



CACSHCNEWS

Governor Brown Releases His Draft Budget for 2011-2012

By: Laurie A. Soman, 02/02/2011

On January 10, 2011, the Brown Administration released its first draft budget to address a projected deficit of \$25.4 billion for the next 18 months - the last six months of the current fiscal year and Fiscal Year 2011-2012. The Governor's budget proposes to close the budget deficit as well as to provide a \$1 billion budget reserve. The Governor wanted to pass budget legislation by March 1 and to put several propositions on the ballot in a special election in June to provide funding to support the budget.

There are three components to the Administration's draft budget: 1) "realignment" of certain programs to the county level; 2) revenue solutions totaling \$12 billion; and 3) budget reductions totaling \$12.5 billion.

Realignment

The Administration proposes to shift a variety of programs to the counties along with dedicated funding for five years (1% of the sales tax and 0.5% of the Vehicle License Fee). Mental health services, foster care, and child welfare are included in programs proposed for realignment. A proposed Phase II of realignment, tentatively scheduled for Fiscal Year 2014-2015, would shift responsibility for costs of some programs from counties to the state, which may include In-Home Support Services and CCS.

Revenue Solutions

Proposed revenue solutions comprise \$12.0 billion (45%) of the solutions in the proposed budget. Most of the revenue solutions are from extending existing tax rates and fees for five years, which originally were raised in 2009 for a two-year period, including the vehicle license fee, sales tax rate, income tax surcharge, and dependent exemption credit.

Budget Cuts

The proposed \$12.5 billion in spending reductions include the following cuts to health and human services and other programs:

Medi-Cal: The Governor proposes \$1.7 billion in cuts, which include co-pays for both adults and children for outpatient services, dental services, emergency room visits, and inpatient hospital stays. The budget would reduce Medi-Cal provider rates by 10% for physicians, pharmacists, clinics, medical transport, home health, and some hospitals; these rate

See **BUDGET** on Page 3.

CACSHCNEWS is produced by a consortium whose members work toward the common goal of improving systems of care for children with special health care needs in California:



- ◆ Los Angeles Partnership for Special Needs Children (LAPSNC)
- ◆ Family Voices of California (FVCA)
- ◆ Children's Regional Integrated Service System (CRISS) Project
- ◆ USC University Center for Excellence in Developmental Disabilities (UCEDD) at Childrens Hospital Los Angeles

FAMILY VOICES
of California



If you...

- would like to contribute news items, please submit via email: cacshcnews@gmail.com
- have any questions about this newsletter, please contact Kathryn Smith, MN, RN: kasmith@chla.usc.edu

To receive CACSHCNEWS, please send an email message to mward@chla.usc.edu with "CACSHCNEWS" in the subject line.

Next Issue Date:
July/August, 2011

CACSHCNEWS

Previous issues available at

<http://www.cshcn-ca.org/index.php?pageid=29>



Special Features

In This Issue

Page 2: Special Features

Page 4: Articles

Page 8: Resources and Reports



California Ranks Last in U.S. on Index Measuring System of Care for CSHCN, Study Finds
(California) (Catalyst Center)

Prepared By: The Child and Adolescent Health Measurement Initiative (CAHMI)
Lucile Packard Foundation for Children's Health
November 17, 2010

Patient & Family Centered Care Partners: Building the Community of Health Care Providers and Patients for Quality Improvement

PFCC Partners recognizes that the quality of healthcare outcomes is improved when the expertise of the health-care providers is partnered with the experience of the patients and families. Patient & family centered care is about partnering to design policies, programs, and individual care plans for the best possible outcomes. PFCC Partners is committed to building a community where health-care providers, administrators, ancillary staff, patients, and families coming together to define best practices, share resources, connect with peers, and access support and tools for integrating PFCC into their organizations. Whether you are an individual starting your organization on the journey to patient & family centered care, or an organization with expertise to share, or a patient or family member with a desire to improve care, we hope that you will join this community to promote and integrate PFCC practices.

For more information, please go to the website at www.pfccpartners.com.

Family Resources and Supports Institute 2011: We Have a Story to Tell

13th Annual Training for Early Start

Date: March 29 - 30, 2011

Location: Crowne Plaza Hotel, Foster City, CA

Fee: \$75 per person

Registration Deadline: March 14, 2011

The California Department of Developmental Services (DDS), in collaboration with Early Start Family Resource Centers and other community partners, invites you to participate in the Family Resources and Supports Institute, We Have a Story to Tell. This 13th annual training event, sponsored by DDS and coordinated by the WestEd Center for Prevention and Early Intervention as part of the Early Start Comprehensive System of Personnel Development, provides support to persons working in family resource centers. This Institute reflects Early Start's commitment to parent-professional partnerships and collaborative relationships among service providers delivering quality supports and services to children. Sessions offer innovative tools and strategies to help you do your work even better. Participants have many opportunities to celebrate and learn from each other throughout the Institute and at the networking reception, The Story on the Street.

