



## **Welcome to the first edition of the Title V OSCSHN Newsletter**

For the past several years, most of you have been receiving the CaCoon Flyer and/or the Community Connections Network Communicator, separate newsletters produced by each program. We have combined these two newsletters and are expanding the publication to include information about all the programs and services under the Title V umbrella. These include CaCoon, Community Connections Network, Family Support, Oregon Medical Home and Framework for Integrating Special Health Services (FISHS). In addition the newsletter will feature important information and news on health care, research and resources for children with special health needs.

This joint newsletter also follows our new Title V vision to integrate and strengthen our community-based programs into a system of services that is more accessible and responsive to families and communities. This course for Title V was guided by findings and recommendations from family focus groups and feedback from partners throughout Oregon. It is also reflected in our newly adopted mission statement:

**Children with Special Health Needs' mission** is to improve the health, development and well being of children and youth with special health needs. We:

- partner with families, communities, providers, and agencies.
- provide leadership in policy development, advocacy and in assessing levels of care and services,
- support efforts to coordinate and maximize resources.
- work with communities to strengthen their capacity to meet the needs of children and their families, and
- honor the strengths and diversity of families.

We hope you enjoy this publication and find the content helpful in your practice. Please let us know how we might improve future editions.

*Catherine Renken, Assistant Director*

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## Providers and Parents Collaborate

The involvement of families in OSCSHN program activities is important and highly valued by Title V Programs. Parents are supported to participate in planning, development and evaluation of services, and to become leaders in promoting comprehensive, quality health care for children and youth with special health needs (CYSHN).

Two grant-funded Title V programs, Oregon Medical Home Project and FISHS, are working with community providers and families to increase integration and access to services for CYSHN. In addition, the Title V Family Involvement Network at CDRC has recently hired two family consultants who will also be working with families across the state and with Title V Programs. (See page 3.)

Participation of parents and input from them about their needs, concerns, and challenges is essential to our programs and to community providers as we work to improve and integrate services. FISHS and Oregon Medical Home have held forums and developed family resource groups and parent/provider Resource Teams in communities across the state which have provided vital information and insight.



### The Oregon Medical Home Project

A medical home is an approach to primary health care that develops partnerships with families and community providers in order to provide the comprehensive services required by CYSHN and their families. The Oregon Medical Home Project has developed model partnerships with primary health care practices in six communities, including Salem, Albany, Ontario, Medford, Bend, and SW Portland. Each practice has a resource team, consisting of a physician, a community health nurse, office staff and parents, who collaborate to improve care. As core members of these teams, parents help guide the improvement efforts, provide feedback, develop parent-to-parent sharing, and assist families of CYSHN to identify resources in their communities and on the state and national level. The resource teams are supported by the Oregon Medical Home website: [www.oregonmedicalhome.org](http://www.oregonmedicalhome.org).

Oregon Medical Home Project hopes to extend the statewide network of parent and professional resource teams state-wide, and also ensure ongoing fiscal and agency support for the parent-professional Resource Teams.

For more information about Oregon Medical Home, contact Pat Tangeman, Coordinator, at 503-494-3232 or via E-mail : [tangeman@ohsu.edu](mailto:tangeman@ohsu.edu).

### FISHS: Framework for Integrating Special Health Services



FISHS integrates family participation at every level of activity in its efforts to increase integration and access to services at the state, community and program levels. Initially, focus groups were conducted in nine Oregon communities to gather information from parents regarding their concerns related to finding services, the challenges they face in caring for their children, and different experiences of parents in urban vs. rural areas. Each group was comprised of parents of CYSHN who had direct experience seeking, scheduling and getting services for their children within the past year.

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*“If someone would just sit down and say, ‘what do you need’ instead of saying ‘Well, we think, we talked about this and we think you did.....’”*

Parent, FISHS Focus Group 2003

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Five themes emerged from the discussions:

- 1) Respectful and shared communication;
- 2) Coordinated and comprehensive health care;
- 3) Flexible and adequate health insurance;
- 4) Family centered accessible services; and
- 5) Supports for families.

