



Title V Has New Leadership

Robert (Bob) Nickel, MD, assumed the position of Director of OSCSHN services following Cathy Renken's retirement on July 15. Bob is a Developmental Pediatrician and Professor of Pediatrics at OHSU. Formerly the Director of the Eugene CDRC Office, Bob has practiced more than 24 years providing care for children with special needs and is nationally recognized for his work in early identification of children with special needs and for developing competencies for their care in the primary care office. His book, *The Physician's Guide to Caring for Children with Disabilities and Chronic Conditions*, which he authored and co-edited with Larry W. Desch, is used statewide and is nationally recognized. His dedication to a family centered, proactive approach to health care for children with special needs is reflected in his efforts in the Oregon Medical Home Project.



Diane and Bob

Diane Smith, MA, RD, LD, has recently assumed the role of Community-Based Services Manager following Kathy William's retirement on July 1. Diane previously was Nutrition Training Director for the CDRC Leadership Education (LEND) training project. Diane has worked for 15 years in community programs and clinics serving children with special needs developing innovative program delivery strategies and building collaboration with community partners to improve health outcomes.

For a personal message from Bob, go to Page 2.

For a personal message from Diane, go to Page 7.

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Inclusion in Community Recreation

Dave Oleson, PT

Participation in recreation offers the chance to learn new skills, to develop feelings of self-esteem and belonging, and to experience a physically active lifestyle.

When we talk about recreational activities for people with disabilities, what we're really talking about is inclusion, and inclusion poses challenges. Some organizations meet these challenges by acting as advocates and by modeling inclusive recreational programs. Two examples are the adaptive ski programs at Timberline and Mt. Hood Meadows. Organizations like these simply overcome any obstacles posed by an individual's disability.

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Inclusion in Community Recreation, *Cont. from page 1*

At the community level, inclusion is more difficult. First and foremost, community organizations must have an attitude favoring inclusion. Their administration must have a commitment to inclusion and actively support their staff and community to adapt programs and activities for people with disabilities. Portland Parks and Recreation has a good commitment to inclusion. They have an Inclusion Specialist on staff who will help anyone who may need assistance accessing their recreational activities.

Without this type of structure in place in an organization, it becomes necessary to do a little sleuthing. Facilities should allow tours where activities can be viewed and staff can be questioned. Appointments can be made with program administrators to assess inclusion. For such an assessment, an evaluation checklist is available on the Disability Solutions web site: www.disabilitysolutions.org.

Look for *Evaluating Inclusion in Community Recreation* in the Newsletter archives, *May/June 1996, Volume 1, Issue 1*.

Your can reach Dave at: 503-494-2718, or olesond@ohsu.edu

Why Use Aquatics for Children with Special Health Needs

Jeanne Baldwin, DPTP

Children love playing, moving, and learning in water. Aquatic therapy provides opportunities to improve strength, movement patterns, and functional skills in a warm and relaxing environment. Aquatic therapy is both enabling and stimulating due to the properties of water and the "out of ordinary" environment. The effects of warmth, a reduced gravity environment and bounciness promote respiration, development of perceptions, and freedom and exploration of movement.

The water experience will create a time for smiles, communication and increased independence. Aquatic therapy programs give children and their families recreational and social opportunities to splash and play while connecting and learning.

You can reach Jeanne Baldwin at Providence Neurodevelopmental Center for Children
503-215-2233

Bob's Corner: *The Director is Usually In* **Dr. Robert Nickel**

I'm writing to introduce myself and to tell you about changes in the Title V OSCSHN office.

This summer, Cathy Renken and Kathie Williams retired after long careers of exemplary service to the children and families of Oregon. We will miss them dearly and we will work to continue their good works. With their departure, I assumed the position of Director in July and Diane Smith became our new Community-Based Services Manager in September.

I am a developmental pediatrician and professor of pediatrics in the Department of Pediatrics at OHSU and former Director of the Eugene CDRC. For those of you who appreciate a little history, I grew up in Wichita, Kansas and graduated from Wichita East High School. Both of my parents were educators. I attended Stanford University and graduated from medical school at the University of California, San Francisco, and completed my pediatric residency in the University of California programs in San Francisco and San Diego. After completion of my residency, I had a number of "odd jobs" in San Diego. These included Director of the Chicano Clinic, consultant to an inpatient child and adolescent psychiatric facility, a month covering a primary care pediatric practice, and

interim Director of the Outpatient Department at Children's Hospital. While working at Children's, I developed a strong interest in the care of children with disabilities and chronic conditions. This led to my fellowship in developmental pediatrics at the University of Washington, Seattle, and then my joining the staff of the Eugene CDRC office in July 1980. I have enjoyed my 24 years in Eugene immensely and will miss the many colleagues, children and families who have touched my life.

