Families of CYSHN: Helpful Resources, Family Perspectives

OR F2F HIC is closely affiliated with the Oregon Center for Children and Youth with Special Health Care Needs (OCCYSHN) at OHSU and funded by a grant from the Maternal and Child Health Bureau.
Objectives

- Introduce providers and care coordinators to a family perspective on peer support
- Inviting conversations that enhance the relationship
- Share reliable resources for families post-diagnosis or on a diagnostic journey
  - condition-specific
  - financial
  - legal/educational
  - specialty
  - leisure and recreational
- Introduce Services and support available from the Oregon F2F HIC

Links will be emailed to participants upon request.
The Problem:

“We are overwhelmed, scared, confused, angry, and in the dark. Who will help us?”
Eventually, things will become clear.

But for now, there are many people who can help you.

Your providers, teachers, social workers, case managers and other professionals can all be sources of support and information.

But there are some other helpers who are free and available all hours of the day: OTHER PARENTS.”
1) Normalizes experiences

**Benefit to PCP:** once a family starts to share and feel comfortable talking, their stress level goes down and ability to learn goes up.

2) Parents get feedback on their experiences. “*That doesn’t seem normal to me...maybe you want to check that out.*”

**Benefit to PCP:** Parent might bring something to your attention that she otherwise would have just accepted as ‘normal.’ (absence seizures, for example)
3) Parents learn about resources you may not have heard of, (camps, reading programs, play groups, sports programs)

**Benefit to PCP:** participating in fun activities is good for everyone. Less isolation = better health.

**Another benefit to PCP:** this parent can keep you informed of good programs in the community

4) Parents learn how to manage the education, insurance, pharmacy, and other systems

**Benefit to PCP:** A parent who knows how to navigate systems can work more easily with your care coordination staff.

5) Parents can benefit from others’ transition experiences. Hearing about others’ successes can help ease worries and fears.

**Benefit to PCP:** families will help you manage their children’s transitions
Some clues that a parent may benefit from peer support

- “Oh, we don’t go out too much, it’s just too hard.”
- “Oh, my child would never let us do that!”
- “Oh, it’s just easier to keep the (food, pets, etc) locked up so my child doesn’t get into them.
- “Have YOU ever seen a child like this?”
- “None of our other family members understand what it’s like for us.”

Listen for comments like these and ask for more information!

Sometimes we are embarrassed or reluctant to tell you everything. We may lack confidence or simply be more reserved. Sometimes, it doesn’t occur to us to tell you more about our family, even though you can help!
Suggested wording for making a parent-to-parent referral

- “Do you know any other parents who are going through what you are going through? Would you like to?”

- “Sometimes my patients find it helpful to talk with other parents whose child has the same condition. I know of a program…”

- “If you ever feel like your family and friends aren’t “getting it” let me know because I can refer you to a program that might be able to help.”
A Few Peer Programs you can refer to – Spanish and English (Partial List)

**Oregon Family to Family Health Information Center**
- Clearinghouse for over 100 groups in Oregon plus many other health resources

**Swindells Child Disability Resource Center**
- Free lending library and current training on many subjects

**FACT**
- All things education and person-centered thinking

**Autism Society of Oregon**
- All things autism-related

**NW Down Syndrome Association**
- All things Down syndrome-related and inclusive education

**United Cerebral Palsy**
- Also serves families whose children have conditions that mimic CP

These groups have paid staff, will serve families regardless of where they live, phone lines are answered reliably, and can readily respond in Spanish and/or Russian.
RESOURCES AND MORE!

