



A Compendium of Family-Centered, Family-Directed Field Experiences

The MCHB Family-Centered and Family-Directed Practices Workgroup¹ collected examples of family-centered, family-directed field placements for trainees. Each example is accompanied by a contact name and address for more information. This compendium aims to stimulate interest in developing innovative family-centered field placements and using contemporary resources, such as self-assessment tools, to promote family-centered practices.

1. The following workgroup members compiled the compendium:
Barbara Levitz, Mark Smith, Susan Horky, Tanya Baker-McCue, Tawara Goode

Part One: Overview

Field experiences to promote family-centered and family-directed practices are designed as “family mentorships,” in which the goal is to learn from families. Such experiences provide trainees with an opportunity to:

- Acquire a better understanding of how children with special needs’ families function at home and in the community
- Learn about a family’s perspective on disability and special health care needs
- Hear about a family’s successes and challenges in accessing community resources, partnering with professionals, and advocating for their child within educational, health, and other service and support systems
- Gain enhanced skills in family-centered communication, acknowledging the importance of cultural and linguistic competence
- Interviewing a parent advocate and shadowing the advocate at a formal planning meeting
- Reviewing materials written about families to evaluate the use of “person-first language”
- Helping a family-led organization develop a grant proposal for funding
- Working with a family to engage in administering MCH programs, such as reviewing the state’s block grant application, guiding development of a family advisory group at the state level, or strengthening hospital-based services

Field experiences, tailored for the type of training program and trainees, can occur through a selection of such activities as:

- Conducting a home visit and community outing with a family
- Conducting an in-depth interview with a family you know in medical centers and clinics or as a member of an interdisciplinary team
- Assisting a family with an issue requiring advocacy
- Attending and interacting with families at parent support groups, advocacy or other training, or organizational meetings
- Interviewing the staff members of a Family Resource Center, such as a parent-to-parent program or a Parent Training and Information Center
- Navigating family-focused Web sites with a family to assess accessibility and usefulness
- Using an assessment tool to interview family-centeredness in a practice setting, sharing results with program administrators, and recommending strategies for improvement, if needed

For additional ideas, activities, or program design and development, refer to the following documents at www.aucd.org:

Ogburn, E., Roberts, R., Pariseau, C., Levitz, B., Wagner, B. Moss, J., Adelman, R. (2006, October). *Promising practices in family mentorship: A guidebook for MCHB-LEND training programs*: Silver Spring, MD. Association of University Centers on Disabilities.

Cohen, D., Feuer, S., Goldfarb, F., Lalinde, P., Smith, M., Yingling, J., Pariseau, C., Pepper, N. (2006, October). *LEND Family Discipline Competencies*: Silver Spring, MD. Association of University Centers on Disabilities.

Part Two: Sample Program Models

1. **University of New Mexico LEND**
2. **University of Nebraska Medical Center Munroe-Meyer Institute Delivery of Chronic Care Project; Munroe-Meyer Institute LEND**
3. **Parent Partners in Health Education Training Program, New York State Developmental Disabilities Planning Council**
4. **Westchester Institute for Human Development LEND and the School of Public Health, New York Medical College**
5. **Department of Maternal and Child Health, School of Public Health University of North Carolina at Chapel Hill**
6. **University of Florida Pediatric Pulmonary Center Faculty-Related Training Activities in Family Centered Care**
7. **Georgetown Center for Human and Child Development and the National Center for Cultural Competence Curricula Enhancement Series**

I. University of New Mexico LEND

Course Syllabus: Family–Professional Collaboration Component

Purpose:

The purpose of the family professional component is to provide information and practice in working in a family-centered model of service delivery. Each fellow/trainee will gain increased experience, and knowledge of:

- the philosophy and principles of a family-centered approach,
- the importance and value of family-professional collaboration,
- strategies to identify and build on the strengths of families,
- the benefits of family involvement, and
- the diverse definitions of “family culture.”

This component seeks to ensure that trainees/fellows acquire the skills and understanding necessary to develop and maintain collaborative partnerships with the families they serve.

Objectives:

At the end of the family-professional component, the fellows/trainees will:

- have an increased understanding of the importance and value of family- professional collaboration;
- be able to identify specific methods for responding to the identified needs of families;
- have learned new strategies for involving families as partners in their work; and
- have gained experience in developing and strengthening family -professional partnerships.

Expectations:

Trainees will have met with faculty members to identify a specific activities through which they can demonstrate a family-professional partnership. Activities may include partnering with family members in activities such as program planning, co-instruction, program implementation, program evaluation, and/or advisory/governance opportunities.

