

DSSC

# Family Support Newsletter

## Governor Shaheen Signs Work Incentives Act

### Special points of interest:

- Allows workers with disabilities to retain medical insurance (Medicaid)
- Bill had bipartisan support at all levels
- HB 350 takes effect August 14, 2001

On June 15, 2001, Governor Jeanne Shaheen signed into law HB 350 The Work Incentive Act, marking the beginning of a new era for thousands of persons with disabilities who could, over time, break out of the cycle of poverty and earn significant wages but still retain their necessary long-term health insurance coverage.

According to Project Dollars and Sense, the establishment of the Work Incentive Program reforms a system that is out-dated and based on a perception that a person with a disability cannot be productive and self-sufficient. With the advances in education, medicine and technology many persons with disabilities possess the skills to be competitively employed; but for the barriers imposed by the threat of losing one's health benefits program. Enactment of this bill means people with disabilities can look for and hold down real careers with real futures. It would also allow for a return on the many dollars of investment the state makes in education and training. In addition, passage of the bill opens the door to a pool of qualified workers, which New Hampshire businesses so desperately need.

This bill was developed in a cooperative effort between representatives of many disability organizations and the Department of Health and Human Services. Many people have worked very hard to research this issue and craft a new law to meet the needs of the citizens of the state.

It was clear as the bill made its way through the legislature that many representatives realized that it

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## We Listen to You...

Over the past year we have asked for your feedback as we look at unmet family needs across the county and plan for the coming year. This year the Council and team looked at the results from the Quality Outcomes Survey which many of you filled out this past Spring and the survey we did in the last newsletter.

The main Family Support issues raised by families were:

- Lack of availability of respite providers and limited availability of respite funds.
- Need for more recreational opportunities for children especially teenagers.
- Continued need for access to information on accessing community resources including financial planning, day and after school care, health care and assistive technology.
- Legislative advocacy to campaign for better services including lack of funding for health, dental and other services.
- Another major concern identified by the Family Support Council and DSSC Board of Directors is funding for the waiting list for services and the increased pressure on the Family Support Council to fill in the gaps while families are waiting for adult services.

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## Helping Children Cope with Stress



**An attitude of love, understanding, and acceptance helps children get through difficult times.**

Any major change in a child's life can cause stress. Common sources of stress are the birth of a new sibling or the divorce or separation of parents. Stress also can be caused by the death of a relative or a beloved pet, a family move, separation of parents for extended periods, pressure to succeed, overly strict discipline, and natural disasters (even when the child has only seen them on television).

Not all stress can, or should, be avoided. Young children do not view the world as adults do. Misunderstandings or feelings of confusion can build up and leave children with stress they cannot handle alone. Young children cannot easily verbalize these feelings, so we adults must be aware of physical or behavioral signs of stress: loss of appetite, sleep troubles, nightmares, headaches, stomachaches, or regressive behaviors such as thumb sucking or regression in toileting skills.

Children often deal with stress through their play. They may act out events they find disturbing. One child may re-create an airplane crash after hearing about or seeing a real airline accident on television. Another may use dolls to have a conversation about or play out divorce or family relationships. This type of play helps children cope with events and feelings that might otherwise be overwhelming.

Adults play an important role in helping children cope with stress by providing a supportive atmosphere in which to talk about or play out concerns. We need to acknowledge and accept the feelings children express and give them our support. An attitude of love, understanding, and acceptance helps children get through difficult times.

If you have questions about how you can support the developmental needs of your infant or toddler, please call the Infant & Toddler Program at 749-4015.

### Estate Planning

Just a quick reminder that we have information on estate planning for families with a child with a disability. If you are interested in having a copy of this information mailed to you, call anyone in Family Support. Even though we just had a speaker in last winter, we do plan to offer this on a regular basis so watch future newsletters for the next scheduled session.

### The Council Develops a Plan for FY 02

The Family Support Council held a planning meeting on June 4 2001 to which we invited families and representatives of DSSC programs and Board of Directors. At this meeting we developed some goals for the upcoming year.

The Council realizes in order to continue its work on behalf of families that we need to have a strong and committed Family Support Council. To this end, recruitment to the Council and training for council members is a major goal for the coming year. We would love to hear from you if you would like to help us by joining the Council in its monthly meetings or joining one of our subcommittees. Please call Chuck Raymond at 743-3909 if you are interested.

