

## Appendix E: State Plan Online Survey Reports

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### Phase 1 Consumer and Provider Standards Survey Report, May 2016

Medical Home & Community-Based Services and Supports

### Phase 2 Consumer and Provider Standards Survey Report, October 2016

Access to Care & Eligibility and Enrollment

### Phase 3 Consumer and Provider Standards Survey Report, May 2017

Screening, Assessment and Referral & Transition to Adulthood

### Phase 4 Consumer and Provider Standards Survey Report, September 2017

Family-Professional Partnerships and Insurance & Financing

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# Kansas Special Health Care Needs Program

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## Kansas Systems Integration Grant Consumer and Provider Standards Survey

May 2016

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## Key Findings

The sections below include findings from the Standards of Care for Children and Youth with Special Health Care Needs (CYSHCN) survey, which was administered and analyzed by Wichita State University's Center for Applied Research and Evaluation (CARE). The following is a brief overview of the findings:

- A total of 118 participants (94 providers and 24 consumers) at least partially completed the survey. Most of them reside and provide or receive services in Northeast and South Central regions of Kansas.
- In general, consumers/caregivers tended to provide less positive responses than providers across almost all items except those under "Care Coordination."
- **Overall Standards** - The average responses on a 4 point Likert scale (1= "not well at all" to 4= "very well") in terms of meeting overall standards shows that the majority of participants, both providers and caregivers, either chose 2 ("not very well") or 3 ("fairly well"). The average for all statements was between 2.06 and 2.89 with providers typically rating statements slightly more positively than consumers.
- **Plan of Care** - The average of participants' responses to *plan of care* standards ranged between 2.07 and 2.78. Providers mostly chose "fairly well" while consumers typically answered 2 "not very well" or 3 "fairly well."
- **Pediatric Preventative and Primary Care** – For questions in this area, consumers tended to answer "not very well" or "fairly well", and most providers answered "fairly well." The average across questions was between 2.07 and 3.26.
- **Care Coordination** – Providers mostly answered "not very well" to these questions while consumers were more divided between "not very well" and "fairly well" for this category. This is the only category in which the responses of providers tended to be more negative than those of consumers. The averages across all questions ranged from 2.21 and 3.42.
- **Plans of Care Development** – The mean response across questions for this category ranged from 2.09 to 2.73. Providers mostly answered "not very well" or "fairly well" while the majority of consumers chose "not very well."
- **Specialty Care** - The average response across all questions ranged from 2.0 to 2.92, with responses from consumers again being slightly more negative than those from providers.
- **Agreements Between Health Systems and Agencies** – Responses regarding agreements between the health system and various community agencies and programs were skewed toward the negative with the majority of providers choosing "not very well" and

consumers answering either “not well at all” or “not very well” with an average range of 1.83 to 2.5.

- **Respite care** – A majority of consumers (at least 60%) responded “not well at all” to all questions in this category while providers again answered slightly more positively but still primarily selecting “not very well.” The averages across questions ranged from 1.5 to 2.32.
- **Home Health Care** – Averages for responses across consumers and providers were fairly consistent in this category with a range of 2.2 to 2.35. Responses to questions in this category tended to be distributed across all answer options, more so than in others.

### Summary of Survey Results

The purpose of the on-line survey was to gain input from service consumers (people who receive services or caregivers/parents/guardians) and service providers about how well the current system is meeting the standards of care for CYSHCN. This report provides a snapshot of Kansas participants’ perceptions focusing on the core domains for system standards for a) Medical Home and b) Community-based Services and Supports. The survey invitation was sent out by KDHE on March 18th and the survey was closed on April 25th, 2016. A total of 94 providers and 24 consumers at least partially completed the surveys. In this report, some questions on summary tables were reworded for consumers and are noted with asterisks (\*). The specific reworded questions are included in the Appendix. In a limited number of instances, a question was asked of only one group. The tables below indicate where a group didn’t receive the question with “–”. For each question, the response with the largest percentage is highlighted for both providers (yellow) and consumers (green).

**Region (Table 1)** – The largest number of providers live and provide services in the South Central and Northeast regions. The same is true for consumers.

<b>Table 1: In what region do you “live” vs. “provide/receive services most frequently”?</b>								
<b>Region</b>	<b>Providers</b>				<b>Consumers</b>			
	<b>Live in</b>		<b>Providing Services</b>		<b>Live in</b>		<b>Receiving Services</b>	
	<b>#</b>	<b>%</b>	<b>#</b>	<b>%</b>	<b>#</b>	<b>%</b>	<b>#</b>	<b>%</b>
<b>Northwest</b>	9	10%	7	13%	2	8%	2	11%
<b>Northeast</b>	20	21%	13	24%	9	38%	9	50%
<b>Southwest</b>	18	19%	10	19%	3	13%	1	6%
<b>Southeast</b>	11	12%	8	15%	2	8%	2	11%
<b>North Central</b>	13	14%	4	7%	2	8%	0	0%
<b>South Central</b>	23	24%	12	22%	6	25%	4	22%
<b>Total Responses</b>	<b>94</b>		<b>54</b>		<b>24</b>		<b>18</b>	

**Meeting Overall Standards (Table 2)** –The majority of participants reported that the current system did not meet the overall standards very well (2) or met them fairly well (3).

<b>Table 2: How well do most service providers meet the following overall standards?</b>							
<b>Question</b>	<b>Provider/ Consumer</b>	<b>Not well at all (1)</b>	<b>Not very well (2)</b>	<b>Fairly well (3)</b>	<b>Very well (4)</b>	<b>Mean</b>	<b>Total Resp.</b>
2.1 Provide access to health care services 24 hours a day, seven days a week?	Provider	9%	23%	52%	16%	2.73	64
	Consumer	29%	24%	29%	18%	2.35	17
2.2 Provide health care services that encourage the family to share in decision making?	Provider	3%	20%	61%	16%	2.89	64
	Consumer	6%	19%	56%	19%	2.88	16
2.3 Provide health care services that encourage the family to give feedback on services?	Provider	3%	37%	48%	13%	2.7	63
	Consumer* <sup>1</sup>	18%	47%	29%	6%	2.24	17
2.4 Perform health assessments that are comprehensive (i.e., cover a wide-range of issues/possible concerns)?	Provider	8%	22%	52%	19%	2.81	64
	Consumer	17%	28%	28%	28%	2.67	18

2.5 Develop, maintain, and update a plan of care that includes all of the following elements: Has been developed with the family and other members of a team, addresses family care clinical goals, encompasses strategies and actions needed across all settings, and is shared effectively with families and among and between providers?	Provider	9%	41%	45%	5%	2.45	64
	Consumer	13%	56%	25%	6%	2.25	16
2.6 Conduct activities to support self-management (by the child or family) of the child's health and health care.	Provider	5%	45%	45%	5%	2.5	62
	Consumer* <sup>2</sup>	7%	33%	53%	7%	2.6	15
2.7 Promote quality of life, healthy development, and healthy behaviors across all life stages.	Provider	5%	28%	54%	13%	2.75	61
	Consumer	13%	33%	53%	0%	2.4	15
2.8 Integrate care with other providers?	Provider	8%	35%	48%	10%	2.59	63
	Consumer* <sup>3</sup>	31%	44%	13%	13%	2.06	16
2.9 Encourage a system of care coordination in which the health care team and families of the child work together?	Provider	9%	20%	58%	13%	2.73	64
	Consumer	18%	41%	29%	12%	2.35	17
2.10 Make sure that information is shared accurately and in a timely manner with families and between providers?	Provider	5%	40%	49%	6%	2.57	64
	Consumer* <sup>4</sup>	27%	33%	33%	7%	2.2	15
2.11 Perform care tracking (including sending of reminders to families and clinicians about necessary services before they are needed) through a registry or other method?	Provider	10%	56%	31%	3%	2.27	62
	Consumer	-	-	-	-	-	-
2.12 Provide care that is effective (i.e., makes a positive difference for the child)?	Provider	3%	25%	61%	11%	2.8	61
	Consumer	13%	27%	40%	20%	2.67	15

**Plans of Care (Table 3)** – The average responses for all questions in this category were “not very well” or “fairly well.” Consumers tended to rate these statements more negatively than providers.

<b>Table 3: How well do most service providers meet the following standards regarding plans of care?</b>							
<b>Question</b>	<b>Provider/ Consumer</b>	<b>Not well at all (1)</b>	<b>Not very well (2)</b>	<b>Fairly well (3)</b>	<b>Very well (4)</b>	<b>Mean</b>	<b>Total Resp.</b>
3.1 Develop, maintain, and update a comprehensive, integrated plan of care?	Provider	6%	37%	46%	11%	2.62	63
	Consumer	-	-	-	-	-	-
3.2 Include family and other members of a team in the development of the plan of care?	Provider	2%	32%	54%	13%	2.78	63
	Consumer* <sup>4</sup>	13%	38%	38%	13%	2.5	16
3.3 Address family care clinical goals in the plan of care?	Provider	3%	44%	44%	10%	2.6	63
	Consumer* <sup>5</sup>	13%	33%	40%	13%	2.53	15
3.4 Encompass strategies and actions needed across all settings in the plan of care?	Provider	3%	52%	39%	6%	2.48	62
	Consumer	-	-	-	-	-	-
3.5 Share the plan of care effectively with families and among and between providers?	Provider	6%	47%	39%	8%	2.48	62
	Consumer* <sup>6</sup>	27%	40%	33%	0%	2.07	15

**Pediatric Preventive and Primary Care (Table 4)** – Consumers and providers tended to answer “not very well” or “fairly well” to most statements in this category. Consumers responded most negatively about item 4.11 regarding the standard of completing pre-visit assessments to ensure that needs are met.

<b>Table 4: How well do service providers meet the following standards regarding pediatric preventative and primary care?</b>							
<b>Question</b>	<b>Provider/ Consumer</b>	<b>Not well at all (1)</b>	<b>Not very well (2)</b>	<b>Fairly well (3)</b>	<b>Very well (4)</b>	<b>Mean</b>	<b>Total Resp.</b>
4.1 Follow Bright Futures Guidelines for screening and well child care including oral health and mental health services?	Provider	9%	30%	51%	11%	2.63	57
	Consumer	-	-	-	-	-	-

4.2 Focus care on overall health, wellness, and prevention of secondary conditions?	Provider	3%	20%	66%	10%	2.83	59
	Consumer	13%	13%	56%	19%	2.81	16
4.3 Provide access to medically necessary services to promote optimal growth and development?	Provider	3%	26%	57%	14%	2.81	58
	Consumer* <sup>7</sup>	6%	31%	38%	25%	2.81	16
4.4 Maintain and avert deterioration in functioning?	Provider	4%	16%	71%	9%	2.86	56
	Consumer* <sup>8,9</sup>	6%	6%	56%	31%	3.13	16
4.5. Prevent, detect, diagnose, treat, ameliorate, or palliate the effects of physical, genetic, congenital, developmental, behavioral, or mental conditions, injuries, or disabilities?	Provider	3%	28%	59%	10%	2.76	58
	Consumer	-	-	-	-	-	-
4.6 Provide children and youth with special needs with recommended immunizations according to the Advisory committee on Immunization Practices (ACIP)?	Provider	3%	5%	53%	38%	3.26	58
	Consumer* <sup>10</sup>	6%	13%	44%	38%	3.13	16
4.7 Provide reasonable access to routine, episodic, urgent, and emergent physical, oral health and mental health care?	Provider	4%	25%	56%	16%	2.84	57
	Consumer* <sup>11</sup>	25%	31%	25%	19%	2.38	16
4.8 Make reasonable wait times and same day appointments available for physical, oral health, and mental health care?	Provider	9%	38%	45%	9%	2.54	56
	Consumer	7%	47%	27%	20%	2.60	15
4.9 Make accommodations available for special needs such as provision of home visits versus office visits?	Provider	22%	45%	29%	3%	2.14	58
	Consumer* <sup>12</sup>	33%	40%	13%	13%	2.07	15
4.10 Use scheduling systems that recognize the additional time involved in caring for children and youth with special needs?	Provider	13%	36%	44%	7%	2.45	55
	Consumer* <sup>13</sup>	13%	40%	27%	20%	2.53	15
4.11 Complete pre-visit assessments with the family to ensure that the medical home team provides family-centered care and is better able to make necessary referrals?	Provider	23%	39%	35%	4%	2.19	57
	Consumer* <sup>14</sup>	31%	31%	23%	15%	2.23	13

**Care Coordination (Table 5)** – Care Coordination is the only category in which consumers tended to answer more positively than providers across all questions. Specifically, the majority of consumers reported that the system was meeting the standard “fairly well” or “very well” related to items 5.5. (providing appropriate resources matching the child/family’s primary language) and 5.6. (appropriate resources to match the culture of the child/family).

<b>Table 5: How well do service providers meet the following standards regarding care coordination?</b>							
<b>Question</b>	<b>Provider/ Consumer</b>	<b>Not well at all (1)</b>	<b>Not very well (2)</b>	<b>Fairly well (3)</b>	<b>Very well (4)</b>	<b>Mean</b>	<b>Total Resp.</b>
5.1 Provide access to patient and family-centered care coordination?	Provider	13%	38%	43%	7%	2.45	56
	Consumer	-	-	-	-	-	-
5.2 Care coordinators serve as a member of the medical home team?	Provider	15%	47%	31%	7%	2.31	55
	Consumer* <sup>15</sup>	15%	38%	31%	15%	2.46	13
5.3 Care coordinators assist in managing care transitions across settings and developmental stages?	Provider	17%	51%	26%	6%	2.21	53
	Consumer* <sup>16</sup>	14%	43%	29%	14%	2.43	14
5.4 Care coordinators provide appropriate resources to match the health literacy level of the child and their family?	Provider	15%	44%	37%	4%	2.21	52
	Consumer* <sup>17</sup>	8%	46%	31%	15%	2.54	13
5.5 Care coordinators provide appropriate resources to match the primary language of the child and their family?	Provider	17%	42%	32%	9%	2.34	53
	Consumer	0%	17%	25%	58%	3.42	12
5.6 Care coordinators provide appropriate resources to match the culture of the child and their family?	Provider	15%	55%	23%	8%	2.23	53
	Consumer	0%	33%	42%	25%	2.92	12

**Plans of Care Development (Table 6)** – On a number of questions in this category, consumers were again more positive than providers (i.e., 6.1., 6.2., 6.3., etc). However, average responses across all questions were between “not very well” and “fairly well.”

<b>Table 6: How well do the plans of care developed with a Care Coordinator meet the following standards?</b>							
<b>Question</b>	<b>Provider/ Consumer</b>	<b>Not well at all (1)</b>	<b>Not very well (2)</b>	<b>Fairly well (3)</b>	<b>Very well (4)</b>	<b>Mean</b>	<b>Total Resp.</b>
6.1 The plan of care is developed jointly and shared among the primary care provider and/or the specialist serving as the principal coordinating physician, and the child or youth with special health care needs and their family?	Provider	10%	42%	44%	4%	2.42	48
	Consumer* <sup>18</sup>	27%	18%	18%	36%	2.64	11
6.2 The plan of care is implemented jointly with the child, their family, and the appropriate members of the health care team?	Provider	10%	35%	49%	6%	2.51	49
	Consumer* <sup>19</sup>	18%	27%	18%	36%	2.73	11
6.3 The plan of care addresses the physical, oral, and mental health problems identified as a result of the initial and ongoing evaluation?	Provider	12%	37%	47%	4%	2.43	49
	Consumer	18%	36%	9%	36%	2.64	11
6.4 The plan of care describes the implementation and coordination of all services required by the child and their family?	Provider	11%	32%	54%	2%	2.51	47
	Consumer* <sup>20</sup>	18%	45%	9%	27%	2.45	11
6.5 The plan of care identifies the strengths and needs of the child and family?	Provider	12%	32%	54%	2%	2.51	50
	Consumer	27%	36%	18%	18%	2.27	11
6.6 The plan of care incorporates and states the child and family’s goals with clinical goals?	Provider	8%	44%	46%	2%	2.42	48
	Consumer* <sup>21</sup>	18%	45%	9%	27%	2.45	11
6.7 The plan of care guides the roles, activities, and functions of the family, and the care team?	Provider	15%	42%	40%	4%	2.33	48
	Consumer	18%	64%	9%	9%	2.09	11
6.8 The plan of care includes routine evaluation as well as updating the plan in partnership with the family as needed (at least every 6 months)?	Provider	12%	39%	39%	10%	2.47	49
	Consumer* <sup>22</sup>	27%	36%	9%	27%	2.36	11

6.9 The plan of care clearly identifies and delineates the roles, responsibilities, and accountabilities of all entities that participate in a child’s care coordination activities?	Provider	15%	44%	35%	6%	2.33	48
	Consumer* <sup>23</sup>	18%	45%	9%	27%	2.45	11
6.10 The plan of care is maintained and updated with evaluative oversight?	Provider	13%	47%	34%	6%	2.34	47
	Consumer* <sup>24</sup>	18%	55%	9%	18%	2.27	11
6.11 The plan of care is used to make timely referrals and track receipt of services?	Provider	12%	38%	44%	6%	2.44	50
	Consumer	18%	45%	18%	18%	2.36	11

**Specialty Care (Table 7)** – As with other categories, average responses across all questions tended to be “not very well” or “fairly well.” For the item 7.7 regarding a full continuum of services being available for behavioral health needs was rated particularly low in this category with the majority of both consumers and providers choosing “not well at all” or “not very well.”

**Table 7: How well does specialty care provided to them meet the following standards?**

Question	Provider/ Consumer	Not well at all (1)	Not very well (2)	Fairly well (3)	Very well (4)	Mean	Total Resp.
7.1 Shared management of the child between pediatric primary care and specialty providers is permitted?	Provider	4%	23%	67%	6%	2.75	48
	Consumer	-	-	-	-	-	-
7.2 Systems such as satellite programs, electronic communications, and telemedicine to enhance access to specialty care, regional pediatric centers of excellence where available, and other multidisciplinary teams of pediatric specialty providers are used where needed?	Provider	13%	47%	32%	9%	2.36	47
	Consumer* <sup>25</sup>	18%	55%	9%	18%	2.27	11
7.3 Physical health, oral health, and mental health is coordinated and integrated?	Provider	15%	50%	31%	4%	2.25	48
	Consumer* <sup>26</sup>	25%	42%	8%	25%	2.33	12

7.4 Pediatric centers of care (e.g., cardiac, regional genetics, end stage renal disease, perinatal care, transplants, hematology/oncology, pulmonary, craniofacial, and neuromuscular) are made available to the children and their families (when needed)?	Provider	10%	17%	63%	10%	2.73	48
	Consumer* <sup>27</sup>	25%	42%	8%	25%	2.33	12
7.5 The system that serves children Title V CYSHCN (children and youth with special health care needs) programs, LEND and UCEDD Centers for individuals with developmental disabilities, is included in specialty care where available?	Provider	15%	34%	44%	7%	2.44	41
	Consumer	-	-	-	-	-	-
7.6 Durable medical equipment and home health services that are customized for children and youth with special needs is included in specialty care?	Provider	12%	28%	49%	12%	2.6	43
	Consumer	8%	17%	50%	25%	2.92	12
7.7 A “full continuum” of services for children’s behavioral health needs, including acute services in a 24-hour clinical setting, intermediate services, and outpatient services and community support services is provided?	Provider	24%	51%	24%	0%	2.0	45
	Consumer* <sup>28</sup>	30%	40%	10%	20%	2.2	10

**Agreements Between Health Systems and Agencies (Table 8)** – Over 40% of respondents, both consumers and providers, answered “not well at all” or “not very well” to all questions in this category. As with other categories, consumers tended to rate the items more negatively than providers.

