Flu and Children/Youth with Special Health Care Needs (CYSHCN)

With flu season in full swing, families should take steps now to ensure that everyone in the household is as protected as possible, especially children/youth with special health care needs/disabilities.

A recent study from the Centers for Disease Control and Prevention (CDC), based in part on a survey of families developed in partnership with Family Voices which was distributed through Family-to-Family Health Information and FV State Affiliate Organization networks, reveals these key findings relevant to CYSHCN:

- Only half of children with neurologic and neurodevelopmental conditions are vaccinated against the flu each year.
- Families view their child’s doctor as the main source of information about the flu.
- Many pediatricians do not recognize intellectual disability as a high-risk condition for the flu.

These findings are significant because in a report published last year, CDC documented that 64% of children with underlying health conditions who died from the flu had a neurologic disorder or neurodevelopmental condition.

If children with intellectual disabilities are vulnerable to flu complications, and families depend on their pediatrician for advice, yet doctors are not aware of the risk, are we inadvertently placing children with neurologic disorders at risk? What can we do?

Families and providers must learn about the complications of the flu for CYSHCN and take steps to prevent avoidable illness. Families can share information and concerns with their child’s provider, including risks of flu complications for children with neurologic and neurodevelopmental conditions. Families should follow CDC guidelines that any individual over 6 months of age receive the flu shot; children under the age of 6 months cannot get the flu vaccine and so it is very important that all other family members get vaccinated and take precautions to keep germs from spreading.

By Michelle Diament

Despite an increased risk for complications from the flu, many children with intellectual disability, cerebral palsy and other disorders are not vaccinated to protect against the virus.

Just half of children with neurologic or neurodevelopmental conditions receive the flu vaccine each year, according to a report published Thursday in the U.S. Centers for Disease Control and Prevention’s Morbidity and Mortality Weekly Report.

That’s similar to the vaccination rate for all children, but presents a dilemma because kids with special needs face bigger risks of hospitalization or even death if they contract the flu, officials said.

“Among the most vulnerable for influenza-related conditions are children with neurologic conditions,” said Anne Schuchat, director of the National Center for Immunization and Respiratory Diseases at the CDC. “We found that we have room for improvement.”

For the study, the CDC surveyed parents of more than 1,000 children with neurologic or neurodevelopmental conditions as well as about 400 physicians who treat children with special needs. They found that even though most parents rely on doctors to provide information about vaccines, many doctors fail to identify children who face high risk from the flu.

The CDC’s Schuchat said this is particularly significant on the heels of the 2009 H1N1 flu outbreak when a disproportionate number of kids with neurologic disorders died. Intellectual disability and epilepsy were two of the most common conditions affecting children who died that year. Yet, among doctors surveyed for the new CDC study, the conditions were two of the least likely to be identified as high risk.

“It’s very important that we vaccinate these children and those around them,” Schuchat said. “I hope that we can do better in the future.”

http://www.disabilityscoop.com/2013/09/13/cdc-disabilities-flu/18707/
Roadmap to IDEA: What You Need to Know About IEPs & IEP Meetings

When Congress reauthorized IDEA 2004, they made significant changes to Individualized Education Programs (IEPs) in several areas, including:

- content of IEPs
- IEP meeting attendance
- IEPs by agreement
- review and revision of IEPs
- transition
- alternate means of participating in meetings

This article will provide you with a roadmap to changes in IEPs and IEP meetings under IDEA 2004.

Content of IEPs

Some requirements for the contents of IEPs changed. Others remained the same.

Present Levels of Performance. In IDEA 97, IEPs were required to include “a statement of the child’s present levels of educational performance...”

Under IDEA 2004, the child’s IEP must include “a statement of the child’s present levels of academic achievement and functional performance ...”

Present levels of academic achievement and functional performance are objective data from assessments.

Annual Goals. Under IDEA 97, IEPs were required to include a “statement of measurable annual goals, including benchmarks or short-term objectives.” IDEA 2004 eliminated the requirements for “benchmarks and short-term objectives” in IEPs - except that the IEPs of children who take alternate assessments must include “a description of benchmarks or short-term objectives.”

