According to the National Survey of Children with Special Health Care Needs (NS-CSHCN), a medical home is not a building, house, or hospital. It is, however, an approach to providing continuous and comprehensive primary pediatric care from infancy through young adulthood, with availability 24 hours a day, seven days a week. A professional, whom families trust, provides care within a structure that values families as integral members of their child’s health care team. This resource was created with Federal Title V funding to support discussion about medical home and make decisions about medical home easier for families, especially related to children with special health care needs (CSHCN). CSHCN are defined as those at increased risk for a chronic physical, developmental, behavioral, or an emotional condition, who also require health and related services beyond those required by children generally. Using the Healthy People 2020 goals established by the U.S. Department of Health and Human Services, the Office for Children with Special Health Care Needs is here to provide medical home information and resources for Arizona’s 241,067 children with special health care needs, and their families.

Our goal is to improve the long-term health and well-being of children and youth with special health care needs. We are passionate about providing this resource because research indicates that medical homes provide appropriate, coordinated preventive and ongoing services that lead to healthier lives. At the same time, good health promotes growth and participation in education, social interaction, recreation and community life, as well as employment, volunteerism and post-secondary education for young adults. We hope you may use this resource to learn what the NS-CSHCN reveals about medical home access in Arizona. Also, at the end of this resource we provide helpful suggestions and extra resources for those considering a medical home. We encourage all children with special health care needs to benefit from ongoing care and support as they gradually assume more responsibility for their own health needs.
THE OFFICE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS PROMOTES THE MEDICAL HOME BY:

- Assisting families in identifying family centered medical homes.
- Promoting best practices around medical home among providers and health care systems.
- Promoting family and youth involvement at all levels of decision-making.
- Providing resources and training around medical home for families and professionals.

NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS

The NS-CSHCN is completed every four years and takes a close look at the health and functional status of children with special health care needs in the U.S. The survey gathers information about their physical, emotional and behavioral health, along with critical information on access to quality health care, care coordination of services, access to a medical home, transition services for youth, and the impact of chronic condition(s) on the child’s family. All of the data in this resource are from this survey and were accessed through www.childhealthdata.org.

All children included in the 2009/10 NS-CSHCN are children with special health care needs and therefore have at least one ongoing health condition. The CSHCN Screener used in the survey is a non-condition specific, consequences-based screening tool used to identify CSHCN. To qualify as CSHCN on the Screener, a child must experience at least one of the following five consequences:

1. Need or use of prescription medication
2. Above routine use of medical care, mental health or educational services
3. Being limited/prevented in their ability to do the things most children the same age can do
4. Use of specialized therapies (physical, speech, occupational)
5. An emotional, developmental or behavioral problem for which a child needs treatment or counseling and that has lasted or is expected to last 12 months or more

The following table shows the prevalence of some health conditions present for children with special health care needs in Arizona, compared to the national averages:

Table 1: Prevalence of health conditions and comorbidity* among CSHCN 2009/2010, Arizona and National.

