



The PACC Family Connection Newsletter

Issue No. 12

Winter 2002

Dear Families,

In this issue, we will begin a series of three articles about Assistive Technology, written by a specialist in the field who works with the Institute for Community Inclusion at Children's Hospital. As her article in this issue describes, assistive technology can be anything from an off-the-shelf item, such as velcro to something very "high tech" such as a specially adapted computer device. All these devices, whether simple or complex, have one thing in common: they help people who have special health care needs or disabilities to be more independent or do things they would not have otherwise been able to do.

With the winter months fast approaching, we are also including some information about adaptive winter sports. We encourage you to take the time to inquire about the possibilities for your child; there are many! For example, a child who does not walk can have the experience of skiing down a slope like any other child.

Finally, please take time to look over this issue's "Freebies" column. We are so grateful to the many wonderful donors who are anxious to support our families and our program. We hope you can take advantage of one of these offerings.

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What is Assistive Technology?

By Sue Cusack, Technology Specialist at the Institute for Community Inclusion

What do Velcro, large button calculators and computers have in common? Let me give you a clue: what happens when they are grouped together with a pencil grip, a tape recorder and a talking alarm clock? From name stamps to laptop computers, these items reflect a small sample of tools or devices that "assist" a person with a disability to do something that might not otherwise be possible. The more formal name for these tools and devices is assistive technology.

Assistive technology sounds complicated, scientific, and expensive. Is this always true? In most cases, the answer is no. Many assistive technologies are commonly available in places like your supermarket or stationery and hardware stores. Here are a few examples that may be useful:

- ♦ PostIt(tm) flags can be used in books or manuals to mark important information
- ♦ Remote doorbells found in hardware stores can be used to get someone's attention in another part of your home or place of employment if you need assistance.

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Get Out On The Slopes And Ski This Winter

By Kathy Chandler, Ability Plus

AbilityPlus is a non-profit organization that hosts programs for people with disabilities at many mountains in New England. People of all ages and all abilities and disabilities ski with us each year. All the programs have adaptive equipment available and trained and qualified volunteer instructors ready and excited to take you out on your lesson. Each program is a little different and has its own characteristics, but all have the same premise that moving down the mountain is an experience that everyone should try. "If you can get to our door, we can teach you to ski" and you will have fun doing it. That is the essence of our motto. For people with disabilities skiing helps to promote freedom, inspire independence and renew self-esteem. This is a win-win situation for everyone involved. Everyone gets excited by the experience, the student, the volunteer instructors and the parents or friends who have shared in this fun opportunity. All lessons are by reservation, run from mid-December through March, so call the mountain of your choice and go out and have a ball. If you would like more information call the AbilityPlus office 978 365 6200 and check out the web site at www.abilityplus.org. The AbilityPlus affiliates are:

Waterville Valley - Waterville Valley, NH - 603 236 8311 ext. 3175

Attitash/ Bear Peak - Bartlett, NH - 603 374 2368 ext.2688

Bretton Woods - Bretton Woods, NH - 603 278 3398

Gunstock - Laconia, NH - 800 486 7862

Mt. Snow - Mt Snow, VT - 802 464 1100 ext.4699

Stowe - Stowe, VT - 802 253 3000 ext.3689

Wachusett Mountain - Princeton, MA - 978 464 2300 ext. 3718

- ♦ For some people, an inexpensive electronic organizer from a stationery store can make all the difference in their ability to independently keep track of their daily responsibilities.
- ♦ A trackball may be just the right tool to support a person who is having difficulty with a traditional mouse.

Whether the recommendation for assistive technology includes an off-the-shelf device from your local hardware store, or a sophisticated computer system, there are a few important things to keep in mind. ***The person using the technology needs to be actively involved in the technology decision, and trained in the use of the technology.*** Ongoing maintenance, repair and upgrading are also services that must be made available to the technology user.

Online Resources:

Massachusetts Assistive Technology Partnership (MATP) provides information and referral on assistive technology products and services; helps individuals to access funding; discusses and individual's right to assistive technology devices, supports and services under the law; operates an electronic bulletin board and a website, and publishes a quarterly newsletter on project activities and on rights and resources.

Phone: (617) 355-7820; TTY (617) 355-7301; Fax (617) 355-6345

www.matp.org

ABLEDATA is an online database containing information on more than 27,000 assistive technology products (over 18,000 of which are currently available), from white canes to voice output programs. The database contains detailed descriptions of each product including price and company information. The database also contains information on non-commercial prototypes, customized and one-of-a-kind products, and do-it-yourself designs.

www.abledata.org

Support Services for Families from the State

There are several state agencies which offer support services to families who have children with special health care needs. One of these, DMR (Department of Mental Retardation) offers services which are not limited to families who have children with mental retardation. Up to the age of 18, a child may qualify when ***4 of the following 7 areas of functioning are affected by the child's special need:*** self-care, learning, receptive and expressive language, mobility, capacity for independent living, economic security, and self-direction.

