Children and Youth with Special Health Care Needs: A Maricopa County Needs Assessment & Implications for Policy & Systems Changes

Maricopa County, Arizona

June 2013

ACKNOWLEDGEMENTS

This report was commissioned in March 2013 by the Maricopa County Department of Public Health (MCDPH) and was funded in part by the Bureau of Women's and Children's Health as made available through the Arizona Department of Health Services (ADHS). This project is supported by funds from the Department of Health and Human Services (DHHS), Health Resources and Services Administration, Maternal and Child Health Bureau, under grant number 93.994 and title for $33,950.00. The information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by the U.S. Government, DHHS, or HRSA. This report was prepared by Saguaro Evaluation LLC (www.saguaroevaluation.com), a small evaluation and social service consulting group with expertise in needs assessment, training, and human services program evaluation. The needs assessment of children and youth with special health care needs (CYSHCN) began in March 2013 and the report was completed in June 2013. We would like to recognize the thoughtful input and assistance of the program staff within MCDPH, ADHS, the CYSHCN Advisory Group, Gompers Habilitation Center, Scottsdale Training and Rehabilitation Services, the Family Involvement Center, and the Chandler CARE Center, and Chandler Unified School District. Moreover, we would like to thank all the parent/caregiver, youth, and provider participants for sharing their time and experiences with us. For questions and/or to requests this resource in an alternate format, please contact PHPIO@mail.maricopa.gov or Maricopa Department of Public Health, Office of Community Empowerment, 4041 N. Central Avenue, Phoenix, AZ 85012, phone number: (602) 506-6900.

TABLE OF CONTENTS

List of Tables v
List of Figures vi

Executive Summary vii

Introduction 1
Prevalence 1
Race, Ethnicity, and Gender 2
Insurance Coverage 2
Access to Care 2
Methodology 2
Participant Demographics 3
Parent/Caregiver Focus Groups 3
Providers 6
Parent/Caregiver Surveys 6
III. Key Findings: Focus Groups 7
Vision of Health 7
Major Themes 8
Training and Education 8
Medical and Behavioral Health Providers 8
Community Awareness and Advocacy Training 9
Other Training and Education for Parents/Caregivers and CYSHCN 10
Resource Training for Providers and Parents/Caregivers 10
Training for School Staff 11
Coordination of Care 12
Health Navigator 12
Centralized Medical Records, Intake, and Data 13
Continuity of School and Home Plans 13
Provider Communication Across Settings 14
Provider Turnover 14
Family and Child Voice 15
Provider Accountability 15
Primary Needs 16
Basic Needs: Food, Transportation, Safety, and Respite 16
Higher Risk Populations within CYSHCN: Families in Crisis, Undocumented Families, and Children in Foster Care 17

Insurance Coverage 18
Access to Services 18
Holistic Care 19
Culture and Religion 20
Transitional Services for Youth and Families 21
IV. Key Findings: Online Parent/Caregiver Surveys 22
Reported Conditions of CYSHCN 22
Coordination of Care 23
Comparison with National Data 23
V. Conclusions and Recommendations 23
Evaluator Recommendations 25
Next Steps 26

Appendix A: Methodology 27
Appendix B: Consent Form 32
Appendix C: CYSHCN Parent/Caregiver Survey 33
Appendix D: Focus Group Agendas 38
Appendix E: Small Group Questions 41
Appendix F: Focus Group Flyer 44
Appendix G: Training and Education Recommendations by Population 45
Appendix H: Focus Group Lessons Learned 46
Appendix I: Listening Sessions: Community Priorities 48

LIST OF TABLES

1. Demographics of parent/caregiver focus group participants 4
2. Demographics of parent/caregiver online survey participants 6

LIST OF FIGURES

1. Comparison of CYSHCN by race in Arizona and the Nation 2
2. City of residence of online survey participants 7
3. Percentage of reported conditions experienced by CYSHCN 22
4. Participant satisfaction with child's services 23
5. Parent/caregiver reported coordination of care 23

EXECUTIVE SUMMARY

When compared nationally, Arizona's children and youth with special health care needs (CYSHCN) are less likely to have insurance and adequate health care coverage, and /or are more likely to experience greater barriers accessing specialized care.[1] However, since little is known about the health care experiences and needs in of CYSHCN in Maricopa County, Maricopa County Department of Public Health (MCDPH), with funding from the Arizona Department of Health Services, Office of Children with Special Health Care Needs, hired external evaluators to perform a countywide needs assessment. The purpose of this needs assessment was to identify the needs and gaps in services from families and CYSHCN in Maricopa County.

Methods

Eight separate focus groups including parents/caregivers (English and Spanish), youth, and providers were conducted in Maricopa County in April and May 2013. Additionally, hard copy and online surveys for parents/caregivers (English and Spanish) were widely distributed and used to enhance focus group findings.

Major findings

Five major themes emerged from the analysis of all focus groups (parents/caregivers, providers, and youth) and the corresponding CYSHCN parents/caregiver survey questions. Below are the identified themes and the subthemes within each major category:

Training and education

- Medical and behavioral health provider training
- Community awareness and advocacy training
- Other training and education for parents/caregivers and CYSHCN
- Resource training for parents/caregivers and providers
- Training for school staff

Coordination of care

- Health navigator
- Centralized medical records, intakes and data
- Continuity of school and home plans
- Provider communication across settings
- Provider turnover
- Family and child voice
- Provider accountability

Primary needs

- Basic needs (food, transportation, safety and respite)
- Higher risk populations within CYSHCN (families in crisis, undocumented families, and children in foster care)
- Insurance coverage
- Access to service

[1] NS-CSHCN. (2010). *Arizona report from the 2009/10 National Survey of Children with Special Health Care Needs* [Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website].

Holistic care

- Integrating the physical, mental, behavioral, emotional, and social needs of their children and families into one program
- Emphasizing the child's needs, strengths, and culture across the life span and one-stop medical homes[2]
- Integrating culture and world view in the health and service plans as appropriate
- More Spanish-Speaking providers and interpreters

Transitional services for youth and families

- More funding and standardization of programs for youth transitioning from high school to vocational training, to a rehabilitation program, and/or to college and youth transitioning from the children's system of care to the adult system on their 22nd birthday

Conclusions and recommendations

Parents/caregivers and youth shared a holistic view of health and a realistic perspective of their needs, services, and health conditions. The service providers' experiences and perspectives related to the needs of both families and providers strengthen the assessment and added valuable feedback to the list of recommendations. Families and providers remain hopeful that through the following recommendations and policy and systems changes, the health of all CYSHCN in Maricopa County will improve:

- Increase training and education for parents, youth, legislators and their staff, school staff, doctors and specialists, and other providers including in-home services (see appendix G for more detail).

- Improve care coordination by: 1) advocating for policies that integrate the behavioral, mental/emotional, and medical services as well as increase communication and collaboration among providers (medical home); 2) integrating health care services by creating and maintaining a centralized resource bank, as well as centralizing medical records and intake procedures; and 3) increasing funding to implement a health coordinator model for CYSHCN in Maricopa County.

- Advocate for unencumbered funding to assist families with primary needs: 1) food; 2) rent and utilities assistance; 3) transportation; and 4) medications and services not covered by insurance.

- Promote a holistic care approach for CYSHCN in Maricopa County by: 1) advocating for insurance coverage for children and youth regardless of legal status, and expanding

[2] Definition of medical home: "The America Academy of Pediatrics (AAP) believes that the medical care of infants, children, and adolescents ideally should be accessible, continuous, comprehensive, family centered, coordination, compassionate, and culturally effective. It should be delivered or directed by well-trained physicians who provide primary care and help to manage and facilitate essentially all aspects of pediatric care. The physician should be known to the child and family and should be able to develop a partnership of mutually responsibility and trust with them." AAP http://pediatrics.aapublications.org/

insurance coverage criteria to include more CYSHCN families; 2) increasing preventative care; 3) extending and standardizing services through the life span, from early intervention programs to youth beyond the 22nd birthday; 4) advocating for policy limiting the number of patients pediatricians and other specialists see in a day (to increase quality of health care visits).

- Extend services to youth beyond the 22nd birthday focusing on transitional services such as job coaching, careers, insurance, social skills, etc.

- Promote sustainability by: 1) advocating for increase funding; 2) increasing providers' accountability; 3) advocating for college/university curricula to include more thorough training for students who will be working with CYSHCN; and 4) providing stipends for parents/caregivers and youth who spend time advocating and helping create policies.

Next steps

This report will also help inform the MCDPH Community Health Improvement Plan as it relates to CYSHCN. Listening sessions will be coordinated to share with the community what was learned during the focus groups and to give the community an opportunity to engage in priority setting. Findings and recommendations from listening sessions will be used by MCDPH and a steering committee of the future CYSHCN Coalition to guide strategic planning efforts and enhance their overall mission to engage in health policy promotion activities for CYSHCN within Maricopa County. Additionally, findings will be shared with community partner organizations serving CYSHCN to better inform service planning and identify areas of improvement.

Children And Youth With Special Health Care Needs: A Maricopa County Needs Assessment And Implications For Policy And Systems Changes

INTRODUCTION

The Maricopa County Department of Public Health (MCDPH) as part of the Health in Arizona Policies Initiative received additional Title V funding from the Arizona Department of Health Services, Office for Children with Special Health Care Needs to conduct a needs assessment for families, children, and young adults with special health care needs and their providers in Maricopa County.

The purpose of this needs assessment was to identify the needs and gaps in services from families and providers of children and youth with special health care needs (CYSHCN) in Maricopa County. The needs analysis was also designed to explore the following local health policy questions:

- What are the most prevalent health policies concerns affecting CYSHCN?
- What health policies currently work well for CYSHCN?
- What is missing in terms of health policy specific to CYSHCN?

Listening sessions will be coordinated to share needs assessment findings with the community and give them an opportunity to engage in priority setting. Needs assessment findings and recommendations will be used by MCDPH and a steering committee of the future CYSHCN Coalition to guide strategic planning. The CYSHCN Coalition will be made up of MCDPH staff, CYSHCN provider agency representatives, parents/caregivers of CYSHCN, and youth with special health care needs. The coalition's overall mission will be to engage in health policy promotion activities for CYSHCN within Maricopa County. Additionally, this report will help inform the MCDPH Community Health Improvement Plan as it relates to CYSHCN. Findings will be shared with community partner organizations serving CYSHCN to better inform service planning, identify areas of improvement, and aid in future funding applications. A summary presentation based on the report will be used to disseminate findings to parents/caregivers of CYSHCN and their providers within Maricopa County.

Prevalence

Children and youth with special health care needs (CYSHCN) in Maricopa County experience varied, and frequently multiple, physical/medical, developmental, behavioral and emotional conditions. The severity of any given condition can vary from mild to severe making CYSHCN historically challenging to limit and define. Like Maricopa County, this report will use the Maternal and Child Health Bureau's (MCB) definition to define CYSHCN as *children up to age 21, who have or are at risk for a chronic physical, developmental, behavioral, emotional or potentially disabling condition and who also require health and related services of a type or amount beyond that required by children generally.*

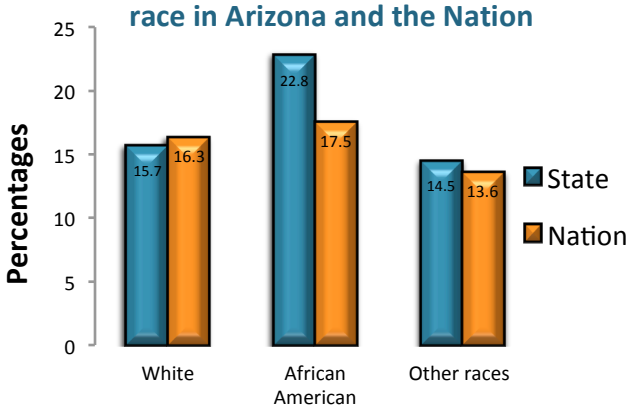
Using the MCB definition of CYSHCN, the 2009-2010 National Survey of Children with Special Health Care Needs (i.e. 2009-2010 National Survey) estimated 241,067 children under the age of 18 years old living in Arizona had a special health care need.[3]

[3] NS-CSHCN. (2010). *Arizona report from the 2009/10 National Survey of Children with Special Health Care Needs* [Child and Adolescent Health Measurement Initiative, Data Resource Center for Child and Adolescent Health website]. Retrieved from www.childhealthdata.org.