Community and families have always been the focus of my professional career and the basis for my personal commitment to live gracefully and to make a difference. My new role as Director of Oregon's Title V Programs presents the opportunity to continue this commitment and to focus on the development of systems of care as well as the provision of direct service.

I look forward to meeting all of you. Diane and I, and all of the Title V staff, are committed to maintaining the high standards established by Cathy and Kathie. I will keep you updated on our activities through this newsletter. Please also feel free to contact either Diane or myself.

Bob: 503-494-6961, nickelr@ohsu.edu

Diane: 503-494-3210, smithdi@ohsu.edu

Voices of Families

Special Olympics Ski Program

Evelyn Lowry, FIN Family Consultant

Imagine swooshing down the snowy ski slopes. It is exciting. The crowd is cheering. Here comes the next gate and you must carefully maneuver around it in the right direction, skiing as fast as you can, without losing your footing. The slope is steep, challenging and cold. This sounds like a ski race. It is! It's a Special Olympic ski race!

Special Olympics is a competitive recreational program for athletes with cognitive disabilities for ages eight and above. Sports programs include skiing, swimming, track, bowling, volleyball, soccer, softball, basketball to name a few. Like any athlete, Special Olympic athletes must practice, train and compete.

All sports programs enable participants to compete, keep in shape and have a lot of fun with friends. Special Olympics athletes do the same. In the ski program, athletes with cognitive disabilities are given the opportunity to show off skills on the downhill and cross country ski

slopes. Every weekend in the months of January and February, these athletes are found on the slopes of Mt. Hood practicing their skills in any kind of weather.

Our family has supported Special Olympics and participated in the ski program for over 10 years.

Skiing has given my son Jeff confidence in himself. He has developed skills that many people without disabilities don't have. He has made a lot of friends. Every year we are excited for the next year's season.



Jeff on Mt. Hood, 2003

Special Olympics Oregon, visit www.soor.org
Phone: 503-248-0600 1-800-452-6079

Therapeutic Horseback Riding

Teresa Rice, FIN Family Consultant

Therapeutic horseback riding has gained recognition as a powerful form of therapy for children with disabilities. Parents of children who struggle with both physical and emotional/behavioral challenges have found that working with horses improves their children's conditions.

Two of my three children suffer from emotional/behavioral conditions. At one point about 2 years ago, as I sought help for my two sons, I was fairly desperate. We had been through all of the standard forms of intervention and I felt like I had tried everything to no avail. We had hit a plateau and I was frustrated that we had not made more progress in getting their symptoms under control.

Then I remembered that my mom had given me an article several months before about a woman in Estacada who had a therapeutic riding program. I dug it out and called Carrie Perry at Blue Heaven Therapeutic Riding Academy who invited us to come and give it a try. Though most of her work is with children who have physical disabilities, she did not turn us away.

Over the next year, the boys learned how to groom and tack the horses, how to ride safely and appropriately, and to respect an animal that was significantly more



Cody Rea on Seven with trainer

powerful than they were. While they struggled with making friends with peers, they developed friendships with the animals and quickly grew attached to

"Buddy" and "Bill" and the other horses.

They worked on teamwork with each other and with the horses. By the end of our time with Carrie and the horses, the boys had grown to love the time they spent there. They were able to work together and help each other for limited amounts of time. They were able to control their bodies and their words while with the horses so as not to upset or spook them. They learned how to calm themselves and saw how their calmness transferred to the horses. These things made our time at Blue Heaven priceless.

Working with animals has proven to be the best thing I have ever done with my boys. They have grown in their ability to be empathetic, patient, loving and caring to other living things. In return, the horses loved them back. For this, I cannot thank Carrie enough.

Blue Heaven Therapeutic Riding Academy is located in Estacada, OR. For more information, contact Carrie Perry at 503-630-2250 or visit the web site: www.blueheavenacademy.org.

What is Hippotherapy?