Download more information and register online at <http://www.wested.org/cs/cpei/print/docs/214>.

An estimated one in seven children in California has a special health care need, yet the state ranked worst in the nation on a composite index that measures whether these children have adequate health insurance, receive basic preventive care, and receive medical care that is comprehensive, ongoing, and family-centered, according to a study released today. Children with special health care needs (CSHCN) are those who have a chronic condition that requires health care beyond what is needed by most children. Conditions may range from mild, manageable asthma to highly complex conditions such as cerebral palsy or heart disease.

"These children are one of the most vulnerable segments of our society, and in many senses the system in California is not doing well for them," said David Alexander, a pediatrician who is president and CEO of the Lucile Packard Foundation for Children's Health, which commissioned the study. Nearly all CSHCN in California experience some limitations in their daily lives. However, about one in four of the 1.4 million special needs children in California experiences difficulties severe enough that they are unable to do things other children their age can do. These children and their families usually have the most difficulty in finding medical and dental care, child care, transportation, educational assistance, medical equipment, consistent health insurance, and a range of other services.

"This is particularly concerning because advances in medical care mean that many children are surviving who previously would not have, and it will become increasingly difficult for our already overburdened system to care for them adequately," Alexander said. The composite index noted in the study does not evaluate the quality of the medical treatment that individual children receive, which is often excellent, Alexander said. Rather, it assesses adequacy of insurance, access to care, and other measures of how well the system functions, such as whether families are involved in the care. "We must make significant improvements in these areas," he said.

The study, Children with Special Health Care Needs: A Profile of Key Issues in California, analyzes the most recently available data from two surveys of parents sponsored in every state by the U.S. Maternal and Child Health Bureau: the 2007 National Survey of Children's Health and the 2006 National Survey of Children with Special Health Care Needs. "Children with special health care needs in

See **SYSTEM OF CARE** on Page 3.



Special Features

SYSTEM OF CARE (Continued from Page 2)

California have exceptionally complex conditions, and there is no question that many families are struggling to meet their basic requirements," said lead study author Christina Bethell, professor in the Department of Pediatrics at Oregon Health and Science University and director of the Child and Adolescent Health Measurement Initiative, where the study was conducted. "One of our significant findings was that nearly one in four of these children has parents who cut back or stopped working due to their child's health. This has a tremendous impact not only on families but also on employers."

In other key findings:

* Ethnic/racial and economic disparities in California are stark among CSHCN. Children of color and publicly insured children are much more likely to have poorer health status and sub-optimal health care.

* CSHCN are much more likely to repeat a grade and to miss more days of school than children without special needs.

* California ranked 45th among states in addressing the transition from pediatric to adult care.

The barriers to creating a higher quality system are longstanding and complex, with no single solution, Alexander said. Ensuring that all children have adequate health insurance and streamlining the way care is financed are two important steps, he said. Advocates and policymakers also need to press for treating children in an environment where their multiple health and social needs can be coordinated and families can be involved in decision making, Alexander said.

Although California ranks poorly on many indicators, the state is not alone, Alexander said. "Throughout the country, children with special needs receive care in a system that is poorly designed to meet their specific requirements. As health reform is implemented, we must be sure that the needs of this growing population finally are addressed."

About the Foundation: The Lucile Packard Foundation for Children's Health—a non-profit public charity, works to improve children's health by bringing public attention to key issues, particularly those related to CSHCN.

About CAHMI: The Child and Adolescent Health Measurement Initiatives—a research and policy group based at Oregon Health & Science University that focuses on the development, implementation, and strategic dissemination of data based on measures of child and adolescent health and health care quality.

The full report and the executive summary are available at <http://www.lpfch.org/specialneeds/press.html>.

BUDGET (Continued from Page 1)

reductions have already been stayed by the courts and the case will be heard by the US Supreme Court. Adult Medi-Cal enrollees face limits on services, including doctor visits and prescriptions, and maximum benefit dollar caps on medical supplies and durable medical equipment. The budget proposes elimination of Medi-Cal coverage for Adult Day Health Care Services. The budget also proposes to redirect \$1 billion from First 5 reserves to fund Medi-Cal for children aged 0-5, which must be submitted to voters for approval during the June special election. The Governor also proposes redirecting \$200 million of First 5 revenues through 2015.

Healthy Families Program: The Governor proposes cutting \$135.7 million from the program, including elimination of the vision benefit (some vision care remains available through Healthy Family plans, such as treatment of eye injuries and eye surgery) and increasing premiums which would affect 565,000 children. Premiums would increase for enrollees with incomes at 150-199% of the Federal Poverty Level (FPL) from a family maximum of \$48 to \$90 and for enrollees with incomes at 200-250% of FPL from a family maximum of \$72 to \$126. Co-pays also would increase for ER visits and would be established for inpatient hospital stays.

