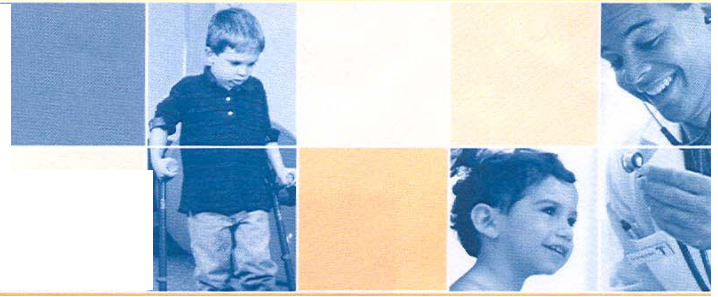


CHILD DEVELOPMENT AND REHABILITATION CENTER



Oregon Center for Children and Youth with Special Health Needs

A NEWSLETTER CONNECTING OUR COMMUNITIES

Winter 2006

Title V Has a New Name and a New Director

Our Title V Program has been granted status as a Center at OHSU. We are now the Oregon Center for Children and Youth with Special Health Needs (CYSHN). This new name and status gives clear recognition of our leadership and advocacy roles for children and youth with special needs in Oregon.

The new designation of Center status appropriately describes the focus and dedication of our activities within the Child Development and Rehabilitation Center (CDRC). As one of the three main units within CDRC, we will continue to work to fulfill our mission, which is to improve the health, development and well being of children and youth with special needs. We do this by:

- Partnering with families, community providers and agencies;
- Providing leadership in policy development, advocacy, and in assessing levels of care and services;
- Supporting efforts to coordinate and maximize resources;
- Working with communities to strengthen their capacity to meet the needs of children and their families;
- Honoring the strengths and diversity of families.

The Oregon Center also has new leadership. As many of you know, Dr. Robert Nickel has returned to practice in the Eugene CDRC, though he will still be active in the Portland office working with families in the Autism Treatment Network.

Our new director, Dr. James C. Ledbetter, M.D., F.A.A.P, comes to us from the Colorado Department of Public Health and Environment where he was the Medical Consultant at the Health Care Program for Children with Special Needs. As a Developmental Pediatrician specializing in Developmental and Behavioral Health, Dr. Ledbetter has a thorough understanding of the MCH Title V system and Medicaid for children. He has had extensive experience in collaborating with other state Title V programs for CYSHN through the Medical Home Initiative. His strong teaching skills and particular interest in utilizing technology-based innovations in training will be an added bonus to our community partners in pediatrics and public health. Dr Ledbetter has three daughters and is moving to Oregon from the mountains of Colorado with his wife, Jennifer, and 10 year old daughter, Grace.

For a personal message from Dr. Ledbetter, turn to page 2.

Oregon Center Updates: Needs Assessment and Program Priorities

Diane Smith, Community Based Service Manager

In this Issue:

Title V Has a New Name and New Leadership.....	1
Oregon Center Updates.....	1
Message from the Director.....	2
Voices of Families	3-4
Resources: Brookes Publishing & More.....	5-6
Title V Contact Information.....	8

Thank you to all our partners for participating in our Needs Assessment, which was part of the five-year Maternal Child Health (MCH) Block Grant application. Focus groups, key informant interviews and survey findings helped to guide us in the process of setting priorities for our work activities and program development. Three performance measure outcomes were identified as being important areas of focus in Oregon:

1. Providers report confidence in caring for Children and Youth with Special Health Needs (CYSHN);
2. Families of CYSHN report that costs not covered by insurance are usually or always reasonable;
3. Families who live in rural areas report their needs are usually or always met.

Continued on page 7





From the Crow's Nest

Dr. James Ledbetter



Hello Readers,

It is a pleasure to start the new year as the new director of the Oregon Center for Children and Youth with Special Health Needs (CYSHN). My wife, Jennifer, my daughter, Grace, and I are settling into our new home in Portland, and I am very excited to take the helm of the Oregon Center for CYSHN. The term “helm” brings to mind many analogies between sailing and the Title V Program for CYSHN here in Oregon, but I will try not to go overboard (no pun intended here). However, if you knew of my love for sailing, you would understand that a few analogies are irresistible.

