



# The Beacon



**The NC Family to Family Health Information Center  
A project of The Exceptional Children's Assistance Center  
Home to Family Voices of NC**

January, 2009

FAMILY VOICES®

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## Welcome from the NC Family to Family Health Information Center (HIC)!

This monthly electronic newsletter is designed to provide parents with links, resources, information and activities of particular interest to the issues of children with special health care needs.

To be added or removed from "The Beacon" mailing list: [hic@ecacmail.org](mailto:hic@ecacmail.org)



Click on a snowflake to link to important health information and resources:



**The NC Family to Family Health  
Information Center at ECAC**  
A project of The Exceptional Children's  
Assistance Center

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*Winter*

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## Upcoming Events:



- January 15, 2009 Workshop “How to be an Effective Health Care Advocate” 6:00pm-8:00pm Sparta NC.
- January 20-21, 2009 Autism Awareness Seminar 9:00am-1:30pm Ft. Bragg NC  
Workshop “Health Care Transition: From Pediatric to Adult Health Care” to be presented Jan. 20th 12:25pm.
- January 20, 2009 Workshop “Transitioning from Pediatric to Adult Health Care”. 2-4pm Mooresville NC for parents and youth!



- February 7, 2009 **SPANISH** Workshop “Care Notebook” 10:30am-Noon Winston Salem NC.
- February 24, 2009 Workshop “How to be an Effective Health Care Advocate” 6:00-8:00pm West Jefferson NC.
- February 28, 2009 Workshop “How to be an Effective Health Care Advocate” 3:00pm-5:00pm Charlotte NC.

For more information or to register for any of these events please call  
**(800) 962-6817 ext. 35.**

## WEB LINKS for January

<b>Topic</b>	<b>Link to Web Article</b> Simply click on title to be taken directly to the web page!
<b>Children and Youth with Special Health Care Needs</b>	<a href="#"><u>NC Client Assistance Program</u></a>
<b>Transition</b>	<a href="#"><u>Transitioning Adolescents with Special Needs to Adult Health Care</u></a>
<b>Monthly Health Topic:</b>	<a href="#"><u>Seasonal Flu</u></a>
<b>Disaster Preparedness/ Emergency Planning</b>	<a href="#"><u>First Aid and Safety</u></a>
<b>Financial Concerns Insurance Issues</b>	<a href="#"><u>NC Health Insurance Risk Pool</u></a>
<b>Advocacy</b>	<a href="#"><u>Talking to your child's doctor about your seriously ill child</u></a>
<b>Cultural Awareness</b>	<a href="#"><u>Guide to Cultural Awareness</u></a>
<b>Legal Information</b>	<a href="#"><u>Family Medical Leave Act Final Rule</u></a> & <a href="#"><u>Revised FMLA Certification Form</u></a>
<b>Provider Issues</b>	<a href="#"><u>Health Care Quality Improvement Resource</u></a>
<b>Families as Leaders</b>	<a href="#"><u>Ideas for Change in America</u></a>



## Best Practice Bulletin



The goal of the NC Family to Family Health Information Center is to provide resources, material and information on health related issues to parents of children with special health care needs. One method of providing information is through our "Best Practice Bulletin". The term "Best Practice" is an idea that there is one way that is more effective at delivering a particular outcome than any other (Wikipedia 2009).

In this Best Practice Bulletin we are highlighting the Family-Centered Care tools just released by Family Voices. These tools are designed as an opportunity for health care practices and families to assess current areas of strength and identify areas for growth, plan future efforts, and track progress toward family-centered care. To review these materials simply click on the links below:

[Family Tool](#)

[Provider Tool](#)

[Users Guide](#)

In the introduction of the Family Tool it states:

*"Health care visits for children, youth and their families can be more than getting shots, having ears examined or treated the physical symptoms of an illness. Each visit is an opportunity for families, youth and health care providers to partner to assure quality health care for the child and to support the family's needs in raising their child. This enhanced aspect of the family and health care provider relationship is called family-centered care."*

The tools are not designed to provide a score but to be used as a opportunity for reflection and quality improvement activities related to family-centered care within outpatient health care practices. For example, should one of the questions reveal a potential issue, this could begin a respectful discussion with the medical provider about ways to improve health care services. Likewise, medical providers can use the tool to promote family-centered care activities within their practice.

For more information about family-centered care please see visit our website and review the materials by clicking here: [Medical Home](#). Should you have questions or wish to discuss this concept further, please contact Wendy Ward at (800) 962-6817 ext. 35 or email [hic@ecacmail.org](mailto:hic@ecacmail.org) .

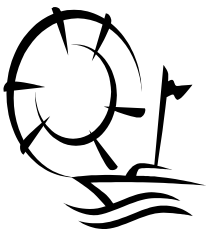


# *Lending Library*

The NC Family to Family Health Information Center is adding health and disability specific books to the lending library at The Exceptional Children's Assistance Center. Our library has over 2,000 books which are available to NC parents at no charge. To borrow a book or other library item, please call Shandra Umazar, ECAC's librarian at **(800) 962-6817 ext. 13**.

Health related books/materials added this month:

- ***Count Us In Growing Up with Down Syndrome*** by Jason Kingsley and Mitchell Levitz (Book)
- ***100 Questions & Answers about Communicating with Your Healthcare Provider*** by John A. King, MD and Cynthia R. King, PhD, NP, MSN, RN, FAAN (Book)



The purpose of the e-letter is to assist families and the professionals working with them to better understand issues and resources related to health care for children and youth with special needs so that they may make informed choices. Funding comes, in part, from the U.S. Health Resources and Services Administration (HRSA). The views and opinions herein do not necessarily reflect views or policies of HRSA, The NC Family to Family Health Information Center, or The Exceptional Children's Assistance Center.