<b>Table 8: How well do the agreements between the health systems and various community agencies and programs meet the following standards?</b>							
<b>Question</b>	<b>Provider/ Consumer</b>	<b>Not well at all (1)</b>	<b>Not very well (2)</b>	<b>Fairly well (3)</b>	<b>Very well (4)</b>	<b>Mean</b>	<b>Total Resp.</b>
8.1 Shared financing is promoted?	Provider	24%	47%	27%	2%	2.07	45
	Consumer	-	-	-	-	-	-

8.2 Systems for timely communications and appropriate data sharing are established?	Provider	17%	50%	30%	2%	2.17	46
	Consumer	-	-	-	-	-	-
8.3 Access and coordination of services for individual children and their families is ensured?	Provider	11%	51%	33%	4%	2.31	45
	Consumer* <sup>29</sup>	33%	42%	17%	8%	2	12
8.4 Collaboration between community-based organizations and agencies, providers, health care systems, and families is promoted?	Provider	10%	45%	45%	0%	2.35	49
	Consumer* <sup>30</sup>	45%	18%	36%	0%	1.91	11
8.5 Responsibilities across the various providers, and community-based agencies serving children and their families are specified?	Provider	17%	50%	31%	2%	2.19	48
	Consumer* <sup>31</sup>	42%	33%	17%	8%	1.92	12
8.6 Families are supported through linking families to family organizations and other services and supports?	Provider	7%	41%	48%	4%	2.5	46
	Consumer	42%	42%	8%	8%	1.83	12

**Respite Care (Table 9)** – This category tended to receive the lowest ratings with no more than a couple of people responding “very well” to any item. The majority of consumer responses were “not well at all” and almost over 40% of providers responded either “not very well” or “not well at all” for all questions.

<b>Table 9: How well do service providers meet the following standards regarding respite care for families and caregivers?</b>							
<b>Question</b>	<b>Provider/ Consumer</b>	<b>Not well at all (1)</b>	<b>Not very well (2)</b>	<b>Fairly well (3)</b>	<b>Very well (4)</b>	<b>Mean</b>	<b>Total Resp.</b>
9.1 Respite care is made available to all families and caregivers (both planned and emergency)?	Provider	28%	50%	23%	0%	1.95	40
	Consumer	70%	20%	0%	10%	1.5	10
9.2 Families and caregivers are informed about available respite services and help to access them?	Provider	33%	38%	30%	0%	1.98	40
	Consumer	60%	20%	10%	10%	1.7	10
9.3 Transportation is made available when out-of-home respite services are needed to help a child and family access these services?	Provider	33%	41%	26%	0%	1.92	39
	Consumer	60%	20%	20%	0%	1.6	10

9.4 Families and caregivers of the child or youth are screened for respite care needs?	Provider	26%	53%	21%	0%	1.95	38
	Consumer* <sup>32</sup>	70%	10%	10%	10%	1.6	10
9.5 Families and caregivers are provided with appropriate and timely referrals to providers that are qualified to serve children and youth with special needs?	Provider	18%	32%	50%	0%	2.32	38
	Consumer	60%	10%	20%	10%	1.8	10
9.6 A system is in place for ensuring timely referrals for families of children and youth with special needs that have emergency respite needs?	Provider	29%	45%	26%	0%	1.97	38
	Consumer* <sup>33</sup>	60%	10%	10%	20%	1.9	10

**Home Health Care (Table 10)** – Average responses to items in this category fell between “not very well” and “fairly well” for both consumers and providers. However, over 40% of consumers answered “not well at all” to items 10.2. (home health care provided in home) and 10.3. (home health care is accessible).

<b>Table 10: How well does the system meet the following standards regarding home health care?</b>							
<b>Question</b>	<b>Provider/ Consumer</b>	<b>Not well at all (1)</b>	<b>Not very well (2)</b>	<b>Fairly well (3)</b>	<b>Very well (4)</b>	<b>Mean</b>	<b>Total Resp.</b>
10.1 Home health care is a covered benefit that includes health care for the child and supportive care for the family?	Provider	14%	41%	43%	3%	2.35	37
	Consumer	42%	8%	33%	17%	2.25	12
10.2 Home health care is provided in the family's home by licensed professionals who have experience in pediatric care?	Provider	18%	32%	50%	0%	2.32	37
	Consumer	40%	20%	20%	20%	2.2	10
10.3 Home health care is accessible to families?	Provider	-	-	-	-	-	-
	Consumer	42%	17%	25%	17%	2.2	12

## Appendix

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### Appendix A: Questions reworded for consumers

**Table 2**

*#	Provider question text	Consumer question text
1	Provide health care services that encourage the family to give feedback on services?	Provide health care services that encourage the family to give feedback on the services they receive?
2	Conduct activities to support self-management (by the child or family) of the child's health and health care.	Conduct activities to support self-care to manage health (by the child or family)?
3	Integrate care with other providers?	Providers learn what each other are doing are doing to help develop a plan of care?

**Table 3**

*#	Provider question text	Consumer question text
4	Include family and other members of a team in the development of the plan of care?	Include family and other members of the team in the team when creating or changing of the plan of care?
5	Address family care clinical goals in the plan of care?	Family health care goals (i.e., results the family wants out of care) are included in the plan of care?
6	Share the plan of care effectively with families and among and between providers?	Share the plan of care with families and between providers?

**Table 4**

*#	Provider question text	Consumer question text
7	Provide access to medically necessary services to promote optimal growth and development?	Provide access to medically necessary services to promote the best possible growth and development?

8 9	Maintain (8) and avert deterioration (9) in functioning?	Help your child(ren) stay healthy? (8)
		Help prevent your child(ren) from becoming ill? (9)
10	Provide children and youth with special needs with recommended immunizations according to the Advisory committee on Immunization Practices (ACIP)?	Provide recommendation on when your child with special health care needs should receive immunizations?
11	Provide reasonable access to routine, episodic, urgent, and emergent physical, oral health and mental health care?	Provide reasonable access to routine, episodic (from time to time), urgent (need quick assistance but not serious enough to go to emergency room), and emergency physical, oral health and mental health care?
12	Make accommodations available for special needs such as provision of home visits versus office visits?	Make special arrangements available for special needs, such as providing home visits instead of office visits?
13	Use scheduling systems that recognize the additional time involved in caring for children and youth with special needs?	Schedule appointments to allow for the additional time involved in caring for children and youth with special needs?
14	Complete pre-visit assessments with the family to ensure that the medical home team provides family-centered care and is better able to make necessary referrals?	Complete pre-visit assessments with the family to make sure that the medical home team provides care that meets the family's needs and that the team is better able to make necessary referrals?

**Table 5**

*#	Provider question text	Consumer question text
15	Care coordinators serve as a member of the medical home team?	Someone at the doctor's office helps coordinate services as part of the child's personal care team?
16	Care coordinators assist in managing care transitions across settings and developmental stages?	Care coordinators assist in managing care transitions across settings and developmental stages (e.g., when a child changes providers, possibly due to needing additional services or needing different providers because of his/her age)?
17	Care coordinators provide appropriate	Care coordinators provide appropriate

	resources to match the health literacy level of the child and their family?	resources to match the health literacy level (i.e., how well a person understands health information) of the child and their family?
<b><u>Table 6</u></b>		
<b>*#</b>	<b>Provider question text</b>	<b>Consumer question text</b>
18	The plan of care is developed jointly and shared among the primary care provider and/or the specialist serving as the principal coordinating physician, and the child or youth with special health care needs and their family?	The plan of care is developed with the family of the child?
19	The plan of care is implemented jointly with the child, their family, and the appropriate members of the health care team?	The plan of care is carried out by the appropriate members of the health care team while including the child or youth and their family?
20	The plan of care describes the implementation and coordination of all services required by the child and their family?	The plan of care describes how it will be carried out and how the services required by the child and their family will be coordinated?
21	The plan of care incorporates and states the child and family's goals with clinical goals?	The plan of care includes in writing the child's and family's goals in addition to the clinical goals?
22	The plan of care includes routine evaluation as well as updating the plan in partnership with the family as needed (at least every 6 months)?	The plan of care includes regular progress checks and updating of the plan with the family as needed (at least every 6 months)?
23	The plan of care clearly identifies and delineates the roles, responsibilities, and accountabilities of all entities that participate in a child's care coordination activities?	The plan of care clearly identifies and describes the roles and responsibilities of all parties that participate in a child's care coordination activities?
24	The plan of care is maintained and updated with evaluative oversight?	The plan of care is maintained and updated with oversight by someone who makes sure it's effective?

**Table 7**

<b>*#</b>	<b>Provider question text</b>	<b>Consumer question text</b>
25	Systems such as satellite programs, electronic communications, and telemedicine to enhance access to specialty care, regional pediatric centers of excellence where available, and other multidisciplinary teams of pediatric specialty providers are used where needed?	Various methods are used where needed to help with access to specialty care? (These may include: satellite programs, electronic communications, and telemedicine used to access regional pediatric centers and other multidisciplinary teams of pediatric specialty providers)?
26	Physical health, oral health, and mental health is coordinated and integrated?	Services for physical, oral, and mental health are coordinated so they work together?
27	Pediatric centers of care (e.g., cardiac, regional genetics, end stage renal disease, perinatal care, transplants, hematology/oncology, pulmonary, craniofacial, and neuromuscular) are made available to the children and their families (when needed)?	Pediatric centers of care are made available to the children and their families (when needed)? (Pediatric centers of care may include: cardiac, regional genetics, end stage renal disease, perinatal care, transplants, hematology/oncology, pulmonary, craniofacial, and neuromuscular)
28	A “full continuum” of services for children’s behavioral health needs, including acute services in a 24-hour hour clinical setting, intermediate services, and outpatient services and community support services is provided?	A complete range of services for children’s behavioral health needs are provided? (May include: acute services in a 24-hour hour clinical setting, intermediate services, and outpatient services and community support services)?

**Table 8**

<b>*#</b>	<b>Provider question text</b>	<b>Consumer question text</b>
29	Access and coordination of services for individual children and their families is ensured?	Services are accessible and coordinated for each child and their families?
30	Collaboration between community-based organizations and agencies, providers, health care systems, and families is promoted?	Community-based organizations and agencies, providers, health care systems, and families are encouraged to work together?

31	Responsibilities across the various providers, and community-based agencies serving children and their families are specified?	Responsibilities are specified between the various providers and community-based agencies serving children and their families?
<b><u>Table 9</u></b>		
<b>*#</b>	<b>Provider question text</b>	<b>Consumer question text</b>
32	Families and caregivers of the child or youth are screened for respite care needs?	Providers do screening with families and caregivers to determine whether they need respite care?
33	A system is in place for ensuring timely referrals for families of children and youth with special needs that have emergency respite needs?	A system is in place to make sure timely referrals to respite providers are made for families that have emergency respite needs?

## About the Community Engagement Institute

**Wichita State University’s Community Engagement Institute** is dedicated to improving the health of Kansans through leadership development, research and evaluation, organizational capacity building, community collaboration, and public health and behavioral health initiatives. The Community Engagement Institute maintains six Centers with skilled staff that work directly with community coalitions, nonprofits, government entities, health and human services organizations, and support groups. The Centers are:

- Center for Applied Research and Evaluation
- Center for Behavioral Health Initiatives
- Center for Leadership Development
- Center for Organizational Development and Collaboration
- Center for Public Health Initiatives
- IMPACT Center

*Want to know more about this report? Contact Tara Gregory, Ph.D., Director of the Center for Applied Research and Evaluation, at [tara.gregory@wichita.edu](mailto:tara.gregory@wichita.edu)*



WICHITA STATE  
UNIVERSITY

COMMUNITY ENGAGEMENT  
INSTITUTE

*Center for Applied Research and Evaluation*

*Strengthening Organizations, Strengthening Communities*

## **Kansas Special Health Care Needs Program**

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### **Kansas Systems Integration Grant Consumer and Provider Standards Survey Report**

**October 2016**

Evaluation Conducted by the Center for Applied Research and Evaluation

Tara Gregory, PhD and Jung Sim Jun, MSW



# 2016 Consumer and Provider Standards Survey Report

## Eligibility/Enrollment and Access to Care

### Key Findings

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The sections below include findings from the 2<sup>nd</sup> Standards of Care for Children and Youth with Special Health Care Needs (CYSHCN) survey, which was administered and analyzed by Wichita State University's Center for Applied Research and Evaluation (CARE). The following is a brief overview of the findings:

#### Overall

- A total of 79 participants (41 providers/38 consumers) at least partially completed the surveys.
- Most of the respondents reside and provide or receive services in Northeast and South Central regions.
- In general, consumers/caregivers tended to provide slightly more positive responses than providers except regarding Access to Care (timeliness) and Transportation Assistance.

#### Eligibility & Enrollment

- **Overall** - The average responses on a 4 point Likert scale (1= "not at all" to 4= "large extent") in terms of meeting Eligibility and Enrollment standards showed that the majority of participants, both providers and caregivers, either chose "small extent" or "moderate extent". The overall mean responses ranged from 2.24 to 2.84 with consumers typically rating statements slightly more positively than providers.
- Categories including Written Policies & Procedures and Comprehensive Member Service Programs showed more varied responses from consumers. A large portion of consumers chose from "not at all" to "moderate extent".

#### Access to Care

- **Overall** –The average responses in meeting Access to Care standards showed that the majority of both providers and consumers either selected "small extent" or "moderate extent". The overall mean responses ranged from 2.15 to 2.93.
- In general, consumers rated Access to Care slightly more positively than providers except the Access to Services (timeliness) and Transportation Assistance categories.

### Provider Only Questions

- **Pediatric Specialist as a Primary Care Provider (PCP)** – 52% of providers chose a “small extent” regarding to what extent pediatric specialists are able to serve as a PCP.
- **Accessibility by Patients/Families** – At least 67% of providers indicated a “small extent” of agreement that written policies and procedures are in place that are accessible by patients/families.
- **Access to Pediatric Specialists** – At least 58% of providers selected a “small extent” in providing access to pediatric specialists (including face-to-face or telemedicine).

### Consumer Only Questions

- **Appropriate Waiting Time** – The majority of consumers believed that the appropriate amount of time to wait for behavioral/mental health, pediatric primary care, children’s hospitals, urgent care, and lab, x-ray and other diagnostic services is less than one week (less than one day to six days).
- The following percentage of consumers indicated that they should wait “one day or less” for the following services: urgent care (83%), hospitals (38%), diagnostic testing services (48%).
- **Transportation Assistance** – 41% of consumers selected “not at all” regarding how well the system does at asking families if they need transportation assistance to access needed services.

The tables below present the overall average response rates for Eligibility and Enrollment as well as Access to Care (see legend for color coding).

Table A. Overall Eligibility & Enrollment

Category	Audience	Average Response
Outreach Activities	Providers	Small Extent
	Consumers	Small Extent
Continuity of Care	Providers	Small Extent
	Consumers	Moderate Extent
Written Policies & Procedures	Providers	Small Extent
	Consumers	Moderate Extent
Comprehensive member services	Providers	Small Extent
	Consumers	Small Extent
Insurance Information	Providers	Small Extent
	Consumers	Moderate Extent

Table B. Overall Access to Care

Category	Audience	Average Response
Access to Services (Geographically)	Providers	Small Extent
	Consumers	Moderate Extent
Access to Services (Timely)	Providers	Moderate Extent
	Consumers	Small Extent
Freedom of Choice	Providers	Small Extent
	Consumers	Moderate Extent
Written Policies and Procedures	Providers	Moderate Extent
	Consumers	Moderate Extent
Transportation Assistance	Providers	Small Extent
	Consumers	Small Extent

Legend:

Not at All
Small Extent
Moderate Extent
Large Extent

## Summary of Survey Results

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The purpose of the on-line survey was to gain input from service consumers (people who receive services or caregivers/parents/guardians) and service providers about how well the current system is meeting the standards of care for CYSHCN. This report provides a snapshot of Kansas participants' perceptions focusing on the core domains for system standards including a) Eligibility and Enrollment and b) Access to Care. The survey invitation was sent out by KDHE on August 25th and the survey was closed on October 24th, 2016. A total of 41 providers and 38 consumers at least partially completed the surveys. In order to increase participants' understanding, most of the questions for consumers/family/caregivers were reworded. Please see Appendix A for specific question comparison between providers and consumers. For this report, questions for providers are mostly presented with corresponding consumers' response rates noted with asterisks (\*). In a limited number of instances, a question was asked of only one group. The tables below indicate where a group didn't receive the question with “-”. For each question, the response with the largest percentage is highlighted for both providers (blue) and consumers (orange).

**Region (Figure 1 & 2) –** The largest number of providers live and provide services in the Northeast and South Central regions. The same is true for consumers.