For all but the smallest sailboat it takes a team, coordinated in every effort, to propel the ship smoothly and expeditiously as it sails to its goal. I am fortunate that I am coming aboard a ship with an excellent crew who are skilled in addressing the needs of children and youth with special health care needs in Oregon and dedicated to insuring that families participate in and are satisfied with the decision making at all levels of their child’s care. I am also fortunate to replace a skipper who has provided gentle and true guidance during his watch.

Dr. Bob Nickel came to this position only a little more than a year ago, but returns to Eugene with the recognition of having injected new excitement and enthusiasm into the Oregon Center for CYSHN. He has provided a clear vision as the program adjusts its course to fulfill its responsibilities for CYSHN in the 21st century. Thank you Bob for a job well done.

In the last decade of the 20th century, the federal government has mandated a change in the role of state

programs for children and youth with special health care needs. The Oregon Center for CYSHN is moving from providing or paying for medical care for these children and youth with chronic conditions to the linking of their families to the necessary services that exist, or need to exist, within their communities. In this way families can make personal decisions germane to accessing quality healthcare in a coordinated, comprehensive and family-centered way. This requires a public health model that utilizes data and outcome measurements to promote policy development and underscores the importance of community-based services, even in the more rural areas of Oregon, and links them with specialty services concentrated in the bigger cities.

Many sailing vessels have a station high in the main mast that allows its occupant an excellent survey of where the ship is heading as well as where it has been. At the same time it allows an unequaled perspective of the entire ship itself. This post is called the **crow’s nest**, and it seems an apt name for the column that allows me to share my perspective on the issues that our program faces in the early years of the new millennium as we plot our new course.

It is indeed a pleasure and an honor to assume the leadership of an important and necessary program that serves a valuable, but vulnerable, population. I am excited about the opportunity we have to make a positive impact in helping families of CYSHN to navigate the healthcare system with as much ease as is possible.

Contact Information: 503-494-6961, ledbettj@ohsu.edu

Oregon Center Staff Changes: Hello to Caroline, Goodbye to Claire

Caroline Neunzert, RN, MSN, has joined our Community-Based Team as Public Health Nurse Consultant in the CaCoon Program. Caroline is a pediatric nurse with experience in public health as well as care coordination. She has been an active school volunteer and is currently a school board member. Her broad background will be a valuable resource for communities. Caroline and her husband live in Tigard and have two teenage daughters. Caroline can be reached at: 503-494-8618, neunzert@ohsu.edu

Claire Tranchese has left her position as the administrative coordinator for the Community Connections Network to pursue a new role as a program technician for the OHSU Office of Rural Health. The Oregon Center extends a heartfelt thanks to Claire for all her support over the past three years. Claire’s contribution to CCN and other Oregon Center activities has been outstanding, and, while we will miss her, we wish her great success in her new role.

Voices of Families: Ryan's Story

By Angela Palandeni

I have a seven-year-old son named Ryan who was diagnosed with Asperger's syndrome three years ago. I suspected something was different with Ryan from the time he was a newborn, but his actual diagnosis came through NW Regional ESD, and then also through CDRC at OHSU. Along with Asperger's, Ryan also has sensory integration disorder, which is our biggest challenge at this time. To help Ryan get the help he needs, I have had to learn how to advocate for him through the medical world and also through the school system. I know that I can't always be there for Ryan, so I am in the process of trying to teach Ryan how to be a self-advocate. It's important to me that he be aware of his needs, that we recognize and embrace them as a family, and that we work together to figure out a way to help him feel and be successful. In order to do this, it's necessary that I know Ryan's legal rights and what help is available. I'm not an expert by any means, but I have learned a few lessons along the way.

I know that it can be overwhelming and intimidating when you have a special-needs child, especially when your child is first diagnosed and you have so much to figure out and understand. It's like being suddenly sent to college straight from kindergarten, with huge gaps in your knowledge and a sick feeling of being lost and overwhelmed. I know the stages that you can go through, having gone through them myself. Denial, guilt, blame, hopelessness. and then coming to terms with the diagnosis and moving forward. Moving forward! With or without a disability, life

"... when your child is first diagnosed and you have so much to figure out and understand. It's like being suddenly sent to college straight from kindergarten, with huge gaps in your knowledge and a sick feeling of being lost and overwhelmed."

happens. I can't predict what the future holds, but I can prepare my son for life. In the meantime, I am learning how to navigate the medical lingo, insurance billing codes, IEP meetings, and all the other areas that encompass life with Ryan. The most important thing in my life is to help Ryan, and the best way that I can do this is by learning all that I can about all these areas, and making sure that Ryan gets the individual help he needs. It's not a "one shoe fits all" approach with disabilities. What works for one child/family may not work for another. The key is to learn all that you can, and figure out what works for you.

