



Making Connections

VOLUME 6, ISSUE 1

SPRING, 2007

CENTER ON DISABILITIES AND HUMAN DEVELOPMENT—EDK 293

Idaho Family

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Idaho Family Support 360 News!

We now have two Family Resource Centers! Our newest center based in Idaho Falls will serve the amazingly large Region 7. Not sure what counties are part of Region 7? Look below for a list of what counties are now served by Idaho Family Support 360!

Region Two Family Resource Center

Lynn McCollough has joined our team and we are thrilled to welcome her! She has helped many families get the support they need just in her first few months!

Some of the different types of support include a mattress needed after a family member acquired a traumatic brain injury, eye glasses, help to attend a conference, gas vouchers and respite care just to name a few. In addition, the team has helped community providers with researching support needs and funding resources.

Lynn continues to recruit interested family members for the Family Action Board (FAB). The goal of this group is to help our Region 2

Family Resource Center develop resource priorities, to provide a way that parents can get support from other parents, and to help policy makers understand what families experience in Region 2. If you are interested in joining FAB, call Lynn at (208)885-3743 or (800) 393-7290.

Region Seven Family Resource Center

Shelly Nelson is our newest team member and we are lucky to have her! She has been a part of several community development projects in and around Idaho Falls including the Children with Disabilities Foundation and the Equal Access Playground project.

The Family Resource Center will be housed with the Health and Welfare Programs at the State Building on Shoup Avenue in Idaho Falls. Shelly will be visiting many communities around the region to let families know about our project and how they can access information, and resource details as well as how they can apply for support dollars.

The Region 7 Family Resource Center is staffed part-time, and Shelly will be out in the community quite a bit. Don't hesitate to leave her a message! For more information, contact Shelly at (208) 528-5905 or contact our team at (800)393-7290.

Status Report!

We wanted to say a special thank you to the following groups without whom we would not be where we are today!

- ◆ The Idaho Family Support Policy Council.
- ◆ The Idaho Health and Welfare team at the Central Office and the regional teams in 1, 3 and 5.
- ◆ The incredible team of families and professionals in Region 7!
- ◆ The Family Action Board in Region 2.
- ◆ The Idaho Council on Developmental Disabilities and Cooperative Advocacy, Inc.

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Region 2

Counties: Latah, Clearwater, Idaho, Lewis & Nez Perce

County Seats: Moscow, Orofino, Grangeville, NezPerce & Lewiston

Region 7

Counties: Bonneville, Butte, Clark, Custer, Fremont, Jefferson, Lemhi, Madison & Teton

County Seats: Idaho Falls, Arco, Dubois, Challis, St. Anthony, Rigby, Salmon, Rexburg, & Driggs

Other resources you can call to see if there is a parent support group in your area!

Family Resource Center in Region 2

Serving the areas around Moscow, Lewiston & Grangeville.
Call Lynn at:
1 (208)885-3743

Family Resource Center in Region 7

Serving the areas around Idaho Falls, Rexburg & Salmon.
Call Shelly at:
1 (208) 528-5905

Idaho Parents Unlimited, Inc. (IPUL)

1 (800) 242-IPUL (4785)
www.idahoipul.org

Idaho Federation of Families for Children's Mental Health

1 (800) 905-3436
www.idffcmh.org

Epilepsy Foundation of Idaho

1 (208) 334-4340
www.epilepsyidaho.org

Autism Society of America

1 (800) 3AU-TISM
www.autism-society.org

MAKING CONNECTIONS

Family Groups Across Idaho

Many families in Idaho participate with different kinds of support groups. There are disability specific groups on Autism or Epilepsy for example, as well as parent groups organized to provide support across the wide range of ages, disabilities, family types and needs. Sometimes it feels like these types of groups come and go, but what are some of the things that make a group strong? We talked to Lorena Freund from Coeur d'Alene about this because she has been part of the effort in Region 1 to support parents in partnership with the Idaho Department of Health and Welfare with the parent group: Parents Reaching out to Parents (PROP).

Q: Lorena, what does it take to get parents to turn out?

A: Some parents don't get a break or a chance to talk to other non-judgmental adults, so being able to access 2 hours of daycare or respite while we meet is really helpful.

Q: Do you think the daycare really

makes that big of difference?

A: Yes, I've had moms come in and just sit quietly for an hour and tell me this one time per week is all they have to catch their breath.

Q: What kind of schedule is

PROP on to get together?

A: PROP now meets in Coeur d'Alene once a week on Wednesdays from 12:30-2:30. We've added meetings in St. Maries and Kellogg! St. Maries parents meet the 1st and 3rd Mondays at 10:30-12:30 and Kellogg parents meet every Monday from 2-3:30.

Q: What do you do at these meetings?

A: Well, the Coeur d'Alene meeting is a good example to use. I bring sandwich fixings and many of the parents also bring something to contribute. We grab something to eat, introduce ourselves and share what has been happening in their week.

