



Connecting

Connect

Family Support is the Heart of our Mission.

September - November, 2011

Volume 16, Number 3

Medicaid Critical to Special Needs Families

In Washington, a special commission of twelve Senators and Representatives, known as the Joint Select Committee on Deficit Reduction will address the nation's long-term deficit issues between September and December of this year. This task will involve difficult choices. The results of the decisions made in this process are likely to have significant implications for children and youth with special health care needs.

The following information is excerpted from a report from Family Voices and Georgetown University Health Policy Institute and includes additional information specific to Arizona. The complete report can be seen at <http://ccf.georgetown.edu/index/medicaid-children-and-youth-with-special-health-care-needs>.

Children and youth with special health care needs are more likely to be covered by Medicaid than other children. They are more likely to require Medicaid's comprehensive benefit and cost-sharing protections because of their relatively extensive health care needs.

Medicaid's comprehensive benefits and cost-sharing protections also provide a measure of economic stability to the families. In some instances, the care and supports that Medicaid offers can be what allows children to be cared for at home and in their community, rather than in a hospital or nursing home.

Of the 74 million children in the United States, approximately 14% (10.2 million children) meet the criteria of having a special health care need.

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Ry-Ry's grandmother is in the process of adopting him. He receives a variety of services through Medicaid funded programs. "We would be bankrupt if we'd had to pay out-of-pocket for the services he needs," she said.

From the Director

Recent figures show Arizona moved near the top of the national rankings in poverty. About 1 in every 5 Arizonans, or 1.2 million residents, lives below the federal poverty level. Arizona now ranks 5th in the nation - only Mississippi, Louisiana, Georgia and the District of Columbia post worse rankings.

Our state is experiencing difficult economic conditions, but it's interesting to note that during the Great Depression, when economic conditions were extremely dire with catastrophic rates of unemployment, poverty, and hunger, our country thought about the crisis in a very different way.

A number of historians have noted that our public discourse during the Great Depression focused on the effects of the crisis on people and families, and expressed a shared concern for the well-being of American citizens. Now, it seems many politicians talk only in terms of deficits, entitlements, taxes, and government shutdown.

Sound financial management of state and federal government is clearly necessary and very important, but social stability is absolutely vital. Where, on the balance sheet, will we find the impact of their decision-making on human suffering and desperation? Without more inclusive language to inform a necessary debate about how to put the country on a better financial footing, we run a great risk of making choices that harm children and families. There is an inescapable moral element to this type of public decision-making: How do we avoid causing harm to those already heavily burdened by economic hardship, and how do we maximize the effect of our resource allocations to encourage the healthy growth and development of children and the families who support them? This basic question needs to be at the center of our discussions on budget deficit reductions.

If we want to "slash entitlements" like Medicaid, let's make sure to remember that millions of children with disabilities and special health needs are covered under its provisions. If we want to allocate resources carefully and wisely, let's start by recognizing we are talking about human beings.



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Parent to Parent support is the heart of Raising Special Kids. Information about local services, educational programs, advocacy, or special health care needs is available in both Spanish and English. Services are provided at no charge to families in Arizona.

Raising Special Kids is a 501(c)3 non-profit organization.

36% or 3.6 million of these children rely on Medicaid or CHIP for all or part of their health care coverage.

In most instances, Medicaid is the sole source of coverage for these children, but it also often plays the role of supplemental coverage for those with private insurance. The majority have private insurance, but 33% report their child's coverage is inadequate in meeting their needs. For these families, Medicaid can help fill coverage gaps and make the private coverage more affordable.

The rate of children and youth with special health care needs who lack coverage is lower than that of children in the general population. Currently, more than nine in ten have health insurance, although as noted above, it is often not adequate to address their needs.

Routes to obtaining Medicaid coverage:

1) Eligibility Based on Being Part of a Low-Income Family.

If a family meets a state's Medicaid income eligibility requirements, they can enroll their child through the Medicaid "poverty level" categories, regardless of whether the child has a disability or special health care needs.

Federal Poverty Level Minimum Eligibility Requirements for States

Under the poverty level eligibility categories, all states, must offer Medicaid for children ages zero to five whose family income is up to 133 percent of the federal poverty level (about \$29,000 for a family of four) and children ages six through 18 in families with income up to approximately \$22,000 for a family of four. States have the option to expand Medicaid to children above these minimum thresholds, and all states have opted to do so through Medicaid or the Children's Health Insurance Program (CHIP). Enrollment in Arizona's CHIP, KidsCare, has been frozen since January 1, 2010 due to lack of funding, and the program is unable to approve new applications.

2) Eligibility Based on Receipt of Supplemental Security Income (SSI).

One requirement to qualify for SSI: a child's family income below 75% of the FPL. There are some families who are able to obtain Medicaid coverage through SSI because the child requires an institutional or hospital level of care. Arizona has been a leader in providing more care in home environment as opposed to institutional settings.

Arizona leads in helping families keep their children in the home environment.

Arizona has been a national leader in providing the option of home or community-based for people with long term care needs. In states where access to Medicaid coverage required institutional placement, many families felt they had no choice but to institutionalize their children leaving families faced with the agonizing decision to institutionalize or relinquish custody of their disabled child.

There is growing evidence that children, even those with complex health care needs, are best raised at home, as members of their families and communities. The increasing inclusion of children and people with disabilities in schools, workplaces and the community in general, along with advances in the accessibility of medical technology for use in the home have contributed to this trend. This has resulted not only in better health outcomes, but more cost-effective care. Care provided at home is typically a fraction of the cost in hospitals, nursing homes or other congregate care settings.

3) Eligibility as "Medically Needy."

This is coverage for people, including children, who may have income that is too high to qualify for Medicaid, but whose medical expenses are significant enough to bring their income below a state's eligibility threshold. States can also charge families premiums that would bring the family income to below the Medicaid eligibility level. Data suggest that in 2010, approximately 800,000 children were covered under this "spend down" option. The Medicaid Reform package approved by Arizona's Legislature as part of the FY 2012 budget will eliminate this option.