IDEA 2004 added new language about “academic and functional goals.” IEPs must now include “a statement of measurable annual goals, including academic and functional goals ...”

Educational Progress. IDEA 97 required IEPs to include a statement about how the child’s progress toward the annual goals would be measured, how the child’s parents would be regularly informed about “their child’s progress toward the annual goals,” and whether the child’s progress was sufficient.

In IDEA 2004, the child’s IEP must include “a description of how the child’s progress toward meeting the annual goals...will be measured and when periodic reports on the progress the child is making toward meeting the annual goals (such as through the use of quarterly or other periodic reports, concurrent with the issuance of report cards) will be provided.”

Special Education and Related Services. IDEA 2004 includes important new language about research-based instruction.

The child’s IEP must include “a statement of the special education and related services and supplementary aids and services, based on peer-reviewed research to the extent practicable, to be provided to the child ... and a statement of the program modifications or supports for school personnel ...”

http://www.wrightslaw.com/idea/art/iep.roadmap.htm
Accommodations and Alternate Assessments. IDEA 2004 contains new language about “individual appropriate accommodations” on state and district testing and new requirements for alternate assessments. The child’s IEP must include:

"...a statement of any individual appropriate accommodations that are necessary to measure the academic achievement and functional performance of the child on State and districtwide assessments..."

" ...if the IEP Team determines that the child shall take an alternate assessment on a particular State or districtwide assessment of student achievement, a statement of why (AA) the child cannot participate in the regular assessment; and (BB) the particular alternate assessment selected is appropriate for the child..."

Transition. Congress made extensive changes to the legal requirements for transition. IDEA 97 required “a statement of transition services needs” (beginning at age 14) and “a statement of needed transition services for the child” (beginning at age 16). The statement of transition services needs at age 14 was eliminated.

Under IDEA 2004, the first IEP after the child is 16 (and updated annually) must include:

"...appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills ... and the transition services (including courses of study) needed to assist the child in reaching these goals. (Section 1414(d)(1)(A))

When Members May Be Excused from IEP Meetings

A member of the IEP team may be excused from attending an IEP meeting if the member’s area of curriculum or service will not be discussed or modified and if the parent and school agree.

A member of the IEP team may also be excused if the member’s area of curriculum or service will be discussed or modified, if the member submits a written report to the parent and the IEP team in advance, and if the parent provides written consent. (Section 1414(d)(1)(C))

Developing the IEP

In developing the IEP, the IEP team shall consider:

• the child’s strengths
• the parent’s concerns for enhancing the child’s education
• the results of the initial evaluation or most recent evaluation
• the child’s academic, developmental, and functional needs (Section 1414(d)(3)(A))

The IEP team shall consider special factors for children:

• whose behavior impedes learning
• who have limited English proficiency
• who are blind or visually impaired
• who are deaf or hard of hearing (Section 1414(d)(3)(B))

http://www.wrightslaw.com/idea/art/iep.roadmap.htm
Educational Placements

The law about educational placements is in Section 1414(e). Parents are members of the team that decides the child’s placement. The decision about placement cannot be made until after the IEP team, which includes the parent, reaches consensus about the child’s needs, program, and goals.

Although the law is clear on this issue, the child’s “label” often drives decisions about services and placement, leading school personnel to determine the child’s placement before the IEP meeting. These unilateral actions prevent parents from “meaningful participation” in educational decision-making for their child. When Congress added this provision to the law in 1997, they sent a message to school officials that unilateral placement decisions are illegal.