These themes guided the organization of a statewide consortium held in October 2003 in which parents joined with service providers, advocacy groups and representatives from state agencies to listen to family stories, identify

*(Continued on page 3)*

current efforts that incorporate family partnerships and develop a list of ideas that will develop integrated and accessible systems that involve parents in decision making.

FISHS is currently working in Coos and Curry counties where parent forums have met separately and with physicians to identify and implement changes in their community. Similar efforts will commence in Hood River, LaGrande, Lincoln City, and Medford in the second and third years of the project.

For information on FISHS, contact: Holly Bridenbaugh at 503-494-1664, or via E-mail at [bridenbh@ohsu.edu](mailto:bridenbh@ohsu.edu).

## CDRC Parent Consultants

The Title V OSCSHN Program is expanding its family involvement efforts. Our Family Involvement Network has hired two parents of children with special needs to work with families across the state whose children have chronic health conditions or disabilities. Consultants Evelyn Lowry and Theresa Rea will collaborate to develop a network of families who will assist our programs and inform us about issues that concern families. They will also develop educational opportunities and informational materials for families on health care, community services, and systems of care. This is an exciting opportunity for us and we are very happy to welcome Evelyn and Theresa.

We are interested in connecting with individual families as well as family-driven groups. In addition, we will be seeking participation from families for input on decisions and programs and policies. To obtain more information and/or to participate, contact one of the following:

<u>Name</u>	<u>Phone</u>	<u>E-mail</u>
Evelyn Lowry	503-494-7657	<a href="mailto:lowrye@ohsu.edu">lowrye@ohsu.edu</a>
Theresa Rea	503-494-7657	<a href="mailto:reat@ohsu.edu">reat@ohsu.edu</a>

*Family Involvement Coordinator:*  
 Becky Adelman 503-494-7657 [adelmann@ohsu.edu](mailto:adelmann@ohsu.edu)

### Theresa Rea, Family Consultant

Theresa is the parent of 3 children ages 5 to 12. She has extensive interest and background in systems of care for children and wrap around services. She is currently working on an advanced degree at Portland State University and is working on building community partnerships.

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## Parent comments: FISHS Focus Group 2003

*"My biggest problem is communication and we have endless numbers of doctors involved. I seem to have a communication link that involves eight different doctors and sometimes have to go through eight people... Then we get flown to Portland to do something and... They don't ever tell the people down here what they did, when they did it and why... you end up chasing your tail for days or weeks sometimes."*

*"I moved here a few years ago and found that neither the doctors or the school district could provide me with information as to where I could go for services. Luckily, I met a woman who had a child with a disability and she told me about... If I hadn't found that link, I think I would have been floating around out there for a long time."*

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*Evelyn Lowry and Theresa Rea*

### Evelyn Lowry, Family Consultant

Evelyn has a 21 year old son, Jeff, with moderate mental retardation and an 18 year old daughter, Sarah, who is a freshman at the University of Denver. She has spent many years as an advocate for both her children. Due to the nature of Jeff's disability, most of her advocacy time is spent working on committees such as the Washington County DD Council, Washington County Accessibility Council, Parent to Parent, Oregon PTI parent partner, Hillsboro Special Education Advisory Committee and site councils in the Hillsboro School district representing students with special needs. She has also founded parent support groups, worked on the family-professional leadership training project, the Blueprint Project and participated in various trainings such as Partners in Policymaking. She is looking forward to representing and working with families and the Title V teams.



## FUNDING FOR SPECIAL NEEDS



Children with special needs often require unique equipment, supplies and activities that are crucial to their health and/or enhance their quality of life. Often, these essentials are not covered by insurance and may be impossible to acquire, or may critically impact the family's financial well-being. Funding special needs items is a challenge, but there are sources that can help.

The OSCSHN Office administers the following special funds: Family Support Program, Zetosch Funds, CDRC Gift Fund, and Street Rods Fund. Criteria and eligibility requirements for each are outlined below. For more information, or to apply for these funds, contact Patty Day: 503-494-8704 1-800-452-3563, x 8704, [dayp@ohsu.edu](mailto:dayp@ohsu.edu)

OSCSHN Resource Specialist Pat Langston, is developing a manual of resources and is interested in identifying funding sources through other programs or in the community. To request assistance in identifying resources, or to provide resource information, contact Pat: 503-494-2765 1-800-452-3563, x. 2765, [langstop@ohsu.edu](mailto:langstop@ohsu.edu).

