

Children with Special Health Care Needs in Rhode Island: Changes in Access and Quality from 2001-2005/6

Results from the National Survey of Children with
Special Health Care Needs (SLAITS) 2001 and 2005/6

Prepared by:

Karen Bogen, Ph.D.

Jane Griffin, MPH

RI Medicaid Research and Evaluation Project

Department of Human Services

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Methods

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs.

- Random digit dial phone survey
- Part of the SLAITS program
- Data collection in 2001 and 2005-06

RI Sample: RI children <18 years old with Special Health Care Needs

- 2001 (N=35,265, n=750)
- 2005-06 (N=41,782, n=850)
- Special health care needs were measured using 5 FACCT questions (described on next page)
- In 2001, 14.1% of RI children had a special health care need; in 2005-06, 17.2% of RI children had a special health care need.
- Only selected measures where reliable data was available in both time periods

Selection of Sample of Children with Special Health Care Needs

Uses five FACCT (Foundation for Accountability) Screening Questions to determine if there is a child in the household with special health care needs. To be included in sample, parent of child must answer yes to one of the five screening questions and state that condition will last 12 months or longer.

Introductory statements

The next questions are about any kind of health problems, concerns, or conditions that may affect your child's [physical health,] behavior, learning, growth, or physical development. Some of these health problems may affect your child's abilities and activities at school or at play. Some of these problems affect the kind or amount of services your child may need or use.

1. Does your child need or use more medical care, mental health or educational services than is usual for most children of the same age?
 - 1a. (IF YES) Is your child's need for medical care, mental health, or educational services because of any medical, behavioral, or other health condition?
 - 1b. (IF YES) Is this a condition that has lasted or is expected to last 12 months or longer?
2. Does your child currently need or use medicine prescribed by a doctor, other than vitamins?
 - 2a. (IF YES) Is your child's need for prescription medicine because of any medical, behavioral, or other health condition?
 - 2b. (IF YES) Is this a condition that has lasted or is expected to last 12 months or longer?

Selection of Sample (continued)

3. Is your child limited or prevented in any way in his or her ability to do the things most children of the same age can do?
 - 3a. (IF YES) Is your child's limitation in abilities because of any medical, behavioral, or other health condition?
 - 3b. (IF YES) Is this a condition that has lasted or is expected to last 12 months or longer?
4. Does your child need or get special therapy, such as physical, occupational or speech therapy?
 - 4a. (IF YES) Is your child's need for special therapy because of any medical, behavioral, or other health condition?
 - 4b. (IF YES) Is this a condition that has lasted or is expected to last 12 months or longer?
5. Does your child have any kind of emotional, developmental or behavioral problem for which he or she needs treatment or counseling?
 - 5a. (IF YES) Has your child's emotional, developmental, or behavioral problem lasted or is it expected to last 12 months or longer?

Analysis by Health Insurance Coverage

The analyses in this report are stratified by the child’s health insurance coverage at the time of interview. There are three analysis groups, as shown in the table below, plus a total column, for each of the two years the data was collected.

The Total row for each year includes all children with special health care needs, including children who have some other kind of insurance than Medicaid or Private and also includes those with no health insurance. The Both Row includes children with both Medicaid and private insurance (also known as Katie Beckett). The group with no insurance is not included in the analysis because the numbers are too small.

Analysis Groups

	2001			2005-06		
	Unweighted n	Weighted N	Weighted %	Unweighted n	Weighted N	Weighted %
Medicaid	172	8,191	23%	189	12,531	30%
Private	493	22,613	64%	531	22,492	54%
Both	57	3,035	9%	94	5,308	13%
None	28	1,426	4%	35	1,430	3%
TOTAL	750	35,265	100%	850	41,782	100%

Characteristics of Children

Table 1
Characteristics of Children with Special Health Care Needs in RI by Health Insurance Coverage

	Medicaid		Private		Both		TOTAL	
	2001 (N=8,191)	2005-6 (N=12,531)	2001 (N=22,613)	2005-6 (N=22,492)	2001 (N=3,035)	2005-6 (N=5,308)	2001 (N=35,265)	2005-6 (N=41,782)
Child's Age								
<5	30.0	11.8	8.4	14.5	28.5	14.5	15.5	13.5
5 - 11	40.7	42.9	43.5	39.9	36.2	46.9	42.4	41.4
12 – 17	29.3	45.3	48.2	45.6	35.4	38.7	42.1	45.1
Sex								
Male	67.3	61.6	58.7	60.7	58.4	67.3	60.9	61.8
Female	32.7	38.5	41.4	39.3	41.6	32.7	39.2	38.1
Race								
White, Non-Hispanic	51.5	57.4	90.1	90.2	74.8	63.9	79.2	76.6
Black, Non-Hispanic	11.4	10.5	2.8	2.9	8.7	11.4	5.5	6.2
Hispanic	27.8	22.0	3.2	4.2	11.0	15.3	10.0	11.6
Other	9.3	10.1	4.0	2.7	5.6	9.5	5.3	5.7
Poverty Level								
<100%	45.9	53.9	1.2	2.8	20.9	25.1	13.9	21.5
100-199%	40.8	37.9	12.4	11.4	36.5	40.8	21.7	22.8
200-399	11.5	7.6	46.4	41.6	22.3	21.1	36.1	29.0
≥ 400%	1.8	0.6	40.0	44.3	20.3	13.1	28.4	26.7

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2001 (N=35,265, n=750) and 2005-06 (N=41,782, n=850).

