Child TRENDS

NAHIC

ADOLESCENT HEALTH HIGHLIGHT

Publication # 2013-08

October 2013

Chronic Conditions

By M. Jane Park, M.P.H., Claire D. Brindis, Dr.P.H., Brigitte Vaughn, M.S., Megan Barry, B.A., Lina Guzman, PhD., and Amanda Berger, Ph.D.

Fast Facts:

1. Although most adolescents are healthy, 31 percent had at least one chronic condition in 2012.[1] Chronic conditions are physical or mental conditions that are expected to last a long time. Such conditions vary in severity—from those that, when well-managed, interfere minimally with daily life, to those that are more serious and, in rare cases, fatal.[3]

2. Common chronic conditions include learning disabilities, obesity/overweight, allergies, asthma, and attention deficit disorder/attention deficit hyperactivity disorder (ADD/ADHD).[1,2,5]

3. The overall proportion of adolescents with chronic conditions has increased since the 1980s. Much of the increase is due to greater prevalence of three common problems: obesity/overweight; asthma; and mental health and learning disorders, particularly ADD/ADHD.[6,7]

4. Among adolescents with a special health care need, nearly one-third missed seven or more days of school in the previous year; and among parents of adolescents with a special health care need, more than one-quarter incurred more than $1,000 annually in out-of-pocket expenses connected with their child's care.[1]

Adolescence is a critical period for identifying and managing chronic conditions

Although most adolescents are healthy, others have long-lasting or potentially long-lasting physical or mental conditions that undermine their health and well-being. Compared with adults, adolescents have low rates of chronic conditions.[2] Nonetheless, adolescence is a pivotal time for focusing on these conditions and their implications.

It is important for young people with chronic conditions to take an increased role in managing their conditions during this transitional period between childhood and young adulthood. In that way, they will increase their chances of entering adulthood with the ability to participate in typical adult social, educational, and economic activities to the fullest extent possible.

It is also important to focus on chronic conditions in adolescence because symptoms of, or heightened risk for, some conditions emerge during these years. Consider mental health disorders[3,4] or overweight/obesity,[8,9] for example. The median age for the onset of anxiety and impulse control disorders, two common mental health disorders, is 11.[4] As for obesity, roughly 18 percent of all 12- to 19-year-olds were obese in 2009-2010,[9] and many of them are likely to remain so into adulthood. In fact, one study showed that 83 percent of very obese 10- to 14-year-olds were still very obese at ages 21-29.[8,9] With careful monitoring and early intervention, such conditions

can be managed to allow for the greatest function possible or, in some circumstances, conditions can clear up altogether.[3,7,10]

This *Adolescent HealthHighlight* focuses largely on physical chronic conditions. Mental health disorders, which affect one in five adolescents, are covered in detail in the *Mental Health Disorders Highlight* in this series.

In 2012, it was estimated that about three out of 10 adolescents (31 percent) between the ages of 12 and 17 had at least one chronic condition.

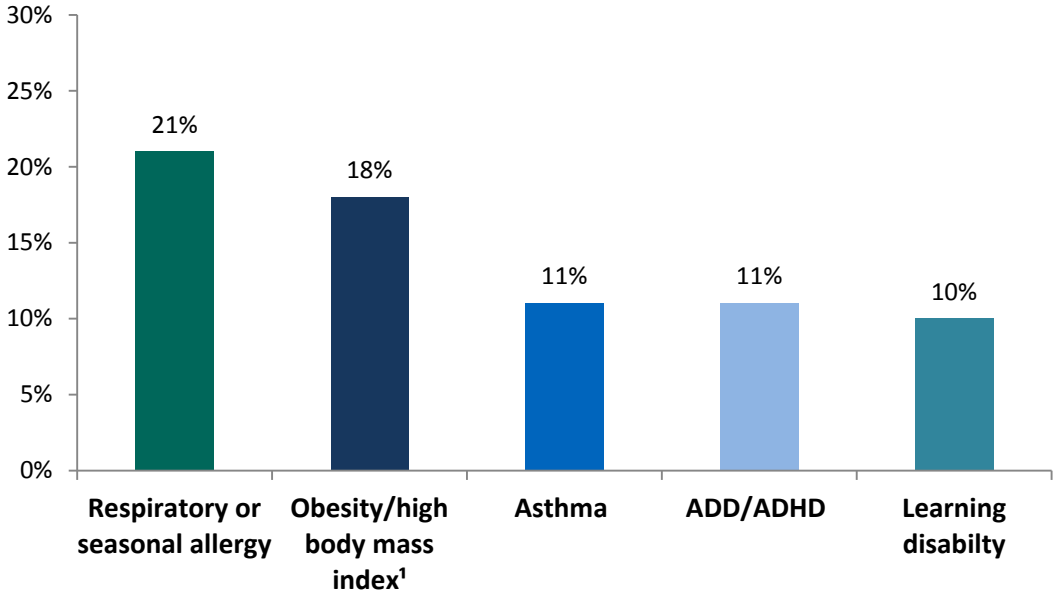
In 2012, it was estimated that about three out of 10 adolescents (31 percent) between the ages of 12 and 17 had at least one chronic condition.[1] Other estimates of the prevalence of chronic conditions among children and adolescents range widely—from 10 percent to 30 percent.[11] This variation appears to be largely due to differences in how experts define and measure chronic conditions.[3,12]

