

August 2006

Issue # 47



High School Transition Forum for Parents

Family Support will be sponsoring a series of trainings for parents who have a child in high school who has a disability. The purpose of the trainings is to give information and allow for questions in these important areas:

Adult Services

Guardianship

Life Planning for the Future

Legislative Actions that Impact Us

Special Needs Trusts



Inside this issue:

Trainings/Workshops	2
Partners in Health	3
Dispute Resolution	4
Special Needs Trusts	5
Another Training	6
FS Picnic Pix	7
August Raffle	8

We are in the process of securing speakers but we are hoping to be able to address all the above areas. The last High School Transition Forum was held in 2004 and was well attended and feedback was most positive. If you are unable to attend this series, the next forum series will be in Fall 2008. A targeted mailing with further details and a sign up sheet will be sent to all families on our mailing list with children ages 15 to 21. Other families are invited but should contact me to obtain the details: call Hugh at 749-4015 or email hphilbrick@communitypartnersnh.org

Save these dates: Sept 20, Sept. 27, Oct 4, and Oct. 11. Times will be 6:30 to 8:00 P.M. As in the past, you may sign up only for the workshops that interest you.

UNH Work Study Students

It's time for UNH students to be returning to classes! Once again, I'll be hiring students as recreation facilitators to help with the inclusion of your child into an activity of your choice. Please start planning now as to what he/she might enjoy doing on a consistent basis so that I can present a variety of opportunities to those students who really want to work with our kids with some special needs. I need to hear from you as soon as possible to make this work for all of us. Need some ideas? How about water aerobics, an art class, or Girl or Boy Scout meetings? What about band practice or any other after school activity? Call Betsy at 749-4015.



Parent Training Offered

The Autism Spectrum Support Group continues to meet as a group on the 1st Wednesday of the month in Rochester at 6:30 PM. On **October 4**, there will be a **Social Skills Workshop** entitled *Helping Children Navigate the Social World: Tools and Strategies for Parents and Others*. It will be conducted by Cathy Apfel, M.Ed., from the Institute on Disability. Specific areas of expertise include Positive Behavior Interventions and Supports, Autism Spectrum Disorders, and strategies for supporting children with emotional and behavioral challenges. Call Betsy for further information at 749-4015.

Volunteer Educational Advocate Program to be Held in Seacoast Area

Beginning in mid-October, PIC will be offering their 10 week Volunteer Advocate training from 4:30 to 8:30 PM on Wednesday evenings. Location and exact date to be announced. This is a great opportunity for parents to learn everything you ever wanted to know about Special Education and the law!

For Dads Only....

Fathers of children up through the age of 5 are meeting to learn more about Early Supports & Services and how to get more involved in the care of their child who has some delays. The Executive Director of Community Partners, Brian Collins, will be there along with staff from the Early Supports and Services Program. Save the date! It will be a good time to meet other fathers and enjoy some pizza and soda. The meeting will be on **Thursday, September 21, 2006** from 6:00-7:30 PM at Community Partners Rochester Community Office 25 Old Dover Road, Rochester, NH.

Sibling Support Group Meetings will continue!

Wentworth Douglass Hospital is supporting this opportunity for sibs, ages 8-12 and Colleen will be the facilitator again! She will be emailing those who have attended in the past. Save these Saturdays from 9:30 to 11:30: **September 9, October 28, November 18, and December 16**. Call Betsy at 749-4015 if you're interested or want additional information.

The Red Book: Social Security's Guide to Employment for SSDI and SSI Recipients

One of the Social Security Administration's (SSA) highest priorities is to help individuals with disabilities achieve independence by helping them to take advantage of employment opportunities. This book is a general reference source about the employment-related provisions of Social Security Disability Insurance (SSDI) and the Supplemental Security Income (SSI) programs. Its purpose is to provide a working knowledge of the technical provisions involved so that they can advise individuals with disabilities appropriately and recognize when to seek case-specific guidance from SSA. It is available by calling Social Security or online at:

<http://www.socialsecurity.gov/disabilityresearch/redbook.htm>

Welcome to our new Partners in Health Coordinator!

My name is Judy Saddler and I began working as the Family Support Coordinator for the Partners in Health Program on July 10th. In many ways I feel like I'm "home" again. I spent 10 years working in the Family Support Program at Community Developmental Services in Region 8 (Rockingham County) as a resource coordinator. In 2003 I took another position in health care but found I really missed working with families so I was thrilled to be offered this opportunity.

Last week I mailed all of the PIH families a letter of introduction; I will be calling each of you over the next few weeks to touch base, schedule a home visit if you'd like one and discuss ways we can collaborate to help you meet the challenges of your child's chronic health condition.

My office hours are 8:30 to 4:30. You can reach me at 749-4015 #209. If I'm not available, please leave me a message and a good time to reach you.