Disability Measures

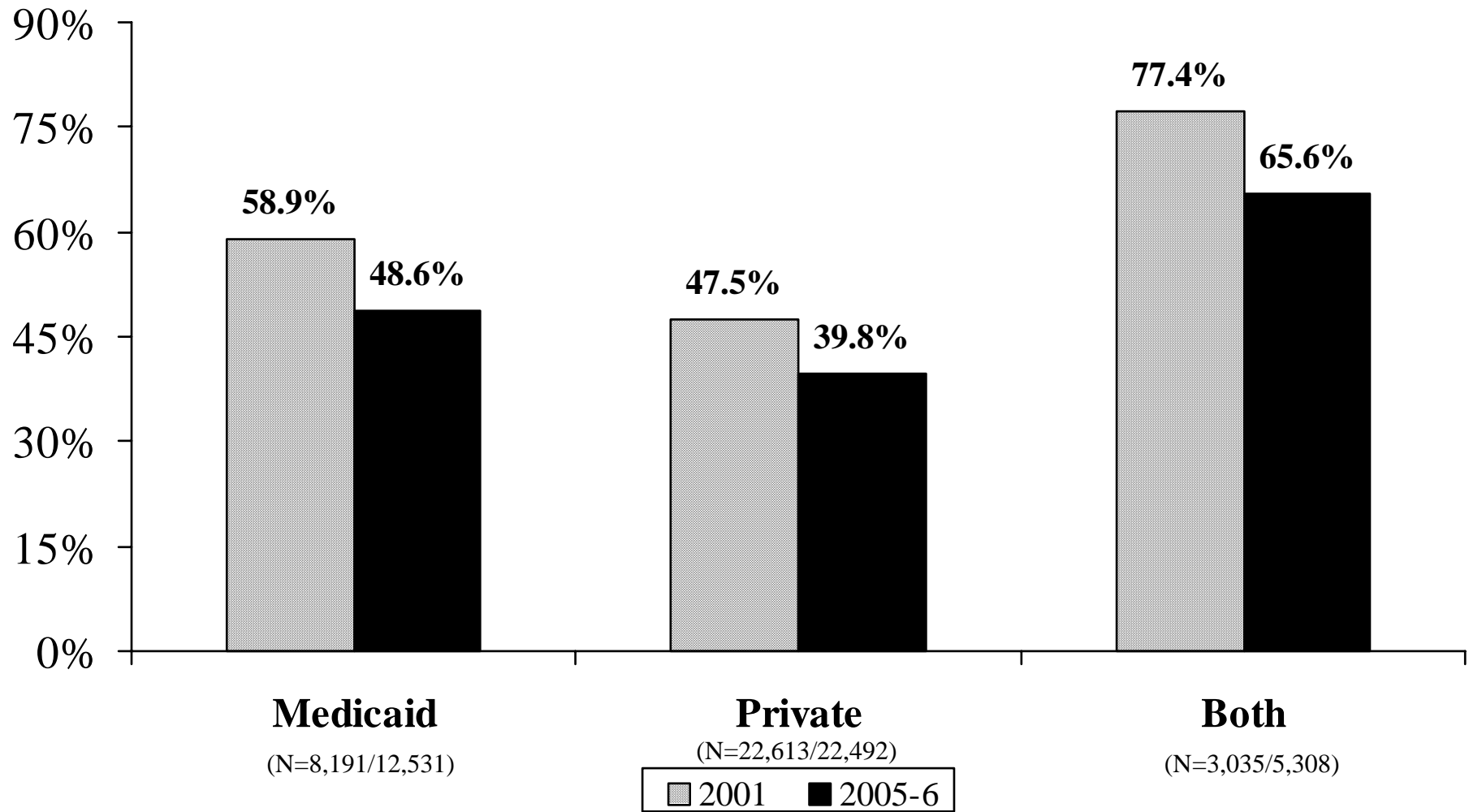
Table 2
Disability Measures[±] for RI Children with Special Health Care Needs by Health Insurance Coverage

	Medicaid		Private		Both		TOTAL	
	2001 (N=8,191)	2005-6 (N=12,531)	2001 (N=22,613)	2005-6 (N=22,492)	2001 (N=3,035)	2005-6 (N=5,308)	2001 (N=35,265)	2005-6 (N=41,782)
Percent of children who need or use more medical care than most children same age	58.9	48.6	47.5	39.8	77.4	65.6	52.6	46.0
Percent of children who need or use medicine prescribed by doctor	75.9	74.5	83.5	80.9	85.1	78.1	81.1	78.4
Percent of children who are limited or unable to do things most children same age do	27.8	23.1	13.6	14.3	49.2	32.7	20.4	19.7
Percent of children who need or get physical/occupational/speech therapy for condition	27.8	26.3	16.0	20.2	55.2	31.2	22.7	23.5
Percent of children who have emotional/behavioral/developmental issues for which he/she needs treatment	33.1	42.9	24.0	24.1	53.5	48.3	28.6	33.4

[±] Disability measure = 5 FACCT screening questions. The numbers in this table reflect the percentages who said that the selected child met this condition

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2001 (N=35,265, n=750) and 2005-06 (N=41,782, n=850).

Figure 1: Percent of RI Children with Special Needs Who Need or Use More Medical Care than Most Children of Same Age



