



Massachusetts Family-to-Family Health Care Information & Education Center

A project of Mass Family Voices @ Federation for Children with Special Needs, funded by a 2004 Real Choice Systems Change Grant from the Centers for Medicare and Medicaid Services.

Topical Conference Call: Tuesday, August 30, 2005

Topic: Back to School Readiness: What Every Parent Needs to Know to Ensure Their Child's Special Health Care Needs Are Met During the School Day

Goal: To learn about the process of transitioning a child with special health care needs to school or back to school, school health services and regulations, school-related health care documents, and resources and supports for families.

Conference Call Summary:

♥ **Welcome** – *Beth Dworetzky, Mass Family Voices @ Federation for Children with Special Needs*

Mass Family Voices is project at the Federation for Children with Special Needs, and a state chapter of Family Voices, a national, grassroots organization of families, friends and professional partners who speak on behalf of children and youth with special health care needs. Mass Family Voices is also a Family-to-Family Health Care Information and Education Center, funded by a 2004 Real Choice Systems Change grant from the Center for Medicare and Medicaid Services. One Family-to-Family Center activity is to offer topical conference calls on subjects of interest to families of children and youth with special health care needs.

Thank you very much for taking the time to participate in today's call about children with special health care needs who are first transitioning to school or just returning to school, presented by Deborah Croucher, the Masstart Program Coordinator.

♥ **When Your Child with Special Health Care Needs Goes to School** - *Deborah Croucher, RN, BS, Masstart Program Coordinator*

Parents: Do Your Homework: *Preparation is key to ensuring your student's success*

As the end of summer draws near, families are purchasing or dusting off book bags, sharpening pencils and collecting rulers, crayons, paper and other school supplies. For children with special health care needs, the list of school supplies may also include: incontinence supplies, gastronomy tubes, gloves, tracheostomy care supplies, feeding formula, a log book, physician's orders, and medications.

If your child with a disability is first entering school and requires specially designed instruction in order to access the general curriculum, hopefully you have already met with your child's Team and developed an IEP (Individualized Educational Program: <http://www.fcsn.org/peer/ess/pdf/ideafs.pdf>). The school

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nurse is part of your child's Team in planning for both the health and educational needs of your child. Health care needs that impact the school day are a condition for requirement of an IEP. 504 Accommodation Plans (<http://www.concordspedpac.org/section504.html>) are an option if your child does not have educational needs, but needs special accommodations for health care in the school setting so that the student can access the general school curriculum. Health Care Plans and Emergency plans should reflect not only the child's specific medical needs/interventions, but should also address building egress, transportation, fire drills and fires, lock down situations, proximity to exits and nursing access, provision for services in the event of the inability to access the nurse, and power failures, among others.

If the student is returning to school, families will also need to review their child's paperwork. This may include an IEP or 504 Accommodation Plan, and the Individualized Health Care Plan (IHCP).

As you review your child's paperwork, note any changes that may be necessary to ensure your child's special health care needs are met during the school day. **It is very important to note whether or not these changes affect your child's ability to participate in the school day.**

Will your child need more out-of-class time to have medical needs met? Will additional staff be needed to ensure your child's needs are met? If so, make sure to include these modifications and/or accommodations on the child's IEP or 504. As you review these documents, make a list of health-related issues to discuss with the school nurse. Be sure to also document and address your child's transportation needs, and how your child's needs should be met during field trips and during after school activities, like participation in school-sponsored clubs.

If school nursing services are required in order for a child to receive a free and appropriate education (FAPE), then those services should be listed on the IEP and the student's Health Care Plans may also be attached to the IEP. As Health Care Plans may require frequent updating to reflect changes in the student's medical status, the parent(s) may give written consent that the entire IEP Team does not have to reconvene every time there is a change to the student's health services, unless the changes affect the way that your child is able to access his or her educational program, for example if they can only attend a half day or will have to reduce their attendance, if they now require an aide or other one to one support etc.