### Funding Administered Through Title V

#### **OSCSHN Family Support Program (FSP) \$500 /child per year**

##### **General Eligibility**

- Children birth to 21 years of age
- Families must live in Oregon or pay Oregon income tax
- Children and families who are not United States citizens must be lawfully admitted to the United States on a visa or permit in order to qualify (parents status will qualify the child).
- Children must be enrolled in a TITLE V Program (CDRC specialty clinics, CaCoon, Community Connections Network (CCN), or Oregon Medical Home Project.)

##### **Medical Eligibility**

FSP is for children who have long-term developmental, physical or medical conditions. (Cognitive, emotional or behavioral problems alone would not qualify.) All three of the following elements must exist for a child to be eligible:

1. The special health need is complex enough to: a) Restrict growth and development, or, b) restrict the ability to engage in usual activities, or, c) create a functional limitation.
2. The condition requires specialty medical care or more medical services than a typically developing child of the same age
3. The condition has lasted, or is likely to persist, at least 12 months to lifelong.

## Financial Eligibility for FSP

- Annual cap of \$500.00 per child, per year.
- Family financial need will be determined by the individual who is facilitating the request for FSP funds on behalf of the family
- FSP dollars are the payment of last resort.
- Due to limited funding, priority should be given to those families who have a true demonstrated need.

### Examples of FSP Covered Services

**Adaptive equipment:** wheelchairs, van lifts, helmets, walkers, standers

**Assistive technology educational devices:** communication boards, computers

**Disposable medical supplies:** diapers, catheters, gloves, lancets

**Medical Equipment:** nebulizers, ear molds; **Oral appliances:** latham devices

**Therapeutic Bowel Supplies:** enemas

**Short term therapeutic activities:** equestrian therapy, swimming

**Equipment Rental:** wheelchairs, hospital beds, breast pumps

**Formula/specialized nutrition:** formula, vitamins for metabolic, medical foods

**Specialized nutrition & feeding supplies:** bottles, nipples, blood testing appliance

**Interpreter services:** for private doctor appointments, meetings, peer groups, etc.

**Reimbursable expenses: Lodging and Transportation** (30+miles one way) for medical appointments, meetings, conferences **Orthotics:** braces, UFOs, casting, prothesis

**CRISIS FUND:** One time option for medication or other emergency need.

## Non-Title V Funds Administered by OSCSHN

### Zetosch Funds Limited to \$1000 - \$1500/year for all Zetosch funds

- A private endowment established to enable children to attend school, to enhance educational opportunities or enable the child to participate in activities related to their educational program or IEP.
- Children must be Oregon residents, enrolled in a school program, and registered at CDRC.
- Funds must be used for equipment related to educational needs, such as computers, communication technology, software, wheelchairs, and van lifts, or for services such as driving evaluations.

### CDRC Gift Fund \$400/ child per year

- For children (birth to 21) served by CDRC.
- See FSP list above for services

### Street Rods Fund \$1000/ child per year

- Private fund for residents of Southern Oregon Counties (Klamath, Jackson, Josephine, Curry, Coos and Douglas).
- Funds can be used to purchase services, equipment, supplies, transportation and lodging.

Apply through the Eugene CDRC Clinic: Marianne Taylor 541-346-0455, 1-800-637-0700

# Resources



## Oregon Ability!

Finally, a central site for resources.....

[www.oregonability.org](http://www.oregonability.org)

Oregon Ability is a new information and referral website designed to help individuals with disabilities and their families find resources relevant to their lives and their needs. Included are organizations offering a wide range of programs, products and services of interest to people with disabilities and their families throughout the state of Oregon.

The process is very simple for users to complete, and the information is verified with each organization prior to posting. Individuals and organizations can add and update their own information on the site and are periodically reminded to do so.

