

The Arc of Illinois Family to Family Health Information and Education Center

2009 Statewide Transition
Conference
Schaumburg, IL

What is F2F HIC?

- 50 Family to Family Health Information and Education Centers nationwide
- Serving families and youth with special health care needs up to age 21
- Funded by Health Services and Resources Administration (HRSA) Maternal and Child Health Bureau (MCHB)
- Current funding until 5/31/10

F2F HIC staff

- Faye Manaster, Project Director
- Roseann Slaght, Project Assistant
- Deb Fornoff, Developmental Disability Specialist
- Octavia Byars, Transition Specialist

We are here to help you!

- Over 100 years combined special needs parenting experience
- Our families experience transition first hand every day
- Part of national network of families:
Family Voices www.familyvoices.org

Faye Manaster

- Project Director
- Parent
- Maya, age 28, is deafblind and has cerebral palsy
- Maya reads/writes Braille, uses tactile sign language
- Maya works as sign language teacher at high school in Chicago

Faye Manaster



Roseann Slaght

- Project Assistant/Trainer
- 4 children, including 2 adult sons with multiple disabilities
- Resides in Winnebago County
- Early Childhood Family Specialist for Starnet, Licensed Massage Therapist
- Sibshop trainer

Octavia Byars

- Two children-Tremaine is 3, in early childhood, and has Cerebral Palsy and Epilepsy
- Has been with F2F since September 2009
- Lives in suburban Cook County
- Degree in Criminal Justice
- Ex- Police Officer and former coordinator for Family Support Network

Deb Fornoff

- Deb and her husband have two children
- Bradley is 19, a high school senior in transition, and has Down syndrome
- Has been with F2F since January, 2009
- Illinois Life Span staff member since February, 2004
- Lives in Central Illinois
- MS in Education, Counselor Education
- Also worked as a Parent Liaison in EI, for Family Support Network of Illinois, and as a school counselor

Deb Fornoff



Transition Touchpoints

***Paths to Adult Health
Insurance Coverage***

Why is insurance a transition concern?

- Health insurance coverage rates for youth
Ages 18-30 years are lowest in nation
- Many youth with special needs not eligible for Medicaid
- Odds of getting employment-based insurance keeps dropping
- Staying on parent's insurance can be risky

Who are youth with disabilities?

- 2% of youth 19-21 are considered to have a disability
- Many youth with IEPs do not qualify for SSI
- 13,902 youth ages 18-21 on SSI in 2008
- About 16,066 students youth ages 18-21 had IEPs in 2008

Access to health care is a vital part of transition planning

- If parent modifies work hours due to transition needs, family health coverage may be at risk
- Available transition options may permit parent to stay on the job, but may not be optimal for youth
- Look before you leap!

Look before you leap

- Check out options before deciding
- Ask questions about your specific needs
- Find out what is and is not covered
- Ask how much things cost
- Don't "enroll" until you have answers
- Find out who can help you
- Don't assume your insurance coverage will stay the same

What do we know about health insurance, youth and families

- 60% of Illinois children have private insurance (up to age 19)
- 31% of youth 19-29 years are uninsured
- 12% of uninsured youth have chronic conditions
- Options to stay on parent's insurance are limited

New Illinois insurance law

- New law was passed 9/08
- Can cover adult children up to age 26
- Allows them to stay on parent's insurance
- Not related to disability status
- Includes college students
- Extending Parental Health Insurance to Unmarried Dependents

New Illinois insurance law

- Additional information about this law can be found on the Illinois Department of Insurance website
 - **Illinois Insurance Facts**
 - **Young Adult Dependent Coverage**
 - **<http://insurance.illinois.gov/pressRelease/pr08/HB5285DependentCoverage.pdf>**

1969 Law allowing “disabled adult child” to stay on parental insurance

- Illinois Statute... (215 ILCS 5/367b)

(a) This Section applies to the hospital and medical expense provisions of a group accident or health insurance policy.

(b) If a policy provides that coverage of a dependent of an employee or other member of the covered group terminates upon attainment of the limiting age for dependent persons specified in the policy, the attainment of such limiting age does not operate to terminate the hospital and medical coverage of a person who, because of a handicapped condition that occurred before attainment of the limiting age, is incapable of self sustaining employment and is dependent on his or her parents or other care providers for lifetime care and supervision . . .