One study found that children and youth with special health care needs spend seven times as many days in hospitals as other children; receive five times as many prescription drugs; and see health care providers (physicians and non-physicians) far more frequently. Overall, their health care expenditures are more than three times the average for other children.

“health care expenditures are more than three times the average for other children.”

— P. Newacheck and S. Kim, “National Profile of Health Care Utilization and Expenditures for Children with Special Health Care Needs,” *Archives of Pediatrics and Adolescent Medicine*, 159 (January 2005): 10–17.

Close to eight in ten children and youth with special health care needs enrolled in Medicaid and CHIP—some 2.9 million children—rely on these programs as their primary source of health care coverage. These children typically enroll in Medicaid because they lack access to affordable employer-based insurance and cannot secure an individual policy or because the private coverage does not cover critically important services and supports.

Because private insurance typically is designed to address acute health problems rather than chronic illness and disability, it often places limits on services important to children and youth with special health care needs, therapies (speech, physical and occupational), durable medical equipment and mental health care.

“Because private insurance typically is designed to address acute health problems rather than chronic illness and disability, it often places limits on services important to children and youth with special health care needs.”

As a secondary source of coverage, Medicaid also assists families with the cost-sharing required by their private insurance. Over time, the cost of the co-payments, co-insurance charges and deductibles associat-

ed with caring for a child with special health care needs could be financially debilitating to a family. For a child with more severe health care needs such as cerebral palsy, the study found that not only would the child’s medical needs not be met, but that the child would exceed the coverage limits under the plan and that the family could expect to pay more than \$9,000 out-of-pocket in one year. However, if a family is able to secure Medicaid as a secondary source of insurance, the care the child needed would be covered and the family would be protected against excessive out-of-pocket spending by Medicaid cost-sharing rules.



Zane’s private insurance would not have covered the range of medical services he has needed.

Families’ Voices

Georgetown University and Family Voices interviewed a series of families about issues concerning insurance coverage and health care reform. Major themes from the family interviews were:

1. Medicaid is a lifeline for children and youth with special health care needs.
2. Medicaid “fills in the gaps” and keeps families from financial ruin (many said they would be bankrupt without Medicaid).
3. Coordinating care and insurance can be a full-time job.
4. Families struggle to find providers to see their children (finding providers in general let alone ones who accept Medicaid is challenging—particularly for adult children with special health care needs).

How does Arizona compare?

A complete chart with information on Medicaid eligibility for each state is included in the report from Family Voices and Georgetown University Health Policy Institute. The complete report can be viewed or downloaded at <http://ccf.georgetown.edu/index/medicaid-children-and-youth-with-special-health-care-needs>.

State	Medicaid, 0-1 Years	Medicaid, 1-5 Years	Medicaid, 6-19 Years	CHIP	Program Type
Alabama	133%	133%	100%	300%	S-CHIP
Alaska	175%	175%	175%		M-CHIP
Arizona	140%	133%	100%	200% (closed)	S-CHIP
Arkansas	200%	200%	200%		M-CHIP
California	200%	133%	100%	250%	COMBO
Colorado	133%	133%	100%	250%	S-CHIP
Connecticut	185%	185%	185%	300%	S-CHIP
Delaware	200%	133%	100%	200%	COMBO

Resources Online:

- Factsheet: <http://www.commonwealthfund.org/Publications/Data-Briefs/2005/Sep/How-Medicaid-and-EPSTDPromote-Healthy-Child-Development-Among-Children-with-Special-Health-Care-N.aspx>
- Children And Health Care Reform: Assuring Coverage That Meets Their Health Care Needs <http://www.kff.org/healthreform/upload/7980.pdf>

Terms to know

Medicaid - A joint federal and state program that helps with medical costs for families with dependent children, the aged, blind, and disabled who are in financial need. Medicaid programs vary from state to state.

AHCCCS - Arizona Health Care Cost Containment System is the Medicaid program in Arizona.

CHIP - The Children's Health Insurance Program is a program administered at the state level, providing health care to low-income children whose parents do not qualify for Medicaid.

FPL - Federal Poverty Level - the amount of annual income used in determining eligibility for some programs. (See box on page 3.)

SSI - Supplemental Security Income - A federal income supplement program funded by general tax revenues (not Social Security taxes) to help aged, blind, and disabled people, with little or no income.

DDD - Division of Developmental Disabilities is Arizona's state agency that provides supports and services for eligible people who have autism, cerebral palsy, epilepsy or intellectual disability.

ALTCS - Arizona Long Term Care Services provides acute and long term care services under federal guidelines and federal funds (Title XIX).

Title XIX (19) - Federal program, created by Public Law 89-97, Title XIX, a 1965 amendment to the Social Security Act, administered by the states, that provides health care benefits to indigent and medically indigent persons.

Block grants - Funding provided as a fixed lump sum of money for each state. (If Medicaid is changed to this funding method it would change the entitlement to Medicaid services based on income or disability.)

Entitlement - Type of program under which beneficiaries have a legal right to the benefits if they meet eligibility conditions specified by the law that authorizes the program. Examples at the federal level include Social Security, Medicare, and Medicaid.

Medicare - A federal system of health insurance for people over 65 years of age and for certain younger people with disabilities.

Raising Special Kids Calendar

Register through our online calendar or call 602-242-4366 or 800-237-3007.

Our office location is a fragrance-free environment, please avoid wearing fragrances.

Disability Empowerment Center, 5025 E. Washington St., #204, Phoenix, AZ 85034

IFSP Basics

NEW

For parents of children birth to 3. Learn the basics of the process for developing an Individualized Family Service Plan.

Thu. 10/20/11, 10:00 – 12:00 noon

Turning 3, What's Next? AzEIP to Preschool Transition

Learn how to transition your child from AzEIP services to preschool services provided by the school district.

Wed. 11/9/11, 10:00 – 12:00 noon

Positive Behavior Support

Training on effective techniques for behavior management.