The first public version of the site is now available with more than 500 sites verified. It is Oregon Ability's hope that the community of families, providers, and advocates will contribute their vast knowledge about available local resources to this central repository and this will become an invaluable information resource.

**For information, contact:** Sharon Lewis, Project Director, [sharon@oregonability.org](mailto:sharon@oregonability.org) 503.756.1214

### **OHSU Patient & Visitor Guide**

**Need lodging or directions for visits to OHSU?**

[http://www.ohsuhealth.com/patient\\_guide/index.asp](http://www.ohsuhealth.com/patient_guide/index.asp)

## UCP Classifieds Advertise Used Equipment

<http://www.ucpaorwa.org>.

The Oregon & SW Washington UCP website has a classified section where notices are posted to buy, sell, trade or donate equipment, supplies and other goods. Go to the website and choose *Classifieds* from the menu.

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*Do you know parents who want information about their child's special needs?*

*Do you need materials in other languages?*

### The Jean Baton Swindells Resource Center for Children and Families

[Swindells@providence.org](mailto:Swindells@providence.org)  
1-800-833-8899 ext. 52429, 503-215-2429

The Resource Center responds to inquiries statewide by phone or e-mail. It:

- Provides information on a variety of disability-related subjects and supportive services.
  - Works with a variety of special needs groups throughout the state to develop resources and enhance activities.
  - Conducts computer searches for hard to find materials, including information in other languages.
  - Lends books, videos and other materials statewide from the E.L. Wiegand Foundation Library
  - Has a Family Advisory Board of 12 families and professionals.
  - Is developing a parent-designed Care Notebook.
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# Resources



## Supporting Family Participation

Visit the Family Voices Website: <http://www.familyvoices.org>

Family Voices is a link between families in every state and policymakers in state capitols and Washington, D.C. Family voices provides access to up-to-date, accurate information about health policies and issues. It also offers resources and guides to encourage the active participation of families within Title V Programs through the *Title V Toolbox for Family Participation*:

- ◆ *Making it Work*: A manual for recruiting, hiring and retaining family representatives.
- ◆ *Family Handbook*: A handbook for families to become familiar with programs and services.
- ◆ Link to *National Center for Cultural Competence*: A Title V sponsored site for information on making your CSHCN or MCH program more culturally integrated.
- ◆ Many other valuable resources



### **CDRC Family Collection Available Through Doernbecher Family Resource Center**

The CDRC collection of resources about special needs has been moved to the OHSU Library and is now available through the Doernbecher Family Resource Center (FRC) and through the Oregon Public Library interlibrary loan process. Parents can check out books on site at the FRC when their child is a patient at Doernbecher, or order them through their local library anywhere in the state. Materials are included in the OHSU library catalog on the web: [www.ohsu.edu/library](http://www.ohsu.edu/library).

For information, call Chris Leland, FRC Coordinator, 503-418-5390, [lelandc@ohsu.edu](mailto:lelandc@ohsu.edu) or Pat Langston, 503-494-2765, 1-800-452-3563, x2765, [langstop@ohsu.edu](mailto:langstop@ohsu.edu)

## **Oregon Youth Leadership Forum**

### **Junior and Senior High Students with Disabilities**

- Attend a week long leadership-training program June, 2004 at Western Oregon University in Monmouth
- Explore personal leadership and employment plans
- Engage in peer support and mentoring
- Obtain information and resources related to assistive technology, community support and civil rights

**Contact Lisa McMahon: 503-232-9154 x125, [mcmahonl@ohsu.edu](mailto:mcmahonl@ohsu.edu)**

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**Would you like to continue to receive this newsletter?**

We would like to be able to send it to you electronically. If you have an E-mail address that we can send it to - please E-mail Claire Tranchese at [tranches@ohsu.edu](mailto:tranches@ohsu.edu).

If you do not want to receive the newsletter please E-mail or call Claire at 503-494-4586.

**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**  
503-494-1664

**FSP - Family Support Program**  
503-494-8704

**CDRC Toll Free: 1-800-452-3563**  
**OSCSHN Office FAX: 503-494-2755**  
Web: <http://cdrc.ohsu.edu/oscs hn>

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