

 **Maternal and Child Health Bureau**

**Seminars on Adolescent Health:
"What's health got to do with it?
Transitions for Youth with Special
Health Care Needs."
June 23, 2004**

Health Resources and Services Administration
Maternal and Child Health Bureau

**Moderator: Trina Menden Anglin, M.D., Ph.D.,
Chief, Office of Adolescent Health**

**"New Driver"
Safety Initiative**

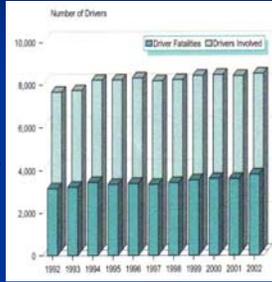
By Ashleigh Turner

Dangerous Drivers

A written test is all it takes for an Arizona 15 year-old to get a driver's permit. No previous experience is necessary (or legal) and although a licensed, "responsible" driver is required to be in the passenger seat at all times, panic on the learner's side can be difficult to control; resulting in a dangerous driver. Many teenagers and inexperienced drivers, in general, do not get proper training for the various driving conditions.

Statistics

- Motor Vehicle Accidents are the leading cause of death for 15 to 20 year olds
- In 2002, 3827 young drivers were killed in motor vehicle crashes with an additional 324,000 injured
- Fatalities for the age group rose 21% from 1992 to 2002
- Police-reported crashes for this age group cost taxpayers an estimated \$40.8 Billion in 2002.
- These problems are suspected to be linked to driver inexperience, risk-taking behavior and immaturity



Driver's Ed. Used to Exist

I had the opportunity to ask an Administrative Specialist of the Phoenix Union High School District Superintendent about the existence of Driver's Education. This was their response:

"Drivers Ed was discontinued in the PUHSD about 20-25 years ago. It was discontinued because of the high cost. We're not sure what it would cost the PUHSD to bring Drivers Ed back because we haven't pursued that possibility for many years."

My Story

My family and I were nearly home from an awesome Fourth of July vacation in Texas when we were involved in a traumatic car accident. I had recieved my driver's permit the previous May and was driving on a seemingly safe stretch of I-10 when a combination of events caused me to lose control of my car. I had read the manual on how to recover from fish-tails and skids but panic and adrenaline were catalysts for disaster.



...continued



The car rolled twice and came to a rest on all four wheels. My sister was ejected and was not expected to survive. My parents were, for the most part, alright but the car was demolished: the entire drivers side and roof was crushed. To the left is a picture of the car after the accident. My sister, thankfully, pulled through but I received a spinal cord injury as a result from a compression fracture to my neck.

Solution

- Reintroduce Drivers Education as a class for high school students wishing to get a driver's license
- Make the class mandatory
 - Student must present proof of passing the class in order to get license
- Classes will include:
 - How to control a car in different conditions
 - The effects of driving while fatigued or "under-the-influence"
 - Virtual reality or off-campus "behind-the-wheel" driving
 - Presentations by D.O.T. officials

The Process

Before being granted a drivers license, students are required to take (and pass) a full semester of drivers' education, including "behind-the-wheel" training.

The Arizona DOT will form a curriculum (if one does not already exist) consisting of lessons essential to operating a vehicle safely: road hazards, weather conditions, etc.

Incentives for Students

- Greater understanding of the danger of motor vehicles
- Experience and knowledge
- Class credit
- Lower Insurance rates
- Less likely to be involved in avoidable accidents
- Better Drivers!!!

Incentives for the Public

- Less traffic jams as a result of accidents
- Lowered risk of being involved in a car wreck
- Lower insurance rates
- Less innocent fatalities
- Less taxpayer money spent to clean up wrecks
- Better Drivers!!

Issues to Examine

- High school districts and Arizona must work together:
 - High schools teach the classes and ADOT grant those who have passed the class a license
- Arizona works with insurance companies to give good drivers rate discounts
- Funding
- Getting Students Into It!!

With Your help,
Arizona will be a safer state
For All.