- Each trainee will be responsible for facilitating a 15 minute discussion with the LEND team to reflect on their individual family-professional experience.
- A written reflection paper will outline the trainees' family-professional experience. The paper should be 2-3 pages typed and include a description of the plan, implementation process; any identified barriers/challenges, accomplishments/outcomes, and lessons learned in collaborating with families.

Family-Practica Project/Assignment (2005-2006):

Each trainee/student is paired with a family of a child with a disability over the two academic semesters. Throughout the year, brown bag lunch sessions are scheduled for group discussion, support, and feedback. Students are encouraged to maintain a journal of their observations and reflections, and meet individually with the family and core faculty member at least once each semester. A two to three page reflection paper is due at the end of the year that details project experience, challenges, and lessons learned.

During the first semester:

Trainees/students spend time with the family in a series of structured activities, such as doctor visits, Individualized Family Service Plan (IFSP) / Individualized Education Plans (IEP) conference meetings, therapy sessions, family recreational outings, and errands. The student's role during the structured time is predominantly that of an observer. **A minimum of 8** contact hours is required within the first semester and provides students and families with a chance to get to know each other in preparation for the more intense relationship that develops during the second semester.

During the second semester:

Trainees/students are required to spend a **minimum of 16 contact hours** with the family. How this time is spent is defined by family priorities for the kind of assistance they want

from the student. Each student/family pair will then develop an individualized, mutually agreed upon written plan for what the student and family will accomplish together. The following are some examples of practica projects:

- Make a video tape of a child who is transitioning to a new program to assist the providers in the new environment
- Create an "all about me" book for a child's transition to a new school
- Create a scrapbook with the family of the child's first years
- Assist a family of a child with intense needs to grocery shop and prepare a meal
- Provide one-to-one attention to the sibling of a young child with multiple needs
- Locate and summarize information about a rare genetic disorder
- Create a record keeping book for a child who has multiple medical and therapy providers
- Assist family in daily routines and chores
- Help locate respite/childcare providers
- Research eligibility for services, programs, or entitlement benefits such as SSI, Medicaid, etc

The plan is signed by the student, family, and core faculty member in the beginning of the second semester and reviewed at least once by all parties before the end of the semester.

Goals of the practica experience and assignments:

- Provide an opportunity to view children with disabilities and their families outside of a clinical setting
- Provide the opportunity to recognize that services or recommendations that may appear to be urgent from a professional perspective become less important when viewed within the context of the family's daily routine

- Provide an opportunity for students to listen to families' choices and priorities
- Provide an opportunity to build collaborative partnerships with families

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**2. University of Nebraska
 Medical Center
 Munroe-Meyer Institute Pediatric
 Medical Resident
 Interdisciplinary Requirements on
 Family-Centered Care**

Delivery of Chronic Care practica (6 hours)
 Pediatric Medical Residents on rotation at MMI are expected to complete each of two chronic care practica during their rotations. The practica are based on the Project DOCC curriculum. All DOCC activities are supervised by parents trained in the curriculum who are compensated for their time by the School of Pediatrics.

- The first involves the home visit in which the Resident visits the home of a child with a disability and/or chronic health care needs. The visit is supervised by two training parents, the first being the resident parent who describes varying aspects of the child's care: the child's routines, medical procedures, medications, home adaptations, and other aspects of daily life specific to the child's medical condition or disability. The second teaching parent's role is to expand the discussion, generalizing the specific issues being discussed to some of the broader concerns regarding parenting a child with special health care needs/disabilities. The visit is scheduled for approximately 90 minutes to allow for adequate sharing of information and the opportunity to discuss questions the Resident may have.
- The second practica involves the medical history interview. The Resident is provided with a series of questions to ask the training parent. The interview offers the Resident an opportunity to delve into areas of concern outside of an acute care frame of reference: insurance concerns, educational issues, family relationships, gaps and barriers to needed services, and the like. The goal of the interview is to integrate the child's health and disability issues into the broader framework of the family experience.

Residents also have the opportunity to attend annual noon conferences that are presented by the program coordinators, providing an overview, rationale for, and history of the program at MMI.

Munroe-Meyer Institute LEND Family–Professional Collaboration Component

LEND Interdisciplinary Leadership Project (42 hours)

In teams of 2 or more students, trainees participate in a mentored Interdisciplinary Leadership Project during their training period. The student teams consist of approximately 2 or more students representing different disciplines with overall direction provided by a faculty member or a professional collaborator in the community. In consultation with their disciplinary and interdisciplinary advisors, specific project assignments will be determined based on student interest and institute/community opportunities. Each project should have interdisciplinary staff representation and should provide students with an opportunity to develop and demonstrate leadership skills. Projects will be varied in nature and scope and may be based at MMI or with a community organization or agency. Including a family component in each project is strongly encouraged. Each project should have a goal or outcome that can be achieved within 4 to 6 months during the student's training period (may be a sub-project within a larger program or project). Examples of Interdisciplinary Leadership Projects include: community and systems level policy activities, grant writing, survey or needs assessment, development of training or educational materials, participation on a community agency or organization task force, advocacy activities, or development or enhancement of clinical programs.