Thu. 10/13/11, 10:00 – 12:00 noon

Thu. 11/3/11, 4:00 – 6:00 pm

Fire Station 217

Thu. 11/17/11, 10:00 – 12:00 noon

Thu. 12/15/11, 3:00 – 5:00 pm

The Journey to Adulthood

Provide young adults and parents with information about physical, emotional and social changes that adolescence and puberty bring to every child.

Thu. 9/29/11, 10:00 – 12:00 noon

Thu. 11/3/11, 6:00 – 8:00 pm

Fire Station 217

Getting and Keeping the First Job

Assist young adults and parents with identifying the importance of employment for youth with disabilities and special needs.

Thu. 9/29/11, 5:00 – 7:00 pm

Thu. 10/20/11, 4:00 – 6:00 pm

Fire Station 217

Notice our
ALTERNATE LOCATION
(workshop times listed in red)

Fire Station 217, Community Room
10434 E. Baseline Rd.
Mesa, AZ 85212

Understanding 504

Learn about the rules and regulations of a 504 Plan and how it differs from the IEP(IDEA).

Wed. 9/28/11, 10:00 – 12:00 noon

Wed. 11/23/11, 6:00 – 8:00 pm

Guardianship

Turning 18, What's Next?

Making the decision; understanding the process. Learn what guardianship involves before your teen turns 18. You will also learn about alternatives to guardianship.

Thu. 10/20/11, 6:00 – 8:00 pm

Fire Station 217

Mon. 11/7/11, 10:00 – 12:00 noon

Thu. 12/1/11, 3:00 – 5:00 pm

IEP Basics

Learn about the purpose of IEP's, parents' role in the process, and how to prepare for meetings.

Thu. 10/27/11, 6:00 – 8:00 pm

Tues. 11/8/11, 2:00 – 4:00 pm

Tues. 12/13/11, 6:00 – 8:00 pm

Advanced IEP Training

Receive an in-depth view of the IEP and strategies to help maximize the potential of each student. (Recommended: First attend IEP Basics.)

Thu. 10/6/11, 3:00 – 5:00 pm

Transition from Preschool to Kindergarten

Learn eligibility differences and strategies for an effective transition into school age services.

Fri. 12/2/11, 10:00 – 12:00 noon

High School Transition

Learn how the transition plan in a student's IEP in high school can prepare for higher education, employment, and life in the community. Resources discussed.

Thu. 12/1/11, 10:00 – 12:00 noon

Bully-Free Environments

Learn how to recognize bullying, effectively respond, and build positive solutions.

Thu. 10/6/11, 10:00 – 12:00 noon

Tues. 11/15/11, 3:00 – 5:00 pm

Wed. 12/7/11, 10:00 – 12:00 noon

Parent/Professional Collaboration

Techniques for effective advocacy. What to ask, how to ask for it.

Wed. 11/9/11, 1:00 – 3:00 pm

Organizing Your Child's Records

Bring your child's special education, ISP, therapy and medical records to this "make and take" session to create your own filing system.

Fri. 10/7/11, 10:00 – 12:00 noon

IEP 1-to-1 Consultation

Bring your child's IEP for review, as well as your questions and concerns.

Call for an appointment:
602-242-4366 or 800-237-3007.

Attendance at all workshops is at NO COST.

For Southern Arizona workshops please call 520-324-3150 or visit www.pilotparents.org

NORTHERN ARIZONA WORKSHOPS

Register via website calendar at www.raisingsspecialkids.org or call 928-523-4870

Positive Behavior Support

Training on effective techniques for behavior management
Tue. 9/20/11 5:00 – 7:00 pm
Institute for Human Development
Northern Arizona University
Large Conference Room
Parking lot P-13 off Riordian Rd.

DOUBLE WORKSHOP

Parent Professional Collaboration & Special Ed. Overview

1) Techniques for effective advocacy. What to ask, how to ask for it. 2) Learn the basics of Special Education
Fri. 9/16/11 1:00 – 4:00 pm
Mohave Community College
3400 Highway 95
Bullhead City, AZ 86442

DOUBLE WORKSHOP

504/IEP - What is the Difference? AND Special Ed. Overview

1) The difference in the law, eligibility and the processes of 504 and IEP will be covered. 2) Learn the basics of Special Education
Sat. 9/17/11 8:00 – 12:00 noon
Arizona's Children Association
228 London Bridge Rd., Ste. 202
Lake Havasu City, AZ 86403

DOUBLE WORKSHOP

The Journey to Adulthood & Bully Free Environments

1) Provide young adults and parents with information about physical, emotional and social changes that adolescence and puberty bring to every child. 2) Learn how to recognize bullying, effectively respond, and build positive solutions.
Fri. 10/14/11 8:30 – 12:30 pm
Kingman Hospital
3269 Stockton Hill Road
Mohave Room – B

DOUBLE WORKSHOP

Self Advocacy for Youth AND Getting and Keeping the First Job

Learn how students can independently advocate for themselves (youth are welcome to join their parents in this combination workshop). Young adults and parents identify the importance of employment for youth with disabilities and special needs.

Sat. 10/15/11 8:00 – 12:00 noon
Arizona's Children Association
228 London Bridge Rd. Ste. 202
Lake Havasu City, AZ 86403

Bully Free Environments

Learn how to recognize bullying, effectively respond, and build positive solutions.
Tue. 10/18/11 5:00 – 7:00 pm
Institute for Human Development
Northern Arizona University
Large Conference Room
Parking lot P-13 off Riordian Rd.

Understanding 504 Plans

Learn about the rules and regulations of a 504 Plan and how it differs from the IEP (IDEA).
Tue. 11/15/11 5:00 – 7:00 pm
Institute for Human Development
Northern Arizona University
Large Conference Room
Parking lot P-13 off Riordian Rd.

