



CARE FOR KIDS



Early & Periodic Screening, Diagnosis & Treatment

Volume 8 • Number 3 • Fall 2001

Well-Child Care

for the Child with Developmental Disabilities

*Don Van Dyke, MD, Professor, Pediatrics; Director, Division of Developmental Disabilities
Susan Eberly, MA, Program Associate Center for Disabilities and Development
University of Iowa Hospitals and Clinics*

What is your role as a primary health care provider for a child with disabilities? It is much the same role as that you play for the other children in your care, but four areas require special attention:

1. Basic health care must remain a priority. When several specialists and a range of other service providers are seeing a child, basic health care can get lost in the shuffle. It is important that children have a medical home to oversee their basic health care.

2. Family support is crucial. When you help a family to function better, you help all of its children. Consider whether other family members are also in need of medical or mental health care.

3. Care coordination is more important, and more complex. Iowa Child Health Specialty Clinics and the Iowa Early ACCESS program can help with this process.

What disabilities are most common in Iowa?

We don't have the data to answer that question precisely. However, the conditions that most often bring people to the Center for Disabilities and Development (formerly University Hospital School) are:

- ADHD
- Behavior disorders
- Brain injury
- Cerebral palsy
- Diabetes
- Genetic conditions
- Learning disabilities
- Mental retardation
- Sleep disorders
- Spina bifida

In Iowa, where 11.8% of all school age children used special education services in 1998-99, chances are that some of the children you serve have disabilities.

4. Advocating for needed services may be part of the care you provide. To do this well requires an understanding of federal laws relating to children with disabilities and of services (local, state, and national) that families can tap. You can find more information about this on insert page 2.

BASIC HEALTH CARE

As with any child, at each visit you will want to monitor physical, mental, emotional, and social growth and development. This will include periodic assessment to determine the child's health status. For children with complex conditions, a pre-visit questionnaire, to be completed by the family, can be a useful tool (see Capute, 1996). Reviewing this and the child's health care records (your own and those from other health care providers who are seeing the child) before you see the child can make each visit more productive.

(continues on page 2)

Well-child care for the child with developmental disabilities

(continued from page 1)

Perinatal risk factors that place a child at risk include:

- Congenital malformations
- Child is small or large for gestational age
- Birth weight < 1500 g
- Apgar score of < 3
- Neonatal convulsions
- NICU treatment
- Head circumference < or > 3 standard deviations from the mean
- Apnea, multiple episodes
- Abnormal growth
- Chronic health conditions

Preventive health care is crucial for all children. Preventive care checklists for children with specific disabilities are particularly useful for children who have uncommon genetic syndromes or congenital anomalies. You can find such checklists in *Preventive Management of Children with Congenital Anomalies and Syndromes* (Wilson, 2000).

As you update the child's history during the visit, note the accomplishment of milestones, and watch for patterns that may serve as early warning signs. For example, language difficulties may be a precursor to learning disabilities.

As part of the office visit, you should observe the parenting skills of the child's family members and other care givers, as well as how the child interacts with others. Environmental factors that place a child at risk include parents or care givers who:

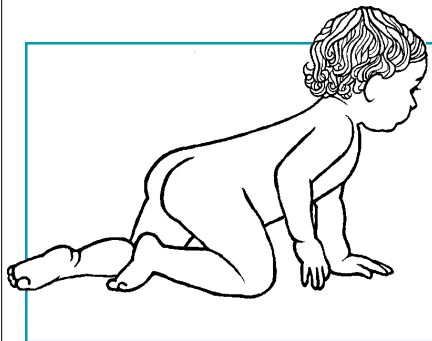
- Are teenagers
- Are single parents
- Lack family support
- Had poor prenatal care
- Have poor physical/mental health
- Have provided the child incomplete/no immunizations
- Lack education
- Show signs of abuse/neglect

(in parent or child)

- Are involved with child protective services
- Abuse drugs/other substances
- Are unemployed
- Live in poverty

The presence of perinatal or environmental risk factors suggest the need for further evaluation.

