

**2013-2014 LEND Leadership Project**

**FAMILY-FOCUSED DISABILITY ORGANIZATION INTERVIEW**  
**Information and Instructions for Trainees**

Families regularly seek information from health and education professionals on issues related to parenting their child, teen or young adult with developmental disabilities or other special health care needs. They request assistance about where to find support and how to access community services and resources in order to address issues they confront in their everyday lives, particularly when new concerns emerge. For many years, parents have reported that often the most helpful information and support they receive has been from other families, particularly those associated with parent support and advocacy groups, parent-staffed centers, and family support providers. Types of family-focused disability organizations include parent-to-parent programs, parent support groups, organizations for specific disabilities, family support councils, family support provider organizations, family resource centers, special education and other parent centers, special education PTAs, parent training and information centers and community parent centers, family-to-family healthcare information and education centers and more.

The Family-Focused Disability Organization Interview should provide a useful experience in learning more about how family-focused disability organizations help families of children, youth and adults with developmental disabilities and other special health care needs.

**Trainee Learning Objectives:**

- 1) Be able to describe ways that family-focused disability organizations support and assist families of individuals with developmental disabilities and other special health care needs throughout the life span or during specific phases in life.
- 2) Acquire knowledge about how an organization's website can serve as a useful tool in helping families to access information, resources, services and supports.
- 3) Gain awareness about ways that disability organizations involve families in program planning, implementation and evaluation.
- 4) Understand how cultural considerations and socio-economic factors may impact on how disability organizations assist and support families of individuals with disabilities and special health care needs.

Your assignment is to identify a family-focused disability organization of interest to you that you would like to learn more about because it could potentially be helpful to you, families you are currently working with or with whom you might work in the future. This learning experience will occur through a guided interview conducted by telephone (or in person) with an organization located either nearby or at a distance *and* through a review of its website. In selecting an organization, the criteria is that this must be a local, state or national organization whose primary role is to provide information and support to families.

To help you to choose an organization with which to conduct your interview, a guide “*Resources to Access Family-Focused Disability Organizations*” is being provided and is also posted on Moodle. Although some of the national organizations on this list serve families directly themselves or through their local or state affiliates, they are included in this document because only because they are a resource in providing contact information for other organizations that can assist families with a variety of special needs. Please use this list to identify other organizations that maybe of interest to you. However, the organization you choose does *not* need to be one that is accessed through these resources.

The information you acquire through your interview will be shared through a brief presentation and group discussion with LEND trainees and faculty which may include displaying the organization’s website, if one exists. Sharing this information collectively will expand our knowledge of potential family-focused resources. Additionally, each trainee’s *Post-Interview Notes Form* will be posted by LEND training staff on Moodle in the leadership project section so that it is easily available to fellow trainees and LEND faculty. The *Post-Interview Notes Forms* will also be posted as resources on a shared drive for staff of the WIHD Community Support Network (CSN) who provide information and assistance to families.

#### **Instructions and timeline:**

- Review the questions listed below, **what you should find out during the interview**, as a guide in conducting the interview.
- Use the resources described above *or* your own ideas, interests and experiences to identify and select an organization with which to conduct your interview.
- After identifying a family-focused disability organization you wish to interview, email the name of your organization choice to Jean Marie Reck in the LEND Training office at [jreck@wihd.org](mailto:jreck@wihd.org). If the organization you identify has already been selected by another LEND trainee, you will be notified and requested to choose a different organization to avoid duplication. If your selection is deemed by faculty to not be a good choice or appropriate for this assignment, you will be provided with an explanation and asked to choose a different organization with suggestions. Jean Marie will keep a roster with the LEND trainee names and their selected organizations.
- After confirmation of your selection, contact the organization you wish to interview, identify a specific representative of this family-focused disability organization, and schedule a mutually convenient day and time to conduct the interview by telephone or, if you prefer, in person. If the family-focused disability organization you select has a website, review the website from the perspective of “family-friendliness” *prior to* conducting the interview. It is recommended that you try to schedule this interview during your LEND independent work time for this project.
- After completing the Family-Focused Disability Organization Interview, your assignment is to download, complete and submit the *Post-Interview Notes Form* on Moodle before November 7<sup>th</sup>. Print a copy for yourself as a reference for your presentation and the discussion session on Thursday November 7, 2013. A copy of this form should also be

included in a LEND portfolio of materials you develop and assemble throughout the training year.

- **We will meet on Thursday November 7, 2013** to share the information gathered from the interviews. Each trainee will present a brief summary of no more than five to seven minutes sharing highlights of his/her organization interview based on the post-interview notes and briefly answering questions. Trainees will have an option of displaying the organization's website using an internet connection. **A group facilitated discussion will follow the individual presentations which will summarize the key themes and lessons learned.**

#### **What you should find out during the interview:**

- In what ways does the organization specifically assist families of individuals with developmental disabilities and other special health care needs?
- Does the organization assist families of individuals with disabilities throughout the lifespan or does it specialize in a particular phase in life?
- What methods does the organization find most effective in providing information to families seeking assistance in accessing resources, services and supports?
- Does the organization have a local, regional, state or national focus? Is it associated or affiliated with a larger network that assists families of individuals with developmental disabilities and other special health care needs? If so, briefly identify and describe that network.
- Does the organization have its own website or is it a part of another organizational website? If so, would you describe the website as "family-friendly" and designed for easy access to information, resources, services and supports? If there are links on the website, which of the links do you think are most useful for families?
- How are families involved in the organization's program planning, implementation and evaluation? (For example, working as staff, serving on a board of directors or an advisory group, as trainers, volunteers, providing peer-to-peer support, participants in research, etc.)
- In what ways, if any, do cultural considerations and socio-economic factors impact on how the disability organization assists and supports families of individuals with disabilities and special health care needs?
- After learning more about this organization, would you consider this organization to be a valuable resource for families? Why or why not?