- Each student will propose a leadership project in October.
- Upon completion, the student will finish a final project abstract and report on these experiences with faculty and other students

in the student seminar to improve interdisciplinary sharing among staff and students.

LEND Community-Based Services Coordination Activity (8 hours)

This activity provides students with a “real life” experience in providing family-centered, culturally-competent service coordination to a family with a child with a neurodevelopmental or related disability or a special health care need. Placement in the community enables students to gain an in-depth knowledge of an agency providing service coordination activities and the range of services they provide and offers a local networking opportunity for students. Students then share their experiences in a student seminar through a student-led discussion of their service coordination activities. This activity is coordinated and supervised by the LEND Family Coordinator.

Activities:

1. Each student will meet with the LEND Family Coordinator and be assigned to a service coordination through a local program providing service coordination services (e.g., Early Intervention Program).
2. The student will arrange to meet the service coordinator and become familiar with the specific agency and its specific confidentiality requirements.
3. A target family will be identified and the student will review the case file to become familiar with the family and the service coordination process. The service coordinator and student will discuss the family's case (e.g., the child's disability, the family's cultural practices and beliefs, the IFSP, the agencies involved, etc.).
4. The student will shadow the services coordinator during one or more face-to-face contacts with the family, preferably during routine coordination activities.
5. Following the shadowing experience, the student will complete a brief assessment/report of the case, including the strengths

of the family, the services needed, the services obtained, the service coordination process, and any areas identified as needing improvement.

6. The reports and experiences of each student will be discussed individually with the LEND Family Coordinator and presented to the group for discussion during the student seminar.

Independent Service Coordination Activity (8 hours)

The Independent Service Coordination Activity offers students a first-hand experience providing family-centered, culturally-competent service coordination to a child with a neurodevelopmental or related disability or a special health care need and his/her family.

Activities:

1. The student will consult with a family to identify a service-related need or an area of concern. The family will be identified and selected within the student's clinical work under the guidance of the disciplinary advisor or with the assistance of Mark Smith from the MMI patient population.
2. The student will discuss the identified needs with the disciplinary advisor, interdisciplinary advisor, or clinic service coordinator.
3. All potential (internal and external) resources that are available to meet the identified family's needs will be explored.
4. The student will identify one or more agencies to investigate the specific resources available within each agency. (This includes contacting the agency about its purpose and the services they provide.)
5. The information obtained will be discussed with the advisor and/or Mark Smith to determine the appropriateness of information, and a plan will be developed to discuss the information with the family.

6. The information will be provided to the family and will be documented and placed in the medical record. A brief summary of the service coordination activity will be finished upon completion of the activity.

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3. Parent Partners in Health Education New York State January 2008

Parent Partners in Health Education (PPHE) is a curriculum to train medical residents about working with families and children with developmental disabilities. Funding for PPHE projects is provided by the NYS Developmental Disabilities Planning Council. The NYS Council on Graduate Medical Education provides technical assistance to grantees and is conducting the overall program evaluation of the grants. This newsheet is provided to inform you about this important project and to invite your inquiries about how you can adopt the curriculum. Updates will be issued periodically by the NYS Council on Graduate Medical Education.

Exciting programs to enhance resident training to support families and children with developmental disabilities are happening at 12 New York teaching hospitals, where 16 pediatric and family medicine residency programs are implementing PPHE.

Why were 12 teaching hospitals interested in implementing PPHE? Mostly, because they felt that PPHE would improve the quality of resident training to work with families and children with developmental disabilities. The PPHE curriculum fits nicely with the ACGME and AOA standards while enhancing existing training.

The goals of the PPHE curriculum are to:

- Improve medical residents' awareness of the day-to-day issues faced by families caring for children with disabilities;
- Improve residents' knowledge of non-medical supports and potential sources of referrals within the community;
- Increase collaboration and communication between residents, non-medical human service professionals and families of children with disabilities;
- Enhance residents' skills for developmental disabilities as part of an overall Patient-Centered approach to the care of children with disabilities and their families; and
- Enhance satisfaction with primary care services for children with developmental disabilities and their families.

