

Colorado LEND Family Mentorship Program Spring 2013

Family-Focused Advocacy Organization Interview

One of the most important aspects of life with disabilities is a family's ability to reach out and create a network of support from the resources in the community. It is vital for a family, as well as the professionals working with them, to learn to navigate and use these organizations for all different areas of need. Families need emotional support, education, insurance information, legal counsel, assistance navigating systems of care, recommendations for therapy providers, assistance with IEPs and advice on working with schools, etc.

The Advocacy Organization Interview should provide a useful experience in learning more about how family-focused advocacy 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 a family-focused advocacy organization supports and assists families of individuals with developmental disabilities and other special health care needs.
- 2) Acquire knowledge about how an organization's websites can serve as a useful tool in helping families to access information, referrals, and resources.
- 3) Understand how an advocacy organization involves families in program planning, implementation and evaluation.

Your assignment will be to choose a family-focused advocacy organization that you would like to learn more about because it may be helpful to families you currently serve or with whom you may work in the future. This will be accomplished through 1) a guided interview with an organization conducted by telephone or in person and 2) through review of its website. A list of Family-Focused Advocacy Organizations and an interview template are attached.

Please use the interview questions below to write a **1-2 page review** of the organization. The information you acquire will then be shared through a facilitated group discussion in class on **April 9, 2013**.

Family-Focused Advocacy Organizations

Autism Society of Colorado (or of America)	ARC of Colorado (or US)	Autism Speaks
Empower Colorado	Family Voices of Colorado	PEAK Parent Center
Alliance of Genetic Support Groups	El Grupo Vida	Hands and Voices
Easter Seals Colorado	Autism Society of Boulder	Federation of Families for Children's Mental Health
Mile High Down Syndrome Association	Nat'l Dissemination Center for Children with Disabilities (NICHCY)	NAMI (National Alliance on Mental Illness)
Mile Hi Down Syndrome Association	NADD (National Association of the Dually Diagnosed)	The Williams Syndrome Association
Imagine (CCB for Boulder County)	Keshet of the Rockies	National Fragile X Foundation

You are welcome to pick another organization than those listed here, but please let Harriet Austin know your choice before you start.

Interview Template

What you should find out during the interview:

(Note: When calling, try to imagine how the process would feel for a parent reaching out to identify much-needed resources and support. Did someone answer right away? Were they approachable? If you left a message, did anyone call you back?)

- What is the mission of this organization? What population was it created to serve? Does it provide short-term or long-term assistance?
- In what ways does the organization assist families of individuals with developmental disabilities and other special health care needs?
- How are families involved in the organization's program planning, implementation and evaluation?
- What methods does the organization find most effective in providing information to families seeking assistance in accessing referrals, resources, services and supports?
- Do cultural considerations impact on the involvement of families with this organization?
- Does the organization have a local, regional, state or national focus? Does it have an association or affiliation with a larger network that assists families of individuals with developmental disabilities and other special health care needs?
- Does the organization have its own website or is it part of another organizational website? If so, is the website designed to help access information, referrals and resources? If there are links on the website, which of the links are family-friendly and most useful for families?
- After learning more about this organization, would you consider this organization a valuable resource for families? Why or why not?