Figure 1. Regions to Live in

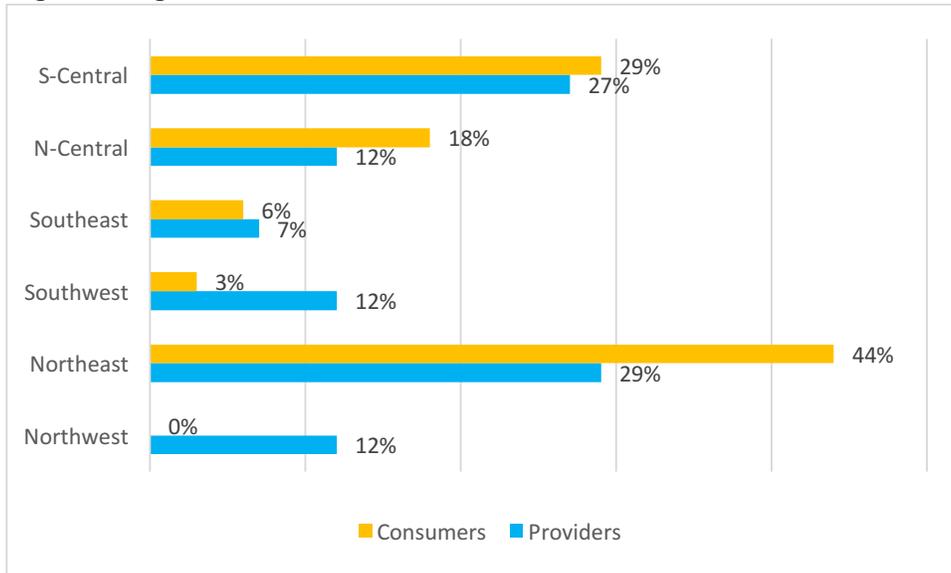
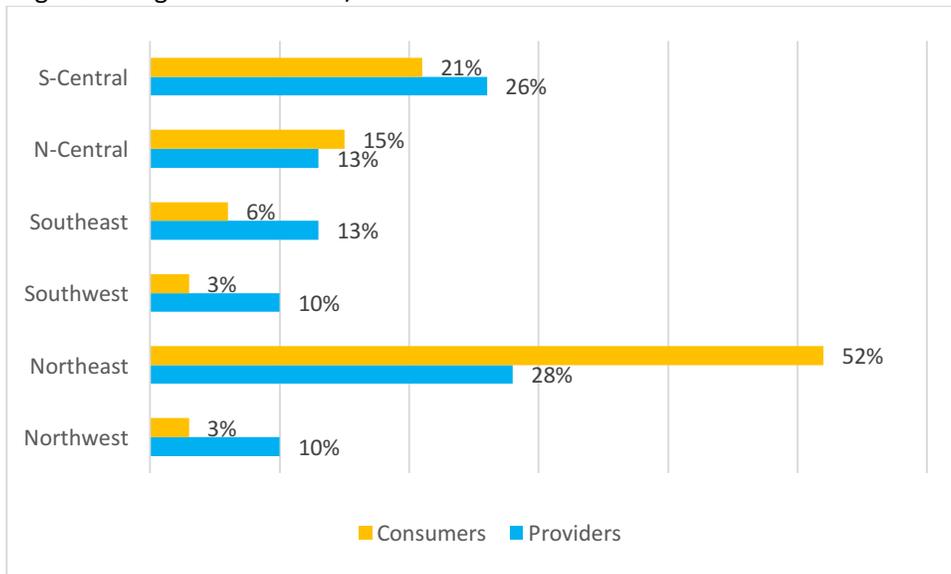


Figure 2. Regions to Provide/Receive Services



## Eligibility & Enrollment

**Outreach Activities (Table 1)** – The average response for all questions in this category was “small extent” or “moderate extent.”

<b>Table 1.</b> Regarding outreach activities to enroll children and youth into public and private insurance coverage*:							
Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
1.1 To what extent are strategies designed to effectively reach CYSHCN and their families?	Provider	7%	37%	50%	6%	2.57	30
	Consumer*	23%	17%	47%	13%	2.5	30
1.2 To what extent are outreach activities proven to be effective in reaching CYSHCN and their families?	Provider	7%	60%	27%	6%	2.33	30
	Consumer*	20%	27%	37%	16%	2.5	30
1.3 To what extent are the outreach activities coordinated with relevant family organizations at the state and community level?	Provider	23%	37%	33%	7%	2.23	30
	Consumer*	23%	37%	27%	13%	2.3	30

**Continuity of Care (Table 2)** – The majority of providers and the largest portion of consumers agreed that the continuity of care was ensured to a “small extent” during the enrollment and transition period.

<b>Table 2.</b> To what extent is continuity of care ensured during periods of enrollment and transition (e.g. changes in or temporary loss of public and private insurance coverage)? *						
Respondents	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
Provider	10%	59%	28%	3%	2.24	29
Consumer*	13%	34%	33%	20%	2.73	30

**Written Policies & Procedures (Table 3)** – The average response for all questions in this category was “small extent”. Providers most often responded “small extent” while consumers varied from “not at all” to “moderate extent”.

<b>Table 3.</b> To what extent are written policies and procedures in place for the following*:							
Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
3.1 Transitioning CYSHCN between non-network and network providers?	Provider	13%	46%	38%	3%	2.33	24
	Consumer*	8%	38%	42%	12%	2.58	26
3.2 Communication with the medical home and family to ensure continuity of care?	Provider	17%	42%	33%	8%	2.33	24
	Consumer*	23%	23%	35%	19%	2.5	26
3.3 Allowing new enrollees (or who have recently changed health plans) to continue seeing out-of-network providers up to 6 months after enrollment?	Provider	21%	46%	29%	4%	2.17	24
	Consumer	-	-	-	-	-	-

**Comprehensive Member Service Programs (Table 4)** – Most of the providers indicated that the current system provided comprehensive services to a “small extent” while consumers varied from “not at all” to a “moderate extent.” For questions 4.5 through 4.9 (below), answers from consumers tended to skew more negatively than providers.

**Table 4.**  
To what extent are comprehensive member service programs available to provide services such as the following\*:  
(NOTE: Comprehensive member service programs should have specialized staff and connections to relevant family organizations at the state and local level.)

Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
4.1 Family resource needs	Provider	10%	48%	38%	4%	2.38	21
	Consumer*	22%	22%	30%	26%	2.59	27
4.2 Insurance coverage options	Provider	10%	38%	38%	14%	2.57	21
	Consumer*	27%	27%	31%	15%	2.35	26
4.3 Eligibility and enrollment questions	Provider	5%	43%	38%	14%	2.62	21
	Consumer*	26%	7%	41%	26%	2.67	27
4.4 Covered and non-covered services	Provider	4%	48%	38%	10%	2.52	21
	Consumer*	15%	41%	22%	22%	2.52	27
4.5 Navigating the medical and community system of care available for CYSHCN	Provider	19%	52%	24%	5%	2.14	21
	Consumer*	30%	26%	26%	18%	2.33	27
4.6 Enrollee status	Provider	14%	38%	33%	15%	2.48	21
	Consumer	-	-	-	-	-	-
4.7 Complaints and grievances	Provider	10%	61%	29%	0%	2.19	21
	Consumer*	31%	23%	31%	15%	2.31	26
4.8 Selection of a primary care provider	Provider	10%	48%	29%	13%	2.48	21
	Consumer*	30%	30%	26%	14%	2.26	27
4.9 Selection of medical home with experience in serving CYSHCN	Provider	14%	43%	33%	10%	2.38	21
	Consumer*	30%	26%	26%	18%	2.33	27

**Written & Oral Insurance Information (Table 5)** – Answers from providers tended more toward the negative (“small extent”) versus those of consumers (“moderate extent”).

<b>Table 5.</b> To what extent is written and oral information regarding insurance eligibility and enrolling a child/youth into public or private insurance coverage*:							
Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
5.1 Culturally appropriate for CYSHCN and their families?	Provider	10%	48%	32%	10%	2.43	21
	Consumer*	10%	19%	39%	32%	2.94	31
5.2 Provided in a manner and format appropriate for the population including for those families who have limited English proficiency or sensory impairments?	Provider	10%	52%	28%	10%	2.38	21
	Consumer*	7%	32%	42%	19%	2.74	31

**Overall Eligibility & Enrollment (Figure 3)** – Participants’ mean responses for each category listed above were averaged and are presented below. Overall, consumers rated each category slightly more positively than providers.

Figure 3. Overall Mean Responses for Eligibility & Enrollment



## Access to Care

**Access to Services in a Geographic Area (Table 6)** – The average responses for providers in this category were “small extent” to “moderate extent.” Consumers mostly chose “moderate extent.”

<b>Table 6.</b> To what extent does the system have the capacity to ensure CYSHCN access to appropriate primary and specialty services, in their geographic area, including*:							
Questions	Respondents	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
6.1 In-network providers	Provider	5%	38%	48%	10%	2.62	21
	Consumer*	29%	21%	38%	12%	2.33	24
6.2 Referrals to out-of-network physical, mental, and dental care providers	Provider	5%	57%	29%	10%	2.43	21
	Consumer*	17%	29%	42%	12%	2.5	24
6.3 Pediatric primary care	Provider	10%	29%	48%	14%	2.67	21
	Consumer*	17%	13%	50%	20%	2.75	24
6.4 Pediatric specialists	Provider	14%	43%	38%	5%	2.33	21
	Consumer*	35%	4%	52%	9%	2.35	24
6.5 Children’s hospitals	Provider	14%	38%	38%	10%	2.43	21
	Consumer*	13%	29%	42%	16%	2.63	24
6.6 Pediatric regional centers	Provider	10%	38%	48%	5%	2.48	21
	Consumer	-	-	-	-	-	-
6.7 Ancillary providers	Provider	5%	48%	48%	0%	2.43	21
	Consumer**	22%	20%	39%	19%	2.56	24
6.8 Physical, speech, or occupational therapy	Provider	-	-	-	-	-	-
	Consumer	21%	25%	42%	12%	2.46	24
6.9 Urgent care services	Provider	-	-	-	-	-	-
	Consumer	21%	17%	38%	24%	2.67	24
6.10 Laboratory, x-ray, or other places where diagnostic testing occurs	Provider	-	-	-	-	-	-
	Consumer	25%	17%	38%	20%	2.54	24

**Note:** Question 6.7 Consumer\*\* percentage was calculated by averaging 6.8, 6.9, and 6.10 response rates.

**Appropriate Waiting Time (Table 7)** – Questions 7.1 through 7.8 were only asked of consumers. Respondents perceived that “less than 1 week (2-6 days)” would be the most appropriate amount of waiting time; however, in terms of urgent care, children’s hospital, and diagnostic testing, the majority of respondents chose “one day or less.”

<b>Table 7. Consumer Only</b>							
In your opinion, what is an appropriate amount of time to have to wait to be able to receive these services? Please rate each one:							
Questions	One day or less (1)	Less than 1 week: 2-6 days (2)	1 to 2 weeks: 7-13 days (3)	2 to 3 weeks: 14-20 days (4)	At least one month: 21 days + (5)	Mean	Total #
7.1 Behavioral/mental health care providers	0%	55%	18%	14%	13%	2.86	22
7.2 Dental care providers	5%	36%	32%	14%	13%	2.95	22
7.3 Pediatric primary care (in your insurance network)	26%	39%	22%	4%	9%	2.3	23
7.4 Pediatric specialists (in your insurance network)	14%	27%	14%	23%	22%	3.14	22
7.5 Children’s hospitals	38%	19%	14%	5%	24%	2.57	21
7.6 Physical, speech, or occupational therapy	0%	41%	32%	23%	4%	2.91	22
7.7 Urgent care services	86%	5%	19%	0%	0%	1.24	21
7.8 Laboratory, x-ray, or other places where diagnostic testing occurs	48%	39%	9%	4%	0%	1.7	23

**Access to Services in a Timely Manner (Table 8)** – Except for the first two questions, providers and consumers showed a similar pattern of responses. Most selected “moderate extent” except regarding pediatric specialist and children’s hospitals, for which answers skewed toward “small extent.”

**Table 8.**  
To what extent does the system have the capacity to ensure CYSHCN access to appropriate primary and specialty services, in a timely manner, including\*:

Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
8.1 In-network providers	Provider	0%	52%	43%	5%	2.52	21
	Consumer*	37%	16%	37%	10%	2.21	19
8.2 Referrals to out-of-network physical, mental, and dental care providers	Provider	5%	52%	38%	5%	2.43	21
	Consumer*	21%	16%	47%	16%	2.58	19
8.3 Pediatric primary care	Provider	5%	33%	48%	14%	2.71	21
	Consumer*	16%	26%	42%	16%	2.58	19
8.4 Pediatric specialists	Provider	5%	62%	28%	5%	2.33	21
	Consumer*	21%	42%	32%	5%	2.21	19
8.5 Children’s hospitals	Provider	0%	48%	47%	5%	2.57	21
	Consumer*	17%	39%	39%	5%	2.33	18
8.6 Pediatric regional centers	Provider	0%	52%	48%	0%	2.48	21
	Consumer	-	-	-	-	-	-
8.7 Ancillary providers	Provider	5%	43%	52%	0%	2.48	21
	Consumer**	19%	18%	44%	18%	2.63	19
8.8 Physical, speech, or occupational therapy	Provider	-	-	-	-	-	-
	Consumer	21%	21%	42%	16%	2.53	19
8.9 Urgent care services	Provider	-	-	-	-	-	-
	Consumer	17%	22%	39%	22%	2.67	18
8.10 Laboratory, x-ray, or other places where diagnostic testing occurs	Provider	-	-	-	-	-	-
	Consumer	20%	10%	50%	20%	2.7	20

**Note:** Question 8.7 Consumer\*\* percentage was calculated by averaging 8.8, 8.9, and 8.10 response rates.

**Pediatric Specialist as a PCP (Table 9. Providers Only)** – A slight majority (52%) of providers indicated that pediatric specialists are able to serve as a primary care provider (PCP) to a “small extent.”

<b>Table 9. Provider Only</b>							
To what extent are pediatric specialists able to serve as a primary care provider?							
(NOTE: The pediatric specialist should have a demonstrated clinical relationship as the clinical coordinator of care for a CYSHCN.)							
Questions	Provider	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
9.1	Provider	10%	52%	24%	14%	2.43	21

**Freedom of Choice (Table 10)** – The majority of consumers indicated freedom of choice in choosing or changing a PCP to a “moderate extent” while providers varied from a “small extent” to a “moderate extent.”

<b>Table 10.</b>							
To what extent is freedom of choice preserved regarding*:							
Questions	Respondents	Not at all (1)	Small extent (2)	Mode -rate extent (3)	Large extent (4)	Mean	Total #
10.1 How patients choose a primary care provider (PCP)?	Provider	10%	35%	45%	10%	2.55	20
	Consumer*	14%	9%	50%	27%	2.91	22
10.2 How patients may change their PCP, if automatically enrolled by their health plan?	Provider	15%	40%	35%	10%	2.4	20
	Consumer*	9%	14%	50%	27%	2.95	22

**Written Policies & Procedures (Table 11)** – Providers and consumers tended to agree that written policies and procedures are in place to a “moderate extent” regarding choosing a PCP and to a “small extent” for changing a PCP.

<b>Table 11.</b> To what extent are written policies and procedures in place regarding*:							
Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
11.1 How patients choose a primary care provider (PCP)?	Provider	11%	32%	47%	10%	2.58	19
	Consumer*	9%	32%	41%	18%	2.68	22
11.2 How patients may change their PCP, if automatically enrolled by their health plan?	Provider	11%	47%	26%	16%	2.47	19
	Consumer*	14%	36%	32%	18%	2.55	22

**Accessibility by Patients/Families (Table 12. Providers Only)** – At least 67% of providers tended to agree that written policies and procedures are in place and accessible by families to a “small extent.”

<b>Table 12. Provider Only</b> To what extent are written policies and procedures in place, and accessible by patients and/or their families, regarding:							
Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
12.1 How patients choose a primary care provider (PCP)?	Provider	11%	67%	17%	5%	2.17	18
12.2 How patients may change their PCP, if automatically enrolled by their health plan?	Provider	11%	72%	11%	6%	2.11	18

**Access to Pediatric Specialists (Table 13. Provider Only)** – At least 58% of providers tended to agree that the access to pediatric specialists provided to a “small extent.”

<b>Table 13. Provider Only</b>							
To what extent is access to pediatric specialists provided, including face-to-face or via telemedicine (as specified in a child’s/youth’s plan of care), in the following instances:							
Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
13.1 Without prior authorization from a child’s primary care provider (PCP) or contractor (e.g., health plan)	Provider	16%	58%	26%	0%	2.11	19
13.2 Whether or not such pediatric specialists participate in a PCP or contractor’s provider network	Provider	11%	63%	26%	0%	2.16	19

**Transportation Assistance (Table 14. Consumer Only)** – The largest portion of consumers selected “not at all” regarding how well the system does at asking families if they need transportation.

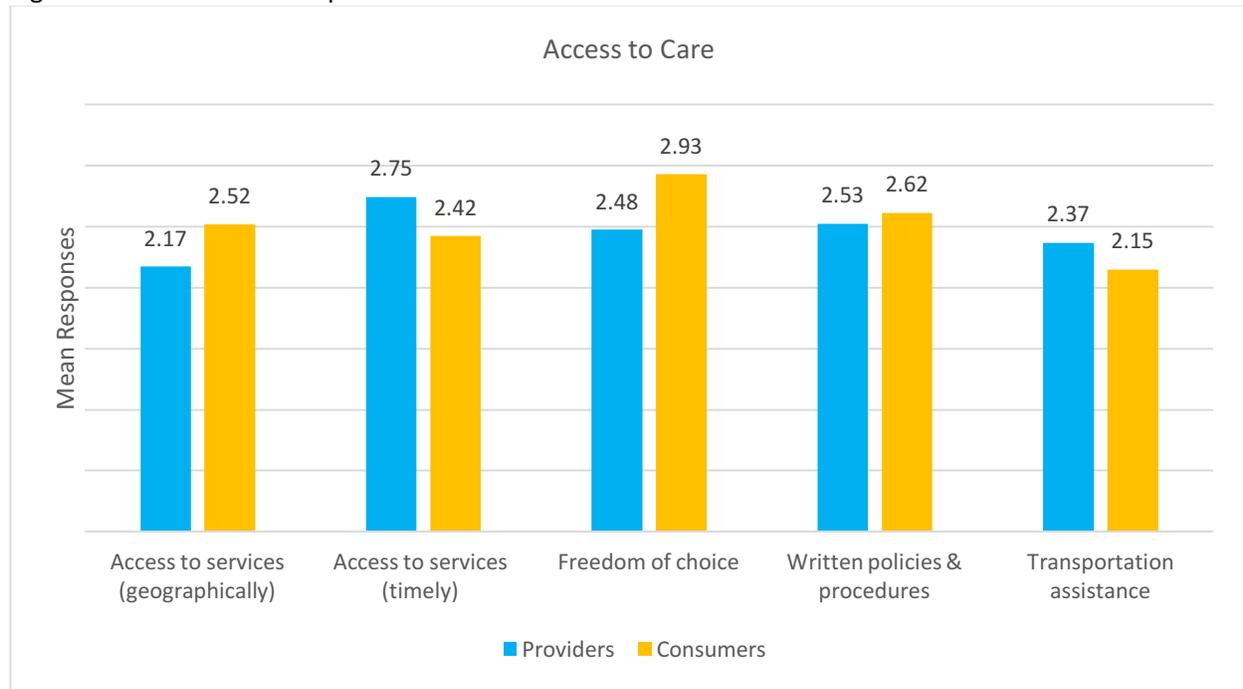
<b>Table 14. Consumer Only</b>						
How well does the system do at asking families if they need transportation assistance to access needed medical services?						
Respondents	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
Consumer	41%	32%	9%	18%	2.09	22

**Transportation Assistance (Table 15)** – The largest portion of providers selected “small extent” and consumers chose “not at all” regarding what extent the system provides transportation assistance when families have difficulties accessing needed services.