Record the child's height and weight, head circumference, and blood pressure. For children with certain conditions, such as Down syndrome, special growth charts are available (see insert page 2). Hearing and vision screening should follow the EPSDT Care for Kids screening schedule. A dental examination should be performed, and referral for dental care made if needed.



A complete physical examination of the unclothed child should be carried out. Immunizations should be administered. Hematocrit/hemoglobin, urinalysis, and a blood lead level test should be provided as per EPSDT Care for Kids guidelines.

As appropriate, administer a TB test and obtain other laboratory studies. Children at risk should also be tested for HIV, hepatitis, or other sexually acquired infections. Girls who are sexually active should be referred to a gynecologist for assessment and anticipatory guidance. All Iowa children should receive blood lead testing (see "Results of Lead Testing," page 3). Make a written record of what you learn during the exam, noting any acute or chronic medical

concerns that call for further evaluation or referral.

Ongoing health care management via a child's medical home can often prevent the development of secondary conditions and identify areas of concern in a timely and effective manner. A key role of a child's primary care provider is to refer the child and the family to resources when (or even before) they need them.

FAMILY SUPPORT

Contrary to popular belief, two-thirds of the families of children who have severe disabilities have rates of divorce, serious mental illness, and ongoing dysfunction that are no greater than those of other families (Wilson, 29).

But the interplay between organic and environmental factors is very important. For example, research shows that low birth weight children have more learning disorders later in life than their normal birth weight peers — except in families in which the parents are well-educated. For children with educated parents, environment — family — apparently offsets the negative factors related to low birth weight (Capute, 428).

Clearly, one of the most important roles of the health care provider is that of a reliable ally who supports and encourages the family. So:

- Encourage parents as they learn about their child, and share their excitement as their child progresses, even in small ways.
- Listen to and acknowledge their feelings, positive and negative.
- Provide information about their child's condition and what it will mean for the child — and the family.
- Repeat and re-explain with patience; emotionally charged information is often more difficult to retain and understand.

(continues on page 7)

Results of Lead Testing for Iowa Children

*Brian McPartland and Rita Gergely
Bureau of Lead Poisoning Prevention
Iowa Department of Public Health*

- **ALL Iowa children** should be routinely tested for lead poisoning using a blood lead test.
- This test is required by state and federal law for children covered by Medicaid.

The Iowa Department of Public Health (IDPH) recommends that all children be tested for lead poisoning using a blood lead test, and state and federal law require this for children covered by Medicaid. The results of recent data analyses make clear the need for such testing.

In September of 1999, IDPH developed a procedure to match Medicaid data with blood lead data from the STELLAR (Strategic Tracking of Elevated Lead Levels and Remediation) database. This child-specific database holds all blood lead test results reported to the Iowa Department of Public Health. IDPH can use STELLAR to identify multiple blood lead tests on an individual child; store address information for each child; and record all case management actions, such as home nursing visits, chelation, and environmental investigations.

Data matches target key concerns

The IDPH lead program carries out two types of matching of STELLAR data with Medicaid data. In the first match, it uses the results to determine the percentage of Medicaid vs. non-Medicaid children who are be-

ing tested and the prevalence of lead poisoning among the Medicaid and non-Medicaid populations.

In January 2000, IDPH used the first type of match to analyze, by birth cohort, data on blood lead levels in Iowa children. Using the STELLAR database, IDPH estimated the percentage of children younger than 6 years old who had received at least one blood lead test, and to evaluate trends in blood lead testing.

IDPH now has complete data on children born in 1992, in 1993, and 1994.

Of children born in Iowa in 1994:

- 42.0% of all children enrolled in Medicaid were tested; **17.7 were found to be lead-poisoned**
- 39.0% of all children not enrolled in Medicaid were tested; **7.3 were found to be lead-poisoned**

In the second type of match, IDPH reviews claims data to identify EPSDT Care for Kids screens that were done at an appropriate age for blood lead testing. These claims are matched to the STELLAR database to determine whether a blood lead test was done. The names of children who received a screen, but did not receive a blood lead test, are being referred back to the local childhood lead poisoning prevention programs so that they can contact the

provider to discuss the need for a blood lead test. For example, Mother and Child Health Services in Marshalltown is piloting a project to contact the providers of these screens. They will review the requirement to do a blood lead test in conjunction with an EPSDT Care for Kids screen. The agency will also track the number of children who receive a blood lead test as a result of the provider having been contacted.

