New SWAAAC Initiative to Impact Literacy

Literacy consists of the ability to think, listen, speak, read and write effectively. Consider for a moment the impact deficits in just one of these areas might have on a student's ability to learn and engage in education. Imagine a sixth grade student hearing, "... read chapter 12 of your social studies text, there's going to be a quiz," and knowing he will fail the quiz because he cannot read the book. Imagine another student who knows the answers to the questions on the quiz, but fails because he cannot write or speak the answers.

The development of functional literacy skills is paramount to accessing and making progress in the general education curriculum. Furthermore, literacy proficiency has been linked repeatedly to drop-out rates, employment and socioeconomic status. Literacy must be a fundamental educational priority for all students; and every educator, every related service provider has a responsibility to that priority.

Over the next three years the Colorado Department of Education SWAAAC program will embark on a quest to impact literacy learning outcomes for students with disabilities through a targeted and rigorous professional development agenda. The schedule will include workshops with nationally renowned Assistive Technology trainers, half day sessions with local consultants, webinars and mentorships. The initiative will also seek to objectively quantify student outcomes that are related to the effective implementation of educator interventions.

Be a part of this exciting initiative that promises to make a difference. For more information, please visit our website at http://swaaac.com/ProfDevelopment.html.

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The 2013 AT Expo: Technology for Living & Learning, hosted by ATP, will feature vendors showcasing the latest innovations in hardware, software, educational materials, Assistive Technology devices and solutions for home, school, work and play. Colorado organizations that provide services to individuals with disabilities or to those who are experiencing problems associated with aging will also be present. Visit the Annual Events section of our website for more information, driving directions and a list of participating exhibitors at www.assistivetechnologypartners.org.
CLINIC SPOTLIGHT:  
Sweet Dreams for Brooklyn

Brooklyn is a bright 3 year old with severe spastic quadriplegic cerebral palsy. She has significant technology needs in all areas - including mobility, seated positioning, nighttime positioning, communication and general switch access for play and learning. Brooklyn lives at home with her parents and little brother in Nebraska. She travels to Colorado for speciality care at Children’s Hospital Colorado (CHC) and was referred to our clinic program by Dr. Joyce Olezsak, initially for a Nighttime Positioning Assessment because she was sleeping poorly. She is also being seen by our team for assessment of technology needs in the areas of wheelchair seating and mobility, switch access and augmentative/alternative communication.

When Brooklyn was first seen by Kelly Waugh, PT, MAPT, she was only sleeping 3 hours each night, crying and waking frequently - as much as 6-8 times per night. She tends to get stuck in uncomfortable positions at night due to her cerebral palsy and inability to control her movements. Her parents told us that when she was younger, she used to get her legs caught in the rails of her crib. She has tried numerous medications to help her sleep, but these have not worked. Her family has tried different mattresses, pillows and wedges to help Brooklyn stay in a comfortable position, but these have not helped either.

Brooklyn moved to a regular bed when she was 4 years old; however she developed skin breakdown on her back from sleeping on a standard mattress. She has been unable to lay on her side because she has abnormal muscle tone and movement. If she is put on her stomach she gets abrasions on her face from rubbing on the mattress.

When Brooklyn was first seen in our clinic, she was sleeping in a big bean bag chair as this seemed to help prevent skin breakdown. However, she was still averaging only 3 hours of sleep each night. Despite her lack of sleep at night, Brooklyn was not napping during the day. She was very irritable during the day, frequently crying. Needless to say, everyone was exhausted!

Brooklyn's body forces her to sleep in very uncomfortable positions at night. This increases the risk of developing a scoliosis and worsening of her hip contractures. She sleeps at night with her hips adducted (knees together), which may be contributing to her joint stiffness and loss of joint range of motion.

As part of the Nighttime Positioning Assessment, Brooklyn was positioned in the Dreama Nighttime Positioning Mattress, a product manufactured in Britain by Jenx, Ltd. Brooklyn seemed to prefer lying on her back instead of on her side, and so specific support components were tried to help stabilize and elevate her. We talked about the possibility that Brooklyn feels unstable at night due to her inability to control her movements or posture, and that may make her feel uncomfortable and anxious. Her family thought that a trial of the Dreama Mattress was appropriate. Therefore the parents were trained on how to set up the bed and we sent it home for a trial.

