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412.648.8714

Families and Physicians in Partnership Mini-Elective Spring 2019

<u>Course Dates:</u>	January 8, 15, 22, 29 Tuesdays, 5:00-6:30 PM
<u>Maximum Students:</u>	20
<u>Class Year:</u>	MS1 and MS2
<u>Course Directors:</u>	Angela Garcia, MD Assistant Professor, Physical Medicine & Rehabilitation Nancy Murray, MS President of The ARC of Greater Pittsburgh @ ACHIEVA
<u>Contact Information:</u>	Nancy Murray, MS nmurray@achieva.info 412-995-5000
<u>Registration:</u>	Betsy Nero, Office of Medical Education betsy@medschool.pitt.edu

Description:

With a focus on caring for and treating children and adults with life-long disabilities and special health care issues, *Families and Physicians in Partnership* is a series of vibrant discussions from which medical students will take away new insights about disability. In this course, families of children and adults with disabilities and special health care issues will share their experiences in an effort to improve health outcomes.

As future physicians, medical students will learn how they can work in partnership with families to improve health care delivery, systems, and outcomes for children and adults experiencing life-long disabilities. Students will gain a valuable perspective of people with disabilities outside the healthcare context, as a member of a family as well as an individual unto themselves, not a disability.

Medical students will come away from the course with:

- An understanding that all families are different, each with unique strengths, values, beliefs, and challenges;
- A view of families as resources with whom they can partner and learn from in order to achieve better health outcomes;
- A consideration of their own personal beliefs, values, and attitudes about people with disabilities and their capacity to create positive change.

Course Objectives:

1. To help develop clinical skills for working with people with disabilities and their families.
2. To help students discern health care disparities associated with experiencing disability.
3. To develop a greater understanding of the "social model" of disability-- the rejection of the medicalization of disability in favor of an understanding of disability that focuses on social factors that disable, such as stigmatization and a lack of accommodation.
4. To develop an understanding that all families are different, each with unique strengths, values, beliefs, and challenges.
5. To develop a view of families as resources with whom they can partner and

learn from in order to achieve better outcomes for a person experiencing a disability.

6. To consider their own personal beliefs, values, and attitudes about children and adults with disabilities and special health care issues and their families.

7. To develop a deeper understanding of the difficulties faced by caregivers when creating a treatment plan.

Requirements:

Active participation and attendance in all 4 sessions. Write three “take aways” after each session and share in a closed Facebook (or other selected digital social-platform). Conversations on the topic, take aways, and other insights continue in the closed Facebook group.

Pre-requisites:

None

COURSE OUTLINE

FAMILIES AND PHYSICIANS IN PARTNERSHIP

Course Directors: Angela Garcia, MD and Nancy Murray, MS

Dates: January 8, 15, 22, 29—5:00-6:30 PM

Location: Scaife Hall, Rooms 422 A&B

Mini-Elective Resources:

Disease versus Disability: The Medical Humanities and Disability Studies, Diane Price Herndl, PMLA, Vol. 120, No.2 (Mar. 2005), pp. 593-598.

SESSION 1: Disability Overview: This session will give a general overview of disability. A discussion-focused lecture is led by the course director and an expert on the history of disability policy and its varying impacts on those experiencing different disabilities. Additionally, learners and presenters will discuss differing viewpoints on whether disability is a condition that lives inside the body or is simply a different way of being while experiencing obstacles imposed from the outside. Lastly, learners will be introduced to the variation of disparities of health and health outcomes related to differing disabilities.

Following this session, learners will be able to:

- List key events in the history of U.S. disability policy;
- Differentiate between the medical and social models of disability;
- Describe some health and health care disparities associated with having a disability.

SESSION 2: Parents as Presenters. This session will be presented by the course director and parents of children and adults experiencing disabilities and special health care issues. The parents will offer their perspectives with the course director presenting a broad overview of issues faced by families of children and adults with special health care needs, including the transition from pediatrics to adult health care. Foci of the discussion will include ways in which families and physicians can apply best practices to collaborate and improve health outcomes.

Following this session, learners will have a better understanding of:

- What family/physician partnerships are;
- Why family/physician partnerships are important;
- Issues faced by families of children and adults with special health care needs, including the transition from pediatrics to adult health care.

SESSION 3: Growing up Together: Siblings. This session will be presented by siblings of people experiencing disability and special health care issues in tandem with the course director. As people with disabilities are living longer and more inclusive lives, discussion will center on how to infuse a long-term view of patient-centered care which takes into consideration research which shows that siblings may be in the caregiver/decision maker role longer than any other family member—including parents.

Following this session, learners will have a better understanding of:

- Family dynamics of growing up with a sibling experiencing a disability;
- Differences in experiences among siblings;
- Ways physicians can help siblings prepare for a caregiver/decision maker role.

SESSION 4: The Long Term Effects of Families as Caregivers. This session will be presented by family members who are also caregivers for their family member with a disability and special health care issues and the course director. This session will highlight the long term impacts of caregiving.

Following this session, learners will have a better understanding of:

- The long term impact of caregiving on families;
- How to take into consideration the patient, caregivers and other family members when developing a care plan;
- How to consider the long term needs of the family.

Student Preparation: Learners should come prepared to reflect on their experiences throughout the duration of the mini-elective, participate in discussions, and complete a brief evaluation.