

Continuum of Care for People with Lifelong Disabilities Update

The Continuum of Care for People with Lifelong Disabilities has been busy implementing the charge of RC34-05, which was passed by the APTA House of Delegates in 2005. This taskforce represents a critical need in society as a whole and physical therapy as a profession. You may ask why???

*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)

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

The group met for an onsite work meeting at APTA headquarters. The group has refined their mission to address the issues in transitioning people with lifelong disabilities to adult oriented health care and further the physical therapist's role in the prevention, diagnosis, providing ongoing supports, and intervention of movement dysfunctions of people with lifelong disabilities in order to promote the highest quality of life.

The tasforce members include: Mary Fran Delaune PT, MPT (APTA Practice Section), Toni Doty MS, PT, PCS (Pediatric Practice Section), Mary Massery PT, DPT, (CardioPulmonary), Kirsten Ness PT, PhD (Oncology), Ellen Hamilton (Orthopedics), Pamela Unger PT, CWS (Electrotherapy/Woundcare), Robbie O'Shea PT, PhD (Neurology), Lucy Henck-Jones (Geriatrics), (Acute Care). Nancy Cicirello PT, MPH, EdD (Pediatrics) Robert Eskew PT, MS, PCS (Pediatrics), Laura Case PT, DPT, MS, PCS (Pediatrics), Heather Jenkins PT, DPT, ATP (Pediatrics), Margo Orlin PT, PhD (Pediatrics), Mary Jane Rapport PT, PhD (Pediatrics), Lorrie Sylvester (Pediatrics), Karolyn Grimm PT, MS, CSCS(Aquatics), Anne Turner PT, PhD (Pediatrics).

The goals being addressed by the taskforce include the following:

1. Improve the content of entry level education within the context of a doctoring profession.

Strategy: Identify core knowledge and skills for delivering care and addressing the transition needs of adolescents and adults with lifelong disabilities

Strategy: Incorporate core knowledge and skills into appropriate association documents

2. Educate members and stakeholders to create an environment of autonomous practice for physical therapists working with people with LLD.

Strategy: Develop educational tools

Strategy: Provide multisectional programming at conferences (AC 2008)

Strategy: Provide strategies for teaching the didactic and affective core knowledge

Strategy: Increase awareness of PTs/ PTAs

3. Explore and promote the role of physical therapists in a variety of practice settings to the membership and public

Strategy: Delineate the role of the PT as a resource to other healthcare provider

Strategy: Promote the role of the PT as a resource to other health care providers in increasing access to and coordination of health care services to those individuals with lifelong disabilities

Strategy: Develop a business case

Strategy: Collaborate with external stakeholders

4. Explore the magnitude of the issues.

Brainstorm/survey members to identify issues

Develop document accessible to all APTA members

Develop transition guidelines for physical therapists

Various strategies and products will be developed for entry level curriculum, clinicians, and consumers. As an overview of the issues affecting both consumers and all physical therapists, a white paper, and Guidelines for transition to adulthood are being developed. The focus of the educational products is to infuse the issues of lifelong disability into already existing documents and instructional models. For example, this group has worked on enhancing the CAPTE criteria to highlight issues of LLD and a variety of case scenarios to be available for instruction. For practicing clinicians fact sheets, a resource compendium, and speaker list for continuing education topics are being developed. As these products are developed and approved they will be available to physical therapists from all sections, both now and in the future, through the APTA.

At CSM 2008, the taskforce met to exchange drafts of projects and plan some ideas for possible multisectional programming at CSM 2009. In addition, a variety of therapists came forward to volunteer assistance with specific tasks within their expertise.

Mark your calendars!! The following kick off session with a panel of speakers from the taskforce is planned for the 2008 Annual Conference:

**The Continuum of Care for People with Life-long Disabilities:
Exploring the Issues and Roles for Physical Therapists
June 14, 2008, from 1:00 PM-4:00 PM**

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/