Race, Ethnicity, and Gender

Comparisons of National and Arizona data on CYSHCN by race, ethnicity and gender show that the prevalence of CYSHCN in Arizona was similar to national prevalence rates by gender and Hispanic origin. Larger differences are portrayed in Figure 1 whereby Arizona had more African American CYSHCN than reported nationally (22.8% vs. 17.5%).[3]

Figure 1. Comparison of CYSHCN by race in Arizona and the Nation



Note. "Other races" include Hawaiian, Pacific Islander, Alaska Native, and Asian.

Insurance Coverage

According to the 2009-2010 National Survey, Arizona's CYSHCN were more likely to have been without insurance at some point within the last year than their national counterparts (14.2% vs. 9.3%).[3] Moreover, at the time of the survey in 2009, 39.2% of Arizona's CYSHCN who were insured stated they did not have adequate coverage compared to 34.3% nationally.[3]

Access to Care

CYSHCN living in Arizona also experienced more difficulties accessing care when compared to CYSHCN nationally. In 2009-2010, 29.7% of Arizona's CYSHCN experienced an unmet need for specialized health care services compared to 23.6% nationally.[3] A larger percentage of Arizona's CYSHCN needed a referral and had difficulty getting it than CYSHCN nationally (30.2% vs. 23.4%).[3] When sick, 14.7% of Arizona's CYSHCN did not have a usual source of care or relied on the emergency room for care (compared to 9.5% nationally).[3]

While CYSHCN in Arizona, compared to their nationwide counterparts, are less likely to have insurance, are less likely to have adequate health care coverage, and /or are more likely to experience greater barriers accessing specialized care, little is known about CYSHCN health care experiences and needs in Maricopa County. For this reason, MCDPH, with funding from the Arizona Department of Health Services, hired external evaluators to perform a countywide needs assessment. This needs assessment is designed to inform future initiatives in the arenas of policy and service delivery for CYSHCN, their families, and their service providers.

METHODOLOGY

Eight separate focus groups were conducted in Maricopa County between April and May 2013. Three focus groups included English-Speaking parents/caregivers of CYSHCN, one with Spanish-Speaking parents/caregivers of CYSHCN, three with CYSHCN providers, and one with youth who had special health care needs. Additionally, hard copy and online surveys for parents/caregivers were widely distributed in Maricopa County and used for analysis. The online survey links were emailed along with weekly reminders to more than 400 providers, agencies, and organizations that, in turn, distributed the information to clients, staff, and colleagues. The link was also published in several support groups and agency online newsletters reaching over 1000 Maricopa County residents. Although a youth survey was developed and administered, these results were not included in the needs assessment due to limited youth participation. Both the focus groups and surveys targeted the following areas of interest: 1) parents/caregiver and child demographics; 2) care coordination; 3) types of services used;

4) satisfaction with services; 5) barriers and gaps to services; 6) current health policies and; 7) priorities of a future CYSHCN Coalition.

A mixed methods approach to data collection, such as using focus groups and surveys, allowed for a thorough and complete analysis using both qualitative and quantitative data. Third party evaluators from the Saguaro Evaluation Group (SEG) collected and analyzed data so as to maintain the highest integrity of data collection and value-neutral analyses. The combination of external evaluation using qualitative and quantitative data, known as triangulation, is often used in social science to provide independent observations of the population in order to strengthen the ability to draw conclusions and confidence in the validity of such conclusions. When analysis appears to be contradictory, an additional source of data may help elaborate or clarify the inconsistencies. Notes and observations taken by SEG evaluators and MCDPH staff during focus groups were also used for triangulation.

For more comprehensive description of focus group and survey eligibility, recruitment, consent procedures, format, and data analysis, see appendix A. Examples of consents forms, CYSHCN parents/caregivers surveys, focus group agendas, small group questions, focus group flyers, and lessons learned are available in appendices B through H.

Participant Demographics

Parent/Caregiver Focus Groups

Parents/caregivers were eligible to participate in the focus group if they had a child with special health care needs. Prior to starting the focus group discussion, parents/caregivers were asked to complete a brief Participant Form about themselves and their child with special health care needs. A total of 28 completed questionnaires were collected from five focus groups. Parents/caregivers responded to demographic questions about themselves and their child. Table 1 on the following page presents these results.

Most of the participants spoke English as the primary language at home (67.9%), followed by Spanish (28.6%). The majority of children had public insurance (78.6%), followed by children with both private and public insurance coverage (21.4%), and only two children had private insurance (7.1%).
The average age of parents/caregivers was 42 years, while the average age of CYSHCN was ten years. The greatest number of participants identified as White (62.1%), followed by Hispanic, Latino, or Mexican (24.1%). Almost half of families in the focus groups lived in Phoenix (n=13) followed by Peoria (n=4). Other cities represented in the focus groups were Mesa, Peoria, Tempe, Glendale, Gilbert, Chandler, and Scottsdale. The majority of parents/caregivers reported their child experienced needs in more than one area of care. Table 1 presents these findings.

Table 1. Demographics of parent/caregiver focus group participants

	Parents/Caregivers		Child	
	N	%	N	%
Gender				
Female	21	75.0%	8	28.6%
Male	6	21.4%	20	71.4%
Transgender	1	3.6%	0	0.0%
Insurance (child only)				
Public	n/a	n/a	22	78.6%
Private	n/a	n/a	2	7.1%
Both	n/a	n/a	6	21.4%
None			0	0.0%
Hispanic/Latino	10	35.7%	10	35.7%
Race				
White	18	62.1%	19	63.3%
Asian	1	3.3%	1	3.3%
African American or Black	2	6.7%	3	10.0%
Hispanic/Latino*	7	24.1%	7	23.3%
Bi-Racial	1	3.3%		
Language spoken at home				
English	19	67.9%	19	67.9%
Spanish	8	28.6%	8	28.6%%
Mandarin	1	3.5%	1	3.5%
Age				
Range	20-66 years		7 months-21 years	
Average	42 years		10 years	
Annual income				
Range	$1-$80,000			
Average	$41,867			

Providers

A total of 20 providers participated in the focus groups representing a wide variety of services, agencies, and organizations: behavioral health providers; school counselors; psychologists; attorneys; early childhood specialists; special education teachers; pediatricians; vocational counselors; nurses; and speech, occupational and physical therapists. Providers spent from 5% to 100% of their time working directly with clients. On average, the providers attending the focus groups spent 52% of their time providing direct services to CYSHCN.

Parent/Caregiver Surveys

Online survey participants were able to assess the surveys in English or Spanish for a total of four weeks in May 2013. While many families have more than one child with special health care needs, survey participants were instructed to respond to questions thinking about the child with the most needs. A total of 79 individuals surveys were wholly or partially completed (75 in English and 4 in Spanish). The number of participants per question may differ due to missing responses. Partial surveys were used. Survey data were analyzed separately to assess for any major discrepancies in the responses between surveys. A few differences were found when comparing the English and Spanish survey data. After accounting for these differences, the two data sets were combined for analysis (N=79). See appendix A for comprehensive information regarding the online survey development, eligibility, recruitment, format, and analysis. A sample of the English survey is provided in appendix C.

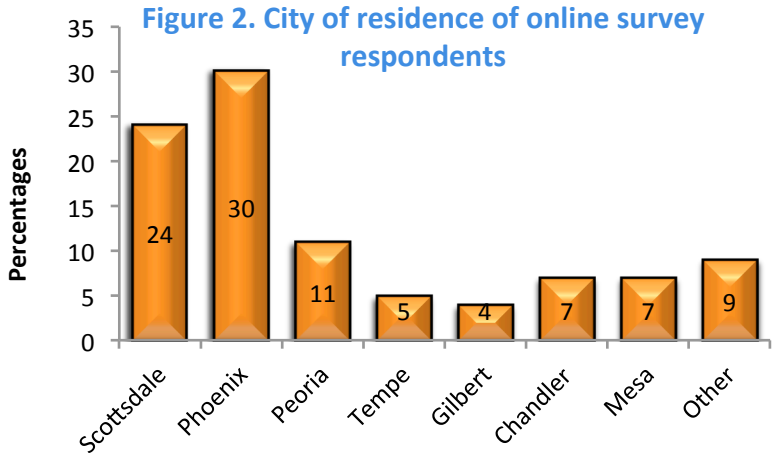
Table 2 illustrates the demographic characteristics of online survey participants. Almost 94% of respondents identified as female (n=74). The average age of parent/caregiver respondents was 45 years. All participants completed the survey in their primary language. The average annual family salary was $55,974. Parents/caregivers reported the gender of their CYSHCN as: male (73.7%), female (22.4%), and transgender (3.9%). The ages of children range from 6 months to 21 years old with the average child age of 13 years. Regarding insurance coverage, 31.6% of parents/caregivers with CYSHCN reported having both public and private insurance; 32.9% had only private insurance; 24.1% had only public insurance; and 2.5% had no insurance.

Table 2. Demographics of parent/caregiver online survey participants

	Parents/Caregivers		Child	
	N	%	N	%
Gender				
Female	74	93.8%	17	22.4%
Male	5	6.2%	56	73.7%
Transgender	0	--	3	3.9%
Insurance (child only)				
Only Public	n/a	n/a	19	24.1%
Only Private	n/a	n/a	26	32.9%
Both Public and Private	n/a	n/a	25	31.6%
None	n/a	n/a	2	2.5%
Missing	n/a	n/a	7	8.9%
Race				
White	68	86.1%	53	67.1%
Black or African American	4	5.1%	4	5.1%
Native American	1	1.3%	2	2.5%
Multiracial	0	0.0%	6	7.6%
Hispanic/Latino/Mex.*	6	7.6%	10	12.7%
Missing	0	---	4	5.1%
Language spoken at home				
English	79	85.9%	79	85.9%
Spanish	6	6.5%	6	6.5%
Mandarin	7	7.6%	7	7.6%
Age				
Range	22years-64 years		6 months-21 years	
Average	45 years		13 years	
Annual income				
Range	$17,000-$150,000			
Average	$55,974			

* Parents who chose "other" and wrote Hispanic/Latino/Mexican as a race

Figure 2 shows the distribution of where participants currently lived across Maricopa County. The majority of survey respondents lived in Phoenix (30%), Scottsdale (24%), and Peoria (11%). Respondent also lived in Glendale, Tempe, Gilbert, Chandler, and Mesa. Other category included one respondent from each of the following cities: Tolleson, Maricopa, Cave Creek, and Avondale. The majority of respondents identified as White (n=68), four identified as Black or African American, one identified as Native American. The survey allowed for respondents to write their race if it did not appear in the list of categories. Six respondents wrote "Hispanic" as their race.



KEY FINDINGS: FOCUS GROUPS

Vision of Health

Each parent/caregiver and youth focus group opened by asking participants to describe what healthy or improved health looked like for themselves (youth) or for their child. Their responses included a description of holistic health that crossed the life span. Parents/caregivers and youth responded "*being able to adjust to life as adults*" and acquiring "*healthy coping skills*." Parents/caregivers and youth envisioned improved health as becoming independent, living in a house or group home, securing a job/career, having a family, and obtaining an education. Educational aspirations ranged from high school diplomas, vocational/job training certification, and college degrees. Both parents/caregivers and youth also mentioned learning how to manage chronic conditions; maintaining a positive outlook in life; and acquiring good nutrition, physical exercise, and healthy sleep habits. Improved health was also perceived as socializing, making friends, and having healthy interpersonal boundaries and relationships.

"…finding a job, picking a college, saving up for a car, [and] getting my license." – Youth

"I think about nutrition and health too because it seems like my kids who have a mental health issues that they don't eat right and they always crave carbs" – Parent/Caregiver

"Happiness… to be able to feel like normal, regular kids" – Parent/Caregiver

Understanding the parent/caregiver and youth's vision of health was key to providing context to the needs and gaps in services for CYSHCN. The holistic view of health shared by focus group participants showed a realistic perspective of the child's needs and conditions as well as a hope for improvement through the recommendations identified as major themes.