Adolescents may have more than one condition, which can pose greater risk to their healthy development. Among adolescents with chronic conditions in 2007, 42 percent had two or more conditions.[1]

Common chronic conditions in adolescence include respiratory or seasonal allergies (21 percent); obesity (18 percent); asthma (11 percent); attention deficit disorder/attention deficit hyperactivity disorder (ADD/ADHD, 11 percent); and learning disabilities (10 percent) (see Figure 1).[5] Many other conditions affect relatively few adolescents; these conditions include developmental delays (3 percent); speech problems (3 percent); vision problems not corrected by glasses or contact lenses (2 percent); hearing problems (1 percent); diabetes (1 percent); and seizures (1 percent).[1] Rarer still is cancer. In 2008, fewer than 7,500 adolescents between the ages of 10 and 19 were diagnosed with cancer (less than 1 percent).[13] However, between 1990 and 2009, cancer was one of the most common causes of death among adolescents ages 10 to 17, after unintentional injuries, homicide, and suicide.[5]

Prior research has shown that conditions of greater severity were more common among adolescents from families with lower incomes, perhaps reflecting the difficulty these families may face in accessing health care services that could help identify and manage chronic conditions before they become severe.

FIGURE 1: Prevalence of selected common chronic conditions in adolescents ages 10-17



[1]Obesity/high body mass index calculated among adolescents ages 12 to 19
Source: National Health and Nutrition Examination Survey 2007-2010 data (obesity/high body mass index data) and National Health Interview Survey 2008-2010 data

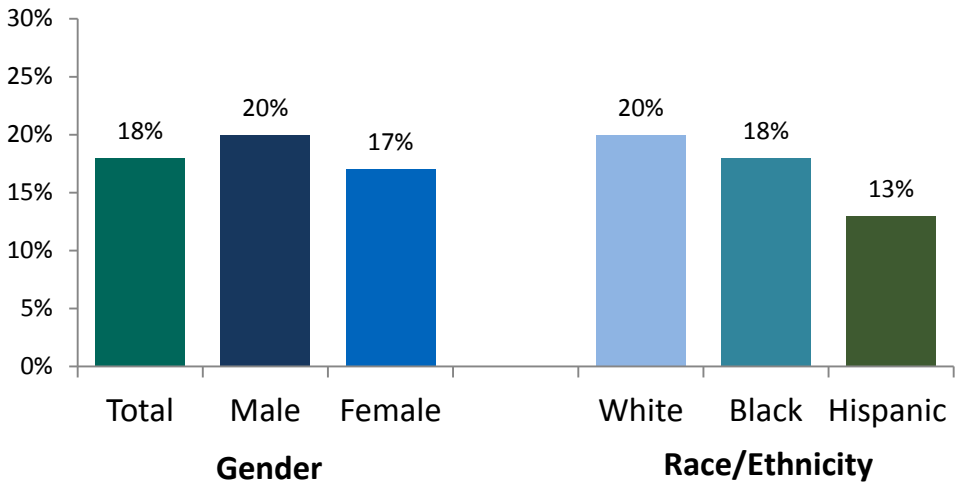
Special health care needs and group differences in risk

Since the late 1990s, many experts in the field of child health have adopted measures of "special health care needs" to identify children and adolescents requiring services. These measures are based on a parent's responses to questions about their child's elevated need for health care services and the impact of the physical or mental health condition on the adolescent.[14,15] In 2009-2010, an estimated 18 percent of adolescents between the ages of 12 and 17 were identified as having special health care needs (see Figure 2).[1]

Experts have attributed the rise in obesity to several factors, including societal changes that have contributed to decreased physical activity levels, increased time spent in sedentary activity, and increased consumption of foods and beverages that are high in calories, sugar, and fat, but low in nutrients.