**The Contributors
& Resources**

- Inputs on the subject have been given by:
 - Amanda Turner, 19
 - Mary Turner, 42
 - Ms. Cathy Mitchell's 5th Hour Senior English Class North High School
Phoenix Union High School District
 - Mike Kaddatz, Phoenix Police Department
 - Numerous Instructors from North High School
 - Jennifer Baumann, Administrative Specialist, Sr. to Arthur Lebowitz, Assistant Superintendent for Instruction & Accountability, Phoenix Union High School District

Resources Page 2

- National Highway Traffic Safety Administration
www.nhtsa.dot.gov
- Graph Courtesy of:
National Center for Statistics and Analysis

The Path That Got Me Here...

- OCSHCN
- ASU/SWI Activities
- School
- DDCI



Thank You

Ashleigh Turner
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Tsunami Program

Arizona Department of
Health Services
Office for Children with
Special Health Care Needs

What is the Tsunami Program?

- ◆ A statewide network composed of youth with special health care needs and families who have children with special health care needs. These individuals work with OCSHCN staff in order to build a more family centered, culturally effective system of health care. Training and leadership development is a key component of this program.

What is the Tsunami Program? Con't

- ◆ Tsunami Youth and Families are compensated for their expertise, time and expenses.
- ◆ Tsunami Youth and Families are provided with training and technical assistance related to their work with OCSHCN.



Who are Children with Special Health Care Needs?

- ◆ Has been diagnosed as having a chronic disease (e.g., asthma, diabetes, Traumatic Brain Injury, Sickle Cell, spina bifida, cerebral palsy)
- ◆ Has health related functional limitation(s) for regular activities of daily living
- ◆ Has required for the past year, or will require for more than one year, health services beyond those received by the average child

How are Tsunami Youth and Families recruited?



- ◆ CRS
- ◆ Community Teams
- ◆ Parent Groups
- ◆ Youth Groups
- ◆ Non-Profits

Family Centered Involvement

- ◆ Parent and Child Involvement – Meaningful involvement of children, youth and their families in all aspects of care and in the development, planning, implementation and evaluation of programs and policies of the system of care.

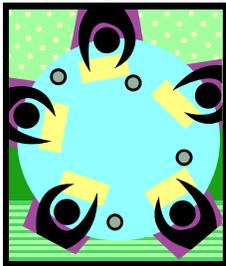
Family Centered Involvement Con't

- ◆ Partnerships and Collaboration – Effective policy and service delivery systems are best developed through action, learning, relationship development and building on the strengths of the existing systems and communities. Partnerships and collaborations within the Arizona Department of Health Services and external to the Department will be defined in all our work with families, agencies, communities, providers and other systems of care.

Family Centered Involvement Con't

- ◆ Family Centered System of Care – Children, youth and their families are more able to meet their needs when they are supported within a system of care built on parent and professional partnerships, cultural competency and community based approaches

Examples of Past, Present and Future Tsunami Work



- ◆ Champions Grant
- ◆ Community Development & Assessments
- ◆ Physician Resident Training Program
- ◆ Youth Leadership
- ◆ Curriculum and Document Development
- ◆ Training for Providers

Contact Information



Office for Children with
Special Health Care
Needs
Arizona Department of
Health Services

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Phoenix, AZ 85007
wk: 602-542-1860
fx: 602-542-2589



Adolescent Health Webcast
June 23, 2004

**HRTW Data: What Do We Know?
What Can We Do?**

Kathy Blomquist
Co-Director, HRTW National Center





How many CYSHCN?

10.3 million (13%) <18

SOURCE: Blumberg 2003 - Estimating the Prevalence of Uninsured Children: An Evaluation of Data from the National Survey of CSHCN, 2001.