Reviewing and Revising the IEP

The IEP must be reviewed at least once a year to determine if the child is achieving the annual goals. The IEP team must revise the IEP to address:

- any lack of expected progress
- results of any reevaluation
- information provided by the parents
- anticipated needs (Section 1414(d)(4)(A))

Revising IEP by Agreement, Without an IEP Meeting

IDEA 2004 changed the process by which IEPs can be amended or modified. If the parent and school agree to amend or modify the IEP, they may revise the IEP by agreement without convening an IEP meeting. The team must create a written document that describes the changes or modifications in the IEP and note that, by agreement of the parties, an IEP meeting was not held. (Section 1414(d)(3)(D))

Alternative Ways to Participate in Meetings

School meetings do not have to be face-to-face. IEP and placement meetings, mediation meetings, and due process (IEP) resolution sessions may be convened by conference calls or videoconferences. (Section 1414(f))

In-State and Out-of State Transfers

If a child transfers to a district in the same state, the receiving school must provide comparable services to those in the sending district’s IEP until they develop and implement a new IEP. If a child transfers to another state, the receiving district must provide comparable services to those in the sending district’s IEP until they complete an evaluation and create a new IEP. (Section 1414(d)(2)(C))

Multi-Year IEPs

Fifteen states may request approval to implement optional “comprehensive, multi-year IEPs” for periods of no longer than three years. IEP review dates must be based on “natural transition points.” Parents have the right to opt-out of this program. The parent of a child served under a multi-year IEP can request a review of the IEP without waiting for the “natural transition point.” (Section 1414(d)(5))

http://www.wrightslaw.com/idea/art/iep.roadmap.htm
Study Finds Postsecondary Programs Boost Outcomes

By Shaun Heasley

Individuals with intellectual disabilities who attend postsecondary programs are finding greater success in the job market than those who do not pursue further education, a new study suggests.

Graduates of postsecondary programs reported higher rates of employment since completing high school, according to findings published online this month in the Journal of Intellectual Disabilities. The research offers support for a growing number of programs at colleges and universities specifically geared toward young adults with developmental disabilities.

For the study, researchers interviewed administrators and surveyed 34 graduates from two postsecondary programs — one focused on providing supports so students can participate in typical college classes and the other offering a more specialized program just for those with disabilities. Researchers asked about the work experiences of the graduates who completed postsecondary programs between 2011 and 2013.

The graduates’ experiences were then compared to data from the federally-funded National Longitudinal Transition Study 2 on the post-high school outcomes of individuals with intellectual disabilities who did not attend postsecondary programs.

Researchers found “steep gains” for individuals in both the specialized and inclusive postsecondary offerings.

Slightly over half of those who did not seek additional education after high school said they had been employed in the last two years. By comparison, roughly 9 in 10 of those who graduated from a postsecondary program reported that they had worked outside their home or former school in the same time period.

“There is a growing body of evidence that suggests that (postsecondary education) programs for individuals with (intellectual disabilities) are highly effective as a means to increase employment rates for such individuals,” wrote Eric J. Moore of the University of Tennessee and Amy Schelling of Grand Valley State University in their findings. “Such data can and should be used to encourage further propagation of (postsecondary) programs for individuals with IDs and provides justification for pilot programs of similar kinds in countries wherein (postsecondary) programs have not yet been made available for individuals with IDs.”

http://www.disabilityscoop.com/2015/01/20/study-postsecondary-outcomes/19972/
Family-Centered Care: From Theory to Practice
Guidelines for Families of Children with Special Health Care Needs (CSHCN)

Introduction
There are 11.2 million CSHCN in the United States, representing 1 in 5 US households. The Maternal and Child Health Bureau (MCHB), part of the US Department of Health and Human Services, Health Resources and Services Administration, helps CSHCN and their families by administering programs and policies such as State Title V and MCH Programs, Community Health Centers, and Medicaid. Since 1989, MCHB has worked with State Title V and other partners to implement a common agenda for CSHCN:

Provide and promote family-centered, community-based, coordinated care for children with special health care needs and facilitate the development of community-based systems of services for such children and their families.¹

What is Family-Centered Care?²
Family-Centered Care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice which results in high quality services.

The foundation of family-centered care is the partnership between families and professionals:

- Families and professionals work together in the best interest of the child and the family. As the child grows, s/he assumes a partnership role.
- Everyone respects the skills and expertise brought to the relationship.
- Trust is acknowledged as fundamental. Communication and information sharing are open and objective.
- Participants make decisions together.
- There is a willingness to negotiate.

Who are Families of CSHCN?³
We all come from families. Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, or as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support.