The PPHE Curriculum offers didactic and experiential learning to complement elements in existing resident program curricula. Each project uses the *Parent Partners in Health Education* curriculum, which consists of the following components:

- **Parent Interviews** designed to help the resident gain an understanding of the experiences of raising a child with a disability from the perspective of the family.
- Four **Didactic Lectures** that contain specific, detailed content including an orientation session, Assessment of Developmental Disabilities in Primary Care – Denver II, Legal Aspects and Accessing Services for Children with Disabilities, and Doctor-Patient-Family Communication.
- **Community Agency Interviews** that allow the medical residents to learn directly about available community resources and including at least one interview with an agency providing services to the paired family.
- **Clinical Experiences** that provide direct experience with children with developmental disabilities and giving the resident the opportunity to develop essential skills and highlight the integration of clinical, family and community aspects of care.
- **Community Medicine Case Presentations** through which residents share medical, social, and educational details about their assigned family and child with other residents and faculty.
- **Small Group Discussions** that provide a forum where residents can share in informal peer-to-peer exchanges.

- **Personal Reflection Logs** that allow residents to record notes, feelings, and experiences about their contacts with children, parents, and providers.

Although using the same curriculum, residency programs are applying the curriculum differently. **Some of the different models** are:

- One-year programs offered in the year that pediatric residents have their behavioral and developmental rotation.
- Multi-year programs either for PGY-2s and PGY3s, or for all three residency years.
- Concentrated programs conducted during 3-4 week sessions.

For more information about PPHE and a complete list of the Parent Partners in Health Education Grants email gme@health.state.ny.us.

To learn more about how one of these grantees has implemented this program at New York Medical College contact:

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**4. LEND Family Mentorship
Westchester Institute for Human Development and The School of Public Health
New York Medical College**

The Family Mentorship Leadership Project provides trainees a useful experience in learning more, through a first-hand visiting experience, about how a family of a child with special needs functions both at home and in the community. Two visits are scheduled with a designated volunteer family to learn more about their perspectives on developmental disabilities and special health care needs as well as some of the challenges they may face in advocating for their child.

The goal of this activity is for trainees to learn from a family about the impact of having a child with a disability, their experiences working with professionals from various disciplines, and the responsiveness of service systems to the family's needs and desires. This experience will offer trainees an opportunity to understand the steps that a family might be using to work with their school district, health providers, or other formal systems of support. Trainees will have the chance to see the child as a member of his/her community.

Learning Goals:

- To understand the impact a child with developmental disabilities and special health care needs may have on the entire family.
- To learn about the emotions experienced and stages of adjustment parents go through when a child is diagnosed with a developmental disability or special health care need requiring ongoing care.
- To appreciate the value of good collaboration between parents and professionals.
- To learn about community resources available for children with special needs and their families.

- To consider obstacles, challenges, opportunities, and outcomes of school and community inclusion for children with developmental disabilities or special health care needs.
- To understand the importance of family-centered and family-directed practices.
- To increase awareness of how personal attitudes and biases can affect a professional's relationship with children with developmental disabilities and special health care needs and their families, including issues of a philosophical, emotional, or ethical nature.
- To increase appreciation of the potential, capabilities, and contributions of children with developmental disabilities.

Outline of project activities (2007-08):

- Trainee completes a pre-Family Mentorship Self-Assessment
- Trainee completes an information data form that includes preferences for family location, child's age, disability or special health care needs, and other special requests
- A Family Mentorship Coordinator contacts each mentor family about availability; pairs families with trainees; sends families the trainees' information and other pertinent program information including learning goals
- After receiving the family match with contact information, trainees contact their mentor family
- A mutually convenient time is scheduled for a first visit
- Trainee conducts the visit
- Trainee completes a Family Visit Interview and Observation form (not working directly from this form during the visit, but rather using the form as an outline of what to discuss with the family)
- Trainee arranges a time to accompany the family on a community outing (restaurant, shopping mall, supermarket, community recreation activity, church/synagogue/temple, doctor's appointment, neighborhood playground, etc.)
- Trainee completes a Community Visit Observation form which serves a summary of the experience and may include a narrative description of the visits with a personal reflection to be included in his/her LEND portfolio
- Trainees meet to present and discuss the outcomes of the Family Mentorship activities with other trainees and faculty
- Trainee completes a post-Family Mentorship Self-Assessment
- Mentor family completes a Family-Centered Competency Assessment to evaluate the trainee's family-centeredness
- Trainee completes a Family Mentorship Feedback Form to assess his/her experience with the mentor family
- Trainee and Family Mentorship Coordinator follow up with appropriate thank you to mentor family
- Family Mentorship Coordinator evaluates the trainees' experiences and the overall program for any revisions or program improvement

Family Home Visit Interview and Observation Form:

1. In what town does the family live?
2. How old is the child with a disability?
3. Who are the family members?
4. Briefly describe what the family views as the child's greatest strengths?
5. Briefly describe what the family views as their greatest strengths?
6. What are the family's greatest concerns?