Brooklyn's parents reported the following remarkable results at a follow-up visit 2 1/2 weeks after beginning to use the Dreama Mattress.

1. **Brooklyn sleeps all night for 11 hours without waking.** She falls asleep on her own, and is not waking up at all during the night. She is happier during the day, she is more communicative and is showing better head control when sitting. Her mother feels that her attention span has improved and she is showing better cognitive endurance - being able to work on games for longer, etc. She even naps during the day which she had never done before!

2. **Reduced muscle tone and stiffness.** Brooklyn's mother reported that

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her muscles are more relaxed and joints are looser when awaking - less tone and stiffness. She stays in good alignment throughout the night in the mattress because of the positioning components.

3. **No skin redness** after sleeping 11 hours in an elevated position, on her back.

4. **Brooklyn is now off all sleep medications.** Prior to the use of this specialized positioning mattress she was taking Clinazopam and Melatonin, and had also tried Clonodine previously.

5. **Brooklyn’s startle reflex seems to have diminished.**

As further confirmation of the benefits of this mattress systems for Brooklyn, her mother reported that when she travels to Denver and stays in a motel, Brooklyn’s poor sleep quality and duration returns. In other words, when she is at home using the trial Dreama Mattress she sleeps well, when it is not available she sleeps poorly, and when she goes back home using the Dreama Mattress she sleeps well again.

After these significant positive outcomes were reported, we submitted a report to Brooklyn’s health insurance plan which outlined Brooklyn’s problems in this area, and the medical justification for a positioning mattress to address these problems. We recommended purchase of the Dreama Nighttime Positioning Mattress as a Durable Medical Equipment benefit.

As of this writing, the mattress has been approved by the insurance company and Brooklyn is awaiting delivery. In the meantime, she is still using the loaner Dreama Nighttime Positioning Mattress at home, sleeping well at night and continuing to nap on the mattress during the day. Because she continues to experience poor sleep quality during her frequent and regular stays in Denver, we are exploring solutions for a more portable, light weight system for travel.
VOLUNTEER CORNER

Heppner+Bourque

There are many generous volunteers who contribute their time and talent to Assistive Technology Partners each week. To honor and thank them, we have decided to include a volunteer corner as a regular section in our quarterly newsletter.

In this issue, we would like to thank Lisa Heppner and JC Bourque of Heppner+Bourque (www.heppnerandbourque.com). Heppner+Bourque is an award-winning creative services group that specializes in marketing for Colorado based companies. They are located in the RiNo Arts District and offer a variety of services including copy writing, graphic design, web development, photography and video.

Lisa and JC started volunteering with ATP over 10 years ago. They are exclusively responsible for helping ATP move forward with our branding and marketing effort over the last 2-3 years. Their inspiration and countless hours of work have captured ATP’s mission and vision to create a professional new look and feel. JC and Lisa have served on the ATP Advisory Council as well as the ATP Marketing Committee. Not only have they shared their time and expertise, but they have donated numerous, pro bono marketing materials and contributed resources for a number of our research projects.

ATP would like to thank JC and Lisa for their invaluable support and generosity throughout the years. We look forward to our continued work together.

ATP’s Clinic Coordinator Kelly Waugh, PT, MAPT, Publishes Clinical Guide to Standardized Wheelchair Seating Terms and Measures

Full time wheelchair users and their caregivers understand the impact of a poorly fitting wheelchair can have on comfort, health and the ability to function optimally during school, work or recreation. How a person sits in their wheelchair - their “seated posture” - can affect pressure distribution across the buttocks, control of head position, the ability to transfer, or even how well a person can breathe and swallow. The dimensions, angles and placement of a wheelchair’s seating support components can have a significant impact on this seated posture. For example, the angle of the upper body in space relative to the lower body, can affect a wheelchair user’s balance and ability to reach for something with their arms.

