



Analysis of the 2001 New Jersey State and Local Area Integrated Telephone Survey (SLAITS) Data

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Background

The timeliness, consistency, and quality of care received by children with special health care needs is of critical importance (Huang, Kogan, Yu, & Strickland, 2004). It is particularly important during the period of time in which they are transitioning from care received by a pediatrician to that of a physician specializing in adults. It requires a careful coordination of the pediatrician, the family, and the new physician (Rosenberg, Onufer, Clark, Wilkin, Rankin, & Gupta, 2005), yet this may not always occur successfully (Smaldone, Honig, & Byrne, 2005). It is important to obtain collective input from all parties in order to make the transition process as seamless as possible. Therefore, the purpose of this study is to provide the New Jersey Department of Health and Senior Services, Division of Family Health Services (DHSS:FHS), with information on the factors that influence successful medical transitions.

The first phase of this study is an in-depth analysis of the 2001 State and Local Area Integrated Telephone Survey (SLAITS), which was developed and administered by the National Center for Health Statistics of the Centers for Disease Control and Prevention. This analysis is important for several reasons. First, the medical transition process is identified by a DHSS: FHS taskforce as an important area to examine for their required needs assessment activities. Second, a national comparison of states using measures from the SLAITS data to determine the best conditions for children with special health care needs found New Jersey ranks 39th out of 51 states (Blumberg & Bramlett, 2005). This finding is not only surprising but also dubious since New Jersey has such a strong infrastructure

in place to support children with special health care needs. Therefore, a closer look at New Jersey's SLAITS information is not only important but necessary.

New Jersey State and Local Area Integrated Telephone Survey (SLAITS): Methods

SLAITS began in 2000 and was conducted using a national sample. Households were called utilizing a random-digit-dial-up, and the person most knowledgeable of the health and health care needs of those in the household was interviewed. The survey focused on the health care needs and services of children under the age of 18; however, the present study focused only on the SLAITS' Children with Special Health Care Needs data. Additionally, only data from the state of New Jersey were used, resulting in a final analytical sample of 744 respondents. To address the complex sample survey design, weights were used as well as the SAS 9.1 statistical software.

Results

Age Comparison

As seen in Table 1, in comparison to that of younger children (i.e., those under 14 years of age), the group of older children was more female than male and had more mothers who completed their high school education but have not attained a four year college degree. In terms of insurance, fewer older children had public insurance such as Medicaid and SCHIP and a greater proportion of them had no insurance. However, overall, the majority of children did have some type of health insurance, with most of them having private insurance (see Table 1).

The distribution of severity level of a child's medical condition was equal between younger and older children,

Table 1: Socio-Demographic Characteristics of Older and Younger Children With Special Health Care Needs in New Jersey: Weighted 2001 Data

	Younger Children (0 to 14) N=220,741		Older Children (15 to 17) N=46,063		Total New Jersey N=266,804	
	N	%	N	%	N	%
Child's Gender*						
Female	83,200	37.7	23,478	51.0	106,677	40.0
Male	136,482	61.8	22,586	49.0	159,067	59.6
Unknown	1,059	0.5	0	0.0	1,059	0.4
Child's Race/Ethnicity*						
White (Non-Hispanic)	148,595	67.4	34,099	74.0	182,694	68.5
Black (Non-Hispanic)	32,882	14.9	5,840	12.7	38,722	14.5
Hispanic	25,552	11.6	3,487	7.6	29,038	10.9
All Other	13,615	6.2	2,637	5.7	16,253	6.1
Mother's Education*						
Less Than High School	19,820	9.2	5,794	13.1	25,614	9.8
High School/GED	69,818	32.3	11,270	25.5	81,087	31.2
More than High School	54,708	25.3	17,758	40.1	72,466	27.8
College Degree & Beyond	71,689	33.2	9,444	21.3	81,133	31.2
Insurance Type‡						
Medicaid*	39,584	17.9	4,681	10.16	44,265	16.6
SCHIP*	24,915	11.3	2,523	5.5	27,438	10.3
Private	179,633	81.4	36,863	80.0	216,496	81.1
Title V	9,853	4.5	563	1.2	10,416	3.9
Uninsured	8,402	3.8	5,538	12.0	13,941	5.2
Other±	17,938	8.1	4,446	9.7	22,384	8.4
‡ Categories are not mutually exclusive. Children may have more than one insurance type. ± Other category includes Military Insurance, Native American Health Insurance, Single Type Service, or other type of insurance. * Significance at a p <= .05						

with respondents ranking younger children slightly more severe than older children (see Table 2). As expected, most children with special health care needs had a usual source of care (i.e., a “medical home”) and a personal care doctor; however, while the majority of children had pediatricians as their personal care doctor, a significant proportion of older children also mentioned general doctors as their personal care doctors. Fortunately, when asked about difficulty in obtaining a referral to a specialist, most respondents affirmed that no problems existed and this was true for both older and younger children (see Table 2).

