

# ARIZONA CHILDREN WITH SPECIAL HEALTH CARE NEEDS

## Transition Resource

### INTRODUCTION

The transition to adulthood is a critical period of development. Transition is a period of learning, skill building and goal setting experienced by young people as they move from adolescence into adulthood. During this time, young people experience extra stress and need extra help. This resource was created with Federal Title V funding, to bring together current information regarding the health and well-being of youth with special health care needs, transitioning into adulthood. Children and youth with special health care needs are defined as those at increased risk for a chronic physical, developmental, behavioral, or an emotional condition

and also require health and related services, of a type or amount, beyond

that 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 transition support for the 241,067 children with special health care needs in Arizona.

Our goal is to improve the long term health and well-being of youth with special health care needs. We are passionate about providing this resource because youth with transition services are more likely to have their health needs met as adults. At the same time, good health is necessary for youth as they seek employment, additional education, volunteering, social relationships, recreation and community life. We hope you use this resource to learn what the *National Survey of Children with Special Health Care Needs (NS-CSHCN)* reveals about transition services in Arizona. Also, at the end of this resource we provide helpful suggestions and links those in transition may find useful. We encourage all children with special health care needs to benefit from ongoing care and support as they gradually assume more responsibility for their health needs.

continuity through stages  
support during critical periods  
**resilience**  
**lasting effects**  
personalization  
**decision-making**  
discussion and planning  
**lifelong health**  
face challenges independence  
**OUTCOME 6: TRANSITION TO ADULT CARE**  
**reduce stress**  
no gaps in care  
involvement  
self care skills

**THE OFFICE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS ASSISTS YOUTH IN TRANSITION BY:**

- Promoting best practices for healthcare transition
- Partnering with the Department of Education and other entities responsible for transition
- Promoting self-determination for youth with special health care needs
- Providing resources and training around healthcare transition 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.—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](http://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 different types of health conditions present for children with special health care needs in Arizona compared to the national averages:

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

Current health condition**	Prevalence Among CSHCN		% of CSHCN with condition listed who also have at least one other condition asked about in survey	
	National (N=40,242)	Arizona (N=789)	National	Arizona
ADD/ADHD	30.2%	28.4%	77.4%	82.3%
Allergies	48.6%	48.7%	79.1%	77.1%

Current health condition**	Prevalence Among CSHCN		% of CSHCN with condition listed who also have at least one other condition asked about in survey	
	National (N=40,242)	Arizona (N=789)	National	Arizona
Anxiety Problems	17.1%	17.2%	95.3%	94.8%
Arthritis or Other Joint Problems	2.9%	4.3%	86.9%	82.0%
Asthma	35.3%	33.7%	80.0%	80.0%
Autism Spectrum Disorder	7.9%	7.6%	93.2%	92.4%
Behavioral or Conduct Problems	13.5%	15.8%	96.5%	97.7%
Blood Problems	1.5%	1.4%	82.4%	100.0%
Cerebral Palsy	1.6%	2.4%	92.6%	88.8%
Cystic Fibrosis	0.3%	0.0%	76.2%	0.0%
Depression	10.3%	12.4%	96.5%	97.8%
Developmental Delay	17.6%	16.9%	92.3%	95.9%
Diabetes	1.7%	1.9%	52.7%	53.8%
Down Syndrome	1.1%	1.4%	89.6%	91.6%
Epilepsy or Seizure	3.1%	2.5%	87.0%	92.2%
Head Injury, Concussion or Traumatic Brain Injury	1.4%	2.1%	97.3%	100.0%
Heart Problems	3.0%	2.6%	79.6%	73.7%
Intellectual Disability or Mental Retardation	5.8%	5.8%	99.4%	100.0%
Migraines or Frequent Headaches	9.8%	8.4%	92.5%	97.6%
Muscular Dystrophy	0.3%	0.3%	85.5%	100.0%

\*Comorbidity is defined as the presence of additional conditions along with the initial diagnosis.