3 DOUBLE WORKSHOPS

Positive Behavior Support AND The Journey to Adulthood

9:00 am - 11:00 am
11:30 am - 1:30 pm
(See descriptions in first column)
Locations will be at the local Chapter Houses in each city:
Tue., Oct. 25 - Red Mesa
Wed., Oct. 26 - Kayenta
Thur., Oct. 27 - Rough Rock

3 TRANSITION WORKSHOPS in PAGE, AZ

Preparing for the Transition to Adulthood

Each workshop will feature a presentation by the Arizona Department of Education Parent Information Network:
Beginning with the End in Mind

How to plan for the transition from high school to adult life.

Getting and Keeping the First Job

Learn how students can independently advocate for themselves (youth are welcome to join their parents in this combination workshop). Young adults and parents identify the importance of employment for youth with disabilities and special needs.

Wed. 10/26/11
9:30 am - 12 noon
OR
1:00 pm - 3:30 pm
Page, AZ (Location TBA)

Guardianship Turning 18, What's Next?

Making the decision; understanding the process. Learn what guardianship involves before your teen turns 18. You will also learn about alternatives to guardianship.
Wed. 10/26/11 5:00 pm - 7:30 pm
Page, AZ (Location TBA)

FOR DETAILS CALL 928-523-4870

New recommendation for meningitis vaccine

While state law only requires one vaccine for meningitis, state health officials are now recommending an additional booster to provide the best protection against the potentially fatal disease. The initial vaccine is typically administered at age 11, and the booster is now commonly recommended by age 16.

The U.S. Centers for Disease Control and Prevention (CDC) adopted new recommendations in June regarding vaccination for all pre-teens and teens 11-18 years of age and college freshmen living in dormitories.

Meningococcal disease, commonly called meningitis, is a serious bacterial infection that can cause swelling of the lining around the brain and spinal cord (meningitis) or blood infection (meningococemia). Each year, up to 2,800 people get the disease, which strikes quickly and can lead to death and other devastating complications, within hours of first symptoms.

The symptoms of meningococcal disease are very similar to those of the flu or other common viral illnesses, which is why sometimes the disease is misdiagnosed as something less serious. Symptoms may include sudden high fever, headache, stiff neck, nausea, vomiting, confusion and exhaustion. As the disease progresses, a purplish rash may also appear.



A person may not have all of these symptoms or have them all at the same time. Since the disease moves quickly, it is very important to seek medical attention immediately if two or more of these symptoms are present, or if the symptoms are unusually sudden or severe.

See more information from the Arizona Department of Health Services at www.azdhs.gov/phs/immun.

Stay in the know

Sign up for weekly e-news

A convenient weekly email summarizing news, affecting families of children with disabilities or special health care needs in Arizona is available for free. You can sign up to receive our "Monday Memo" at Raising Special Kids' website: www.raisingpecialkids.org. Just click on the button to sign up for e-news and you'll be on your way to staying up to date on the latest news, including political issues, social events, resources, workshops, conferences, support groups, and more.

Ventilator coverage changes

Families of children receiving services for ventilators through the Division of Developmental Disabilities should have received a letter explaining a change in the way these services are covered.



Beginning October 1 Ventilator services will now be paid for under medical insurance coverage (acute health plan). Call your provider and insurance plan to ensure your medical insurance covers the provider you have been using.

If your family receives these services but you did not receive a letter from the Division of Developmental Disabilities, contact your support coordinator or refer to the Member Handbook for the acute health plan with which you are enrolled.

Let the Super Committee know your story

Arizona's Senator Kyl and April Grady, Senior Health Analyst focusing on Medicaid Issues, are on the Joint Select Committee on Deficit Reduction (Super Committee). The committee has broad authority to propose changes in federal programs including the Affordable Care Act and Medicaid. Many of the services funded through Medicaid in Arizona benefit families of children with special health care needs. If your family is receiving services funded by Medicaid such as those below, you may want to express to Senator Kyl, Ms. Grady and the Super Committee how essential these services are.



- Arizona's Medicaid program - Arizona Health Care Cost Containment System (AHCCCS)
- Arizona Long Term Care Services (ALTCS) received through the Division of Developmental Disabilities (DDD) or Elderly and Physically Disabled (EPD). These may include respite, physical therapy, occupational therapy, speech therapy, habilitation, attendant care.

Be sure to mention you are from Arizona and include a photo of your child. If you prefer to phone, call: 202-224-4521. Send email to Judith Gheuens, Health Counsel to Senator Kyl: Judith_Gheuens@Kyl.senate.gov.

Accessible Instructional Materials (AIM)

Basics for Families

The Individuals with Disabilities Education Act (IDEA, 2004) requires that states and school districts provide accessible versions of instructional materials to students with disabilities in a timely manner.

Guidebooks have been developed by PACER and the National Center on Accessible Instructional Material especially for families that are available for download at <http://aim.cast.org/learn/aim4families>. The following is an introduction to these materials:

Some students with disabilities have difficulty reading textbooks and other learning materials. For example, a student who is blind may not be able to see the book, and a student who has a physical disability may not be able to hold the book. To succeed in school, these students and others like them need learning materials in specialized formats called “accessible instructional materials” or “AIM.” The

federal special education law, the Individuals with Disabilities Education Act (IDEA), includes a requirement that schools provide AIM to elementary and secondary students with disabilities who need them. (See NIMAS Information from the U.S. Department of Education link at end of document.)

This booklet will help you and other members of your child’s Individualized Education Program (IEP) team decide:

1. whether the student needs AIM
2. what type of specialized format the student needs
3. how to access the materials for the student
4. what supports the student needs to use AIM

Read more at:

http://aim.cast.org/learn/aim4families/aim_basics_families

Empowerment Scholarship Accounts

Empowerment Scholarship Accounts (ESA) went into effect July 20 to provide education for qualified students, and must include reading, grammar, mathematics, social studies and science. The accounts allow families to put 90 percent of state money allocated for the education of a child with a disability toward private school or private education services such as speech or occupational therapy or saved for college.

The Arizona Department of Education reports that 86 children have received awards totaling about \$1 million through the accounts for the current school year. A lawsuit has been filed to block the accounts by The Arizona School Boards Association and Arizona Education Association.