Approximately 8% of respondents reported delayed or foregone care for their child with special health care needs. A larger proportion of these were older

children (see Table 2). When asked the reasons for the delayed and foregone care, respondents cited these reasons most often:

- Did not have money to pay for provider (76.7%)
- Type of care not covered by health plan (64.7%)
- Appointments conflict with other home or work responsibilities (42.5%)
- Could not get approval from the health plan or doctor (34.7%)
- Child has to wait too long to see provider in the office (29.2%)

An additional response given was that the provider did not have the necessary skill required for the child's care need, but this was more frequently reported by respondents with older children (30.5%).

Figure 1: Children With Special Health Care Needs Experiencing Delayed Care By Parents' Severity Ranking

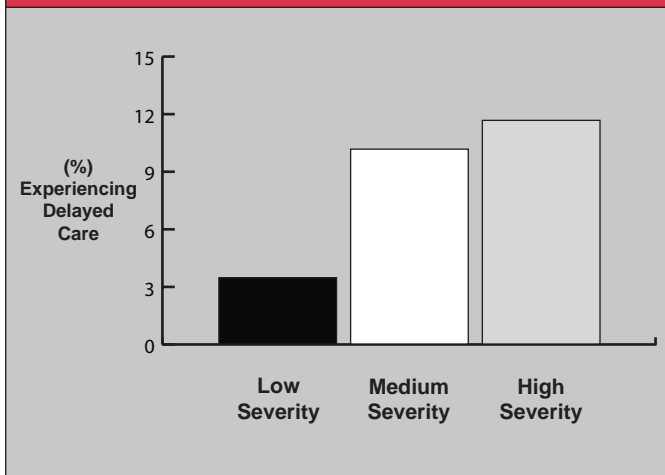


Figure 2: Reasons for Delayed Care Among Children With Moderate and Highly Severe Medical Conditions

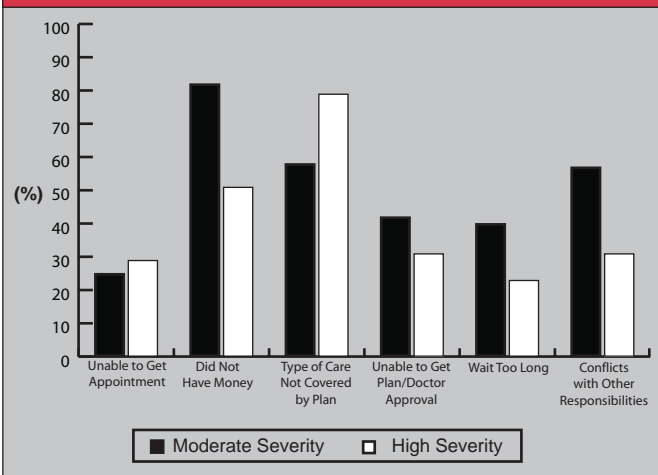


Table 2: Health Care of Older and Younger Children With Special Health Care Needs in New Jersey: Weighted 2001 Data

	Younger Children (Ages 0-14) N=220,741		Older Children (Ages 15-17) N=46,063		Total New Jersey N=266,804	
	N	%	N	%	N	%
Severity of Condition[‡]						
Low Severity	72,709	33.5	14,264	31.2	86,973	33.1
Moderate Severity	99,641	45.8	24,636	53.8	124,276	47.2
High Severity	45,023	20.7	6,860	15.0	51,883	19.7
Has Usual Source of Care						
Yes	209,326	94.8	42,895	93.1	252,222	94.5
No	10,743	4.9	2,766	6.0	13,509	5.1
Don't Know/ Not Applicable	671	0.3	403	0.9	1,074	0.4
Has Personal Care Doctor/Nurse						
Yes	193,889	87.8	39,459	85.7	233,348	87.5
No	25,186	11.4	5,909	12.8	31,095	11.7
Don't Know/ Not Applicable	1,666	0.8	695	1.5	2,361	0.9
Type of Care Doctor/Nurse*						
General Doctor	24,287	12.5	10,017	25.4	34,304	14.7
Pediatrician	155,501	80.2	23,977	60.8	179,477	76.9
Other Specialist	9,591	5.0	4,543	11.5	14,134	6.1
Nurse Practitioner	4,015	2.1	922	2.3	4,937	2.1
Physician Assistant	496	0.3	0	0.0	496	0.2
Has Had a Problem With Specialist Referral						
Yes	35,850	16.2	7,698	16.7	43,548	16.3
No	162,916	73.8	35,987	78.1	198,904	74.6
Don't Know/ Not Applicable	21,975	10.0	2,378	5.2	24,352	9.1
Has Had Delayed Care						
Yes	14,331	6.5	7,467	16.2	21,798	8.2
No	206,410	93.5	38,596	83.8	245,006	91.8
Don't Know/ Not Applicable	0	0.0	0	0.0	0	0.0