Developmental Services: The budget cuts \$750 million by continuing the existing 4.25% reduction in regional center operations and provider payments, and the redirection of \$50 million from state First 5 to cover services for children 0-5. The budget also proposes to establish "statewide service standards" for regional center purchase of services, including eligibility, duration, frequency and efficacy, qualification of providers, service rates, and parental/consumer responsibilities, yielding over \$600 million of the \$750 million in cuts.

Mental Health Services: The budget proposes to redirect Proposition 63 funds to local mental health managed care services, EPSDT mental health, and AB 3632 services.

CaWORKS: The budget proposes \$1.5 billion in cuts through reducing the cash assistance time limit from 60 months to 48 months and a 13% reduction in CaWORKS grants from \$694 for family of three to \$604.

IHSS: The budget would cut funding IHSS by \$500 million by reducing hours of assistance by 8.4% and retaining last year's reduction in hours by 3.6%, for a total 12% reduction in hours, and eliminating domestic and related services for people in shared living situations and for minors. In addition, all IHSS recipients would be required to obtain physician certification that IHSS services are necessary to prevent out-of-home care; without the certification recipients would lose IHSS services.

Child Care: The budget proposes \$750 million in cuts to child care by eliminating subsidized child care for children aged 11-12 years, reducing of program income eligibility criteria to 60% of state median income from 75%, and a 35% across-the-board reduction of the subsidies to child care providers.

For More Information

CA Department of Finance: www.dof.ca.gov

CA Budget Project: www.cbp.org

Legislative Analyst's Office: www.lao.ca.gov

Articles

Authors Investigate Coping Among Parents of Children With and Without a Health Care Home

(MCH Alert, 2/11/2011)

"Children who had a health care home were more likely to have parents who reported coping very well," state the authors of an article in the *Journal of Pediatric Health Care* published online on February 2, 2011. Healthy People 2010 identified the need to increase the number of children with special health care needs (CSHCN) with access to a health care home. In addition to being associated with well-being and health outcomes, aspects of the health care home, such as family-centered care and care coordination, are likely associated with parents' ability to cope with the day-to-day demands of parenting, but this relationship has not been fully explored in a large sample of families. A contextual approach to families with CSHCN recognizes the interdependence of families with the health care system and the role of extra-family factors in coping. The article describes a study to determine whether certain provider-level factors, as a process of care, are associated with parental coping with the day-to-day demands of raising a CSHCN, while controlling for individual-level factors.

Data for this secondary analysis were from the 2007 National Survey of Children's Health (NSCH). The subsample of CSHCN was the focus for this study. The study sample included 18,352 CSHCN (19.2 percent of the entire NSCH sample). The analyses explored relationships between level of parental coping, process-of-care variable (including the presence of a health care home and specific subparts of the health care home - family-centered care and care coordination), predisposing variables (child age and mother's education level), and enabling variables (poverty and insurance status).

The authors found that:

* Based on the health care home composite score, 51.4 percent (n=9,435) of CSHCN in this sample had a personal doctor or nurse and met criteria for adequate care on every component of the health care home.

* Compared with children whose parents reported not coping well, a significantly higher proportion of children who had a health care home who did not receive help coordinating care and who did not need extra help coordinating care had parents who reported coping very well.

* As parents' satisfaction with communication among health professionals increased, the proportion of those coping not very well decreased.

* Children were more likely to have a parent coping very well if the child was older, the parent reported not needing additional help with care coordination, and/or the score on the family-centered care scale was higher.

See **COPING: PARENTS** on Page 5.

Research Examines Quality of Life Among Parents of Children with Cancer

(MCH Alert, 2/18/2011)

"This study extends previous research on the impact of childhood cancer on the family," state the authors of an article published in *Quality of Life Research* online on February 2, 2011. The authors of the article recently published a study implicating stress as a mediator between caring for a child with cancer and poor parental quality of life (QOL). This previous study, however, addressed only differences between parents of children with cancer and parents caring for children without cancer. It did not assess potential sources of variation in parental QOL among parents caring for children with cancer. The article examines which specific cancer- and treatment-related factors are associated with adverse parental QOL outcomes and whether caregiver burden and stress mediate these relationships.

The case-only sample was drawn from the larger longitudinal study of parents of children with or without cancer or a brain tumor. The final sample included 75 children with cancer and their parent who was most involved in caregiving, of whom all but 3 were the child's biological parent. Key diagnosis and treatment variables were abstracted from the child's medical record. All participating parents completed an in-person interviewer-assisted survey that included items about sociodemographic characteristics, health behaviors, and a series of validated self-reported measures. Participants also completed a follow-up interviewer-assisted phone survey 3-6 months after their initial interview. Data were analyzed cross-sectionally.