Eligibility

- Available to students identified as having a disability under IDEA or Section 504
- Must have attended public or charter school as a full time student (100 days of the 180 possible of the last school year)

Funding Levels

- Dependent upon disability classification. The dollar amount will be determined by the school finance formula, taking into account ‘weights’ for different categories of disability, grade levels, teacher tenure and school location.
- The account will be funded with 90% of the individual student’s funding level
- 3% will go to Arizona Department of Education and Treasurer’s Office for administrative costs

What can the funds be used for?

- Tuition at private schools (non-publicly funded)
- Textbooks and materials required by private school
- Educational therapies
- Tutoring Services
- Tuition and/or fees from a private online learning program
- Curriculum
- Fee for standardized achievement tests, placement exams, or exams related to postsecondary admissions
- Contributions to College Savings Plan (529)
- Tuition or fees at a postsecondary institution
- Bank fees charged for the management of the ESA

Pros

1. Offers parents an option to place the child in a private program
2. Allows parents to fund a college savings plan with unspent funds from their ESA
3. May be an attractive option for families that are in a dispute with a public school or charter

Cons

1. Parents give up their special education rights under IDEA (Free and Appropriate Public Education - FAPE)
2. Parents may not have access to related services like Transportation, Speech Therapy, Occupational Therapy, Physical Therapy and Assistive Technology

Español

Medicaid Es Crítico para Familias con Necesidades Especiales

Porqué el seguro privado o la elegibilidad por bajos ingresos no son suficientes

En Washington, una comisión especial de 12 senadores y representantes, conocidos como el Comité Conjunto Selecto Sobre Reducción del Déficit abordará cuestiones sobre el déficit a largo plazo del país entre septiembre y diciembre de este año. Esta tarea envolverá decisiones difíciles y tendrá un profundo impacto en las vidas de muchos niños y familias. Es muy probable que los resultados de las decisiones adoptadas en este proceso tendrán repercusiones significativas para los niños y jóvenes con necesidades especiales para el cuidado de la salud.



La siguiente información es un extracto de un reporte de Voces de la Familia y el Instituto de Normas de Salubridad de la Universidad de Georgetown, e incluye información adicional específica de Arizona. El reporte completo puede verse en <http://ccf.georgetown.edu/index/medicaid-children-and-youth-with-special-health-care-needs>.

- Es más probable que los niños y jóvenes con necesidades especiales para el cuidado de la salud sean cubiertos por Medicaid que otros niños. Es más probable que requieran la protección de beneficios integrales y participación de gastos de Medicaid debido a sus relativamente extensas necesidades para el cuidado de la salud.
- La protección de beneficios integrales y participación de gastos de Medicaid también proveen una medida de estabilidad económica a las familias. En algunos casos, la atención y el apoyo que ofrece Medicaid puede ser lo que permite que los niños sean atendidos en su hogar y su comunidad, en lugar de en un hospital o instalación de cuidado.
- De los 74 millones de niños en los Estados Unidos, aproximadamente el 14% (10.2 millones de niños) cumple con los criterios de necesidades especiales para el cuidado de la salud.
- El 36% ó 3.6 millones de estos niños dependen de Medicaid o de CHIP para toda o parte de su cobertura para el cuidado de la salud.

La abuela de Ry Ry está en el proceso de adoptarlo. El recibe una variedad de servicios a través de los programas que son financiados por Medicaid. "Estaríamos en bancarota si hubiéramos tenido que pagar de nuestro bolsillo por los servicios que él necesita," dijo.

- En la mayoría de los casos, Medicaid es la única fuente de cobertura para estos niños, pero frecuentemente juega el papel de cobertura suplementaria para aquellos con seguro privado. La mayoría tienen seguro privado, pero 33% reportan que la cobertura de sus hijos no es suficiente para satisfacer sus necesidades. Para estas familias, Medicaid puede ayudar a cubrir las brechas de cobertura y hacer más asequible la cobertura privada.
- El porcentaje de niños y jóvenes con necesidades especiales para el cuidado de la salud que carecen de cobertura es más bajo que el de los niños en la población general. Actualmente, más de nueve de cada 10 tienen seguro de salud, aunque como se señaló anteriormente, frecuentemente no es suficiente para satisfacer sus necesidades

Rutas para obtener cobertura de Medicaid:

1) Elegibilidad por Ser Parte de Una Familia de Bajos Ingresos.

Si una familia cumple con los requisitos de elegibilidad de ingresos del estado para Medicaid, podrá inscribir a su hijo/a a través de las categorías de "nivel de pobreza" de Medicaid, sin importar si su hijo/a tiene una discapacidad o necesidad especial para el cuidado de la salud.

2) Elegibilidad por Recibir Ingresos Suplementarios de Seguridad (SSI por sus siglas en inglés).

Un requisito para calificar para SSI: los ingresos de la familia del/la niño/a ascienden a menos del 75% del nivel federal de pobreza. Hay algunas familias que pueden obtener cobertura de Medicaid a través de SSI debido a que su niño/a requiere atención a nivel institucional o de hospital. Arizona ha sido un líder proveyendo más atención en el entorno del hogar en lugar de en instituciones.

Hay creciente evidencia de que los niños, incluso aquellos con necesidades complejas para el cuidado de la salud, se desarrollan mejor dentro de su hogar, como miembros de sus familias y comunidades. La creciente inclusión de niños y personas con discapacidades en escuelas, sitios de trabajo y la comunidad en general, en conjunto con los avances en la accesibilidad a tecnología médica para su uso en el hogar, han contribuido a esta tendencia. Esto ha resultado no sólo en mejores resultados para la salud, sino que también son más eficientes al costo. La atención brindada en el hogar normalmente cuesta menos que la que se brinda en hospitales, hogares de descanso u otros entornos de cuidado en conjunto.

3) Elegibilidad como “Medicamento Necesitado/a.”

