

Parents as Mentors

Parent Orientation Packet



*University of Iowa
Hospitals and Clinics*

*Center for Disabilities and Development
100 Hawkins Drive
Iowa City, Iowa 52242-1011*

Dear Parents,

Welcome to the 2005-2006 *Parent as Mentors* (PAM) Program. I appreciate your willingness to participate in this very important program. It is a unique opportunity to help educate and influence the personal and professional attitudes and experience of future healthcare providers.

Enclosed is information regarding your role in the PAM program. There is also an ILEND Consultant information form and a Family Participation form that needs to be returned to me. Your trainee will contact you in the near future to set up a meeting. Please contact me with any questions regarding the PAM program.

A final thought: "What we lack are not scientists but poets and people to reveal to the heart what the heart is ready to receive." Joseph Campbell.

You have a unique gift to share, and I am sure you will find your trainee ready to receive it. Enjoy the process.

Sincerely,

Carney Derksen
Patient/Family Representative
Center for Disabilities and Development
University of Iowa Hospitals and Clinics
319 353 7387
Catherine-derksen@uiowa.edu

Nationally designated as Iowa's University Center for Excellence in Disabilities

**Parents as Mentors Program
Assignment Letter**

Thank you for agreeing to participate in the ILEND Parent as Mentors Program. As a parent you have the unique ability to provide meaningful information to healthcare trainees regarding the qualities you and your family find most helpful and look for in healthcare professionals. Other families like yours have graciously agreed to bring ILEND trainees into their lives. I am hopeful that through these visits, students will have an opportunity to learn directly from you in the relaxed and informal atmosphere of your home and community. And that you, too, see this as an enriching experience.

You will be paired with a _____ ILEND trainee. Throughout the semesters the trainee will visit your family four times, hopefully in a variety of settings (home, park, pool, shopping, IEP meeting therapy, etc.). The purpose of these visits is:

- 1) To give the ILEND Trainee an opportunity to see beyond an individual's illness or diagnosis and to experience the individual at home in the community from the family's perspective and the trainee's personal perspective.
- 2) To help the ILEND trainee recognize and acknowledge his/her own biases and personal beliefs.
- 3) To provide an opportunity for the trainee to view families/consumers as teachers from whom health professionals can learn.

Before each visit, please generate two or three points that you want to communicate. Think back to your initial contact with physicians, therapists, etc. (i.e., language used, information shared, compassion shown, etc.), and remember your reactions then and perhaps what you would have liked handled differently. I have enclosed forms for you to use in identifying the specific points you would personally like to make when the ILEND trainee visits. It may be helpful to have this list handy during the visit.

Please give careful thought to how each visit will be structured. For instance, if you have a lot of thoughts you would like to share regarding your family's experiences, being at the dinner table with an active family may not be the best arrangement. On the hand, if your message is to have the student experience first hand how your household functions, being in the midst of the juggling scene of a family dinner may be just the right setting. Above all, do what is best for you and your family!

Included in your parent orientation packet is an evaluation form to be filled out and returned to me after the final visit. The "Family Feedback and Student Evaluation Form" will provide me and the training directors with your comments and responses to this experience, which will help us plan for future family visits. The student evaluation part will be placed in each student's record.

The ILEND trainee assigned to you and your family is _____.
The trainee is responsible for making the initial contact to you within the next week to ten days.

If you have any questions at any point about your participation in the family visit experience, please contact me at 319-353-7387 or catherine-derksen@uiowa.edu. I know that your time is precious and I am grateful for all your efforts.

Sincerely,

Carney Derksen, Patient/Family Representative
Parents as Mentors Coordinator
Center for Disabilities and Development
100 Hawkins Drive
Iowa City, IA 52242

Parents as Mentors Program
Family Participation Form

Family-centered interdisciplinary training for ILEND trainees involves a variety of activities with programs, providers and parents. The *Parents as Mentors* experience is one critical component of training.

The focus of the program is to provide trainees with the opportunity to learn directly from a family. This program provides students with an in-depth experience, spending time with a family that has a child with special needs, with the objective of acquiring an increased understanding of their daily challenges, joys and priorities. Through the sharing of a variety of activities with the family, the trainee will increase their knowledge about various service delivery systems and their responsiveness to family needs from the family's perspective.

Please fill out the form below and sign to indicate your desire to participate in the *Parents as Mentors* Program for the coming year. Please mail back in the enclosed envelope.

Your Name: _____

Address: _____

City, State, Zip: _____

Phone: _____ E-mail address: _____

Child's Name: _____ Sex: _____ Child's birthdate: _____

Please describe your child's interest, likes or dislikes: _____

Please list any medical conditions and/or disabilities: _____

Currently, what services or therapies is your child receiving? _____

Please describe your child's school program. _____

Your signature _____ Date _____

A VISIT WITH YOUR *PARENTS AS MENTORS* TRAINEE

OUR FAMILY

Information about our family, who we are:

Significant changes in our lifestyles as a result of the special health care needs of our child?

Other pertinent information we would like to share:

Points to be covered during home visit: *Before the trainee visits, think about specific points you would like to cover. (ie. How ere told about you were told about your child's diagnosis? What was or was not helpful?)

1.

2.

3.

(It may be helpful to have this list accessible during the visit with your trainee.)