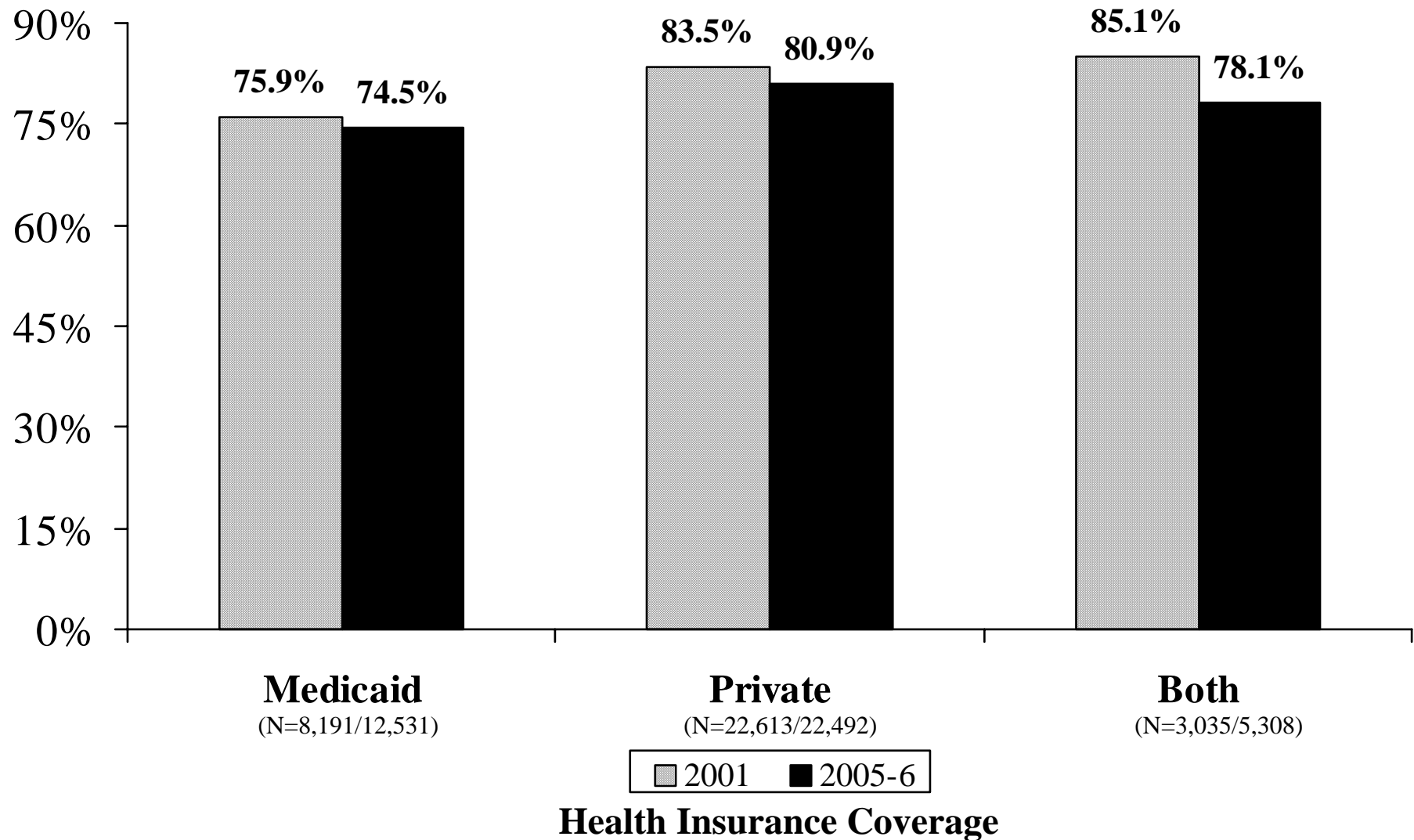
Health Insurance Coverage

Data Source: National Survey of Children with Special Health Care Needs – Rhode Island Sample

NCHS: CDC, 2001 (N=35,265) (n=750), CDC, 2005-6 (N=41,782) (n=850)

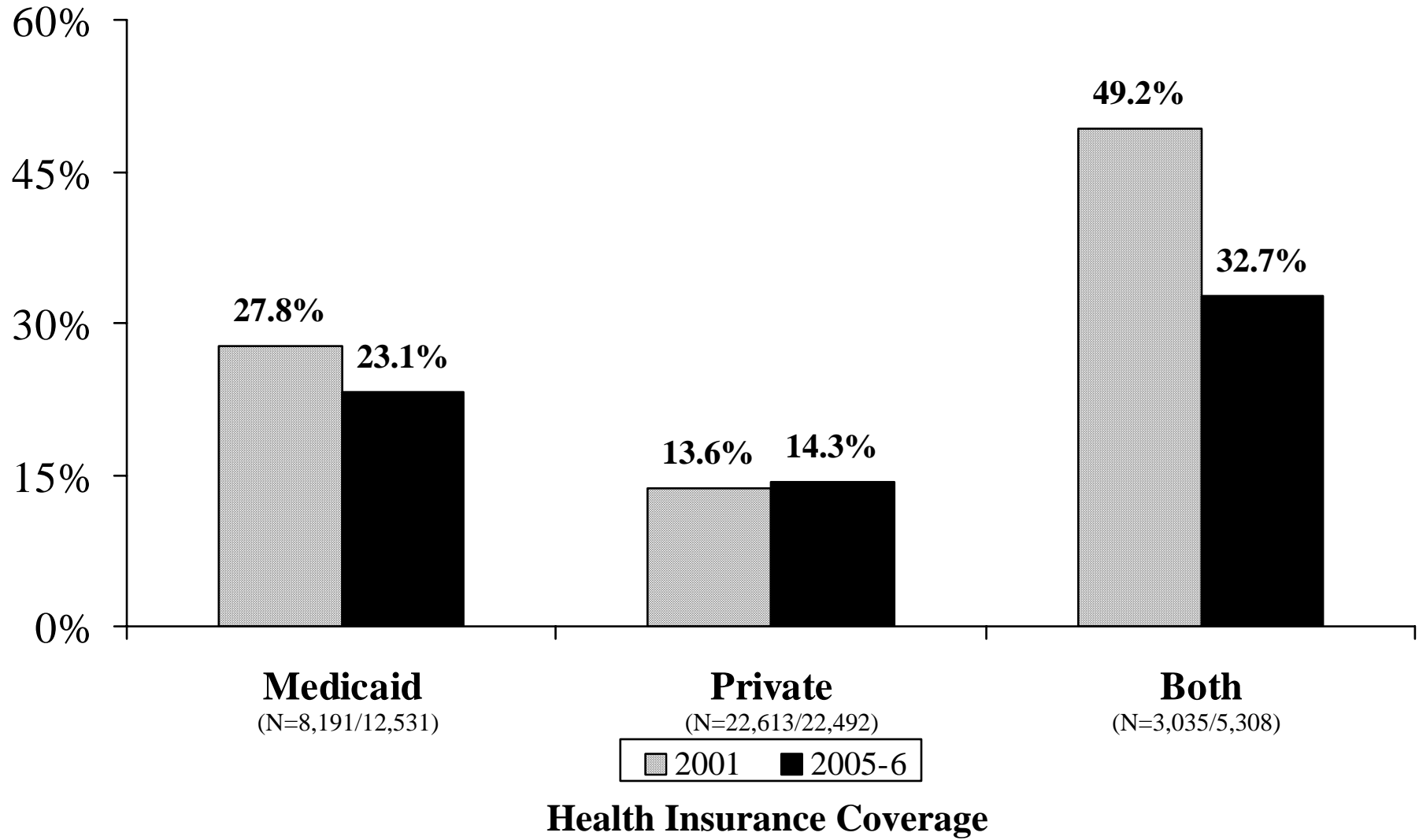
Analysis – RI Medicaid Research & Evaluation Project

Figure 2: Percent of RI Children with Special Needs Who Needs or Uses Medicine Prescribed by Doctor