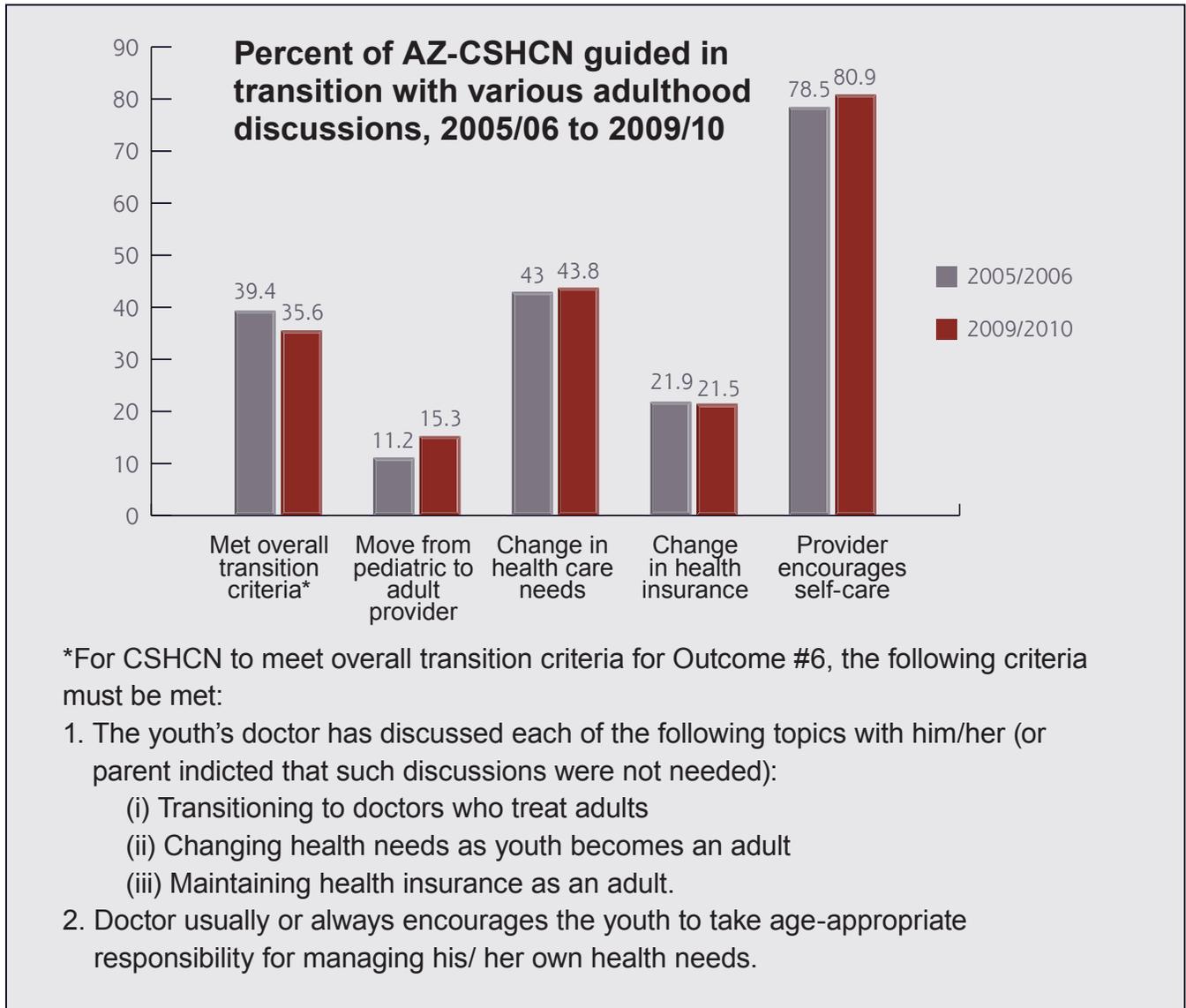
\*\*Condition prevalence first surveyed from NS-CSHCN in 2009/10 was asked with two items: "ever told" and "is condition current". Only current prevalence is included here.

Grayed out cells are estimates based on sample size too small to meet standards for reliability or precision and may not be accurate.

## ARIZONA TRANSITION GRAPHS

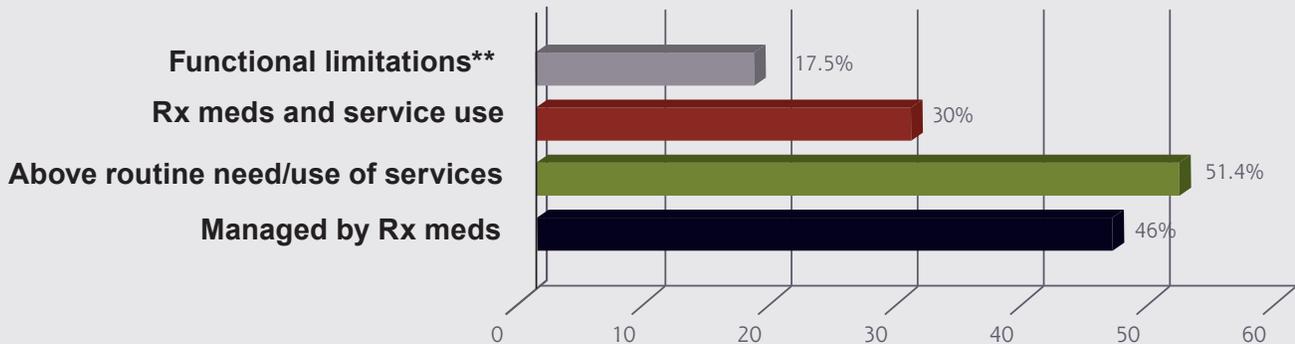
In the *NS-CSHCN*, Outcome #6 is a group of questions that relates to transition services for AZ-CSHCN, age 12–17 years old, as they move to adult services.