Successful outcomes in prescribing wheelchairs requires a correct match between the seating support system and the user’s body. However, there is currently tremendous variation in the terminology and measures used to objectively describe the linear and angular dimensions of a wheelchair seating system, and to define a wheelchair seated person’s posture. The field of wheelchair seating is interdisciplinary, and clear communication is critical to effective decision making and positive outcomes for the consumer. A common vocabulary of terms and measures is needed by clinicians, suppliers, technicians and manufacturers for accurate translation of assessment information into a seating prescription, and for effective set up of the prescribed product.

The widespread use of standardized terminology and measures by those involved in wheelchair service delivery would lead to significant advances in clinical practice and fundamental research. ATP’s Clinic Coordinator, Kelly Waugh, has been working hard to address this goal; therefore, we are very proud to announce the completion of a comprehensive resource for practitioners involved in wheelchair service delivery and research: A Clinical Guide to Standardized Wheelchair Seating Measures of the Body and Seating Support Surfaces.

Ms. Waugh is the primary author of this resource manual, and the director of a two year project funded by the Paralyzed Veterans of America (PVA) Education Foundation.

The overall goal of this project is to increase the adoption and use of standardized measures and terminology related to wheelchair seated posture and seating equipment parameters. The clinical guide, the primary product of this project, translates a highly technical international standard into a format and language that is easier to understand and clinically useful. In conjunction with Dr. Barbara Crane of the University of Hartford, Ms. Waugh has provided two full day trainings on the guide - an “invite only” workshop at ATP in Denver in November of 2012, and most recently a pre-symposium course at the 29th International Seating Symposium in Nashville, Tennessee. Ms. Waugh will also be delivering training on the guide at the annual RESNA conference in Seattle, Washington in June.
SATELLITE UPDATES

ATP-WestTAC

Earlier this month, Denice Roberts gave a presentation to the Hearing Loss Association of America’s (HLAA) monthly meeting using the AT for Hearing Demonstration Kit. The Kit contains devices to help people who are deaf or hard of hearing in each room of the house. Several of the devices are signalling systems which turn sound into light alerting the occupant of a phone call, doorbell or alarm. Denice also demonstrated the Telecommunications Equipment Distribution Program (TEDP) Phone Cart. TEDP is a program offered through the Colorado Commission for the Deaf and Hard of Hearing to provide free amplified phones for people who qualify. TEDP has recently added new phones: Serene C-60AP, Clarity Alto, geemarc AmpliPHOT050 and the cordless, Clarity Professional XLC2 to their inventory.

Applications can be found at www.ccdhh.com. Contact Denice at 970.248.0877 to schedule an appointment to select the best phone for your needs. Appointments are also available at the Denver and Colorado Springs ATP offices.

Expert Reviewers Needed

Assistive Technology Partners is conducting a research study on product usability testing, and we need assistance from professionals who work with assistive technology and with people with cognitive disabilities. We will be testing 50 assistive technology and mainstream products over the next 2 years with people with cognitive disabilities. We will then provide feedback to consumers on usability, and to designers on how they can improve their product. We need feedback from experts in the field on these products regarding pros and cons and potential barriers to use by people with cognitive disabilities. Reviewers will be asked to fill out an online survey which takes approximately 20 minutes.

If you are interested in contributing to our research study as an expert reviewer, please contact Brian Burne at 303.315.1287 or at brian.burne@ucdenver.edu.

Upcoming Trainings

Assistive Technology Partners has a wonderful line up of trainings for you to choose from over the upcoming months. For more information visit the Upcoming Events page under the Events section of our website - www.assistivetechnologypartners.org. From there you can download informational brochures and access online registration.

- **Dragon NaturallySpeaking for Beginners** - Presented by Denice Roberts, MEd and Hosted at STRIVE in Grand Junction.
- **Wheelchair Seating for Postural Control and Function** - Presented by Kelly Waugh, PT, MAPT, ATP and Hosted at Assistive Technology Partners in Denver.
- **Empower Student Success with the iPad** - Presented by Jim Sandstrum, MA, CCC-SLP and Hosted at Anschutz Medical Campus in Aurora.

To keep up to date on the latest ATP trainings join our electronic mailing list. Please contact elizabeth.woodruff@ucdenver.edu to be added to the list.

You can also stay up to date on ATP trainings and other such happenings by liking Assistive Technology Partners on Facebook.