The authors found that:

* Having a child with an activity limitation was associated with significantly worse mental health-related QOL, as was having a child on active or maintenance cancer treatment. Controlling for time since diagnosis and other treatment factors did not impact these results.

* Being married or partnered was associated with significantly better mental health-related QOL.

* Having a college degree or a more advanced degree and reporting poor sleep were associated with significantly worse mental health-related QOL.

* When burden was included in the model of poor mental health-related QOL, the effect of having a child with an activity limitation was attenuated but remained significant. The effect of having a child on active or maintenance treatment was no longer statistically significant. Including caregiver burden in the model also attenuated the effects of being married or partnered, being highly educated, and reporting poor sleep.

See **QUALITY OF LIFE** on Page 5.

Articles

Policy Statement: Principles of Health Care Financing (Catalyst Center)

By: Russell Libby
Pediatrics, Vol. 126, No. 5, October 25, 2010

The American Academy of Pediatrics advocates that all children must have health insurance coverage that ensures them access to affordable and comprehensive quality care. Access to care depends on the design and implementation.

See **HEALTH CARE FINANCING** on Page 7.

COPING: PARENTS (Continued from Page 4)

* Maternal education level, poverty status, and insurance status were not significant in the model.

"The findings of this study highlight the interconnectedness of families and systems of care," conclude the authors, adding that "support and resources for parents of CSHCN are imperative so parents can provide the best health care for their children."

Drummond A, Looman WS, Phillips A. 2011. Coping among parents of children with special health care needs with and without a health care home. *Journal of Pediatric Health Care* [published online on February 1, 2011].
Abstract available at [http://www.ipedhc.org/article/S0891-5245\(10\)00386-X/abstract](http://www.ipedhc.org/article/S0891-5245(10)00386-X/abstract).

QUALITY OF LIFE (Continued from Page 4)

* After adding stress to the model, the effect of having a child with an activity limitation was further attenuated but remained marginally significant, while the effect of caregiver burden was completely explained. The effect of poor sleep was also attenuated by controlling for stress.

* Children's symptom severity was associated with parental physical health-related QOL. This relationship was not mediated by parental psychosocial factors.

"The findings show that caregiver burden and stress mediate the effect of caring for a child who is in active cancer treatment or has activity limitations on parental mental health-related QOL," conclude the authors. They suggest that "screening parents for excessive burden, stress, or mental health problems, and assisting them to find appropriate support services or treatment may be essential in improving the health and QOL of both parents and children."

Litzelman K, Catrine K, Gangnon R, et al. 2011. Quality of life among parents of children with cancer or brain tumors: The impact of child characteristics and parental psychosocial factors. *Quality of Life Research* [published online on February 2, 2011].
Abstract available at <http://www.springerlink.com/content/3482810657766916>.

Analyzing Patterns of Comorbidity, Functioning, and Service Use for Children with ADHD (MCH Alert, 2/18/2011)

"Professionals and parents need to be aware of the high prevalence of mental health/neurodevelopmental comorbidities among school-age children with ADHD [attention-deficit hyperactivity disorder] in the United States," write the authors of an article published in *Pediatrics* online on February 7, 2011. ADHD is one of the most common cognitive and behavioral disorders currently diagnosed in U.S. school-age children, with an estimated annual societal cost of \$34 billion to \$52 billion. Children with ADHD have elevated problems in many areas, including academic functioning and strained social and family relationships. Studies also show that children with ADHD commonly exhibit additional mental health and neurodevelopmental comorbidities, including learning disabilities, epilepsy, tic and communication disorders, conduct disorder, anxiety, and depression. The study described in this article uses data from the National Survey of Children's Health (NSCH) to examine patterns of comorbidity, functioning, and service use for children with ADHD.

The final study sample includes 61,779 children ages 6 to 17 from NSCH. There were 5,028 children available for the analyses that examined factors associated with outcomes for children with ADHD. Measures included ADHD and comorbidities, child and family functioning, and service use.

The authors found that:

* Parent-reported diagnosed prevalence of ADHD for all children ages 6 to 17 was 8.2 percent, corresponding with more than 4,010,000 cases nationwide.

* Children with ADHD were more likely than other children to have each of 10 other mental health and neurodevelopmental disorders. Nine of the disorders remained significant after adjustment for sociodemographics. In total, 67 percent of the children with ADHD had at least 1 other reported mental health/neurodevelopmental disorder, compared with 11 percent of other children.

* Among children with ADHD, 33 percent had 1 comorbidity, 16 percent had 2, and 18 percent had 3 or more.