For more information . . .

- *Special Needs Future Planning: GROUP HEALTH INSURANCE FOR "ADULT" CHILD WITH SPECIAL NEEDS?*
- This document with additional information is available on the website of Brian Rubin, JD and member of The Arc of Illinois Board of Directors.

New Federal Health Insurance Law

- Michelle's Law
- Effective for plan years beginning on or after October 9, 2009, Michelle's Law requires group health plans to continue healthcare coverage for dependent students who would otherwise lose their coverage because of a medically necessary leave of absence from a postsecondary educational institution.
- Michelle's Law (Public Law 110-381) prohibits a group health from terminating coverage of a dependent child under the plan due to a medically necessary leave of absence from a postsecondary educational institution before the date that is the earlier of (A) the date that is 1 year after the first day of the medically necessary leave of absence; or (B) the date on which such coverage would otherwise terminate under the terms of the plan or health insurance coverage.

What are the 4 paths?

- Remain on parent's insurance
- Medicaid coverage (AABD)
- Get employment-based insurance
- Health Benefits for Workers with Disabilities

What does the data say?

Health insurance coverage rates for youth ages 18-30 years are lowest in nation.

**Percentage of Uninsured Americans by Age
1995, 2000, and 2007**

Age	1995	2000	2007
18–20	21.5	23.7	23.5
21 – 24	29.9	29.7	31.9
25 – 34	21.4	21.6	26.0
35 – 44	15.4	15.2	18.4
45 – 54	12.3	11.5	15.4
55 – 64	12.4	12.3	12.0

The table above shows the levels of uninsured by age groups over time.
 Source: Employee Benefit Research Institute estimates from the Current
 Population Survey, March 1996, 2001, and 2008 Supplements.
<http://www.ebri.org/pdf/FFE135.10Sept09.Final.pdf>

Why is this a concern?

- Many youth with special needs are not eligible for Medicaid.
- *Adults with disabilities who do not have children must FIRST be eligible for SSI in order to qualify for the Medicaid program for adults with disabilities (AABD: Assistance to the Aged, Blind and Disabled).*
- *HBDW only if you have a job*

Who qualifies for SSI?

Anyone who is:

- aged (age 65 or older);
- blind; or
- Disabled
- And meets additional criteria

What does “disabled” mean for an adult? An individual age 18 and older is "disabled" if he or she has a medically determinable physical or mental impairment, which:

- results in the inability to do any substantial gainful activity;
- and can be expected to result in death;
- or has lasted or can be expected to last for a continuous period of not less than 12 months.
- www.ssa.gov

Many students with IEP's will not be eligible for Medicaid.

- The 2007/2008 Special Ed Profile Reports on the ISBE website indicated that there were 318,478 students in Illinois with IEP's in that school year.
- 42.54% or around 133,761 of those students were categorized as having a Specific Learning Disability.
- 22.14% or about 70,065 were categorized as having Speech or Language Impairment.

Some students who qualify for SSI as children will not qualify as adults.

- Today, 90% of children with disabilities or special health care needs survive into adulthood, and they account for one-half of all health care expenditures for children, even though they represent about 15%–18% of all American children.
- *From **Primer on Health Care Access for Young Adults with Disabilities**, Patience Haydock White and Leslie Gallay, April 2005, Issue 27, a Policy Brief from the MacArthur Foundation Research Network on Transition to Adulthood and Public Policy, University of Pennsylvania, Dept. of Sociology*

Relationship between Medicaid and SSI

- Medicaid is the major source of health insurance for low-income youth, and, as of 1999, it was the source of health insurance for 80% of adults under age 65 with severe disabilities.
- Eligibility and services vary by states, and in IL, Medicaid covers youth until age 19, so long as the family meets state income eligibility criteria.
- Once they are 19, however, youth risk losing Medicaid coverage unless they have children of their own who qualify or they are eligible for Supplemental Security Income (SSI).
- Estimates are that 400,000 youth in the national Medicaid program with serious chronic health conditions are at risk of losing Medicaid and are unlikely to qualify for SSI.