It has taken me almost three years to see Ryan's disability as a blessing in my life. Looking back, I realize that because of Ryan I have learned a great deal on a variety of different disabilities, become a more patient parent, and also become more tolerant of other people and their circumstances. Not to mention the people that I have met, worked with, and formed friendships with along the way! It's been said it takes a village to raise a child, which in my case includes doctors, therapists and specialists, and that's okay. I'm grateful for the help. And maybe, somehow, someday, I can help make another person's sudden journey from kindergarten to college a little less bumpy.



A Journey to Advocacy: How to Use your Story for Change

Family stories are a powerful tool to use when trying to improve systems, share with others or get involved to help others. Learning to tell your story to help others is an important right of passage that everyone goes through on their way to advocacy. To learn how to use your story, choose a workshop from any of the dates below. Each workshop will teach you how to use your family and personal experiences raising a child with special needs to make a difference. If you would like to meet other family members and get connected, this is the place for you!

Call Jammie Farish at 503-557-6441 for locations and to register!

Sessions are from 6pm—8pm January 4th, January 18th 6pm - 8 pm, February 1st 6pm - 8 pm, February 15th 6pm – 8pm

Voices of Families: Marie's Cookbook

By Marie and Susan Blanchard

From Marie:

Last December after almost three years of when I started writing it, I finished my first cookbook. In March, 2002 I was visiting friends with my mom and my friend said she wanted to write a cookbook. That night they cooked Salmon Balls and gave me the recipe because I wanted to write a cookbook too. All of the rest of my 34 recipes were invented by me.

My mom helps me cook. We try out all the recipes before I type them up and do a drawing for each one. My mom prints them off the computer and binds them into a book. The chapters are Fruit Salad, Mac & Cheese, Noodle Surprise, Salads, Quesadillas, Smoothies, Breakfast, Dessert, and Main Dishes.

As soon as I finished this first cookbook, I started work on a second cookbook. So far, I have chapters on cookies, rice dishes, and meatball recipes.

Last June at my school, the Lake Oswego Review picked one kid to interview. They picked me because I wrote a cookbook, I'm on the honor roll, and I have cerebral palsy. They interviewed me and one of my friends, Paige. They came to my house to take pictures of me cooking recipes from my cookbook. The story was a whole page and a half in the Lake Oswego Review on July 7, 2005 and is included in the cookbook.



Marie and Susan Blanchard

From Mom:

Marie has always been a very social, creative and imaginative child. She is always coming up with new ideas, whether it's a recipe, a drawing, or an idea for a project. She has a very unique artistic style. One year she was into beading and created long strands of colorful beads that now hang in our dining room doorway.

Marie was born not breathing and later was diagnosed with cerebral palsy. When she was young we had no idea whether she would be able to walk or talk, or what her level of function would be. Currently Marie is 13 and uses a walker for short distances, a wheelchair for long distances, and she walks without any device around the house or classroom. Her athetoid cerebral palsy affects the movement of all her muscles, and thus her speech is difficult to understand. As she gets older and remembers to end her words, and also to take breaths between sentences, her speech becomes clearer.

As her mom, I would like people to see the unique, wonderful, creative young woman who is my daughter – rather than seeing a child who is different and limited. She is more limited by society's attitudes than by her disability. Recently I heard a new term, which I think helps us change how we view people who seem different, and that is: "diverse-ability". We ALL are diverse in many ways. Just as I don't want my most limiting traits to identify me, I bet you don't either.