<b>Table 15.</b> To what extent is transportation assistance provided to families that have difficulties accessing needed medical services*:						
Respondents	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
Provider	11%	58%	16%	15%	2.37	19
Consumer*	35%	30%	20%	15%	2.15	20

**Overall Access to Care (Figure 4)** - Participants’ (both providers and consumers) mean responses for the Access to Care standards were averaged and are presented below. Overall, consumers rated the categories slightly more positively than providers except related to Access to Services in a Timely Manner and Transportation Assistance.

Figure 4. Overall Mean Responses for Access to Care



## Appendix A: Survey questions reworded/reorganized for consumers

Q#	Provider	Q#	Consumer
4	<p>Regarding outreach activities to enroll children and youth into public and private insurance coverage:</p> <ol style="list-style-type: none"> <li>2 To what extent are strategies designed to effectively reach CYSHCN and their families?</li> <li>3 To what extent are outreach activities proven to be effective in reaching CYSHCN and their families?</li> <li>4 To what extent are the outreach activities coordinated with relevant family organizations at the state and community level?</li> </ol>	5	<p>When you think about what the system does to <u>enroll</u> children into public and private insurance coverage:</p> <ol style="list-style-type: none"> <li>1) How well does the system do at reaching CYSHCN and their families?</li> <li>2) How often do these efforts result in CYSHCN and their families getting enrolled?</li> <li>3) How involved are the organizations that provide services to you?</li> </ol>
5	<p>To what extent is <u>continuity of care</u> ensured during periods of enrollment and transition (e.g. changes in or temporary loss of public and private insurance coverage)?</p>	6	<p>How well does the system do at making sure your care isn't interrupted even during periods of enrollment and transition (e.g. changes in or temporary loss of public and private insurance coverage)?</p>
6	<p>To what extent are <u>written policies and procedures</u> in place for the following:</p> <ol style="list-style-type: none"> <li>1) Transitioning CYSHCN between non-network and network providers?</li> <li>2) Communication with the medical home and family to ensure continuity of care?</li> <li>3) Allowing new enrollees (or who have recently changed health plans) to continue seeing out-of-network providers up to 6 months after enrollment?</li> </ol>	7	<p>Please tell us how well the system is doing at making sure <u>written policies and procedures</u> are in place for...:</p> <ol style="list-style-type: none"> <li>1) Helping families of CYSHCN understand the differences if using non-network versus network providers?</li> <li>2) Making sure there's communication with the medical team and families so that care isn't interrupted?</li> </ol>

7	<p>To what extent are <u>comprehensive member service programs</u> available to provide services such as the following: (NOTE: Comprehensive member service programs should have specialized staff and connections to relevant family organizations at the state and local level.)</p> <ul style="list-style-type: none"> <li>• Family resource needs</li> <li>• Insurance coverage options</li> <li>• Eligibility and enrollment questions</li> <li>• Covered and non-covered services</li> <li>• Navigating the medical and community system of care available for CYSHCN</li> <li>• Enrollee status</li> <li>• Complaints and grievances</li> <li>• Selection of a primary care provider</li> <li>• Selection of medical home with experience in serving CYSHCN</li> </ul>	8	<p>To what extent does the system have someone available in your community who can help you with:</p> <ul style="list-style-type: none"> <li>• Finding family resource</li> <li>• Explaining insurance coverage options</li> <li>• Answering eligibility and enrollment questions</li> <li>• Explaining the differences in covered and non-covered services</li> <li>• Assisting to navigate the medical and community system of care available for CYSHCN</li> <li>• Filing complaints, grievances, or concerns</li> <li>• Guiding selection of a primary care provider</li> <li>• Guiding families of CYSHCN in selecting a medical home, or primary care provider, who has experience serving CYSHCN</li> </ul>
8	<p>To what extent is written and oral information regarding insurance eligibility and enrolling a child/youth into public or private insurance coverage:</p> <ol style="list-style-type: none"> <li>1) Culturally appropriate for CYSHCN and their families?</li> <li>2) Provided in a manner and format appropriate for the population including for those families who have limited English proficiency or sensory impairments?</li> </ol>	4	<p>How well does the system do at making sure the information you receive regarding insurance eligibility is...:</p> <ol style="list-style-type: none"> <li>1) Respectful of your individual beliefs, values, and culture?</li> <li>2) Provided in a way that is easy to understand, including for those who have limited English skills or vision/hearing difficulties?</li> </ol>

9	<p>To what extent does the system have the capacity to ensure CYSHCN <u>access</u> to appropriate primary and specialty services, in their geographic area, including:</p> <ul style="list-style-type: none"> <li>• In-network providers</li> <li>• Referrals to out-of-network physical, mental, and dental care providers</li> <li>• Pediatric primary care</li> <li>• Pediatric specialists</li> <li>• Children’s hospitals</li> <li>• Pediatric regional centers</li> <li>• Ancillary providers</li> </ul>	9	<p>How well does the system do at making sure the services listed below are fairly easy for children with special health care needs and their families to get to (e.g., not too far away)? Please rate each one:</p> <ul style="list-style-type: none"> <li>• Behavioral/mental health care providers</li> <li>• Dental care providers</li> <li>• Pediatric primary care (in your insurance network)</li> <li>• Pediatric specialists (in your insurance network)</li> <li>• Children’s hospitals</li> <li>• Physical, speech, or occupational therapy</li> <li>• Urgent care services</li> <li>• Laboratory, x-ray, or other places where diagnostic testing occurs</li> </ul>
	<p>No question</p>	10	<p>In your opinion, what is an appropriate amount of time to have to wait to be able to receive these services? Please rate each one:</p> <ul style="list-style-type: none"> <li>• Behavioral/mental health care providers</li> <li>• Dental care providers</li> <li>• Pediatric primary care (in your insurance network)</li> <li>• Pediatric specialists (in your insurance network)</li> <li>• Children’s hospitals</li> <li>• Physical, speech, or occupational therapy</li> <li>• Urgent care services</li> <li>• Laboratory, x-ray, or other places where diagnostic testing occurs</li> </ul>

10	<p>To what extent does the system have the capacity to ensure CYSHCN <u>access</u> to appropriate primary and specialty services, in a timely manner, including:</p> <ul style="list-style-type: none"> <li>• In-network providers</li> <li>• Referrals to out-of-network physical, mental, and dental care providers</li> <li>• Pediatric primary care</li> <li>• Pediatric specialists</li> <li>• Children’s hospitals</li> <li>• Pediatric regional centers</li> <li>• Ancillary providers</li> </ul>	11	<p>Based on your responses to the previous question, how well does the system do at making sure children with special health care needs and their families have <u>timely access</u> to the following services? Please rate each one:</p> <ul style="list-style-type: none"> <li>• Behavioral/mental health care providers</li> <li>• Dental care providers</li> <li>• Pediatric primary care (in your insurance network)</li> <li>• Pediatric specialists (in your insurance network)</li> <li>• Children’s hospitals</li> <li>• Physical, speech, or occupational therapy</li> <li>• Urgent care services</li> <li>• Laboratory, x-ray, or other places where diagnostic testing occurs</li> </ul>
11	<p>To what extent are pediatric specialists able to serve as a primary care provider? (NOTE: The pediatric specialist should have a demonstrated clinical relationship as the clinical coordinator of care for a CYSHCN.)</p>		<p>No question</p>
12	<p>To what extent is <u>freedom of choice</u> preserved regarding:</p> <ul style="list-style-type: none"> <li>• How patients choose a primary care provider (PCP)?</li> <li>• How patients may change their PCP, if automatically enrolled by their health plan?</li> </ul>	12	<p>How well does the system do at making sure families with children with special health care needs can <u>make their own choices</u> about the following? Please rate each one:</p> <ul style="list-style-type: none"> <li>• Choosing a primary care provider (PCP)?</li> <li>• Changing their PCP?</li> </ul>
13	<p>To what extent are <u>written policies and procedures</u> in place regarding:</p> <ul style="list-style-type: none"> <li>• How patients choose a primary care provider (PCP)?</li> </ul>	13	<p><u>How well does the system do at making sure</u> written policies and procedures are in place for the following? Please rate each one:</p>

	<ul style="list-style-type: none"> <li>How patients may change their PCP, if automatically enrolled by their health plan?</li> </ul>		<ul style="list-style-type: none"> <li>Choosing a primary care provider (PCP)?</li> <li>Changing your PCP?</li> </ul>
14	<p>To what extent are <u>written policies and procedures</u> in place, and accessible by patients and/or their families, regarding:</p> <ul style="list-style-type: none"> <li>How patients choose a primary care provider (PCP)?</li> <li>How patients may change their PCP, if automatically enrolled by their health plan?</li> </ul>		No question
15	<p>To what extent is <u>access to pediatric specialists</u> provided, including face-to-face or via telemedicine (as specified in a child's/youth's plan of care), in the following instances?</p> <ol style="list-style-type: none"> <li>Without prior authorization from a child's primary care provider (PCP) or contractor (e.g., health plan)</li> <li>Whether or not such pediatric specialists participate in a PCP or contractor's provider network</li> </ol>		No question
	No question	14	How well does the system do at asking families if they need <u>transportation assistance</u> to access needed medical services?
16	To what extent is <u>transportation assistance</u> provided to families that have difficulties accessing needed medical services	15	How well does the system do at helping families find and get <u>transportation assistance</u> when it is difficult to access needed services?

## About the Community Engagement Institute

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**Wichita State University's Community Engagement Institute** is dedicated to improving the health of Kansans through leadership development, research and evaluation, organizational capacity building, community collaboration, and public health and behavioral health initiatives. The Community Engagement Institute maintains six Centers with skilled staff that work directly with community coalitions, nonprofits, government entities, health and human services organizations, and support groups. The Centers are:

- Center for Applied Research and Evaluation
- Center for Behavioral Health Initiatives
- Center for Leadership Development
- Center for Organizational Development and Collaboration
- Center for Public Health Initiatives
- IMPACT Center

*Want to know more about this report? Contact Tara Gregory, Ph.D., Director of the Center for Applied Research and Evaluation, at [tara.gregory@wichita.edu](mailto:tara.gregory@wichita.edu)*



WICHITA STATE  
UNIVERSITY

COMMUNITY ENGAGEMENT  
INSTITUTE

*Center for Applied Research and Evaluation*

*Strengthening Organizations, Strengthening Communities*

## **Kansas Special Health Care Needs Program**

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### **Kansas Systems Integration Grant Consumer and Provider Standards Survey Report**

May 2017

**Evaluation Conducted by the Center for Applied Research and Evaluation**

Tara Gregory, PhD and Jung Sim Jun, MSW



# 2017 Consumer and Provider Standards Survey Report

## Screening/Assessment/Referral and Transition to Adulthood

The sections below include findings from the 3rd Standards of Care for Children and Youth with Special Health Care Needs (CYSHCN) survey, which was administered and analyzed by Wichita State University's Center for Applied Research and Evaluation (CARE).

### Key Findings

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#### Overall

- A total of 79 participants (65 providers/14 consumers) at least partially completed the surveys.
- Most of the respondents reside and provide/receive services in the South Central, Southeast, or North Central regions.
- In general, consumers/caregivers tended to provide slightly more positive responses than providers in the Screening/Assessment/Referral standard questions. However, for the Transition to Adulthood standards, consumers were slightly more negative than providers.

#### Screening/Assessment/Referral

- Results from the survey showed that the majority of participants, both providers and caregivers, believe the system is meeting Screening/Assessment/Referral standards to a "moderate extent".
- The overall mean responses ranged from 2.45 to 2.95 (on a scale of 1 to 4) with consumers typically rating statements slightly more positively than providers except regarding "State Newborn Screening" and "Referring to Needed Services."

#### Transition to Adulthood

- The average responses in meeting Transition to Adulthood standards showed that the majority of both providers and consumers either selected "small extent". The means for questions ranged from 1.67 to 2.61 (on a scale of 1 to 4).
- In general, providers tended to rate statements slightly more positively than consumers.
- The lowest means across all questions were for consumer responses related to processes and practices with adult medical homes.

The tables below represent the overall average responses regarding the extent to which the system is meeting the specific standards for Screening/Assessment/Referral and Transition to Adulthood (see legend below for color coding). Due to the very small participation rate for the consumers, the collected responses might not be representative for the population, and the overall comparison would need to be interpreted with caution.

**Table A. Screening, Assessment, and Referral**

Category	Audience	Average Response
Upon enrollment & transfer	Providers	Moderate Extent
	Consumers	Moderate Extent
Initial assessment	Providers	Moderate Extent
	Consumers	Moderate Extent
State newborn screening	Providers	Moderate Extent
	Consumers	Moderate Extent
Comprehensive screening	Providers	Moderate Extent
	Consumers	Moderate Extent
Further assessment	Providers	Moderate Extent
	Consumers	Moderate Extent
Referring to the needed services	Providers	Moderate Extent
	Consumers	Moderate Extent

**Table B. Transition to Adulthood**

Category	Audience	Average Response
Transitioning from pediatric to adult care	Providers	Moderate Extent
	Consumers	Small Extent
Transition assessment	Providers	Small Extent
	Consumers	Small Extent
Transfer package	Providers	Small Extent
	Consumers	Small Extent
Transition quality improvement	Providers	Small Extent
	Consumers	Small Extent
Policy for the adult medical home approach	Providers	Small Extent
	Consumers	Small Extent
Identifying providers	Providers	Small Extent
	Consumers	Small Extent
Welcoming & orienting	Providers	Small Extent
	Consumers	Small Extent
Confirm the transfer	Providers	Small Extent
	Consumers	Small Extent

**Legend:**

Not at All
Small Extent
Moderate Extent
Large Extent

## Summary of Survey Results

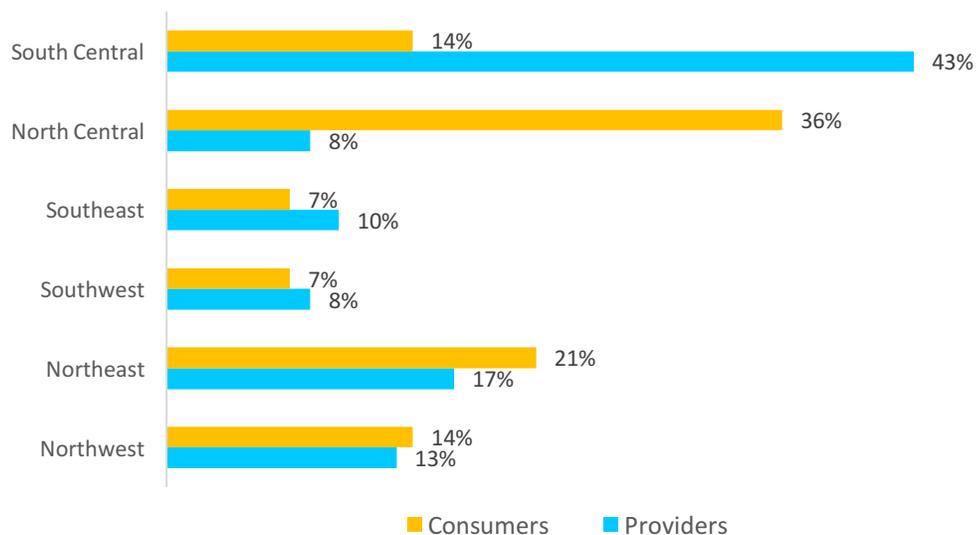
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The purpose of the on-line survey was to gain input from service consumers (people who receive services or caregivers/parents/guardians) and service providers about how well the current system is meeting the standards of care for CYSHCN. This report provides a snapshot of Kansas participants' perceptions focusing on the core domains for system standards including a) Screening, Assessment, and Referral and b) Transition to Adulthood. The survey invitation was sent out by KDHE on March 16<sup>th</sup> and the survey was closed on April 26<sup>th</sup>, 2017. A total of 65 providers and 14 consumers at least partially completed the surveys. However, the participants' actual completion of the survey was very low, and the survey results may not be representative, especially for consumers.

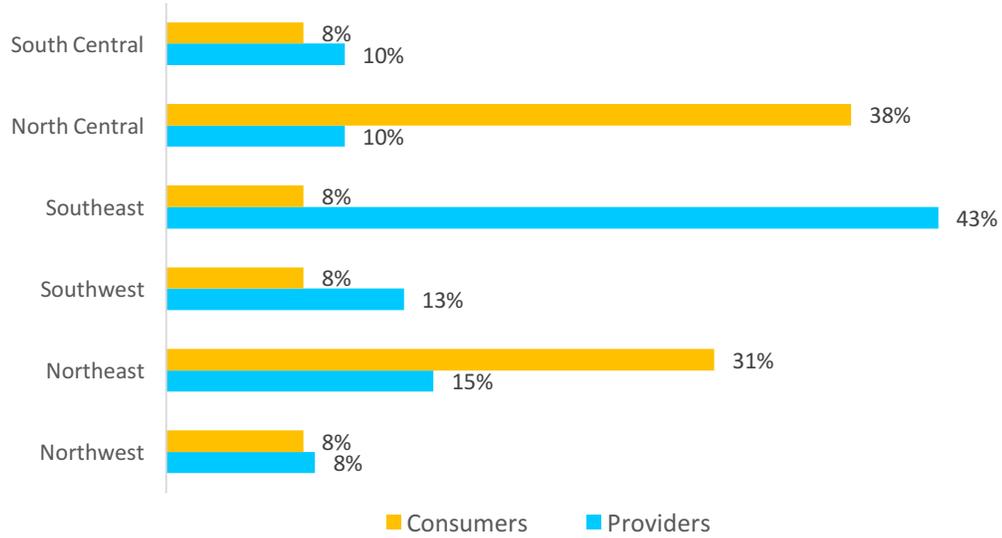
In order to increase participants' understanding, most of the standards were re-worded for the questions for consumers/families/caregivers. Additionally, because some questions had limited applicability depending on the respondents' role (consumer or provider), a few were asked only of a particular group. If a question was not asked of a particular group, a dash (-) was used to denote the absence of data. See Appendix A for specific question comparison between providers and consumers. For each question, the response with the largest percentage is highlighted for both **providers (blue)** and **consumers (orange)**.

**Region (Figure 1 & 2)** – The largest number of providers live in the South Central region while the largest number provide services in the Southeast region. For consumers, the largest percentage live and receive services in the North Central region.

**Figure 1. Live in**



**Figure 2. Provide/Receive Services**



**Screening, Assessment, & Referral**

**Upon Enrollment and Transfer** – The average response for all questions in this category was “moderate extent.” However, responses from providers were more varied across questions than was the case for consumers.

