

**Understanding Family Perspective Curriculum**  
**Instructors: Paula Lalinde, M.A. & Idelio Valdes, Self Advocate**

The Understanding the Family Perspective curriculum is a four-part, interactive lecture series to be provided to all pediatric residents during their one-month developmental behavioral rotation. This curriculum helps to build the residents' understanding of the issues and concerns of families who have a child with a disability. The lecture series is also developed and delivered by a parent of a child with a disability and an adult with a disability.

In addition to the lecture series the pediatric residents have a home visit experience with a family who has a child with a disability. During the one-month rotation, the resident visits with the family in their home for two to three hours. In this context the resident is able to experience first hand the rewards and challenges of raising a child with a disability.

Below is a brief description of the lecture series:

**Self Determination – Idelio Valdes**

The residents begin the session by watching a 1-hour HBO special, Without Pity Video. This video introduces the viewer to five different individuals with disabilities and their families. It challenges the viewer to reflect upon their own attitudes and beliefs and sensitizes them to the real challenges that people face. The primary message is that people with disabilities want respect, not pity. The residents engage in a discussion of the video with a focus on how the tenets of the video apply to the role of the physician in providing care to young adults and adults with disabilities. Additional information about resources for adults with disabilities will be provided.

**Supports and Services for Children with Disabilities and Their Families – Paula Lalinde, M.A.**

This interactive session begins with the question, “*What do all parents want for their children?*” The responses generate an understanding about the systems of care that serve children with disabilities, including education, health (the medical home), mental health, family supports, community access, and integration.

The legal and financial supports to this system are incorporated into the discussion including IDEA, Developmental Disabilities Act, Section 504 of the Rehabilitation Act, and SSI. A packet of national, state and local resources are provided.

**Building and Maintaining Rapport While Delivering Diagnostic News with Diverse Populations – Helen Masin, Ph.D. & Paula Lalinde, M.A.**

Delivering diagnostic news can be a very stressful time for both the physician and the family. When the physician and the family come from differing cultural backgrounds, communication can be even more challenging. The anxiety and challenges of this difficult time can be managed more effectively when rapport is established between the physician and the family.

In order to provide residents with practical tools for managing these challenges, we have developed an experiential learning module that will enable residents to self assess and practice their skills in this arena. The module begins with a role-play of the residents delivering diagnostic news to a family. The cultural scenarios will be adjusted to ensure that the family and the physician come from different cultural backgrounds.

Following the initial role-play, the residents will participate in an interactive learning experience covering building rapport and demonstrating cultural competency. Residents will then view and discuss a 15-minute video on delivering diagnostic news.

The residents will then repeat the initial role-play scenario and apply the skills learned in building rapport, demonstrating cultural competency, and delivering diagnostic news. Students will self assess their performance from the first to the second role-play and discuss the relevance of these skills to their clinical practice.

### **Supporting the Grieving Family – Paula Lalinde, M.A.**

This session is designed to support pediatricians' work with families who have lost a child. Current research has dispelled many long held beliefs about children and death and this session presents current research findings and how these findings translate into best practices when pediatricians are suddenly faced with a grieving family.

### **Learning outcomes:**

1. Pediatricians will understand what is considered a 'normal' range of responses to grief for parents and siblings.
2. Pediatricians will understand the loss of a child with a disability from the family's perspective versus society, medical or community.
3. Pediatricians will recognize the importance of their role with the family who has lost their child.

### **Outline of Content:**

- A. Evidence Based Practices: Building a Bridge Between Theory, Research, and Practice
- B. What Does Research Tell Us? The Personal Growth Model & Grief Reaction Checklist  
Hogan, N.S., Greenfield, D.A., Schmidt, L.A. (2001), The development and validation of the Hogan Grief Reaction Checklist, *Death Studies*, pp. 1-32
- C. Disenfranchised Grief: Parents of Children with Disabilities & Individuals with a Disability
- D. Actions/Behaviors that Help or Hinder the Family's Healing Process

### **Suggested Readings:**

1. Cummings, P. *This Is Our Child, This Is Your Patient*.
2. Doka, K.J. (Ed.) (2002), Disenfranchised Grief, New Directions, Challenges, and Strategies for Practice. *Disenfranchised Grief & Individuals with Developmental Disabilities*. Champaign, Illinois: Research Press.
3. Bolton, I. (2001). My Son...My Son A Guide to Healing After Death, Loss, or Suicide. Bolton Press Atlanta, pp. 107.
4. *Suggestions For Medical Personnel*. The Compassionate Friends, 1986.