* Children from families with low incomes were approximately 1.4 times more likely to have ADHD than were children from families with incomes of 400 percent of the federal poverty level (FPL) or greater. The risk for having 3 or more comorbidities among children with ADHD was 3.8 times higher for children from families with low incomes vs. those from the most affluent families (30 percent vs. 8 percent.)

See **CHILDREN WITH ADHD** on Page 6.

CHILDREN WITH ADHD (Continued from page 5)

* Children with ADHD had more reported problems across every indicator of functioning than other children.

* Children with ADHD had higher odds of activity restriction, school problems, grade repetition, and poor communication; their social competence scores were lower and parent aggravation higher. For children with ADHD, the odds of poorer functioning increased in a step-wise fashion with increasing numbers of comorbidities.

* Among children with ADHD, functioning was consistently lower for children from families with lower incomes than for those from families with incomes of 400 percent FPL or greater.

* Children with ADHD consistently used more health, mental health, and education services than did other children. Among children with ADHD, service use increased with each additional comorbidity.

The authors conclude that "comparative effectiveness studies of primary care treatment strategies for ADHD in children have been identified as an Institute of Medicine priority. Our findings indicate that such studies are urgently needed."

Larson K, Russ SA, Kahn RS, et al. 2011. Patterns of comorbidity, functioning, and service of use for US children with ADHD, 2007. *Pediatrics* [published online on February 7, 2011]. Abstract available at <http://pediatrics.aappublications.org/cgi/content/abstract/peds.2010-0165v1>.

Effect of Medicaid and SCHIP Expansions on Child Mortality

(MCH Alert, 11/20/2010)

Medicaid and State Children's Health Insurance Program (SCHIP) "expansions worked equally well in improving the health of Black children and White children. At the same time, the Medicaid and SCHIP expansions do not appear to have reduced relative racial disparities in child mortality, which remained unchanged in this time period," state the authors of an article published in the December 2010 issue of the *American Journal of Public Health*. Most research on the impact of the expansions of coverage has focused on improvements in access to care and use of services. The article examines the association between child mortality and those expansions and the effect of the expansions on racial disparities in child mortality.

The researchers (1) obtained the complete National Center for Health Statistics individual-level multiple-cause-of-death mortality data from 1985 through 2004 from a public use data archive; (2) extracted records for children ages 1-

See **SCHIP EXPANSION** on page 7.

Percentages of Children with Special Health Care Needs Receiving High-Quality Services

(MCH Alert, 1/21/2011)

"This article presents new findings on the degree to which children with special health care needs are receiving high-quality care, as evidenced by the successful attainment of six quality indicators that together can be viewed as representing the essential elements of a system of care," write the authors of an article published in the February 2011 issue of the *American Journal of Public Health*. Programs addressing the unique needs of children with special health care needs (CSHCN) or children at increased risk for special health care needs, have long been a component of the public health system. The Maternal and Child Health Bureau has established six quality indicators to describe what families of CSHCN should be able to expect from the service system: (1) family partnership in decision-making and satisfaction with care, (2) receipt of care through a medical home, (3) adequate health insurance, (4) early and continuous screening and surveillance, (5) services that are organized for ease of use, and (6) effective transition planning for adult health care. Together, these quality indicators represent the essential elements needed for a high-quality system of services. Working with state Title V CSHCN programs, families, and other stakeholders, MCHB developed a monitoring strategy for assessing progress toward attaining the six quality indicators and the systems goal using the National Survey of Children with Special Health Care Needs (NS-CSHCN), a large-scale telephone-based survey of parents of CSHCN. This article presents results from the 2005-2006 NS-CSHCN on the proportion of children for whom each quality indicator is met as well as the proportion for whom all six quality indicators and, hence, a system of services, are in place. State-level estimates are also provided.

The authors found that:

* Quality indicator #1: Criteria for the decision-making and satisfaction quality indicator were met for 57.1 percent of CSHCN during 2005-2006. State success rates for this indicator ranged from 46.6 percent to 65.7 percent.

* Quality indicator #2: An estimated 47.1 percent of CSHCN had all five components of the medical home quality indicator met during 2005-2006. State success rates for this indicator ranged from 36.9 percent to 57.4 percent.

* Quality indicator #3: Overall, 62.0 percent of CSHCN had all components of the health insurance quality indicator met during 2005-2006. State success rates for this indicator ranged from 53.5 percent to 73.5 percent.

* Quality indicator #4: An estimated 63.8 percent of CSHCN had the screening and surveillance indicator met during 2005-2006. State success rates for this indicator ranged

See **QUALITY CARE** on Page 7.

Articles

QUALITY CARE (Continued from Page 6)

from 50.3 percent to 79.9 percent.

* Quality indicator #5: An estimated 81.1 percent of CSHCN had the ease-of-use quality indicator met during 2005-2006. State success rates for this indicator ranged from 82.6 percent to 94.3 percent.