If your child is found eligible for DMR services, then services will be provided when resources become available. One of the possible services from DMR involves family support which can include an allocation of funds to the family (called Flexible Funds). Families may use these funds as they see fit to support their child. For example, a family may choose to use the funds to buy an air conditioner for the child's bedroom. Or, they can use the funds to pay a babysitter so that they parents can get out on an evening for a break so that they feel re-energized as they care for their child.

Any family who asks for DMR services is entitled to a determination by the department.

If you think your child might qualify according to the above criteria, we **encourage** you to contact your DMR office. You should call your nurse practitioner to get the name and number of the DMR representative serving your region. And, if you feel you would need help in DMR's determination process, please ask for that help. DMR offers resource people who can help you.

How Has Children's Hospital Been Treating You?

Have you had a particularly good or bad experience with Children's Hospital — whether in-patient or outpatient? If so, the hospital would like to know. You can register your comments with the Patient Relations Department by calling 617-355-7673. Please let them know how the hospital is doing; it's a very important way to identify both trouble spots and areas of strength.

FREEBIES

Free Software Available

If you own, or have access to, a PC (IBM compatible computer), and would like free dictionary and/or encyclopedia software, please contact: Linda Freeman, PACC Family Coordinator at 617-355-8789, to have a copy of the software mailed to you.

Free G-Tube Supplies Available

PACC has received a box of g-tube supplies. The box includes: kangaroo pump sets, enteral feeding tubes, dressings and syringes. If you could use these supplies, or know someone who could, please contact: Linda Freeman, PACC Family Coordinator, at 617-355-8789.

Power Lift for Wheelchair Van Available

PACC has learned of a full size lift for a wheelchair van that is available at no cost. This lift has been used in an ambulance and is no longer needed. It is in fine working condition. For more information, contact Linda Freeman at 617-355-8789.

Do You Need a Break?

If you think you could take the time for a free one or two-night getaway in a local hotel, let us know. PACC is anxious to help parents and caregivers get a break by being a guest at a Boston area hotel. If you can find someone to care for your children, we will make every effort to match you to a convenient hotel. Contact your LPC or Linda Freeman, PACC Family Coordinator (617-355-8789) if you are interested.

WeMedia Magazine: free subscription

WeMedia magazine is offering a free one-year subscription. The magazine is a glossy lifestyle magazine which covers issues important to the millions of people with disabilities interested in a quality life without compromise. It was started as the Official Magazine in North America of the Sydney 2000 Paralympic Games. The company also offers www.wemedia.com, a free comprehensive online resource providing targeted information, products and services. The Website concentrates on news, sports, accessible and assistive technologies, politics and advocacy, shopping, employment, education, finance, and real estate from a disability perspective.

To take advantage of this offer, call toll free 800-877-935-6789 or access their website at www.wemedia.com/freemagazine.

Did You Know...

There are two great websites for finding adapted toys:

www.dragonflytoys.com - lets you "describe" your child's strengths, weakness, (for example, motor skills, vision skills) area so the suggestions you get back for toys are much more tailored to your specific needs. Be sure to click on "search by child profile" to be able to use this search approach.

www.familyvillage.wisc.edu/at/adaptive-toys.html - gives you access to different companies and their catalogs about specially adapted toys. (Family Village is a great website for lots of different information concerning disabilities and special health care needs.)

This is just one of many "tips" you can find in **PACC's very own website**. The website covers a lot of different topics, including recreation, nutrition, and school issues. All the tips have been contributed by parents of children with special health care needs.

Check it out!

www.childrenshospital.org/ici/pacctips

Massachusetts Catastrophic Illness in Children Relief Fund

This is a new fund, announced in September. The fund is intended to provide financial assistance to families experiencing a medical condition requiring services that are not otherwise covered by a private insurer, federal or state health care assistance, or any other financial resource.

The Fund accepts applications for expenses related to the medical needs of children 18 years old or younger who are residents of Massachusetts. In order to be eligible, a family must have expenses related to a child's medical condition that exceed 10% of the family's gross annual income up to \$100,000 and 15% of any portion of the annual family income that exceeds \$100,000. The applicant must also be under the care of a licensed health provider who has staff privileges at a hospital licensed or accredited to provide pediatric or neonatal care.

Financial assistance may include, but is not limited to, payment or reimbursement for the costs of medical treatment, inpatient or outpatient hospital care, prescription drugs, nursing care, and physician services. The Commission will consider other reasonable expenses and may pay for expenses related to experimental treatment in certain circumstances.

Applications may be submitted for expenses that are already owed or paid for services that the child has received and for expenses for proposed services.

