer satisfaction increases because patients and families recognize that their needs and perspectives are valued by health care professionals, organizations, and institutions.

Resources for Implementation

- MCHB ITAC Training Toolbox: www.aucd.org/itac
- “Promising Practices in Family Mentorship”: www.aucd.org/LEND. Created by Family Faculty in 2006, this guidebook describes a variety of family mentorship activities in MCHB LEND programs.
- Institute for Patient- and Family-Centered Care: www.ipfcc.org
- Partnering with Patients, Families, and Communities: An Urgent Imperative for Health Care. Recommendations from the 2014 Macy Foundation Conference on Partnering with Patients, Families, and Communities to Link Inter-professional Practice and Education.
- Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System: Recommendations and Promising Practices. B Johnson, M Abraham, J Conway Institute for Patient- and Family-Centered Care 2008.
- Achieving Family and Provider Partnerships for Children With Special Health Care Needs. D Denboba, M McPherson, M K Kenney, B Strickland, P Newacheck. Pediatrics. October 2006, Vol. 118 / Issue 4.

Strategies for Implementation

Methodology for implementation of a family mentoring component within a training program’s curriculum will be unique to each institution, reflecting its needs and focus. The following example demonstrates how Cincinnati Children’s Hospital Medical Center (CCHMC) includes family mentoring in its Leadership Education in Neurodevelopmental Disabilities (LEND) training curriculum.

- The purpose of the Family Mentoring Project (FMP) is to address four of the MCHB leadership competencies: family-centered care/cultural competence, self-reflection, working with communities and systems, and critical thinking.
- The program continually recruits volunteer families of children with a variety of developmental disabilities from diverse cultures and SES. Family consent is obtained in accordance with the hospital’s policies.
- One to two trainees are matched with a volunteer family of a child with a developmental disability at the beginning of the academic year. Matching is based on several criteria, including the individual trainee’s discipline and their expressed interest in learning more about a specific diagnosis.
- The trainee(s) meets with the family three times over the course of the academic year, once in the family’s home and twice out in the community. This allows the trainee(s) to observe the family as a unit and identify barriers to community inclusion.
- Each trainee is required to maintain a journal in which they record their experiences with the family and how these experiences have helped them address the MCHB competencies.
- Trainees meet as a group twice during the academic year to share and discuss new insights and understanding of issues faced by families of children with special health care needs. The LEND Family Faculty member helps facilitate and guide the discussions.
- At the end of the academic year, each trainee writes a self-reflection essay in which they challenge their personal biases and belief system and describe the project’s impact on their future work with children with disabilities and their families.
- At the conclusion of the project, feedback is sought from both families and trainees using surveys.

Addressing Barriers

The primary barrier to implementation of family mentoring programs in health care training is recruitment of families. Families of children with special health care needs face many barriers to participating as educators in training programs, with lack of time being most often cited. In addition, geographical location of the training program can affect the ability to recruit families from diverse cultures. Language barriers can be an additional challenge. For this reason, it is important for programs to identify cultural brokers who can develop a trusting relationship with the families, while explaining to them the purpose and value of diverse family participation in the program.

Lack of funding and systems-centered attitudes towards family inclusion may also serve as barriers to family-professional partnerships, such as family mentoring. Finally, once the mentoring component is implemented, it is often difficult for trainees and families to coordinate schedules.

Evaluating Success

It is essential for programs to regularly assess trainees' professional development. At the end of the academic year, the CCHMC LEND program asks both participating families and trainees to provide feedback on the project, including suggestions and areas for improvement. This helps ensure that the project remains a meaningful experience for both the families and the trainees. In addition to evaluating the project, families provide feedback to the trainee(s) they mentored.

Families as Presenters and / or Panelists

Definition

Best practice in disability-related services dictates that family members of individuals with developmental disabilities provide a first-person perspective critical to the successful development of effective policies and practices. The role of a family sharing their unique lived experience is crucial for programs to incorporate in a variety of settings. Being a family member or parent of an individual with a developmental disability cannot be learned in any university course and must be deliberately incorporated as invaluable assets to training programs.