Ésta es cobertura para las personas, incluyendo a los niños, que puedan tener ingresos demasiado altos para calificar para Medicaid, pero cuyos gastos médicos sean lo suficientemente significativos como reducir sus ingresos más abajo del umbral de elegibilidad del estado. Los estados también pueden cobrar primas a las familias que reducirían sus ingresos familiares poniéndolos debajo del nivel de elegibilidad de Medicaid. La información indica que en 2010, aproximadamente 800,000 niños fueron cubiertos bajo esta opción de “reducción por gastos”. El paquete de Reforma de Medicaid aprobado por la legislatura de Arizona como parte del presupuesto del año fiscal de 2012 eliminará esta opción.

Un estudio encontró que niños y jóvenes con necesidades especiales para el cuidado de la salud necesitan pasar siete veces más días en el hospital que otros niños; reciben cinco veces más medicamentos de prescripción; y ven a proveedores para el cuidado de la salud (médicos y no médicos) mucho más frecuentemente. En general, sus gastos para el cuidado

de la salud son más de tres veces el promedio para otros niños.

Cerca de ocho de cada 10 niños y jóvenes con necesidades especiales para el cuidado de la salud inscritos en Medicaid y CHIP – alrededor de 2.9 millones de niños – dependen de estos programas como su principal fuente de cobertura para el cuidado de la salud. Estos niños suelen inscribirse en Medicaid porque carecen de acceso a un seguro asequible por medio del empleador y no pueden obtener una póliza individual, o porque la cobertura privada no cubre los apoyos y servicios de importancia crítica.

Debido a que el seguro privado normalmente está diseñado para enfrentarse a problemas agudos de la salud en lugar de enfermedades crónicas y discapacidad, frecuentemente establece límites en importantes servicios para niños y jóvenes con necesidades especiales para el cuidado de la salud, terapias (del habla, física y ocupacional), equipo médico duradero y atención para la salud mental.

Como una fuente secundaria de cobertura, Medicaid también ayuda a las familias con la participación de gastos requerida por sus seguros privados. A través del tiempo, el costo de los copagos, cargos de coseguro y deducibles asociados con el cuidado de niños con necesidades especiales para el cuidado de la salud, podría ser financieramente debilitante para la familia. En el caso de niños con necesidades más severas para el cuidado de la salud tales como parálisis cerebral, el estudio encontró que no sólo no se satisfacerían sus necesidades médicas, sino que se superarían los límites de cobertura bajo el plan y la familia podía esperar desembolsar más de \$9,000 al año. Sin embargo, si una familia puede obtener Medicaid como fuente secundaria de seguro, la atención necesaria para el/la niño/a se cubriría y la familia se protegería contra gastos excesivos de desembolso por medio de las reglas de participación de gastos de Medicaid.

Voces de la Familia

La Universidad de Georgetown y Voces de la Familia entrevistaron a una serie de familias sobre cuestiones relativas a la cobertura de seguros y la reforma del cuidado de la salud. Los principales temas de las entrevistas familiares fueron:

continúa en la página 12

1. Medicaid es un salvavidas para niños y jóvenes con necesidades especiales para el cuidado de la salud.
2. Medicaid “rellena los huecos” y evita que las familias se enfrenten a la ruina financiera (muchos dijeron que sin Medicaid hubiesen declarado bancarota).
3. Coordinar la atención y el seguro puede ser un trabajo de tiempo completo.
4. Las familias luchan por encontrar proveedores que vean a sus hijos (encontrar proveedores en general es un desafío, y aún más encontrar a aquellos que acepten Medicaid – especialmente para los hijos adultos con necesidades especiales para el cuidado de la salud).

CALENDARIO EN ESPAÑOL

Por favor llamar al 602-242-4366 o 800-237-3007 para confirmar su asistencia a los talleres.
 Disability Empowerment Center, 5025 E. Washington St., #204, Phoenix, AZ 85034.
 Somos una oficina libre de fragancias.

El Comportamiento Positivo

El vínculo entre las familias las intervenciones y el apoyo conductual positivo es muy importante.

Lunes 9/19/11, 10:00 am – 12 pm

Lunes 11/14/11, 12:30 – 2:00 pm

Lunes 12/5/11, 10:00 – 11:30 am

Al cumplir los 18 años, que sigue?

Tutela: Tomando la Decisión y Entendiendo el Proceso
 Aprenda lo que la Tutela implica y sus alternativas antes de que su adolescente cumpla los 18 años de edad.

Jueves 9/15/11, 3:00 – 5:00 pm

Jueves 10/20/11, 3:30 – 5:30 pm

Jueves 12/8/11, 12:30 – 2:00 pm

Conceptos Basicos del IEP

Aprender acerca del propósito del IEP a través de una visión general del documento y reunión.

Miércoles 9/21/11, 10 am – 12:00 pm

Jueves 10/13/11, 12:00 – 2:00 pm

Jueves 11/10/11, 9:30 – 11:30 am

Miércoles 12/7/11, 6:00 – 8:00 pm

Al cumplir los 3 años, que sigue?

Intervención Temprana
 Aprenda sobre los requerimientos para la transición e ideas para lograr un proceso mas fácil.

Lunes 10/19/11, 12:30 – 2:00 pm

Lunes 11/14/11, 10:30 am – 12 pm

Es su Hijo Blanco de Burlas?

Estrategias de Intervención para Padres de Niños con Discapacidades.

*Una forma de abuso en la escuela a través de la intimidación, tiranía y aislamiento.

Lunes 10/17/11, 1:30 – 3:00 pm

Transición de Escuela Secundaria (High School)

Aprenda como el plan de transición en el IEP de su estudiante de Escuela Secundaria (High School) puede prepararlo para una educación superior, empleo, vida en la comunidad y recursos disponibles.

Jueves 10/20/11, 6:00 - 8:00 pm

Jueves 12/8/11, 10 am– 12 pm

Organizando los archivos de sus niños/a

Aprenda modos efectivos para organizar sus archivos.

Fri. 10/7/11, 10 am – 12 pm

Transición del preescolar al kindergarten

Aprenda las diferentes formas de elegibilidad y estrategias para una transición efectiva a los servicios de edad escolar.