Prevalence of special health care needs differs by gender, race/ethnicity, and income. Survey data from 2009-2010 show that male adolescents had higher rates of special health care needs than did female adolescents, and that white adolescents had higher rates than did their black and Hispanic peers (see Figure 2).[1] Prior research has shown that conditions of greater severity were more common among adolescents from families with lower incomes,[11] perhaps reflecting the difficulty these families may face in accessing health care services that could help identify and manage chronic conditions before they become severe.

FIGURE 2: Percent of adolescents with special health care needs, by gender and race/ethnicity, ages 12-17, 2009-2010



Source: National Survey of Children with Special Health Care Needs 2009-2010 data

Trends in the incidence of chronic conditions

For nine percent of children and adolescents with a chronic condition, the condition cleared up within six years, according to a recent study.

The overall proportion of adolescents with chronic conditions has increased since the 1980s. Much of the increase is due to greater prevalence of three common chronic problems: obesity/overweight; asthma; and mental health and learning disorders, particularly ADD/ADHD.[6,7] Obesity/overweight among children is defined by the body mass index (roughly speaking, a ratio of weight to height)[16] in relation to sex-specific age-growth charts. The causes of the increases in these conditions are complex and not clearly understood. Experts have attributed the rise in obesity to several factors, including societal changes that have contributed to decreased physical activity levels, increased time spent in sedentary activity, and increased consumption of foods and beverages that are high in calories, sugar, and fat, but low in nutrients.[17] Greater incidence of ADD/ADHD is due in part to improved screening, which has led to increased ADD/ADHD diagnoses.[6] Some increases in the incidence of chronic conditions appear to be the hopeful consequence of medical advances that have enabled more children with previously life-threatening conditions, such as cystic fibrosis, to live longer

and survive into adolescence and even adulthood. Because many of these trends are expected to continue, the proportion of adolescents with chronic conditions will likely increase.[6] On a positive note, research also shows reversal in some conditions among children and adolescents. For nine percent of children and adolescents with a chronic condition, the condition cleared up within six years, according to a recent study.[7]

Many of the chronic conditions that occur in adolescence affect work performance in adulthood.

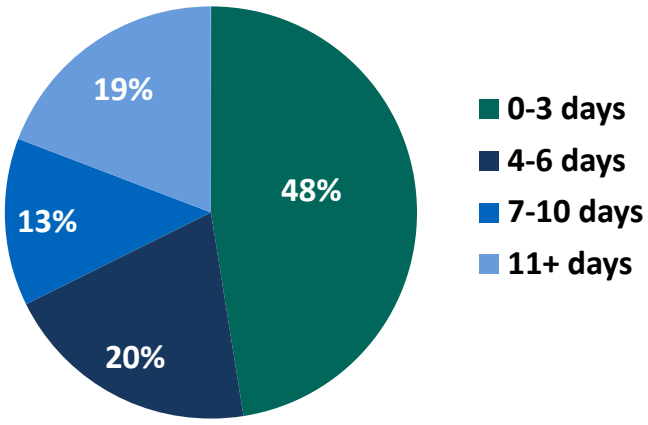
Implications of chronic conditions for adolescents

Adolescents with chronic conditions often need extra services and support, such as specialty medical care or equipment; services required vary depending on the condition and its severity.[3] These adolescents also need the preventive services that are recommended for all adolescents to promote healthy development and prevent health-damaging behaviors.[3,18] Still, some adolescents with chronic conditions fail to receive the preventive services recommended for all adolescents, or the additional care that could help them to manage and improve their conditions. Most adolescents with special health care needs do have insurance (96 percent in 2009-10).[1] Yet one in four (26 percent) had at least one unmet need for health care services or equipment.[1] Adolescents with special health care needs also tend to receive low levels of coordinated care, including lack of physicians' communication with other clinicians. In 2009-10, among those needing these types of services, only slightly more than half (56 percent)of families reported receiving coordinated care.[1]

The extent to which adolescents are affected by their condition varies considerably. This variation in impact reflects factors such as the severity of the condition and the degree to which adolescents obtain services that help them to manage the condition. Among adolescents with a special health care need in 2009-10, about half missed three or fewer days of school during the past year because of their condition, and nearly one-third missed seven or more days (see Figure 3).[1] Those in lower-income families generally missed more school days than did adolescents in more affluent families.[1] These statistics have changed little since 2001.[1]

FIGURE 3: Days of school missed due to special health care need (SHCN), among adolescents ages 12-17 with a SHCN, 2009-2010*

More than one-quarter of parents(26 percent) of an adolescent with special health care needshad more than $1,000 in out-of-pocket expenses related to their child's condition in 2009-10.