Best for Programs That

- ...view Family as a Discipline
- ...wish to further trainees', professionals' and others' understanding of family-centered care directly from the parent perspective
- ...value best practices in disability-related services
- ...could benefit from a lived experience perspective on the impact of disability in various service areas
- ...appreciate the many competencies that families can provide

Discussion of Need

The need for families to serve as presenters and/or panelists is beyond measure. Family members put a “face” on disability and help audiences focus on children and families, not on diagnoses and systems. Families also have the unique ability to illustrate the impact of disability on various outcomes and spark ideas for alternative approaches or interventions. Furthermore, families provide a powerful voice to influence system-wide decisions. Having families serve as presenters/panelists within programs is significant in providing professionals with the motivation needed to keep their work focused on the real needs of all children with disabilities and their families.

Discussion of Benefits

Any presenter can share knowledge, or the understanding that comes from education. Family members share wisdom, which only comes from the experience of the journey. Well-told family stories have the potential to touch hearts, change minds, and impact policies. As a result of families sharing their stories as presenters or panelists, audiences receive the encouragement and motivation they need to continue in their work and to find new, creative ways to make a difference in a child's life.

Resources for Implementation

- The LEND Family Discipline Network – www.aucd.org
- LEND Family Competencies - <https://tinyurl.com/LENDFamilyCompetencies>
- National Gateway to Self-Determination: SUCCESS in Telling Your Story – <http://ngsd.org/people-disabilities/create-your-story>
- Action Information Sheet “From Experience to Influence: The Power of a Parent's Story” - www.PACER.org
- The National Early Childhood Technical Assistance Center – Early Childhood Bulletin “Family Experiences: Ways to Lead Change Through Telling Your Story” - www.nectac.org

Strategies for Implementation

Many programs successfully include parents and caregivers of children with disabilities as presenters and/or panelists within their instruction. There are a variety of ways a program could institute the family perspective directly into their training. Some very effective methods include:

Start with existing faculty and/or trainees who have personal experience with disabilities – If a program is currently serving family trainees, learning to effectively share their stories can easily be worked into their curriculum as a competency.

- Organize a panel of parents/family members – This is a perfect project for existing trainees to network within the community (faculty should assist in identifying potential contacts) to identify family members to serve on a panel (or to join them on a panel if the trainee is a family member him/herself. Some things to keep in mind when organizing a panel:
 - Have set goals for panelists – Consider providing panelists a set amount of time to “share their story” but also request that they share two or three “takeaway points” for the audience. For example, if a program’s trainees are medical providers, allow parents ten minutes to share their story then ten minutes to share three ways medical providers could have helped them more during their journey, or one thing medical providers really excelled at with them and one thing the family wishes their medical provider would have done differently. Goals should be very specific to the audience, while also providing the family member time to share their own personal, unique perspective.
 - Accommodate parent schedules – Family members who have children with special health care needs usually have a tight schedule. Be sure to accommodate their schedules and be mindful of their time as much as possible.
 - Consider the demographics of the panel so that a variety of experiences are shared with the audience. There should be a cross-section of cultural differences, age ranges, various disabilities, socio-economic status, and variety in types of schools attended.

Addressing Barriers

- Planning and preparing a parent story takes time and energy. Be sure to give family members enough time in between inviting them to present and the actual presentation date.
- Limited family resources may pose a potential barrier, especially when trying to assure a wide range of demographics on a panel. Consider offering to provide bus passes, a small stipend for child care, or any other resources available.
- Some audiences may have misperceptions of parents’ abilities to provide value to their learning experience. Faculty should make it abundantly clear that families are the experts within their own discipline.
- Presenting a parent story can be emotionally challenging as difficult memories resurface or fears for the future rise to the surface. Should a presenter begin to cry while sharing their story, the audience should be understanding but should avoid responding with pity. Have water and tissues handy.

Evaluating Success

Understanding the impact of families as presenters/panelists within programs is important from both the presenter perspective, as well as from the audience perspective. Some ways your program can evaluate success include:

- Debrief with presenters after the session
- Distribute an audience evaluation form for feedback. Share the results with the presenter(s), as well.
- Consider having families present to familiar audiences first (e.g. faculty, peers) and progressively grow toward broader audiences (organizations, policymakers).
- Family members acting as presenters/panelists should prepare focused questions to gather feedback from faculty and/or peers as they prepare their presentation, such as did the story make logical sense, what were the takeaway points, etc.