Title V CYSHCN: 1,255,152 (0-18*)

SOURCE: *Title V Block Grant FY 2002 Application*
* Most State Title V CSHCN Programs end at age 18

SSI Recipients: 959,379 (0-17)
321,114 (13-17)



Data on Youth with Disabilities

- US Census
- Centers for Disease Control
- Department of Education
- Department of Labor
- Social Security
- Family Leadership Groups
- Youth Leadership Groups
- Commonwealth Fund
- Cornell University Rehabilitation Research and Training Center for Economic Research
- UCSF-Disability Statistics Center
- Others



Gateway to the Data
www.hrtw.org

- **Systems & Services**
- **Youth Involvement**
- **Health Care**
- **Tools & Solutions**





Desired Outcomes for Performance Measure 6: Transition to Adulthood

Topics for Data Collection:

- 1 **HRTW Systems Development**
- 2 **Youth Participation in Decision Making**
- 3 **Accessible & Affordable Health Insurance**
- 4 **Medical Home / Adult Health Care**
- 5 **Education, Employment, Recreation and Independent Living**



Using Data

Planning for data collected from your project:

- **Status of population**
- **Looking at youth over time**
- **Pre-post intervention**
- **Comparison of results**
 - Same population
 - Different diagnosis
 - Different age groups
 - Typical youth



HRTW Project - Outcome Data

- **KY TEACH Project: 1999- 2003**
Kentucky Youth Transitioning to Employment and Comprehensive Healthcare

- **Yearly surveys of all KY CSHCN and Shriners Hospitals for Children-Lexington graduates 18-21 years**



HRTW-KY Survey of Graduates (12/2002)

- **RESPONSE RATE: 50%**
192 Commission and 143 Shriners Graduates

- **GENDER: 61% female**
females return surveys more often than males
(population sent the surveys was 56% female)

- **RACE:** 90% White
- **AGE:** 21.0 (mean)



Health Care: Access & Use

- **86%** have a **family doctor** vs 75% of 18-24 year olds on the KY BRFSS

- **28%** have a **specialist**

- **22%** had **not visited a physician** in the previous year vs 22% of 18-19 year olds

- **40%** had been to the **emergency room** in past year vs 25% of 18-24 year olds nationally



Health Care Insurance Status

- **No insurance: 29%**
vs 29% of youth ages 18-24 in KY
- **Medicaid: 45%**
vs 9% of youth ages 18-24 in KY
- **Total employer based: 30%**
Work benefit: 7% Family Insurance: 23%



Transition &..... Health Care Insurance

NO HEALTH INSURANCE first yr after graduation

- 40% college graduates
- 50% high school graduates who don't go to college

NO HEALTH INSURANCE

- 40% between 19 - 29 will be uninsured during the year
2x twice rate of adults ages 30 to 64

SOURCE: Commonwealth Fund 2003



Health Care Access & Use: What to Do?

Graduates have doctors but go to ER at double rates of US young adults:

- Teach early detection
- Teach and practice contact with MDs
- Teach how to use insurance responsibly
- Plan ahead for health care and insurance



Health Perceptions

- **43% say their health is excellent /very good**
vs 51% KY youth 18-24 years
- **23% say their health is fair or poor**
vs 7% of US and KY youth 18-24 years
- **41% say they are sad, lonely, depressed a lot**



Risk Factors

- **Taking medications: 45%**
- **Smoking: 23%** vs 35% of Kentuckians 18-24
- **Alcohol: 13%** vs 18% American high school students
- **Children: 18% have children**
- **Mothers: 47% are not married** vs 30% of pregnancies in KY to



Risk Factors: What to Do?

- **Teach about medications**
- **Promote health related to smoking, drinking, drugs**
- **Teach about sexuality**
- **Promote mental health**



Education & Work

- **18% dropped out of high school**
vs 12% of KY youth
- **44% of respondents are working**
15% full time; 29% part-time and/or summers
vs 88% of youth ages 18-24
- **39% are not working and not in school**
- **36% on SSI and 18% of those working**
- **28% are VR Clients - 54% of those ARE working**



Education & Work: What to Do?

- **Encourage expectations of families for home chores**
- **Encourage expectations for work**
- **Support youth's aspirations**
- **Plan for driving and transportation**
- **Resolve toileting issues**
- **Find opportunities for participation in work and community**



Independence Skills

- **77% use computers**
- **57% use the internet**
- **55% drive vs 65% of youth with chronic illness/disabilities and 90% of general adult population**
- **44% of those who would like to work say they need transportation**



Independence

- **59% live with parents**
vs 56% men; 43% women ages 18-24
(2000 Census)
- **16% married or ex**
vs 10% men; 18% women ages 18-24
(2000 Census)
- **18% have children; 47% are unwed**



Independence: What to Do?