For more information about lead poisoning in Iowa, please contact the IDPH Bureau of Lead Poisoning Prevention at 1-800-972-2026.

*University Hospital School
Has a New Name:*

The Center for Disabilities and Development

This July, University Hospital School in Iowa City officially became the Center for Disabilities and Development at the University of Iowa Hospitals and Clinics. UHS first opened its doors in 1948. Since then, it has served as Iowa's only tertiary program with a full range of health care and other services for people with disabilities. Today, as the Center for Disabilities and Development, it is a resource for infants, children, and adults.

Lead Poisoning: Myths that Place Our Children at Risk

Rita Gergely, Chief, Bureau of Lead Poisoning Prevention
Iowa Department of Public Health

Myths that Place Our Children at Risk

Common myths that put children at risk because they can keep a child from getting a blood lead test include:

MYTH 1

My practice doesn't include any lead-poisoned children.

- Most lead-poisoned children have no visible symptoms.
- You need to perform a blood lead test to identify a child with lead poisoning.
- If you don't test, it is unlikely you will ever identify a lead-poisoned child.

MYTH 2

The test is too expensive.

- Medicaid, HAWK-I, and group insurance plans will pay for blood lead tests.
- Iowa's two public health laboratories do the analysis for a reasonable price.
- Counties with local lead testing programs can help pay for tests when a family can't.

MYTH 3

Blood lead testing requires venipuncture.

- The initial blood lead test can be a finger stick done in the office.

MYTH 4

AAP calls for targeted testing of children.

- Under AAP (and CDC) guidance, ALL Iowa children should be given blood lead tests.
- Both AAP and CDC call for state committee review of blood lead testing and housing data from the state.
- If the percent of pre-1950 housing and the percent of children with high blood lead levels are both above certain levels, then universal testing is called for. This is the case in Iowa.

MYTH 5

Only one blood lead test, at 9-12 months, is needed.

- Many infants with normal blood lead levels at 12 months are lead-poisoned by 18 to 24 months. Retesting after 12 months is crucial.

MYTH 6

Children should be tested by the health department.

- Children are much more likely to get a blood lead test if you do one while they're in your office.
- Many families don't make it to the health department when you refer them.

MYTH 7

It is difficult to get information about lead testing procedures.

For information, contact the IDPH Bureau of Lead Poisoning Prevention:

- Call 1-800-972-2026
- Visit <http://www.idph.state.ia.us/eh/lead/lead.htm>

Recent data analyses by the Iowa Department of Public Health show that only 44 percent of the children born in 1995 have received at least one blood lead test. In some counties, this rate is more than 80 percent, but with the number of Iowa children with lead poisoning reaching nearly 18% in some populations, it is important that we increase the

rate of testing to more than 80 percent in all Iowa counties. The Iowa Bureau of Lead Poisoning Prevention plans to accomplish this by:

- Linking the first blood lead test to administration of the MMR vaccine at 12-15 months
- Linking additional blood lead tests to well-child visits

- Matching EPSDT Care for Kids claims with blood lead testing data to identify cases in which the screens did not include a blood lead test
- Educating providers and the public health community about the necessity for blood lead testing

REQUIRED LEAD ASSESSMENT:

Protecting Iowa's Children

I. Determine the child's level of risk.

A child is at **HIGH** risk if the answer to **ANY** of the questions below is **YES**.
A child is at **LOW** risk if the answer to **ALL** the questions below is **NO**.

II. Test the child using a blood lead test.

Test according to the chart below. **ALL** children, both high risk and low risk, must be tested using a blood lead test.

