

Family Centered Care

Why Family-Centered Care is important to MCH Leadership

Children with disabilities are members of families. It is these families who are the constant over the child's lifetime, and who have the child's best interests at heart. If MCH leaders are to work to improve systems of care for children and youth with special health care needs, it is vital that they recognize and lead with the philosophy of family-centeredness in their teaching, their service provision, their research and their advocacy.

Over-arching Goal

For MCH LEND graduates to gain a sense of understanding into the perspectives of families of children with neurodevelopmental and related disabilities.

Understanding is demonstrated by the capacity to step outside oneself and acknowledge the perspective of another person by way of articulating an appreciation of the place that person describes. A family's perspective may encompass the complexity of the on-going struggles they face on a daily basis, their emotions, adaptations and adjustments; their pride in their child's potential, contributions and capabilities; their concerns about the obstacles and challenges they face; their thoughts and hopes for the future.

Competencies

1. LEND trainee will be able to discuss the impact of a child with a disability on the whole family – parents, siblings, extended family members – which encompasses the emotions experienced and stages of adjustment and coping each has, or is going through, and the meaning of this impact within the context of their own culture.
2. LEND trainee will be able to discuss the family's access to a medical/dental "home", and the family's perspective on their achievement of partnerships with professionals. Key to these partnerships are the elements of trust, communication, a sharing of decision-making and a willingness to negotiate. The medical home concept also includes the fiscal, social and community supports that allow or prevent children with disabilities and their family's access to resources and the systems they need.
3. LEND trainee is able to discuss the current hopes and concerns of a family with a child with disabilities, as well as those for the future.
4. LEND trainee demonstrates self-reflection about how s/he can be a better professional based on experiences gleaned from families and perspectives shared by families.
5. LEND trainee generates independent or new questions and issues related to the concerns of families.

Acquisition of competencies – Activities and Measurements

Competency 1

LEND trainee will be able to discuss the impact of a child with a disabilities on the whole family – parents, siblings, extended family members – which encompasses the emotions experienced and stages of adjustment and coping each has, or is going through, and the meaning of this impact within the context of their own culture.

Activities

1. Weekly interactions in Family Mentor, covering a variety of experiences that include time in the family's home, visits to medical, dental, therapy appointments with the family, school visits, and recreational activities.
2. Observation of Initial Diagnostic Assessments and Interdisciplinary evaluations in the Developmental Disabilities Clinic, and the Family Conference; observation of a genetic counseling or medical genetic assessment session in the general Genetics Clinic.
3. Team activity: The Family Interview, assessment and report

Measurements: During conversation with MCH mentor, dialogue time with other trainees, and on-line discussions at Learn@UW:

LEND trainee shares the perspective of family members – parents, siblings, members of the extended family circle – about the impact of their mentor family member's disability. This sharing is gleaned from the activities listed above: trainee's opportunity to talk to his/her mentor family, the family they work with in their team activity and listening to staff and family in conversation during clinical observations.

Examples:

- how the parent felt when the diagnosis was first made
- how parents or siblings have adjusted and continue to adjust
- their feelings about how they cope
- their values and beliefs about disability in the context of their race and culture

Competency 2

LEND trainee will be able to discuss the family's access to a medical/dental "home", and the family's perspective on their achievement of partnerships with professionals. Key to these partnerships are the elements of trust, communication, a sharing of decision-making and a willingness to negotiate. The medical home concept also includes the fiscal, social and community supports that allow or prevent children with disabilities and their family's access to resources and the systems they need.

Activities

1. During a family mentor visit, trainee will talk to the parents or caregivers of their child and ask questions regarding their experiences and impressions about the medical home concept. Trainee will have the Questions to Guide Your Family Mentor Experience as a guide if needed, on-line at the MCH LEND Learn@UW site.
2. Trainee will have the opportunity during observations of family meetings at clinic appointments to listen to staff and families talk about whether they have a "point of contact" for their child regarding medical/health issues.
3. Trainee will have the opportunity to ask the family in their Team activity, the Family Interview, about their experience with the medical home concept, whether or not they have one, or a main point of contact, their experiences in finding a provider who addresses this concept of a medical home for them.

Measurements: During conversation with MCH mentor, dialogue time with other trainees, and on-line discussions at Learn@UW, LEND Trainee discusses or shares:

- information about the child's health care provider(s). The child does/does not have a medical home arrangement, in that one provider helps to guide the child through the medical system as different medical needs arise, and different specialists are required to address those needs.
- information about the child's dental visits; whether or not he/she has a consistent dentist who has followed the course of development of the child and how this has/has not worked for the child and family.
- the family's perspective on whether or not they are in a partnership with professional(s), that contain trust, communication, a sharing of decision-making and a willingness to negotiate.
- the family's impressions about their access to other community resources; what those resources are and whether or not the family has been able to use those resources; i.e., Childcare and Respite resources the family may need
- Public health services for immunizations or nutrition needs, if needed
- Early intervention and education services
- Advocacy and parent training
- Other systems or supports?