Other areas where we will focus our work over the next year will be in developing recreation opportunities for teenagers, and setting a schedule of training opportunities for the year for families including a training in the Fall on how to get the best use out of using the Internet. As always we continue to recruit respite providers. If you know of anyone who would be interested in providing some respite for a family please put them in touch with Christina Dumont, Respite Coordinator, at 749-4015.

## The Year In Review

The Family Support Council would like to update you on some of the activities of the Family Support Program over the past year.

- The Family Support Program redesigned and expanded the DSSC website with links to Family Support, other DSSC services, as well as useful sites on the web. You can visit us at [www.dssc9.org](http://www.dssc9.org).
- The Family Support Program sponsored a number of workshops during the year on topics that included information on guardianship and financial planning, special education law and futures planning for families.
- The Family Support Program organized two ski trips to Mount Sunapee, a sleigh ride at Christmas, and what is looking like an annual council picnic to White Lake State Park in the summer.
- The Recreation Committee helped to organize a number of events for the Teen Social Group including , archery, mini golf, swimming , and bowling.
- The Family Support Council participated in a local legislative breakfast to increase awareness of the issues faced by families who have a child with a developmental disability.
- The Family Support Council paid for 20 families and 4 staff to attend the Family Support Conference weekend in Bartlett in May.
- The Family Support Council gave summer recreation scholarships to 54 individuals and families this summer.
- The Family Support Council continued its support of the Leadership series organized by the Institute on Disability by sponsoring two families to attend from Strafford County.
- The Family Support Program worked with the local radio station, WHEB, to help 74 families with food baskets for Thanksgiving.
- The Family Support Program received a small grant from the United Way to work on developing a parenting series for families where one or both parents have a developmental disability themselves.
- The Family Support Program continued work in reaching out to older parents and helping them in planning for the future for their son or daughter.
- Our Respite program worked with 123 families.
- The Family Support Program continues to support groups for Parents of Children with C.P., Parents of Children with Down Syndrome, Parents of Adult Children, and the Father's Group.
- The Family Support Program publishes a quarterly newsletter that is mailed to all our families.

The Family Support Program worked with 261 families in the past year. We helped families in a variety of ways from accessing community resources and benefits, helping pay for home modifications, respite and adaptive equipment and assisting parents to meet and support each other.

## Work Incentives Act

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makes little fiscal sense to simply pay people to stay home and it makes even less sense to penalize people if they try to lift themselves up and get a job and try to become self sufficient.

The bill had strong support from the governor and received unanimous support and approval in all of the legislative committees and on the floor of both houses. It is a new day in the lives of many people with disabilities in New Hampshire.

## Teen Social Group Update

We had 16 teens, family members and friends at Hilltop Fun Center for miniature golf and swimming after at the home of Marc and Cathie Lacasse. It was a blistering hot day and after a tough morning on the golf course, the water was great! Papa Gino's in Rochester generously donated some pizza to the teen group and very little was left over. The rest of you teenagers out there are welcome to join in the fun anytime! We had 3 new teens this time and it's always a pleasure to see both new and old faces.

## Respite Saturday

What do you think of having a respite Saturday? We have been thinking about a Saturday around November where parents/guardians could drop off their family members for a few hours. This service would be available to families who are eligible for services through family support. Our thought is that parents could take advantage of this time to go do their holiday shopping or other errands. Please let us know what you think of this idea by calling Christina at 749-4015 ext.222.

## Who Needs Help with Recreational Activities?

Once again, we will be trying to hire work/study students from UNH to facilitate the inclusion of young people with disabilities in the activity of their choice or that of the family. Once a student has been interviewed, I provide them with possible opportunities and then I connect the family with the student. Some training and support is provided prior to any independent facilitation. Please keep in mind that the activity is to be your choice and consistent (such as weekly) and one in which your child needs support. Call Betsy for further information

### TLC Computer

The TLC Computer is now online. Please feel free to come in and check out any disability related websites. At the same time, look over our books we have to loan to families.

## Challenges with Finding Respite Providers

Finding someone to help provide respite is challenging. The most successful way of recruiting providers is for families to find their own providers. Families can ask friends, neighbors, bus drivers, waitress, bank tellers, school aids, teachers, and people in doctor's offices. Anyone you and your child have contact with could be a possible provider. You never know who is willing to help out until you ask. People who see you with your child and know you, are more willing to help out then if we just tell them about you. So please look around your community, if you have a good experience at a restaurant with a certain waitress, ask her if she would like to become a Respite Provider.

Call Christina at 749-4015 ext.222 for more details on how to work together on finding Respite Providers.