Major Themes

Five major themes emerged from the analysis of all three types of focus groups (parents/caregivers, providers, and youth):

- Training and education
- Coordination of care
- Primary needs
- Holistic care
- Transitional services for youth and families

Each of these major themes is broken into subthemes and explored with quotes from focus group participants to illustrate findings. Aside from a few differences between English and Spanish-speaking participants, the major themes and subthemes were found to be consistent across all focus group types (parents/caregivers, providers, and youth). Cases where there was a difference between Spanish and English speaking parents/caregivers are noted. Direct quotes from focus group participants were italicized and used verbatim from transcripts to further illustrate themes.

Training and education

Across all focus groups, participants identified diverse training and education opportunities as a priority for improving the health and experiences of CYSHCN in Maricopa County. Within the theme of training and education, the following subthemes were identified: medical and behavioral health provider training; community awareness and advocacy training; other training and education for parents/caregivers and CYSHCN; resource training for parents/caregivers and providers; and training for school staff. See appendix G for a complete chart of training and education recommendations by group (e.g. provider, parent/caregiver, school staff, etc.).

Medical and behavioral health providers

There was a general consensus across all focus groups that medical and behavioral health providers (including pediatricians, nurses, dentists, medical specialists, therapists, social workers, psychologists, etc.) need more training related to working with CYSHCN. Specific mention was made of training of providers on child development. In many groups, parents/caregivers noted they had to train their providers on their child's condition or diagnosis. Special emphasis was placed on additional training for in-home providers including specialists and early interventionists. Parents/caregivers and providers highlighted the importance of home-based services to families with CYSHCN. However, they also signaled the need for more training and higher education requirements across all in-home providers. Additionally, providers and parents/caregivers highlighted the need for further training in cultural competency in order for providers to better integrate the child and families' culture, religion, and world view into their care and service plans.

"When the therapist comes in or we go to them, they are fresh out of college, they have no experience, give us the text book answer every single time, like, I've heard that ten times already, it hasn't worked" – s/Caregiver

"[The doctor] knows jack about autism or sensory. She knows nothing… so, pretty much I ask for it and she gives it." – Parent/Caregiver

"It would look good if we don't have to spend so much time educating the people who are supposed to help"- Parent/Caregiver

"There is not a lot of breathing room financially…[for] real effective training to build their [staff] skill sets. There is not enough funding for a lot, for supervision! And you can't take people off line!" – Provider/Caregiver

Participants and providers also advocated for provider training in order to create standardized protocols, collective understanding of diagnoses, and common language across settings.

"ADHD is all fine and dandy if I diagnose it, but then the parent is told, "Well, we are not going to provide services unless an MD gives us the same diagnosis" – Provider

Community awareness and advocacy training

All focus groups signaled the overwhelming need to raise community awareness for CYSHCN. Several youth mentioned being bullied in school by other students who don't understand their SHCN. Youth gave general feeling that they *"kind of stick it out"* and that it *"is a little embarrassing at times."* One parent/caregiver described feeling judged in public and at the doctor's office. Another parent/caregiver mentioned stares on public buses and taxi drivers losing their patience when children were loud or having a hard time keeping still. Providers also stated the general need for more community acceptance and understanding of CYSHCN.

"I don't feel I should be punished for [my special need] by other people"- Youth

"Looking at adaptations and about acceptance, you know, so she can be about in the community" – Parent/Caregiver

"We are going to the bigger picture of having people mentally accepting special needs" – Provider

Participants discussed possible solutions and ways to increase community awareness such as a National CYSHCN Awareness Day or a marketing campaign promoting diversity, special health care needs, and understanding. Advocacy training was also highlighted as an essential way to raise

community awareness. Emphasis was placed on advocacy training on all levels: providers, legislators and their staff, families, and children and youth themselves.

According to participants, advocacy training included: 1) how policies work; 2) what policies are currently in place; and 3) how to advocate for policies or policy reform. Furthermore, providers stated the need to train legislators and their staff about the unintended consequences of policies prior to voting. Self-advocacy skills being taught to CYSHCN at an early age was recommended by both parents/caregivers and providers as important. Parents/caregivers and youth also expressed a desire to *"sit at the table when policies are being written,"* learn how to advocate, and recognize opportunities.

"…explain to families how and when policies change, parents don't understand how an IEP [Individualized Education Plan] changes depending on grade, or how the process works in general" – Provider

Other training and education for parents/caregivers and CYSHCN

Beyond advocacy training, many topics were highlighted as important educational opportunities for families and CYSHCN. Parents/caregivers and youth both requested more education on healthy nutrition. Parents/caregivers wanted their children to know how to pack a healthy lunch and how to work towards the overall goal of achieving better health. Regarding safety, parents/caregivers requested cardiopulmonary resuscitation (CPR) and first aid trainings available in English and Spanish. Youth requested basic safety training when interacting in the community. Parents/caregivers and providers requested more training in child development and more training in parenting skills so to reduce false or unrealistic expectations and increase positive strategies for raising a CYSHCN. Providers also highlighted the need for basic health literacy training for parents/caregivers. This concern was confirmed when parents/caregivers reported difficulties finding and using the health information needed to care for their CYSHCN. Youth themselves asked for training on identifying their learning style and how to best communicate their needs to teachers.

"I think that there should at least be like classes that you can take with your family, so that everybody can be informed on what's going on…. They should be able to participate and learn." – Youth

Resource training for providers and parents/caregivers

Resources were a common theme across all focus groups. When asked by facilitators to list services available for CYSHCN as well as services currently being utilized by families, participants were able to brainstorm an abundant and diverse list of resources available. However, facilitators observed that, individually, most participants (outside of those providers specializing in community referral) only knew a handful of services and were surprised to hear about other services available. Much collaboration and networking of resources happened during and after focus groups. In both the parents/caregivers and provider groups, participants shared resources and personal/professional contact information. Hence, while abundant resources were available to families, it was clear there is a greater need for wide spread awareness of services and/or a central resource place to acquire information about services for CYSHCN. MCDPH Strategic Partnerships Coordinator as well as another provider mentioned the existence of the Maricopa County online resource database housed at

www.findhelpphoenix.org. However, all parents/caregivers and the majority of providers were unaware of this resource. Moreover, the providers who knew about the database stated it was out of date and therefore, ineffective.

"They [the providers] don't give you that resource they just leave you like, just hanging there"- Parent/Caregiver

"They [the parents] don't know the resources and they don't know where to start" – Provider/Caregiver

"There was a resource but she didn't even know about it! So she could have been very easily picked up and taken to the appointment but she didn't know about it" - Provider

The conversation about the community's lack of knowledge regarding available resources was always followed by a discussion on how to eliminate this barrier. Resource and referral training was delineated as a priority for both parents/caregivers and providers. Many parents/caregivers shared feeling *"lost"* and *"overwhelmed"* when looking for resources. Parents/caregivers mentioned not knowing where to go for resources or what specialists *"were good."* One common suggestion was a central resource bank or database online and in print for both parents/caregivers and providers.

Participants agreed an electronic and inclusive list of services and providers should be available to providers and families and continuously updated. In addition to agency and program names and contact information, the resource list should also include eligibility requirements making it easier to determine whether it is a match for one's children and youth. Participants acknowledged the existence of a resource book updated on a yearly basis. However, when parents/caregivers and providers tried to access services, they found many services were discontinued due to funding changes and/or their children did not qualify for these services.

"An easier way to share these kinds of resources…a central database that is actually updated and kept current!" - Provider

"The issue is not knowing about the resources." – Parent/Caregiver

"From my perspective there is a lot available but people don't seem to know about it! So, some sort of like synthetizing all of the resources, you know?" – Parent/Caregiver

Training for school staff

Across all focus groups, there was a consensus that school staff (teachers, aides, school nurses, therapists and administrators) needed more intense training regarding CYSHCN. In particular, parents/caregivers and youth recognized children spend many hours of their lives in school; therefore, well-trained school staff makes a significant difference. For example, a youth discussed difficulty understanding the written word, but was better able to identify concepts and ideas when they were presented orally. Other youth needed one-on-one time with tutors or teachers in specific topics such as math. Other youth needed *"quiet time"* or *"time alone"* to work at school or take a test. The youth in the focus group pushed for all teachers to attend Individualized Education Plan

(IEP) meetings to learn more about their students with special needs and attend mandatory yearly training on CYSHCN. Parents/caregivers and youth both expressed a concern that teachers did not know, understand, or follow through with the activities included in the IEP.

"Teachers actually taking the like time to understand those students, spending… like getting to know them on a little bit more of a personal level"- Youth

"Educated staff in schools! I would say all staff, all staff from teachers to nurses to psychologists to OTs [Occupational Therapist]" – Parent/Caregiver

Coordination of care

Within the major theme of coordination of care, the following subthemes were identified: implementing a health navigator role in care; centralized medical records, intakes and data; continuity of school and home plans; provider communication across settings; provider turnover; family and child voice; and provider accountability.

Health navigator

As previously stated, parents/caregivers across focus groups shared feeling "*fragmented*," "*lost*," and "*overwhelmed*" when coordinating the care of their CYSHCN. Many parents/caregivers said they were the ones coordinating all of services. Several mentioned they would benefit from a professional outside of their child's normal service providers to coordinate care and connect with appropriate community resources (e.g. a health navigator, a health coordinator, or a case manager). Regarding current case managers and Division of Developmental Disabilities workers, parents/caregivers expressed frustration with high staff turnover and lack of individualization of care. They envisioned a health navigator as being a professional connected to the child for the long term. So, while many children move from service to service and program to program, their health navigator would ideally stay with them making connections, advocating for individualization of care, and ensuring the child receives the services needed at each stage of life.

"I would like to see this case manager idea come to fruition! Where the kids with special needs, whether it's mental health, or behavioral, or medical… there is a professional person that is versed on the services, that kind of knows services available and has a manageable case load, important!" – Parent/Caregiver

Centralized medical records, intake, and data

Providers and parents/caregivers discussed the need for an electronic, centralized, and comprehensive record of medical, behavioral, and mental health history of their CYSHCN. They envisioned these records as including the entire health history of the child/youth and made available to providers and parents/caregivers. Parents/caregivers felt strongly that centralized records would reduce errors on intake forms, help prevent medication mistakes, and reduce the number of interactions with providers. The comprehensive medical records would increase communication and continuity of services when CYSHCN are between providers.

"What about if there was a medical record that encompasses every dynamic of the person, so that way, whatever provider is looking at the person, they have a whole look at the health of that individual?"- Provider

"My ten year old was hospitalized and, I myself had to drive to the agency's medical record department and sit and wait for the medical records. I waited for a week!" – Parent/Caregiver

Youth and parents/caregivers also suggested centralized intake and evaluation practices. Since the majority of service providers have their own intake process, parents/caregivers and youth are "*forced to relive*" painful experience of the past (e.g. a parent/caregiver talked about her daughter having to relive her suicide attempt over and over again when seeking services) in order to receive services. Additionally, parents/caregivers also noted frustration with the lengthy amount of time spent filling out similar types of paperwork at each agency or organization.

"Every time we have to go to re-app [reapply] for services, to have to kind of bring back all that junk out, and force her to relive it, just so we can qualify for another year! It is wrong!" – Parent/Caregiver

Additionally, centrally located, current data on CYSHCN was requested by providers in order to secure funding and stay abreast of the needs of CYSHCN in Arizona. While national data was easily accessible, providers expressed a need for current local data on Arizona and Maricopa County's CYSHCN.

"Accurate data could play a role in that and making available um… how many dollars are saved due to the services for families and children, and then making that data available in a user friendly format may target what really is important." – Provider

Continuity of school and home plans

Providers and parents/caregivers alike identified the need for school plans to carry over into the home environment. Participants discussed at length the need for continuity between what happens at school and what happens at home so each setting may reinforce the other to better support CYSHCN. It was discussed that while schools have their own plans, parents/caregivers may not have the information, skills, or support they need to continue with the plans at home.