- **Encourage computer skill development**
- **Plan for transportation**
- **Practice housekeeping skills**
- **Practice social skills**
- **Practice self care skills**
- **Practice community involvement**
- **Improve socioeconomic level of families**



Health Affects Everything!

- **Health & Employment**
- **Health & Housing**
- **Health & School**
- **Health & Community Living**
- **Health & Recreation**
- **Health & Inclusive opportunities**



Systems Changes: KY Commission

Philosophy and Mission:

- Executive staff focus – parent and youth advisors
- MCH Block Grant Performance Measure
- Building transition into care coordination
- Web-based data and information system includes transition checklist





Systems Changes: KY Commission (2)

Expectations for Staff

- Job descriptions
- Personnel evaluations
- Quality review of records
- Regional managers
- Staff development
- Professional parent on staff





More Systems Changes (3)

Expectations for Youth

- Starting early - Life Maps
- Focus on many transitions
- Work, camps and independence-building experiences
- Disability Mentoring Day
- Girl Scout Troop





More Systems Changes (4)

Collaborations in the Community

- Physicians and health care providers
- Independent living and employment
- Schools - health promotion/ transition for all
- Parent groups
- Summary of Services
- Website: <http://chs.ky.gov/commissionkids>





Nuggets to Take Away

- **NEW FOCUS** - Programming does not cost much
- **DEDICATED STAFF** - Responsibility/resource
- **INFUSE HEALTH** - into already existing groups
- **INTERAGENCY COLLABORATION** - works best with specific programs/activities/planning
- **START EARLY** - transition takes time for families and youth; have high expectations





Know the OUTCOMES of your services

<ul style="list-style-type: none"> ■ Quality of life ■ Prevention of secondary conditions ■ Health care access and use ■ Health insurance ■ Informed decision making by youth 	<ul style="list-style-type: none"> ■ Education ■ Recreation ■ Independent living ■ Work
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**Selected Data & Needs
for YSHCN (1)**

Social Security Administration

Table 25 - By diagnostic group and age, 12/02
http://www.ssa.gov/policy/docs/statcomps/ssi_asr/2002/table25.htm

- Age breakdowns:
Under 5, 5-12, 13-17, 18-21, 22-29 and higher
- Note: First time ages 18-29 are available



**Selected Data & Needs
for YSHCN (2)**

- **National Survey for CSHCN**
 Data Resource Center interactive website
www.cshcndata.org
- **A Portrait of Adolescents in America, 2001**
 FACCT/RWJ
http://www.facct.org/facct/doclibFiles/documentFile_522.pdf



Selected Data & Needs for YSHCN (3)

- **“Why Young Adults Become Uninsured and How New Policies Can Help:** May '03; Commonwealth Fund
www.cmwf.org/programs/insurance/collins_riteofpassage_ib_649.pdf
- **“Is the Health Care System Working for Adolescents? Perspectives from Providers”**
October '03; MCH Policy Research Center: 202-223-1500



Selected Data & Needs for YSHCN (4)

- **“America’s Adolescents: Are They Healthy?”**
National Adolescent Health Information Center, 2003
<http://youth.ucsf.edu/nahic/lmg/2rev.pdf>
- **“Quality of Health Care for Children and Adolescents: A Chartbook”** Commonwealth Fund, April 2004
www.cmwf.org/programs/child/leatherman_pedchartbook_700.pdf



Web Resources: Youth Leadership

- **Family Voices KASA (Kids As Self Advocates)**
www.kasa.org
- **National Youth Leadership Network**
www.nyln.org



**Web Resources:
Education**

- **IDEA PRACTICES**
www.ideapractices.org
- **National Dissemination Center for Children with Disabilities**
www.nichcy.org



Adolescent Health Webcast - June 2004

**What's Health Got to Do With Transition?
EVERYTHING!**

Patti Hackett, MD
Team Lead & Co-Director
Healthy & Ready to Work National Center
www.hrtw.org
2004






**MCHB & State Title V CSHCN
Federal Mandates**

- **Amended Legislation for Title V of the Social Security Act (1989)**
"Facilitate the development of community-based systems of services"
- **Healthy People 2010 Objective 16-23**
"Increase the proportion of States and territories that have service systems for CSHCN."