**Table 1**

Upon enrollment and transfer between public and private insurance coverage:							
Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
1.1 To what extent is a consistent plan in place for identifying CYSHCN to ensure referrals to appropriate types and sources of enhanced care?	Provider	7%	32%	41%	20%	2.75	44
	Consumer	-	-	-	-	-	-
1.2 To what extent are the families’ <i>cultural beliefs</i> taken into consideration when referring them to the appropriate services?	Provider	7%	42%	38%	13%	2.58	45
	Consumer	9%	27%	55%	9%	2.64	11
1.3 To what extent are the families’ <i>native languages</i>	Provider	2%	33%	29%	36%	2.98	45

taken into consideration when referring them to the appropriate services?	Consumer	9%	9%	55%	27%	3.00	11
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**Initial Assessment** – The largest portion of providers and the majority of consumers agreed that a documented initial assessment was provided to a “moderate extent” promptly after enrollment in a health plan.

**Table 2**

Promptly after enrollment in a health plan, to what extent are all CYSHCN provided a documented initial assessment that is conducted with input from the child’s family or caregiver?						
Respondents	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
Provider	8%	38%	38%	18%	2.65	40
Consumer	0%	30%	70%	0%	2.70	10

**State Newborn Screening** – The average response for all questions in this category was “moderate extent” for both providers and consumers.

**Table 3**

Regarding the State Newborn Screening:							
Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
3.1 To what extent is the information delivered to providers and parents in a timely fashion?	Provider	7%	18%	43%	32%	3.00	28
	Consumer	20%	10%	70%	0%	2.50	10
3.2 To what extent are arrangements for necessary follow-up services documented?	Provider	4%	30%	37%	30%	2.93	27
	Consumer	20%	20%	60%	0%	2.4	10
3.3 To what extent is the need for repeat screening and follow-	Provider	4%	30%	37%	30%	2.93	27

up communicated to the health plan and providers by the hospital or state program?	Consumer	10%	30%	60%	0%	2.50	10
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**Not Receiving Newborn Screening Results** – The following two questions were asked of only providers.

**Table 4**

Provider Only						
When newborn screening results are not received:						
Questions	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
4.1 To what extent does the child’s health plan have a documented plan and process to follow-up with a hospital or state health department?	19%	41%	33%	7%	2.30	27
4.2 To what extent does the child’s medical home have a documented plan and process to follow-up with a hospital or state health department?	0%	33%	59%	7%	2.74	27

**Comprehensive Screenings** – Answers from providers tended more toward the negative (“small extent”) versus those of consumers (“moderate extent”) regarding the questions about comprehensive and culturally/developmentally appropriate screenings.

**Table 5**

In terms of receiving periodic, developmentally appropriate, and recommended comprehensive screenings:							
Questions	Respondents	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
5.1 To what extent are the screenings listed below done with the CYSHCN patients’	Provider	2%	36%	47%	14%	2.73	25

<i>cultural preferences</i> in mind as part of a well-child or other preventive visit?	Consumer	3%	10%	85%	3%	2.88	8
5.2 To what extent are the screenings listed below conducted using the patients' <i>native languages</i> as part of a well-child or other preventive visit?	Provider	2%	48%	26%	24%	2.73	25
	Consumer	0%	28%	48%	25%	2.98	8
5.3 To what extent are the screenings listed below done with the CYSHCN patients' <i>cultural preferences</i> in mind in response to <u>triggering events</u> (such as hospitalization, trauma, or sudden onset of new symptoms)?	Provider	2%	44%	37%	17%	2.69	23
	Consumer	8%	18%	75%	0%	2.68	8
5.4 To what extent are the screenings listed below done with the CYSHCN patients' <i>native languages</i> in response to <u>triggering events</u> (such as hospitalization, trauma, or sudden onset of new symptoms)?	Provider	2%	48%	30%	21%	2.70	24
	Consumer	0%	21%	66%	13%	2.93	8

**Note:** For questions 5.1 to 5.4, all percentages were calculated by averaging subcategory response rates including five health screenings of physical, oral, mental, developmental, and psychosocial. More specific results by subcategories can be found in Appendix B – Table C.1 through C.5.

**Further Assessment** – On average, providers and consumers indicated that the system meets standards regarding screening efforts, results and further assessment to a “moderate extent.”

**Table 6**

To what extent are screening efforts, results, and referrals for further assessment:
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Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
6.1 Documented?	Provider	4%	23%	46%	27%	2.96	26
	Consumer	0%	0%	83%	17%	3.17	6
6.2 Relayed to the child's medical home?	Provider	4%	44%	40%	12%	2.60	25
	Consumer	13%	50%	38%	0%	2.63	8
6.3 Relayed to the child's family?	Provider	0%	19%	54%	27%	3.08	26
	Consumer	13%	13%	75%	0%	3.38	8
6.4 Coordinated among all screening entities, to the extent feasible, including:	Provider	4%	52%	35%	8%	2.48	24
	Consumer	14%	32%	39%	14%	2.54	7

**Note:** For question 6.4, the percentage was calculated by averaging subcategory response rates including four different care settings of clinical, medical homes, child care, and schools. More specific results by subcategories can be found in Appendix B – Table D.

**Referral to the Needed Services** – Although somewhat varied, average responses on questions in this category were “small extent” or “moderate extent”.

**Table 7**

Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
7.1 Following a screening and assessment, to what extent are the CYSHCN and their family referred to needed services including: Pediatric specialists, Therapies, Early intervention, Special education, Family organizations, Community-based agencies	Provider	2%	26%	39%	33%	3.03	24
	Consumer	5%	37%	46%	13%	2.67	8
7.2 To what extent is follow-up provided for the CYSHCN and their families to ensure such referrals are completed?	Provider	4%	38%	50%	8%	2.63	24
	Consumer	13%	50%	38%	0%	2.25	8
7.3 To what extent do the referral services and systems	Provider	0%	58%	33%	8%	2.50	24

listed above ensure follow-up with the child’s medical home and other members of the child’s care team after visits?	Consumer	14%	43%	29%	14%	2.43	7
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**Note:** For question 7.1, the percentage was calculated by averaging subcategory response rates including six services of pediatric specialists, therapies, early intervention, special education, family organizations, and community-based agencies. More specific results by subcategories can be found in Appendix B – Table E.

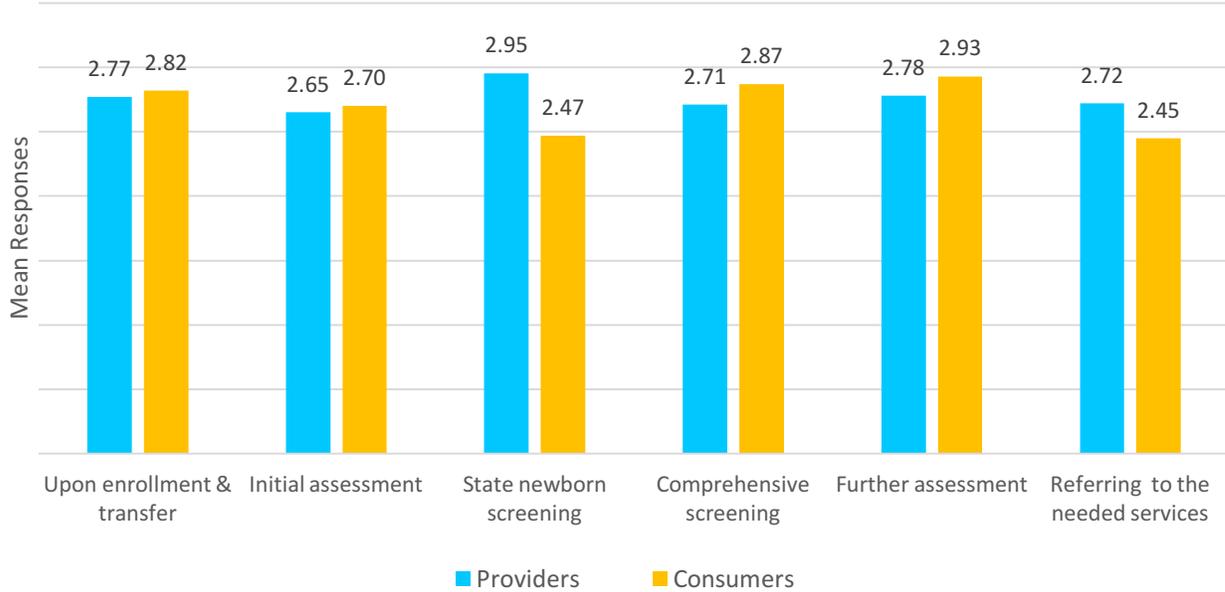
**Protocols for Follow-up** – The largest portion of the providers indicated that the system’s protocols and documentation methods were in place to a “small extent” or “moderate extent.”

**Table 8**

<b>Provider Only</b>						
To what extent are protocols and documentation methods in place for the primary care provider, medical home, or other entity to follow-up with the child and family regarding:						
Questions	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
8.1 Appropriate services and referrals are made based upon the completed assessment findings	0%	33%	58%	8%	2.75	24
8.2 Barriers to care	0%	50%	38%	13%	2.63	24
8.3 Assistance in addressing barriers to obtaining needed follow-up	0%	46%	42%	13%	2.67	24

**Overall Screening, Assessment, & Referral** – Participants’ mean responses for each category listed above were averaged and are presented below. Overall, consumers rated each category slightly more positively than providers except the questions regarding state newborn screening and referral to needed services. However, this needs to be interpreted with caution due to the small number of participants, especially consumers.

**Figure 3. Overall Mean Responses for Screening, Assessment, & Referral**



### Transition to Adulthood

**Transitioning from Pediatric to Adult Care Setting** – The average responses for providers in this category ranged from “small extent” to “moderate extent.” Consumers tended to select “small extent” more often than providers.

**Table 9**

In terms of process for youth with special health care needs (YSHCN) transitioning from pediatric to adult care system:							
Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
9.1 To what extent are policies and processes for transition preparation/planning in place within the health plan for YSHCN and their families?	Provider	8%	48%	40%	4%	2.40	25
	Consumer	20%	40%	40%	0%	2.20	5
9.2 To what extent are policies and processes for transition	Provider	4%	36%	52%	8%	2.64	25

preparation/planning in place within the medical home for YSHCN and their families?	Consumer	20%	40%	40%	0%	2.20	5
9.3 To what extent are YSHCN encouraged to learn about their health care as part of this transition preparation process?	Provider	4%	36%	48%	12%	2.68	25
	Consumer	20%	60%	20%	0%	2.00	5
9.4 To what extent are YSHCN encouraged to engage in their health care as part of this transition preparation process?	Provider	4%	32%	52%	12%	2.72	25
	Consumer	17%	50%	17%	17%	2.33	6

**Individual Flow Sheet** – Questions 10.1 through 10.2 were only asked of providers. Providers were fairly critical of this area with the largest percentage choosing “small extent.”

**Table 10**

<b>Provider Only</b>						
To what extent is an individual flow sheet or registry for identifying transitioning YSHCN maintained by:						
Questions	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
10.1 The health plan to track completion of the transition process?	16%	56%	24%	4%	2.16	25
10.2 The medical home to track completion of the transition process?	8%	64%	24%	4%	2.24	25

**Transition Assessment** – Responses for both providers and consumers tended toward “small extent” except regarding families’ cultural beliefs being respected (moderate extent).

**Table 11**

Questions	Respondents	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
11.1 To what extent are a transition readiness assessment and plan of care (including a	Provider	18%	55%	23%	5%	2.14	22

medical summary and emergency care plan) typically developed when a YSHCN reaches age 14?	Consumer	25%	50%	25%	0%	2.00	4
11.2 To what extent are the above transition assessment and plan of care regularly updated after age 14?	Provider	9%	55%	32%	5%	2.32	22
	Consumer	20%	40%	40%	0%	2.20	5
11.3 To what extent are the transition assessment and plan of care updated in partnership with the YSHCN and his/her family or caregiver?	Provider	9%	43%	39%	9%	2.48	23
	Consumer	17%	50%	33%	0%	2.17	6
11.4 To what extent are a family's cultural beliefs respected in the development of the transition assessment and plan of care?	Provider	9%	35%	43%	13%	2.61	23
	Consumer	17%	17%	67%	0%	2.50	6

**Transfer Package** – The largest portion of providers selected a “moderate extent” while consumers’ answers skewed toward a “small extent.”

**Table 12**

A transfer package includes a final transition readiness assessment, plan of care with transition goals, and medical summary and emergency plan.							
Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
12.1 To what extent is the transfer package prepared with the new adult medical home, prior to the transfer of a YSHCN from a pediatric to an adult medical home?	Provider	29%	29%	33%	10%	2.24	21
	Consumer	20%	60%	20%	0%	2.00	5
12.2 To what extent is the transfer package communicated with the new adult medical	Provider	25%	30%	40%	5%	2.25	20

home, prior to the transfer of a YSHCN from a pediatric to an adult medical home?	Consumer	20%	60%	20%	0%	2.00	5
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**Pediatric Medical Home Consultation** – This question was asked of providers only.

**Table 13**

Provider Only						
Questions	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
To what extent is the pediatric medical home available for consultation assistance with the adult medical home as needed?	14%	29%	43%	14%	2.57	21

**The 3-6 Months Following Transfer** – The following questions were asked of providers only.

**Table 14**

Provider Only						
In the 3-6 months following transfer of a YSHCN to an adult medical home:						
Questions	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
14.1 To what extent is a process in place in the pediatric medical home to confirm transfer?	16%	56%	24%	4%	2.16	25
14.2 To what extent is a process in place in the pediatric medical home to obtain feedback on the YSHCN’s transition experience?	8%	64%	24%	4%	2.24	25

**Transition Quality Improvement** – Only providers were asked question 15.1 regarding collaboration between providers in transition quality improvement. But providers and consumers tended to respond “small extent” regarding co-management between pediatric and adult health care providers for transition quality improvement.

**Table 15**

In terms of a transition quality improvement process:							
Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
15.1 To what extent does the transition quality improvement process include collaboration between pediatric and adult health care providers?	Provider	30%	35%	30%	5%	2.10	20
	Consumer	-	-	-	-	-	-
15.2 To what extent does the transition quality improvement process include co-management between pediatric and adult health care providers?	Provider	26%	42%	26%	5%	2.11	19
	Consumer	25%	50%	25%	0%	2.00	4

**Policy for the Adult Medical Home Approach** – Question 16.1 was asked only of consumers. Providers and consumers tended to select “small extent” for the other questions. It should be noted that the mean consumer response on these questions were among the lowest on this survey (see highlighted means). However, with only three respondents, this should be interpreted with caution.

**Table 16**

Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
16.1 How well does the system do at having rules in place that describe how adult medical homes accept and partner with new YSHCN?	Provider	-	-	-	-	-	-
	Consumer	33%	67%	0%	0%	1.67	3
16.2 To what extent is a policy in place that describes the adult medical home approach to accepting and partnering with new YSHCN, including legal changes at age 18?	Provider	21%	47%	26%	5%	2.16	19
	Consumer*	33%	67%	0%	0%	1.67	3

**Individual Flow Sheet Maintenance** – These questions were only asked of providers.

**Table 17**

<b>Provider Only</b>						
To what extent is an individual flow sheet (or registry) maintained for identifying transitioning YSHCN through 26 years of age:						
Questions	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
17.1 By the health plan to track completion of the transition process?	18%	41%	35%	6%	2.29	17
17.2 By the medical home to track completion of the transition process?	17%	61%	17%	6%	2.11	18

**Identifying Providers** – Although the largest percentages of both providers and consumers selected “small extent” for this question, relatively large numbers responded “not at all” or “moderate extent” regarding how easy it is to find providers.

**Table 18**

To what extent is a process in place for identifying providers who are interested in caring for YSHCN:							
Questions	Respondents	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
How well does the system do at making it easy to find providers who want to care for YSHCN?	Provider	31%	36%	23%	10%	2.13	20
	Consumer	25%	50%	25%	0%	2.00	4

**Note:** Providers’ response rates were combined/averaged (at the adult medical home level and at the health plan level) for the comparison with the consumers’ response.

**Welcoming and Orienting** – The majority of both providers and consumers responded as a “small extent” in terms of welcoming and orienting a new YSCHN. Once again, this question received the lowest mean response for consumers (1.67). As noted, however, the low number of respondents makes accurate interpretation difficult.

**Table 19**

Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
To what extent does a process exist for welcoming and orienting young adults within the adult medical home?	Provider	17%	56%	22%	6%	2.17	18
	Consumer	33%	67%	0%	0%	1.67	3

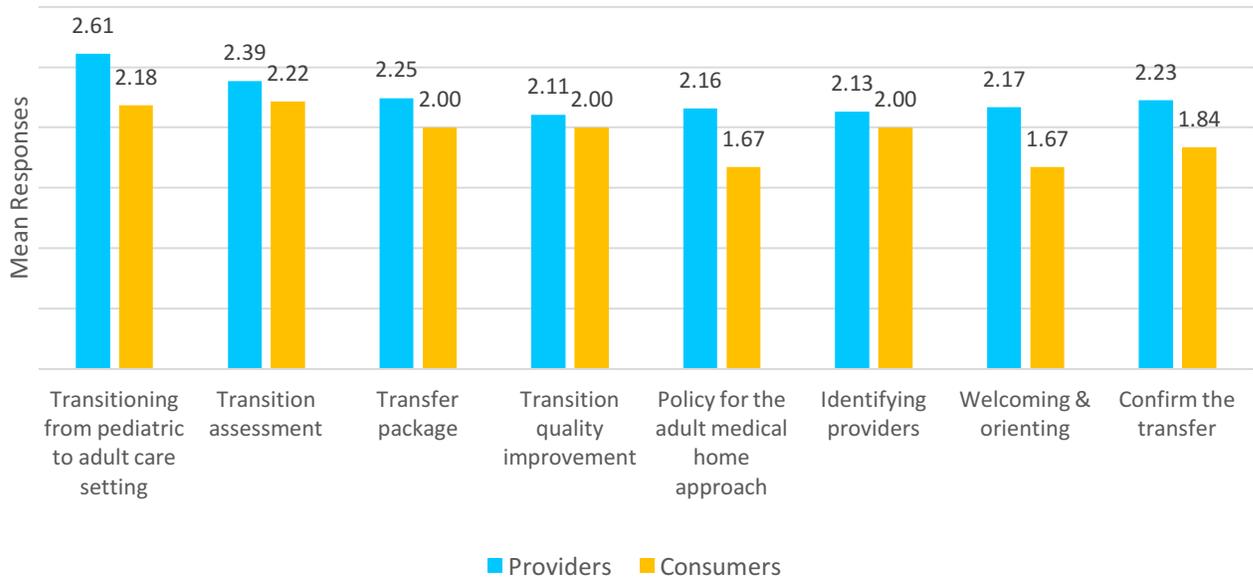
**Confirm the Transfer** – Providers’ average responses tended to be “small extent” while consumers chose more varied responses from “not at all” to “moderate extent”. This section also contains some of the lowest mean responses for consumers (see highlighted numbers below). Again, this result should be viewed with caution given the low number of respondents (3 consumers).