Communication Between Home and School: Your child will be attending school for many years. Open communication is key in successfully integrating your child with special health care needs safely into the school day. Be sure to work out a way to communicate (a log book, e-mail, phone calls, etc) with school personnel, especially the school nurse, as she is the "pivot point" for all health related services in school.

Any new treatments, procedures, or medications and any changes in your child's current regime, require a physician's order if these things need to be done in school. Ensure that all of your child's medical care needs are provided for by:

- Obtaining a written order for all care needed from the physician before your child goes to school, and
- Any equipment, supplies and/or medications are provided to the school by you in advance of the first day of school. Your child may not carry his medication to the school; you need to bring it in to the nurse yourself, in original containers with the name of the medication, the dose, and frequency.

Many parents ask if their child can carry his or her own medication to school and if their child can self-administer medications. In the *School Health Manual* there is a section on self-medication regulations (<http://www.mass.gov/dph/fch/schoolhealth/medadmin.htm>). The school nurse will work with your child and physician to determine if your child may be permitted to self-medicate during the school day. This includes inhalers and there is specific language, written in January 2005, regarding self-monitoring and treatment of students with Diabetes (<http://www.massfamilyvoices.org/diabetes.doc>).

If you get stuck: Your child's physician or subspecialty care provider can help you secure what is needed for your child in school. Additionally, if your child has private duty nursing, the nurse manager at your home care agency can help. Your vendor for supplies and equipment can also address specific training needs required in school. You should also contact the resources mentioned above, or speak directly with Debbie Croucher at (Deborah.croucher@state.ma.us) at 508-792-7880. Debbie will be happy to provide assistance and help you identify additional resources.

Understanding the System:

Whether your child is first going to school, or entering a new school, let the school nurse know your child is coming. Establishing an open dialogue with the nurse is important. Please remember, when the school nurse asks for documentation or physician's orders, it's not because s/he doesn't believe you. It's because there is a process that governs the practice of school nursing. The school nurse is the person responsible for health care in the school setting, and must follow a set of laws (<http://www.mass.gov/dph/fch/schoolhealth/lawsregs.htm>), standards of practice, regulations, policies and procedures in providing services to student's during the school day.

It's a good idea to make an appointment to meet with the nurse and visit the school prior to the first day and check the proximity of the health office to your child's classroom(s), if that is important to your child's care. When you meet with the nurse, remember to address any changes that may have occurred over the summer. This is also a time to provide needed prescriptions, medications, other supplies, physician's orders, and other documentation the nurse may require. You should also ask:

- Is the school nurse in the building all day, or only during certain hours?
- Who is the back up if the nurse is not there? Determine what the school's backup plan is for nursing services if no nurse is present, or is absent, and your child requires one.
- If someone, other than the school nurse (a delegate), will be administering medication or performing a treatment or procedure for your child, has the school nurse trained this person? School nurses can make a determination whether or not a treatment, procedure, or medication can be administered by someone other than a nurse (delegation), and they are responsible for the decision, training involved, and the assessment of competency regarding the delegation (<http://www.mass.gov/dph/fch/schoolhealth/medadmin.htm>).

Parents need to take the lead in meeting the school nurse, the teachers and other school personnel that will be with your child during the school day. Understandably parents may be nervous about sending their child to school, and likewise, school personnel may be nervous about your child's medical needs. The Massachusetts Department of Public Health has a free service, called MASSTART (Massachusetts Technology Assistance Resource Team: <http://www.mass.gov/dph/fch/masstart.htm>) that can help families and schools feel more comfortable about how a student's medical needs will be met during the

school day. Regional MASSTART staff provide consultation to families and school staff to address individual health care plans. They can speak knowledgeably about coordination of services, provide written information and resources, and if requested, can provide training that school staff may need. MASSTART staff is also available by phone and e-mail to provide technical assistance. Brochures, in English, Espanol and Portugues are available at <http://www.mass.gov/dph/fch/masstart.htm>.