* Quality indicator #6: An estimated 41.2 percent of adolescents (ages 12-17) with special health care needs experienced a fully met transition quality indicator during 2005-2006. State success rates for this indicator ranged from 24.0 percent to 54.4 percent.

High-quality systems: During 2005-2006, 17.7 percent of CSHCN received care consistent with all quality indicators and could thus be considered as receiving care in a high-quality system.

The authors conclude that "although this assessment documents a degree of success nationally in meeting the quality indicators and to a lesser extent the systems goal, continued and concerted efforts by government and private agencies, health care professionals, and families are needed to ensure that children with special health care needs receive the high-quality care they need."

Strickland BB, van Dyck PC, Kogan MD, et al. 2011. Assessing and ensuring a comprehensive system of services for children with special health care needs: A public health approach. *American Journal of Public Health* 101(2):224-231. Abstract available at: <http://ajph.aphapublications.org/cgi/content/abstract/101/2/224>.

HEALTH CARE FINANCING (Continued from Page 5)

mentation of payment systems that ensure the economic viability of the medical home; support and grow the professional pediatric workforce; promote the adoption and implementation of health information technology; enhance medical education, training, and research; and encourage and reward quality-improvement programs that advance and strengthen the medical home.

Health insurance plans must be portable from state to state, with administrative procedures to eliminate breaks and gaps in coverage to ensure continuous coverage from year to year. Plans should ensure free choice of clinicians and foster coordination with public and private community-based programs for infants, children, and adolescents through the age of 26. The scope of services provided by all health plans must include preventive, acute and chronic illness, behavioral, inpatient, emergency, and home health care. These plans must be affordable and have cost-sharing policies that protect patients and families from financial strain and are without risk of loss of benefits because of plan design, current illness, or preexisting condition.

SCHIP EXPANSION (Continued from Page 6)

17, along with the cause of death, year of death, state of residence, and child demographic characteristics (age and race); and (3) tabulated the number of deaths from natural (disease-related) and external (injuries, homicide, and suicide) causes, by state, year, three racial categories (black, white, and "other"), and three age categories (ages 1-4, 6-11, and 12-17). They analyzed data for the broad categories of natural and external causes of mortality, developed descriptive trends in mortality rates by age and race, and studied the relationship between Medicaid and SCHIP eligibility and child mortality.

The authors found that:

* Mortality declined across the time period among all age and racial groups.

* The absolute difference between black and white mortality rates also declined over the period. However, the black-white mortality ratio, reflecting relative racial disparities in child mortality, remained unchanged for all children.

* The degree of Medicaid expansion (represented by the proportion of children in a particular age group who would be eligible for Medicaid or SCHIP) was significantly related to the natural-case mortality rate, suggesting that a 10-percentage-point increase in eligibility results in a 3.73 percent decline in child mortality. However, the decline in child mortality was not linear, suggesting that there were factors affecting mortality that were greater in some years than in others.

* Medicaid and SCHIP expansions were associated with declines in child mortality due to external causes.

* The coefficient for black race was virtually identical in models with and without the Medicaid and SCHIP eligibility indicator — for both natural-cause and external-cause mortality. Similarly, an interaction effect between black race and the eligibility indicator was nonsignificant.

"It is not evident from this study that expanded health insurance coverage for children was a successful strategy for reducing relative racial disparities in child mortality through 2003," conclude the authors. They add, "reducing racial disparities may require many different types of changes at the national and community level, of which improved health insurance coverage is just one such change."

Howell E, Decker S, Hogan S, et al. 2010. Declining child mortality and continuing racial disparities in the era of the Medicaid and SCHIP insurance coverage expansions. *American Journal of Public Health* 100(12):2500-2506. Abstract available at <http://ajph.aphapublications.org/cgi/content/abstract/100/12/2500>.

Resources & Reports

The Case for Inclusion: An Analysis of Medicaid for Americans with Intellectual and Developmental Disabilities

(Catalyst Center, 11/1/2010)

By: United Cerebral Palsy
2010 Report

The 2010 Case for Inclusion report (medicaid.ucp.org) ranks all 50 states and the District of Columbia (DC) for Medicaid services provided to persons with intellectual and developmental disability (ID/DD). The fifth annual rankings reveal:

- * Despite significant progress, all states have room to improve outcomes and services for individuals with ID/DD, particularly in the current economic climate.
- * Too many Americans with ID/DD still do not live in the community, although real and notable progress have been made since last year.
- * Certain states are making substantial progress.
- * Too much money is still spent isolating people in large institutions, with nominal change since 2009.
- * Waiting lists have increased dramatically, but performance is quite mixed by state; most are not serving everyone in need.