Source: National Survey of Children with Special Health Care Needs 2009-2010 data

Adolescents with chronic conditions face special challenges as they prepare to assume adult roles and responsibilities. For example, many of the chronic conditions that occur in

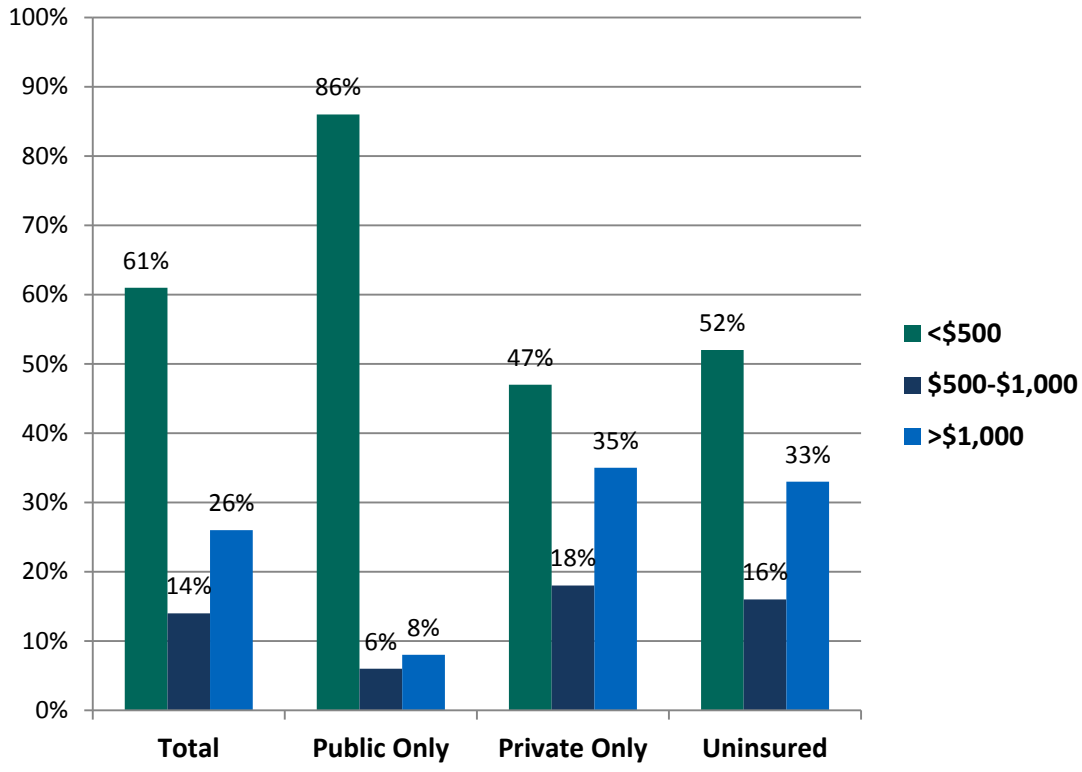
adolescence affect work performance in adulthood. Mental health disorders (such as depression) and physical health problems (such as asthma and diabetes) take a heavy toll on productivity in the form of sick days and underperformance in the workplace.[19,20] Recognizing the importance of this period, health experts have issued "transitional care" guidelines for the adolescent's primary care clinician.[18]However, in 2009-10, only two in five adolescents with special health care needs (40 percent) received recommended transitional services.[1]

Ten percent of parents of adolescents with special health care needs spend 11 or more hours weekly providing, arranging, or coordinating health care for their adolescent.