"There is no consistency between what happens at home and what happens in schools." – Parent/Caregiver

"The Home Plan. As a teacher, I didn't even know about a home plan! I was writing the OT, PT… and I said, okay what can my parents do at home? Not once had the therapist say, 'let's create a home plan to do that!'" - Provider

"They are two separate plans. Or home plans and school plans are not coordinated at all. Because neither entity has the support the time to attend every other meeting and it's not good for the students."- Provider

Provider communication across settings

Participants from all focus groups expressed concern and frustration at the lack of communication between medical, behavioral health, and school providers. Parents/caregivers and providers referred to different agency and organization *"silos."* Improving communication among providers would improve the response time, continuity, and coordination of care for CYSHCN. Additionally, better communication amongst medical and behavioral health providers would enhance provider perspective of the CYSHCN, holistically, while promoting coordinated and informed decision-making. Moreover, school providers discussed disconnect between schools, home environments, and outside providers, signaling the need for better connection and communication between all three entities.

"You have these silos, and you think they would be so simple for people to work with one another and to have that process, just continue…. And it's just not!" - Provider

"We look at the child as a whole person and we say "you know what? We are going to prescribe you this based on physical health" and yet, you have a mental health provider here, or behavioral health over here." - Provider

Provider turnover

Parents/caregivers expressed frustration at the high turnover rates of support staff, especially home-based providers who work closely with their children. Youth participants also acknowledged this challenge and felt their case managers were too overloaded to provide individualized care. According to parents/caregivers, frequent staff changes lead to frustration at having to explain their situation again as well as reluctance to trust new providers. Providers highlighted the tremendous pressure on front line staff and the lack of support and education offered by many agencies.

"I think they should hire some more, and spread out their case loads so that way they can get more involved" - Youth

"..training them [case managers] retraining them and then will be turn over. So, then I have to be retraining again. I was going in and taking over the supervisor and writing the service plan because I had better understanding of my daughter goals than she did!" – Parent/Caregiver

Family and child voice

All focus groups signaled the need for family and child voices to be included at the legislature and in care plans and coordination. In order for their voices to be heard, advocacy training was suggested for parents/caregivers and CYSCN; thereby increasing effective communication with various providers as well as policy makers. Specific to decision-making, youth and parent/caregiver participants wished for more say in medication and treatment plans. Youth participants shared a general lack of autonomy in their own services. Conversely, parents/caregivers who expressed taking an active role in their child's care felt providers saw them as a *"problem parent"* or *"neurotic."* Both parents/caregivers and youth expressed concerns with over reliance on medication and lack of additional supports. In particular, they mentioned the desire to have more options in therapeutic approaches (e.g. art or music therapy) and medication choices.

"…they tell her either you wanna do it our way or we're gonna say you're not wanting to comply" – Youth
"Basically I don't have one [a role in services]. It's always up to them…"- Youth

Provider accountability

Providers, parents/caregivers, and youth alike highlighted the need for more provider accountability. Some providers expressed their disapproval of the way other agencies operate and use (or misuse) funds. Parents/caregivers called for consistent protocols and timelines when switching or transitioning services or providers. Parents/caregivers experienced gaps between services, long waiting lists for new services, and lack of information regarding program application deadlines. Parents/caregivers and youth also discussed the need for schools to be held more accountable for following IEPs. Additionally, parents/caregivers and youth asserted the need for clearly defined grievance policies and procedures to report when providers are not fulfilling their obligations. All groups were adamant about the need for increased provider accountability in all settings (medical, behavioral health, and school).

"I've been waiting six months for a psyche eval…the referral is already been approved!" – Parent/Caregiver

"*There are agencies that aren't doing a good job! And they aren't spending their money well! So performance-based contracting!" - Provider*

"Sometimes they [the school] don't follow the IEPs, but they should" – Youth

"…we went like five weeks without care and the program coordinator, whatever she is called, she said, 'she [in-home provider] is not coming?' and I said, 'No! We haven't seen her in five weeks!'"- Parent/Caregiver

Primary needs

Within the major themes of primary needs, the following subthemes were identified: basic needs; higher risk populations within CYSHCN; insurance coverage; and access to services.

Basic needs: Food, transportation, safety, and respite

In all focus groups, participants discussed the need for funding to help with basic needs such as food security, transportation costs, respite, and safety. Providers shared examples of families and young adults reaching the newly lowered limit of food boxes. Parents/caregivers shared struggles paying for food, clothing, transportation costs (gas and public transportation), and/or uncovered medical services or medications. Some parents/caregivers struggled to find part-time jobs with flexible schedules or work from home in order to accommodate their child's needs.

Regarding transportation challenges, families varied in their access to transportation. Many families had one car or none and were reliant on public transportation. Parents/caregivers asserted the Maricopa County public transportation system was not equipped to accommodate CYSHCN. Parents/caregivers shared stories of being kicked out of taxis, receiving dirty looks from other riders, and long travel times in the heat. Friends and family members were occasionally able to offer transportation. Many providers stated time and liability issues as precluding them from offering rides.

Both parents/caregivers and youth discussed the need to increase safety for CYSHCN when traveling or attending programs alone. Youth discussed the idea of cell phones to keep them safe when attending programs in the evening. Youth and parents/caregivers discussed the idea of training young children and youth about personal safety. Youth talked about attending some programs in the evenings and not feeling safe when having to go home (e.g. dark streets, long walks to buses, unsafe neighborhoods). In the Spanish-Speaking focus group, many parents/caregivers feared their children, especially those who were low functioning, were unsafe in the school buses, public transportation, school, and during child-only therapy appointments. Some parents/caregivers in the Spanish-Speaking focus group talked about wanting to be part of the therapy session, but not allowed. Others talked about their children coming from school with bruises and not able to get any information from teachers concerning how their child was hurt. One parent/caregiver was "*appalled*" there were no policies mandating providers to inform parents/caregivers with all the details before, after, and during the use of seclusion or *"scream rooms."*

In all groups, respite services were highlighted as essential to the health of the family unit. However, many parents/caregivers expressed concern over leaving their child with unknown adults. They wished to be able to choose and train their own trusted respite providers. Most parents/caregivers

requested additional respite hours and respite providers who were trained in dealing with children who had more *"severe [behavioral] special needs."*

Providers pointed to the lack of unencumbered funds as the reason they are unable to offer additional financial help to families for basic needs. Providers discussed the need to be creative when helping families overcome financial challenges, but also stated most providers do not have the ability or time to be creative.

"When the family's basic meets are met the parent's capacity to participate increases." – Provider

"Respite is a valuable service that we benefitted from…in giving us a break! … like our boys can go to a center where they can sign up and they go for the weekend. And they have fun! And you kind of get a break!" – Parent/Caregiver

"It's huge barrier; it's transportation. You can't cross-city boundaries with Dial-a-ride! There're so many transportation barriers…" – Provider

"Without my bus card I couldn't seek a lot of services coz the gas is expensive and I don't have a car" - Youth

Higher risk populations within CYSHCN: Families in crisis, undocumented families, and children in foster care

Three higher risk populations identified by both parents/caregivers and providers included families in crisis, undocumented families, and children in foster care. First, participants spoke of many families with CYSHCN who experience times of crisis (e.g. financial, hospitalization, police involvement, runaways and suicide attempts). Parents/caregivers asserted first responders and providers were not experienced or trained in how to support CYSHCN and their families in crisis. Next, providers and parents/caregivers shared the unique challenges experienced by CYSHCN when one or both parents/caregivers were undocumented immigrants, regardless of the child's immigration status. Undocumented parents/caregivers expressed being afraid of seeking services and having their status discovered. The parents/caregivers were reluctant to receive government support in fear it might negatively affected their chance to apply for U.S. residency in the future. Finally, parents/caregivers stated many providers are not trained in how to best support children in foster care and adoptive families. Resource parents/caregivers (historically referred to as foster parents) expressed particular difficulty in finding providers who understand the unique needs of children in foster care and how to access the system of services available (e.g. Reactive Attachment Disorder specific therapy).

"Well, there has been so many times that my wife and I have thought of not fostering! Because we don't want to deal with this…We both have full time jobs… we don't have the time to deal with these kids, these severe special needs! We do it, we can't say no to them! … if we have someone that is a case manager we could … if they manage that busy work that needs to happen, it would make life so much easier on us! To the point that we could do the things we need to do" – Parent/Caregiver

"...set aside time for parents who are in a crisis or struggling" – Parent/Caregiver

"…with undocumented workers and their families, and they are just surviving… they don't have the same resources as other kids that are U.S. citizens."- Provider

Insurance coverage

Across parent/caregiver groups, CYSHCN had various types of insurance coverage from exclusively public or private to both public and private. The children of focus group participants all had some form of insurance coverage. In all focus groups, concerns over insurance coverage and qualifications were shared. Parents/caregivers and providers discussed the various challenges associated with qualifying for public health insurance as well as qualifying for long-term care. Many parents/ caregivers felt their children should qualify for DDD (Division of Developmental Disabilities) or Arizona Long Term Care System services, but did not. Parents/caregivers shared concerns that public insurance eligibility criteria only favored very low-income families and/or certain disabilities and that many children on the autism spectrum did not qualify. Providers and parents/caregivers mentioned other important insurance gaps such as childless adults, 21-year-old youth refusing or forgetting to apply before their 22nd birthday, undocumented CYSHCN, lack of case management services with private insurance, and inconsistency between public and private insurance about services for youth in transition.

Participants agreed that private insurance often covers fewer services than public insurance. Some parents/caregivers mentioned being discouraged when providers ask for payment in advance because any reimbursement from insurance companies is always uncertain. While parents/caregivers were grateful for public health insurance, they expressed frustration with lack of coverage of prescribed medications, non-traditional and *"cutting edge"* therapies (e.g. art, music, and equine therapy, brain-based services, allergy testing, and nutritional support). Parents/caregivers and providers indicated the need for more public insurance contracted providers and pharmacies in their area.

"From the teacher side, I know families that I work with and struggle with getting health care and getting outside services through private health care" - Provider

"Art therapy and music therapy, [behavioral health insurance provider] won't cover it for me. Because I told them a long time ago I don't want to do you know, individual counseling it's not working for me so could I try this you know a different alternative kind of therapy and they wouldn't do it" – Youth

Access to services

Parents/caregivers and providers highlighted timely access to services as essential to the health of CYSHCN. However, participants shared numerous obstacles to accessing services. Parents/caregivers expressed frustration at the lack of early diagnosis due to provider reluctance and/or long waits for developmental pediatricians. Once children received a diagnosis, parents/caregivers stated services were not always immediately available. Parents/caregivers and providers attributed long waiting lists for services to lack of funding and/or lack of qualified providers. Parents/caregivers highlighted the need for more providers available in all parts of Maricopa County. Parents/caregivers shared concerns regarding spending too many hours in their cars or using public transportation to take their child to appointments. Parents/caregivers also lamented the high cost of gas and inconvenience

public transportation. Additionally, parents/caregivers suggested there be more flexible provider hours outside of weekdays and school hours. Parents/caregivers whose children have high needs said they were often unable to work, keep employment, or comply with all the medical and behavioral health care visits their child required. For this reason, many parents/caregivers asserted the need for more in-home providers to cut down on drive time, lower outside childcare costs for siblings, and allow for better more personalized care and support.

"Make sure that schools are fully staff[ed] in the areas that are supposed to be! Because it seems that in that special ed. area they never have enough staff! Even teachers! Psychologists! Therapists! Everywhere is not staff enough!" – Parent/Caregiver

"I think that they should broaden the doctors that are available to use, so we are not driving half way across town to see a mental health professional when there are some in my neighborhood as it is!" – Parent/Caregiver

Holistic care

Parents/caregivers called for a more holistic view of care such as integrating the physical, mental, behavioral, emotional, and social needs of their children and families into one program. Likewise, providers presented the working with *"the whole child"* concept, which emphasizes the child's needs, strengths, and culture across the life span. Several providers and parents/caregivers believed services and funding should not stop at the youth's 22nd birthday, but instead should continue across their life span. Moreover, providers and parents/caregivers identified the need for holistic services to be dynamic and able to accommodate families and children at every stage of life and every level of care. Many barriers to holistic care were previously noted by participants and included lack of communication between providers, insufficient funds, and few highly qualified and well-trained providers.