Family Members from the Community Serving on Advisory Boards, as Research Participants, or Consultants on Thesis Preparation

Definition

Traditionally family members are invited to give feedback long after the project has been developed or implementation has begun. Many LEND programs have utilized the wisdom of family members before best practices were defined for family involvement by having family members on the steering committee from the beginning.

Best for Programs That

- ...teach or train Family- Patient Centered Care to Pre-service health professionals
- ...provide care to individuals with developmental disabilities or their families
- ...offer research through a University program which will affect or have an impact to a person with a developmental disability or their family
- ...offers a doctoral program where the topic could be in the area of developmental disabilities, patients or families of those in either of these topics
- ...have input on the development, review or feedback of policies or legislation

Discussion of Need

It is a well-known fact that the involvement of the “user” at the creation of an idea results in a better product in the end. It is also known that satisfaction of those receiving that “product” is much higher when the user is at the table during creation, implementation and evaluation. According to MCHB, “Family-Centered care” is defined as an approach to “planning, delivery and evaluation of health care” with the cornerstone being the collaboration between the families and professional. When considering research, according to “Turnbull, Friesen & Ramirez 1998,” Participatory Action Research (PAR) is a model of research that focuses on the partnership between the researcher and the intended beneficiaries. Lastly, according to the Institute for Patient and Family-Centered Care (IPFCC) one of their four Core Concepts is Collaboration. Collaboration is “Patients, families, health care practitioners and health care leaders collaborating in policy and program development, implementation and evaluation; in research, in facility design, and in professional education, as well as in delivery of care.”

Discussion of Benefits

The quality of the education can be improved by the involvement of family members in a collaborative role as an advisor. According to IPFCC the benefit of using family members as advisor is better understanding and empathy for the challenges that affect the patient and family. Communication between professionals and family members is improved, quality is raised and skills to manage conflict are improved. The unique perspective of the family member cannot be duplicated with full effect secondhand but must be heard first hand. According to the Patient-Centered Outcomes Research Institute (PCORI), the involvement of family members and patients is essential to assure the research is useful to the researcher *and* to those it is intended to benefit. According to the 2016 family discipline survey of more than 200 LEND long-term trainees, the majority believe that the involvement of family members as advisors is Very Highly Important, 53% (N=237), and more than 61% believe it is very highly important for family members to participate in program planning, implementation and evaluation.

Resources for Implementation

- Institute for Patient and Family Centered Care: <http://www.ipfcc.org>
- Getting Started Building Patient and Family Advisory: http://www.ipfcc.org/resources/getting_started.pdf
- Patient-Centered Outcomes Research Institute (PCORI): <https://www.pcori.org>
- Building Patient-Centeredness in the Real World: The Engaged Patient and the Accountable Care Organization: <http://www.nationalpartnership.org/research-library/health-care/building-patient-centeredness-in-the-real-world.pdf>
- Maternal and Child Health Bureau, Family-Centered Care: <https://mchb.hrsa.gov/chscn/pages/family.htm>
- LEND Family Competencies <https://tinyurl.com/LENDFamilyCompetencies>
- Pathways to LEND/Parent Portfolio fgoldfarb@chla.usc.edu

Strategies for Implementation

Including the family members of individuals with disabilities on Advisory Boards, as Research Participants, or Consultants on Thesis Preparation can take many forms. Certainly, there needs to be a good fit between the goals of the board, research or academic endeavor and the family members as they represent the broader community. Consider the following strategies:

- Start with the National LEND Family Discipline which is comprised of the family faculty from LEND programs across the country.
- Utilize the Family Mentoring process to support potential family advisors
- Recruitment can include parent professionals in community agencies, support group leaders, Partners in Policymaking graduates and parents serving on disability related advisory boards and boards of directors.
- Remember many family members often wear two hats; their paying job which usually is outside the medical field, and the hat of an advisor which often does not pay the bills.
- Identify leaders and researchers who are committed to inclusion and who have enough experience with the broader disability community to represent perspectives beyond their own lived experience
- Be strategic in recruiting family leaders who add a diverse perspective and represent the community affected by the work
- Establish policies and procedures that ensure all voices are involved and valued in the process

Addressing Barriers

- Build funding for family involvement into the budget. Families should be compensated through pay, travel and/or meal reimbursements, childcare vouchers, and/or other tangible benefits.
- Many hospitals or clinics believe because they have a good relationship with their patients and families, they have the information they need. This is not always true. Be strategic in considering the individuals and communities affected by your research, programming or services and strategically incorporate those perspectives into your planning and leadership teams. Not all family members are equally suited to every role. For example, you may need to seek out family members who also hold academic appointments in order to involve them in thesis preparation. They should nevertheless be encouraged to bring that lived experienter perspective to the conversation and not forced to suppress or obfuscate that source of knowledge and expertise.
- Because community-based family members' knowledge may not be academic in nature, but lived knowledge through experience, they may require a primer or targeted mentorship to meaningfully contribute to research team discussions.