[‡] Severity of condition categories were created by using the reported severity ranking of respondents ranging from 0 to 10. Low severity was 0 to 3, moderate severity was 4 to 6 and high severity was 7 and above.

* Significance at a p < .05

Table 3: Socio-Demographic Characteristics of Older and Younger Children With Special Health Care Needs in New Jersey: Weighted 2001 Data

	Low Severity <i>N= 86,973</i>		Moderate Severity <i>N=124,276</i>		High Severity <i>N=51,884</i>	
	N	%	N	%	N	%
Insurance Type						
Medicaid*	7,487	8.6	18,550	14.9	17,559	33.8
SCHIP*	5,653	6.5	14,019	11.3	7,766	15.0
Private*	76,666	88.2	104,598	84.2	32,229	62.1
Title V*	1,850	2.1	5,209	4.2	3,358	6.5
Uninsured	5,289	6.1	4,697	3.8	3,956	7.6
Other	8,104	9.3	11,298	9.1	2,467	4.8
Has Usual Source of Care						
Yes	83,233	95.7	116,116	93.4	49,201	94.8
No	3,197	3.7	7,726	6.2	2,585	5.0
Don't Know/ Not Applicable	543	1.0	434	0.4	97	0.2
Has Had a Problem With Specialist Referral*						
Yes	10,777	12.4	21,157	17.0	11,218	21.6
No	65,271	75.1	93,475	75.2	37,325	71.9
Don't Know/ Not Applicable	10,925	12.6	9,644	7.8	3,341	6.4
How Well Doctors Communicate With Other Type of Care Providers?*						
Well	45,633	54.2	72,937	59.2	32,681	63.4
Not Well	11,620	13.8	23,752	19.3	12,385	24.0
Don't Know/ Not Applicable	26,895	32.0	26,589	21.6	6,479	12.6
Doctors Have Discussed Child's Health When Becomes Adult?						
Yes	4,248	41.5	10,306	54.8	3,702	53.0
No	6,002	58.6	8,161	43.5	3,278	47.0
Don't Know/ Not Applicable	0	0.0	326	1.7	0	0.0
Plan for Dealing With Changing Needs Made?						
Yes	2,105	49.5	5,545	53.8	2,621	70.8
No	1,632	38.4	4,223	41.0	1,081	29.2
Don't Know/ Not Applicable	512	12.0	538	5.2	0	0.0
Doctors Have Discussed Child's Future Need for Adult Doctors?						
Yes	1,118	26.3	2,996	29.1	1,126	30.4
No	2,980	70.2	7,309	70.9	2,576	69.6
Don't Know/ Not Applicable	150	3.5	0	0.0	0	0.0