During the discussion of holistic care, parents/caregivers and providers discussed the need for interdisciplinary teams, integrative knowledge approaches, and one-stop medical homes.[4] Providers talked openly about the *"medical home"* concept as the way to achieve integrated care that was currently being pursued in Maricopa County. The medical home model was described as patient-centered, comprehensive, team-based, accessible and coordinated care. While parents/caregivers did not use the term medical home, they alluded to the model continuously while talking about holistic approaches to care for their children.

In their vision of health, both parents/caregivers and youth highlighted the need for nutritional training as well as exercise. All groups mentioned particular concern for the rising obesity rates among children in the U.S. Additionally, youth and parents/caregivers shared concerns over medication caused weight gain. All groups referred to the availability of parks and recreational

[4] Definition of medical home: "The America Academy of Pediatrics (AAP) believes that the medical care of infants, children, and adolescents ideally should be accessible, continuous, comprehensive, family centered, coordination, compassionate, and culturally effective. It should be delivered or directed by well-trained physicians who provide primary care and help to manage and facilitate essentially all aspects of pediatric care. The physician should be known to the child and family and should be able to develop a partnership of mutually responsibility and trust with them." AAP http://pediatrics.aapublications.org/

centers, after school activities, and summer camps as ways to engage CYSHCN in physical activity. While such programs exist, parents/caregivers stated that the programs were rarely offered in their area, not equipped for CYSHCN, and/or too expensive. Increased availability and scholarships to attend such programs were mentioned as possible ways to overcome these barriers.

"…you have physical health and behavioral health while working together that's the conceptual goal. It's just going to take a long time because, again, we have two different training camps of people working that really don't understand each other well. So, it's gonna be a huge learning curve! …Then you are gonna have families not understanding what a medical home is" – Provider

"The medical home… the idea of combining the medical, physical, behavioral and all records to be available between providers" – Provider

"I want coordination of quality holistic care!" – Parent/Caregiver

Culture and religion

The topics of religion and spirituality were more prominent in the Spanish speaking focus group. Spanish-speaking parents/caregivers more often mentioned the need for spiritual and religious education for CYSHCN. Many of these families attended church together, but most of the time, their CYSHCN could not attend Sunday service due to lack of adequate support and training. Parents/caregivers expressed the need for spiritual education and guidance for their children beyond what they could provide themselves.

Another aspect of religion and culture that was more widely discussed across parent/caregiver and provider groups was the lack of culturally competent providers. In many cultures and families, religion is part of the everyday life and integral to healing. Parents/caregivers highlighted the need for culture and religion to be integrated in the health and service plan as appropriate. Cultural competency training for providers was previously noted as a way to overcome this barrier. Moreover, Spanish-speaking parents/caregivers asserted the lack of Spanish-speaking providers and/or access to interpreters as a daily hurdle for securing adequate care for their CYSHCN.

"If you go with the definition of culture, is mind, body and spirituality, and how you view the world is now consider a key element of cultural proficiency." – Provider

"You have to totally understand the other culture in order to translate that… this is the same… sometimes concepts don't exist in another language" – Provider

Transitional services for youth and families

A common theme across all focus groups was transitional services for youth with special health care needs and their families. The two areas of concern were youth transitioning from high school to vocational training, to a rehabilitation program, and/or to college and youth transitioning from the children's system of care to the adult system on their 22nd birthday.

Providers and parents/caregivers called for increased funding to support additional programs as well as increased insurance coverage for youth after their 22nd birthday. They also brought up concerns over lack of housing and transportation for CYSHCN who have turned 22. Providers and parents/caregivers asserted many youth are not independent at 22 years of age and described dire consequences of cutting services.

For youth transitioning out of high school, there seemed to be no consistent protocols across schools; each school tends to offer different levels of support and timelines. Providers, parents/caregivers, and youth advocated for standardized protocols across school districts that offered comprehensive vocational evaluation, job coaching and training, and employment placement. They requested that transitional programs start early in high school (sophomore year) and involve both the youth and their family in decision-making. Providers also mentioned parents/caregivers sometimes having unrealistic expectations about their child's abilities and future prospects. One provider offered the example of a mother who insisted her child would attend college, although the provider questioned the child's ability to do so. Providers and parents/caregivers further described the inconsistency between home, outside providers, and schools during the transition planning process. Both called for all providers including Division of Developmental Disabilities workers, specialists, teachers, and case managers to attend transition planning in addition to the parents/caregivers and youth.

Other providers reiterated the previous challenge with unfamiliarity of different programs, eligibility concerns, and limited autonomy for their youth in the transitioning process. Parents of children and youth with Autism Spectrum Disorder also identified transition as a focus of concern. Families often believed their youth needed programs with more emphasis on life skills and college preparation in order to be successful at the college level. When discussing life skills, parents/caregivers wanted youth to learn about healthy boundaries, making friends, socializing, and having positive relationships.

"they do have the diagnosis; they're too high functioning to qualify for the funding. But their kid can't go out and work, they can't go out and get a job. They are not going to be successful in school, they need support and then there is nothing available. And those are the kids that end up doing nothing, forever!" – Provider
"One high school starts freshman, one senior, whatever they start I mean they should have it all the same." – Youth

"a lack of housing and resources that are available to those that are transitioning out. The lack of transportation; the lack of some of the jobs." – Provider

Numerous times in each group, providers, parents/caregivers, and youth emphasized the overall need for increased sustainable funding for programs, services, training, advocacy, and community awareness initiatives.

KEY FINDINGS: ONLINE PARENT/CAREGIVER SURVEYS

Reported Conditions of CYSHCN

When asked to select the areas of special health care needs their children are experiencing (medical/physical, mental/emotional, behavioral, development, and other), 54% of parents/caregivers selected three or more areas (n=44%). The majority of parents/caregivers reported their child had developmental needs and at least one other area of need (n=62; 76%). Almost 87% of parents/caregivers reported their child was limited or prevented in his/her ability to do the things that most children his/her age do (n=71). The survey also provided a space for parents/caregivers to describe their child's limitations. See the following examples:

"He has asthma, seizures, and an allergy to latex which prevents him from doing physical activities" – Parent/Caregiver

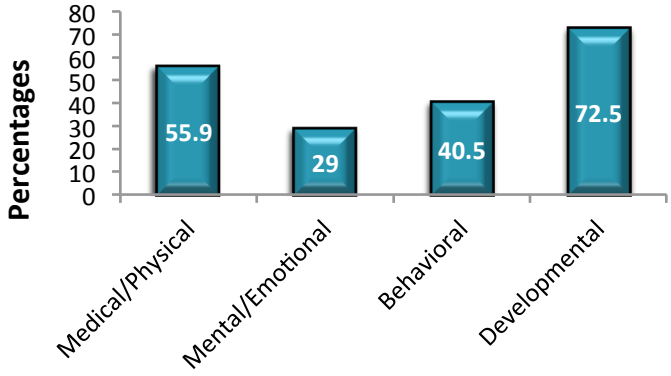
"He does not read or write. He is 19, but his IQ is more like first grade – third grade." – Parent/Caregiver

"She is deaf, so she is limited in a lot of ways due to language barrier." – Parent/Caregiver

"ADHD [Attention Deficit Hyperactive Disorder] and anxiety, on medication. Has a 504 plan at school." – Parent/Caregiver

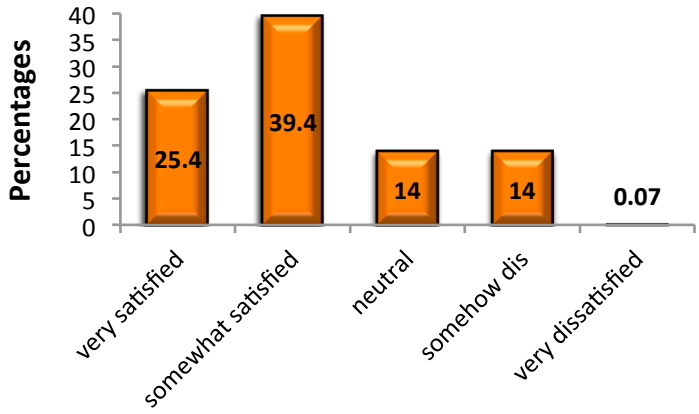
The online survey prompted parents to choose all special health care needs that their child was experiencing. Figure 3 illustrates the parent/caregiver responses. The developmental delays category was the most common category selected by parents to describe their child's special health care need (72.5%), followed by medical/physical (55.9%). As it was previously mentioned parents/caregivers were able to select more than one response.

Figure 3. Percentage of Report Conditions Experienced by CYSHCN



Overall, parents/caregivers were satisfied with the services their children and/or youth received with 64.8% reported as being somewhat to very satisfied. Figure 4 illustrates their responses.

Figure 4. Participant satisfaction with child's services



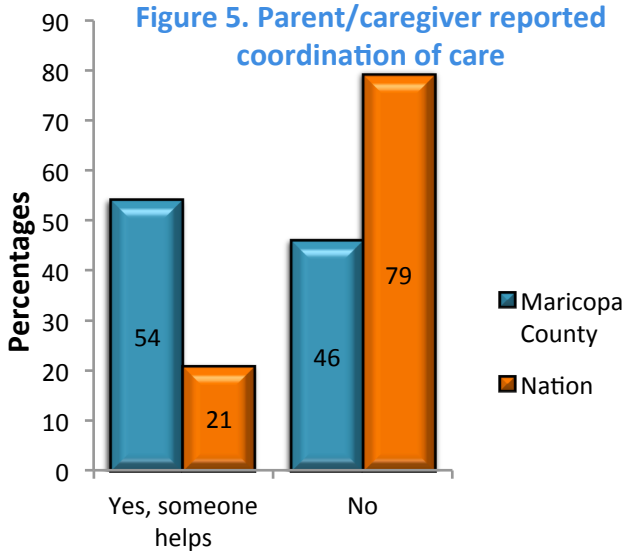
Coordination of Care

In a question allowing parents/caregivers to select more than one response, respondents were asked who coordinates the care of their CYSHCN. The majority of parents/caregivers indicated they coordinate the care of their CYSHCN (n=62; 87%), followed by case managers (n=27; 38%), and medical homes (n=19; 27%) Other respondents indicated teachers, nurses, and child care providers as helping coordinate services.

Comparison with National Data

When comparing the coordination of care reported nationally to the Maricopa CYSHCN survey data, over half (54.1%) of Maricopa survey respondents reported someone helped coordinate care for their child as oppose to only 21% of CYSHCN parents/caregivers nationwide (see Figure 5).

Figure 5. Parent/caregiver reported coordination of care



Responses of open-ended questions were analyzed using the same triangulation method as focus group data. Themes and subthemes were identified from survey data and compared to already coded focus group themes. All themes and subthemes found and discussed in the focus group analysis were present in survey data (e.g. training and education, holistic care, coordination of care, etc.). No additional themes were found. Further discussion of qualitative findings follows in the conclusion and recommendations section.

CONCLUSIONS AND RECOMMENDATIONS

The purpose of this report is to analyze and summarize findings obtained through assessment of health care experiences and needs of CYSHCN in Maricopa County, from the perspectives of parents/caregivers, youth and providers who serve CYSHCN and their families. Data was collected which described the impact of current health policies on CYSCHN, identifying effective health policies as well as potential policy gaps. Data was obtained through parent/caregiver, youth and provider surveys administered during focus group meetings, (provide numbers across all or provide none) online surveys and through parent/caregiver, youth and provider focus group discussion via observer notes (verified for accuracy by participants during the focus groups).