<table>
<thead>
<tr>
<th>Current health condition**</th>
<th>Prevalence Among CSHCN</th>
<th>% of CSHCN with condition listed who also have at least one other condition asked about in survey</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>National (N=40,242)</td>
<td>Arizona (N=789)</td>
</tr>
<tr>
<td>ADD/ADHD***</td>
<td>30.2%</td>
<td>28.4%</td>
</tr>
<tr>
<td>Allergies</td>
<td>48.6%</td>
<td>48.7%</td>
</tr>
<tr>
<td>Current health condition**</td>
<td>Prevalence Among CSHCN</td>
<td>% of CSHCN with condition listed who also have at least one other condition asked about in survey</td>
</tr>
<tr>
<td>---------------------------</td>
<td>-------------------------</td>
<td>------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>National (N=40,242)</td>
<td>Arizona (N=789)</td>
</tr>
<tr>
<td>Anxiety Problems</td>
<td>17.1%</td>
<td>17.2%</td>
</tr>
<tr>
<td>Arthritis or Other Joint Problems</td>
<td>2.9%</td>
<td>4.3%</td>
</tr>
<tr>
<td>Asthma</td>
<td>35.3%</td>
<td>33.7%</td>
</tr>
<tr>
<td>Autism Spectrum Disorder</td>
<td>7.9%</td>
<td>7.6%</td>
</tr>
<tr>
<td>Behavioral or Conduct Problems</td>
<td>13.5%</td>
<td>15.8%</td>
</tr>
<tr>
<td>Blood Problems</td>
<td>1.5%</td>
<td>1.4%</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>1.6%</td>
<td>2.4%</td>
</tr>
<tr>
<td>Cystic Fibrosis</td>
<td>0.3%</td>
<td>0.0%</td>
</tr>
<tr>
<td>Depression</td>
<td>10.3%</td>
<td>12.4%</td>
</tr>
<tr>
<td>Developmental Delay</td>
<td>17.6%</td>
<td>16.9%</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1.7%</td>
<td>1.9%</td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>1.1%</td>
<td>1.4%</td>
</tr>
<tr>
<td>Epilepsy or Seizure</td>
<td>3.1%</td>
<td>2.5%</td>
</tr>
<tr>
<td>Head Injury, Concussion or Traumatic Brain Injury</td>
<td>1.4%</td>
<td>2.1%</td>
</tr>
<tr>
<td>Heart Problems</td>
<td>3.0%</td>
<td>2.6%</td>
</tr>
<tr>
<td>Intellectual Disability or Mental Retardation</td>
<td>5.8%</td>
<td>5.8%</td>
</tr>
<tr>
<td>Migraines or Frequent Headaches</td>
<td>9.8%</td>
<td>8.4%</td>
</tr>
<tr>
<td>Muscular Dystrophy</td>
<td>0.3%</td>
<td>0.3%</td>
</tr>
</tbody>
</table>

*Comorbidity is defined as the presence of additional conditions along with the initial diagnosis.
**Condition prevalence first surveyed from NS-CSHCN in 2009/10 was asked with two items: “ever told” and “is condition current”. Only current prevalence is included here.
*** ADD/ADHD is Attention-Deficit/Hyperactivity Disorder

Grayed out cells are estimates based on sample size too small to meet standards for reliability or precision and may not be accurate.
In the NS-CSHCN, Outcome #2 is a group of questions that relates to medical homes for CSHCN, age 0–17 years old. Outcome #2 includes questions regarding having a personal health care provider, having a usual source of coordinated care, and having family centered care with an effective referral system. The graphs below summarize the results for Arizona.

*For CSHCN to meet Outcome #2, the following criteria must be met:
1. Has at least one personal doctor or nurse
2. Received family-centered care in the previous twelve months
3. Has no problems getting referrals when needed
4. Has usual source(s) of wellness and sick care
5. Receives effective care coordination

- Effective care coordination and family centered care are the two medical home subcomponents least likely to be met in Arizona and nationally.
- AZ-CSHCN are less likely to meet Outcome #2 compared to the national average, 36% vs. 43%.
AZ-CSHCN, without a medical home, are more likely to miss school, have a family member who stopped working or restricted their work hours, and have unmet needs for services/equipment as compared to their peers, with a medical home.

*For CSHCN to meet Outcome #2, the following criteria must be met:
1. Has at least one personal doctor or nurse
2. Received family-centered care in the previous twelve months
3. Has no problems getting referrals when needed
4. Has usual source(s) of wellness and sick care
5. Receives effective care coordination

AZ-CSHCN, without a medical home, are more likely to miss school, have a family member who stopped working or restricted their work hours, and have unmet needs for services/equipment as compared to their peers, with a medical home.

AZ-CSHCN with more reported conditions are less likely to have a medical home than those with fewer reported conditions.
CARE COORDINATION

Effective care coordination is a vital component of the medical home. Unfortunately, data from the NS-CSHCN shows that Arizona lags behind the nation in providing care coordination of CSHCN.

Table 2: Percent of CSHCN who receive effective care coordination, which includes help with coordination of care and satisfaction with communication among providers, and with schools.

<table>
<thead>
<tr>
<th></th>
<th>2005/06</th>
<th>2009/10</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Nationwide</strong></td>
<td>46.0%</td>
<td>42.3%</td>
</tr>
<tr>
<td><strong>Arizona</strong></td>
<td>39.8%</td>
<td>40.2%</td>
</tr>
</tbody>
</table>

DATA ALERT: Changes in survey methodology from 2001, 2005/06 and 2009/10 may have an impact on the observed differences between survey years. Formal statistical analyses to test those differences require special consideration due to the inclusion of a cell phone sample in 2009/10. Additional information is available in the 2009 NS-CSHCN Codebook.