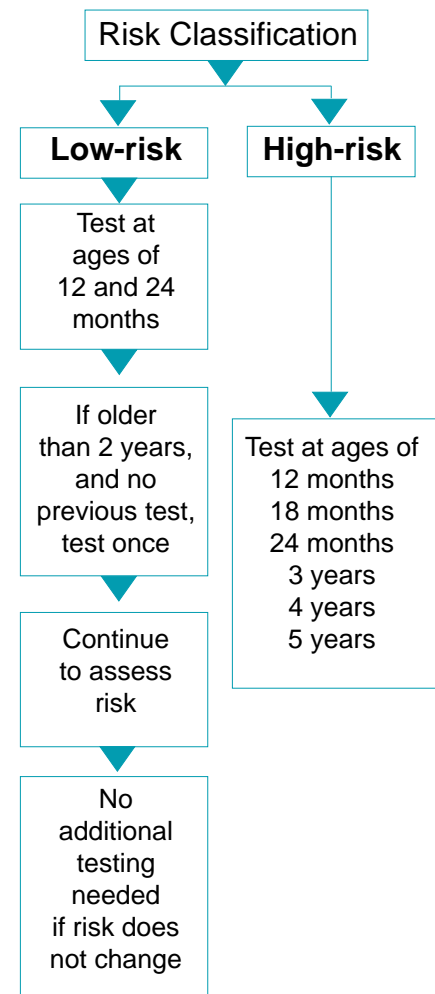
I. Assess level of risk: *Ask parents if any of these risk factors exist for their children:*

1. Has your child ever lived in or regularly visited a home or childcare site built before 1960?
2. Have you noticed any peeling or chipping paint in or around the pre-1960 house that your child has lived in or frequently visited?
3. Is the pre-1960 house that your child has lived in or frequently visited being remodeled or renovated by:
 - Stripping, sanding, or scraping paint on the inside or outside of the house?
 - Removing walls and/or tearing out lath and plaster?
4. Does the child eat non-food items such as dirt?
5. Have any of your other children or their playmates had lead levels ≥ 15 (g/dL)?
6. Does your child live with or frequently come into contact with an adult who works with lead on the job or as a hobby:
 - Battery plant worker
 - Battery recycling worker
 - Ceramics worker
 - Foundry worker
 - Old home renovator
 - Painter
 - Plumber
 - Scrap metal worker
 - Sheet metal worker
 - Shooting range worker
 - Stained glass worker
 - Welder
7. Does your child live near a battery plant, battery recycling plant, or lead smelter?
8. Do you give your child any home or folk remedies? (Examples: azarcon, greta, pay-loo-ah)
See also "Traditional remedies that contain lead," www.epa.nsw.gov.au/leadsafe/remedies.htm
9. Does your child eat candy that comes from Mexico or is purchased from a Mexican grocery store? (Examples: picarindo, vero palerindas)
10. Has your child ever lived in Mexico, Central America, South America, Africa, Asia, or eastern Europe, or visited these areas for a period longer than 2 months?

II. Test the child using a blood lead test:

After determining the risk classification, **ALL** children should be given a blood lead test according to the chart:

Basic Lead Testing Chart (based on risk and age)



Resources for Well-Child Care of Children with Disabilities

HEALTH CARE

Print and On-line Resources

American Academy of Pediatrics Recommendations for Preventive Pediatric Health Care, www.aap.org/policy/re9939.html

Capute, AJ, et al. (1996). *Developmental Disabilities in Infancy and Childhood, Vol. 1.*

Publications of the CDC National Center on Birth Defects and Developmental Disabilities (NCBDDD), at www.cdc.gov/ncbddd/dh/scpub.htm, and CDC Health topics, www.cdc.gov/health/diseases.htm

Wilson, GN, et al. (2000). *Preventive Management of Children with Congenital Anomalies and Syndromes.* Includes preventive care checklists for specific disabilities.