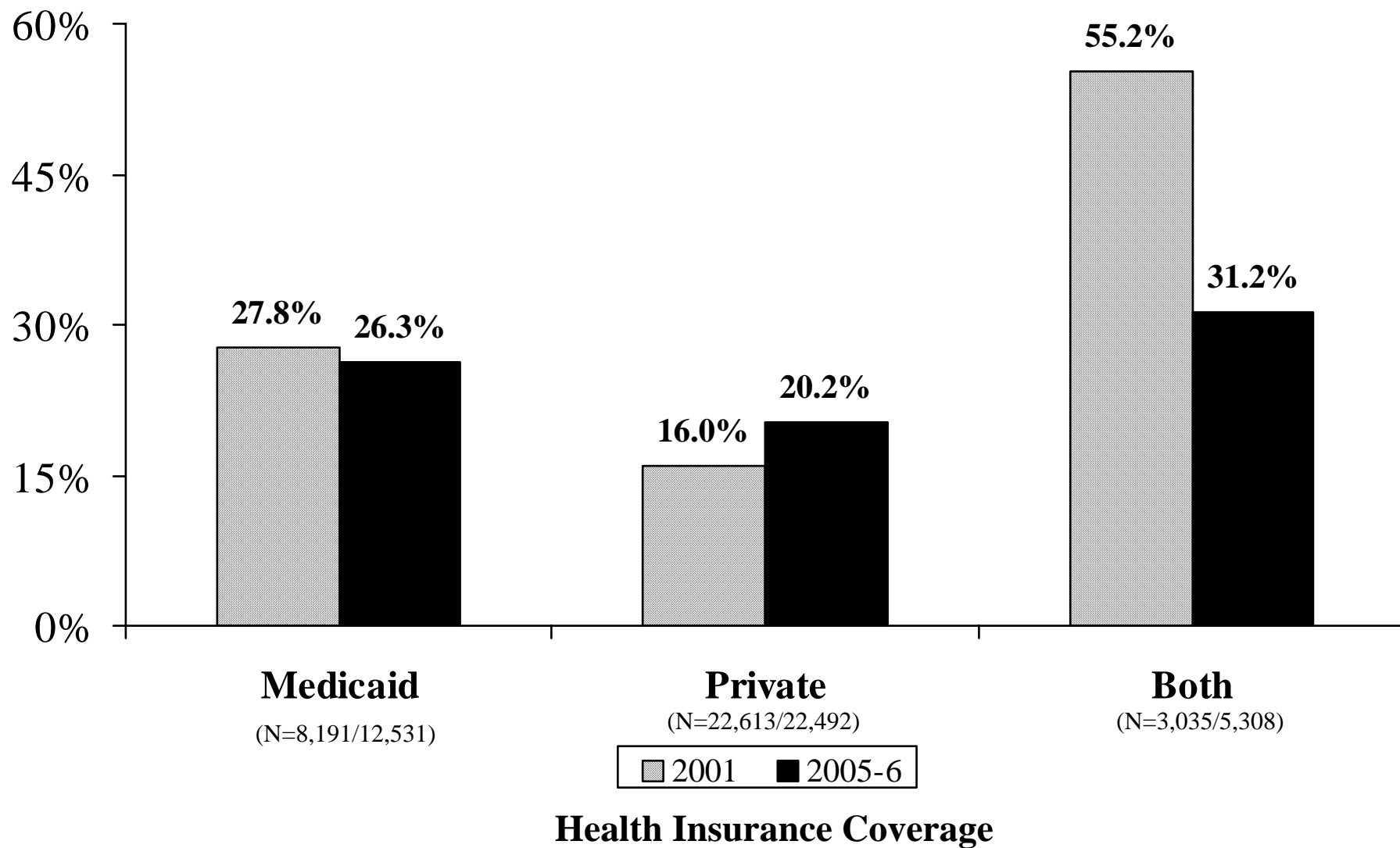
Data Source: National Survey of Children with Special Health Care Needs – Rhode Island Sample
 NCHS: CDC, 2001 (N=35,265) (n=750), CDC, 2005-6 (N=41,782) (n=850)
 Analysis – RI Medicaid Research & Evaluation Project

Figure 3: Percent of RI Children with Special Needs Who are Limited or Unable to Do Things Most Children Same Age Do



Data Source: National Survey of Children with Special Health Care Needs – Rhode Island Sample
 NCHS: CDC, 2001 (N=35,265) (n=750), CDC, 2005-6 (N=41,782) (n=850)
 Analysis – RI Medicaid Research & Evaluation Project

Figure 4: Percent of RI Children with Special Needs Who are Need or Get Physical/Occupational/Speech Therapy

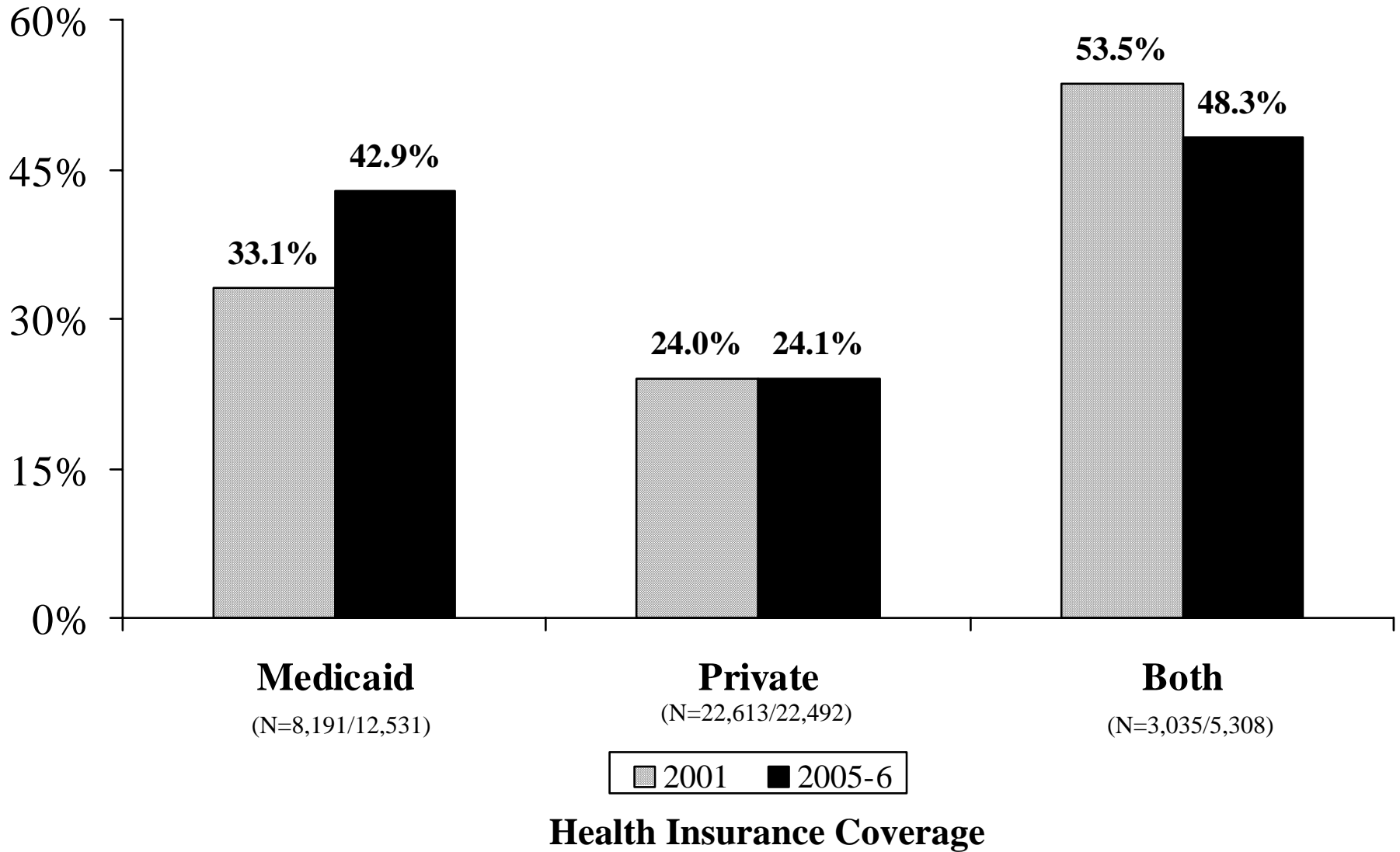


Data Source: National Survey of Children with Special Health Care Needs – Rhode Island Sample