The School Health Services Unit (<http://www.mass.gov/dph/fch/schoolhealth/index.htm>), another program of the Massachusetts Department of Public Health, develops the specific regulations that govern school nursing, screenings, administration of medications, delegation, management of life-threatening allergies, and other practices. Their guidebook, *The School Health Manual*, which is provided to all school nurses, will be available on-line in November, but many of the regulations are currently posted on the website.

Additional Resources

Directions: Resources for Your Child's Care (www.mass.gov/dph/fch/directions/index.htm).

“Directions” is an organizing notebook and a resource guide for families of children with special health care needs. It is organized into 10 chapters, and contains hints about tracking information about your child, and many forms to help you organize that information. There is a chapter that specifically addresses school-related issues, and another that provides information about emergency preparedness. This notebook can be downloaded from the website. Families can also order a free copy. Order forms are on the website. ***Directions*** is also available in Espanol.

Federation for Children with Special Needs: If you need help understanding state and federal special education laws, or would like to attend any number of free workshops about developing an IEP, your family’s rights, transition, access to the general curriculum, and much more, call the Federation for Children with Special Needs at 1-800-331-0688 or visit them on the web at www.fcsn.org.

Massachusetts Family-to-Family Health Care Information and Education Center has developed a brochure (<http://www.familyvoices.org/Ihcpbrochure.pdf>) about developing health care plans for families of children and youth with special health care needs.

Conference Call Questions & Answers

1. If a child receives 1:1 private duty nursing at home, what happens in school?

It’s important to document the child’s routine at home, and your nursing agency nurse manager, or private duty nurse can help with this so that together, you can decide what care can be managed at home and what will be needed in school. There are no hard and fast rules about what any school has in terms of nursing resources, so it’s important to know what your child’s needs could be and communicate those to the educational team. Often this is a point of negotiation, and again, your nursing agency or MASSTART (<http://www.mass.gov/dph/fch/masstart.htm>) can help the school determine what has to be done during the day, who can do it, what training may be needed for the school staff or an individual nurse etc.

Many families ask if the nurse that provides services at home can also provide services in school. Sometimes the school is happy to have the family identify a provider. If the provider and the school are

willing, this is an arrangement that can be worked out with the school, but the school also has the option of hiring their own provider. If MassHealth is paying for a child's private duty nursing, and nursing services are also needed during the school day, the school can bill for services through the Municipal Medicaid Program (http://www.fcsn.org/publications_resources/newsline/nl25n4.pdf)

2. What types of things should a family consider when preparing an Emergency Preparedness Plan? Schools address Emergency Preparedness for the entire student population, but realize there may be special circumstances to address for children with special health care needs. If the school is locked down, or there's a fire, power outage, etc. they need to develop contingency plans to ensure a student's special health care needs are met. There is a section in the *Directions* Manual that specifically addresses Emergency Preparedness.

If a child may need emergency services as part of their Individualized Health Care Plan, these needs should be specifically addressed in an **Individual Emergency Plan** separate from the school Emergency Preparedness Plan. The Individual Emergency Plan should address what defines an emergency for the child, the observations required along with the attendant actions and emergency services that are required, such as calling 911, etc. This individual plan should also consider what the child's needs would be in the event of a school wide emergency such as a lock down or biological hazard.

3. Is the Health Care Plan a legal document?

While there are no standard forms for Health Care Plans, these plans contain individual-specific information and documentation, and define the nurse's or delegated person's responsibility, and are therefore legal documents.

4. What's the recommended timeline for the transition process?

If a child is going to a new school, it's best to allow at least two months for transition. This gives everyone enough time to plan for your child's needs. Keep in touch over the summer. Be available as a resource. If a child is transitioning from early intervention to school, you should allow 3 months for transition, but if this child has major medical issues, it's best to start 6 months in advance because it takes more time to identify and locate needed classrooms services.