If you have any suggestions on publishers who might be interested in Marie's Cookbook, please let us know. Marie makes original drawings on each of the front and back covers of her cookbooks, and she's such a busy girl, she hardly has time! Or, if you are interested in buying a cookbook, you can contact us by email at:

Marie: smileheart44@yahoo.com

Susan: smilingheart9@yahoo.com

RESOURCES

Brookes Publishing Company and the *Preview Newsletter*

The Brookes Publishing website is a rich source of information about publications, resources, and current issues regarding disability. Brookes Publishing publishes resources in early childhood, early intervention, inclusive and special education, developmental disabilities, learning disabilities, communication and language, behavior, and mental health. Resources range from curricula and assessment tools to graduate- and undergraduate-level textbooks, professional references, and practical handbooks.

Brookes describes its mission as being: to help children and adults with disabilities lead fulfilling and self-directed lives; to ensure early intervention for children with special needs and children at risk; to prepare educators for the challenges they face in today's inclusive classrooms; and, to provide professionals with research-based theory and practice, because "one without the other just isn't enough".

To this end, Brookes offers three free monthly e-mail newsletters that include updates on new titles, original articles, links to features and excerpts, and research-based strategies on early childhood, education, and disabilities. These newsletters can be accessed at the Brookes Publishing Website: www.brookespublishing.com.

When College Is the Goal.....

The November Disabilities Newsletter, *The Preview*, reviewed two new books helpful for making the transition to college for youth with disabilities. A full review of both books can be found at: www.brookespublishing.com/store/books/getzel-742x/index.htm

Going to College: Expanding Opportunities for People with Disabilities, edited by Elizabeth Evans Getzel, M.A., & Paul Wehman, Ph.D., is described as a required resource for anyone who educates or coordinates services for individuals with disabilities. It provides case studies, best practices, program guidelines, and strategies to prepare for and succeed in college.



Life Beyond the Classroom: Transition Strategies for Young People with Disabilities, Third Edition, by Paul Wehman, Ph.D., provides a framework for defining and planning transition, addresses facilitation and support, and discusses ways to individualize transition service delivery for people with specific types of disabilities. This edition includes new emphasis on secondary school restructuring, self-determination, person-centered planning, college and other post-secondary alternatives, and use of the internet to enhance transition and work.



The November e-newsletter also included the article, ***When College Is the Goal for Students with Disabilities*** by Suzette Guiffre based on **Going to College: Expanding Opportunities for People with Disabilities**. Guiffre summarizes the information provided in this book and offers tips for helping students know what to expect in college and how to plan for the best possible chance of success. Topics include: how to plan for transition to post-secondary education; tips for overcoming challenges to gaining access; different definitions of disability by ADA and IDEA; issues related to confidentiality and disclosure of disability; and, results of the National Transition Study-2 (2000) commissioned by the US Department of Education. You can access the full article on the Brookes Publishing website: www.brookespublishing.com/newsletters/dd-1105.htm

USEFUL WEBSITES

National Center on Secondary Education and Transition coordinates national resources, offers technical assistance & disseminates information. It is based at the **University of Minnesota's PACER Center** and can be found on the web at: www.ncset.org, or by phone at 1-612-624-2097.

The George Washington University HEATH Resource Center maintains excellent information about financial aid for students with disabilities: www.heath.gwu.edu.

Oregon Department of Education maintains a "Transition Toolbox" newsletter that includes current information regarding various tools, resources specific to Oregon. This can be found at: www.ode.state.or.us.

The Institute on Community Inclusion offers a wide range of publications and videos under the category of Education & Transition/Person-Centered Planning at: www.communityinclusion.org/publications.

RESOURCES

Looking Ahead to 2007: Scholarships and Internships

Deadlines for the Anne Ford Scholarship and the Summer Technology Internship have passed for 2006, but these opportunities are usually offered each year. Information is available on the websites below to help plan for 2007. You may also find information about other opportunities at the websites listed under *Useful Websites* on page 5 of this newsletter.

Summer Information Technology Internship for College Students with Disabilities, Administered by AAPD (American Association of People with Disabilities) and sponsored by Microsoft Corporation. Undergraduate students interested in pursuing careers in information technology are encouraged to apply. Accepted candidates work in various agencies in the executive branch of the federal government. Roundtrip air travel and housing will be provided to interns, and each student receives a stipend. For information, visit the AAPD website: www.AAPD.com.