## DSSC Summer Outing at The Works

On June 21<sup>st</sup> DSSC held its annual summer outing at The Works in Somersworth. Although it was a cool overcast day, it appeared that a good time was had by all. The rain held off for most of the outing. People were swimming in the warm heated pools, singing their favorite Karaoke tunes with Kenny Tibbets, dancing, and eating a traditional BBQ meal of hamburgers and hotdogs. If you missed the outing this year, make sure you don't miss the fun next year. We can help out with transportation to the annual outing if needed. We hope to see even more families there next year!!!

# The Council Needs You!

Hi all you families out there, I hope your summer has been going well for you and yours. I'm Chuck Raymond, the Chairperson of the Family Support council. Deirdre has put together several short notes for this publication that we hope will interest you and will maybe bring you to the meeting table. What meeting table? Your Family Support Council! They're the folks who keep an eye on the store so to speak and try to find ways to help you and the rest of our families. We need your support and would love to see some new faces at our September meeting that is scheduled for September 17 at 6:30 at Crosby Road. The plans we made for the coming biennial period are ambitious, but they should be.

Come on to our place on September 17<sup>th</sup>, put your best foot forward, and help yourselves as well as all those families in Region 9. One of our goals is to establish a training program for new council members. This will give you a good perspective on what is required of us in performing the duties of a Family Support Council member.

If you have any questions, comments or suggestions please call me at 743-3909. I look forward to meeting some new candidates on September 17<sup>th</sup>.

## Workshops Available

### 2001 Back to School Conference on Autism

September 22, 2001 from 8:00 - 3:00 at Yoken's

Sessions will be on teaching critical thinking skills to students with autism and on developing social and communication skills. The cost is \$65.00 (includes continental breakfast and lunch). For more information or to register call PhatArt4 at (866) 742-8278.

### Explosive/Noncompliant Children and Adolescents

with Dr. Ross Greene at Concord High School

Thursday, Aug. 23, 2001 - 9:00 to 3:00

Target Audience: Parents, teachers, and community members who work with easily frustrated children and adolescents who are hard to manage. Call 225-0811 or email [jhand@csd.k12.nh.us](mailto:jhand@csd.k12.nh.us)

## Available Free to Families

The following items have been donated to DSSC from families whose children have outgrown them. They are available free to any family who can use them. These items are at the Crosby Road offices of DSSC—call Gerry at 749-4015 if you would like to come in and see them first. Please contact her and let her know which item you are interested in and we will draw names on Sept. 4, 2001.

### Chair



**Height: 2 1/2 Feet**  
**Tray: 2 foot square and slides front to rear**  
**Small tear on padded seat**

### Stroller



**Black Seat Insert:**  
**Hips 8 1/2 inches**  
**Height to headrest 18"**  
**Has chest supports**  
**Includes Attachable Clear Tray (Leaning against side)**

### Walker



**Height 18"**  
**Front to Back: 24"**  
**Side to Side: 21"**  
**Padded arm rest**  
**Adjustable Seat**

## The NH Leadership Series

The following is a letter from Lori Bouchard, a parent and former member of our Family Support Council in Region 9. She recently attended the Institute on Disability's Leadership Program and found it to be such a positive experience that she wanted to share it with others.

"I am a recent graduate of the NH Leadership Series. I am also a parent of 2 children with autistic spectrum disorders. My dear friend recommended I go, and I'm so glad I did. I learned so much!! I have come away from the series with a wonderful education. I learned stuff about every topic they offered. The majority of things I can't thank the Leadership Series enough for. I was feeling extremely overwhelmed and full of many questions, but the Leadership Series taught me the steps and practices of how to get an idea started, to follow through and make it become a reality. I met a truly wonderful bunch of people whom I am hopeful to stay in contact with. If you are a parent with a child that has a disability and are so full of questions as I was, this is a wonderful vehicle for you. You will meet many people truly willing to stick their necks out for you and help direct you, too. I will miss these wonderful folks, and I hope to be in contact with them in the future. If you are involved with family support and haven't attended and would like to, please tell someone who has gone through the series. Ask them about it and their experiences, too. I feel I have been blessed in a big way by going through the series, and the leadership for me was a godsend. I feel I had a very educational, enlightened, and wonderful experience. To all the graduates of the 2000-2001 series, congratulations on your graduation. May you and your loved ones' visions for the future all come true."

For more information on the Leadership Series, call Beth Dixon at 228-2084.