Q: That's it? I thought parent groups were often more formal

than that, lobbying law makers, fund raising and so on.

A: A group can do whatever they want to do. PROP is also a non-profit organization so we have board meetings and fund raising events too. But that doesn't take the place of the scheduled weekly or every other week meetings when we are there for each other. Some weeks we have 8-10 parents, we're not just for moms but dads too! My biggest attendance in Coeur d'Alene was 35.

Q: Wow! That seems like a lot.

A: It was! I try to facilitate the meetings to make sure all parents participate to the level they want to and that we are focused on supporting each other. When we get bigger than 35 or so, it can be hard for parents to connect with each other, but we'll never turn anyone away! If your readers are in Region 1, please join us!

Groups near you!

Twin Falls: 'ASAP' Parent Group meets 1st Wednesday of each month, 6pm. Call Jenny for location (208)308-8480—some child care available.

Coeur d'Alene, Kellogg, & St. Maries: Questions? Call Lorena at (208) 769-1409. See above for

details on meeting times.

Terreton: Eastern Idaho Autism Awareness group. Call Cindy at (208) 339-4827 for more details.

Idaho Falls: Parent to Parent meets every Friday from 12-2 over lunch and child care is available. Call Amy at (208) 542-0875 for more information!

Boise: 'IFAD' is a group for family

of adults with disabilities. They share information via email and at meetings. For details, call Debbie at (208) 229-0555.

If you know of more groups, please call us today so we can share this with other families! Families tell us the most helpful thing to them is information shared by other families!

Keys to Effective Parent Groups

If you are interested in getting a group together in your area, here are some tips we've heard from other groups around the state.

PARTNERSHIPS

In looking for a place to meet, is there a church or child care location (for example, Head Start) that might be interested in helping provide an hour or two of day care? Talk to the team at your local Health and Welfare developmental disability or infant toddler program to see if there might be a way to access some funds to help pay for respite care during meetings. You'll never know what is

possible until you try building partners!

THE 3 B'S

Be consistent: meet on the same day at the same time. This helps families remember and plan.

Be welcoming: parents of children with disabilities at any age often feel judged and on the spot; there needs to be a place where they are accepted.

Be creative: parents across Idaho have found ways to create groups that provide so much to the parents who attend. If you want to get a group together in your area, you can do it!

KEEP IT SIMPLE

If you are focused on providing support to parents, they will help you expand your efforts to match the vision of the group. For example, your group might want to work with policymakers on state or federal funding. Or, they might want to create a resource in your town, like an accessible playground. Maybe, your group will be focused on getting some social events going. All have value!

Call us at (800) 393-7290 or contact the organizations listed to the left if you'd like some ideas about creating a group near you!

Who is Katie Beckett Anyway?

Every time we meet with parent groups, we are asked a wide variety of questions. So, we've decided to add a feature to our newsletter to try to answer some of these questions. If you have a question we can answer for you and other families too, please call us at (800) 393-7290.

We have heard from families that experiences applying for Katie Beckett differ from region to region. Although that shouldn't be the case, it seems to happen. So, to discuss specific circumstances about your family, contact your local Health and Welfare office and ask for the Katie Beckett coordinator. If you feel like your questions still aren't answered, give us a call and we'll be happy to try to help!

In a nutshell, Katie Beckett allows families who don't qualify for State funded medical assistance (what we call Medicaid) because they make too much money, to be considered for help if they have a minor child with a developmental disability. There are a couple of key points to being

eligible: a diagnosis, impact upon at least three life areas (example: mobility, self-care, communication), and the need for significant supports—or an ICFMR level of care. This concept is important to know! ICFMR level of care means that a child would qualify to be in an Intermediate Care Facility for the Mentally Retarded. This is like a group home or institution. This DOES NOT mean that your child must live in a facility or group home, it just means he or she meets that level of need.

Katie Beckett is a program based on an actual person and what her family went through. The federal government designed this program as an option a state can choose to offer. Not all states have this program! Idaho is lucky to have it. If eligible for this program, a child receives a Medicaid card that provides medical, dental, pharmacy, and some other services like Personal Care Services or in-home supports. There are a couple of things you might want to know about this program so you can

ask how it might impact your family.

First, whenever you are part of a state funded program, you are going to be asked about your income and resources. But, in Katie Beckett—it's not the parents' income that is asked about. It is the child's income and resources that are an issue. If your child has a bank account, stocks, bonds—whatever—you will have to share that information as it could affect your child's eligibility. Another tidbit: as your child nears 18, he or she will need to be assessed for what kinds of adult programs (called waivers) they will be eligible for. Katie Beckett is a program for children—it isn't available to adults. Last tip: just because you have a Medicaid card, it doesn't mean you can find a provider. That can be tough, especially in our small towns.