Evaluating Success

- Long-term implementation of research strategies in partner communities. One of the benefits to PAR is the sustained community investment in research interventions. Long-term follow up evaluations can demonstrate the degree to which the research-based practices continue.
- Involvement of family and community members in research and program planning often also results in ongoing partnerships with program collaborators that last beyond the research cycles. These partnerships can be documented through formal (e.g. Memorandums of Understanding or MOUs) and informal (e.g. partner profiles) means.
- Conversion metrics for involving research leadership and participants in other program activities (as family mentors, family trainees, presenters, etc.)

Family-Focused Topics

Definition

Training curricula that incorporate topics specifically focused on family and disabilities.

Family-focused topics are viewed as a valuable component of the training curriculum for faculty, trainees, and children with disabilities and their families.

Best for Programs That

- ...aim to support, build or strengthen their family faculty component.
- ...have already incorporated family members in other aspects of their program.
- ...aim to include family-focused topics in new context and different developmental stages.
- ...already have an explicit framework of content knowledge, basic or advanced skills and leadership competencies.

Discussion of Need

Family-focused topics are essential for strengthening family involvement in any training, clinical and research program working with individuals with disabilities and special health care needs. However, the inclusion of the same family-focused topic would have a different impact on the program depending on who delivers it, a family faculty, a social worker, or a physician. In addition, the impact of this inclusion will vary if the family-focused topic stands alone or it is embedded in a competency-based curriculum modeled after the MCH Leadership competency # 8: Family-Centered Care (FCC).

Discussion of Benefits

The frequency in which family-focused topics are used in a program will influence the benefits drawn from this type of involvement. For example, the use of several family-focused topics in several of the different contexts and the developmental stages of a program may have a greater influence in improving the learning experience for trainees; compared to isolated and sporadic usage.

The use of isolated family-focused topics will be less beneficial than clusters of topics used in the context of learning environments already enriched with family-centered care policies and practices.

Resources for Implementation

- NDD Curriculum Resources: A repository for curricular materials currently being used within the LEND network. Email Tara Minor for access: tara.j.minor@vanderbilt.edu
- LEND Family Competencies - <https://tinyurl.com/LENDFamilyCompetencies>
- The Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities
<http://supportstofamilies.org/about/history-of-the-family-support-movement/>
- Sibling Leadership Network - <https://siblingleadership.org/>
- Strengthening Family Involvement in LEND Training Programs Webinar:
https://www.aucd.org/template/event.cfm?event_id=7986
- Institute for Patient and Family Centered Care Partnering with Patients and Families to Design a Patient and Family-Centered Health Care System
<http://www.ipfcc.org/resources/PartneringwithPatientsandFamilies.pdf>
- The ITAC Training Toolbox is a resource for implementation strategies: www.aucd.org/itac

Strategies for Implementation

This type of family involvement could be implemented in isolation or embedded in enriched family centered practices at different stages of program development to progressively build strong and substantial family-centered practices and policies for children with developmental disabilities or special health care needs. Specific and adapted training strategies could lead to different evaluation of outcomes.

Examples of explicit frameworks: basic definition of Family Centered Care (FCC), the skill of eliciting family input in a meaningful way, leadership in implementing a FCC model. Additional family-focused curriculum topics could be: Family-Centered/Family-Directed Practices; Family/Professional Collaboration; Family Advocacy; Sibling Issues through the Life Course; The Impact of Policy on Family Support and Family Quality of Life; Family Involvement in Program Planning, Implementation and Evaluation; Using Self-Assessment Tool to Evaluate Individual and Organizational “Family-centeredness”; and Ethical Issues: Family/Professional Partnerships in Healthcare Decision-Making.