The American Hippotherapy Association

Hippotherapy is a treatment that uses the multidimensional movement of the horse. The term comes from the Greek word "hippos" which means horse. Specially trained physical, occupational and speech therapists use this medical treatment for clients who have movement dysfunction. Historically, the therapeutic benefits of the horse were recognized as early as 460 BC. The use of the horse as therapy evolved throughout Europe, the United States and Canada. Hippotherapy uses activities on the horse that are meaningful to the client. Treatment takes place in a controlled environment where graded sensory input can elicit appropriate adaptive responses from the client. Specific riding skills are not taught (as in therapeutic riding), but rather a foundation is established to improve neurological function and sensory processing. This foundation can then be generalized to a wide range of daily activities.

Why the Horse?

The horse's walk provides sensory input through movement which is variable, rhythmic and repetitive. The resultant movement responses in the client are similar to human movement patterns of the pelvis while walking. The variability of the horse's gait enables the therapist to grade the degree of sensory input to the client, then use this movement in combination with other clinical treatments to achieve desired results. Clients respond enthusiastically to this enjoyable learning experience in a natural setting.

Physically, hippotherapy can improve balance, posture, mobility and function. Hippotherapy may also affect psychological, cognitive, behavioral and communication functions for clients of all ages. Clients who may benefit from hippotherapy can have a variety of diagnoses: examples include Cerebral Palsy, Multiple Sclerosis, Developmental Delay, Traumatic Brain Injury, Stroke, Autism and Learning or Language Disabilities. However, hippotherapy is not for every client. Each potential client must be evaluated on an individual basis by specially trained health professionals.

About the American Hippotherapy Association (AHA)

Formed in 1993, the American Hippotherapy Association's mission is to promote research, education and communication among physical and occupational therapists and others using the horse in a treatment approach based on principles of classic hippotherapy. Registered therapists in hippotherapy are located throughout the United States and Canada.

For more information, go to the AHA web site: www.americanequestrian.com

North American Riding for the Handicapped Association (NARHA)

PO Box 33150 Denver, Colorado 80233 800-369-RIDE (7433)

NARHA is a national non-profit organization that promotes the benefit of the horse for individuals with physical, emotional and learning disabilities. For individuals with disabilities, equine-assisted activities have been shown to improve muscle tone, balance, posture, coordination, motor development as well as emotional well-being. And it's fun! For more information and to locate a stable near you, go to the NARHA web site: www.narha.org



FUNDING FOR SPECIAL NEEDS

The Title V OSCSHN Family Support Program (FSP) provides funding for recreational and educational activities, as well as many other special needs items and equipment. For more information, or to apply for these funds, contact Patty Day or Pat Langston: 503-494-8303, or toll free: 1-877-307-7070

Title V Conference

Oregon Services for Children with Special Health Needs
Child Development and Rehabilitation Center
Oregon Health & Science University
707 SW Gaines Rd
PO Box 574
Portland, OR 97207-0574



mental health



behavioral issues

Statewide Conference
Embassy Suites Hotel
Tigard, Oregon

RECREATIONAL RESOURCES



Oregon Disability Sports

Oregon Disability Sports (ODS) is a statewide sport program designed to provide opportunities for personal growth and achievement for children, youth and adults with a wide variety of physical disabilities. It provides a number of traditional sport competitions, lessons, and clinics, including summer sessions; and actively co-sponsors other programs. ODS also provides the Challenge Games, uniquely adapted events for individuals with any degree of functional ability who have the desire to compete. ODS also serves as an informational and referral clearinghouse and publishes both a newsletter and a comprehensive Disability Sport Resource Directory available on the ODS website. While the website is being reconstructed, contact Executive Director Ian Jaquiss for information and materials: 503-241-0850, (voice/TTY) 800-869-8180, orgames@open.org.
Service and Mailing Address: 721 NW 9th Avenue, Suite 300, Portland, OR 97209

Oregon Special Olympics

Founded in 1972, Special Olympics Oregon is a year-round program offering 14 different Olympic-style sports to athletes with mental retardation. Throughout the state of Oregon, over 5,000 athletes participate in Special Olympics. Through Special Olympics, people with mental retardation enjoy the opportunity to be treated as people, not just as disabled. In sport, athletes gain self-confidence, social competency and other enhanced skills, both physical and social.