INFORMATION YOU CAN USE NOW TO HELP YOUR CHILD WITH SPECIAL NEEDS

Your County Here    Date
FREE for Oregon residents, courtesy of Swindells Center
Community-Based Programs

**CaCoon**
- Specially-trained nurses
- Home visits
- Care coordination assistance
- No income requirement
- Can work with your child’s physician
- In 35 of 36 Oregon counties (not Wallowa)
- Sometimes work with children up to age 21

Call County Health Department, ask to speak with CaCoon Nurse

**Community Connections Network (CCN)**
- Family-centered approach
- Multi-disciplinary team
- No income requirement
- Ideas, resources, and guidance
- Family Liaison follow up
- Located in:
  - Albany
  - Clatsop County
  - Coos Bay
  - Hood River
  - Ontario
  - Salem
  - Seaside
  - The Dalles
  - Tillamook
  - Newport

Call OCCYSHN at 877-307-7070
Community Developmental Disabilities Programs ("DD Services")

- Disability must have origin in the brain
- Occurred prior to the age of 18
- Expected to last indefinitely
- Result in significant impairments in two or more functional areas: (self care, communication, cognitive, mobility, self direction, ability to work and live independently)
- The impairments must not be primarily related to: mental illness, substance abuse, an emotional disorder, Attention Deficit/Hyperactivity Disorder (ADHD), a learning disability or sensory impairment

If your child has been denied services as ineligible, you may appeal.

It is important that these services are obtained before age 18.

NEW OPPORTUNITIES ARE AVAILABLE THROUGH THE K PLAN!
Children’s Intensive In-Home Services
(for Children who Qualify for DD Services only)

**Intensive Behavior Program**

Provides support services for children up to age 18 who demonstrate intense behaviors that are dangerous to themselves or others.

Typically, the entire household must make extreme adaptations to keep everyone safe.

**Eligibility:** Evaluation conducted by CIIS staff and reviewed by the CIIS behavioral team. Family income is not a factor for eligibility.

971-673-2995

If your child does not qualify for the intensive program, he may still be eligible for a behavior consultation through the Oregon Technical Assistance Corporation or a private behavioral consultant.

Ask your Service Coordinator.
<table>
<thead>
<tr>
<th>Program</th>
<th>Description</th>
<th>Eligibility</th>
<th>Contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medically Fragile Program</td>
<td>Support services for children who have very intense medical needs, are technology dependent and require nursing care.</td>
<td>A clinical criterion as conducted by MFCU nursing staff with input from the families and medical community.</td>
<td>971-673-3000</td>
</tr>
<tr>
<td>Medically Involved Program</td>
<td>Support services for children who have a medical condition requiring total assistance with all activities of daily living (ADLs). These children are not technology dependent but due to their size and weight require maximum interventions.</td>
<td>Evaluation conducted by CIIS staff with input from the families and medical community.</td>
<td>971-673-2990</td>
</tr>
</tbody>
</table>
Specialty Clinics at OHSU/CDRC
(partial list)

- Autism
- Genetic Evaluation and Counseling
- Brain Anomalies
- Down Syndrome
- Craniofacial Disorders
- Hemangioma/Birthmarks
- Feeding and Swallowing
- Gastroenterology
- Cystic Fibrosis
- Metabolic/PKU
- Neurodevelopmental Delays
- Rett syndrome
- Cleft Palate
- Craniofacial Disorders
- Spina Bifida
- Sleep Disorders
- Cardiology
- Hemophilia
- Diabetes
Friendly, supportive parents of children with special health needs will help families navigate appointments, transportation, etc.

Jennifer Horner, March of Dimes Family Navigator in NICU.
Financial RESOURCES (partial list!)

211
A free, information and referral helpline for Oregon. You can get help from a live person with interpreters ready to help in 150 different languages. Housing, food, emergency supports.

800-723-3638 • www.oregonsafenet.org

Oregon HELPS!
Free, confidential, and easy prescreening website to help families determine eligibility for 33 assistance programs. On line only.

www.oregonhelps.org

ZETOSCH FUNDS
Sidney and Lillian Zetosch Fund
Grants for the purchase of adaptive equipment to help Oregon’s low-income children 0 – 21 with special health needs. Equipment must help child achieve educational goals. Families must be referred by a service provider or teacher.