**Table 20**

In terms of a process to confirm the transfer between the pediatric and adult medical home of a YSHCN:							
Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
20.1 Making sure the transfer actually took place?	Provider	-	-	-	-	-	-
	Consumer	33%	67%	0%	0%	1.67	3
20.2 To what extent does this process assist the YSHCN with ongoing care management?	Provider	19%	38%	38%	6%	2.31	16
	Consumer	33%	67%	0%	0%	1.67	3
20.3 To what extent does this process assist the YSHCN with referral to adult specialists and other community supports?	Provider	18%	47%	29%	6%	2.24	17
	Consumer	33%	33%	33%	0%	2.00	3
20.4 To what extent does this process assist in obtaining feedback about the care received by the YSHCN’s during the transfer of care process?	Provider	25%	44%	25%	6%	2.13	16
	Consumer	33%	33%	33%	0%	2.00	3

**Overall Transition to Adulthood (Figure 4)** - Participants' mean responses for Transition to Adulthood standards were averaged and are presented below. Overall, consumers rated the categories less positively than providers. It should be noted that the averages for all participants' responses indicates they believe the system is meeting standards "small extent" in these categories.

**Figure 4. Overall Mean Responses for Transition to Adulthood**



## Appendix A. Survey questions reworded for consumers

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Q#	Provider	Q#	Consumer
4	<p>Upon enrollment and transfer between public and private insurance coverage:</p> <p>4.a. To what extent is a consistent plan in place for identifying CYSHCN to ensure referrals to appropriate types and sources of enhanced care?</p> <p>4.b. To what extent are the families' cultural beliefs taken into consideration when referring them to the appropriate services?</p> <p>4.c. To what extent are the families' native languages taken into consideration when referring them to the appropriate services?</p>	4	<p>Thinking about when families enroll and transfer between public and private insurance coverage:</p> <p>4.a. How well does the system do at considering families' cultural beliefs when referring them to services?</p> <p>4.b. How well does the system do at taking into account families' native languages when referring them to services?</p>
5	<p>Promptly after enrollment in a health plan, to what extent are all CYSHCN provided a documented initial assessment that is conducted with input from the child's family or caregiver?</p>	5	<p>After families enroll in a health plan, how well does the system do at making sure all CYSHCN get an initial health assessment that includes input from the child's family or caregiver?</p>
6	<p>Regarding the State Newborn Screening:</p> <p>6.a. To what extent is the information delivered to providers and parents in a timely fashion?</p> <p>6.b. To what extent are arrangements for necessary follow-up services documented?</p> <p>6.c. To what extent is the need for repeat screening and follow-up communicated to the health plan and providers by the hospital or state program?</p>	6	<p>When a CYSHCN gets a State Newborn Screening:</p> <p>6.a. How well does the system do at giving parents information in a timely manner?</p> <p>6.b. How well does the system do at making sure plans for needed follow-up services are documented?</p> <p>6.c. How well do hospitals or state programs do at letting families and the health plan know about the need for repeat screening and follow-up?</p>
7	<p>When newborn screening results are not received:</p>		

	<p>7.a. To what extent does the child’s health plan have a documented plan and process to follow-up with a hospital or state health department?</p> <p>7.b. To what extent does the child’s medical home have a documented plan and process to follow-up with a hospital or state health department?</p>		No question
8	<p>In terms of receiving periodic, developmentally appropriate, and recommended comprehensive screenings:</p> <p>8.a. To what extent are the screenings listed below done with the CYSHCN patients’ cultural preferences in mind as part of a well-child or other preventive visit?</p> <p>8.b. To what extent are the screenings listed below conducted using the patients’ native languages as part of a well-child or other preventive visit?</p> <p>8.c. To what extent are the screenings listed below done with the CYSHCN patients’ cultural preferences in mind in response to triggering events (such as hospitalization, trauma, or sudden onset of new symptoms)?</p> <p>8.d. To what extent are the screenings listed below done with the CYSHCN patients’ native languages in response to triggering events (such as hospitalization, trauma, or sudden onset of new symptoms)?</p> <ul style="list-style-type: none"> <li>• Physical health screening</li> <li>• Oral health screening</li> <li>• Mental health screening</li> <li>• Developmental screening</li> <li>• Psychosocial screening</li> </ul>	7	<p>When you think about receiving screenings that are right for the child’s age and complete enough to provide all the needed information:</p> <p>7.a. How well does the system do at making sure the following screenings are done in a way that meets CYSHCN families’ cultural preferences when the child has a well-child or other preventive visit?</p> <p>7.b. How well does the system do at making sure the screenings below are done using the patients’ native language when the child has a well-child or other preventive visit?</p> <p>7.c. How well does the system do at making sure the screenings below are done in a way that meets CYSHCN families’ cultural preferences when the child has a triggering event (such as hospitalization, trauma, or sudden onset of new symptoms)?</p> <p>7.d. How well does the system do at making sure the screenings below are done using the patients’ native language when the child has a triggering event (such as hospitalization, trauma, or sudden onset of new symptoms)?</p> <ul style="list-style-type: none"> <li>• Physical health screening</li> <li>• Oral health screening</li> <li>• Mental health screening</li> <li>• Developmental screening</li> </ul>

			<ul style="list-style-type: none"> <li>• Psychosocial screening</li> </ul>
9	<p>To what extent are screening efforts, results, and referrals for further assessment:</p> <p>9.a. Documented?</p> <p>9.b. Relayed to the child’s medical home?</p> <p>9.c. Relayed to the child’s family?</p> <p>9.d. Coordinated among all screening entities, to the extent feasible, including:</p> <ul style="list-style-type: none"> <li>• Clinical care settings</li> <li>• Medical homes</li> <li>• Child care settings</li> <li>• Schools</li> </ul>	8	<p>How well does the system do at making sure screening efforts, results, and referrals for further assessment are:</p> <p>8.a. Documented (i.e., so that a record exists)?</p> <p>8.b. Communicated to the child’s medical home?</p> <p>8.c. Communicated to the child’s family?</p> <p>8.d. Set-up with the following screening settings:</p> <ul style="list-style-type: none"> <li>• Clinical care settings</li> <li>• Medical homes</li> <li>• Child care settings</li> <li>• Schools</li> </ul>
10	<p>Following a screening and assessment, to what extent are the CYSHCN and their family referred to needed services including:</p> <ul style="list-style-type: none"> <li>• Pediatric specialists</li> <li>• Therapies (Occupational, Physical, Speech etc.)</li> <li>• Early intervention</li> <li>• Special education</li> <li>• Family organizations</li> <li>• Community-based agencies</li> </ul> <p>10.a. To what extent is follow-up provided for the CYSHCN and their families to ensure such referrals are completed?</p> <p>10.b. To what extent do the referral services and systems listed above ensure follow-up with the child’s medical home and other members of the child’s care team after visits?</p>	9	<p>After a screening and assessment, how well does the system do at referring CYSHCN and families to needed services including:</p> <ul style="list-style-type: none"> <li>• Pediatric specialists</li> <li>• Therapies (Occupational, Physical, Speech etc.)</li> <li>• Early intervention</li> <li>• Special education</li> <li>• Family organizations</li> <li>• Community-based agencies</li> </ul> <p>9.a. How well does the system do at following-up with CYSHCN and their families to make sure they actually access the services they were referred to?</p> <p>9.b. How well does the system do at following-up with the child’s medical home and other care team after visits?</p>
11	<p>To what extent are protocols and documentation methods in place for the primary care provider, medical home, or other entity to follow-up with the child and family regarding:</p>		

	<ul style="list-style-type: none"> <li>• Appropriate services and referrals are made based upon the completed assessment findings</li> <li>• Barriers to care</li> <li>• Assistance in addressing barriers to obtaining needed follow-up</li> </ul>		No question
12	<p>In terms of process for youth with special health care needs (YSHCN) transitioning from pediatric to adult care system:</p> <p>12.a. To what extent are policies and processes for transition preparation/planning in place within the health plan for YSHCN and their families?</p> <p>12.b. To what extent are policies and processes for transition preparation/planning in place within the medical home for YSHCN and their families?</p> <p>12.c. To what extent are YSHCN encouraged to learn about their health care as part of this transition preparation process?</p> <p>12.d. To what extent are YSHCN encouraged to engage in their health care as part of this transition preparation process?</p>	10	<p>Thinking about the process for youth with special health care needs (YSHCN) moving from pediatric to adult care systems:</p> <p>10.a. How well does the system do at making sure the health plan has rules and instructions for transition planning?</p> <p>10.b. How well does the system do at making sure the medical home has rules and instructions for transition planning?</p> <p>10.c. How well does the system do at encouraging YSHCN to learn about their health care as they prepare to move?</p> <p>10.d. How well does the system do at encouraging YSHCN to participate in their health care as they prepare to move?</p>
13	<p>To what extent is an individual flow sheet or registry for identifying transitioning YSHCN maintained by:</p> <p>13.a. The health plan to track completion of the transition process?</p> <p>13.b. The medical home to track completion of the transition process?</p>		No question
14	To what extent are a transition readiness assessment and plan of care (including a medical summary and emergency care plan) typically developed when a YSHCN reaches age 14?	11	How well does the system do at creating a transition readiness assessment and plan of care (including a medical summary and emergency care plan) when a YSHCN turns 14?

	<p>14.a. To what extent are the above transition assessment and plan of care regularly updated after age 14?</p> <p>14.b. To what extent are the transition assessment and plan of care updated in partnership with the YSHCN and his/her family or caregiver?</p> <p>14.c. To what extent are a family's cultural beliefs respected in the development of the transition assessment and plan of care?</p>		<p>11.a. How well does the system do at regularly adding new information to the transition assessment and plan of care after children turn 14?</p> <p>11.b. How well does the system do at adding new information to the transition assessment and plan of care with the child's and family's input?</p> <p>11.c. How well does the system do at respecting families' beliefs, values, and culture while making the transition assessment and plan of care?</p>
15	<p>A transfer package includes a final transition readiness assessment, plan of care with transition goals, and medical summary and emergency plan.</p> <p>15.a. To what extent is the transfer package prepared with the new adult medical home, prior to the transfer of a YSHCN from a pediatric to an adult medical home?</p> <p>15.b. To what extent is the transfer package communicated with the new adult medical home, prior to the transfer of a YSHCN from a pediatric to an adult medical home?</p>	12	<p>A transfer package includes a final transition readiness assessment, plan of care with transition goals, and medical summary and emergency plan.</p> <p>12.a. How well does the system do at collecting the information for the transfer package before a YSHCN is transferred from a pediatric to an adult medical home?</p> <p>12.b. How well does the system do at explaining the information in the transfer package to the new adult medical home before a YSHCN is transferred?</p>
16	<p>To what extent is the pediatric medical home available for consultation assistance with the adult medical home as needed?</p>		<p>No question</p>
17	<p>In the 3-6 months following transfer of a YSHCN to an adult medical home:</p> <p>17.a. To what extent is a process in place in the pediatric medical home to confirm transfer?</p> <p>17.b. To what extent is a process in place in the pediatric medical home to obtain feedback on the YSHCN's transition experience?</p>		<p>No question</p>

18	<p>In terms of a transition quality improvement process:</p> <p>18.a. To what extent does the transition quality improvement process include collaboration between pediatric and adult health care providers?</p> <p>18.b. To what extent does the transition quality improvement process include co-management between pediatric and adult health care providers?</p>	13	<p>How well does the system do at making sure both the pediatric and adult health care providers work together to improve the quality of the transition process?</p>
19	<p>To what extent is a policy in place that describes the adult medical home approach to accepting and partnering with new YSHCN, including legal changes at age 18?</p>	14	<p>How well does the system do at having rules in place that describe how adult medical homes accept and partner with new YSHCN?</p> <p>14.a. How well does the system do at having rules in place that describe the legal changes at age 18?</p>
20	<p>To what extent is an individual flow sheet (or registry) maintained for identifying transitioning YSHCN through 26 years of age:</p> <p>20.a. By the health plan to track completion of the transition process?</p> <p>20.b. By the medical home to track completion of the transition process?</p>		<p>No question</p>
21	<p>21. To what extent is a process in place for identifying providers who are interested in caring for YSHCN:</p> <p>21.a. At the adult medical home level?</p> <p>21.b. At the health plan level?</p>	15	<p>How well does the system do at making it easy to find providers who want to care for YSHCN?</p>
22	<p>To what extent does a process exist for welcoming and orienting young adults within the adult medical home?</p>	16	<p>How well does the adult medical home do at welcoming young adults and showing them around the medical home?</p>

23	<p>In terms of a process to confirm the transfer between the pediatric and adult medical home of a YSHCN:</p> <p>23.a. To what extent does this process assist the YSHCN with ongoing care management?</p> <p>23.b. To what extent does this process assist the YSHCN with referral to adult specialists and other community supports?</p> <p>23.c. To what extent does this process assist in obtaining feedback about the care received by the YSHCN's during the transfer of care process?</p>	17	<p>Once a YSHCN has been transferred from a pediatric medical home to an adult medical home, how well does the system do at the following:</p> <p>17.a. Making sure the transfer actually took place?</p> <p>17.b. Making sure the adult medical home provides ongoing care management?</p> <p>17.c. Making sure the YSHCN gets referred to adult specialists and other community resources?</p> <p>17.d. Making sure to find out whether the YSHCN has a good experience with his/her care?</p>
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## Appendix B. Detailed Survey Results

**Comprehensive Screenings (Table 5)** - In terms of receiving periodic, developmentally appropriate, and recommended comprehensive screenings:

**Table C. 1**

5.1 To what extent are the screenings listed below done with the CYSHCN patients' <i>cultural preferences</i> in mind as part of a well-child or other preventive visit?							
Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
1) Physical health screening	Provider	0%	20%	50%	24%	3.04	25
	Consumer	0%	0%	100%	0%	3.00	8
2) Oral health screening	Provider	0%	42%	46%	12%	2.69	26
	Consumer	0%	13%	75%	13%	3.00	8
3) Mental health screening	Provider	4%	56%	32%	8%	2.44	25
	Consumer	13%	13%	75%	0%	2.63	8
4) Developmental screening	Provider	0%	28%	52%	20%	2.92	25
	Consumer	0%	0%	100%	0%	3.00	8
5) Psychosocial screening	Provider	8%	36%	48%	8%	2.56	25
	Consumer	0%	25%	75%	0%	2.75	8

**Table C. 2**

5.2 To what extent are the screenings listed below conducted using the patients' native languages as part of a well-child or other preventive visit?							
Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
1) Physical health screening	Provider	0%	44%	32%	24%	2.80	25
	Consumer	0%	13%	63%	25%	3.13	8
2) Oral health screening	Provider	0%	54%	23%	23%	2.69	26
	Consumer	0%	38%	38%	25%	2.88	8
3) Mental health screening	Provider	4%	50%	21%	25%	2.67	24

	Consumer	0%	38%	38%	25%	2.88	8
4) Developmental screening	Provider	0%	44%	32%	24%	2.80	25
	Consumer	0%	25%	50%	25%	3.00	8
5) Psychosocial screening	Provider	4%	48%	24%	24%	2.68	25
	Consumer	0%	25%	50%	25%	3.00	8

**Table C. 3**

5.3 To what extent are the screenings listed below done with the CYSHCN patients' cultural preferences in mind in response to triggering events (such as hospitalization, trauma, or sudden onset of new symptoms)?							
Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
1) Physical health screening	Provider	0%	41%	36%	23%	2.82	22
	Consumer	13%	0%	88%	0%	2.75	8
2) Oral health screening	Provider	0%	46%	38%	17%	2.71	24
	Consumer	0%	38%	63%	0%	2.63	8
3) Mental health screening	Provider	4%	43%	39%	13%	2.61	23
	Consumer	13%	13%	75%	0%	2.63	8
4) Developmental screening	Provider	0%	48%	35%	17%	2.70	23
	Consumer	0%	25%	75%	0%	2.75	8
5) Psychosocial screening	Provider	4%	43%	39%	13%	2.61	23
	Consumer	13%	13%	75%	0%	2.63	8

**Table C. 4**

5.4 To what extent are the screenings listed below done with the CYSHCN patients' native languages in response to triggering events (such as hospitalization, trauma, or sudden onset of new symptoms)?							
Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
1) Physical health screening	Provider	0%	46%	33%	21%	2.75	24
	Consumer	0%	14%	71%	14%	3.00	7
	Provider	0%	52%	28%	20%	2.68	25

2) Oral health screening	Consumer	0%	14%	71%	14%	3.00	7
3) Mental health screening	Provider	4%	46%	29%	21%	2.67	24
	Consumer	0%	25%	63%	13%	2.88	8
4) Developmental screening	Provider	0%	46%	33%	21%	2.75	24
	Consumer	0%	25%	63%	13%	2.88	8
5) Psychosocial screening	Provider	4%	50%	25%	21%	2.63	24
	Consumer	0%	25%	63%	13%	2.88	8

**Further Assessment (Table 6)** - To what extent are screening efforts, results, and referrals for further assessment:

**Table D**

6.4 Coordinated among all screening entities, to the extent feasible, including:							
Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
1) Clinical care settings	Provider	0%	46%	46%	8%	2.63	24
	Consumer	14%	0%	71%	14%	2.86	7
2) Medical homes	Provider	0%	46%	46%	8%	2.63	25
	Consumer	14%	29%	43%	14%	2.57	7
3) Child care settings	Provider	8%	63%	21%	8%	2.29	24
	Consumer	14%	57%	14%	14%	2.29	7
4) Schools	Provider	8%	54%	29%	8%	2.38	24
	Consumer	14%	43%	29%	14%	2.43	7

**Referral to the Needed Services (Table 7)**

**Table E**

7.1 Following a screening and assessment, to what extent are the CYSHCN and their family referred to needed services including:
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Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
1) Pediatric specialists	Provider	0%	24%	44%	32%	3.08	25
	Consumer	0%	29%	57%	14%	2.86	7
2) Therapies	Provider	4%	21%	42%	33%	3.04	24
	Consumer	0%	13%	75%	13%	3.00	8
3) Early intervention	Provider	4%	17%	38%	42%	3.17	24
	Consumer	0%	13%	63%	25%	3.13	8
4) Special education	Provider	0%	25%	42%	33%	3.08	24
	Consumer	0%	38%	38%	25%	2.88	8
5) Family organizations	Provider	4%	38%	29%	29%	2.83	24
	Consumer	0%	71%	29%	0%	2.29	7
6) Community-based agencies	Provider	0%	33%	38%	29%	2.96	24
	Consumer	29%	57%	14%	0%	1.86	7

## About the Community Engagement Institute

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**Wichita State University's Community Engagement Institute** is dedicated to improving the health of Kansans through leadership development, research and evaluation, organizational capacity building, community collaboration, and public health and behavioral health initiatives. The Community Engagement Institute maintains six Centers with skilled staff that work directly with community coalitions, nonprofits, government entities, health and human services organizations, and support groups. The Centers are:

- Center for Applied Research and Evaluation
- Center for Behavioral Health Initiatives
- Center for Leadership Development
- Center for Organizational Development and Collaboration
- Center for Public Health Initiatives
- IMPACT Center

Want to know more about this report? Contact Tara Gregory, Ph.D., Director of the Center for Applied Research and Evaluation, at [tara.gregory@wichita.edu](mailto:tara.gregory@wichita.edu)



WICHITA STATE  
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COMMUNITY ENGAGEMENT  
INSTITUTE

Center for Applied Research and Evaluation

*Strengthening Organizations, Strengthening Communities*

## **Kansas Special Health Care Needs Program**

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### **Kansas Systems Integration Grant Consumer and Provider Standards Survey Report**

September 2017

**Evaluation Conducted by the Center for Applied Research and Evaluation**

Jung Sim Jun, PhD and Tara Gregory, PhD





## 2017 Consumer and Provider Standards Survey Report: Family Professional Partnerships Insurance and Financing



The sections below include findings from the 4th Standards of Care for Children and Youth with Special Health Care Needs (CYSHCN) survey, which was administered and analyzed by Wichita State University's Center for Applied Research and Evaluation (CARE).