5901 SW Macadam Avenue, Suite 100 Portland, OR 97239
Phone: 503-248-0600 Website: www.soor.org



Easter Seals Oregon provides Children's Therapy, Camping Programs, Warm Water Aquatics, Recreation and Respite, and After School Programs in many Oregon Communities. For information about these and other Easter Seals services, visit the website: www.or.easter-seals.org, or call 503-229-5108, 800-556-6020 .

Shriners Hospital for Children Recreation Therapy and Movement Arts Program

3101 SW Sam Jackson Park Road Portland, Oregon 97239 503-221-3780
E-mail: Smarler@shrinenet.org Website: www.shrinershq.org/shc/portland

Mt Hood Meadows Kathleen Priest, Adaptive Coordinator, 503-337-2222 x. 272, www.skihood.com/adaptive
Timberline Adaptive Snowsports Chris Millette, 503-490-7779, timberlineadaptive@hotmail.com

Sportime International is a catalog company that provides unique products tailored to aid professionals in carrying out specific movement programs. **Sportime** is an innovative Physical Education catalog and resource guide with over 400 pages of products and programs for ages Kindergarten through adult. **Abilitations** is a catalog for rehabilitation equipment which aids in the development and restoration of physical and mental ability through movement. Both are available on the web at: www.abilitations.com

Freedom to Move: Movement and Dance for People with Intellectual Disabilities

By Kim Dunphy, B.A., Grad Dip, M.Ed., & Jenny Scott, B.A.



This comprehensive guide — ideal for professionals in disability fields who may not have a dance background — offers a wealth of information, practical advice, and creative stimuli for teaching movement and dance to people of all ages in different community settings.
Available through Brookes Publishing: www.brookespublishing.com/store/books

RECREATIONAL RESOURCES

Parks and Recreation

When seeking recreational activities for your child and family, local Parks and Recreation Departments can be a resource. Contact information can usually be found in the Government listings in the phone book under City, County, Regional and State. When talking with recreation contacts, it is helpful if you describe your special needs and ask about both alternate and inclusive programs. Also, ask about scholarships; there may be funding assistance available.

Portland Parks & Recreation

Disabled Citizens Recreation & Special Needs Accommodations

426 NE 12 Ave, Portland, OR 97232 503-823-4328 v/tt 503-823-4329

Portland Parks and Recreation offers community-based recreation activities and leisure services specially designed for youths and adults who have a disability and/or special needs. Services are designed to assist people in developing and using their leisure time in ways that enhance their health, independence, and well-being. A program is published quarterly and can be requested by phone or can be accessed on the website: www.PortlandParks.org



City of Eugene Specialized Recreation

Hilyard Community Center 2580 Hilyard St. Eugene, OR 97405
Recreation Manager: Sue Harnly, CTRS (voice/TDD): 541-682-5311

Eugene provides a diverse choice of recreation activities to empower its citizens with disabilities to develop active, healthy and playful lifestyles. They serve children, teens and adults with physical or developmental disabilities, alcoholism, addiction and psychiatric disorders. Family members and caregivers, friends with and without disabilities and the general public may also register for classes or utilize our services. www.ci.eugene.or.us/rec/specializedrec

Oregon State Parks

Which Oregon State Parks have ADA accessible trails, restrooms and camping? You can find this information by visiting www.oregonstateparks.org, or by calling 1-800-551-6949.

National Center on Physical Activity and Disability (NCPAD)

The mission of NCPAD is to promote health benefits that can be gained from participating in regular physical activity. The slogan of NCPAD is *Exercise is for EVERY body*, and every person can gain some health benefit from being more physically active. This site provides information and resources that can enable people with disabilities to become as physically active as they choose to be. www.ncpad.org

American Camping Association web site annually publishes a parents' guide to accredited camps, including information on choosing a camp and a section on special needs and specialty clientele. www.ACAcamps.org



Can Do Fun: Adapted Communication and Motor Activities for Rett Syndrome and Other Developmental Disabilities Jane Murphy, M.S., CCC, and Suellen Newby, OTR/L

Can Do Fun is filled with fun, innovative activities and practical ideas that provide motivating ways for special needs individuals with limited language skills to communicate, socialize and learn functional skills. This activity book was developed with the belief that individuals diagnosed with Rett syndrome can successfully communicate and participate when they are given the opportunity and the tools to assist them. *Can Do Fun* provides activities, crafts, games, and songs which can easily be used by parents and caregivers to facilitate participation. Each activity includes goals and learning objectives, directions for implementation, suggestions for adaptations, and picture communication symbols which can be copied and laminated. Permission is given for reproduction of activities for classroom or educational purposes.