NCHS: CDC, 2001 (N=35,265) (n=750), CDC, 2005-6 (N=41,782) (n=850)

Analysis – RI Medicaid Research & Evaluation Project

Figure 5: Percent of RI Children with Special Needs Who Have Emotional, Behavioral or Developmental Issues that Need Treatment



Data Source: National Survey of Children with Special Health Care Needs – Rhode Island Sample
 NCHS: CDC, 2001 (N=35,265) (n=750), CDC, 2005-6 (N=41,782) (n=850)
 Analysis – RI Medicaid Research & Evaluation Project

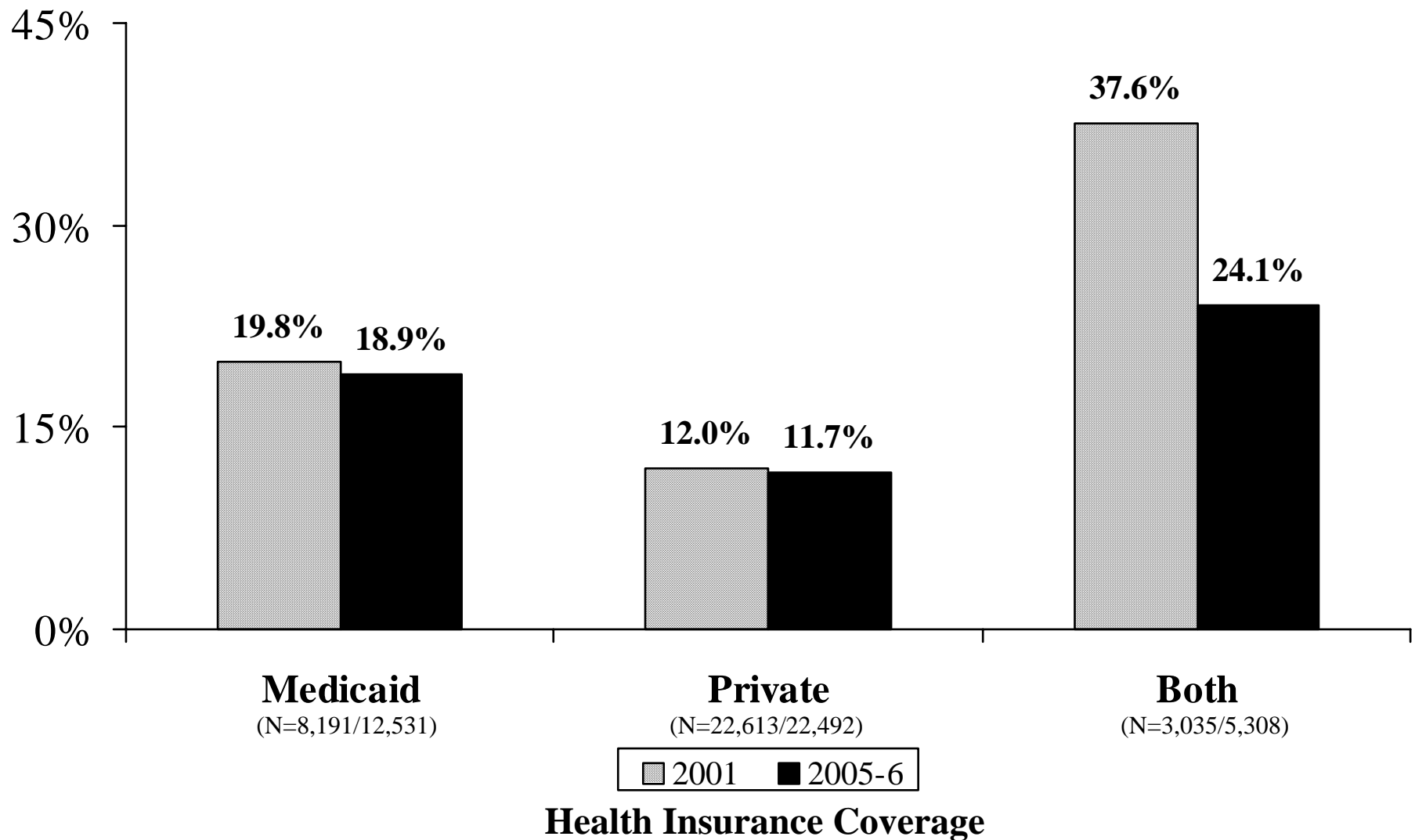
Health and Functional Status

Table 3**Health and Functional Status for RI Children with Special Health Care Needs by Health Insurance Coverage**

	Medicaid		Private		Both		TOTAL	
	2001 (N=8,191)	2005-6 (N=12,531)	2001 (N=22,613)	2005-6 (N=22,492)	2001 (N=3,035)	2005-6 (N=5,308)	2001 (N=35,265)	2005-6 (N=41,782)
How often child is affected by condition								
% Never	35.0	26.2	50.9	48.0	21.4	18.6	44.1	36.9
% Sometimes	41.8	50.3	36.5	38.5	39.9	50.4	38.5	43.8
% Usually	6.6	9.0	5.8	7.3	6.2	3.9	6.0	7.4
% Always	16.1	14.1	6.2	5.6	32.6	27.1	11.0	11.4
How does condition affect child's ability to do things								
% A great deal	19.8	18.9	12.0	11.7	37.6	24.1	17.7	16.8
% Some	50.3	40.9	49.3	42.2	39.7	48.3	47.8	42.9
% Very little	29.2	39.7	38.6	45.6	22.7	27.7	34.3	39.9
Child's health care needs								
% Change all the time	9.9	13.0	2.1	2.7	17.3	6.7	5.3	6.4
% Change once in awhile	39.3	28.3	24.2	21.3	29.5	36.6	28.7	25.5
% Are stable	49.3	56.1	73.2	75.2	53.2	56.7	65.3	66.8
Child receives special education services (% Yes)	38.5	43.5	27.5	27.2	72.9	51.4	34.2	35.6