I'd also like to encourage all of you to consider joining other PIH parents at council meetings which will begin again in the fall. Your ideas and concerns are important. You do not have to make a long term commitment (although you are certainly welcome to); you can come sporadically as your schedule allows.

I look forward to working with you and your family.



Your ideas and concerns are important. I look forward to working with you and your family.

Judy Saddler

Recruitment Info for Partners in Health Council

- Partners in Health is an organization that helps families who have a child with a chronic illness.
- We help families through education and empowerment.
- The Family Council decides what activities to pursue (i.e.: workshops, community outreach, etc.)
- Any family or community member is welcome to our monthly meetings.
- Council officers are asked to make a one year commitment.
- To be a voting member you must attend at least 5 meetings per year.
- Only one person per family may be a voting member.
- All activities are ideas that come from the Council.

News From Partners In Health Family Council

In September the joint councils will be having a breakfast meeting to kick off the new year. We will be talking about being a member of the Council and what responsibilities we have as members. The program is parent-driven and it is very important that parents attend the monthly meetings.

The HOOD Center is also planning to have a state-wide council. These meetings would only be four times a year and will help to shape the direction of PIH. The program needs family participation to provide direction, so I hope to see you there!

Thank you, Tammy Munroe, Chairperson PIH Council





Dispute Resolution: Solving Problems Positively Benefits your Child

When your child has some special needs, extra services and endless appointments with professionals, building partnerships is so important. When parents and schools or others disagree, points can be made without weakening the relationship. Here are a few tips from PACER to help resolve disputes:

- Disagree without being disagreeable. Express that you don't want the disagreement to interfere with your continued partnership.
- Apologize whenever appropriate.
- Make a positive move to start a process of restoring the relationship.
- Accept responsibility for your own part of the problem or issue and solution.
- Realize that neither parents nor professionals have all the answers.
- Pick the battles. Not everything is worth the effort of disagreement and resolution.
- Consider the risks of facing an issue or avoiding it.
- Assume good faith on the part of those with whom you disagree. Try to understand their perspective.
- Make sure that your statements are accurate.
- Base discussion on facts and data rather than opinions or emotions.
- Try to resolve the disagreement as quickly as possible. Don't wait to see if it will go away by itself.
- Separate the problem from the person.
- Begin where the problem started. Do not go up the chain of command unless necessary. Discuss the problem with the person directly involved.
- Be sure the solutions reached are written into the IEP if you are dealing with the school. Ask who will do it and when. Get a copy.
- Use compromise or a trial period as a key to resolution, such as "Let's try this until (a certain date) and see how it goes."
- Monitor what you say in front of your child. This means that parents and school staff/professionals should discuss troublesome issues among themselves as adults. If an older child participates in the IEP meeting or doctor visit, be an example of how to communicate effectively.

Can You Use these Items?

Community Partners has received some donations that we can either loan to you for a period of time or we can give to you. There is a small Rifton Gait Trainer that's good for someone up to 75 pounds.

We also have a Leckey Prone Stander for a young person and a Snug Seat Tiger Push Chair with a foldable frame that is good for up to about the age of 5. We also have a very small walker.

Contact Family Support at 749-4015 if you are interested in any of these.

NH Debates Rules Changes for Special Needs Trusts

by Linda Steir

For as many years as I've followed this issue, it is still very complicated for me to describe. Let me, in my lay person terms and as a parent who has set up a Special Needs Trust for our disabled daughter, try to capture the issue before reporting on today's events at NH Supreme Court.

Some history: In 1972 the Federal Government was overhauling some social service programs. Upon introducing new Medicaid guidelines, some states felt the new federal requirements for what should be provided to folks on Medicaid exceeded what they were currently providing and threatened to not participate. To get all states on board, the feds said, "for those states who have an approved Medicaid State Plan in place that offers less than the new federal Medicaid guidelines, those states will be grandfathered in, allowing their already approved more restrictive practices to stay in place." Those states who already had a more restrictive policy in place were grandfathered in and were called "209(B)" states. As I understand it, at that time (1/1/74) the federal guidelines for special needs trusts were clear that:

- If the trust dispenses money directly to the beneficiary, the disbursement is considered income to the beneficiary
- If the trust dispenses money to a vendor for food or shelter for the beneficiary, it is income to the beneficiary
- If the trust dispenses money to a third party for anything other than food or shelter, it is not income to the beneficiary

So, for more than 30 years NH treated Special Needs Trusts the same as the above federal guidelines. Recently, however, workers at Health & Human Services (HHS), upon reviewing the redetermination applications for adults on Medicaid, began looking at disbursements from Special Needs Trusts in a different light. Workers at HHS began to count as income to the individual, things such as disbursements from trusts for haircuts and special needs summer camps and accessible vans for transportation as "income". Once they considered these disbursements as income, in any given month if the trust paid a third party (hairdresser, modified transportation provider, summer camp) for amounts in excess of allowable Medicaid resource limits, the individual would be found ineligible for Medicaid.