The Westchester Institute for Human Development’s LEND/NY Program, has a dedicated Family Partnerships Curriculum module which spans the training year and incorporates sessions on specific family-focused topics. The module coordinators/key instructors are LEND Family Faculty and other presenters are family members employed as UCEDD staff. Additional training participants include current and former LEND family discipline and self-advocate trainees, siblings, family advocates and family disability leaders. A variety of teaching methods, materials and resources are used including: viewing videos; exploring websites; didactic content; exercises and activities; group discussions and individual self-reflection; using self-assessment tools; parent, self-advocate and sibling panels; share-back of experiences; and suggested on-line and other resources. In addition to the session pre-class assignments that provide background information, two long-term assignments for trainees are the Family-Focused Disability Organization Interview and a Family Mentorship Experience.

Addressing Barriers

Training programs frequently experience competition for limited time as a barrier to incorporating additional training content into their programs. Fortunately, family-focused topics intersect with most other training topics and can be woven into the existing training calendar.

Training programs can create and share a pool of family-focused topics, including assessment of observed barriers and required facilitators to successful implementation. For example, funding agencies may be less inclined to fund the implementation of isolated family-focused topics because isolated topics may lead to limited benefits.

Evaluating Success

Self-assessment of needs, presence of required resources, and use of specific strategies for successful implementation is recommended to guide the selection of specific family-focused topics and method of implementation. Likewise, expected outcomes should be clearly defined prior to implementation, monitored regularly, and evaluated through empirical methods.

Standard evaluation methodology can be utilized to identify the success of training activities focused on families. Participant and faculty evaluation strategies including feedback forms, satisfaction surveys and knowledge assessments that many programs are currently using will provide valuable feedback on the effectiveness of new family focused topics in training.

Families as Trainees

Definition

While there is no universal definition of who is a family trainee in LEND programs, there are three common features: 1) Relative of a person with a disability, 2) Lived experience and 3) Advocacy/Leadership experience. In 2015, 88% of LENDs had family discipline trainees (Goldfarb, 2015). These trainees serve several roles, including: providing the family perspective, representing family support as a discipline and serving as navigators to the systems serving people with disabilities. In general, family trainees participate in the same curriculum as those from other disciplines.

Discussion of Need

There is increasing need for family members in leadership positions working in direct support services and as part of interdisciplinary teams and in policy and systems change. As history has documented, many of the advances in disability policy and practice have been a result of parent and family advocacy. There is need for family members to have access to the same leadership training available to other professionals in the disability field. Conversely, as family centered care becomes the standard and parent-professional partnerships the goal, professionals need an opportunity to learn with and from family members. Including family members as trainees provides that opportunity. Graduating LEND fellows reported that having family trainees in their program important and impactful (Goldfarb et al., 2013-2016). In recognition of the value family members have in LEND programs, LENDs have been including trainees for more than 20 years and family is one of the core LEND disciplines required by MCHB.

Discussion of Benefits

In 2012, the LEND Family Discipline instituted the LEND Family involvement survey. Included in that survey were questions related to the importance and impact of having family trainees. Over 90% of fellows rated the inclusion family trainees as important or very important and rated the impact as high or very high. Examples of the reported benefits include: the helpfulness of hearing about family members views and opinions, increased awareness of the family perspective, broadening their perception to view families as peers and increased appreciation for the value of parent to parent support. Family trainees also reported benefit including increased appreciation of the challenges professionals face in providing care, strengthening the potential for true partnership. Often the family members are a little older and more experienced with service systems and provide a more realistic understanding how systems work.

Best for Programs That

- ...are interdisciplinary
- ...do not require university enrollment
- ...value learning with and from families
- ...have existing family faculty to guide and mentor trainees
- ...are open to differentiating their curriculum to support diverse learners

Resources for Implementation

- NDD Curriculum Resources: A repository for curricular materials currently being used within the LEND network. Email Tara Minor for access (tara.j.minor@vanderbilt.edu)
- LEND Family Competencies - <https://tinyurl.com/LENDFamilyCompetencies>
- Strengthening Family Involvement in LEND Training Programs Webinar: https://www.aucd.org/template/event.cfm?event_id=7986
- Institute for Patient and Family Centered Care Partnering with Patients and Families to Design a Patient and Family-Centered Health Care System <http://www.ipfcc.org/resources/PartneringwithPatientsandFamilies.pdf>
- Pathways to LEND/Parent Portfolio available from Fran Goldfarb at CA LEND; email fgoldfarb@chla.usc.edu
- The ITAC Training Toolbox is a resource for implementation strategies: www.aucd.org/itac