Child vs. Adult SSI

- SSI is a means-tested program designed to supplement Medicaid and other public benefits.
- Children under age 18 who meet the Social Security Administration's (SSA) definition of disability and whose parents meet the SSI income criteria are covered.
- After age 18, many states redetermine eligibility based on adult criteria, including that the individual must be unable to work.
- SSA estimated in 2001 that 30% of those who had SSI as a child were no longer eligible as adults because they were able to work and/or earned more than \$700 per month.
- Many of these youth who lose SSI would also lose Medicaid.

Illinois has Health Benefits for Workers with Disabilities!!

- Individuals with a disability between the ages of 16 and 64 and working may qualify for HBWD. Workers with countable income of up to \$3,159 per month for a single person and \$4,250 per month for a couple may qualify for the program.
- Unlike other Medicaid programs, HBWD allows enrollees to have up to \$25,000 in assets. Depending on their income, enrollees pay a monthly premium based on their income range to receive comprehensive healthcare coverage.

More about HBWD

- The goal of this program is to help people with disabilities work with full Medicaid healthcare benefits.
- HBWD not only encourages enrollees to work, but to increase the number of hours they are currently working.
- Just as the name says, the program provides health benefits for workers with disabilities.

You can have HBWD and waiver services

- Eligibility for Health Benefits for Workers with Disabilities does not effect eligibility for Personal Care Assistants/Personal Support Workers through the Department of Human Services home and community based waivers. (DD or DRS waivers)
- For additional information about HBWD, please go to <http://www.hbwdillinois.com/>

The odds of getting employment-based insurance keeps dropping.

Even those who work may not be able to afford health insurance.

- *“More than eight in ten of the uninsured are in working families—about two thirds are from families with one or more full-time workers and 14% are from families with part-time workers. Only 19% of the uninsured are from families that have no connection to the workforce (Figure 4). Even at lower income levels, the majority of the uninsured are in working families. Among the uninsured with incomes below the poverty level (\$22,025 for a family of four in 2008), 55% have at least one worker in the family.”*
- *From the Kaiser Family Foundation report: **The Uninsured: A Primer**, released October, 2009.*

Why is this a concern?

Health Insurance costs are climbing rapidly.

- *“The cost of employer-sponsored coverage is the most common reason employers cite for not offering health coverage. In 2009, annual employer-sponsored group premiums averaged \$4,824 for individual coverage and \$13,375 for family coverage. Total family premiums have doubled since 2000. The employee’s share of a family premium has also doubled since 2000, averaging \$3,515 in 2009 (Figure 16).⁴²”*
- *From the Kaiser Family Foundation report: **The Uninsured: A Primer**, released October, 2009.*

Why is this a concern?

Workers in blue-collar jobs are much less likely to be insured.

- *“Health coverage varies both by industry and by type of occupation. Across industries, uninsured rates for workers range from 35% in agriculture to just 5% in public administration. But even in industries where uninsured rates are lower, the gap in health coverage between blue and white collar workers is often two-fold or greater (Figure 18). More than 80% of uninsured workers are in blue-collar jobs.”*
- *From the Kaiser Family Foundation report: **The Uninsured: A Primer**, released October, 2009.*

Why is this a concern?

Many individuals with disabilities are unemployed or employed in jobs that do not provide health insurance.

- *“According to the data, 23% of people with disabilities were in the labor force in April, which means that they were either working or looking for work.”*
 - From the Occupational Outlook Quarterly, Summer 2009
- *“Among adults with disabilities of working age (18 to 64), three out of ten (32%) work full or part-time, compared to eight out of ten (81%) of those without disabilities, a gap of forty-nine percentage points.” (N.O.D./Harris, 2000).*
 - From *Employment Facts about People with Disabilities in the United States* - <http://www.nod.org/index.cfm?fuseaction=Feature.showFeature&FeatureID=38>

Why is this a concern?

If most Americans who are insured get health insurance through their jobs (60%), unemployment or underemployment puts families that include someone with a disability at a disadvantage.