- AZ-CSHCN are less likely to receive effective care coordination compared to the national average, 40.2% vs. 42.3% (2009/10).
- Roughly 40% of AZ-CSHCN reported receiving effective overall care coordination in both 2005/06 and 2009/10.

Table 3: Percent satisfaction of CSHCN with individual communication components of care coordination, 2009/10

<table>
<thead>
<tr>
<th></th>
<th>Overall, how satisfied are you with the communication among doctors and other health care providers when needed for care coordination?</th>
<th>Overall, how satisfied are you with the communication between your child’s doctor(s) and school when care coordination is needed?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Nationwide</strong></td>
<td>% Very Satisfied</td>
<td></td>
</tr>
<tr>
<td></td>
<td>62.7%</td>
<td>53.1%</td>
</tr>
<tr>
<td><strong>Arizona</strong></td>
<td>% Very Satisfied</td>
<td></td>
</tr>
<tr>
<td></td>
<td>60.0%</td>
<td>46.5%</td>
</tr>
</tbody>
</table>

- AZ-CSHCN and their families are less satisfied with the communication among their doctors and other health care providers, compared to the national average (60.0% vs. 62.7%).
- AZ-CSHCN and their families are also less satisfied with the communication between their doctors and schools, compared to the national average (46.5% vs. 53.1%).
BEYOND THE SURVEY

The following are questions related to medical homes that cannot be answered by the NS-CSHCN data but are important to consider when evaluating how to improve the health and well-being of CSHCN.

• Does the child have access to the same health care providers within their medical home through changes in family income or health insurance?
• Do families have a choice of providers so they may find the best fit?
• Are comprehensive medical records maintained with a single entity or provider?
• Are families educated about all of the resources and options available to them within their community?

BEST PRACTICES IN A FAMILY-CENTERED MEDICAL HOME ACCORDING TO THE AMERICAN ACADEMY OF PEDIATRICS, INCLUDE PROVIDING HEALTH CARE THAT IS:

• Accessible—Families with private, public or no insurance know where to receive care they can afford, care is provided within their community, and the facilities/equipment/staff are accessible to individuals of various abilities.
• Family-Centered—Family is acknowledged as the constant in the child/patient’s life, and are valued as partners on the health care team.
• Coordinated—All necessary services, which may include specialty care, hospitalization, therapies, durable medical equipment, evaluations, referrals, and more, are coordinated by and all medical records maintained by the medical home.
• Compassionate—Providing care that recognizes family strengths and seeks to provide assistance where and when it is needed.
• Culturally Effective—Staff and providers seek out and understand the unique perspective of each family, work with the family to determine how their perspective may influence attitudes regarding health, and guide decisions around healthcare.
• Comprehensive—Ensuring that the whole person is considered in any health care decision, seeking to identify how mental, physical, emotional and developmental health interact, while ensuring access to providers who are knowledgeable about the patient, the health condition/s and the family at all times.
• Continuous—Ensuring that well, acute and chronic condition care is provided by a member of the health care team, who was involved along with the family, in developing a plan of care; or who is knowledgeable about the plan, patient and family.
BEST PRACTICES IN IMPROVING ACCESS TO QUALITY CARE FOR THOSE WITH MENTAL HEALTH CHALLENGES

Improving social and emotional outcomes for all children, youth and their families and improving access to quality care for those with mental health challenges is the core mission of the National Technical Assistance Center, Center for Child and Human Development, Georgetown University (http://gucchdtacenter.georgetown.edu/). System of care values and principles guide the center’s work with states, tribes, territories and communities. The center promotes services and supports that are:

- Community based
- Comprehensive, coordinated, and collaborative across systems and organizations
- In full partnership with families and youth
- Culturally and linguistic competent
- Individualized, flexible, and coordinated to fit each child and family
- Strength based
- Evidence based or practice based on evidence

COMMON THREADS IN BEST PRACTICES RELATED TO PHYSICAL HEALTH AND BEHAVIORAL HEALTH

As you can see elements of the medical home, sometimes called “health home,” are commonly recognized as best practice, in both physical health and behavioral health. The term best practice is used here to describe programs or policies extensively evaluated and proven effective. Some of these common elements include comprehensive, coordinated, community based services arranged so that families have easy access.

Also, services delivered in a culturally effective manner, with families and youth involved in decision making at all levels. These commonalities work together to provide more efficient and effective care for children and their families when delivered in an integrated health system.