In general, findings suggested families with CYSHCN felt overwhelmed and frustrated at the amount of coordination needed to obtain adequate services for their child due to the complexity of the conditions resulting in the need for a variety of specialists and providers. Discussed at length in all focus groups was the demand for more highly qualified, affordable professionals experienced in working with CYSHCN in a culturally competent manner. Parents/caregivers and providers talked specifically about the need for developmental pediatricians and other specialists (such as dentistry for children with sensory and/or developmental disabilities) who could offer holistic, integrated care. Common in all groups was the desire for more education and training at all levels (providers, parents/caregivers, youth, school staff, legislators and their staff, etc.) (see appendix G for a list of suggested training topics by population). Some participants were especially concerned with poorly trained in-home providers.

With the exception of case managers, most participants agreed they had limited knowledge of community resources available to CYSHCN. While individually participants could only name a few resources, together each focus group was able to aggregate an extensive list of services available to CYSHCN in Maricopa County. The lack of knowledge signaled the need for a centralized resource bank made accessible online to parents/caregivers and providers and maintained with current information.

Along with the need for a central resource bank, participants pushed for intake systems and medical records to be electronic, centralized, and accessible to providers, parents/caregivers, and youth. This type of system would increase provider communication, maintain consistency among providers, improve response time and continuity of care, decrease medication mistakes, avoid errors when completing forms, and provide an opportunity for increased holistic understanding of the diverse needs of CYSHCN.

Parents/caregivers and youth demonstrated limited knowledge of policies affecting CYSHCN. However, they expressed a desire to learn about current policies and how to participate in the policy-making process. Parents/caregivers and providers expressed specifically a desire to be at the table with policy makers when policies are discussed and written to ensure such policies represent a viable means to achieve the intended goals.

The following are further recommendations provided by parents/caregivers survey responses and focus group findings as areas of focus for the future CYSHCN coalition:

- Increase training and education for parents, youth, legislators and their staff, school staff, doctors and specialists, and other providers including in-home services (see appendix G for more detail).

- Improve care coordination by: 1) advocating for policies that integrate the behavioral, mental/emotional, and medical services as well as increase communication and collaboration among providers (medical home); 2) integrating health care services by creating and maintaining a centralized resource bank, as well as centralizing medical records and intake procedures; and 3) increasing funding to implement a health coordinator model for CYSHCN in Maricopa County.

- Advocate for unencumbered funding to assist families with primary needs: 1) food; 2) rent and utilities assistance; 3) transportation; and 4) medications and services not covered by insurance.

- Promote a holistic care approach for CYSHCN in Maricopa County by: 1) advocating for insurance coverage for children and youth regardless of legal status, and expanding insurance coverage criteria to include more CYSHCN families; 2) increasing preventative care; 3) extending and standardizing services throughout the life span, from early intervention programs to youth beyond the 22nd birthday; 4) advocating for policy limiting the number of patients pediatricians and other specialists see in a day (to increase quality of health care visits).

- Extend services to youth beyond the 22nd birthday focusing on transitional services such as job coaching, careers, insurance, social skills, etc.

- Promote sustainability by: 1) advocating for increase funding; 2) increasing providers' accountability; 3) advocating for college/university curricula to include more thorough training for students who will be working with CYSHCN; and 4) providing stipends for parents/caregivers and youth who spend time advocating and helping create policies.

In addition to discussing priorities for the future CYSHCN Coalition, focus group participants also made concrete suggestions for the make-up and structure of the forthcoming team. The following were recommendations by parents/caregivers, youth, and providers:

- Include diverse agency representation, direct practitioners, youth and families with special health care needs, policy institutions, and a resource/navigation agency in the coalition.

- Diversify funding for coalition sustainability.

- Create tangible and measurable outcomes.

- Have a solution-focused agenda.

- Advocate at the legislative level.

Evaluator Recommendations

The large number and complexity of needs shared by focus group and online survey participants demonstrated the high level of vulnerability experienced by CYSHCN and their families in Maricopa County. This assessment highlighted that while there are numerous programs and providers serving the CYSHCN community, their reach and coverage are limited greatly by the lack of awareness of many potential consumers. Similarly, many CYSHCN families are not fully aware of policies currently affecting their services and quality of life. By and large, parents and caregivers in previous pages of this report already expressed the majority of the needs and recommendations. However, the following are additional suggestions for the future CYSHCN coalition from evaluators:

- Raise awareness about community resources and provider services as the first priority to increase access of CYSHCN in Maricopa County to needed care.

- Consider ways to measure the progress and impact of coalition activities on the different sectors related to health care for CYSHCN.

- Work with providers to develop standard evaluation tools and measures in order to provide current, local data on CYSHCN in Maricopa County.

- Team with other CYSHCN-serving organizations to use their conferences, workshops and other established events as opportunities to train families, providers, and CYSHCN themselves on topics such as current policies and how to be an advocate.

- Look for ways to reach out and provide support to higher risk populations within CYSHCN (families in crisis, undocumented families, and children in foster care) including additional help with basic needs, access to services, and training for parents/caregivers

- Use webinars or similar learning platforms such as pod casts and open source video formats to offer training to professionals, paraprofessionals, and families.

- Work with Maricopa County Community colleges and universities to have representatives from key programs (such as social work, psychology, counseling, speech therapy etc.) at the coalition. Their participation may increase opportunities to advocate for curricula changes as well as to promote and expand existing certificate programs. In addition increase scholarship opportunities for in-home providers.

Next Steps

Findings and recommendations will be used by MCDPH and a steering committee of the future CYSHCN Coalition to guide strategic planning efforts and enhance their overall mission to engage in health policy promotion activities for CYSHCN within Maricopa County. Additionally, this report will help inform the MCDPH Community Health Improvement Plan as it relates to CYSHCN. Findings will be shared with community partner organizations serving CYSHCN to better inform service planning and identify areas of improvement.

Appendix A:

Methodology

The needs assessment included separate focus groups with parent/caregivers, providers, and youth (separately) as well as paper and pencil, and online surveys. Additionally, notes were taken on large sticky Poster-Board as the focus groups occurred and participants reviewed them to make sure they reflected what the group discussed. Brief notes taken by Maricopa County Department of Public Health Strategic Partnership Coordinator, who attended five of the focus groups, were also included in the analysis. The analysis was planned to test the validity of the data. Focus groups and survey data were analyzed independently to enhance the analysis and understanding of each component by the other (triangulation). The triangulation method often used in social science evaluation provides, independent observations of the population that strengthen the ability to draw conclusions as well as confidence in the validity of such conclusions. When analysis appears to be contradictory, the other source of data may help elaborate or clarify the inconsistencies.

The areas of interest of the focus groups and surveys were as follows: 1) Demographics (Parent/caregiver and Child) 2) Care Coordination 3) Types of Services Used 4) Satisfaction with Services 5) Barriers and Gaps to Services 6) Health Policies (positive and negative) and, 7) Priorities of Future CYSHCN Council.

Recruitment and Criteria for Eligibility

Focus group participants for all provider, youth, and parent/caregiver focus groups were recruited through printed and online flyer outreach as well as select in-person recruitment SEG evaluators widely distributed flyers in English and Spanish by email and in person to community agencies, school districts, parent organizations, and public institutions (i.e. DDD, MCDPH, etc.). The flyers were forwarded to numerous county and statewide email listservs, posted on many social media pages, and included in a few internal and external agency newsletters. Special outreach efforts were given to organizations specializing in serving Hispanic and American Indian populations. While additional recruitment efforts were made by the agencies hosting the focus groups, very few participants from these agencies attended the events.

Snowball recruitment methods were also used, as focus group participants were encouraged to share information about future groups with their families, friends, schools, and service providers. SEG facilitators performed in-person recruitment efforts at events aimed at CYSHCN and their families including the Child and Family Partnerships Advisory Coalition meeting, Special Olympics Arizona, and the 2013 Self-Advocacy Conference for persons with special health care needs.

Survey recruitment started two days after the last focus group was completed. The surveys were available online and the links were sent along with weekly reminders to

over 400 providers/agencies/organizations who, in turn, distributed the information to clients, staff and colleagues. The link was also published in several support groups and agency newsletters including Native Health and Raising Special Kids reaching over 1000 Maricopa County Residents.

Participant Eligibility

Participants were able register for the focus groups both online and in-person. Facilitators responded to potential participants to determine eligibility by asking qualifying questions regarding the provider type, parent/guardianship, age of child or youth and type of special health care need. Pre-screening phone calls and emails were conducted in English and Spanish. Criteria for focus group eligibility varied by focus group type. Eligibility requirement were described as follows:

Youth Focus Group: Youth aged 14-21 years old with any type of special health care need living in Maricopa County (parental consent required for youth under 18)

Parent/Caregiver Focus Group: Parent or caregiver (resource and adoptive parents included) of child or youth 0-21 years old with any type of special health care need living in Maricopa County

Provider Focus Group: Provider working for an agency, organization, or institution that provides services to CYSHCN in Maricopa County. Provider may be an administrator and/or direct practitioner.

Online Survey Participant: Parents and caregivers (resource and adoptive parents included) over 18 years of age, and parenting a child or youth 0-21 years old with any type of special health care need living in Maricopa County.

Data Collection

Focus Groups
There were a total of eight focus groups held—three focus groups with parent/caregivers in English, one focus group with parent/caregivers in Spanish, one focus group with youth aged 14-21 years old, and three focus groups with various providers. Parent/guardians and youth participants were given a $20 store gift card in exchange for their participation. Additionally, childcare for children under 12 years old was available upon request during parent/guardian focus groups.

Focus groups were scheduled at varied locations across Maricopa County in agencies already serving CYSCHN and their families. Site locations were determined by agency participation in the MCDPH advisory council and location in the Phoenix-Metro area. Days and times of Parent/Caregiver Focus Groups varied on day, time and location in

the Phoenix-Metro area to include mornings, afternoons, evenings and weekends. Light meals were provided for all focus group participants and children in childcare.

Each host site donated a private space to allow the focus group participants to discuss their experiences and opinions confidentially. Both facilitators/evaluators from Saguaro Evaluation Group LLC were present and acted as facilitator or note-taker for all eight focus groups. SEG staff are fully bilingual (English and Spanish) and bicultural and are experienced group leaders.

At the focus group, the facilitator and note-taker began by introducing themselves and explaining the purpose of the focus group. Next, the facilitator went over the informed consent form explained the participants' rights, benefits, risks and confidentiality. After all consents were signed and collected, participants completed a brief demographic survey. Then, the recording devices were started and the facilitator began asking focus group questions one at a time, facilitating discussion, and encouraging equitable group participation. Following each focus group, the facilitator and note-taker discussed the focus group including any emergent themes, surprises, and impressions. The MCDPH project coordinator observed many of the focus groups, but did not participate in the discussion

Parent/Caregiver Survey

In addition to the focus groups, a survey for parents/caregivers of CYSCHN were developed using some of the questions that appear in the CYSHCN National Survey, and by developing new questions based on MCDPH areas of interest for this community assessment. Multiple professionals working at MCDPH, who have expertise in the area of CYSHCN, reviewed the questions and provided feedback prior to the implementation of surveys.

Surveys were hosted by Qualtrics online survey software and available in English and Spanish for four weeks in May and June 2013. The survey links were hosted centrally at Saguaro Evaluation LLC's website. Prior to beginning the survey participants were asked to read and sign an online consent form. However, data was kept separately from consents and no names were used directly on surveys. Survey data was kept confidential by SEG evaluators in a secure database.

Youth Survey

A youth survey (similar to the adult survey) was developed and distributed in self-addressed, stamped envelopes to parents who participated in the parent/caregiver focus groups and had eligible youth in the home. Due to concerns over the vulnerability of the population and informed consent and assent procedures, the survey was only available in hard copy format not online. Unfortunately, only one youth survey was completed and received by evaluators. Therefore, there will be no findings or analysis of youth survey data. SEG evaluators contacted agencies with youth support groups, the Special Olympics and the Self-Advocacy conference in an attempt to have youth

complete the surveys on site. However, no support youth groups were identified and the larger community events were not set up in a manner conducive for survey implementation.