## Transition Time for your 3 year old...

The Parent Information Center will be doing a workshop in Dover on Tuesday, October 23 on Envisioning your Child's Future. This will include information on preparing for your child's transition from Early Supports and Services to the public school system. Bring your questions and concerns and meet other parents of young children. Save the date!

## Gadget of the Month from the TLC

At the Family Support Conference in May, we bid on an adjustable school chair at the auction and now have it to lend to families. The back of the chair adjusts forward and backward and the height of the chair can accommodate the height of the child. It is very well made and sturdy. The age range for proper seating would be approximately 2-6. Please call Betsy with questions about borrowing this great item to see if it would work with your child..



"Simple and easy to adjust, our school chair provides moderate positioning control in a bright attractive package. The seat can be set to allow for more or less side support as needed, and the back can be adjusted for tilt and height" The current retail price is \$145.00. For information or to order, contact Ralph Bagnall at (603) 863-1622 or 647 Washington Rd. Goshen NH 03752

## Partners in Health: The Visioning Series

The Partners in Health Parent Council and staff met for a two part Visioning Series in April and May.

The Council discussed what an 'ideal world' would look like for families, created a vision statement and set goals for the year ahead.

The role of the Partners in Health Council is to oversee supports for families who have a child with a chronic health condition. Partners in Health helps parents and children be their own advocate in learning about resources (including Partners In Health), accessing information and supports, influencing organizations that provide information and support, and helping other parents in the process.

The Council also seeks to educate others in the community involved with the care of children with chronic health conditions, including but not limited to schools, doctors, professionals, friends, and other family members.

Over the next year both the Partners in Health and D.S.S.C. Family Support Councils will work together to improve access to Information & Supports by organizing workshops to teach parents how to access information via the Internet such as : Illness/Disability, Resources, Laws & Regulations, and Advocacy.

The Council will also work to improve communication and community awareness, especially with hospitals, clinics, physicians, and school communities by organizing presentations, providing PIH information packages, and by families sharing stories.

### Thanks

Special thanks to Gina Pearson, Laurie Hochgraf and Tammy Munroe for attending the Visioning Process and for helping to make changes for future parents. If you know of a family with a child with a chronic health condition please tell them about the Partners in Health program. For more information please contact Cheryl Goscinski-Drew, Partners In Health Coordinator at 749-4015 ext. 211.

## Support Groups

There are 2 new support groups available to parents. One is for parents of children with **Autism/PDD** and it meets at the Newmarket Community Church on the 1st Tuesday of each month. Contact person is Tina MacLeod at 659-1282. The other group is for parents of children with **Mitochondrial Disorders**. This informal group is held at various homes throughout central and southern NH, 2 Tuesdays per month. Contact people are Paula at 497-4337 or Jennifer at 456-2872.

## Medical Choices in the Community

In response to parents' requests for more information about what's out there for medical help for their child and/or for themselves, we are offering a series of presentations in the fall. We decided to stray slightly from the norm with some alternative types of treatments and yet include some fairly traditional treatments as well. Our decision to do this came as a result of one parent's success with her child with an autism spectrum disorder who has made some substantial gains from help from a chiropractor. Family Support realized that we could support families by providing information on a few of the many treatments that help both children and their parents! The following is a list of what will be offered:

- **Wednesday, September 12 - Therapeutic Massage/Reiki - Nancy Comeaux Whitford**
- **Wednesday, September 26 - Guided Imagery/Use of Sound, Breath, Humor - Barbara-Joyce Reed**
- **Wednesday, October 17 - Family Chiropractor, Dr. William Reddy**
- **Wednesday, November 7 - Psychiatrist, Dr. Margaret Tilton**

All presentations will be at 7:00 PM and will be held at the Dover Community Office of DSSC. RSVP's will be requested - flyers will be sent out for each one.

**Family Support Raffle**

**August 2001**



Name:

Address:

Tel #

Return no later than Aug 24, 2001

To Gerry Riecks at DSSC (address below)

**DSSC**



Developmental Services of Stafford County, Inc.

113 Crosby Road - Suite 1

Dover, NH 03820

Phone: 603-749-4015

Fax: 603-743-3244

**Email Addresses:**

[hphilbrick@dssc9.org](mailto:hphilbrick@dssc9.org)

[dwatson@dssc9.org](mailto:dwatson@dssc9.org)

[cgoscinski-drew@dssc9.org](mailto:cgoscinski-drew@dssc9.org)

[cdumont@dssc9.org](mailto:cdumont@dssc9.org)

[bcarroll@dssc9.org](mailto:bcarroll@dssc9.org)

[www.dssc9.org](http://www.dssc9.org)