7. What are the professional disciplines with which the child and family has interacted?
 8. How does the family view their experiences in partnering with interdisciplinary teams?
 9. What is the family's view of school and community inclusion?
 10. What aspects of the child's disability present an obstacle to inclusion?
 11. What informal support has proven most helpful in having the child participate in school or community activities?
 12. What formal support has proven most helpful in having the child participate in school or community activities?
4. What were your impressions of the family during this experience? What do they think of you?
 5. If you were a member of this family, what would you do differently?
 6. As a professional in the field, what would you want the formal systems of support to do differently?
 7. How did this visit influence your views on inclusion, disability, or families?
 8. What did you learn from this experience?

For more information, please contact:

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Community Visit Observation Form:

1. Where did you go and what did you do? What was your role?
2. With whom did the child interact? How was the child treated in these interactions?
3. Recall positive and negative examples of language that was used to describe the child.
4. How was the family treated (e.g., level of respect demonstrated)? Do you feel that they were treated in any way differently because of the child?
5. What accommodations or obstacles did you encounter that contributed to the overall quality of the experience for the child?

Post-Interview Impressions Form:

1. What did you feel were the particular strengths of this family?
2. Do you feel that formal systems of support (e.g., school, physicians, etc.) are working in partnership with the family on behalf of the child?
3. What are the more positive or difficult aspects of school and community inclusion for this child?

5. The Department of Maternal and Child Health, School of Public Health, University of North Carolina at Chapel Hill

Family-Centered Field Placements

1. The MCH training program in the Department of Maternal and Child Health at the University of North Carolina at Chapel Hill initiated a model for strengthening and institutionalizing interdisciplinary collaborative training opportunities between the state Title V program and MCHB training programs at UNC. Interdisciplinary training is an effective means for promoting family-centered principles. However, according to published reports, professionals seldom agree upon or implement family-professional collaboration outside the clinical relationship. National performance measures, applicable to all trainees in MCH programs, include family participation, cultural competence, and partnerships with Title V programs. State Title V programs have similar performance measures.

The UNC Leadership Consortium, composed of five MCHB training programs (Social Work, Dentistry, Public Health, Center for Development and Learning—a LEND program, Nutrition), conducts an annual, year-long intensive leadership course for 25 trainees from the five programs. The course includes a workshop on cultural competency. In 2007, the student intern worked with the NC Family Advisory Council members (a state-level policy advisory board for children with special health care needs) to understand better their interest in participating in and contributing to family-centered leadership training, including a workshop explicitly devoted to this topic. The students led a workshop-planning group that met by conference call over several months. Over the course of the planning meetings, the planning committee decided to use the cultural competency workshop as an opportunity to introduce

the concepts that would be explored in the family-centered care workshop. To ensure consistency between these two thematically related workshops, the planning committee included the facilitator for both workshops in the planning meetings. Family council members participated in the cultural competency workshop and a new family-centered care workshop was conducted with leadership trainees and Family Advisory Council staff members. The objectives for the Family-centered care workshop included: 1) to increase trainees' awareness of disability/CYSHCN as an integral component of MCH practice and policy; 2) To increase trainees' appreciation of the importance of family-professional collaboration; 3) To provide trainees with methods of incorporating family perspectives into MCH leadership.

2. This project will focus on the implementation, monitoring, and assessment of patient and family centered care at the UNC Cancer Center. UNC Healthcare, the parent organization for the new UNC Cancer Center, is a part of the Planetree initiative, a model that uses a systems approach to creating practices and policies to support patients and families as members of their healthcare team. The field placement will help UNC Cancer Center meet Planetree designation criteria related to family involvement at the organizational level via the creation and implementation of family advisory councils and the incorporation of the patient/family perspective by engaging families as members of administrative committees. Current levels of family involvement and the existing structures and policies that facilitate or act as barriers to family involvement at the Cancer Center will be assessed. Families', providers', and cancer center staff ideas about how to involve families at the organizational level also will be examined. Information about promising practices will be gathered through literature review and communication with other health care

centers. The project will engage families as active partners, reinforcing the UNC Cancer Center's ability to respond to the diverse needs of the families and cancer patients it serves.

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6. University of Florida Pediatric Pulmonary Center

Faculty-Related Training Activities in Family Centered Care

Formally:

- We [plan to] hold a faculty meeting for the Family Involvement Consultant to talk with faculty about Family Centered Care, to distribute a FCC self-assessment, and to teach about the concepts.
- The Family Involvement Consultant (when present) and the social worker (when Family Consultant is not present) raise issues related to family perspectives in trainings, faculty meetings, patient care meetings, and conference planning and division meetings.
- We do several cultural conference presentations each year and CC is part of FCC.