Lunes 12/5/11, 12:00 – 1:30 pm



Entendiendo los Planes 504

Miércoles 10/19/11, 10 am– 12 pm

Aprender acerca del proposito los requerimientos de la Sección 504, las responsabilidades de las escuelas, y las muestras de 504 acomodaciones.

Familias Resistentes

La estructura más básica para una relación de familia saludable, la habilidad de volver de un trauma o una situación difícil.

Jueves 10/13/11, 6:00 – 8:00 pm

*GALA, @ Valle del Sol
 243 S. Mesa Dr., Mesa, AZ*

Para descripciones de talleres y más información, llame a nuestra oficina al 602-242-4366 o al 800-237-3007 o vea el Calendario en español en nuestra pagina web: www.raisingsspecialkids.org/
 Por favor llámenos para confirmar su asistencia a los talleres.

Community Notes

Accessible fitness center to open in October

The universally accessible Virginia G. Piper Sports and Fitness Center is scheduled to open in October of 2011. The 45,000-square-foot facility will be the first of its kind in the Western United States. In addition to hosting competitive sports programs for persons with disabilities, the center will also accommodate fitness, health and wellness programs.

The center will feature spacious and accessible sports courts, runners' track, pool, fitness/training equipment, locker rooms, showers and dressing areas for people with physical and sensory disabilities.

Located at the Disability Empowerment Center, 5025 E. Washington St., Phoenix, AZ 85034.

Visit <http://disabilitysportscenter.com/>



Thank You

CareScape, Inc.

**Sponsor of the 5th Annual
Dandelion Golf Classic
to Benefit Raising Special Kids**

Your contribution is so important to families raising children with special needs. We are grateful for your community spirit and generosity.

**DDD Provider Fair
Saturday, November 12th
10:00 am – 2:00 pm**

Steele Indian School Park, 300 E. Indian School Rd., Phoenix

Over 60 providers of services through the Division of Developmental Disabilities and Community Partners will be on hand to answer questions on Respite, Habilitation, Attendant Care, Housekeeping, Day Programs, Residential Services, Employment Services, Therapies, and other services and products. Walmart gift cards will be distributed. Fun and Games, Food and Drinks. For more information log on to www.azproviderfair.com.



Co-sponsored by Raising Special Kids

**Conference
Cerebral Palsy
Recent Advances in
Medical Treatment
Sat., October 22, 2011
7:30 a.m. to 12:30 p.m.**

For Parents and Caregivers

Phoenix Children's Hospital
Melvin L. Cohen Conference Center
Rosenberg Children's Medical Plaza
1920 East Cambridge Avenue
Phoenix, AZ 85006

Register at
www.phoenixchildrens.com/events

Free Admission • Free Parking
(Sorry, no respite care provided)
Light refreshments provided

For more information contact:
Karen Pennington, Physician
Relations, at (602) 933-3300 or
kpennington@phoenixchildrens.com

Raising Special Kids News

Positive Behavior Support Seminar



A parent chats with Dan Davidson.

Dan Davidson, Ph.D. BCBA-D of the Institute for Human Development at Northern Arizona University and Robert Klaehn, M.D. ABPN, Certified in Psychiatry and Child Psychiatry, presented at a seminar on Positive Behavior Support sponsored by Raising Special Kids.

Commented one attendee: "The conference was very helpful. We were reminded about medication side effects that we had forgotten and appreciated the strategies that were suggested. I also liked being reminded the rewards are just positive consequences... I am excited to implement new behavior ideas at home."

Services in rural and underserved communities

Summer was a busy time for Raising Special Kids outreach programs. Parent training opportunities and information were shared in remote areas and underserved communities in projects including:

- A partnership with The Navajo Nation Growing in Beauty Program to provide two all-day workshops for families in the northern Arizona communities of Page and Leupp.
- Presentations at The Salt River Pima SRPMIC Disabilities Conference
- Co-sponsorship Family Fun Day in Window Rock
- Hopi Advocacy Meeting
- Co-sponsorship First Things First Family Fun Day in Flagstaff and Window Rock
- Special Needs Activity Day in Kykotsmovi
- Navajo Nation Child Care Development Fund Day Care Provider Training
- Hopi Disability Conference in Tuba City



Scenes from the Hopi Disability Conference and Special Needs Activity Day



DDD Coordinators serving the Hopi Tribe, Page and Tuba City attended Special Needs Activity Day.



In The Spotlight

Making a Difference in the Lives of Children Thank You for referring families to Raising Special Kids

May - July, 2011

ABIL

A Place to Call Home

Aid to the Adoption of Special Kids

Karen Lee
Yareli Lopez

Arizona Care Providers, LLC

Jackie Rivas

Arizona Counseling and Treatment Services

Arizona's Children Association

Linda Starr

Arizona Department of Education

Amy Dill
Betty Schoen

Arizona Department of Health Services

Ralph Figueroa
Jeanette Shea

ASCC

ASU Main

Cathy Bacon

ASU Tempe

Matha Cocchirella

ASU West

Prof Juliet Hart

AZ Child Study Center

Dan Kessler

AZ Virtual Academy

AZA United

Paulina Tiffany

Cardon Children's Medical Center

Amira El Ahmadiyah

Catholic Charities

Anne Andrade

Cenpatico

Chandler Unified School district

Child Care and Referral

Children's Rehabilitative Services

Christina Family Care Agency

Louise Gonzalez

City of Phoenix Early Headstart

Lori Solares

City of Phoenix Head Start

Beth Coleman

Community Info & Referral

Diane Taylor

Copper Canyon High School

Department of Economic Security

Shirley Dowlin

Direct Care Personnel

Desiree Stowell

Division of Developmental Disabilities

Carmen Aguilera
Sarah Anderson
Whitney Barkley
Wendy Barrientos
Ruthann Bilkey
Susan Boness
Sarah Bravo
Lois Brooks
Juana Bush
Kathleen Calder
Lyn Cipolla
Chelle Colton-Rutledge
Annie Converse
Wanda Copeland
Laura Delnar
Tadzia Dennis-Jackson
Alma Espinoza
Maria Fernandez
Francisca Gil-Faddis
Malea Grace
Barbara Greensheid
Jade Guerrero
Kathi Guildig
Megan Hansen
Esther Hasz
Tiffany Hawks
Billy Henderson
Peggy Hidrogo
Jill Keyes-McClements