### Key Findings

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#### Overall

- A total of 55 participants (44 providers/11 consumers) at least partially completed the surveys.
- Most of the respondents reside and provide/receive services in the South Central or Southwest regions.
- In general, providers and consumers/caregivers provided similar responses ("moderate extent") in the Family Professional Partnerships standard questions. However, for the Insurance and Financing standards, consumers were slightly more negative than providers.

#### Family Professional Partnerships

- Results from the survey showed that the majority of participants, both providers and caregivers, believe the system is meeting Family Professional Partnerships standards to a "moderate extent" except in the "Family Advisory Board" category.
- The overall mean responses ranged from 2.2 to 3.2 (on a scale of 1 to 4) with provider's ratings were either equal to or higher than consumers' ratings for most categories.

#### Insurance and Financing

- The average responses in meeting Insurance and Financing standards showed that a large portion of both providers and consumers selected "small extent". The means for questions ranged from 2.1 to 2.8 (on a scale of 1 to 4).
- In general, providers tended to rate statements slightly more positively than consumers.
- The lowest means across all questions were for both provider and consumer responses related to the "Seeking Second Opinion" category.

The tables below represent the overall average responses regarding the extent to which the system is meeting the specific standards for Family Professional Partnerships and Insurance/Financing (see legend below for color coding). Due to the very small participation rate for the consumers, the collected responses might not be representative for the population, and the overall comparison would need to be interpreted with caution.

**Table A. Family Professional Partnerships**

Category	Audience	
	Provider	Consumer
Families as Active Members	Moderate Extent	Moderate Extent
Family Priority & Care Planning	Moderate Extent	Moderate Extent
Connections to Support Programs	Moderate Extent	Moderate Extent
Family Strengths & Beliefs	Moderate Extent	Moderate Extent
Respecting Family Culture	Moderate Extent	Moderate Extent
Providing Information	Moderate Extent	Moderate Extent
Culturally Appropriate Materials	Moderate Extent	Moderate Extent
Asking Feedback	Moderate Extent	Moderate Extent
Family Advisory Boards	Small Extent	Small Extent

**Table B. Insurance and Financing**

Category	Audience	
	Provider	Consumer
Insurance Plan	Moderate Extent	Small Extent
Coverage & Payment Levels to Services	Small Extent	Small Extent
Medically Necessary Services	Moderate Extent	Moderate Extent
Comprehensive Habilitative Services	Moderate Extent	Moderate Extent
Habilitative Services	Small Extent	Small Extent
Authorization Processes	Small Extent	Small Extent
Seeking Second Opinions	Small Extent	Small Extent

**Legend:**

Not at All
Small Extent
Moderate Extent
Large Extent

## Summary of Survey Results

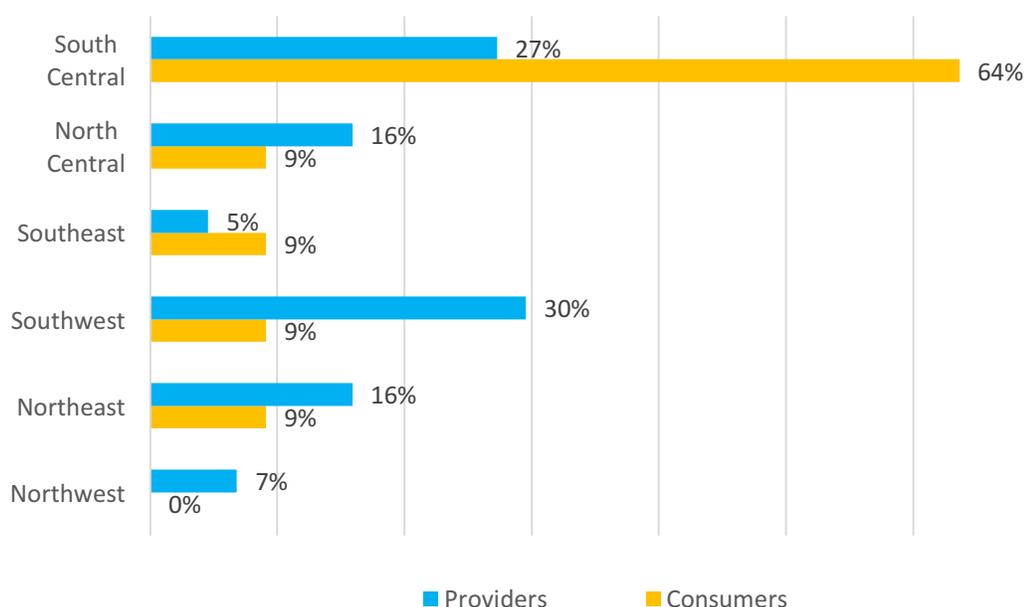
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The purpose of the on-line survey was to gain input from service consumers (people who receive services or caregivers/parents/guardians) and service providers about how well the current system is meeting the standards of care for CYSHCN. This report provides a snapshot of Kansas participants' perceptions focusing on the core domains for system standards including **a) Family Professional Partnerships** and **b) Insurance and Financing**. The survey invitation was sent out by KDHE on August 2<sup>nd</sup> and the survey was closed on September 17<sup>th</sup>, 2017. A total of 55 participants (44 providers and 11 consumers) at least partially completed the surveys. However, the participants' actual completion of the survey was low, and the survey results may not be representative, especially for consumers.

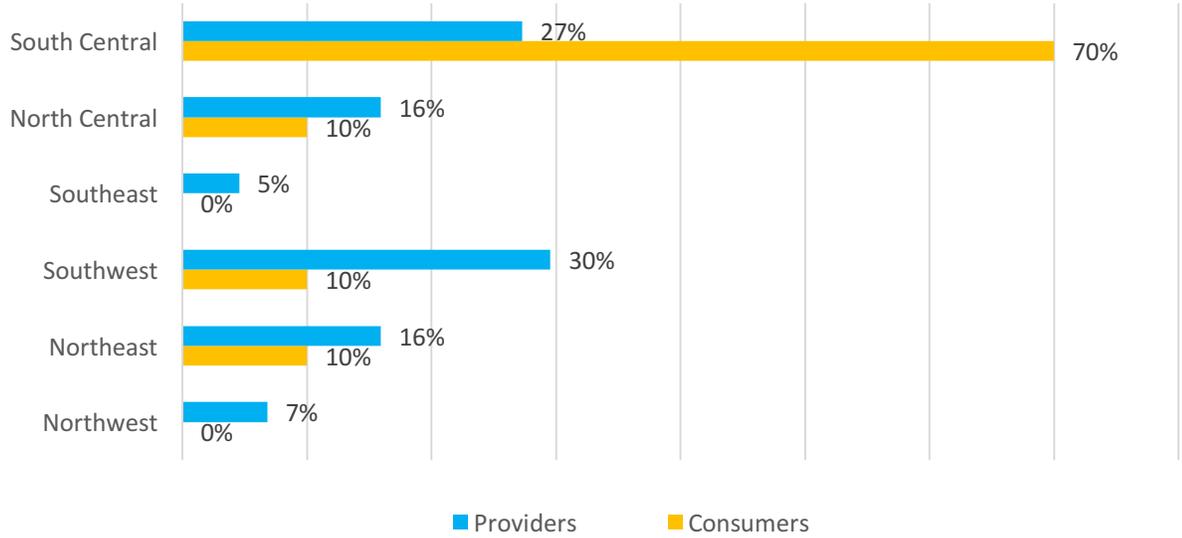
In order to increase participants' understanding, most of the standards were re-worded for the questions for consumers/families/caregivers. Additionally, because some questions had limited applicability depending on the respondents' role (consumer or provider), a few were asked only of a particular group. See Appendix A for specific question comparison between providers and consumers. Appendix B provides more specific results of some questions with sub categories. For each question, the response with the largest percentage is highlighted for both **providers (blue)** and **consumers (orange)**.

**Region (Figure 1 & 2)** – The largest number of responding providers live/provide services in the Southwest region. For consumers, the majority of them live and receive services in the South Central region.

**Figure 1. Live in**



**Figure 2. Provide/Receive Services**



## Family Professional Partnerships

**Families as Active Members** – The average response for all questions in this category was “moderate extent.”

**Table 1**

Question	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
To what extent are families active, core members of the medical home team?	Provider	0%	30%	42%	27%	3.0	33
	Consumer	10%	0%	50%	40%	3.2	10

**Family Priorities & Care Planning** –The largest portion of providers and consumers both tended to select “moderate extent” to the question.

**Table 2**

Question	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
To what extent are family priorities and concerns central to care planning and management?	Provider	0%	12%	55%	33%	3.2	33
	Consumer	0%	15%	55%	30%	3.1	10

**Note:** For consumers, percentages were calculated by averaging subcategory response rates. The following Table 2.1 explains more specific results by subcategories.

**Table 2.1 Consumer Only**

Question	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
5. How well does the system do at making sure that family priorities and concerns are an important part of developing their child’s care plan?	0%	20%	50%	30%	3.1	10
5.a. How well does the system do at making sure that families are a part of ongoing management of their child’s care plan?	0%	10%	60%	30%	3.2	10

**Connections to Support Programs** – The average response in this category was “moderate extent” for providers. Consumers’ responses tended toward “small” to “moderate extent.”

**Table 3**

Question	Respondents	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
To what extent does the system help connect families to family organizations, peer support, and family support programs?	Provider	0%	33%	55%	12%	2.8	33
	Consumer	0%	40%	40%	20%	2.8	10

**Family Strengths & Beliefs** – The largest portion of providers and consumers chose “moderate extent” to this question.

**Table 4**

Question	Respondents	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
To what extent are family strengths and beliefs (including cultural and ethnic identities) respected in the delivery of care?	Provider	0%	15%	55%	30%	3.2	33
	Consumer	10%	0%	60%	30%	3.1	10

**Respecting Family Culture** – Answers from providers tended more toward the positive (“moderate” to “large extent”) versus those of consumers (“moderate extent”) regarding the questions in this category.

**Table 5**

Question	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
To what extent is care delivered in culturally appropriate ways?	Provider	0%	17%	63%	20%	3.0	30
	Consumer	0%	10%	50%	40%	3.3	10
To what extent are family desires for inclusion of extended family members in decision making respected?	Provider	7%	23%	33%	37%	3.0	30
	Consumer	20%	20%	50%	0%	2.6	10

**Providing Information** – On average, providers and consumers indicated that the system meets standards in terms of providing information in a way families prefer to a “moderate extent.”

**Table 6**

Question	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
To what extent are families provided information about the services and supports that they will receive in a method chosen by the family (e.g., written and verbal language of choice)?	Provider	0%	23%	63%	13%	2.9	30
	Consumer	10%	10%	50%	30%	3.0	10

**Culturally appropriate Materials** – Responses on questions in this category were “moderate extent”.

**Table 7**

To what extent are all written materials provided to CYSHCN and their families:

Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
7.1 Culturally appropriate?	Provider	0%	27%	50%	23%	3.0	30
	Consumer	10%	0%	60%	30%	3.1	10
7.2 Provided in the primary language of the family?	Provider	0%	20%	53%	27%	3.1	30
	Consumer	0%	0%	50%	50%	3.5	10
7.3 Provided in a manner and format that is appropriate for families/caregivers who have limited English proficiency?	Provider	0%	37%	47%	17%	2.8	30
	Consumer	0%	11%	67%	22%	3.1	9

7.4 Provided in a manner and format that is appropriate for families/caregivers who have sensory impairments?	Provider	3%	30%	53%	13%	2.8	30
	Consumer	0%	22%	56%	22%	3.0	9

**Asking Feedback** – The largest portion of the providers and consumers indicated that the system asks for feedback from the families to a “moderate extent.”

**Table 8**

Question	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
To what extent do health systems that serve CYSHCN ask for feedback from the family and children on their experience of the care they receive?	Provider	3%	27%	50%	20%	2.9	30
	Consumer	10%	30%	40%	20%	2.7	10

**Family Advisory Boards** – The most frequent responses on questions in this category were “small extent”. Consumers were slightly more likely than providers to rate the system more positively in terms of having family advisory boards in the health system; however, they tended more toward the negative (“not at all”) regarding family advisory boards actually guiding health programs and policies.

**Table 9**

Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
9.1 To what extent do health systems that serve CYSHCN have family advisory boards (or committees), which include families of CYSHCN?	Provider	14%	48%	28%	10%	2.3	29
	Consumer	0%	40%	40%	20%	2.8	10
9.2 To what extent do health systems offer the following related to advisory boards/committees (please rate each one):	Provider	26%	47%	14%	13%	2.1	24
	Consumer	27%	57%	13%	3%	1.9	10
9.3 To what extent do these family advisory boards or committees guide the following (please rate each one):	Provider	12%	58%	15%	14%	2.3	24
	Consumer	40%	43%	17%	0%	1.8	10

**Note:** For questions 9.2 and 9.3, all percentages were calculated by averaging subcategory response rates. The following Tables 9.1 and 9.2 explain more specific results by subcategories.

**Table 9.1**

To what extent do health systems offer the following related to advisory boards/committees (please rate each one):

Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
Training for family members to be active members of advisory boards/committees	Provider	21%	50%	17%	0%	2.2	24
	Consumer	20%	70%	10%	30%	1.9	10
Mentoring for family members to be active members of advisory boards/committees	Provider	17%	58%	13%	13%	2.2	24
	Consumer	20%	70%	10%	0%	1.9	10
Reimbursement to families for participation as active members of these boards and committees	Provider	42%	33%	13%	13%	2.0	24
	Consumer	40%	30%	20%	10%	2.0	10

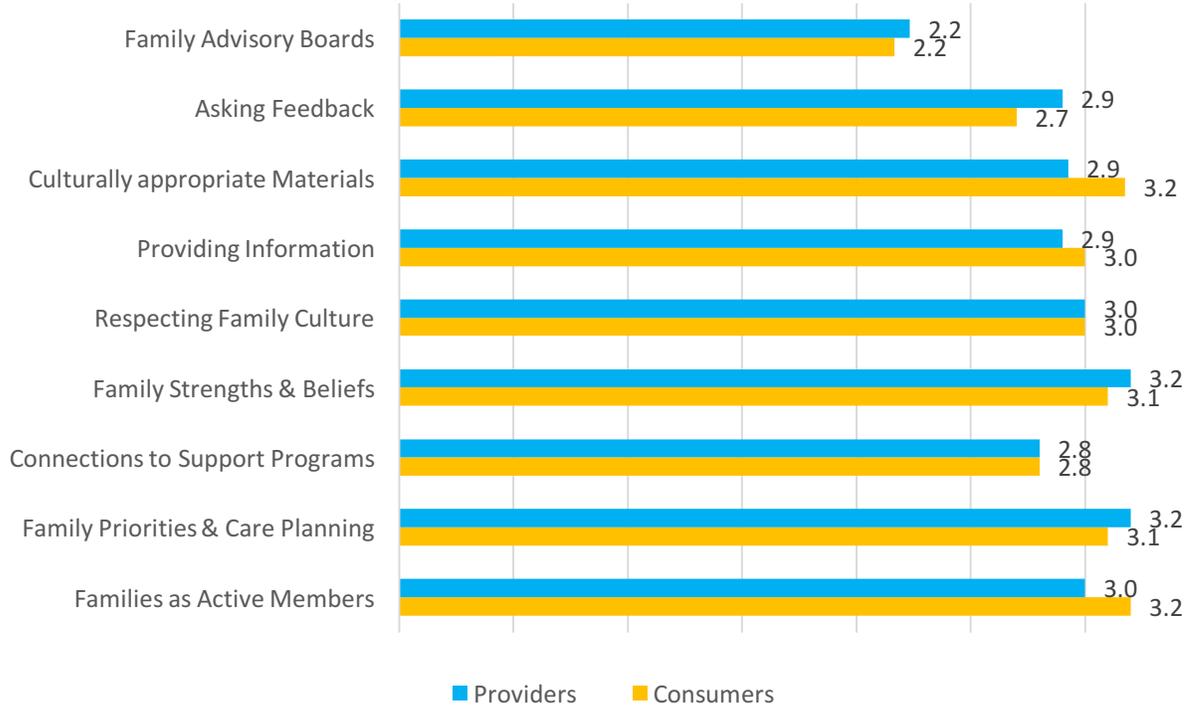
**Table 9.2**

To what extent do these family advisory boards or committees guide the following (please rate each one):

Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
Health system policies	Provider	21%	54%	13%	13%	2.2	24
	Consumer	40%	50%	10%	0%	1.7	10
Health system programs	Provider	8%	58%	21%	13%	2.4	24
	Consumer	40%	40%	20%	0%	1.8	10
Health system quality improvement activities	Provider	8%	63%	13%	17%	2.4	24
	Consumer	40%	40%	20%	0%	1.8	10

**Overall Family Professional Partnerships (Figure 3)** - Participants' mean responses for each category listed above were averaged and are presented below. Overall, providers' ratings were either equal to or higher than consumers' ratings for most categories. However, this needs to be interpreted with caution due to the small number of participants, especially consumers.

**Figure 3. Overall Mean Responses for Family Professional Partnerships**



## Insurance and Financing

**Insurance Plan** – The responses for consumers in this category ranged from “small” to “moderate extent.” Providers tended to select “small extent” more often than consumers.

**Table 10**

In terms of insurance plans for CYSHCN (please rate each one):

Questions	Respondents	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
10.1 To what extent are those plans affordable?	Provider	4%	41%	48%	7%	2.6	27
	Consumer	22%	22%	56%	0%	2.3	9
10.2 To what extent do the plans have cost-sharing policies that protect children and their families from financial strain?	Provider	4%	59%	30%	7%	2.4	27
	Consumer	25%	38%	38%	0%	2.1	8
10.3 To what extent are those plans without risk of loss of benefits?	Provider	11%	44%	42%	4%	2.4	27
	Consumer	25%	25%	50%	0%	2.3	8

**Coverage & Payment Levels to Services** – Providers and consumers both tended to select “small” or “moderate extent” to questions in this category.

