

Hudson Valley Connections

Parent to Parent of New York State

SPRING/SUMMER 2008

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From The Coordinators: *Laura Carfi and Marina McGovern* *Spring Time Planning for Summer Time Fun*

Now is a good time of year to start planning for your children's summertime activities. Inquiring about camps, school programs and vacation possibilities can be exhausting. Add to the responsibility that your child has a disability or special health care needs and that process becomes even more overwhelming. There are many things to consider when searching for a program. Location, staffing, safety are just to name a few. At Parent to Parent NYS we have support parents who may be able to assist you in your search for answers to these questions and inquiries. Please feel free to contact our offices and speak to a parent coordinator and be matched with someone in your area that is familiar with programs, camps, and activities that could work for you.

We have compiled a list of websites that may be helpful to you. At the same time, if you know of a program that you have used and are familiar with, please contact a coordinator to share that information. We always appreciate hearing from parents about their experiences with summer planning.

HELPFUL WEBSITES:

www.resourcenyc.org
www.ncpad.org/get/discover/resources
www.esopuscamps.com
www.parentknow.com
www.frishmanfaber.com
www.hvparent.com/directories
www.mysummercamps.com

FYI:

The NYS Department of Health has a pocket "Health Information Document", called "H.I.DOC." that may be useful to parents. This is a wallet size card that opens up to be a full page document. It holds important information regarding immunizations, health care providers, doctors, medicines, and special care needs. For your convenience, we have enclosed one "H.I. DOC." with this newsletter. If families are interested in obtaining additional cards, contact the NYS Department of Health at: 518-474-2001 or visit http://www.health.state.ny.us/community/special_needs.

Seeking Families to Contribute to Our Newsletter:

We would like to include in our newsletter personal stories from families about experiences that they have had with their child with a disability or special health care needs. If you are interested in contributing poems, stories, or personal testimonies to our parent-to-parent newsletter, please contact a parent coordinator to discuss your ideas and submit your writing for possible publication in one of our issues. Book reviews can also be submitted. We look forward to sharing your experiences raising an exceptional child.

Family/Student Transition Update: Diane Greble

The *Family-Directed Transition Planning Guide* is an informative reference guide to help parents and students become full participants in the transition planning process. A labor of love, co-authored by long-time staff members of WIHD, Jacqueline Fowler and Barbara Levitz, the guide talks about strategies, timelines, planning for employment, college or agency programs, financial resources, housing, healthcare and other community services and supports.

The guide was last published in 2002 and is now being updated with all the latest contact information, not only in Westchester, but Putnam and Rockland, as well. It includes general and "how-to" information that can benefit any family in the Hudson Valley. The transition timeline starts at age 12 and goes through age 22, and it's never too early to prepare.

This new guide will be published in June/July 2008. Please contact mmcgovern@wihd.org to reserve a copy.

In addition, if you have any transition related questions, I am always happy to assist you.

Diane Greble (dgreble@wihd.org)

Library Project:

Parent-to-Parent of New York, the Family to Family Health Care Information and Education Center and the SW BOCES Transition Site have partnered in an outreach program throughout the Hudson Valley to bring information to your local library on many issues that families of children with disabilities may encounter. Included in the packets are the following:

- Parent to Parent Brochures/ connect to other families to share similar issues and concern
- Student/Family Transition Info./ children 12-22 that need help with planning for the future
- Parent to Parent Newsletter
- Fact sheets include the materials developed by the Family-To-Family Health Care Information and Education Center of PTPNYS (see listing in section below).

The packets will be available in June at your library's reference desk. As part of our parent-to-parent network, it would be helpful to have you visit your local library, speak to the reference librarian and let her/him know how helpful and important this material is to families who have children with special needs.

Hudson Valley News E-Group:

If you are interested in joining the e-group, please submit your name to P2PCares@aol.com. Your name will be added and you will receive information of special interest including news releases, events, forums, and workshops in the Hudson Valley area.

RESOURCE GUIDE FOR FAMILIES:

A Guide to understanding supports and services administered through NYS Office of Mental Retardation and Developmental Disabilities.

This guide will prove to be a valuable tool for people with disabilities, parents, and caregivers. Copies of the guide can be downloaded from the Health Care Information and Education section of the Parent to Parent NYS website at www.parenttoparentnys.org

YELLOW PAGES FOR KIDS: [New York Yellow Pages for Kids](http://www.yellowpagesforkids.com/help/ny.htm)

Find educational consultants, psychologists, educational diagnosticians, healthcare providers, academic therapists, tutors, speech language therapists, occupational therapists, coaches, advocates, and attorneys for children with disabilities on the Yellow Pages for Kids for your state. You will also find special education schools, learning centers, treatment programs, parent groups, respite care, community centers, grassroots organizations, and government programs for children with disabilities.