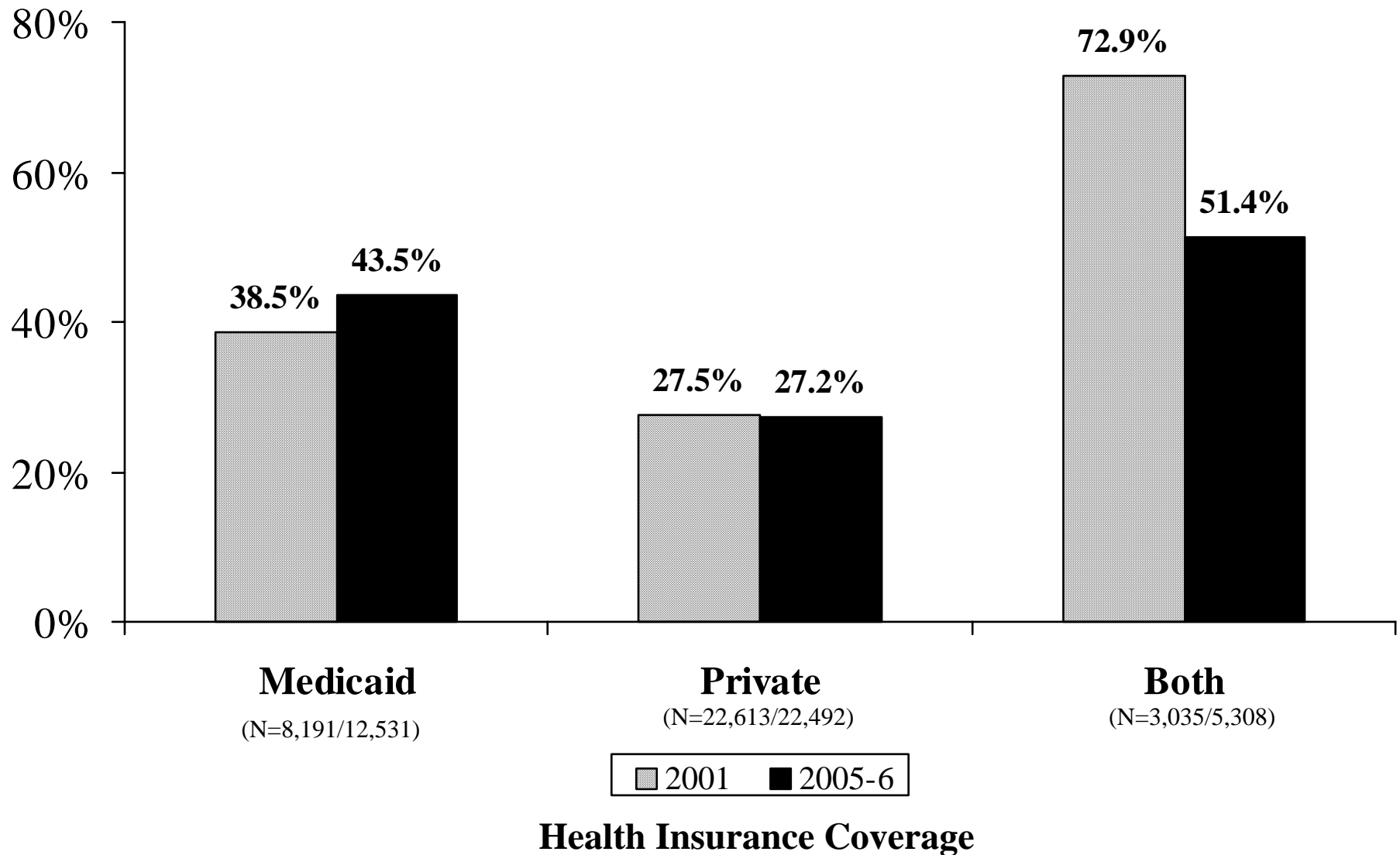
Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2001 (N=35,265, n=750) and 2005-06 (N=41,782, n=850).

Figure 6: Percent of Parents of RI Children with Special Needs Whose Condition Affects Their Ability to do Things a Great Deal



Data Source: National Survey of Children with Special Health Care Needs – Rhode Island Sample
 NCHS: CDC, 2001 (N=35,265) (n=750), CDC, 2005-6 (N=41,782) (n=850)
 Analysis – RI Medicaid Research & Evaluation Project

Figure 7: Percent of RI Children with Special Needs Who Receive Special Education Services



Data Source: National Survey of Children with Special Health Care Needs – Rhode Island Sample
 NCHS: CDC, 2001 (N=35,265) (n=750), CDC, 2005-6 (N=41,782) (n=850)
 Analysis – RI Medicaid Research & Evaluation Project