Competency 3

LEND trainee is able to discuss the current hopes and concerns of a family with a child with disabilities, as well as those for the future. This includes a life-span approach with special attention paid to transition for youth to all aspects of adult life.

Activities

1. After spending time with the mentor family, having shared experiences and listening to the family share their perspective on the hopes and concerns they have about their child, the trainee will be able to articulate this perspective and express a sense of appreciation for those hopes and concerns.
2. Trainee will listen to families as they share their stories during clinic observation and participation.
3. Trainee will ask the family questions during Team activities with a family and listen as they share their perspective.

Measurements: During conversation with MCH mentor, dialogue time with other trainees, and on-line discussions at Learn@UW, LEND Trainee will:

- share their mentor family's hopes for their child with a disability.
- talk about the concerns parents have for their child now and in the future. This might include their concerns for their child's ability to use transportation safely, or shop for themselves, or go to movies and other activities.
- share family's hopes and vision for the future for their child; what they envision their child will be doing, where they will live, whether or not this might include some meaningful employment opportunity for their child, or friendships.
- share some of the fear or worries the family may express about the opportunities their child may/may not have, the risks to their child's vulnerabilities, as well as the successes they hope for.

Competency 4

LEND trainee demonstrates self-reflection about how he/she can be a better professional based on experiences gleaned from families and perspectives shared by families.

Activities

1. Attendance at school meetings, or therapy sessions, or medical visits, listening to other professionals who work with the child in Family Mentor interactions.
2. Seminars, Research lectures, readings
3. The Team activities where the trainee is able to gather information about the professionals who have worked with the child and family.
4. Clinic observations where the trainee has the opportunity to listen to families share their experiences about what they value from professionals and what has helped their child, and also what has not helped, or has hindered the progress of their child.

Measurements: During conversation with MCH mentor, dialogue time with other trainees, and on-line discussions at Learn@UW:

- Trainee reflects upon his vision of his future professional role in re-defining or reinforcing terms as to how it might impact children/people with developmental disabilities and their families.
- Trainee reflects upon the importance of such skills as communication with families, listening and reflective skills, collaboration.
- Trainee reflects upon the impact of affecting positive system change or the desire to have leadership skills to affect change for the future.
- Trainee talks in terms of her profession and the families she may work with, in terms of wanting to make a difference.

Competency 5

LEND trainee generates independent or new questions and issues related to the concerns of families.

Activities

This competency encompasses all of the activities MCH LEND Trainees participate in throughout all of LEND's major areas: Leadership, Research, Community, Culture, Clinical, Team, Public Health and Public Policy, and Family-Centered care.

Measurement

Trainee in dialogue, on-line, in seminar discussions, and in conversations with LEND mentor asks new questions for other trainees and staff to think about, and raises new issues related to the concerns of families.

Definition of a Family

Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support...A family is a culture unto itself with different values and unique ways of realizing its dreams. Together, our families become the source of our rich cultural heritage and spiritual diversity. Our families create neighborhoods, communities, states, and nations.

Family-Centered Care is neither a destination nor something that one instantly 'becomes'. It is a continual pursuit of being responsive to the priorities and choices of families. There is no single approach that is right for all families.

From: <http://www.communitygateway.org/faq/fcc.html>. Family-Centered Care

Principles of Family-Centered Care

- Recognize that the family is the constant in the child's life, while the service systems and the people in those systems constantly change.
- Recognize family strengths and individuality. Respect different methods of coping.
- Treat people with dignity and respect.
- Share information with family about their family member's condition that is complete and unbiased. Do so in supportive and appropriate manner.
- Acknowledge and honor the cultural traditions and values of families, and their racial, ethnic and socioeconomic diversity.
- Encourage and facilitate family-to-family support and networking.
- Implement programs and policies that provide emotional and financial support to meet the needs of families.
- Understand and incorporate the developmental needs of children, adolescents and their families into service delivery systems.
- Facilitate family and professional collaboration at the many levels of service provision:
 - care of the child/youth with special needs
 - development, implementation and evaluation of programs
 - formation of policies

Family-Centered Care

Tool to track progress on competencies

MCH LEND Trainee is able to	Discuss the impact of a child with a disability on the whole family, emotions adjustment and coping family members go through—within the context of their culture.	Discuss the family's perspective on access to a "medical/dental home" concept, as well as fiscal, social & community supports.	Discuss the current hopes and concerns of a family with a child with disabilities, as well as those for the future.	Demonstrate self-reflection about how he/she can be a better professional based on experiences gleaned from family perspectives.	Generate independent and new questions and issues related to the concerns of families.
<i>Competent across multiple experiences</i> (list experiences and dates)					
<i>Needs more experience in specific settings</i> (Identify plan or experiences needed)					