<http://www.yellowpagesforkids.com/help/ny.htm>

Family to Family Health Information and Education Center:

Just a reminder that material for families related to health issues has been developed and is available in two ways. You can go on the Parent to Parent NYS website www.parenttoparentnys.org and click on Family to Family or we can send you a copy in the mail. Contact your local coordinator if interested.

Materials that are available include Medicaid Fact Sheets, Health Care Notebooks, Tips For Handling Medical Appointments, Financial Aid For Children With Special Health Care Needs, Record Keeping Tips, HCBS Waiver In NYS, Section 504 Accommodations, Coping and Stress Reduction Facts and Tips, Healthcare Information On The Internet, Medicaid Prescription Tips for Parents/Caregivers, Understanding Health Insurance and Doctor Selection Fact Sheet.

Parent-to-Parent has an e-group for parents who have children who are medically fragile or have complex medical needs. Email Lisasdesk@verizon.net or visit the Parent-to-Parent NYS website listed above.

Online Support Parent Training:

If you are interested in becoming a support parent on our network, you can now do the training online.

Go to www.parenttoparentnys.org and click on support parent training link. This offers families the flexibility to do the training at their own convenience and pace. A support parent questionnaire can be submitted online or you can contact your local coordinator to receive one in the mail. This must be filled out entirely before you can do the training.

Join our network and help make a difference in the lives of other families. Please call us with any questions. There is also an on-line training for a parent willing to be A Health Care Resource Parent. Check the website or contact Laura Carfi.

If you previously volunteered to be a support parent but have not yet completed the training and submitted the accompanying support parent questionnaire, this would be an excellent way to finalize your recruitment and training.

Links Digest:

As part of the Family to Family Health Care Information and Education Center, Parent to Parent of NYS has established the Links Digest to provide links relevant to the issues of health care. Go to www.parenttoparentnys.org and you will find access to the Links Digest on the home page.

A Parent to Parent Article:

Submitted for publication February 18, 2008 by Marie Pennacchio

Preparing for your End of Year CSE Meeting

As we approach April and May, my mind, heart and soul anticipates the end of year planning meeting for my child. For the past ten years, I have attended annuals as well as the occasional interim meeting for my child. I also attend many meetings as a Parent Member. I can best categorize the annuals as a combination of Spring Cleaning and Bulb planting. Before one can plant, or decide what needs to be planted, I decide what needs to be cleaned up. It is important to begin three to four weeks before the actual meeting date to allow for three stages. **Stage I** is a review of my old IEP, including the categories, and each of the goals as well as my child's interim progress reports. I read through this, all of the teachers' notes, and reflect on my child's year. Where have we come from –wow –it forces me to be thankful for gains and to put current or remaining issues in perspective, and to set new goals. It becomes the springboard for my summer plans with him and my wish list for his future, defined as the coming school year. Usually, there are at least three to five questions that leap out at me. I write them down, and ponder them for three to five days. Are these still significant issues? Ask yourself what the priority is, for where your child will be that next year? Will he still be in elementary school? Will he be transitioning to middle or high school? Is socialization a key concern? Are standardized tests beginning? Where do I want him to be in three years? If I want him to succeed at taking notes, do I need to start teaching him keyboarding now? **Stage II** involves gathering your tools, mat, and garden gloves. Speak with any individuals who are essential for pre-meeting planning, thinking, brainstorming, and flush out ideas and concerns. I always speak with my husband, my son's teachers, the school psychologist, his old therapists, with whom we have kept in contact, and always my two confidants –individuals who love my child, but who can see clearly, outside of my heart, to shed an independent perspective – this is my child's core "team". Last year at this time caused me to re-evaluate classification status, and whether he was ready to be declassified to a 504 with his transition to Middle School—a wish for me, *but was it the best option for my child?* In the end, I decided he would stay classified. **Stage III** involves preparing the ground. I prepare notes for the meeting with any changes requested from his current IEP, either delisting, or adding on. The notes represent the expanded team's thinking before the formal thirty minute or one hour meeting. It allows for true consideration of my child and "out of the box" flexible thinking. It demonstrates that I value everyone's time and opinions, and that the decision about a child's important next year cannot be made in only thirty minutes. If there is an individual whose perspective would add value to the meeting, or if there are differing points of view on an issue, you may decide to invite that person to the meeting. Notice is required, in writing, to your CSE chairperson. **Stage IV** You are ready to plant! Arrive early for your meeting, bringing a picture of your child – these services are for a very real child –yours! Bring bagels [meetings are often before school starts, over lunch, or consecutive], bring any additional questions written down [expedites meeting], bring a notepad and pen. Begin by thanking everyone at the start of the meeting for taking time to pre-plan with you before the meeting. Remember to look back at your child's gains, and team efforts, as you spring forward to plan his next year! And always remember, if things change radically in the fall, you can always ask for another meeting— that's great advocating for one great child!