Participant Forms

Each parent participant completed a Participant Form prior to the focus group that requested demographic information. The form contained no identifying information and collected data regarding age, race and ethnicity and gender for both parent and child as well as areas of child's special health care need, insurance coverage, family income, and languages spoken at home. Parent/caregivers of youth participating in the youth focus group completed a Participant Form for their youth as well.

Participants in provider focus groups also filled out a Provider Participant Form with questions regarding agency demographics, job responsibilities, and percentage of time directly working with CYSHCNs. The Provider Participant Form also had an optional second page for those providers who were also parent/caregivers of a CYSHCN requesting the same demographic information as the Parent Participant Form. Only two providers were eligible to complete this second section.

Confidentiality and Informed Consent

Each adult participant in the provider and parent/caregiver focus groups were asked to sign a Focus Group Consent Form. The consent form and informed consent procedure was verbally explained to participants prior to beginning each focus group. The informed consent form stated all information discussed in the focus groups would be kept confidential, the discussion would be tape-recorded, and the participants have the right not participate and may refuse to answer any focus group question. The informed consent materials were used in both English and Spanish. Special provider consent forms were used for participants in the provider focus group.

For the youth focus group, parent/guardians of youth under 18 years old were asked to sign a parental consent form SEG facilitators explained verbally the consent forms to the parent/caregivers including the risks, benefits, and incentives for their child's participation. In additional to parental consent, the youth themselves were asked to sign a youth assent form for participation in the focus group. Facilitators verbally explained the form to the youth including the purpose of the project as well as risks, benefits, and incentives for participation. Youth over 18 years old signed the Adult Focus Group Consent Form.

Additionally, parent/guardians were able to stay in the room with their child or youth if necessary for emotional or physical/medical support. However, no youth participants requested their parent/guardian remain present during the focus group.

Adults who participated in the online survey were asked to sign a consent form prior to obtaining access to the survey. Consent forms were in Spanish and/or English. (See appendix B for an example of the CYSHCN parent/caregiver survey consent form).

Data Analysis

Focus Group

The first step of the analysis involved transcribing the focus groups recordings to establish a permanent record as well as to facilitate further analysis. The method used during transcriptions faithfully preserved the characteristics of the spoken word by picking up incomplete sentences, partial words and even making notations that capture emphasis on words or phrases.
The analysis following the transcriptions was purely qualitative in nature and consisted of coding the transcripts by following five steps: 1) the two evaluators separately read the focus groups' transcripts and identified major themes; 2) sub-themes were then identified within each theme; 3) the evaluators work together and compared their themes and subthemes and arrived at a consensus regarding the codes; 4) the evaluators then compared their codes with the written notes taken during each focus group and the notes taken by the Maricopa County Department of Public Health Strategic Partnership Coordinator; 5) evaluators examine the transcripts for outliers (cases that appear to lead in the opposite direction than the findings); 6) once more the evaluators discussed and arrived at a consensus regarding the final themes and sub-themes.

Surveys

The survey data was downloaded from Qualtrics to Excel. The English and Spanish surveys were analyzed separately to examine any significant differences in the responses. As no differences were found the data was combined before continuing with the analysis.
Frequencies, percentages, and means were examined when appropriate. Missing responses were minimal and accounted for during data analysis and reporting. Open-ended question responses were collected and analyzed following the same methods as for focus groups.

Participant Forms

Demographic information collected from Participant Forms was entered and analyzed in Excel. Frequencies, percentages, and means were examined when appropriate.

Appendix B:
CYSHCN Survey
ADULT CONSENT FORM

You are invited to participate in a survey on Child and Youth with Special Health Care Needs (CYSHCN) in Maricopa County. This survey is part of an evaluation being conducted by the Maricopa County Department of Public Health (MCDPH) in partnership with Saguaro Evaluation Group LLC.

If you agree to participate, you will be asked to complete a short survey about your child's needs, access to and coordination of care, barriers to services, and policies affecting your child. This survey will take approximately 15 minutes of your time.

Your decision to participate is completely voluntary and you have the right to end your participation at any time without penalty. Participation or non-participation will not impact your child(ren)'s services in any way. You may skip any questions you do not wish to answer. Your survey responses will be completely confidential and data will be averaged and grouped together with responses of other participants.

This survey is part of an evaluation designed to help the MCDPH better understand the needs, gap in services, and policies affecting the CYSHCN communities. It is possible you and your family may not receive any direct benefits from this evaluation. However, information gathered will be used by MCDPH to inform the creation and work of a CYSHCN Council as well as Community Health Improvement plans. Evaluation findings will be shared through presentations and reports developed and used by Maricopa County, State funders, Saguaro Evaluation Group LLC and other community providers.

There is no anticipated discomfort for those completing this survey, so risk to participants is minimal.

If you have any questions about your rights as a participant or any concerns or complaints, please contact Dr. Monica Parsai or Aimee Sitzler at Saguaroevaluations@gmail.com or 480-381-2649. If you have questions about this project, you may contact Mary Mezey, Strategic Partnerships Coordinator at 602-506-6036 or via email at MaryMezey@mail.maricopa.gov.

You will receive a copy of this consent form for your records.

I have read and understand the above consent form; I certify that I am 18 years old or older. By signing below, I indicate my willingness to voluntarily take part in the survey.

_____	_____	_____
Participant Name	Participant Signature	Date

Appendix C:

CYSHCN Parent/Caregiver Survey

1. What is your gender? ○ Male ○ Female ○ Transgender

2. What is your age? _____

3. Are you Hispanic or Latino? ○ Yes ○ No

4. How do you describe yourself? Check all that apply:

   ☐ White
   ☐ Asian
   ☐ Native American
   ☐ Black or African American
   ☐ Other (please specify) _____

5. What is your average annual family income? $_____

6. What language do you usually speak at home? _____

7. What city do you live in? _____

Now, think of your child with special health care needs and answer the following questions (if you have more than one, please think about the child that needs the most services):

8. What is your child's gender? ○ Male ○ Female ○ Transgender

9. What is your child's age? _____

10. Is your child Hispanic or Latino? ○ Yes ○ No

11. How do you describe your child's race? Check all that apply:

   ☐ White
   ☐ Asian
   ☐ Native American
   ☐ Black or African American
   ☐ Other (please specify) _____

12. What kind of health insurance does your child have? Check all that apply:

   ☐ Public (e.g. AHCCCS)
   ☐ Private (e.g. Aetna, Cigna, United HealthCare)
   ☐ None

13. Please select the areas of special health care needs that your child is experiencing. Check all that apply:

- ☐ Physical or Medical (e.g. paraplegia, diabetes, asthma)
- ☐ Mental or Emotional (e.g. depression)
- ☐ Behavioral (e.g. conduct problems)
- ☐ Developmental (e.g. Down Syndrome or other cognitive delays)
- ☐ Other (please specify) _____

14. a) Is your child limited or prevented in any way in his/her ability to do the things most children of the same age can do?

- ○ Yes
- ○ No

b) If you answered yes, in what way(s) is your child limited or prevented?

15. In what cities of Maricopa County does your child receive services related to his condition? Check all that apply:

☐Apache Junction	☐Litchfield Park
☐Buckeye	☐Mesa
☐Carefree	☐Paradise Valley
☐Chandler	☐Peoria
☐Cave Creek	☐Phoenix
☐El Mirage	☐Queen Creek
☐Fountain Hills	☐Scottsdale
☐Gila Bend	☐Surprise
☐Gilbert	☐Tempe
☐Glendale	☐Tolleson
☐Goodyear	☐Wickenburg
☐Guadalupe	☐Youngtown

16. Who helps coordinate or arrange your child's care or services? Check all that apply:

- ☐ Social worker
- ☐ Nurse
- ☐ Case manager
- ☐ Me (parent/legal guardian)
- ☐ Medical Home
- ☐ Doctor's office
- ☐ Nobody
- ☐ Other (please specify)_____

17. What types of services are needed for your child to stay healthy or improve his/her health? Check all that apply:

- ☐ Support and information to manage a chronic condition
- ☐ Preventive services (e.g. vaccinations, physical exam)
- ☐ Specialized medical services (e.g. speech pathology, physical therapy)
- ☐ Other (please specify) _____

18. What keeps you, your family or children from getting needed services other than cost? (This includes nutritional support, specialists, counselor, case manager, etc.)

19. In general, how satisfied are you with your child's services?

- ○ Very satisfied
- ○ Somewhat satisfied
- ○ Neutral
- ○ Somewhat dissatisfied
- ○ Very dissatisfied

20. If you are not satisfied with the services your child receives, please mark all the reasons that apply.

- ☐ Costs was too much
- ☐ Health Plan problems
- ☐ No service in our area
- ☐ No convenient times for appointments
- ☐ Provider did not know how to provide care
- ☐ Child refused to go
- ☐ Lack of resources at school
- ☐ Missed/forgot appointment
- ☐ No insurance
- ☐ No one accepts child's insurance
- ☐ Lack of transportation to get to services
- ☐ Dissatisfaction with provider
- ☐ I did not know where to go for care
- ☐ Treatment is ongoing
- ☐ I am satisfied with my child's services
- ☐ Other (please specify)_____

21. Please list any services that you or your child need and cannot find in the area where you live.

22. Please tell us about any laws, policies, or regulations that help your child live a full life. (This includes workplace, school, community, recreational activities, and health care).

23. Please tell us about any laws, policies, or regulations that make it harder for your child to live a full life. (This includes workplace, school, community, recreational activities, and health care).

24. What should be the main focus of the future team working on issues for children with special health care needs?

Appendix D:
Parent/Caregiver Focus Group Agenda

- Opening remarks
- Housekeeping items
- Introduction of facilitators
- Ground rules
- Purpose of the forum
- Explanation and completion of Adult Focus Group Consent Form
- Discussion question number one (20 minutes)
    - What does healthy or improved health look like for your child?
    - What types of services are needed for your child to stay healthy and/or improve his/her health?
        - Examples: Speech therapists, nutritionist, physical therapy, counseling, medical specialists, etc…
- Work in small groups (20 minutes)
    - Group 1: Access to care and coordination of care
    - Group 2: Awareness and quality of services
    - Group 3: Policies affecting your child
- Presentation of group work (30 minutes)
- Final discussion question (15 minutes)
    - Is there anything else that you or your child need that we have not discussed?
    - What should the priorities and focus be for the team working on issues for children with special health care needs?
- Wrap up
- Distribution of Parental Consent Forms for youth surveys

Youth Focus Group Agenda

- Opening remarks
- Housekeeping items
- Introduction of facilitators
- Introduction of participants
- Ground rules
- Purpose of the focus group
- Discussion question number one (15 minutes)
    - What kinds of services do you feel you need to stay healthy?
- Discussion question number two (15 minutes)
    - How satisfied are you with the services you receive?
- Discussion question number three (45 minutes)
    - What are some regulations (rules) in school that affect you negatively or positively?
    - What are some regulations (rules) in the community you live (e.g. park rules, store rules, etc…) that affect you negatively or positively?
    - What are some rules at work that affect you negatively or positively?
    - What are some rules at your doctor's office, hospital, counselor or any other services you use that affect you negatively or positively?
- Discussion question number four (15 minutes)
    - Where do you go or whom do you ask information about services that are available to you?
- Wrap up

Providers Forum Agenda

- Opening remarks
- Housekeeping items
- Introduction of facilitators
- Ground Rules
- Purpose of the forum
- Explanation and completion of Adult Consent Form
- Discussion questions
    - What resources and services are available to your clients?
    - What gaps or barriers to services do your clients most often experience?
    - What policies (ordinances, laws and regulations) affect (positively and negatively) your clients and their families?
    - What should be the priorities and main focus of the future CYSHCN Council?
- Wrap up
- Distribution of Parental Consent Forms for youth surveys

Appendix E:
Small Group Questions
Group One

You will be discussing questions related to access to and coordination of health care for your child and family. Please share only things that you are comfortable discussing in your small group. First, choose one member of the group to take notes using the large post-it paper. Next, choose someone to report your small group discussion to the larger group.