We would love to hear from you and share families' experiences with Katie Beckett! Give us a call: (800) 393-7290



Did you know? Legislative Updates 2007

October in Idaho is now Disability History Month. Congratulations to everyone it took make this happen! The goal of Disability History Month is to encourage both public and private schools to provide instruction on disability history; as well as to increase awareness and understanding about people with disabilities and their right to live the lives they choose.

Last year we told you about an idea to offer a Family Directed Service System, not unlike the Self Determination Waiver Option which is the adult version. The 2007 Legislative session

resulted in a joint effort to develop this type of service option for families who have a minor child with a disability who qualifies for support services (see above as an example). A work group of stakeholders will come together over the next several months to develop this option. We'll keep you posted!

Voting by Mail is something you may or may not have heard about this session. In case it comes back again next year, you should know that although some people think it increases accessibility to vote, the

reality could be almost the opposite. The importance of the secret ballot cannot be underestimated as we saw after the Help America Vote Act (HAVA) efforts. It is one thing to offer absentee voting as an option, it is altogether different to eliminate all other options.

These are only a few of the events at this year's session. For more information, visit our website: www.connectingfamilies.net or contact the Idaho Council on Developmental Disabilities at (800) 544-2433. Thanks to ICDD for their updates this year!

Events & Activities!

Training on Understanding Communication with Young Children:

Saturday June 9th—9 am-4pm in Idaho Falls. For more info call Shelly at our FRC in Region 7 at (208) 528-5905.

Treasure Valley Resource Fair: June 23rd—9 am-12pm at the Adventure Island Playground in Meridian. For more info call (208) 887-3531.

Race Ya to the Playground: Saturday July 14th—8 am at Tautphaus Park,

Idaho's 2nd Equal Access Playground in Idaho Falls. For more info call (208) 542-0875.

Summer Activities in Boise: Register for adapted summer activities with AdVenture. Call (208) 384-4216 ext. 28 and ask for Joel!

Adaptive Activities in Pocatello: CW HOG offers a wide range of programs including rafting, day camps and kids activities. Call (208) 282-3912 for details.

Adaptive Programs in Ketchum: Sun Valley Adaptive Sports has a ton of activities! Call them at (208) 726-9298 or

visit them online at www.svasp.org!

Special Needs Recreation in and around Coeur d'Alene: Did you know about this program in Kootenai County? Angie Goucher can answer your questions at (208) 769-2317.

Rafting/Climbing/Canoeing in Utah: SPLORE is an organization that creates adventures for people with disabilities. Check out this great opportunity. Call (801) 484-4128 for more info or visit them online at www.splore.org.

If you know of more events or summer activities, let us know!



CENTER ON DISABILITIES AND HUMAN DEVELOPMENT

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Center on Disabilities and Human
Development—EDK 293

Family Resource Center
Idaho Family Support 360 Project
Center on Disabilities and Human Development
University of Idaho
129 W. Third
Moscow, ID 83843



What people are talking about:

The Ashley Treatment: By now, many of you have heard of this controversial situation involving a young girl from Seattle and her parents who sought surgical and medical ways they thought would improve Ashley's quality of life—to lessen the discomfort of puberty, pms and the possibility that Ashley's future, adult size would negatively impact her and her care providers. Learn what the family thought and said for yourself! Visit their website instead of assuming you know what happened by only hearing it through the grapevine.

<http://ashleytreatment.spaces.live.com/blog/>

Martin's Answer to the Ashley Treatment: Martin lives in Illinois with his family. They developed 'Martin's Answer to the Ashley Treatment.' No matter what I or my coworkers feel about what was done to Ashley, Martin says it far better than we ever could.

<http://martintreatment.spaces.live.com/>

As the editor of this newsletter, I feel that I must share a conversation I had with a dear friend about Ashley. My friend has a daughter a few years older than Ashley and she loves her no less than Ashley's family loves her. We both agreed that there is something about what Ashley's mother describes that we could understand. But, there is something that appears to be missing from the input the family sought from lawyers and doctors. Did they ask adults with developmental disabilities what they thought about surgically altering Ashley? All school districts have teenagers with developmental disabilities in attendance—did they try to ask what other teenage girls with disabilities think about PMS and having their periods? Why do we think that a name with an MD behind it has such a better grasp on right and wrong? Just because an 'ethics committee' agreed with the course of medical intervention that included hormone therapy, and multiple invasive, irreversible surgeries, does that mean it was right? Sadly, it was determined by lawyers that Ashley's disability was severe enough to deny her the rights typically afforded to patients. We have not come far enough in this country, but this is one reason we continue to pursue needed family supports!

— Jill Smith

How can you get involved
with Family Support 360?

The Idaho Family Support 360 Project is dedicated to strengthening the current family support system in the State of Idaho. The 20+ member Policy Council for the Project consists of community partners, agencies, individuals with a disability, family members who have a child with a disability, and advocacy groups.

For more information about our Project, the Policy Council, or how to become involved with family support resources in Idaho contact:

jills@uidaho.edu
208-659-1643
800-393-7290

www.connectingfamilies.net