Strategies for Implementation

- Start with a family faculty member
- Family members may have very full plates; some may not be able to commit to a long-term fellowship. Short or medium terms may be a way to get family members started.
- Start by doing an asset map for health, financial and community resources. Share this information with your department to see if they can help “activate” the resources.
- Recruitment can include parent professionals in community agencies, support group leaders, Partners in Policymaking graduates and parents serving on disability related advisory boards and boards of directors.
- Network with minority serving support organizations to increase diversity. Recruiting undocumented families (be aware of language barriers) through connections in the community, specifically through partnerships with community-based organizations and agencies.
- Take advantage of existing materials such as the CA-LEND Pathways to LEND (pre-teaching for LEND family support trainees) and the Parent Portfolio, a tool for gathering relevant family life experiences to develop a family discipline resume
- Provide stipends for family trainees. Most LENDs provide stipends that are on par with stipends for other disciplines.
- If family trainees are working as parent professionals, document how LEND participation is of benefit to the agency – often this will encourage the agency to provide release time and/or reduced work thus allowing the LEND trainee to more successfully integrate LEND into their schedule.
- Family trainees may need additional support/mentoring from their discipline supervisor, but most programs do not need to modify their curriculum.
- Consider having a longer training period, e.g. two years instead of the standard one year LEND program.
- Use the [ITAC toolbox](http://www.aucd.org/itac) for additional implementation strategies: www.aucd.org/itac

Addressing Barriers

- To address the issue of faculty who don't understand the value of having family trainees, talk with programs that currently include family members as trainees.
- If you find that family trainees may be intimidated by trainees from "professional" disciplines, provide emotional and/or academic support needed to the family trainees (as needed) and carve out specific opportunities for their voices to be heard
- Since family trainees may not have the same academic preparation as other disciplines, consider pre-training in areas family trainees may have less experience in (e.g. literature review). See: Pathways to LEND for a model
- Because family members may have very full plates, consider opportunities for shorter term participation (e.g. short term or medium-term trainees) or a longer training term (e.g. two years instead of one).
- Family trainees may have a crisis or just conflicting demands during their training, so consider pre-planning for possible barriers to participation and identify solutions/strategies like asynchronous learning modules or distance learning.

Evaluating Success

Incorporating family members as a trainee may be a multi-step process, so evaluation should include both readiness and then success.

- Evaluating the success of your trainees can include: standard assessments used for all trainees,
- Identification of areas of particular challenge for family trainees (e.g. literature reviews or other more academic tasks); evaluate the success of family trainee specific strategies such as Pathways to LEND.
- Evaluation of trainee recruitment and applicants. Inclusion of family members may require different recruitment strategies than used for other disciplines.

Family Members Participating in Program Planning, Implementation, and Evaluation

Definition

This type of involvement includes family input at all stages of program design, including serving as; members of the planning team, designing models for implementation and/or participating in program evaluation (and subsequent revision). Participation is higher than advisory boards as family members participate on the “front end” rather than just reacting to the program. Family participants may be members of the program faculty, the advisory board, past trainees and/or community members.

Best for Programs That

- ...value family input at all levels
- ...have access to family members who are familiar with the program
- ...are writing initial or renewal applications
- ...may not have family members as faculty or staff
- ...are considering adding family members as faculty/staff and/or trainees
- ...are interested in evaluating the family centeredness of their program

Discussion of Need

Family Centeredness is a core value of all MCHB training program and is considered a fundamental competency. Programs that seek to develop family centered programs logically must demonstrate those values. Family Centeredness, by definition, is a partnership and should exist at all levels - systems, program and individual. Family members participating in program planning, implementation, and evaluation is an example of partnership at the programmatic level. Family input is necessary to a family centered problem. Since 2008 Family Centered Care has been a required component for all MCH trainees with an expectation that all HRSA programs demonstrate 100% Family Centered Care

Discussion of Benefits

Family participation at all levels of program design, implementation and evaluation allows for the family voice to be fully integrated. This increases the likelihood of program success. It also models authentic family involvement to other faculty/staff and to trainees. Too often, families are not included from inception but are invited to participate after the program has been designed. This severely limits the value that be gained from their participation. Family participation increases the likelihood that programs are mindful of cultural considerations. MCH reports that family involvement can transform your capacity to for Family Centered Care (Family Engagement in Title V (MCHB). Fast Facts on Family Participation (Colorado Department of Public Health and Environment) report as among the benefits improved State and community needs assessment process, increased Number of effective family advisers within community/programs and reduced Perpetuation of narrow scope of work in grant proposals.