Informally:

Social worker advocates for family's viewpoint in clinic and patient care meetings

- Family Faculty are present onsite and at meetings, conveying their involvement and the importance of it.
- Family Consultants are present at conferences, conveying the importance of their roles.
- Articles on Family Centered Care are made available to faculty.

Family Centered Field Placement: Criteria/Indicators

UF Pediatric Pulmonary Center

A "Family Centered" Placement includes:

- Didactic/interactive course work on Family Centered Care
- Family perspective presented by Faculty during clinic
- Clinical care is genuinely Family Centered--theoretically
- Family Partners involved in clinical training--theoretically
- Trainees and faculty are provided with articles discussing Family Centered Care
- Family Faculty:
 - Teaching on the concept of FCC
 - Teaching about their family's story
 - Present, co-teaching, a family perspective during all classes
 - Present at conferences, Grand Rounds, etc
 - Division has hired Family Partners on Faculty/staff
 - Family Partners are frequently onsite, visible, involved
 - Family Partners participate in meetings
 - Family Partners meet with administrators to discuss programs and policy
 - Family Advisory Board, or something similar, exists to make recommendations, implement policy, and develop activities for families, trainees and faculty
 - Faculty receive ongoing training from Family Faculty on FCC
 - Trainees conduct home visits
 - Faculty conduct home visits--theoretically

Pediatric Pulmonary Centers Cross Cultural Assessment Form

Please indicate how much you agree or disagree about each of the following statements

	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
1. I believe that parents bring a unique expertise to our relationship.				
2. I believe in the importance of family participation in decision making at the program and policy level.				
3. I believe that parents' perspectives and opinions are as important as those of professionals.				
4. I believe that families bring a critical element to the team that no one else can provide.				
5. I consistently let others know that I value the insights of families.				
6. I work to create an environment in which families feel supported and comfortable enough to speak freely.				
7. I listen respectfully to the opinions of family members.				
8. I believe that family members can look beyond their own child's and family's experiences.				
9. I clearly state what is required and expected of families in their advisory roles.				
10. I help parents set clear goals for their role.				
11. I understand that a child's illness or other family demands may require parents to take time off from their advisory responsibilities.				
12. I feel comfortable delegating responsibilities to families.				

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University of Florida Pediatric Pulmonary Center

7. National Center for Cultural Competence Curricula Enhancement Series

Georgetown Center for Human and Child Development

The National Center for Cultural Competence's Cultural Awareness module is pertinent to a family-centered, family directed field experience. The module has well-researched content on cultural awareness, teaching tools, self discovery exercises, faculty guidance, definitions, resources, and case studies/vignettes that address cultural and linguistic competency in practica. The module series include Cultural Awareness, Cultural Self-Assessment; the Process of Inquiry—Communicating in a Multicultural Environment and Public Health in a Multicultural Environment; and Public Health in a Multicultural Environment.

The Web site is <http://www.ncccurrricula.info/modules.html>.

This Web site might also be helpful: <http://www.ncccurrricula.info/communication/D15.html>

For more information, please contact
National Center for Cultural Competence
cultural@georgetown.edu

Part Three: Self-Assessment Tools to Accompany Family- Centered and Family- Directed Field Placement Experiences

The use of a self-assessment tool (such as the sample Family-Centered Experiences and Competencies Self Assessment included in this section) can be an effective method for trainees to identify their individual family-centered competencies both prior to and after completing field placement. This pre and post self-assessment process also will provide the training program with an opportunity to evaluate the effectiveness of the field experience for their trainees, as individuals and as a group, by reviewing the pre-post comparative data specifically related to the acquisition of family-centered competencies. Additionally, this provides the training program with areas for potential program revision and improvement.

Sample Self-Assessment Tool

Westchester Institute for Human Development and The School of Public Health at New York Medical College

LEADD: Leadership Education and Developmental Disabilities

A Blended Learning Program for Maternal and Child Health Professionals in the U.S. Virgin Islands

Family-Centered Experiences And Competencies

Self-Assessment

Part One: Training Inventory

Life Experiences

I have a family member with a disability or special health care needs: Yes___ No___

If yes, briefly describe the nature of the relationship and the family member's special needs:

Formal Training

I have had formal training in family-centered care: Yes___ No___

If yes, describe the source and duration of training: _____

Field Placements and Practicum Experiences

Field placements and practicum experiences to promote family-centered and family-directed practices are designed as a "family mentorship" in which the goal is to learn from a family. Such experience provides trainees with an opportunity to:

- Acquire a better understanding of how a family of a children with special needs functions at home and in the community
- Learn about a family's perspective on disability and special health care needs
- Hear about a family's successes and challenges in accessing community resources, partnering with professionals, and advocating for their child within educational, health, and other service and support systems
- Gain enhanced skills in family-centered communication, acknowledging the importance of cultural and linguistic competence

These field experiences can occur through a selection of such activities. Begin by using the following checklist:

Family-Centered Experiences And Competencies

Self-Assessment

Instructions: Check off each the following experiences from the list below as applied to your experiences with families of children with developmental disabilities and special health care needs.