Seventeen states shifted by at least five places in the rankings from 2009 to 2010, and 21 states shifted at least six places in the rankings from 2007 to 2010. Highlights include:

- * An impressive 22 states (up by three) from 2009 and an increase from 16 states in 2007 have more than 80% of those served living in home-like settings.
- * From 2005 to 2008, an impressive 13 states reduced the number of Americans living in large institutions by 20% or more.
- * Overall the number of Americans with ID/DD on waiting lists for residential services has increased 56% from 2005 to 2008.

This report focuses on what is being achieved; not how much or how little money is being spent. While current Federal Stimulus funds have alleviated Medicaid spending pressures at the state level to a large extent, Medicaid shortfalls are projected to come roaring back in 2011, if the temporary increase in Medicaid funds run out.

Full report may be found at [http://medicaid.ucp.org/pdf/Case For Inclusion Report 2010.pdf](http://medicaid.ucp.org/pdf/Case%20For%20Inclusion%20Report%202010.pdf).

Legislative Analyst's Office — The 2011-12 Budget: Options to Achieve Savings In The Regional Center System

(Legislative Analyst's Office, 2/1/2011)

Total expenditures for the regional center system, that provides services for persons with developmental disabilities, more than doubled between 1999-00 and 2009-10, leading to a series of actions by the Legislature to slow down the growth in the program. In this report, we describe and assess proposals in the Governor's 2011-12 budget plan to achieve further cost containment in programs administered by the Department of Developmental Services, including community services.

We recommend approval of the Governor's budget proposals to (1) extend the 4.25 percent provider payment reduction and the commensurate reduction to regional center (RC) operations, and (2) obtain additional federal funds for services provided through the developmental centers and the RCs. We also recommend the Legislature either expand the existing Family Cost Participation Program or implement means testing to determine who is eligible to receive these state services. These changes, we would acknowledge, represent a significant departure from the policies originally adopted in the Lanterman Act but would help ensure the long-term sustainability of the program for those consumers with the greatest financial need for its services. (12 pp.)

This report is available at <http://lao.ca.gov/laoapp/PubDetails.aspx?id=2424>.



New Youth-Created Videos on Transition

(TATRA Center Reference Points, 1/21/2011)

The project, Innovative Partnerships for Advancing Youth Employment, provided a paid internship opportunity for students with disabilities to make six short films that addressed transition issues for youth with disabilities. Throughout this process students were exposed to the technical skills needed for high growth industries such as digital media, communication and computer based careers. This innovative PACER project was funded by the Minnesota Department of Employment and Economic Development, through its Vocational Rehabilitation Services branch, provided technical and financial support for this project, using federal economic stimulus funds from the American Recovery and Reinvestment Act. This was a creative collaboration of the postsecondary programs of Bemidji State University and South Central College, the Bemidji and Mankato Workforce Centers, and the Minnesota Valley Education District and Bemidji High School. The videos can be viewed at <http://www.youtube.com/user/pacercenter>.

Resources & Reports

Series Focuses on Philanthropy's Role in Achieving Family-Centered Care for Children (MCH Alert, 1/21/2011)

Promoting Family-Centered Care for Children with Special Health Care Needs examines the role of family organizations in providing information and support for children with special health care needs (CSHCN), their families, and their professional partners. The document, published by Grantmakers In Health as part of the Views from the Field series, specifically addresses the goals and activities of Family Voices and Family-to-Family Health Information Centers (F2F HICs). Topics include the challenges families face in navigating the health care system, financing F2F HICs, select state activities, and what philanthropy can offer.

The document is available at http://www.gih.org/usr_doc/Family-Centered_Care_Kids_Special_Needs_FamilyVoices_January_2011.pdf.



The Affordable Care Act and Children with Special Health Care Needs: An Analysis and Steps for State Policymakers (Catalyst Center, 1/20/2011)

The Affordable Care Act (ACA) provides states with some important tools that can be utilized to help children with special health care needs (CSHCN) and their families access coverage that is universal and continuous, adequate and affordable. However, interpretation of the law and addressing implementation challenges with the unique needs of CSHCN in mind will shape how well the ACA fulfills its promise to this vulnerable population. A new paper developed by the National Academy for State Health Policy (NASHP) for the Catalyst Center reviews and analyzes key provisions of the ACA relevant for CSHCN to help inform state policymakers' decisions in implementing health care reform. The 48-page paper is available now to download for free on the Catalyst Center website.

The paper may be accessed at <http://hdwg.org/sites/default/files/ACAandCSHCNpaper.pdf>.



Benefit Programs: What it Takes to be Eligible in Your State (TATRA Center Reference Points, 1/16/2011)

The Center on Budget & Policy Priorities has an online tool to learn about the eligibility and benefits for programs in your state, including food stamps, Medicaid, CHIP, child care assistance and others.