Implications of chronic conditions for parents

Parents are also affected by their adolescents' conditions. Families may spend significant amounts of time and money seeking care for their adolescent. More than one-quarter of parents (26 percent) of an adolescent with special health care needs had more than $1,000 in out-of-pocket expenses related to their child's condition in 2009-10.[1] This proportion was higher among families whose adolescent was uninsured (33 percent) or privately insured (35 percent), but was quite low when adolescents had public insurance, such as Medicaid or the Children's Health Insurance Program (8 percent) (see Figure 4).[1] The cost to parents is not just financial. Ten percent of parents of adolescents with special health care needs spent 11 or more hours weekly providing, arranging, or coordinating health care for their adolescent in 2009-10. This figure was higher among families with lower incomes.[1]

FIGURE 4: Family annual out-of-pocket expense for adolescent's special health care needs (SHCN), among parents of adolescent with SHCN, ages 12-17, by insurance status, 2009-2010



Source: 2009-2010 National Survey of Children with Special Health Care Needs

The Child Trends DataBank includes brief summaries of well-being indicators, including several that are related to chronic conditions among adolescents

Resources

The Child Trends DataBank includes brief summaries of well-being indicators, including several that are related to chronic conditions among adolescents:

- ADHD: http://www.childtrends.org/?indicators=adhd
- Asthma: http://www.childtrends.org/?indicators=asthma
- Autism spectrum disorders: http://www.childtrends.org/?indicators=autism-spectrum-disorders
- Children with limitations: http://www.childtrends.org/?indicators=children-with-limitations
- Children with special health care needs: http://www.childtrends.org/?indicators=children-with-special-health-care-needs
- Overweight children and youth: http://www.childtrends.org/?indicators=overweight-children-and-youth

Childs Trends LINKS (Lifecourse Interventions to Nurture Kids Successfully) database summarizes evaluations of out-of-school time programs that work (or not)to enhance children's development.

The Data Resource Center for Child and Adolescent Health, host of the National Survey of Children's Health Care and the National Survey of Children with Special Health Care Needs, have more data on their website: http://childhealthdata.org/home.

The Childs Trends LINKS(Lifecourse Interventions to Nurture Kids Successfully) database summarizes evaluations of out-of-school time programs that work (or not) to enhance children's development. The LINKS database is user-friendly and directed especially to policymakers, program providers, and funders.

- Programs related to chronic conditions can be found by selecting the Health Status/Conditions or Obesity boxes under Physical Health.

Evaluations of programs proven to work (or not) in supporting adolescents with chronic health conditions are summarized in various fact sheets. Some facts sheets specific to particular health conditions are:

- Asthma: What works for asthma education programs: Lessons from experimental evaluations of social programs and interventions for children.
- Obesity: What works for the prevention and treatment of obesity among children: Lessons from experimental evaluations of programs and interventions.
- ADHD: What works for acting-out (externalizing) behavior: Lessons from experimental evaluations of social interventions.
- Depression/depressive symptoms, suicidal thoughts or behaviors, anxiety/anxious symptoms, and post-traumatic stress disorder, in addition to other mental health behaviors: What works to prevent or reduce internalizing problems or social-emotional difficulties in adolescents: Lessons from experimental evaluations of social interventions.

Insure Kids Now! http://www.insurekidsnow.gov/), for uninsured adolescents, helps direct families to insurance options.

Several available resources address the special circumstances and challenges faced by children with chronic conditions, as well as their families and caretakers. Among these resources are:

- Insure Kids Now! (http://www.insurekidsnow.gov/), for uninsured adolescents, helps direct families to insurance options.
- The Affordable Care Act includes many provisions to improve access to care for children and adolescents with special health care needs: http://www.healthcare.gov/foryou/family/index.html.

- The Maternal and Child Health Bureau supports many state and private programs to improve the quality of services for all children with special health care needs, including programs to help facilitate a transition to adult health care: http://www.gottransition.org/.
- Low-income families who have a child with a disability may be eligible to receive assistance through the Supplemental Security Income Program: http://www.ssa.gov/kids/parent1.htm. This program also offers services to help adolescents transition to adulthood.
- Parents and adolescents can find additional programs through the "Find Youth Info" site: http://www.findyouthinfo.gov/.
- Many chronic conditions improve if an adolescent has healthier habits.*Let's move!*, sponsors a website that provides ideas for how adolescents, parents, schools, clinicians, communities, and faith-based institutions can help children and adolescents to stay more active: http://www.letsmove.gov/.

Acknowledgements

The authors would like to thank Jennifer Manlove at Child Trends for her careful review of and helpful comments on this brief.