- 1. I have conducted a home visit with a family for whom I provided direct services.
- 2. I have conducted a home visit with a family for whom I did not provide services.
- 3. I have accompanied a family on a community outing such as to a school meeting, doctor's appointment, after-school activity, supermarket, restaurant, shopping center, park, etc.
- 4. I have conducted an in-depth interview with a family in a clinical setting or as a member of an interdisciplinary team.
- 5. I have assisted a family with an issue requiring their advocacy.
- 6. I have attended and interacted with families at a parent support group meeting, parent training program, or at organizational function.
- 7. I have interviewed staff of a Family Resource Center such as a Parent-to-Parent program or a Parent Training and Information Center (PTIC).
- 8. I have navigated family-focused websites with a family and evaluated it's accessibility and usefulness.
- 9. I have interviewed families using an assessment tool to evaluate family-centered practices in a clinical setting or agency, shared results with program administrators, and recommended strategies for improvement, if needed.
- 10. I have interviewed a parent advocate and/or observed her/him at a formal planning meeting for another family.
- 11. I have reviewed materials written about families to evaluate the use of "people-first" respectful language.
- 12. I have helped a family-led organization develop a funding proposal.
- 13. I have encouraged and worked with a family to become involved with a local planning or policy group such as a taskforce or council.
- 14. I have encouraged and worked with a family to engage with the administration of MCH programs such as reviewing state/territory block grant applications, or guiding the development of a family advisory group at the state/territory level.

15. I have encouraged and assisted a family to write an article(s) for a local newspaper about family-friendly services or share their personal experiences.

16. Other related experiences: _____

Part Two: Competencies

Instructions: For each goal below, mark the statement that best reflects your current level of competency.

I am able to:

1. Understand the impact of a child with special needs on general family functioning.
1 = beginning level of understanding
2 = exposed to enough to have gained some insight
3 = average level of understanding
4 = good level of understanding
5 = goal met to your full expectations
2. Identify elements in a family with a child with special needs that are the same as a family with typically-developing children.
1 = beginning level of knowledge
2 = exposed to enough to have gained some insight
3 = average level of knowledge
4 = good level of knowledge
5 = goal met to your full expectations
3. Accept differing priorities and styles of functioning among families of children with special needs.
1 = beginning level of acceptance
2 = exposed to enough to have gained some insight
3 = average level of acceptance
4 = good level of acceptance
5 = goal met to your full expectations
4. Have an awareness of the importance of using “people-first”, respectful language.
1 = beginning level of awareness
2 = exposed to enough to have gained some insight
3 = average level of awareness
4 = good level of awareness
5 = goal met to your full expectation

5. Understand the extent to which my own personal life experiences affect my attitudes and outlook about children with special needs.
 - 1 = beginning level of understanding
 - 2 = exposed to enough to have gained some insight
 - 3 = average level of understanding
 - 4 = good level of understanding
 - 5 = goal met to your full expectations
6. Have an awareness of how families of children with special needs are treated by the public.
 - 1 = beginning level of awareness
 - 2 = exposed to enough to have gained some insight
 - 3 = average level of awareness
 - 4 = good level of awareness
 - 5 = goal met to your full expectation
7. Have an awareness of how families of children with special needs are treated by professionals.
 - 1 = beginning level of awareness
 - 2 = exposed to enough to have gained some insight
 - 3 = average level of awareness
 - 4 = good level of awareness
 - 5 = goal met to your full expectation
8. Understand the importance and meaning of leisure time and friendships to children with special needs and their families.
 - 1 = beginning level of knowledge
 - 2 = exposed to enough to have gained some insight
 - 3 = average level of knowledge
 - 4 = good level of knowledge
 - 5 = goal met to your full expectations
9. Understand the type and extent of relationships at school and in the community that are important for families of children with special needs.
 - 1 = beginning level of knowledge
 - 2 = exposed to enough to have gained some insight
 - 3 = average level of knowledge
 - 4 = good level of knowledge
 - 5 = goal met to your full expectations