As family members, we nurture, protect, and influence each other. Families have strengths that flow from individual members and from the family as a whole. Each family is a culture unto itself, with unique values and its own way of realizing dreams.

Together, our families are the source of our rich cultural heritage and spiritual diversity. Our families create neighborhoods, communities, states, and nations.
Families have long known that their relationship with their child’s doctor is fundamental in ensuring quality health care. This perspective has been substantiated by a growing body of evidence from scientific studies that demonstrates the benefit of family-centered care to the patient, the family, the provider and others. Highlights of this evidence are provided below.

**How Does Family-Centered Care Benefit Families and Patients?**

- Decreased anxiety
- Accelerated recovery time
- Better patient coping during procedures, hospitalizations, and recovery periods
- Increased parent confidence and problem-solving capacity

**How Does Family-Centered Care Benefit Pediatricians and Other Providers?**

- Improved clinical decision making on the basis of better information and collaborative processes
- Improved follow-through when the plan of care is developed collaboratively with families
- Greater understanding of the family’s strengths and caregiving capacities
- More efficient and effective use of professional time and health care resources
- Improved communication among members of the health care team
- An enhanced learning environment for future pediatricians and other professionals in training

**What Can Families do to Initiate or Improve Family-Centered Care?**

Because family-centered care starts with a strong family/provider partnership, the following tips may help you develop skills to be an equal, respected partner. More information is provided in the Family Voices publication *Families Partnering with Providers*, available on the Family Voices website.

1. **Be confident in the knowledge you have about your child.**
   You are your child’s primary care-giver. You know your child the best. You sense when something is wrong. You observe how your child feels, what makes him worse and what makes him better.

2. **Organize and keep information up-to-date about your child.**
   Keep a care notebook on your child, as it will help organize and store information to share with your child’s providers. Download a care notebook from: http://cshcn.org/planning-record-keeping/care-notebook.

3. **Educate yourself about your child’s diagnosis and medical treatment.**
   Be an educated consumer. Read as much as you can and talk with others who can help you.

4. **Communicate openly with your child’s provider.**
   Be honest with your child’s provider. Ask questions when you don’t understand. Ask your child’s provider for additional resources that would help your child and/or your family.

5. **Connect with other families.**
   Other families have been down the same road and connecting with them may provide information and support. Start by contacting your state’s Family-to-Family Health Information Center. Visit the Family Voices’ National Center for Family/Professional Partnerships website for contact information: http://www.fv-ncfpp.org.

6. **Be an advocate.**
   Some parents say that being a mom or dad also means being a chauffeur or a coach or any number of other roles. If you are a parent of a CSHCN, then you also need to be an advocate. Speak up for your child and help him to advocate for himself. Join with others to advocate for all CSHCN.

7. **Learn more about Family-Centered Care.**
   Family Voices has developed tools to help you and your child’s provider better understand and implement family-centered care. Download the FCC Tools from the Family Voices website: http://www.familyvoices.org.

---

2. Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs. DEFINITION OF FAMILY-CENTERED CARE. Available at: www.familyvoices.org/admin/Work_family_centered/Files/FCCare.pdf.
3. Developed and adopted by the Young Children’s Continuum of the New Mexico State Legislature, June 30, 1990.
4. POLICY STATEMENT Family-Centered Care and the Pediatrician’s Role Committee on Hospital Care PEDIATRICS Vol. 112 No. 3 September 2003, pp. 691-696 (reaffirmed May 2007)
What Is Earlysteps?

Earlysteps is Louisiana’s Early Intervention System for children with disabilities and developmental delays ages birth to three (3) and their families. By providing resources and support during those critical years, earlysteps helps children get off to a great start.

What services does earlysteps provide?

Earlysteps services are provided to help your child grow and develop, and to help you support and promote your child’s development. These services include evaluation services, autism screening, speech, physical and other therapies; family training; and transportation assistance. Earlysteps services are provided in your child’s everyday environments- at home, childcare center, or other community setting.

For Referrals Please Contact:
System Point of Entry
602 Parish Rd
Thibodaux La 70301
985-447-6550
Fax: 985-447-6513
http://dhh.louisiana.gov/index.cfm/page/139/n/139