William Kilgore

Dorothy Knox

Carly Konieczny

Valeri Krasevic

Laura Kushemba

Gina Lawrence

Andy Lutz

Maria Elena Mangiameli

Ellyn Manzo

Chelsie Martin

Holly Matheson

Betty McAuley

Martha Mills

Tammy Molash

Marta Monyer

Laura Moore

Jonathan Newby

Courtney Parker

Carla Pate

Karen Patten

Liesl Ponto

Christy Rail

Elva Rama

Lisa Rennells

Jack Schwartz

Kizzy Sepulveda

Dauida Simmons

Mike Smith

Dana Southworth

Susan Stewart

Lola Summers

Cortney Tipton

Susie Tso

Dawn Uhalde

Jo Ann Valdez

Megan Wiley

Elizabeth Williams

Meagan Woefel

Maricruz Yescas

Dreaming Summit Elementary School

Patricia Martin

Emily Center

Family Learning Center

Maritsa Beltran

Family Partners

Family Voices

First Things First

Friendly House

GANE

Gilbert Unified School District

Wendi Howe

Glendale Family Health Center

Linda Fiske

Head Start

Tracy Plank

Hummingbird Early Intervention

Services

Laura Denali

Hurley Ranch Elementary School

Josiah Vasquez

Jewish Family & Children's Services

Heather Ramey

Joni & Friends

Kith and Kin

Olivia Penna

Kyrene School District

Life Development Institute

Justin Coller

Maricopa Health Plan

Terry Dendulk

Maricopa Medical Center Joan Davis

Maryvale Family Health Center (MIHS)

Judith Morales

Melmed Center

Mesa Community College

Red Mountain Branch

Mesa Parent University

Mesa Public Schools

Jan Umhay

Mesa Unified School District

Joan Kern

MIKID

Mountain Park Medical Center

Murphy School District

Jenna DelCostello

Northern Arizona Autism Society of

America

On Angel's Wings

Parenting Arizona

Tresa Blackburn

PEDI Center

Margaret Bunting

Pendergast School District

Phoenix Children's Hospital

Dr. Malcom Anderson

Lois Brooks

Dr. Hoyoung Chong

Tiffany Glick

Susan Larkin

Cynthia Nakamura

Mandy Olliden

Annamarie Ricci

Mia Ruiz

Maritsa Saucedo Graham

Providence, Family Support Partner

Rehab Without Walls

Mandy Cornelius

RISE, Inc.

Carli Auer

Alma Espinoza

Malea Grace

Jordan Robinson

Amy-Lee Verfaillie

Roosevelt School District

SARRC

Scottsdale Unified School District

Shumway Elementary in Chandler

Southwest Human Development

Sharon Mayher

Southwest Network

Annie Custer

Edward Fifer

Sunshine Acres

Tolleson H.S.

Touchstone Behavioral Health

Veronica Gonzales

Tourette Syndrome Assn Support

Group

Traumatic Brain Injury Assn.

U.S. Department of Education

Elizabeth Newton

UMOM

Karly Savoy

University Family Care

Linda Monge

Washington Elementary School

District

Megan Tolway

West Valley Family Development

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Valerie Kemper

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Martha Garcia

Marcia Hanenburg

John Lara

Terri Larkin

Sara Leppert

Ginny Montaño

Sonia Navarro

Sarah Ocampo

Carrie Rice

Dr Karlsson Roth

Terry Sutter

Cathy Uno

Parent Leaders are the heart of Raising Special Kids Thank You!

May - July, 2011

Anthem

Kristina Blackledge

Avondale

Claudia Lizarraga
Gabriela Sanchez Orozco

Chandler

Marty Baio
Beth Maloney
Michael Sanderfer
Noelle White
Shelby Willa

Gilbert

Jessica Gilbert
Enna Graham
Holland Hines
Janet Kirwan
Joelle Warzecha

Glendale

Meriah Houser
Ellen O'Hare

Mesa

Kim Cohill
Colleen Martinez

Phoenix

Paula Banahan
Jeannie Bremerkamp
Jana Caplan
Lisa Case
Bryce Coleman
Debbie Demland
Nancy Gunderson
Nancy Licht
Maria O. Lopez
Kathy McDonald
Maureen Mills
Kathy Moschioni
Marlene Muñoz
Elizabeth Naughton-Ketzler
Susan Ory
Madeline Papazian
Chuck Smith
Paulina Tiffany
Dana Wayne
Leslie Williams

San Tan Valley

Cassandra Yazzie

Scottsdale

Sharon Landay
Steve Lee
Chris Linn
Shauna Mattson
Lynn Michels
Katie Petersen
Mary Quinsler
Ched Salasek

Sun Lakes

Iris Sanabria
Philip Sanabria

Tempe

Janet Romo

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Did you know that you can contribute to Raising Special Kids through United Way? Just enter our agency code **314** on your form.

Raising Special Kids
5025 E. Washington, Suite #204
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Katelyn

Dana was puzzled and concerned when her toddler's speech development was not keeping up with her peers. Although friends offered reassurance, Dana was glad she pursued testing after the results yielded a diagnosis of apraxia.

After Katelyn began receiving Early Intervention services, a therapist referred Dana to Raising Special Kids. Initially Dana resisted the idea, but when she attended a workshop she found other parents who could relate to her experience. "That was the first time I ever felt like somebody 'got it'."

Dana went on to become a Parent Leader. "I'm getting to meet so many other parents and assist other families. I love being there to share with other families."

Please join us in helping families of kids like Katelyn.

To donate online
www.raisingpecialkids.org

Thank you for making a difference for families!