Full Integration

■ Supreme Court decision - Olmstead (1999)

Affirmed the right of individuals with disabilities to live in the community rather than in institutions whenever possible.

Full integration a reality for people with disabilities

means not only changing existing practices that favor institutionalization over community-based treatment, but

also providing the affordable housing, transportation, and access to state and local government programs and activities that make community life possible.



The President's New Freedom Initiative

"Delivering on the Promise" page 111-39 (March 2002)

- Reviewed barriers to community living for PWD
- Compiled reports from 9 Federal agencies.
- Responsibility given to HRSA for developing and implementing a community-based service system for children and youth with special health care needs and their families

Barrier Addressed by Solution / Access to:

1. Comprehensive, family-centered care
2. Affordable insurance
3. Early and continuous screening for SHCN and
4. **Transition services to adulthood**



National Performance Measure #6: Transition

TRANSITION TO ADULTHOOD

Youth with special health care needs (YSHCN)

will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence. (2002)



NPM #6: Outcomes Transition to Adulthood

- 1 HRTW Systems Development
- 2 Youth Participation in Decision Making
- 3 Accessible & Affordable Health Insurance
- 4 Medical Home/Adult Health Care
- 5 Education, Employment, Independent Living and Recreation



HRTW TEAM Experienced, Creative & Can Do!

PACER, MN - **Ceci Shapland** MCHB/DSCSHN - **Monique Fountain, MD**



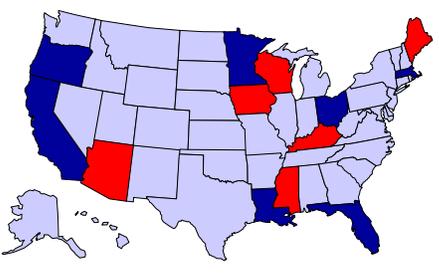
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Comm for CSHCN, KY- **Kathy Blomquist**
Shriners Hospitals for Children - **Betty Presler**



HRSA/MCHB funded HRTW Projects

■ Phase 1 ■ Phase 2





What's important to YSHCN

- What to do in an emergency
- How to get health insurance
- What could happen if condition gets worse
- Learning how to stay healthy

SOURCE: PACER Survey - over 1300 YSHCN (1997)



Transition & Screening





Transition & Screening

- **SCREEN:** Health and life transition needs
- **SECONDARY DISABILITIES**
 - Prevention/Monitor
 - Mental Health, High Risk Behaviors
- **AGING & DETERIORATION**
 - Info long-term effects (wear & tear; Rx, health cx)
 - New disability issues & adjustments



Transition & ... Family Involvement



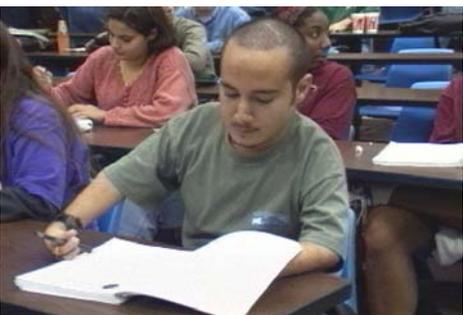


Family & Youth Involvement: Informed Decision Makers

- **YOUTH AND FAMILY-CENTERED**
 - Start early - plan ahead
- **YOUTH INVOLVEMENT**
 - Participation in decision-making
 - Supporting aspirations - raising expectations
- **YOUTH LEADERSHIP**
 - Shaping & Influencing Policy
 - Compensated partners



Transition &.... Medical Home





It Is Not Just About Special Health Needs!