Resources for Implementation

- Family Involvement, the Division of MCH Workforce Development <https://mchb.hrsa.gov/training/hi-family-involvement.asp>
- MCH Public Health Leadership Institute Adaptive Leadership and Increasing Meaningful Partnerships between Families and MCH Partnerships https://mchphli.org/?page=try_a_module

- MCH Training Guidelines For Establishing Family Advisory Boards. <http://media.mchtraining.net/training/documents/hi-fi-Guide-for-Establishing-Family-Advisory-Councils.pdf>
- AMCHP Levels of Family Engagement in Title V MCH and CYSHCN Programs <http://www.amchp.org/programsandtopics/family-engagement/SiteAssets/Pages/default/Family%20Engagement%20Levels%20of%20Family%20Engagement.pdf>
- Fast Facts on Family Participation (Colorado Department of Public Health and Environment) <http://www.chd.dphe.state.co.us/Resources/cms/ps/hcp/Resources/Fast%20Fact%20Sheet%20-%20Revised%20Family%20Participation%20for%20MCH%20audience.pdf>
- Family Engagement in Title V (MCHB) <http://www.amchp.org/AboutTitleV/Resources/Documents/Family%20Engagement%20in%20TitleV.pdf>

Strategies for Implementation

- Provide training and support for family members to help prepare family members for meeting and debrief after the meeting.
- Work with existing family organizations, e.g. Family Voices, Family Resource Centers
- Provide ladders of involvement: helping families develop skills to participate in program planning, implementation, and evaluation
- Involve family discipline graduates
- Investigate Partners in Policymaking in your state. If your state doesn't have one, consider starting one.
- Offer childcare
- Provide translated materials and interpretation at meetings, if needed.
- Involve family members and Self-Advocates in reviewing training applications and interviewing trainees
- Include family members in site visits
- Involve family members in reviewing publications
- Ask mentor parents to review their experience and the trainee they mentored. Compile the data for the benefit of future trainees

Other ideas for implementation are available in the Family Centered Care Section of the [ITAC toolbox](#) for additional implementation strategies: www.aucd.org/itac.

Addressing Barriers

Authentic family participation may not be easy or intuitive. Consider the following strategies to address common barriers:

- Attitudinal barriers as demonstrated by a lack of understanding or resistance by faculty and/or community can be addressed by talking with programs that currently include family members to demonstrate the potential for success.
- In order to recruit high quality family leaders, a clear understanding of their role and the importance of their involvement needs to be articulated and communicated.
- To avoid tokenism, families need training and support if they are to actively participate. This may require additional faculty/staff time.
- Families should represent their community; programs should not only include those who are “easy” to include. This may result in cultural and linguistic barriers to inclusion. Be prepared to engage in cultural and linguistic competency training and require translation of materials and interpretation at meetings as needed.
- Involving families can result in logistical barriers. Programs need to be prepared to be flexible in meeting times, locations and modalities. Consider options for remote or asynchronous participation.

Evaluating Success

Tools for evaluating the family centeredness of your program:

- Family Voices Family Centered Care Self-Assessment Tool
 - Provider Tool: http://www.familyvoices.org/admin/miscdocs/files/fcca_ProviderTool.pdf
 - Family Tool: http://www.familyvoices.org/admin/work_family_centered/files/fcca_FamilyTool.pdf
 - User's Guide: http://www.familyvoices.org/admin/work_family_centered/files/fcca_UsersGuide.pdf
- Institute for Family Centered Care – Self Assessment Tools: <http://www.ipfcc.org/resources/assessment.html>
- Institute for Patient and Family Centered Care Partnering with Patients and Families to Design a Patient and Family-Centered Health Care System: <http://www.ipfcc.org/resources/PartneringwithPatientsandFamilies.pdf>

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