The Anne Ford Scholarship is a \$10,000 award given to a high school senior with an identified learning disability (LD) who is pursuing an undergraduate degree. Eligibility and selection criteria and an online application form can be found on the National Center for Learning Disabilities website: www.ld.org/awards/afscholarinfo.cfm/

It's Tax Time Again— Don't Forget the Oregon State Tax Exemption for Children with Disabilities

The Oregon Tax Code provides an additional tax exemption for parents of children with disabilities in Oregon. The procedure for claiming an exemption for the 2005 tax year is explained in the Oregon *Individual Income Tax Return and Instructions*. The tax booklet explains the criteria to qualify and the forms needed to claim the exemption.

You may reference the Oregon Department of Revenue

Forms 40S and 40 with Instructions at the following link: http://egov.oregon.gov/DOR/PERTAX/formsplit.shtml#2005_Tax_Year.

Spanish translations are available at the following link: <http://egov.oregon.gov/DOR/PERTAX/espanol.shtml>

For general information you may contact Eric Richards, Director of Operations, Office of Student Learning & Partnerships, at the Department of Education at 503.378.3600, Ext. 2330. For advice or individual assistance in completing the tax form, consult a tax professional or the Department of Revenue at 800.356.4222.

Coming Soon to a Website Near You— The 2006 Camp Guide



A camp experience can give a child both confidence and a sense of independence. There are many great camps for children with special health needs, but there are also many inclusive programs to consider that do an exceptional job of including all children.

Our Camp Guide, updated for the 2006 season with information about many local camps, will be available on the Oregon Center for Children and Youth with Special Health Needs (CYSHN) web site in March: www.ohsu.edu/outreach/cdrc/oscsn/

In the meantime, the following websites can give valuable general information about the camp experience for children and youth with special needs, including

checklists and pre-camp exploration tips useful for selecting a camp that will offer the greatest opportunity for the individual child and keep the child safe:

The National Center on Physical Activity and Disability (NCPAD), Discover Camp:
www.ncpad.org/discover/index.html

American Camping Association (ACA):
www.ACAcamps.org

Also, don't forget that there is funding available for camp fees through the Title V Family Support Program. Contact the Oregon Center for information: Call 503-494-8303 or 877-307-7070 (toll free), or e-mail Patty Day, dayp@ohsu.edu, or Pat Langston, langstop@ohsu.edu.

Oregon Center Updates: Needs Assessment and Program Priorities Continued from page 1

Performance Measure Outcome 1

In assuring that providers are confident in providing care for children and youth with complex and rare disorders, the Oregon Center for CYSHN continues to offer many different training opportunities in a variety of settings. Last year, over 725 attendees participated in training and skill development activities. Many different topics were addressed, including adolescent transition, managing challenging behaviors and addressing feeding difficulties. The venues for the presentations included small group community-based forums, conference keynote speakers, and learning collaboratives using interactive video conferencing.

The Oregon Center for CYSHN continues to offer community presentations on many topics of interest and an annual statewide conference. Mark your calendar for the Spring annual conference, April 20-21. The theme of the meeting is "Promoting Parent/Professional Partnerships: Optimizing Care for CYSHN." For information, contact Charlotte Schley: schleyc@ohsu.edu, 503-494-4587 or 1-877-307-7070.

Performance Measure Outcome 2

Adequate Health Care Financing will be a major area of focus for the Oregon Center in the coming years in an effort to ensure that costs not covered by insurance are reasonable. Health insurance data from National Child Survey of Children in 2001 found that 64.7% of CYSHN had private insurance or employment-based coverage, 21.7% had public insurance, 8.1% had both, and 5.2% had no insurance at time of interview. Many families reported that their children's coverage was not adequate to meet their needs: 12% reported that their plan did not usually or always allow their children to see the providers they needed; 14.5% said their benefits did not meet their child's needs; 28.4% reported that costs not covered by the plan were unreasonable.

In order to ensure adequate health care financing, a statewide committee, the Health Care Finance Stakeholders Group, was convened in 2005. In the initial meeting, Bobby Peterson from Wisconsin ABC for Health joined the team to provide technical assistance and help plan action steps. In a subsequent meeting, Priscilla Gould from Lane County United Way joined the group to share information about the activities they have undertaken to assure 100% access to health care for Lane County residents.

