



Extended School Year Services: An Overview

By Elizabeth Mathison, MSW, LISW

Extended school year (ESY) services are defined in Section 300.309 of the IDEA legislation under "Subpart C Free Appropriate Public Education." Basically, ESY services are services beyond the regular school year that are necessary for a student with a disability to make educational progress during the school year. In addition, services must be individualized to meet specific objectives in the Individualized Education Plan (IEP) and must be at no cost to the parents of the child.

Determining eligibility for ESY services can be a difficult task because the decision, using general guidelines, is ultimately left to the discretion of the IEP team. Some important factors to remember and consider in determining whether ESY services are appropriate for your child are:

- EYS services should be considered yearly by the IEP team
- documentation of student performance in relation to IEP goals
- issue of regression (substantial loss) and

recoupment (ability to recover a loss) of critical life skills

- nature & severity of child's disability
- areas of learning that are crucial to the attainment of self-sufficiency and independence
- child's progress, both behavioral and physical
- areas of the child's curriculum needing continuous attention
- child's vocational needs
- ability of the parent to provide in-home educational structure

Our office can assist you in the process of securing ESY services by providing a letter for support and recommendation to the IEP team in advance of the IEP meeting. Please contact our office a minimum of two weeks prior to your child's IEP meeting to discuss obtaining a letter.

For more detailed information on ESY services check out the on-line Resource Guide under the Education tab.

Fundraiser – We Need Your Help!

We are interested in organizing a fundraiser for our clinic.

- The money raised would benefit both our parents and patients.
- Due to the amount of time required to organize such an event and our limited staffing we are hoping some parents will be willing to be on a committee in conjunction with 1 or 2 of our staff members.
- The committee will determine the type and scope of event.

If you are interested please contact Della at 636-3000 as soon as possible.

Summer Camp Information

Now is the time to start planning!

Visit our web site at

www.cincinnatichildrens.org/special-needs and click on Recreation. Here you will find several online camp directories and information about how to obtain printed directories. We also recommend consulting with your MRDD worker about available opportunities.



Planning Birthday Parties for Your Special Needs Child

By Juli Bick & Julie Doyle

Planning a birthday party for a child with special health care needs can pose some interesting challenges, such as finding activities that can be played with other non-delayed children. To help with your next party-planning venture, here are a few helpful tips:

- Decorate wheelchairs and/or mobility devices. Some children feel inhibited to play with children in wheelchairs or other mobility aids because the devices sometimes look a little scary. Decorating the wheelchair with fun streamers, ribbons or even wrapping paper can take the focus off the chair and onto your child.
- Decorate the rest of the house with colorful balloons, streamers and such. Color is stimulating for children with special needs.
- Plan games that can be played hand over hand. Children with minimal motor function can have difficulty playing even the simplest of games. Activities like a bean bag toss can be enjoyed by all, and other children can help your special-needs child hold and throw the bean bags.
- Have a supply of bubbles on hand, or give out mini bubble makers as a party favor. Children of all ages and developmental levels enjoy bubbles. And, for children with fine motor issues, other children can blow bubbles toward your child that he/she can then try to pop - or just enjoy watching.
- Create a pretend band. What child doesn't

enjoy music? If you don't have any child-size instruments on hand, grab some old pots, pans and utensils from the kitchen and let the children tap away. For added fun, you can create your own musical instruments from items you have around the house, such as old milk containers. Ideas for homemade musical instruments can be found at <http://familycrafts.about.com/cs/musicalcrafts/>.

- Have some craft supplies on hand. Craft projects where parents can help make for a fun afternoon. The kids can make picture frames for Polaroid or digital prints, or they can finger paint or make hand prints. Younger children could paint with puddings - then eat it after!
- Plan a themed party, such as a safari/jungle party. Kids can bring their own stuffed animal or make masks to wear - both would make for very cute pictures! Another fun idea is a silly hat theme.

If you have additional ideas or suggestions that you'd like to share, please email them to me (julianne.bick@cchmc.org) and we'll feature those in a future edition of the Family Newsletter. If you're searching for additional party or fun craft ideas visit the Family Fun web site (<http://familyfun.go.com/parties/>).

School Excuses

Just a reminder about school excuses - we are only able to write a school excuse if we have talked to you about your child's illness. School absences are considered necessary when your child is contagious or is too ill to participate in school. Other things to consider are:

- Not all illnesses require your child being absent from school. We can only give permission for your child to stay home if your child is contagious and/or too ill to participate in school. If your child is being kept home because he/she is not willing to go, that needs to be individually addressed.
- We can only say we have spoken to you on a particular day about a specific issue. This needs to be done on the day of the illness. We are not able to give excuses for previous illnesses.

- If your child is sick for two consecutive days and they will be missing their third day of school they need to be evaluated prior to obtaining a school excuse.

School Forms

Just a quick reminder: The school year is almost over - so it may be a good time to start thinking about any forms you will need completed for next year. It is much easier to obtain the forms while school is still in session. Also remember it takes our office 1-2 weeks to get them completed. Please keep that in mind when giving us your forms. We often have a large volume of forms to complete the end of the summer so the sooner you can get them to us the better.



Parent Advocacy and Initiative Towards Day Care and Respite

By Danielle Heiman

Respite centers and day care programs for chronically ill children are located throughout the United States, spanning the country from New York to Tampa to San Antonio to Kansas City. They are often designed to fill the gap between the care that a hospital can provide and children's additional needs, with goals ranging from transitioning towards more independent living for children, to increasing self-worth, happiness and quality of life.