**Table 11**

To what extent are coverage and payment levels adequate to facilitate access to the following services? (please rate each one):

Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
11.1 Pediatric primary care	Provider	4%	23%	54%	19%	2.9	26
	Consumer	13%	25%	50%	13%	2.6	8
11.2 Pediatric specialty care	Provider	7%	44%	37%	11%	2.5	27
	Consumer	13%	38%	38%	13%	2.5	8
11.3 Pediatric surgical care	Provider	15%	52%	22%	11%	2.3	27
	Consumer	13%	25%	50%	13%	2.6	8
11.4 Developmental health services	Provider	15%	37%	44%	4%	2.4	27
	Consumer	25%	13%	50%	13%	2.5	8
11.5 Behavioral and mental health services	Provider	19%	56%	26%	0%	2.1	27
	Consumer	25%	63%	13%	0%	1.9	8
11.6 Inpatient hospital care	Provider	8%	27%	58%	8%	2.7	26
	Consumer	13%	25%	50%	13%	2.6	8
11.7 Emergency department care	Provider	8%	23%	50%	19%	2.8	26
	Consumer	13%	25%	50%	13%	2.6	8
11.8 Home health care	Provider	15%	54%	31%	0%	2.2	26
	Consumer	25%	25%	38%	13%	2.4	8
11.9 Dental care	Provider	15%	54%	31%	0%	2.2	26
	Consumer	25%	63%	13%	0%	1.9	8
11.10 Other specialized pediatric services within a medical home model of care	Provider	11%	48%	41%	0%	2.3	27
	Consumer	29%	43%	29%	0%	2.0	7

**Medically Necessary Services** – The largest portion of providers selected “moderate extent” to the questions in this category; however, consumers’ responses tended to answer more negatively.

**Table 12**

To what extent do CYSHCN have access to medically necessary services that do the following:

Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
12.1 Promote optimal growth and development (including prevention, screening and diagnosis)	Provider	0%	22%	63%	15%	2.9	27
	Consumer	14%	14%	57%	14%	2.7	7
12.2 Maintain and prevent deterioration in functioning	Provider	7%	25%	57%	11%	2.7	28
	Consumer	29%	29%	29%	14%	2.3	7
12.3 Address the effects or needs of various conditions, injuries, or disabilities (regarding physical, genetic, congenital, developmental, behavioral, or mental)	Provider	0%	38%	50%	12%	2.7	26
	Consumer	14%	43%	29%	14%	2.4	7

**Comprehensive Habilitative Services** – The largest portion of providers selected “moderate extent” while consumers’ more often answered “small extent.”

**Table 13**

Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
13.1 To what extent are comprehensive habilitative services available for CYSHCN based upon the child’s individual needs including those specified in an Individualized Family Service Plan (IFSP) or Individual Education Plan (IEP)?	Provider	4%	32%	39%	25%	2.9	28
	Consumer	14%	43%	29%	14%	2.4	7
13.2 To what extent are comprehensive habilitative services available for CYSHCN to do the following? (please rate each one)	Provider	4%	33%	48%	15%	2.8	28
	Consumer	5%	48%	33%	14%	2.6	7

**Note:** For questions 13.2, percentages were calculated by averaging subcategory response rates. The following table 13.1 explains more specific results by subcategories.

**Table 13.1**

To what extent are comprehensive habilitative services available for CYSHCN to do the following?  
(please rate each one)

Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
Prevent deterioration of functioning	Provider	7%	29%	54%	11%	2.7	28
	Consumer	0%	43%	43%	14%	2.7	7
Maintain functioning	Provider	4%	32%	46%	18%	2.8	28
	Consumer	0%	57%	29%	14%	2.6	7
Attain skills or functions never learned due to a chronic or disabling condition	Provider	0%	39%	43%	18%	2.8	28
	Consumer	14%	43%	29%	14%	2.4	7

**Habilitative Services** – Providers and consumers both tended to select “small extent” for questions in this category with one except for consumers regarding habilitative services being a covered benefit.

**Table 14**

To what extent are habilitative services (please rate each one):

Questions	Respondents	Not at all (1)	Small extent (2)	Mode-rate extent (3)	Large extent (4)	Mean	Total #
14.1 A covered benefit	Provider	7%	61%	25%	7%	2.3	28
	Consumer	29%	29%	43%	0%	2.1	7
14.2 Offered in addition to rehabilitative services	Provider	11%	46%	39%	4%	2.4	28
	Consumer	14%	57%	29%	0%	2.1	7
12.3 Of like type and substantially equivalent in scope, amount, and duration to rehabilitative services	Provider	14%	57%	29%	0%	2.1	28
	Consumer	29%	43%	29%	0%	2.0	7

**Provider Payment Policies** – The following questions were asked of providers only.

**Table 15**

To what extent do provider payment policies (please rate each one):

Questions	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
15.1 Promote recruitment and retention of primary care providers (e.g., pediatricians, pediatric nurse practitioners)	11%	70%	15%	4%	2.1	27
15.2 Promote recruitment and retention of pediatric medical and surgical specialists	15%	70%	15%	0%	2.0	27
15.3 Serve to incentivize providers	33%	59%	7%	0%	1.7	27

**Authorization Process** – Answers tended to be “small extent” and “moderate extent” with providers being slightly more negative than consumers.

**Table 16**

To what extent are authorization processes (please rate each one):

Questions	Respondents	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
16.1 Flexible to the unique aspects of CYSHCN	Provider	21%	46%	25%	7%	2.2	28
	Consumer	29%	14%	57%	0%	2.3	7
16.2 Simplified to promote access to services	Provider	32%	39%	25%	4%	2.0	28
	Consumer	14%	43%	43%	0%	2.3	7

**Seeking Second Opinions** – Providers tended to answer more negatively than consumers.

**Table 17**

Question	Respondents	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
To what extent may families of CYSHCN seek second opinions from qualified health care providers without restrictions?	Provider	15%	59%	22%	4%	2.2	27
	Consumer	29%	29%	43%	0%	2.1	7

**Financial Incentives** – These questions were only asked of providers.

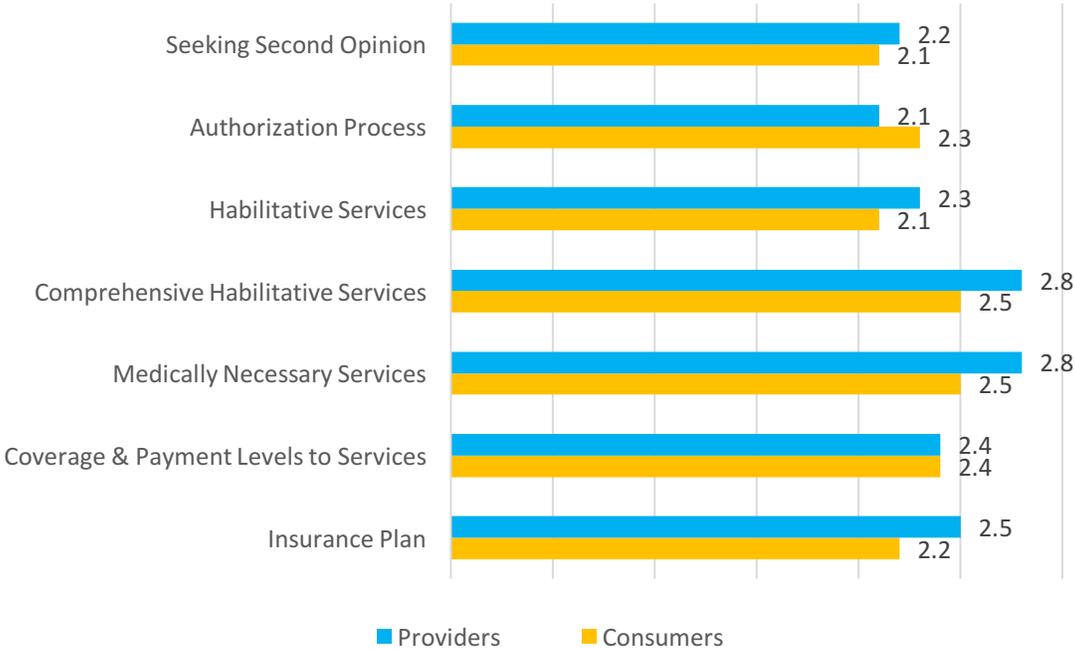
**Table 18**

To what extent are performance or financial incentives in place to promote (please rate each one):

Questions	Not at all (1)	Small extent (2)	Moderate extent (3)	Large extent (4)	Mean	Total #
18.1 Medical homes	27%	58%	12%	4%	1.9	26
18.2 Care coordination	22%	52%	22%	4%	2.1	27
18.3 Enhanced access to services	19%	46%	35%	0%	2.2	26
18.4 Enhanced quality of care	19%	46%	31%	4%	2.2	26

**Overall Insurance and Financing (Figure 4)** - Participants’ mean responses for Insurance and Financing standards were averaged and are presented below. Overall, consumers rated the categories less positively than providers.

**Figure 4. Overall Mean Responses for Insurance and Financing**



## Appendix A. Survey questions reworded for consumers

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Q#	Provider	Q#	Consumer
4	To what extent are families active, core members of the medical home team?	4	How well does the system do at making sure that families are active, important members of their child's medical team?
5	To what extent are family priorities and concerns central to care planning and management?	5	How well does the system do at making sure that family priorities and concerns are an important part of developing their child's care plan?  5.a. How well does the system do at making sure that families are a part of ongoing management of their child's care plan?
6	To what extent does the system help connect families to family organizations, peer support, and family support programs?	6	How well does the system do at connecting families to family organizations, peer support, and family support programs?
7	To what extent are family strengths and beliefs (including cultural and ethnic identities) respected in the delivery of care?	7	How well does the system do at respecting family strengths and beliefs throughout the delivery of care?
8	To what extent is care delivered in culturally appropriate ways?  8.a. To what extent are family desires for inclusion of extended family members in decision making respected?	8	How well does the system do at respecting the family's culture and ethnic identities throughout the delivery of care?  8.a. How well does the system do at respecting family desires for including extended family members in important decision making processes?
9	To what extent are families provided information about the services and supports that they will receive in a method chosen by the family (e.g., written and verbal language of choice)?	9	How well does the system do at giving families information in a way they prefer (e.g., written and spoken language of choice) about the services and supports they receive?
10	To what extent are all written materials provided to CYSHCN and their families:	10	How well does the system do at providing CYSHCN and their families with written information that is:

	<p>10.a. Culturally appropriate?</p> <p>10.b. Provided in the primary language of the family?</p> <p>10.c. Provided in a manner and format that is appropriate for families/caregivers who have limited English proficiency?</p> <p>10.d. Provided in a manner and format that is appropriate for families/caregivers who have sensory impairments?</p>		<p>10.a. Respectful of the individual family's beliefs and customs?</p> <p>10.b. In the primary language of the CYSHCN and their family?</p> <p>10.c. Provided in a way and design that is appropriate for CYSHCN and families/caregivers who are not fluent in English?</p> <p>10.d. Provided in a way and design that is appropriate for CYSHCN and families/caregivers who have sensory impairments (e.g. blindness, hearing loss, etc.)?</p>
11	To what extent do health systems that serve CYSHCN ask for feedback from the family and children on their experience of the care they receive?	11	How well do health systems do at asking for feedback from the CYSHCN and family about their experiences with receiving care?
12	<p>To what extent do health systems that serve CYSHCN have family advisory boards (or committees), which include families of CYSHCN?</p> <p>12.a. To what extent do health systems offer the following related to advisory boards/committees (please rate each one):  Training for family members to be active members of advisory boards/committees  Mentoring for family members to be active members of advisory boards/committees  Reimbursement to families for participation as active members of these boards and committees</p> <p>12.b. To what extent do these family advisory boards or committees guide the following (please rate each one):  Health system policies  Health system programs  Health system quality improvement activities</p>	12	<p>How well do health systems do at making sure they have CYSHCN family advisory boards (or committees) which include families of CYSHCN?</p> <p>12.a. How well do health systems do at making sure they offer the following when they have advisory boards/committees (please rate each one):  Training for family members to help them be active members of advisory boards/committees  Mentoring for family members to help them be active members of advisory boards/committees  Reimbursement to families for being active members of these boards and committees</p> <p>12.b. How well do health systems do at making sure these family advisory boards/committees have a chance to guide the following (please rate each one):  Health system policies</p>

			Health system programs Health system quality improvement activities
13	In terms of insurance plans for CYSHCN (please rate each one):  13.a. To what extent are those plans affordable?  13.b. To what extent do the plans have cost-sharing policies that protect children and their families from financial strain?  13.c. To what extent are those plans without risk of loss of benefits?	13	In terms of <b>insurance plans</b> for CYSHCN, how well does the system do at providing (please rate each one):  13.a. Affordable plans?  13.b. Plans with cost-sharing policies that protect CYSHCN and their families from financial struggles?  13.c. Plans without risk of loss of benefits?
14	To what extent are coverage and payment levels adequate to facilitate access to the following services? (please rate each one) Pediatric primary care Comprehensive and coordinated medical subspecialty services Comprehensive and coordinated surgical specialty services Developmental health services Behavioral and mental health services Inpatient hospital care Emergency department care Home health care Dental care Other specialized pediatric services within a medical home model of care	14	How well does the system do at making sure coverage and payment levels are enough to give CYSHCN and families access to the following services? Please rate each one. Pediatric primary care Pediatric specialty care Pediatric surgical care Developmental health services Behavioral and mental health services Inpatient hospital care Emergency department care Home health care Dental care Other specialized pediatric services within a medical home model of care
15	To what extent do CYSHCN have access to medically necessary services that do the following (please rate each one): <ul style="list-style-type: none"><li>• Promote optimal growth and development (including prevention, screening and diagnosis)</li><li>• Maintain and prevent deterioration in functioning</li><li>• Address the effects or needs of various conditions, injuries, or disabilities (regarding physical, genetic, congenital, developmental, behavioral, or mental)</li></ul>	15	How well does the system do at providing CYSHCNs access to medically necessary services that do the following (please rate each one): <ul style="list-style-type: none"><li>• Promote optimal growth and development (including prevention, screening and diagnosis)</li><li>• Maintain and prevent decline in functioning</li><li>• Address the effects or needs of various conditions, injuries, or disabilities (regarding physical,</li></ul>

			genetic, congenital, developmental, behavioral, or mental)
16	<p><u>Habilitative services are health care services that help you keep, learn, or improve skills and functioning for daily living. Examples include therapy for a child who isn't walking or talking at the expected age. These services may include physical and occupational therapy, speech-language pathology, and other services for people with disabilities in a variety of inpatient and/or outpatient settings.</u></p> <p>16.a. To what extent are comprehensive habilitative services available for CYSHCN based upon the child's individual needs including those specified in an Individualized Family Service Plan (IFSP) or Individual Education Plan (IEP)?</p> <p>16.b. To what extent are comprehensive habilitative services available for CYSHCN to do the following? (please rate each one)</p> <ul style="list-style-type: none"> <li>• Prevent deterioration of functioning</li> <li>• Maintain functioning</li> <li>• Attain skills or functions never learned due to a chronic or disabling condition</li> </ul>	16	<p><u>Habilitative services are health care services that help you keep, learn, or improve skills and functioning for daily living. Examples include therapy for a child who isn't walking or talking at the expected age. These services may include physical and occupational therapy, speech-language pathology, and other services for people with disabilities in a variety of inpatient and/or outpatient settings.)</u></p> <p>16.a. How well does the system do at providing <b>comprehensive habilitative services, which may be included in</b> an Individualized Family Service Plan (IFSP) or Individual Education Plan (IEP), for CYSHCN based upon the child's individual needs?</p> <p>16.b. How well does the system do at providing <b>comprehensive habilitative services</b> for CYSHCNs to do the following? Please rate for each one.</p> <ul style="list-style-type: none"> <li>• Prevent functioning from getting worse</li> <li>• Help keep functioning the same</li> <li>• Help gain skills or functions they never learned because of a chronic or disabling condition</li> </ul>
17	<p>To what extent are habilitative services (please rate each one):</p> <p>17.a. A covered benefit</p> <p>17.b. Offered in addition to rehabilitative services</p> <p>17.c. Of like type and substantially equivalent in scope, amount, and duration to rehabilitative services</p>	17	<p>How well does the system do at providing <b>comprehensive habilitative services</b> that are (please rate each one):</p> <p>17.a. A covered benefit</p> <p>17.b. Offered in addition to rehabilitative services</p> <p>17.c. Similar to rehabilitative services in terms of type of service, amount of service (e.g., number of hours), and length</p>

			of time provided (e.g., number of weeks, months or years)
18	To what extent do provider payment policies (please rate each one): <ul style="list-style-type: none"> <li>Promote recruitment and retention of primary care providers (e.g., pediatricians, pediatric nurse practitioners)</li> <li>Promote recruitment and retention of pediatric medical and surgical specialists</li> <li>Serve to incentivize providers</li> </ul>		No question
19	To what extent are authorization processes (please rate each one): <p>19.a. Flexible to the unique aspects of CYSHCN</p> <p>19.b. Simplified to promote access to services</p>	18	How well does the system do at providing authorization processes that are (please rate each one): <p>18.a. Adjusted to fit the unique conditions of the child</p> <p>18.b. Simplified to increase access to services</p>
20	To what extent may families of CYSHCN seek second opinions from qualified health care providers without restrictions?	19	How well does the system do at allowing families to get second opinions from qualified health care providers without restrictions?
21	To what extent are performance or financial incentives in place to promote (please rate each one): <ul style="list-style-type: none"> <li>Medical homes</li> <li>Care coordination</li> <li>Enhanced access to services</li> <li>Enhanced quality of care</li> </ul>		No question

## About the Community Engagement Institute

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**Wichita State University's Community Engagement Institute** is dedicated to improving the health of Kansans through leadership development, research and evaluation, organizational capacity building, community collaboration, and public health and behavioral health initiatives. The Community Engagement Institute maintains six Centers with skilled staff that work directly with community coalitions, nonprofits, government entities, health and human services organizations, and support groups. The Centers are:

- Center for Applied Research and Evaluation
- Center for Behavioral Health Initiatives
- Center for Leadership Development
- Center for Organizational Development and Collaboration
- Center for Public Health Initiatives
- IMPACT Center

*Want to know more about this report? Contact Tara Gregory, Ph.D., Director of the Center for Applied Research and Evaluation, at [tara.gregory@wichita.edu](mailto:tara.gregory@wichita.edu)*