Outcome #6 includes questions regarding health insurance coverage, changing providers and the increasing need for self-care. The graphs below summarize the results for Arizona.



- In 2009/2010, fewer AZ-CSHCN met all the overall transition criteria compared to the rest of the nation, 35.6% vs. 40.0%.
- AZ-CSHCN are most likely to receive encouragement from their physician to take responsibility for managing their own health needs to the extent possible (80.9%).
- Less than half of AZ-CSHCN have had discussions with their physician regarding transition issues, with lowest rates for discussions on change to adult health care provider and change in health insurance.

**Percent of AZ-CSHCN receiving guidance to make appropriate transitions to adult health care, work, and independence (Outcome #6)\* by type of health need or condition, 2009/10**



\*For CSHCN to meet overall transition criteria for Outcome #6, the following criteria must be met:

1. The youth's doctor has discussed each of the following topics with him/her (or parent indicated that such discussions were not needed):
  - (i) Transitioning to doctors who treat adults
  - (ii) Changing health needs as youth becomes an adult
  - (iii) Maintaining health insurance as an adult.
2. Doctor usually or always encourages the youth to take age-appropriate responsibility for managing his/ her own health needs.

\*\*The functional limitation screener asks if the child is limited or prevented in any way in their ability to do things most children the same age can do because of an ongoing medical, behavioral or other health condition.

- AZ-CSHCN with functional limitations are least likely to meet overall transition criteria.
- Three out of every ten (30%) AZ-CSHCN whose condition is managed by prescription medication and medical service are receiving guidance sufficient enough to meet overall transition to adulthood criteria.
- Over half (51%) of AZ-CSHCN who require or use more than "routine" services meet overall transition criteria.
- Less than half (46%) of AZ-CSHCN whose condition is solely managed by prescription medication meet overall transition criteria.

## BEYOND THE SURVEY

The following are questions relating to transitions that cannot be answered by the *NS-CSHCN* data but are important to consider when evaluating how transition to adulthood can assist in improving the health and well-being of CSHCN into early adulthood:

- Was the transition to adulthood successful? How would we measure that success?
- What transition and self-care planning occurred earlier in life to prepare for transition?
- In what areas are youth taking appropriate responsibility for their own well-being with regard to nutrition, exercise, social role, self-support and reproductive future?

## SUGGESTIONS AND BEST PRACTICES FOR CSHCN IN TRANSITION

- The transition process should begin as soon as possible, with an on-going assessment of transition readiness and progress.
- The adolescent and their family should be involved in all decisions, with the adolescent as the team leader.
- Providers and parents should prepare to facilitate change.
- There is no cut-off age when transition must be completed.
- Avoid transitioning during a medical crisis.
- Coordination of services and providers is essential, especially with a medical home, between the 18<sup>th</sup> and 21<sup>st</sup> birthday.
- Make sure to establish a basic understanding of all related medical conditions, medications, and insurance plans (or know how to access this information).
- Maintain a medical records binder containing personal and emergency information. Forms provided by the American Academy of Pediatrics can be found at:  
**<http://www.acep.org/content.aspx?id=26276>**



## EXTRA RESOURCES:

- National Health Care Transition Center, [www.gottransition.org](http://www.gottransition.org)
- American Academy of Pediatrics/National Center for Medical Home Implementation, [www.medicalhomeinfo.org](http://www.medicalhomeinfo.org)
- Arizona Statewide Independent Living Council, [www.azsilc.org](http://www.azsilc.org)
- Arizona Department of Education, <http://www.azed.gov/special-education/special-projects/secondary-transition/>
- Rehabilitation Services Administration, <https://www.azdes.gov/RSA/>
- Youth on the Move, <http://www.youth-move.org/>
- The Catalyst Center, [www.catalystctr.org](http://www.catalystctr.org)
- Healthy Transitions: Moving from Pediatric to adult Health Care, <http://healthytransitionsny.org>
- Talking with Your Doctor and Other Health Care Professionals, <http://hctransitions.ichp.ufl.edu/gladd/>

We would love to get your input on this resource. Please take a moment to fill out our brief online survey at: <http://www.surveymonkey.com/s/8SQKK5C>

This resource and survey are also available on our website:  
<http://www.azdhs.gov/phs/owch/ocshcn>

## CONTACT US:

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