To receive an application for the Fund, call or e-mail:

Catastrophic Illness in Children Relief Fund
Commission
c/o Division for Special Health Needs
Massachusetts Department of Public Health
250 Washington Street, 4th Floor
Boston, MA 02108-4619
Phone: 800-882-1435
e-mail: division.shn@state.ma.us

New Airline Security Requirements for People with Disabilities

Since the terrorist hijackings and tragic events of September 11, the Federal Aviation Administration has issued directives to strengthen security measures at airline checkpoints and passenger screening locations. Steps were also taken to ensure that the new security procedures preserve and respect the civil rights of passengers with disabilities. For example, air carriers must provide "meet and assist" service (for example, assistance to the gate or aircraft) at drop-off points. The lack of curbside check-in, for certain airlines at some airports, has not changed the requirement for meet and assist service at drop-off points. Also, the limit of one carry-on bag and one personal bag for each traveler does not apply to medical supplies and/or assistive devices. These are just a couple of the new requirements.

Members of the public, who feel they have been the subject of discriminatory actions or treatment by air carriers, may file a complaint by sending an e-mail, a letter or a completed complaint form to the Aviation Consumer Protection Division whose e-mail address is: airconsumer@ost.dot.gov and its mailing address is: U.S. Department of Transportation, Room 4107, C-75, Washington, D.C. 20590.

Recreation Program: For Kids with Special Health Care Needs

Kartwheels, Inc. is a physical activity program for children facing physical, emotional, and social challenges. It is geared for children ranging in ages from 5 to 15 and is held Tuesday, Wednesday and Thursday afternoons at Healthpoint on Winter Street in Waltham. The goal of the program is to get kids to work together. The program is held in eight-week sessions and families may sign up for any part of the program. Fees per session range from \$16 to \$30 per session depending on whether the child does just the gym activities, just the swim or both. There are some scholarships available.

Contact Jeannie Watson, Executive Director, for more information or to sign up at 781-893-6516 or e-mail her at jewatt@aol.com

Upcoming Events

Federation for Children with Special Needs

November 29: Marlboro, 7-9 p.m.: Workshop on Effective Communication

December 5: Ashland, 7-9 p.m.: Workshop on Basic Rights (special education laws)

December 5: Lawrence, 6:30 - 8:30 p.m.: Workshop on Basic Rights (in Spanish)

January 5: Needham, 7-9 p.m.: Workshop on Basic Rights

January 15: South Medford, 7-9 p.m.: Workshop on Basic Rights

January 16: Medway, 7-9 p.m.: Workshop on IEP 2000

January 24: Melrose, 7-9 p.m.: Workshop on IEP 2000

For more information about a workshop, or to register, for these free workshops, call the Federation at 1-800-331-0688.

Annual Federation Conference: Creating a World of Opportunities Saturday, February 9, 2002 at the World Trade Center

There will be 30 workshops, many exhibitors, free resources and NEW assistive technology strand. Check the Federation's website for additional information and registration materials: www.fcsn.org You can also call 617-236-7210 ext. 199

**Save the Date:
Saturday, January 26**



**Radio Disney is
coming to PACC again
this year — with
music, games and all-
around fun!**

**Watch your mailbox for
details!**

Office of Patient Protection: Help with Insurance Problems

Last July 2000, the Office of Patient Protection (OPP) was created by law in Massachusetts. Staff are available to assist insured health plan members with questions and concerns regarding managed care grievances, appeals, denials of care, continuity of care, and independent external reviews.

If you are having problems with denied services, referrals, access to care, or similar issues, you should first contact your health plan. If the problem can not be resolved with the health plan or if they do not get what they believe is an appropriate resolution, families should contact OPP. The OPP will investigate the situation, help consumers understand their health benefits and determine whether or not the health plan is in compliance with the managed care laws, taking appropriate action where necessary to ensure compliance.

It is important to know that the OPP can not help families with an external review when Medicare or Medicaid (MassHealth) is your only source of health services. Families covered by MassHealth must contact the Department of Medical Assistance to obtain information about their hearing process.

For more information, visit the OPP website at www.state.ma.us/dph/opp or call 800-436-7757.

PACC Families:

- Work closely with a pediatric nurse practitioner (PNP) and pediatrician to coordinate care for their child.
- Together with the pediatrician and PNP, design a health plan for their child. The PNP keeps a complete and up-to-date record of their child's care.
- Have access to a Local Parent Consultant (LPC) who is available to provide support, information, guidance and who plans activities/events for parents and families.
- These LPCs can be reached by contacting your PNP. The LPCs, by site, are:
- Children's Medical Office of North Andover: Susan Sleight
- East Boston Neighborhood Health Center: Susan Carr
- Hyde Park Pediatrics: Sheryl Soukup
- Longwood Pediatrics: Tres Ainsworth
- Martha Eliot Health Center: Blanca Quinones
- Pediatric Associates of Brockton: Beth Cerce



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