Wolraich, ML. (1996). *Disorders of Development and Learning — A Practical Guide to Assessment and Management.*

Special Growth Charts

Achondroplasia - www.neurosurgery.org/sections/pediatrc/MCFig2.html

Cerebral palsy - www.kennedykrieger.org/familyreso/cqcharts/gcindex.html

Down syndrome - www.aap.org/policy/re0016.html

Premature infants - www.kidsgrowth.com/resources/articledetail.cfm?id=684

Turner syndrome - www.kidsgrowth.com/resources/articledetail.cfm?id=521

William's syndrome - www.aap.org/policy/re0034.html

Care coordination

LOCAL RESOURCES

Your county Department of Human Services office

<http://www.dhs.state.ia.us/locations/locations.asp>

Your Area Education Agency

<http://www.state.ia.us/educate/aea.html>

Your Child Health Specialty Clinics (CHSC) Regional Center

Phone, toll-free, 866-219-9119

Your Iowa Early ACCESS coordinator

<http://www.state.ia.us/educate/programs/ecese/cfcs/access/access.html>

Iowa COMPASS - Call Iowa COMPASS at 1-800-7799-2001 for the phone number of your local DHS office, AEA, CHSC, or Early ACCESS coordinator. COMPASS can also tell you about other local, state, and national services.

Family support, advocacy for services

FEDERAL PROGRAMS

Learn more about these programs from your Department of Human Services office, Area Education Agency, or the web sites listed.

ADA - The Americans with Disabilities Act prohibits discrimination on the basis of disability by employers, state and local government entities, and places of public accommodation. www.usdoj.gov/crt/ada/adahom1.htm

IDEA - The Individuals with Disabilities Education Act "...assures that all children with disabilities have available to them...a free appropriate public education which emphasizes special education and related services designed to meet their individual needs." Part H provides services for children birth to 2 years who have disabilities. www.dssc.org/frc/idea.htm

An overview of ADA, IDEA: www.kidsource.com/kidsource/content3/ada.idea.html

Title V, Social Security - A program devoted to improving the health of low-income, medically under-served mothers and children. www.mchdata.net/

Title XIX, Medicaid - A joint federal/state program that pays for medical services for people with disabilities, people 65 years and older, children and their caretakers, and pregnant women who meet the program's financial requirements. www.geocities.com/CapitolHill/5974/

Well-child care for the child with developmental disabilities

(continued from page 2)

- Become a knowledgeable provider of information about local resources for families.
- Be alert to times of particular stress.
- Help the family plan for the future.

Families may be especially stressed:

- When a child's diagnosis is first announced
- During a child's major transitions: Home to day care; day care to school; school to college/work
- When the child reaches adolescence
- When the child reaches peak skill levels and progress slows

CARE COORDINATION

Ideally, the family coordinates care with the help of a community care coordinator and their primary care provider so that care doesn't become fragmented, less effective, and more costly. It is important that the primary care provider stay involved in planning services for the child.

In Iowa, families who have a child with a disability can use the care coordination services of Child Health Specialty Clinics (866-219-9119 or CHSC-HDM@uiowa.edu) or Iowa's Early ACCESS system. CHSC provides ongoing resource and referral information, technical assistance and consultation; facilitates service access and delivery; and enhances communication. CHSC serves children birth through age 21. Early ACCESS can assist with care coordination for children birth to 3 (see the summer '01 issue of this news-

letter, or visit w.medicine.uiowa.edu/uhs/EPSDT/sum01/access.cfm).

If a child is being seen by other medical specialties, you can help coordinate this care and prevent duplication of tests or services. Let other specialists know if you want to take on this role. If a child is seen by more than one medical specialist, be sure the family knows which specialist to contact with specific questions.

You may also be asked to help inform day care or school staff about the child's health needs, how to manage the child's care, and who to contact to report health status or concerns.

ADVOCACY

One of your most important roles is that of helping families find the resources they need (see insert page 2). Four federal programs that they — and you — need to be aware of include:

1. Individuals with Disabilities Education Act (IDEA)
2. Americans with Disabilities Act (ADA)
3. Title V, Social Security
4. Title XIX, Medicaid

Other resources that provide funding or services are also available on a local, state, and federal level. Good places to begin are:

- Your Area Education Agency(AEA)
- Your county Department of Human Services (DHS) office
- Iowa COMPASS
- Your Iowa Early ACCESS coordinator

For more information on resources you can use to provide well-child care for children with disabilities, see insert page 2.