10. Understand how a sibling with special needs affects other siblings in the family.
 - 1 = beginning level of understanding
 - 2 = exposed to enough to have gained some insight
 - 3 = average level of understanding
 - 4 = good level of understanding
 - 5 = goal met to your full expectations

11. Have an awareness of the unique needs and challenges for families of children with special needs as they seek and receive medical care and other health-related services.
 - 1 = beginning level of awareness
 - 2 = exposed to enough to have gained some insight
 - 3 = average level of awareness
 - 4 = good level of awareness
 - 5 = goal met to your full expectation

12. Understand the importance and value of family-to-family and other natural supports for families of children with special needs.
 - 1 = beginning level of knowledge
 - 2 = exposed to enough to have gained some insight
 - 3 = average level of knowledge
 - 4 = good level of knowledge
 - 5 = goal met to your full expectations

13. Understand key components in establishing and maintaining parent-professional collaboration for information sharing and decision-making.
 - 1 = beginning level of knowledge
 - 2 = exposed to enough to have gained some knowledge
 - 3 = average level of knowledge
 - 4 = good level of knowledge
 - 5 = goal met to your full expectation

14. Distinguish the differences between system-centered, child-centered, family-centered, and family-directed service delivery.
 - 1 = beginning level of knowledge
 - 2 = exposed to enough to have gained some knowledge
 - 3 = average level of knowledge
 - 4 = good level of knowledge
 - 5 = goal met to your full expectation

15. Have an awareness of the impact of family advocacy in meeting the needs and desires of families of children with special needs.

1 = beginning level of awareness

2 = exposed to enough to have gained some insight

3 = average level of awareness

4 = good level of awareness

5 = goal met to your full expectation

16. Have an awareness of the importance and value of family involvement in program planning, implementation and evaluation.

1 = beginning level of awareness

2 = exposed to enough to have gained some insight

3 = average level of awareness

4 = good level of awareness

5 = goal met to your full expectation

References:

- Cohen, D., Feuer, S., Goldfarb, F., Lalinde, P., Smith, M., Yingling, J., Pariseau, C., Pepper, N. (2006, October). *LEND Family Discipline Competencies*: Silver Spring, MD. Association of University Centers on Disabilities.
- Ogburn, E., Roberts, R., Pariseau, C., Levitz, B., Wagner, B. Moss, J., Adelman, R. (2006, October). *Promising practices in family mentorship: A guidebook for MCHB-LEND training programs*: Silver Spring, MD. Association of University Centers on Disabilities.
- Wisconsin LEND Program Family Mentorship Pre-Post Self-Assessment.

Selected Self-Assessment Resources

Allen, R.I.Petr, C.G,Brown, B.F.C (1995). *Family-Centered Behavior Scale and User's Manual* The Beach Center on Families and Disability, The University of Kansas.

The User's Manual contains instructions on using the Family-Centered Behavior Scale and its companion instrument, Family-Centered Behavior Scale-Importance. In addition, it includes background material about family-centered service delivery; a step-by-step guide to conducting a study to evaluate the family centeredness of your organization; suggestions of things your organization can do to become more family-centered; a list of resources for technical assistance on family centeredness; and a description of the development of the Family-Centered Behavior Scale. This instrument is completed by parents to elicit their opinion about their interactions with a particular staff member. For example: "Cares about the entire family, not just the child with special needs."

Trivette, C.M. & Dunst, C.J. (2003). *Parenting Experiences Scale*. Morganton, NC Orelena Hawks Puckett Institute.

In an article, "Evaluating Family-Based Practices: Parent Experience Scale" in *Young Exceptional Children*, Volume 7 Number 3 (2004), the authors describe how this scale allows program administrators to quickly assess parents' perceptions of experiences regarding family-centered practices and of their own parenting competence, confidence, and enjoyment. In addition to describing this scale, this article provides information about why it is important to assess program practices and how a program might use this scale to gather information from families. It also provides two examples of how program directors and staff could use the information to improve program practices. This instrument is completed by parents to elicit their opinion about how a professional has worked directly with the family. For example: "Treated me with dignity and respect."

McWilliam, P.J. & Winton, P. (1990). *Brass Tacks: A Self-Rating of Family-centered Practices, Model Program Version*. Frank Porter Graham Child Development Center, University of North Carolina at Chapel Hill.

This assessment tool was developed to assist early intervention programs, teams, and professionals in determining the extent to which their practices reflect family-centered approaches. Part #1 is Program Policies and Practices and Part #2 is Individual Interactions with Families. In this instrument, program personnel complete the questions. For example: "Do you allow parents to determine how they will share information about themselves and their children?"