The following are discussion questions:

a. Please describe your child's insurance coverage (e.g. none, public, private, does it cover services of specialists your child may need? Is medication coverage sufficient?).

b. What kinds of issues/problems have you encountered when trying to get needed services?

c. Do your child's providers, specialists, and/or doctors work together or communicate with one another about your child's services? Is it effective? Please, give us examples.

d. What keeps (you, your family, your children) from getting professional services (nutritional support, neurologist, counselor, etc.) other than cost?

Group Two

You will be discussing questions related to your awareness of available services and your thoughts on the quality of services your child receives. Please share only things that you are comfortable discussing in your small group. First, choose one member of the group to take notes using the large post-it paper. Next, choose someone to report your small group discussion to the larger group.

The following are discussion questions:

a. Describe the type of services your child(ren) use? (e.g. doctor, specialists, speech pathologist, counselor, psychologist, case manager, etc.)

b. How satisfied are you with the quality of your child's services?

c. Do you get the services you need for your child(ren)?

    i. What are services that you are not getting now but you would like to have for your child(ren)?

d. Where do you go to learn about services available to your child(ren)?

Group Three

You will be discussing questions related to policies that have to do with your family and or child. Please share only things that you are comfortable discussing in your small group. First, choose one member of the group to take notes using the large post-it paper. Next, choose someone to report your small group discussion to the larger group.

Here is a general description of policy:

Policies include laws, ordinances, mandates, rules and regulations. Policies exist in the workplace, schools, in the areas where we live and where we receive services. Policies greatly influence the choices available to us in our daily lives.

The following are discussion questions:

a. What are some regulations, laws, and ordinances that affect (negatively or positively) your child with special health care needs?

   i. In schools/education

   ii. In the workplace (yours or theirs)

   iii. In the community (e.g. stores, parks, or any public space)

   iv. With service providers (health care providers, counselors, psychologists, social workers, case managers, etc…)

   v. Or in any other area that allows your child(ren) to live a full life

b. What would help make current policies work better for you and your child?

COMMUNITY FORUM

Are you a parent or caregiver of a child or youth with special health care needs? (i.e physical, mental, behavioral and/or developmental)

Come tell us about your experience and be included in a community forum. Your opinion matters!

Tuesday, May 14th 2013, 6-8 pm

Chandler CARE Center
777 E Galveston St.| Chandler, AZ 85225

$20 Target gift card for each participating adult

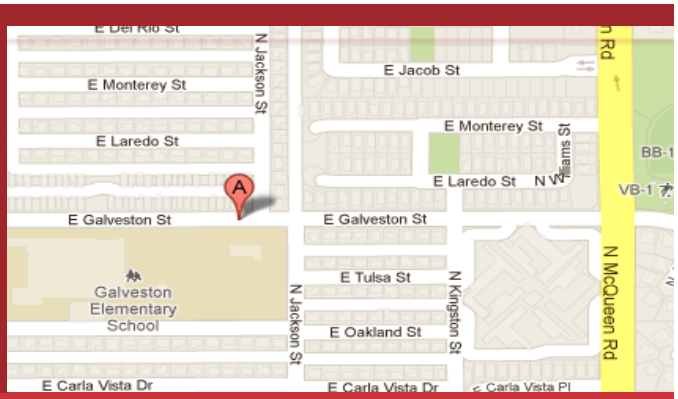
To register for the forum

Call 480-381-2649

or email us at

Saguaro Evaluation Group LLC

saguaroevaluations@gmail.com



CHILDCARE AVAILABLE FOR CHILDREN UNDER 12 WITH RSVP

Appendix G:

Trainings and Education Recommendations by Group

Type of Training	Parents/ Caregivers	Providers	Teachers	Youth	Legislators	Community
Advocacy	X	X	X	X		
Resources	X	X	X	X		
Social skills for youth	X			X		
Managing a chronic condition	X			X		
Cultural competency		X	X			
Boundaries	X			X		
Nutrition	X	X		X		
Learning styles			X	X		
Child development	X					
Job/Career				X		
CPR	X					
Safety				X		
Parenting skills	X					
CYSHCN awareness			X		X	X
Prevention	X	X	X	X	X	X
Health literacy	X			X		

Appendix H:

Focus Groups: Lessons Learned

The following are successes and obstacles experienced by the evaluators and MCDPH staff while organizing, recruiting, and facilitating the eight CYSHCN focus groups for parents/caregivers, providers, and youth.

Focus Group Successes:

- Diverse representation from providers of different disciplines and areas of service for CYSHCN (medical, behavioral health, developmentally disabled, government programs and non-profit)
- Successful recruitment efforts from prior established professional networks
- Gift cards offered to focus group participants
- Acronyms spelled out and definition and examples given for CYSHCN in flyers
- MCDPH funding and involvement spelled out as plus (adaptation due to agency questions)
- Focus group locations varied geographically across Maricopa County, weekday/weekends, and time of day
- Phone call follow ups to key agencies needed for continued recruitment
- All registered participants reminded the day before by phone or email reducing no-shows
- Childcare and meeting space provided through successful collaborations with community agencies already serving CYSHCN and their families
- Focus groups served as excellent networking and education opportunity for providers as well as parents/caregivers
- Wide distribution of focus group flyers and surveys
- Personal/direct outreach worked better than mass emails for participant recruitment
- Parents/caregivers recruited other friends and family members for focus groups

Focus Group Barriers:

- CYSHCN project is new for Department and staff change at beginning of project
- School districts needed advanced notice and time to approve any collaboration for recruitment and/or space
- Agencies hosting the focus groups were not as successful recruiting participants due to population limitations (CYSHCN aged 21 and under and their families) and time of contract (end of fiscal and school year)
- Time of contract was short—people take time to react during the end of school year, and may special events (i.e. Special Olympics Arizona, Self-Advocacy conference, and other agency events) were scheduled during the same time period
- Provider focus groups were only offered during the day---adding an evening focus group and/or teleconference capabilities may increase participation

- No transportation was offered or coordinated for families making it harder for those of lower socio-economic status
- While survey and focus group flyer distribution was wide, participant numbers were lower than anticipated. In future, distribute surveys directly to established groups during meeting times and piggyback focus groups to other parent and provider activities (captive audience)
- Social media was not used as widely for recruitment and may be a successful method in the future

Appendix I:
Listening Sessions: Community Priorities

The purpose of the Children and Youth with Special Health Care Needs (CYSHCN) Needs Assessment was to identify the needs and gaps in services from families and providers of children and youth with special health care needs in Maricopa County. The findings of the needs assessment were disseminated out to the public through eleven listening sessions offered over two months in Fall 2013. The listening sessions gave parents/caregivers and providers the opportunity to provide feedback and engage in priority setting.

This addendum presents the overall participant response to the community listening sessions, including their priorities for future health policy promotion activities related to CYSHCN.

Host Agencies
•Aid to Adoption of Special Kids
•Central Park Neighborhood Cente
•Chicanos Por La Causa
•Disability Empowerment Center
•Family Involvement Center
•Gane Parent Support Group
•HOPE Group, LLC.
•Native American Connections
•Phoenix Day
•Scottsdale Prevention Institute's Centro de la Familia
•Chicanos Por La Causa Migrant Head Start

Listening Sessions

Eleven separate listening sessions were conducted to share the CYSHCN Needs Assessment findings with parents/caregivers and providers in Maricopa County. A total of 121 participants attended the listening sessions.

In order to reach as many participants as possible, listening sessions were offered in collaboration with family-serving agencies geographically dispersed across Maricopa County. See chart table for a complete listing of host agencies. At four of the listening sessions, web technology was used to stream the listening sessions live to off-site attendees. As advertised, healthy snacks, water, on-site childcare, and a drawing for a $25 gift certificate were provided at the listening sessions. In addition, several of the listening sessions offered free flu shots provided by Maricopa County Department of Public Health Community Health nurses half an hour prior to starting the sessions. Due to the large Spanish-speaking population in Maricopa County, three of the eleven sessions were conducted in Spanish.

Listening sessions lasted approximately an hour and a half. To begin, evaluators gave a 45-minute summary presentation of the CYSHCN Needs Assessment process and findings. Then, participants were

given the opportunity to ask questions, provide feedback, and identify priorities for the future CYSHCN Coalition. To assist with future priority setting, each listening session attendee was asked to vote for one of the five major themes identified by the CYSHCN Needs Assessment: training and education, coordination of care, primary needs, holistic care, and transitional services for youth and families. Interestingly, there were no differences between English and Spanish-speaking participants; feedback about future directions and priorities were found to be consistent across all listening sessions. Overall, attendees expressed a greater need for wide spread awareness of services available for families. As with the focus groups, the listening sessions became a forum for networking and sharing available resources. English-speaking groups, in particular, inquired about services applicable for families who needed assistance with health care coverage, transportation, and their basic primary needs.

Priorities

The Maricopa County Department of Public Health (MCDPH) and a steering committee of the future CYSHCN Coalition will use the CYSHCN Needs Assessment findings and recommendations to plan health policy promotion activities. Community feedback and priorities, indicated during the listening sessions, will help advise the Coalition's immediate and long-term action plans.

While listening session participants were able to vote for any of the five major themes, participant voting across all sessions consistently fell into only three of the five areas of recommendation. The majority of listening session participants identified **education and training** as their highest priority for improving the health and experiences of CYSHCN in Maricopa County.

Attendees frequently commented on the interconnection of the five themes. For example, increased education and training would encourage more coordinated and holistic care. If providers received more training about the developmental, physical, emotional, and social needs of CYSHCN than service agencies may begin to integrate holistic care or "whole person" treatment models. Training and education for school staff and parents/caregivers may lead to greater continuity of school and home treatment plans. Advocacy training would empower families, providers, and the community to partner with policymakers in designing opportunities for greater funding and for the standardization of programs for CYSHCN transitioning to adult systems.

In order to increase education and training, attendees suggested leveraging programs and resources that already exist. The CYSHCN Coalition will allow for increased communication and unity between the various entities working with CYSHCN: MCDPH staff, CYSHCN provider agency representatives, parents/caregivers of CYSHCN, medical providers, school personnel, and youth with special health care needs. Several parents/caregivers and providers who attended the listening sessions expressed enthusiasm for participating in the CYSHCN Coalition. Contact information of these attendees was collected and will be used in follow-up communications. In addition to the CYSHCN Coalition, a working inventory or central database with information about services for CYSHCN is essential. Further, it is important to leverage existing training programs and resources to educate the public and professionals working with CYSHCN.

The second ranked priority determined by the parents/caregivers and providers who attended the listening sessions was primary needs. Participants largely expressed that until a child's primary needs (i.e. food, housing, transportation, insurance, etc.) are met, their services will not be effective. The third ranked priority for the future CYSHCN Coalition was coordination of care. Listening session participants seemed to reiterate needs assessment findings, which highlighted the burden of coordination of care that is largely placed on parents/caregivers.

Top three priorities determined by Listening Session participants for future CYSHCN Coalition:

1. Education & Training	2. Primary Needs	3. Coordination of Care
•Parents •Youth •Providers (doctors, specialists, in-home providers, etc.) •Legislators & their staff •School staff	•Food •Rental & utility assistance •Transportation •Services & medications not covered by insurance	•Policies integrating services & increasing communication between providers •Funding for health navigator model •Centralized resource bank •Centralized intake procedures & medical records

Conclusions and Recommendations

In general, those in attendance appreciated the opportunity to learn about the findings of the CYSHCN Needs Assessment. The majority of listening session participants seemed to resonate with the experiences and needs expressed by focus group participants; many attendees asked for copies of the report and presentation.

Across all listening sessions, a greater number of attendees felt education and training was the highest priority for improving health care systems pertaining to CYSHCN in Maricopa County. Attendees also suggested the CYSHCN Coalition focus efforts on the following health care and policy promotion activities:

- Provide training and education opportunities for parents/caregivers, youth, legislators and their staff, school staff, doctors and specialists, and other providers including in-home services.

- Leverage existing training programs and educational resources to educate the public and professionals who work with CYSHCN.

- Increase wide spread awareness of services and/or create a central resource place to acquire information for services for CYSHCN, especially services providing assistance with primary needs such as health care coverage, rental or utility assistance, and transportation.