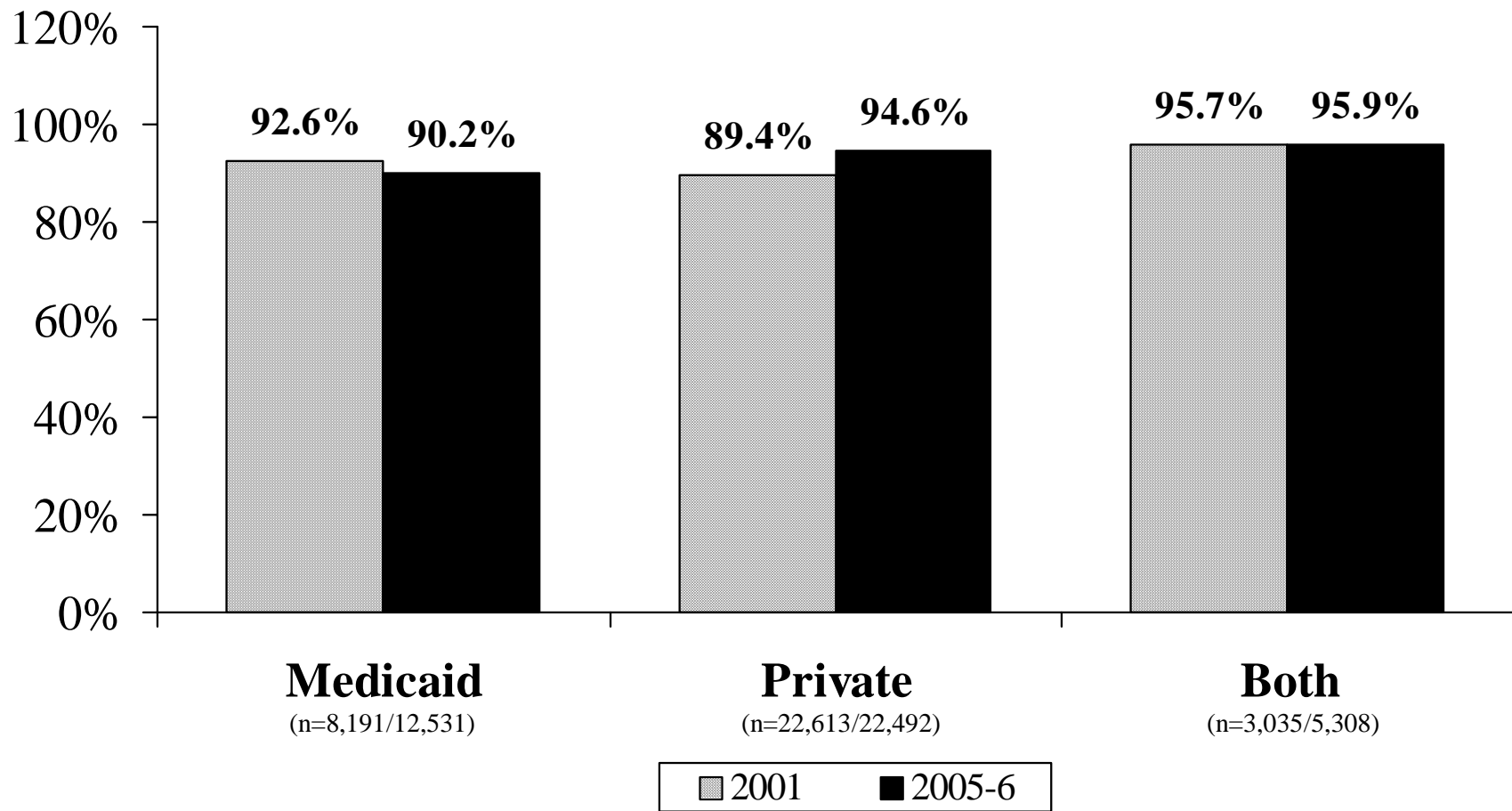
Access to Care

Table 4**Access to Care Measures for RI Children with Special Health Care Needs by Health Insurance Coverage**

	Medicaid		Private		Both		TOTAL	
	2001 (N=8,191)	2005-6 (N=12,531)	2001 (N=22,613)	2005-6 (N=22,492)	2001 (N=3,035)	2005-6 (N=5,308)	2001 (N=35,265)	2005-6 (N=41,782)
Percent of children who have usual source of sick care	92.6	90.2	89.4	94.6	95.7	95.9	90.5	93.4
Percent of children who delay or do not get needed medical care	10.9	8.5	2.7	3.7	6.5	6.7	5.3	6.1
Percent of children who missed >10 days of school due to illness/injury	25.5	20.5	7.4	11.3	26.1	18.2	13.5	14.8
Kind of place child goes for care								
% MD office	53.6	67.6	92.2	93.8	75.0	75.2	80.3	82.5
% Hospital ED	2.4	2.6	1.0	0.6	0.0	1.3	1.3	1.3
% Hospital outpatient	10.4	4.8	2.8	1.0	5.1	4.6	5.3	2.7
% Clinic or health Center	33.6	25.1	3.4	4.4	19.9	18.9	12.5	13.5
% Other Place	0.0	0.0	1.0	0.0	0.0	0.0	0.7	0

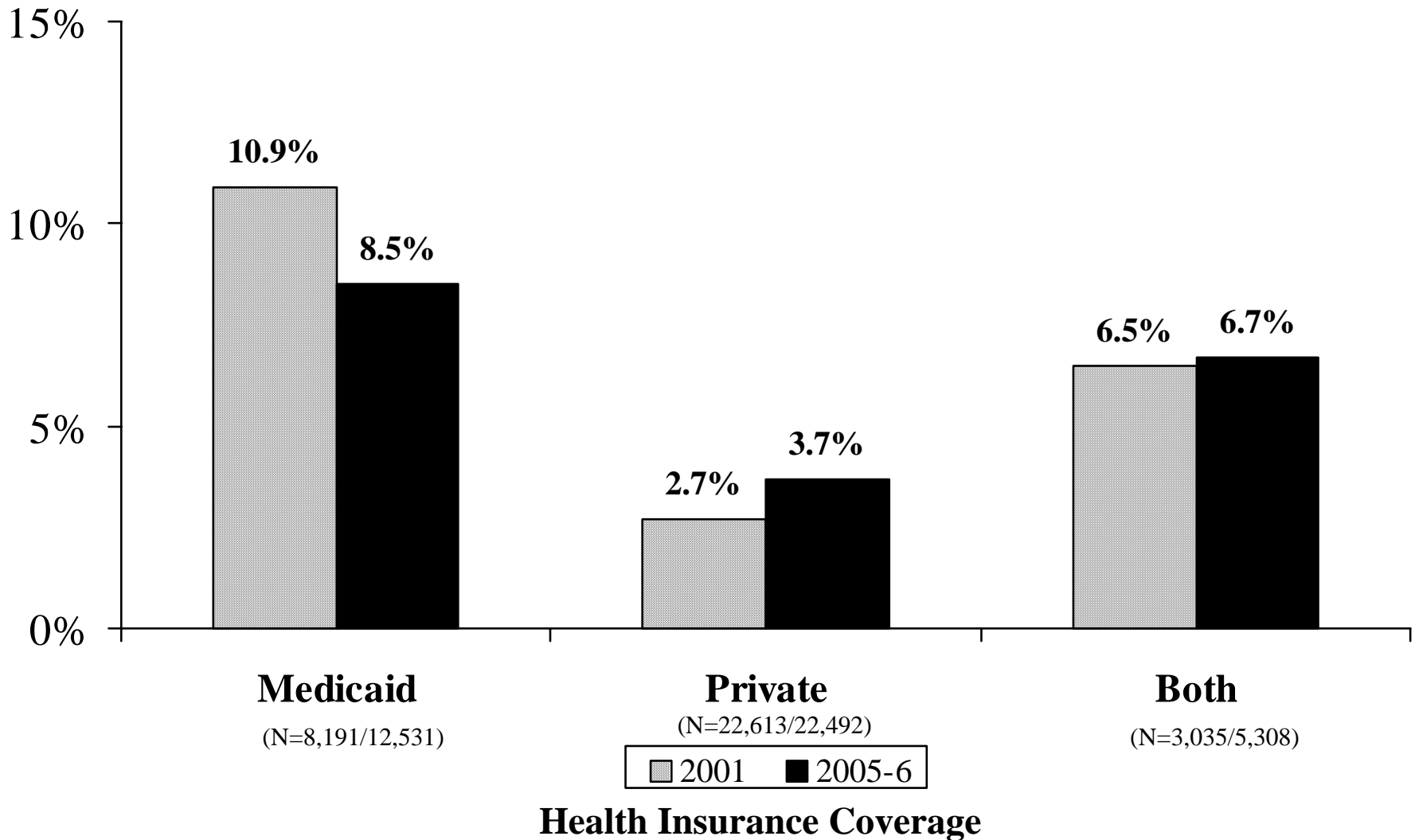
Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2001 (N=35,265, n=750) and 2005-06 (N=41,782, n=850).