Let me simplify this by using my daughter, Marika, as an example. If the allowable income limit for a person with severe disabilities to qualify for Medicaid as their only source of medical health coverage in any given month exceeds \$2,500, that person would be ineligible for Medicaid in that month. So, let's say my daughter, Marika, is in her 30's. We've passed away. We set up a trust to be funded upon our deaths to pay for things the state would not necessarily cover: monthly haircuts, airplane tickets to attend her brother's wedding in California, plowing of the driveway for the home we left her upon our death, etc. In the past, the state allowed the trusts to make those payments directly to the vendor (i.e., the hairdresser had to be paid out of the trust, not through a cash transaction with Marika). Now the rules seemed to have changed. Now, they (the state) would consider all those disbursements income to Marika. So, if in any given month the trust purchased air tickets for

**Are Special
Needs Trusts
endangered in
New Hampshire?**



(Continued on page 6)



Help us Keep in Touch

Changes happen! Please let us know when you move, change your telephone number or your name. The best way would be to send a change of address form from the Post Office and include your new phone number. If you remarry, or for any other reason have a change of name or your child has a change of name, please let us know. Send the information to the attention of Gerry Riecks, the "keeper of the facts," or email her at griecks@communitypartnersnh.org. Thanks.

Watch for Two Upcoming Trainings from PIC in Strafford County

New Comprehensive Seminar: Around the Special Education World in 1 Day: The Parent Information Center's one-day program will provide parents and others with the tools necessary to understand and participate in the special education process. It includes 4 components: Steps in the NH Special Education Process, Disability Awareness Activities, The IEP Clinic, and Effective Communication.

Understanding LD: This workshop presents an overview of learning disabilities, as well as other various disabilities including Asperger's Syndrome, Nonverbal Learning Disability, Central Auditory Processing, and Executive Functioning Impairment. Educational implications and some strategies that can be used to help out will be shared.

Save the Date!
The Family Support Hayride will be on Saturday, October 21st.

(Continued from page 5)

her to go to her brother's wedding in California, and paid for the driveway to be plowed 3 times, and paid for 2 haircuts, and those expenditures from the trust exceeded \$2,500, in that month, she would be ineligible for Medicaid for that month. That would mean, in that month of ineligibility, that if she was hospitalized for treatment of cancer or any other medical emergency, Medicaid would not cover the cost of health services. Further, if she was receiving support from the state for an area agency program, such as a day program or residential services, Medicaid would not reimburse the area agency for services in that month and the trust would have to cover the cost. If, during the month Marika was found ineligible for Medicaid because her trust expended for an airline ticket, etc. and she happened to need to order a new wheelchair, Medicaid would not cover the cost of the wheelchair.

So, the question brought before Supreme Court on 7/21/06 was: Was NH a 209(B) state? Did NH have in place, at 1/1/74, a state Medicaid plan, approved by the feds, that allowed NH to be more restrictive than the feds in the treatment of Special Needs Trusts? Are Special Needs Trusts an endangered species in NH? Stay tuned for the Court's decision. Listen/watch to the half hour long arguments before the NH Supreme Court at this website:

www.courts.nh.gov/cstream/index.asp Look for the Emily Huff appeal.

White Lake Picnic—Fun in the Sun?

We had fun at White Lake State Park last Sunday even though there wasn't a lot of sun. Hard working Family Advisory Council member, Karen Salter and her daughter, Alicia, came up early Sunday morning with Betsy to help set up. We claimed a few picnic tables and grills for families to use as they arrived and provided watermelon, cookies, chips, soda and juice. We rented 9 paddle boats, 2 double kayaks, a canoe and a single kayak over the course of 6 hours! Try to make it next year! It's fun and relaxing to spend some time in this beautiful area. We had over 60 attend this year. Check out some of the pictures!



The Leary Family



Hunter and his dad, John



Pat



Lucas



The Salter's and Lacasse's



Lacasse, Salter, and Brown Families



The Holland Family



Rosa and friends
heading to the Paddleboats



Thomas and Lesley



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August Raffle

Congratulations to Pat Carroll who was last issue's winner of a gardening basket and to Brandon Madden who won the Pizza Hut certificate (donated by Pete Eldredge). This issue's raffle will be for a \$50.00 gift certificate to Wal-Mart to help with school supplies, new clothes, or anything else you need or just want. Send this form to Gerry Riecks Community Partners, 113 Crosby Rd, Dover NH 03820.

Name:

Address:

Tel. #

Return by August 18th and Good Luck!