As next steps, the committee will complete an inventory of health benefits and advocacy resources and identify the

training, advocacy, and legal support services needed to promote health care financing for CYSHN.

The concern of adequate health care is not exclusive to families with CYSHN. Access to Oregon's health care system is severely compromised for all uninsured and underinsured people. The OHSU website committed to healthcare access issues states, "No single entity can solve this problem alone; all stakeholders must participate. Innovative partnerships are needed. Legislative leadership and involvement are essential. Oregon needs new approaches. The old ways no longer work." OHSU encourages a public dialogue to find equitable and compassionate solutions to the crisis of access. The Oregon Center hopes to participate in this dialogue. For more information, log-on to <http://www.ohsu.edu/underserved/>

Performance Measure Outcome 3

Families who live in rural Oregon report greater challenges in meeting the health care needs of their children with special needs. Our office is hard at work on a variety of projects and initiatives to improve service integration and collaboration in Oregon's smaller communities to better meet the needs of these families. Our FISH's (Framework for Integrating Special Health Services) initiative selected 6 rural counties to conduct a needs assessment regarding service integration between families and providers in order to create a plan for improved service. Similarly, our Youth Transition Learning Collaborative teams (also in 6 rural counties) are in the final months of creating a plan to improve service integration for transitioning youth with special needs in their communities. The "Oregon Clicks" project is a web-based, single application process by which families can apply for one program and learn about other services they may be eligible for. It is nearly ready to pilot in the first three Oregon counties, Klamath, Lane and Union.

And finally, our office is excited about the developing website Disability Compass (www.disabilitycompass.org), a project of Disability Navigators, Inc. This web site is being developed to centralize resource information for families and individuals who experience disability. The goal is for the site to be easy to use and keep resource information up to date. The developers are currently reaching out to potential stakeholders to provide information to populate the site. The Oregon Center hopes to support this effort for the benefit of families and providers throughout Oregon.

Diane Smith, Community-Based Services Manager
smithdi@ohsu.edu, 503-494-3210 or 1-877-307-7070

Mark your calendar!
 You are invited to attend our annual statewide conference:
Promoting Parent-Professional Partnerships:
 Optimizing Care for Children and Youth
 with Special Health Needs
 Keynote Speaker: Carl Cooley, MD
 April 20-21, 2006 at the Embassy Suites Hotel
 Washington Square in Tigard, Oregon
 Conference Contact: Charlotte Schley
 Phone: (503) 494-4587 Toll-free: (877) 307-7070
 E-mail: schleyc@ohsu.edu

**We welcome your
 comments and
 submissions.**
Managing Editor:
 Pat Langston
 503-494-2765
langstop@ohsu.edu
**Deadline for submissions for the
 Spring edition is March 15, 2006**

OHSU includes the Schools of Dentistry, Medicine and Nursing; Biomedical Information Communication Center; Center for Research on Occupational and Environmental Toxicology; Vollum Institute for Advanced Biomedical Research; University Hospital; University Clinics (medical and dental); Doernbecher Children's Hospital; and Child Development and Rehabilitation Center.

OHSU is an equal opportunity, affirmative action institution.

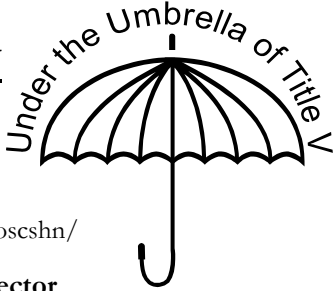
Oregon Center for CYSHN
Contact Information







Toll Free: 1-877-307-7070
 FAX: 503-494-2755

Web: www.ohsu.edu/outreach/cdrc/oscshn/

Dr. James Ledbetter, M.D., Director
 503-494-6961 ledbettj@ohsu.edu

Diane Smith, Community-Based Services Manager
 503-494-3210 smithdi@ohsu.edu



	Community Connections Network 503-494-4586
	CaCoon Care Coordination Program 503-494-4219
	FISHs: Framework for Integrating Special Health Services 503-494-7928
	FSP: Family Support Program 503-494-8303
	FIN - Family Involvement Network 503-418-1476
	SOCS: Strengthening Oregon Community Services 503-494-7928