TIPS FOR PARENTS TO HELP VISITS GO SMOOTHLY

BEFORE THE VISIT

- Give careful thought to what will work for your family. Feel free to say no if it is not a good time and offer alternatives.
- Let the trainee know about how long you expect the visit to last, and whether you plan to serve a meal.
- Approach each visit as a new and unique experience. Issues that are most relevant to your family may have changed since the trainee last visited.
- Think about two or three points you would like to communicate to the student and how to best get those points across. (See "Our Family" form.) The visit should not feel like a lecture to the students. Positive as well as negative ideas are useful.

DURING THE VISIT

- After introducing yourself, give the student a general idea of what will happen during the visit. For example, will you mainly sit and talk in the kitchen, or will the student participate in meal preparation and evening care of the children?
- Let the student know how you would like them to interact with your children and if it is appropriate to discuss the diagnosis in front of the children. Don't leave the student wondering what to do next.
- Avoid making negative generalizations about healthcare professionals such as, "doctors never listen to us." If you cite a specific negative experience, also describe what the medical professional could have done better. Do not use names of professionals.

AFTER THE VISIT

- Consider carefully what you write on the student evaluation form. (See attached "Family Feedback and Student Evaluation Form".) Your comments will have a great impact on how we structure future family visits and will be kept in the student's record.

"CAN I REALLY ASK THEM TO DO THAT?"

Sample Activities for Family Visits

- Accompany your family to buy groceries
- Have a meal with your family
- Accompany your family to park, zoo, mall, place of worship, or wherever else you life takes you
- Observe your child in the setting where services are being provided - (school, childcare, home, therapy, clinic)
- Attend an IFSP/IEP, other conference or doctor's appointment, followed by a discussion with you
- Attend a parent support group meeting, swimming class, play group, bowling league etc. with your family

Let your imagination soar! The idea is for the student to get a taste of the flavor of your life. Above all, relax, have fun and build a new friendship. Enjoy.

FAMILY MENTOR EXPERIENCE QUESTIONS FOR A RAINY DAY

This is a tentative list of questions for the families and trainees to discuss if they feel comfortable doing so. Both families and trainees will be given a copy of the questions so that discussion may be initiated by either party. This list is not all encompassing. Anything the families and trainees feel comfortable discussing is fine. Be aware some of the topics may be sensitive in nature; the families may not feel comfortable discussing these matters with the trainees.

Possible discussion topics may include:

EARLY INTERVENTION/EDUCATIONAL PROGRAMS

- What were the families expectations regarding early intervention and educational programs?
- Were these expectations accurate or did circumstances work out differently than the family had envisioned?
- How did transportation work out for the family, the child, the schools?

THERAPY SERVICES

- Has the child received therapy at a place other than home or day care when the parent was unable to attend?
- Was an alternative mode of transportation needed?
- How did the family find out about these services?
- How did the family go about eliciting these services?
- What measures were taken to ensure that the family was kept abreast of the child's progress and that they were part of the child's team?

DAY CARE

- How did the family find/choose the child's day care/school?
- Were there any obstacles in finding or retaining care?
- Was the family satisfied with the situation, or did they feel they settled for a less than ideal situation because of the circumstances?
- Does the day care/preschool keep the family regularly informed on what the child does during the day and what measures they take to ensure inclusion?

RESPITE SERVICES

- Does the family ever need someone to watch their child?
- How did the family find/choose these services?
- What special circumstances needed to be taken into account (medical needs, size/age of child and siblings, behavioral challenges or aggression, feeding/diapering concerns, communication concerns) when finding respite?
- What was the cost comparison if any, between respite care for a child with special needs and a typically developing child/
- Does the family remember the first time they left their child in the care of someone that was not a family member or close family friend?

PUBLIC SERVICES

- How did the family learn about available services for them and/or their child (SSI, Medicaid, respite services, financial aid, extended day care, school aides, etc.)?
- Did they have any help obtaining these services or the information?

FAMILY

- What adjustments, if any, has the family made to having a family member with special needs?
- What role has the extended family taken in support of the family?
- How have the siblings adjusted to the special circumstances?

Any other topic that the trainees or families can think of?

EXAMPLES OF WHAT PARENTS CAN TEACH PROFESSIONALS

- How and when sensitive information (e.g. diagnosis) should be delivered
- Showing feelings is okay
- Share information openly - "I don't know" is okay
- Parents may have selective hearing or may not understand the words you use
- Definitions of diagnosis are important; not just labels
- Parents need to hear that it is not their fault
- Parents need to hear that it is okay to use respite
- Parents need to know that any question is okay
- Parents need to hear positives

Adapted from: Poyadue, F. S. (1988). Parents as teachers of health care professionals. In Children's health care (pp. 43-45). Washington, DC: The Association for the Care of Children's Health.

Whitehead, A. (1996). International Parent to Parent Conference, New Mexico.

FAMILY FEEDBACK AND STUDENT EVALUATION FORM

Student Name _____ Evaluator's Name _____

Briefly describe the student's communication style. (Consider listening skills, ability to reflect, and manner of approaching family or child.)

What were some of the points you hoped to make to the student?

Explain how you thought the visit went overall. (Was it a positive experience for you and your family? Was the focus on diagnosis, assessment, and treatment or more about the ways in which families respond to and adapt to their child's disability or health care issue?)

Is there a special point or piece of feedback that you wanted to make (or didn't have time to make) that you would like to add or reinforce here?

Please add any other comments you have regarding the visit.