503-494-8618 • www.ohsu.edu/xd/outreach/occyshn
Financial RESOURCES

Help Paying for Prescriptions
Huge database of drug companies’ discount programs, scholarships, coupons, etc.
www.NeedyMeds.org

Developmental Disabilities Consumer Involvement Fund
Funds for families of children with developmental disabilities to attend conferences and trainings related to their child’s condition.
www.ocdd.org/index.php/ocdd/getinvolved/24/

Supplemental Security Income
Generally awarded to children with significant disabilities whose parents meet the income threshold. Consult the Compassionate Allowance List conditions that qualify for fast approval. Starter application kit available.
A few more excellent resources...

**Compassionate Allowances**
for Supplemental Security Income

Over 100 Conditions which allow for “fast tracking” to SSI Eligibility

**GEMSS for School Success**

Easy to read guidelines for care for 25+ genetic conditions. Suitable for parents and professionals.

**Helping Families with SSI applications:**

* AAP Publication 2009
* Guidelines from the SSA

**Camps and Recreation List**
Thank you to Shriner’s Transition Program!
Specialty RESOURCES: Statewide

ORPARC (Oregon Post-Adoption Resource Center)
Free support to Oregon DHS Adoptive and Assisted Guardianship families and Oregon Families who have adopted through any state's child welfare system. Counseling, referrals, resources, and more.
800-764-8367 or 503-241-0799 • www.orparc.org

Special Needs Car Seat Consultation and Fitting
Specially trained safety specialists works with families of children with unique physical or behavioral needs that put them or their families at risk while traveling by car. http://cert.safekids.org (search “Find a Tech”)

Health Information by Mail
OHSU reference librarians will mail articles and other information to families who do not have internet access. Simply call and ask to speak to a Health Information by Mail Reference Librarian. 503-494-8881
http://www.ohsu.edu/xd/education/library/research-assistance/health-information-by-mail.cfm?WT_rank=1
Hello Foundation Speech and Occupational Tele-therapy
Some scholarships available
503-228-2942 www.thehellofoundation.com

A Gift of Time Retreat
September retreat for caregivers. Pamper Yourself!
www.agiftoftimeoforegon.org

Early Assessment & Support Alliance
Helping families identify and treat early signs of psychosis in teens. Evidence based.
503-361-2796 www.easacommunity.org
Specialty RESOURCES

Inclusive Child Care Program
May help pay for increased costs of care related to a child’s special care needs. Coordinates child care subsidies for eligible families. Provides individualized planning to families.

971-673-2286 or 1-866-837-0250 • www.oregoninclusivecc.org

Now, if you can’t remember all of this... Call us!
How we do the work...

One-to-one

Website and list-serve

Family Gatherings

Publications: newsletters and tip sheets
One-to-one support from an experienced Family Liaison

1-855-323-6744  English/Spanish
503-931-8930  Spanish

All Family Liaisons have their own confidential OHSU email accounts.
“I just got this notice from my insurance agent. Can you help me before Obamacare kicks in?”

“My pediatrician told us today that my 26 year old is too old to keep coming there and that this would be her last appointment. How do I find a doctor who understands ____syndrome?”

“I’m working with a family whose 9 year old has ____ and they want to get to the ____ conference. Can you tell me what scholarships there are?”

“The medication costs are killing us. Is there any help out there?”

“I’m moving to Oregon in the fall, can you tell me what kind of services my child with a vent can get?”

“My insurance denied a helmet for my child, but my friends’ insurance paid for hers. How do I appeal?”

“My friend has a home visiting nurse. How do I get one?”

“I think my child’s condition is genetic, but my doctor doesn’t want to authorize the test. Where can I get it done?”
Regional Family Gatherings

Becoming Your Child’s Health Advocate
Information you can use NOW to help your child with special needs.

The Oregon Family to Family Health Information Center invites you to join us for this regional family gathering and listening session.

Roseburg, Oregon: October 2013 (Call for details)*
Newberg, Oregon: September 27, 10:00 am.*

Who: Parents and caregivers of children and youth with special health, developmental, or behavioral needs.

- Learn about Oregon’s health care resources and programs for your child
- Tips and tools for working with your child’s health providers
- Get information about moving from pediatric care to adult care.
- Pick up materials from our travelling “mini resource fair”
- Enjoy light refreshments and meet other families of children with special needs

PLUS: After the presentation, from 10:30, up to 10 families may participate in a special “listening session” and receive a $20 stipend. (You must RSVP to be eligible to receive stipend!)