* Significance at a p < .05

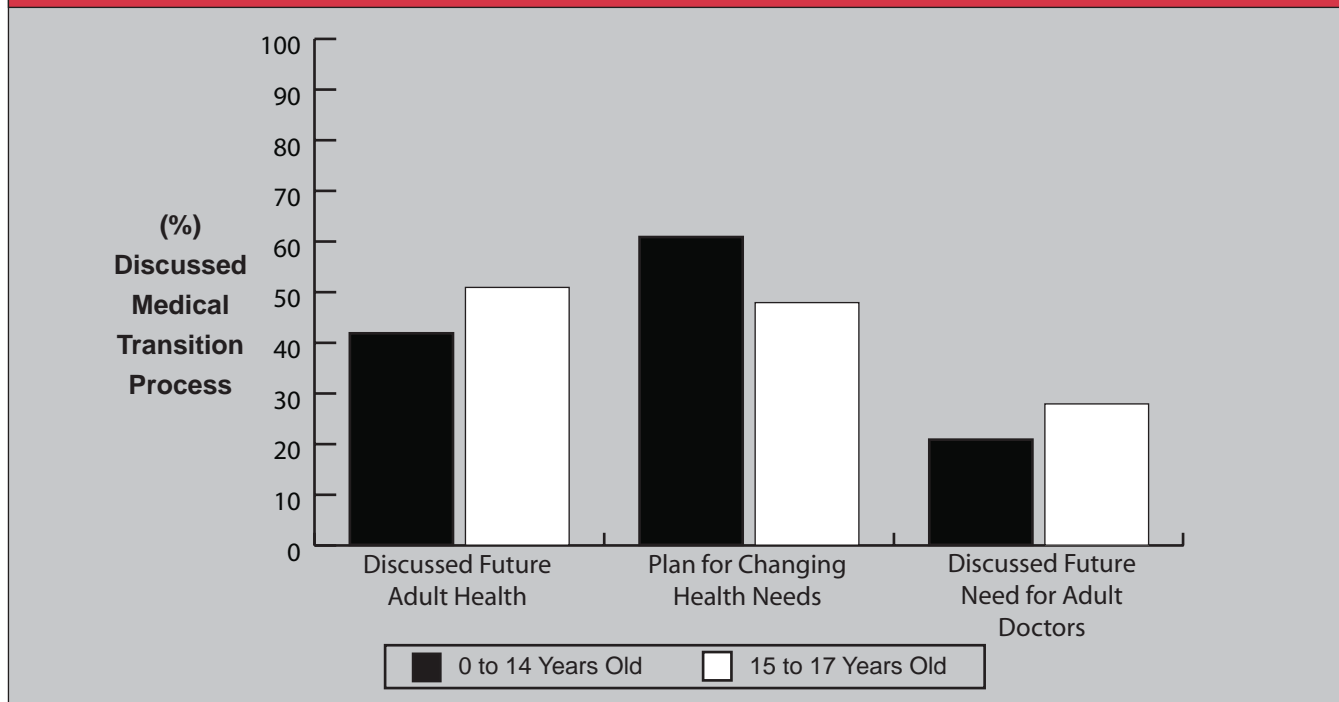
Severity Level Comparison

When delayed and forgone care was compared by severity level of child's condition, children with the most severe medical conditions were more likely to have had delayed care (see Figure 1).

The reasons given for this delayed care by these respondents were many; however, only two

reasons differed significantly from those of the moderate severity group, and those included having more difficulty in getting an appointment with a provider in a timely manner, as well as the inability to get the health plan to cover the necessary care (see Figure 2). This is particularly troubling because children with severe medical conditions not only have a need for emergency care regularly, but also a need for specialized care.

Figure 3: Discussion of Medical Transition Process by Age Categories



Compared to children with low and moderately severe medical conditions, those with highly severe conditions were also more likely to participate in Medicaid, SCHIP, and Title V, which is a Federal and State partnership program that provides health and welfare services to women and children, including those with special needs (see Table 3). Moreover, while all children had a usual source of care, those with highly severe medical conditions had a harder time obtaining a referral to a specialist and also had providers who did not communicate with each other well. These are two factors that are particularly important in establishing coordinated care for children with special health care needs, especially those who have severe medical conditions.

Medical Transition Preparation

Although not significantly different among the severity groups, parents of children with highly severe medical conditions were more likely to have discussed the changing needs and health status of their children when they became adults (see Table 3). Looking at these transition preparation questions by

age, it was clear that parents of older children engaged more with doctors in discussing the child’s health as he or she moved toward adulthood (see Figure 3) Parents of older children were also more likely to discuss their child is future need for an adult doctor (see Figure 3).

Conclusion

Older children experienced more delayed care than younger children, and this was also seen among those with severe medical conditions. A number of reasons were cited for this delayed care such as the inability to obtain approval for certain care and/or the inability to obtain an appointment with a care provider. Older children, finding a provider with the appropriate skills was also a problem. Delayed care due to reasons such as these should not occur in treating any child with special health care needs, especially those with severe medical conditions. These children clearly have health insurance and have a usual source of care. They rely heavily on medical services occurring in a timely manner. It is imperative for them to have appropriate providers

available to them and health plans that are flexible in what is approved care, but clearly from this data, this is not the case.

Findings also showed that regular providers discuss the need for an adult doctor and the child's health status as an adult with parents of older children, but overall, the proportion of doctors who engage parents in this type of discussion is small. Only 11.2% of those with moderate to severe medical conditions actually have engaged in such a discussion with their doctors. Based on these findings, there seems to be an unfulfilled need present in New Jersey for children with special health care needs that should be addressed so that these children can transition from one provider to another with little physical and emotional effort.

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