

COCLLD Minutes from CSM 2008

The following members met from 4:30-6:00 on 2/7/08: Nancy Cicirello, Anne Turner, Laura Case, Robbie O'Shea, Mary Massery, Kiri Ness, and Toni Doty.

- 1) Reviewed and accepted the draft of the Case Scenario format with minor changes to be made by Toni Doty who will email the final draft to the full committee.
- 2) Prioritized some starting points for the Case scenarios to be completed by taskforce members and recruiting specialists: Cystic fibrosis (CS & FS, Mary Massery), ALL (CS Kiri Ness), DMD (FS- Laura Case), Shoulder Overuse Injuries in People with Lifelong Disabilities who use manual Wheelchairs (CS & FS- Ellen Hamilton), People who use alternative communication (FS Nancy Cicirello), Hemophilia and joint dysfunction (CS- Anne Turner)
- 3) Discussion was brought up regarding the need for nonmembers and consumers to have access to information such as fact sheets and we recapped that the primary mission of the taskforce is to support APTA members and therapists could share fact sheets with their clients & families as they deem appropriate. In Nov. the group decided not to place resources on the consumer section but in the future there may be some made available. We may need to revisit this issue with Mary Fran as deliverables become available.
- 4) Multisectional Programming discussed and the following was proposed:

Title: The Continuum of Care for People with Lifelong Disabilities: Understanding the Issues and Forging New Pathways for Physical Therapists.

Why is this needed?

- This taskforce represents a critical need in society as a whole and physical therapy as a profession.
- There are 200,000-500,000 individuals with lifelong disabilities over the age of 60 and this number is expected to double by 2030. (1,2)
- 12.6 million (18%) children in the US have a chronic medical condition. (3)
 - 90% of youth with special healthcare issues survive into adulthood. (4)

References (Draft)

There are approximately 270,000 adult survivors of childhood cancer in the U. S. (5)

Conolly BH. Aging in individuals with lifelong disabilities. *Phys Occup Ther Pediatr*. 2001; 21:23-47.

Hammel, J, Nochajski SM. Aging and developmental disability: current research, programming, and practice implication. *Phys Occup Ther Geriatr*. 2000;18:1-4.

Newacheck, P. W., Strickland, B., Shonkoff, J.P., McPerson, M., McManus, M., Lauver, C., et al. (1998). An epidemiologic profile of childhood chronic illnesses. *Journal of Pediatrics*, 124, 40-48.

Love, L.L., & Malian, I.M. (1997). What happens to students leaving secondary special education services in Arizona. *Remedial and Special Education*, 18, 261-269.

National Cancer Policy Board & National Institute of Medicine. (2003). *Childhood cancer survivorship : Improving care and quality of life*. Washington, D.C.: National Academy of Sciences. Retrieved June 14, 2004, www.nap.edu/books/0309088984/html/

Presenter 1: Barb Conolly PT, PhD will present an overview of the issues—

Presenter 2: A professional adult who has grown up with a developmental disability to introduce the issues involved with having a lifelong disability.

Presenter 3: Mary Massery PT, DPT (Cardiopulmonary) to present a case study involving chronic Asthma diagnosed in childhood which will illustrate multiple system involvement (ie. Cardiopulmonary, musculoskeletal) and the role of the physical therapist when evaluating and providing intervention to this population with lifelong disability.

Presenter 4: Robbie O'Shea PT, PhD (Neurology) will follow up with a case scenario of an adult with cognitive deficits post shoulder surgery who shows up for outpatient therapy. This case will also apply

practical information for physical therapists who evaluate and provide intervention to this population with lifelong disability.

Toni Doty (COCLLD Chair and/or Mary Fran Delaune (Practice) can moderate the panel.

5) Post meeting developments:

Toni Doty discussed this idea with Robbie O'Shea (pediatric program chair) who stated that the multisectional programming will be determined by Pediatrics, Aquatics, Federal, and Geriatrics sections. She asked for a summary by Sat. Feb. 9.

The decision to add Barb Conolly to the presentation was suggested by Toni Doty after the taskforce meeting and a conversation with Barb at CSM.

After the AADD SIG meeting members were identified who would like to help with sexuality and reproductive health of people with lifelong disabilities (from Neuro), 2 pediatric people who are in private practice are possibly interested in exploring private practice issues and 2 DPT students from Ohio State are working on a project entitled "Barriers to Orthopedic Practice for people with developmental disabilities". Maria Jones PhD, PT, ATP has agreed to assist with group 3- the business case (specifically reimbursement/funding options, when treating this population)

Toby Long, Carrie Gadjosik, and Barb Conolly have been recruited as reviewers of documents. All members of the taskforce need to start identifying reviewers from their components.

Thanks for everyone's support and hard work!

Toni