*Call for details: 1-855-323-6744

Childcare will not be available for this event, but babies in arms are welcome!

Resources and More!
Information you can use NOW to help your child with special needs

The Oregon Family to Family Health Information Center invites you to join us for this regional family gathering and listening session.

Wednesday, May 21, 2014
6 – 7:30 pm
Baker County Public Library
2400 Resort St, Baker City, OR

Who: Parents, grandparents, foster parents and guardians of children and youth with special health, developmental, or behavioral needs.

What:
- Learn about dozens of resources and programs to help your child and family
- Pick up materials from our traveling “mini resource fair”
- Meet your Oregon Family to Family Health Info Center Regional Family Liaison
- Meet other families of children with special needs
- Enjoy light supper and maybe win a door prize!

SPECIAL INVITATION FOR PARENTS OF CHILDREN WITH CEREBRAL PALSY!
If you have a child with cerebral palsy, or a disability that mimics CP, you are welcome to have someone join us with Susan Gutisher, the Family Support Director with United Cerebral Palsy. Contact Susan directly if you would like to set up a time to talk 503-447-0381 or sgutisher@ucpww.org

PLUS: We want to hear about your experiences raising a child with special health needs. So, after the presentation, up to 10 families may participate in a special “listening session” and receive a $20 stipend (You must RSVP to be eligible to receive stipend).

For more information and to RSVP: 855-323-6744 or 503-494-0666.
Leave a message indicating you wish to attend the ‘Baker City Event.’ We will call you back to confirm. Childcare will not be available, but babies in arms are welcome!
Also may include “listening session” of 10 families each, capturing families’ impressions on the Oregon Health Care delivery system and their personal experiences.
Welcome

Oregon Family to Family Health Information Center provides information to families who are navigating the complex world of special health care needs. We are family members ourselves, who have first-hand experience raising a child or youth with a chronic health condition, developmental delay or disability, or emotional/behavioral challenges.

Services Include:
- Toll-free phone line (English and Spanish)
- Comprehensive website with information and links to key special needs services
- Newsletters and tip sheets full of practical information written by families for families
- Regional Family Gatherings and trainings in communities all around the state.

There are 61 Family-to-Family Health Information Centers (FFHCs) in the United States and territories. Each is unique, reflecting the needs and experiences of the families it serves.

Family Liaisons in Your Community

Contact a Family Liaison in your area for support, information, and help with your particular situation.

- North Coast: Danielle Caplinger
- Mid Coast: Siena Miller
- Southern Coast: Trace Glickner
- Willamette Valley: Tami Monleviay
- Portland Metro: Shauna Singleton
- Hood River: Monica Marquez
- The Dalles: Aaron Bowman
- Klamath Falls: Valerie Smith
- Umatilla/Morrow: Sharyn Smith
- Russian (speaking in all Oregon): Galina Burley
- Spanish (speaking in all Oregon): Teresa Gomez, call 503-931-85
- For all other areas, call 1-866-323-8744
Newsletters in English/Spanish
Mostly medical and community systems
Postal or Email
Tip Sheets:
- no jargon
- written by family members
- vetted for accuracy

- When Insurance Doesn’t Pay
- DME
- Getting You to the Conference
- Partnering with your Provider
- Get to Know your ENCC
- What are DD services
- Intro to PCPCH
- Navigating your Health Plan
- Moving to Oregon?
Words of wisdom from families
Listening Sessions revealed what families appreciate:

- “(Our doctor) talks to my grandson first, and asks him how he is doing, but then turns to me and says “And how is Grandma doing?” Not once, but every time we go in.”
  Metro

- “They have a care coordinator in the office that takes the time to go over everything with me.”
  Metro

- “They respect us, even when we disagree.”
  South Beach
Questions? Comments?
Thank you!

Contact information:
Tamara Bakewell, Project Coordinator
bakewell@ohsu.edu
503-494-0865
www.oregonfamilytofamily.org