These programs are a means of keeping families together and decreasing hospital stays and readmissions for children. Such centers would be highly beneficial to our community, where the needs for medical intervention services and dependence on various technologies are prevalent.

But the question is.... Where are our day care and respite centers? The fact is, Cincinnati lacks even one such organization to provide relief for chronically and acutely ill children and their families.

Day care and respite centers have proven to be, at times, critical for the long-term stability of the family and child at home. The services they offer are beneficial from the family's point of view, as well as from a total cost containment perspective. On average, community-based services such as day care and respite centers cost one-third of the price of inpatient hospital stays based on a daily rate.

The establishment of such a center would vastly contribute to the community of families that are affiliated with the Center for Infants and Children with Special Needs. The steps to initiate such programs must begin with parent support to raise awareness for the needs of such services. Next, community research must be conducted to establish the needs of families, the available community resources, and the possibility of cooperation and coordination with existing services, such as hospitals. Using the collected information, a program structure, which integrates all of the needs of the community, can be developed.

The next issue of a day care or respite center is funding. In other regions of the United States, such centers receive funding from a variety of sources, which include private insurers, government agencies, and public contributions. Government funding could be achieved by means of the Temporary Child Care for Children with Disabilities and Crisis Nurseries Act of 1986, which provides grants to states to assist agencies in developing care services for children with chronic illnesses, as well as programs that offer an array of family support

services. Many states have family support legislation, which includes appropriations at the state level for support options, including respite programs for children with medical needs. Often federal and state governments form partnerships to develop funding for support services for families. Also, many community-based hospitals have realized the importance of day care and respite services and have developed community-based programs by combining community, state, federal and private funds.

All efforts would require creativity in obtaining funding, and also commitment to learning the skills of medical terminology, medical management, and especially developing cooperative relationships with a wide variety of collaborators.

Day care and respite centers for chronically ill and acutely ill children prove to be extremely valuable for the lives of the children, as well as for their parents and siblings. Cincinnati certainly deserves such a program, and no efforts should be spared in making this project a reality for our community.

This is a subject that we have addressed before, and we urge parents to get more involved in this area. The following individuals are Ohio leaders who, if made aware of these issues, will hopefully push for legislation to aid in the initiation of day care and respite centers in Cincinnati:

J. Nick Baird: Director of Ohio Department of Health
246 North High Street
Columbus, Ohio 43216-0118

Senator Louis W. Blessing:
Senate Building
Room #038, Ground Floor
Columbus, Ohio 43215

Senator Robert Schuler:
3748 Jeffery Street
Cincinnati, Ohio 45236

Majority Floor Leader Representative Patricia Clancy:
3675 W. Galbraith Road #16
Cincinnati, Ohio 45247

Tom Hayes: Director
Ohio Department of Job Family Services
Rhodes State Office Tower
30 East Broad Street; 32 Floor
Columbus, Ohio 43215



Special Needs Resource Directory

Adventures for Wish Kids

What's New

Since the launch of the Special Needs Resource Directory on August 26, 2003, we've had over 6,000 visits to the web site. Around 15-20% of the visits are international.

To continue to meet the needs of our patients and families, we've added a lot of new information to the Special Needs Resource Directory, including:

- Clinical Trials
- Definitions / Medical Terms
- Insurance Issues
- Indiana and Kentucky Resources pages
- Hospice and Palliative Care

In addition, we've enhanced the Assistive Technology / DME and Caregiver Resources pages with new resource information. We've also added additional Summer Programs resources to the Recreation page, just in time for summer fun!

If you have any ideas for additional resources or information that might be helpful to families of children with special health care needs, please send us an email (specialneeds@cchmc.org).

Social Skills Group for Adolescents

The Division of Developmental Disabilities at Cincinnati Children's is conducting a social skills group for adolescents with learning disabilities, titled Building Relationships and Surviving High School. These ongoing sessions are open to 12- to 16-year-olds with an identified learning disability and an IQ greater than 80 without psychosis, conduct disorder or extreme aggression. For more information, contact the Division of Developmental Disabilities Psychology Department at 513-636-5858.

Staff Changes

We said Goodbye to Marilyn who left to pursue other opportunities. We welcome Sara Maurmeier who has been a nurse on the rehabilitation unit here at Children's for the last 1-½ years.

Children with life-threatening diagnoses are eligible for Adventures for Wish Kids - local, fun-filled, free events for the entire family. Events have included things like: a day at Kings Island, Red's games and other sporting events, holiday parties and MUCH more! For more information and an application, contact:

Adventures for Wish Kids
Cincinnati Area Council
8595 Beechmont Ave, Suite 201
Cincinnati, Ohio 45255
513-232-5104
jolvey@fuse.net
www.afwkids.org

Please note that participation in Adventures for Wish Kids does not take the place of a Wish.

Special Olympics Is Coming

Hamilton County Special Olympics Spring Games are Saturday May 8, 2004. Entries are due by March 31, 2004. More information and an application can be obtained by calling 513-271-2606. Please allow ample time for our office to complete the "Physical Examination" form required for participation. In addition to the Spring Games, the Special Olympics offers year round sports opportunities. Visit their web site at www.hcso.net to view the activities calendar.

For Special Olympic information in Butler, Brown, Clermont, Clinton and Warren Counties, contact volunteer coordinators Debi Williams or Diane Ayers at Lakoyta Schools at 513-644-1212, ext. 22086.

Meeting Announcement

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