Available from Mayer-Johnson, Inc.: www.mayer-johnson.com, 1-800-588-4548

New OSCSHN Team Members

Catherine Coffey, PNP, joined the Title V program in January of this year to provide support and coordination between the out-patient clinics and the communities. She has been working primarily in the CDRC Child Development Clinic, becoming familiar with clinic operations and flow. We are delighted to have her now take a more active role in statewide OSCSHN activities. Her experience in the care of high risk pediatric and adolescent patients in the community and her work as a feeding consultant are wonderful enhancements to our team.

Catherine will be attending some of the CCN clinics and joining the CaCoon consultants on county visits to look for ways to improve communication between the out-patient clinics and community providers. In her spare time, Catherine enjoys working with horses and is actively involved in supporting equine therapy. She keeps busy with her family, which includes 4 children, 2 dogs and a fish, and enjoys travel and exploring new places. We welcome Catherine to our team.

You may reach Catherine via e-mail at: coffeyc@ohsu.edu

Candace Artemenko, RN, our newest team member, is familiar to many of you. Candy has worked in the Douglas County Health Department as CaCoon Coordinator as well as nurse consultant for the Douglas Education Service District. She has worked extensively with schools, practitioners and community health providers in community development and direct services. In her spare time she enjoys ethnic cooking and planning gatherings for her large extended family, two pastimes which blend very well!

Her work with the OSCSHN Community Service Program will provide support for two Community Connection Clinics, Coos Bay and Grants Pass, as well as CaCoon consultation in Lane, Douglas, Coos, Curry and Josephine Counties.

You may reach Candace via e-mail at: artemenk@ohsu.edu



Announcing the formation of the New Adolescent Transition Learning Collaborative in Coos, Curry, Hood River, Jackson, Lincoln and Union Counties. If interested in obtaining more information about this great learning opportunity, contact Barb Dworschak in the CDRC Title V office: 503-494-6208, 1-877-307-7070, ext. 4-6208 (toll free), dworscha@ohsu.edu

From Diane Smith, Manager Title V Community Based Services (CBS)

I am thrilled about the opportunity that lies ahead for the Community-Based Services: CaCoon and Community Connections Network. I have joined a team of experienced, talented and creative Public Health Nurses and Community Liaisons working together to improve services and program capacity for children with special needs.

My own career path has taken me from direct services for Children with Special Needs in the Regional Centers of California, to WIC program manager/nutritionist in rural communities, to Oregon State University Extension Service teaching and program development, to my most recent position as Nutrition Training Coordinator and Metabolic Dietitian at the CDRC.

My new role as CBS manager allows me the opportunity to impact policy and to work with you in collaboration and coordination in ways that will make a difference in the lives of the patients and families we serve.

Diane: 503-494-3210, smithdi@ohsu.edu



May 5 & 6, 2005

Statewide Conference
Embassy Suites Hotel
9000 SW Washington Sq Rd
Tigard, OR 97223

For more information,
e-mail schleyc@ohsu.edu
or call Charlotte Schley at
503.494.4587

Don't miss this opportunity to hear knowledgeable speakers on mental health and behavioral issues in children with special health needs!

Join us for a super conference packed with the latest information on the assessment of and strategies for mental health and behavioral issues in children with special health needs. This conference is sponsored by Oregon Services for Children with Special Health Needs (OSCSHN) located at the Child Development and Rehabilitation Center on the Oregon Health & Science University campus in Portland, Oregon. OSCSHN covers services in care coordination (CaCoon), multidisciplinary (CCN), and family involvement network (FIN).

This statewide conference is intended for nurses, physicians, social workers, parents, child care providers, early intervention specialists, health educators, or anyone who may work with children who have mental health or behavioral issues.

Please send us your E-mail address.

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If you wish to be taken off our newsletter mailing list, please contact Char by e-mail or phone:
1-877-307-7070 x4-4587

*We welcome your
comments and
submissions.*

**Deadline for submissions
to the February 2005
edition is January 10, 2005**

Contact Information



Community Connections Network
503-494-4586



CaCoon Program
503-494-4219



Oregon Medical Home Project
503-494-3232



**FISHS: Framework for Integrating
Special Health Services**
503-494-3232



FSP - Family Support Program
503-494-8704



FIN - Family Integration Network
503-494-7657

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