Beginning October 1, 2013, the Arizona Physicians IPA Children’s Rehabilitative Services (CRS) (www.uhccommunityplan.com/plan/details/AZ/324/CHIP/how-to-enroll) program will become an integrated health program, offering most members both physical and behavioral health services. Children who are eligible for the Arizona Health Care Cost Containment System (www.azahccs.gov/applicants/default.aspx) programs, other than CRS, will continue to obtain needed behavioral health services through their local Tribal/Regional Behavioral Health Authority T/RBHA (azdhs.gov/bhs/).
HOW TO INCLUDE DECISION MAKING OPPORTUNITIES FOR FAMILIES AND YOUTH/YOUNG ADULTS IN THE FAMILY CENTERED MEDICAL HOME:

• Provide any information in a format that best meets the needs of the family/young adult, keeping developmental age in mind as well as chronological age.
• Provide information on costs, co-pays, deductibles and non-covered services prior to service delivery.
• Openly discuss all treatment options and possible outcomes.
• Trust the family/young adult to make the decision that is best for them or their child.
• Provide information on various tools or methods of organization for tracking appointments, medications, therapies, providers and community supports.
• Provide information on opportunities and venues for recreation, physical activity, hobbies and socialization.
• Provide ongoing information and answer questions aiming to increase the family/young adult’s knowledge about condition, early signs of condition becoming unstable and use of medication.
• Provide information around options for transportation to and from appointments.

ADDITIONAL RESOURCES:

• Center for Medical Home Improvement, www.medicalhomeimprovement.org/knowledge/practices.html
• American Academy of Pediatrics, position paper on Medical Home, 2002. pediatrics.aappublications.org/content/110/1/184.full
• Arizona Statewide Independent Living Centers, www.azsilc.org
ADDITIONAL RESOURCES (CONTINUED):

• Role of federally qualified health centers in state-led medical home collaboratives, www.nashp.org/sites/default/files/PAVTRI_0.pdf. This publication by the National Academy for State Health Policy (NASHP) looks into the role of health centers in Patient Centered Medical Home collaboratives led by each state.

• Rehabilitation Services Administration, www.azdes.gov/RSA/

• Substance Abuse and Mental Health Services Administration (SAMHSA), www.samhsa.gov

• Raising Special Kids, www.raISINGspecialkids.org/about-us/, Arizona’s Family to Family Health Information Center.

• How consumer advocates can get involved: steps you can take to ensure the medical home is patient centered, www.nationalpartnership.org/site/DocServer/Advocate_Toolkit_How_Consumer_Advocates_FINAL.pdf?docID=4602&AddInterest=1342.
   The National Partnership for Women & Families and a broad coalition of more than 25 of the nation’s leading consumer, labor and health care advocacy groups developed a set of principles designed to help health care providers, lawmakers, employers, and health plans consider consumer interests as they develop delivery system reforms such as the “medical home.”

• The Catalyst Center, www.catalystctr.org

• Georgetown University, Center for Child and Human Development, National Technical Assistance Center for Children’s Mental Health, guchd.georgetown.edu/67211.html

• Community Solutions at the University of Southern Florida, behavioral health information and resources, cfscommunitysolutions.cbcs.usf.edu/

• Measuring Medical Homes: Tools to Evaluate the Pediatric Patient and Family-Centered Medical Home, www.medicalhomeinfo.org/downloads/pdfs/MonographFINAL3.29.10.pdf. This monograph explores the current tools used in measuring Medical Home.
   Measurement tools included in the National Survey of Children’s Health, Patient-Centered Medical Home, Consumer Assessment of Health Care Providers and Systems (CAHPS), Components of Primary Care Instrument, Medical Home Index, and several others.

• The Data Resource for Child and Adolescent Health has an extensive review of the medical home literature found at: www.childhealthdata.org/docs/medical-home/all-other-articles-other-resources-pdf.pdf.

The Office for Children with Special Health Care Needs also offers no-cost training on the Health Care Organizer, a zippered canvas portfolio with tabbed dividers intended to promote communication and coordination with the child’s medical home. This tool offers a way to carry and keep records, organized for easy access, and includes forms where families may keep the child’s medical, behavioral, dental, insurance, family history, school, immunizations, emergency and other important information.

We would love to get your input on this resource. Please take a moment to fill out our brief online survey at: azdhs.gov/phs/owch/ocshcn/index.htm where you may also find this resource.

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