The website can be accessed at <http://www.cbpp.org/cms/index.cfm?fa=view&id=1414>.

Children's Benefits Access Guide is LIVE!

L.A. Care Health Plan and the Disability Rights Legal Center (DRLC) partnered to create the Children's Benefits Access Guide. The guide was funded by the L.A. Care Community Benefits program.

The Benefits Access Guide sets out the health care and related benefits available under Medi-Cal and other governmental programs to children with disabilities, and analyzes agency responsibility to coordinate, provide, and pay for services for eligible children with disabilities.

To develop the Benefits Access Guide, the DRLC drew upon legislative authority, legal precedent, current developments in health policy and the state budget, interagency agreements, and interviews with stakeholders.

This is an online tool to assist the professionals and staff that work with parents, guardians and families of children with disabilities at health plans, community clinics, regional centers, and other agencies with better information about available benefits and agency responsibility. It will be updated periodically to reflect changes in policy and benefits.

The guide can be viewed at <http://www.disabilityrightslegalcenter.org>.



Report: Nutrition and Oral Health Considerations in Children with Special Health Care Needs - Implications for Oral Health Care Providers (Catalyst Center, 11/25/2010)

By: Amr Mours, Jill Fernandez, Marcia Daronch, Lena Zee and Cassandra Jones
Pediatric Dentistry, Vol 32 , No 4

Children with special health care needs are at increased risk for oral diseases. The purpose of this article was to discuss: 1) nutritional and oral health factors routinely observed in most chronic childhood disorders; 2) dietary modifications associated with select systemic disorders and how they may impact oral health in children; and 3) the following factors common to chronic disorders associated with diet modifications-decreased appetite and increased nutritional risk; frequency of food intake; parental overindulgence; long-term use of cariogenic medications; and xerostomia.

Characteristics of childhood disorders that require dietary modifications (congenital heart disease, cystic fibrosis, cancer, AIDS/HIV, diabetes mellitus, and phenylketonuria) are summarized. In addition, healthy dietary modifications and oral health recommendations are suggested. Implementation of these recommendations can assist the dentist and dental team as they join physicians and nutritionists in delivering the best possible care to children with special health care needs.

Resources & Reports

ACA Update of Healthcare.gov's Fact Sheets (Catalyst Center Week In Review - Nov 22, 2010)

This new fact sheet from HealthCare.gov describes what the Affordable Care Act means for Americans with disabilities. The Act will stop insurance company discrimination based on a preexisting condition. Beginning in 2014 the law will prohibit insurance companies from denying coverage or charging more to a person based on their medical history. It will also provide new choices for long-term supports and services, as well as accessible, quality and affordable health care for people with disabilities.

The fact sheet can be viewed at http://www.healthcare.gov/news/factsheets/affordable_care_act_americans_disabilities.html.

.....

Jacob Lesner-Buxton is a Member of the Family Voices Youth Advisory Council

He is presently working on creating a website dealing with the bullying of folks with disabilities. Please see link below and pass on as widely as possible.

http://www.youtube.com/watch?v=o1V_NoFmKXo

2010 State Autism Profiles

The Centers for Disease Control and Prevention (CDC) presented new findings that revealed as many as one in 110 children in the United States are now diagnosed with autism. While no known cure is yet available, autism is treatable. Many states are responding to what is now described as an epidemic by offering more services for children and adults with autism.

Easter Seals has prepared a state-of-the-state report of autism services in the 50 states, the District of Columbia and Puerto Rico. The profiles highlight the number of children with autism who have received the state's special education services, state insurance coverage for autism if available, Medicaid services specific for individuals with autism, educational programs provided to students with autism or training that focused on autism, special education criteria, other state-led resources, and sponsors of autism legislation.

To view the state profiles please visit the Easter Seals at http://www.easterseals.com/site/PageServer?pagename=ntlc8_autism_state_profiles



CHANGES IN REGIONAL CENTER SERVICES FOR CHILDREN AGED 0-3

By Laurie A. Soman, 9/23/09; rev. 3/31/10

Developmental Status	Age at Referral	Revised Program Eligibility Criteria
Hisk Risk Children* *Previously Eligible for Early Starr Program	New Prevention Program	
	0-35 mos	Presence of two or more risk factors using former at-risk criteria: prematurity, low birthweight, seizures, assisted ventilation, biomedical insult, prenatal drug exposure, etc
	24-35 mos	33-49% delay in any one area
	0-35 mos	Child's parent has a developmental disability
Developmental Delay	Early Start Program	
	0-23 mos	33% delay in one or more areas
	24-35 mos	50% delay in one area or 33% delay in two areas
Established Risk Condition	Early Start Program	
	0-35 mos	Presence of conditions such as Down syndrome, cerebral palsy, mental retardation, autism, or epilepsy, fragile X, Angelman Syndrome