Editor: Harriet J. Scarupa

References

[1] Child and Adolescent Health Measurement Initiative. (2012). *The data resource center for child and adolescent health*. Retrieved June 14, 2013, from http://childhealthdata.org/home

[2] Centers for Disease Control and Prevention. (2012). *Chronic disease prevention and health promotion*. Retrieved June 14, 2013, from http://www.cdc.gov/chronicdisease/

[3] Michaud, P. A., Suris, J. C., & Viner, R. (2007). *The adolescent with a chronic condition: epidemiology, developmental issues and health care provision*. Washington, DC: World Health Organization. Retrieved June 14, 2013, from http://whqlibdoc.who.int/publications/2007/9789241595704_eng.pdf

[4] Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. *Archives of General Psychiatry, 62*(6), 593–602.

[5] Centers for Disease Control: National Center for Health Statistics. *Health Data Interactive*. Retrieved June 14, from www.cdc.gov/nchs/hdi.htm

[6] Perrin, J. M., Bloom, S. R., & Gortmaker, S. L. (2007). The increase of childhood chronic conditions in the United States. *Journal of the American Medical Association, 297*(24), 2755-2759.

[7] Van Cleave, J., Gortmaker, S. L., & Perrin, J. M. (2010). Dynamics of obesity and chronic health conditions among children and youth. *Journal of the American Medical Association, 303*(7), 623-630.

[8] Whitaker, R. C., Wright, J. A., Pepe, M. S., Seidel, K. D., & Dietz, W. H. (1997). Predicting obesity in young adulthood from childhood and parental obesity. *The New England Journal of Medicine, 337*(13), 869-873.

[9] Fryar, C. D., Carroll, M.D., Ogden, C.L. (2012). *Prevalence of obesity among children and adolescents: United States, trends 1963-1965 through 2009-2010*. Washington, DC: Centers for Disease Control and Prevention from http://www.cdc.gov/nchs/data/hestat/obesity_child_09_10/obesity_child_09_10.pdf

[10] Halfon, N., & Newacheck, P. W. (2010). Evolving notions of childhood chronic illness. *Journal of the American Medical Association, 303*(7), 665-666.

[11] National Research Council and Institute of Medicine. (2009). *Adolescent health services: missing opportunities.* Washington, DC: The National Academies Press. Retrieved June 14, 2013, from http://www.nap.edu/catalog.php?record_id=12063

[12] van der Lee, J. H., Mokkink, L. B., Grootenhuis, M. A., Heymans, H. S., & Offringa, M. (2007). Definitions and measurement of chronic health conditions in childhood: a systematic review. *Journal of the American Medical Association, 297*(24), 2741-2751.

[13] U.S. Cancer Statistics Working Group. (2012). *United States cancer statistics: 1999-2008 incidence and mortality web-based report.* Retrieved June 14, 2013, from http://apps.nccd.cdc.gov/uscs/childhoodcancerbyprimarysite.aspx

[14] McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P. W., et al. (1998). A new definition of children with special health care needs. *Pediatrics, 102*, 137-140.

[15] Kogan, M. D., Strickland, B. B., & Newacheck, P. W. (2009). Building systems of care: findings from the national survey of children with special health care needs. *Pediatrics, 124* (4), S333-336.

[16] Centers for Disease Control and Prevention. (September 13, 2011). *Healthy weight- it's not a diet, it's a lifestyle!* Retrieved August 29, 2013, from http://www.cdc.gov/healthyweight/assessing/bmi/childrens_bmi/about_childrens_bmi.html

[17] Story, M., Sallis, J. F., & Orleans, C. T. (2009). Adolescent obesity: towards evidence-based policy and environmental solutions. *Journal of Adolescent Health, 45*(3), S1-S5.

[18] American Academy of Pediatrics, American Academy of Family Physicians, & American College of Physicians-American Society of Internal Medicine. (2002). A consensus statement on health care transitions for young adults with special health care needs. *Pediatrics, 110*(6), 1304-1306.

[19] Kessler, R. C., Greenberg, P. E., Mickelson, K. D., Meneades, L. M., & Wang, P. S. (2001). The effects of chronic medical conditions on work loss and work cutback. *The Journal of Occupational and Environmental Medicine, 43*(3), 218-225.

[20] Birnbaum, H. G., Kessler, R. C., Kelley, D., Ben-Hamadi, R., Joish, V. N., & Greenberg, P. E. (2010). Employer burden of mild, moderate, and severe depressive disorder: mental health services utilization and costs, and work performance. *Depression and Anxiety, 27*(1), 78-89.