- *Employment Rate of Persons with Disabilities (Ages 21 to 64) for Illinois = 39.2*
- *Median Household Income*
 - *Households with People with Disabilities = \$38,400*
 - *Households without People with Disabilities = \$61,000*
 - *There is a Gap of \$22,600 between households with and without people with disabilities.*
- *Erickson, W., & Lee, C. (2008). 2007 Disability Status Report: The United States. Ithaca, NY: Cornell University Rehabilitation Research and Training Center on Disability Demographics and Statistics.*

Why is lack of insurance a concern?

- **Comparison of Office Visit and Emergency Room -** *(Average cost to treat a sore throat diagnosis)*
 - Emergency room \$546
 - Doctor's office \$130
- **Procedures**
 - X-ray: chest \$86
 - CT scan: chest \$800
 - Mammography, screening \$150
 - Simple blood test \$32
- **Medication Treatment For 30-day Supply**
 - Abilify Depression/Bipolar disorder/Schizophrenia \$463
 - Actos Type II diabetes \$186
 - Advair Diskus Asthma \$189
 - Nexium Ulcers and acid reflux \$176
 - Seroquel Bipolar disorder/Schizophrenia \$270
 - Singulair Asthma/Allergies \$108
- From **Average Cost of Medical Care Fact Sheet** *based on PacificSource paid claims from January 2009 through June 2009.*

How does this impact people with disabilities?

- *From 2000 to 2006, overall inflation has increased 3.5%, wages have increased 3.8%, and health care premiums have increased 87%.*
 - *Source: Kaiser Family Foundation*
- *About half of the bankruptcy filings in the United States are due to medical expenses.*
 - *Source: Health Affairs Journal 2005*

In summary . . .

- Not all students with IEP's will qualify for Medicaid.
- Not all students with IEP's will qualify for ongoing insurance coverage through parent policies as an adult disabled child.

According to the current statistics . . .

- People with disabilities are less likely to be working at jobs that provide insurance.
- Families that include someone with a disability make less money.
- And health care and insurance costs continue to rise.

But there are possibilities!

- Youth may be able to stay on parent's policy to age 26
- May qualify as an adult dependent child for ongoing coverage through parent
- May qualify for Medicaid and AABD
- May qualify with employment through HBWD
- May find a job that provides insurance coverage!

The balancing act: continuing insurance coverage and meeting family needs

- Depending on disability status, some youth can stay on parent's insurance
- Parent must stay at same job with same insurance - pending Health Care Reform
- Parent must work the same number of hours to qualify (typically full-time)

The 1969 law continues

- Coverage limited to subset of “disabled adult children”
- Read law carefully
- No upper age limit
- Some young adults over 26 will still not be covered

Transition decisions and insurance

If youth qualifies to stay on parent's insurance:

- Parent must be available to work
- Configuring transition supports must match parent's work schedule
- Compromise may be needed
- Plan ahead

Families need back-up plans

- Challenges to job security
- Public insurance available for some - but not all - youth with special needs
- Family Care for parents ends on child's 19th birthday
- New regs prevent parents earning over 133% FPL from enrolling in Family Care
- Current enrollees can remain until child turns 19

All Kids ends on 19th birthday

Some youth qualify for other Medicaid programs

- AABD if youth on SSI
- Family Care if pregnant/parenting and low-income
- Emergency Medicaid
- HBWD if employed and have history of disability

A job with benefits as a goal!

- It is important to include employment with benefits as a goal in transition.
- Keep an eye on Health Care Reform
- Look to the future
- Know your options
- Don't settle for less

Transition impacts the entire family

- Get information ahead of time
- Weigh all of the options
- Health insurance is vital
- Balance family and youth needs
- Develop a back-up plan
- Keep records
- Join The Arc of Illinois

F2F is here to help you!

- The Arc of Illinois Family to Family Health Information and Education Center
 - 866-931-1110 toll free
 - familytofamily@thearcofil.org
- Family Manual for Transition:
 - <http://www.thearcofil.org/familytofamily/documents/documentdetails.asp?did=635>

Let's stay in touch!

- Thank you for attending our presentation
- Stay in touch and let us know how your transition is going
- Call us with your questions about health insurance and transition
- Hope to hear from you soon!