How do I bill for immunizations?

*Edward L. Schor, MD, Medical Director
Division of Family and Community Health
Iowa Department of Public Health*

Billing through the federal Vaccine for Children (VFC) program:

Children who are eligible for VFC vaccine are those who are:

1. Enrolled in Medicaid,
2. American Indian or Alaskan Native, or
3. Uninsured.

Children with private insurance, including children enrolled in Iowa's HAWK-I program, are not eligible for the VFC program.

Billing through Iowa's HAWK-I program:

Physicians are encouraged to assist children to enroll in the HAWK-I program, and to bill the child's subsequent insurer for services, including immunization. In general, physicians should not refer children enrolled in HAWK-I to public health clinics for immunization, since those clinics are prohibited from using VFC vaccine for this population. Some practices have developed special billing arrangements with public health clinics in order to reimburse them for immunizations, using non-VFC vaccine, for insured children.

For more information, please contact Carolyn Jacobson, IDPH, 515-281-4938.

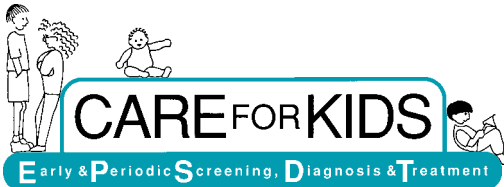
What's in this issue

Well-Child Care for the Child with Developmental Disabilities	1
Results of Lead Testing for Iowa Children	3
New Name: Center for Disabilities and Development	3
Lead Poisoning: Myths that Place Our Children at Risk	4
How Do I Bill for Immunizations?	7
Required Lead Assessment: Protecting Iowa's Children	Insert Page 1
Resources for Well-Child Care of Children with Disabilities	Insert Page 2

If you have questions about **billing**
related to EPSDT Care for Kids services, please call
Provider Services: **1-800-338-7909**

If you have questions about **clinical issues**
and EPSDT Care for Kids services, please call
Edward Schor, MD: **1-800-383-3826**

Please note: Due to budget restraints, the *EPSDT Care for Kids Newsletter* is sent to offices and organizations, rather than to individuals. Readers are welcome to photocopy material from the newsletter to share with others. **The newsletter is also available online at <http://www.medicine.uiowa.edu/uhs/epsdt/>.** If you wish to reproduce material from the newsletter in another publication, whether print or electronic, please obtain permission prior to publication by contacting the editor. Please include the following acknowledgment with reprinted material: Reprinted by permission of the Iowa *EPSDT Care for Kids Newsletter*.



University of Iowa Health Care
Center for Disabilities and Development
University Center for Excellence on Disabilities
100 Hawkins Drive
Iowa City IA 52242-1011

The *EPSDT Care for Kids Newsletter* is published three times a year, in print and online, as a joint effort of the Iowa Prevention of Disabilities Policy Council, the Iowa Department of Human Services, the Iowa Department of Public Health, and the Center for Disabilities and Development, University Center for Excellence on Disabilities. The goal of this newsletter is to inform Iowa health care professionals about the EPSDT Care for Kids program, to encourage them to make use of this important resource, and to provide them with information about a wide range of developments in the field of health care.

NEWSLETTER STAFF

Executive Editors

Claibourne I. Dungy, MD, MPH
Ellen Link, MD
Dianne McBrien, MD
Edward Schor, MD

Production Editor

Susan S. Eberly

Graphics Editor

Loretta Popp

Editorial Board

Robert Anderson, MD
Kay DeGarmo
Cheryl Johnson, MD
Sally Nadolsky
Don Van Dyke, MD
Kathleen VanZandt

*Any correspondence concerning
the newsletter should be addressed to:*

Claibourne I. Dungy, MD, MPH
or Ellen Link, MD
Family Care Center – Pediatrics
University of Iowa Hospitals and Clinics
200 Hawkins Drive 01212 - PFP
Iowa City, IA 52242-1083

PRSR STD
US Postage
PAID
Permit 45
Iowa City, Iowa