

**ADOLESCENTS AND ADULTS WITH DEVELOPMENTAL DISABILITIES
SPECIAL INTEREST GROUP
CSM 2010 Post-Board Report**

Mission Statement

The Adolescent and Adults with Disabilities Special Interest Group was established in 2001 to give therapists an opportunity to meet, confer, and promote patient care through education, clinical practice, and research. This SIG focuses on: 1) Prevention and examination of impairments in the adult with developmental disabilities to ensure maximum participation society, 2) development of intervention guidelines for the adult with developmental disabilities, and 3) promotion of understanding/advocacy of adults with developmental disabilities through research and education

Meeting held on 2/20/10 from 7:00-8:00am at CSM

Leadership change at CSM2010: Lorrie Sylvester, PT, MS took over as chair of the AADD Sig as Toni Doty, PT, PhD stepped down. (Yes, let's all congratulate Toni for successfully defending her doctoral dissertation last week!) Toni will continue in the capacity of Vice Chair of the SIG, but will focus her energies on the Continuum of Care for People With Lifelong Disabilities Task Force and see some of those projects to completion. Toni will continue working on SoPac planning for 2011.

Programming:

CMS 2010 - This year's program, "*The Changing Landscape of PT Interventions*", taught by Mary Gannotti, PT, PhD, Lorrie Sylvester, PT, MS, and Lauren Allison, a college student with developmental disabilities, was well attended and received. It appears that having a consumer of therapy services across the lifespan co-present with SOP and AADD SIG members is an effective and valued educational method. It is encouraging for APTA in general and the SOP/AADD SIG in particular, as we promote the People First philosophy, "Nothing about us without us"! One suggestion we had for future CSM meetings is to schedule AADD SIG programming at a time separate from the School-Based services SIG. It came to our attention that CSM pediatric therapists who attended the School-Based programming also wanted to attend the AADD programming, and vice versa, but were unable to do so as the sessions were concurrent.

Future Programming: One suggestion for our AADD-sponsored CSM 2011 session is to have Robbie O'Shea share her work using the Wii with adults with developmental disabilities living in group homes. Robbie was invited to submit a proposal on Scholar One and agreed to do so. Thanks Robbie!! Other suggestions included:

- ❖ Combined Geriatric/Pediatric session on Universal Design, "Living in Place".
- ❖ AADD and School Based issues: Toni Doty/Jim Martin, Assessment
- ❖ One 2-hour session - Tom Tonniges, MD and Medical Director at Boystown, Nebraska
- ❖ Norman Kunc (keynote?)
- ❖ Mary Ganotti + Lisa Blumberg;

- ❖ “Lest We Forget” – Dr. Sara Westcott in association with a SIG PT or connect with AAIDD too.
- ❖ Estate and Adult-life Planning - Marilyn and Joe Henn (Ohio) do a keynote and associated breakouts on this topic entitled: “*You can’t put a round peg into a square hole*” that helps attendees gain insight into future planning for adults with DD as they age.

SoPac: The first SoPac meeting was well attended and received. (See SoPac committee news.) Some highlights from the wonderful programming were:

- ❖ Deb Thorpe on promoting fitness for youth with cerebral palsy.
- ❖ Janice Brunstrum-Hernandez, MD and Nancy Cicirelo presented information about “Physical Therapy for Adolescents: then and now-What we knew and what we’ve learned”.
- ❖ Toni Doty and Robbie O’Shea presented information about providing seamless health care transitions.

Evaluations revealed a need for more programming to address lifespan issues like estate and adult-life planning that might be valuable at SoPac. See suggestion for Estate and Adult-life planning above. AADD SIG also suggested holding a “movie night or session” where attendees could preview a variety of relevant movies (DVD’s) that might include: *Including Samuel; Crossing Tahoe; King Gimp; Darius Goes West; Music in my Ears; “I’m Tyler”*, and others. We would offer popcorn, drinks...this could be a fun social and learning event. Finally, our AADD SIG is working with the SoPac committee to try to sponsor a child/adolescent/adult with developmental disabilities, and his/her family to attend SoPac at Disneyland. Donna Metzger and Lorrie are working on an application process to be presented at Annual Conference for this event. SoPac planning has started quickly and continues!!

General Programming Ideas for SoPac and CSM: SIG members suggested a variety of programming ideas for CSM and SoPac that included:

1. Kathy and Benjamin Snow doing a joint session about “Disability is Natural”, and discuss PT interventions as they perceived them over the lifespan.
2. Expert Panel on Duchenne’s Muscular Dystrophy
3. Trusts and estate planning; End of life issues (described above)
4. Movie night described above.
5. Employment and independent living...Either one of the above
6. Combined session with Geriatrics: Aging Caregivers and Care-needers; Aging and Lifelong Disability
7. Combined Geriatrics & SOP on “Aging in Place”...issues of aging/ universal design in housing/ etc....Lorrie approached them and they will submit a proposal on Scholar One.

Other AADD Discussion and Activities:

1. **\$300,000 Research Grant** available from a private source. Private funding from a family with a person with polio; Focus on multi-disciplinary/multidisciplinary project. We discussed focusing on Aging with maybe a multisite study. Suggest people in the group get together. Mary: check on RFP

2. World Conference and IPOT: Barb Connolly reported on the WCPT's Theme for 2011 to be "Adolescents and Adults with Developmental Disabilities". Submit presentations for Amsterdam in 2011. March 5 for breakouts? Posters may be later...check website for World Conference.

3. Fact sheets: Fact sheets need to go through the practice committee; cc to Cyndy Sliwa and Sheree York. Fact Sheets are:

Employment

Adult Living (In process)

Self Determination/Self Advocacy: Lorrie will work on this one.

Transition for School To Posts secondary Education – Robbie O'Shea and Nancy Cicerello will work on these.

Interagency Collaboration

Health Care Issues/Aging (In process)

Fitness/Recreation (In process)

Other Ideas????

Fact sheets will go on the Section on Pediatrics' website from the COC-LLD

- 4. Resource Page Outline:**
1. Summary Paragraph introducing the topic
 2. Group members with contact info.
 3. Resources: Website Links, Bibliography
 4. Practical Tips: Evaluation & Intervention

5. Liaison to Practice Committee: Laura Case is a member of Practice Committee, and agreed to be liaison to AADD from Practice Committee...or vice versa. AADD reports to them on what we are up to...keep an active/vocal presence in the Practice Committee's mind.

As always, we welcome your comments and suggestions!! Happy Spring!

Respectfully submitted,

Lorrie Sylvester, PT, MS

AADD SIG Chair

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