Health includes:

- Hygiene
- Nutrition
- Exercise
- Sexuality issues
- Mental health
- Aging issues

Assistive Technology Health Surrogate
 Adult Health Care Advance Directives



Consensus Statement Health Care Transitions

- American Academy of Pediatrics
- American Academy of Family Physicians
- American College of Physicians-American Society of Internal Medicine

CONSENSUS STATEMENT
calls on physicians to:

1. Understand the rationale for transition from child-oriented health care
2. Have the knowledge and skills to facilitate that process
3. Know if, how, and when transfer of care is indicated

(Pediatrics 2002:110 (suppl) 1304-1306)



Transition & ... Medical Home

- Create a **written health care transition plan by age 14**: what services, who provides, how financed
- Apply **primary and preventive care** guidelines
- Ensure affordable, continuous health insurance that includes **transition planning/care coordination**.



Health Care Transition

- The optimal goal of **health care transition** is to provide health care that is family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent in a health care system that is as **developmentally appropriate** as it is **technically sophisticated**.

SOURCE: PEDIATRICS Vol. 110 No. 6 December 2002, pp. 1304-1306. A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs



Transition & ... Community-Based Service Systems





Lessons Learned HRTW Phase I (1)

- **COORDINATION** - A transition coordinator is essential.
- **COLLABORATION** between the pediatric and adult providers is critical for successful health care transition.
- **SCHOOL NURSES** can play an important role if time is allocated for that purpose.
- **EDUCATION** is a key collaborator, but cooperation depends on many variables.



Lessons Learned HRTW Phase I (2)

- **EXPECTATIONS & ASPIRATIONS** - Youth routinely encounter low performance expectations from health care providers and other professionals.
- **YOUTH-CENTERED** - Too many health care professionals direct communications to parents rather than youth. [assent to consent]
- **SELF-DETERMINATION** - Teaching self-determination skills is valuable; allow youth to speak for themselves.



Transition & Access to Health Care Financing



Maintaining
Health
Insurance:
It's Not
Impossible



Jim, age 24, married, earned a pilot license, and has CF. One of the first questions that the doctor asked his Mom when he was 3 months old, was "Where do you want your son to be in 20 years?"

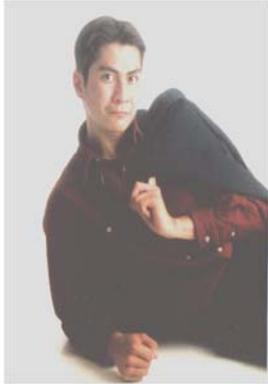
Insurance: Private through employer.

Travis age 24, works for Home Depot, and pays for his own health insurance.

He is a member of the Laguna Tribe of Native Americans.

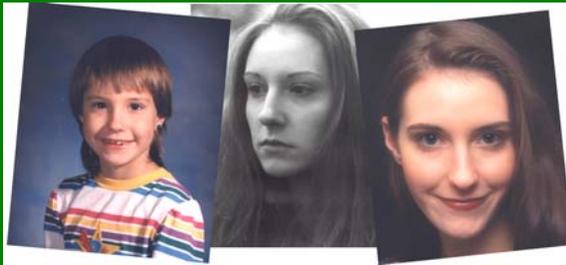
He is deaf, has a metabolic disorder, and a vision impairment.

Insurance: Private through employer



Eden is 22 and is working full time. She has no health insurance. She was first diagnosed with chronic major depression and anxiety as a sixth grader.

Insurance: NONE due to pre-existing condition.





Maya, age 22, graduated from high school at 20, and last year was in an excellent program at the Helen Keller Center on Long Island, working on transitioning skills. But the program was only for one year, and this year, she is at home, with very few services, angry and desperately wanting to work. Maya is deaf and blind. *Insurance:* Medicaid



Mac works part-time with support from a job coach. He and fiancée, Chastity, enjoy going out on dates.

Insurance: Medicaid



Glen, age 30 - professional turf writer and thoroughbred racing analyst. One of only 6 people who provided Beyer Speed Figures for the Daily Racing Form.

Doctors predicted that he wouldn't live to see his 2nd birthday due to SMA. He outlived his Doctor.

He used a motorized wheelchair to move, a portable ventilator to breathe and voice activated software to work at a computer, and acted as if these were minor inconveniences. "I'm just a person who needs more equipment."

Insurance: Court ordered Private through Father & Step-mother



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