Figure 8: Percent of RI Children with Special Needs
Who Have a Usual Source of Care



Data Source: National Survey of Children with Special Health Care Needs – Rhode Island Sample
 NCHS: CDC, 2001 (N=35,265) (n=750), CDC, 2005-6 (41,782) (n=850)
 Analysis – RI Medicaid Research & Evaluation Project

Figure 9: Percent of RI Children with Special Needs Who Delay or Do Not Get Needed Care



Data Source: National Survey of Children with Special Health Care Needs – Rhode Island Sample
 NCHS: CDC, 2001 (N=35,265) (n=750), CDC, 2005-6 (N=41,782) (n=850)
 Analysis – RI Medicaid Research & Evaluation Project

Unmet Health Care Needs

Table 5

Unmet Health Care Needs of RI Children with Special Health Care Needs by Health Insurance Coverage

	Medicaid		Private		Both		TOTAL	
	2001 (N=8,191)	2005-6 (N=12,531)	2001 (N=22,613)	2005-6 (N=22,492)	2001 (N=3,035)	2005-6 (N=5,308)	2001 (N=35,265)	2005-6 (N=41,782)
MEDICAL SERVICE								
Prescription Medication								
% Needed this Service	81.6	79.2	93.6	88.3	81.0	82.1	88.9	84.4
% Did Not Receive Service	4.5	4.8	1.0	0.4	1.6	1.0	1.8	1.8
Number of Children with Unmet Need	301	478	217	74	39	41	567	621
Routine Preventive Care								
% Needed this Service	78.6	77.5	86.2	90.8	84.5	80.1	83.7	84.9
% Did Not Receive Service	1.8	2.9	1.5	0	0	0	1.7	1.1
Number of Children with Unmet Need	118	278	290	0	0	0	488	402
Care from Specialty MD								
% Needed this Service	49.7	49.6	58.6	57.6	66.1	66.4	56.6	55.8
% Did Not Receive Service	5.9	3.3	2.7	3.8	1.4	3.6	3.6	3.6
Number of Children with Unmet Need	239	205	359	493	27	128	724	849

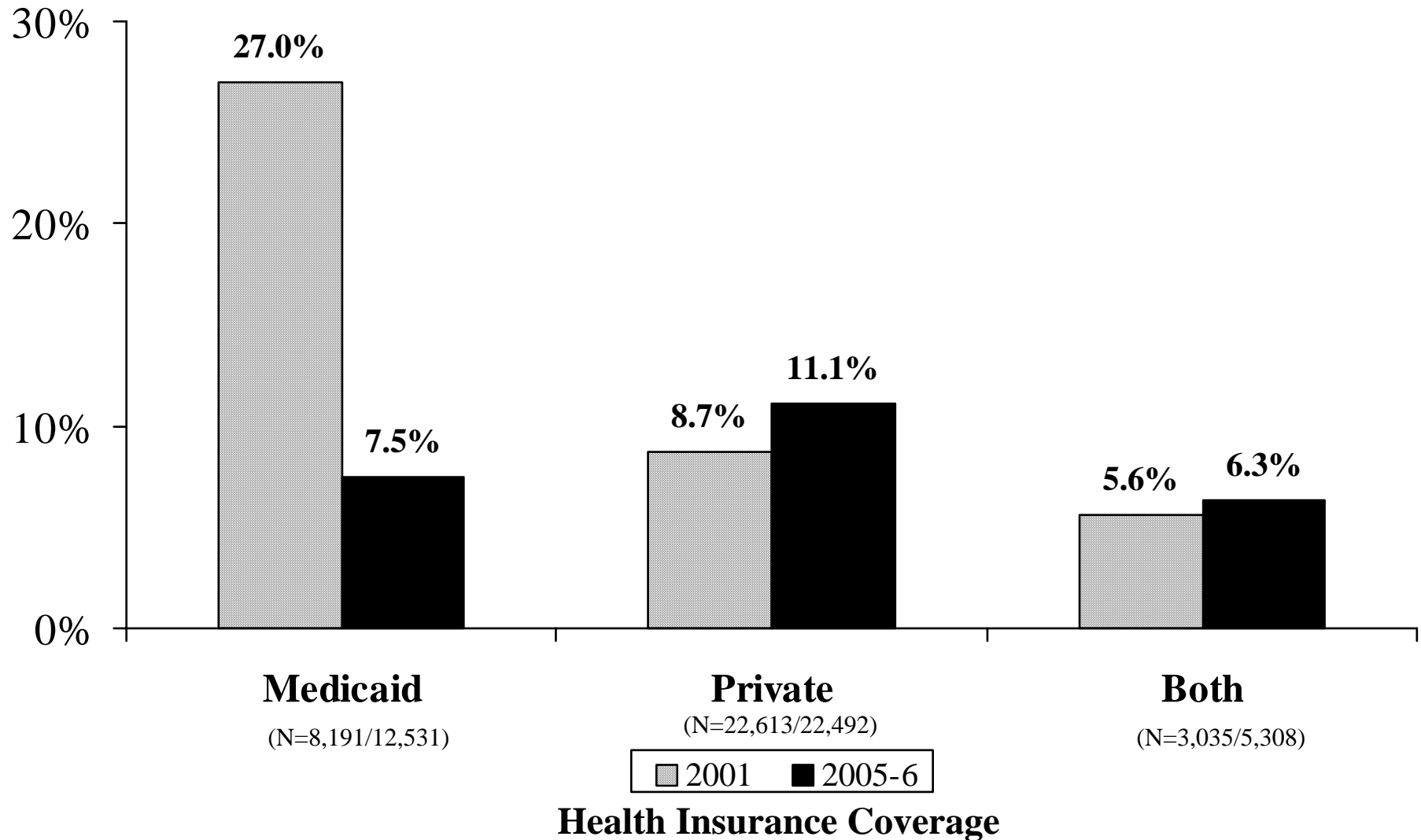
	Medicaid		Private		Both		TOTAL	
	2001 (N=8,191)	2005-6 (N=12,531)	2001 (N=22,613)	2005-6 (N=22,492)	2001 (N=8,191)	2005-6 (N=12,531)	2001 (N=22,613)	2005-6 (N=22,492)
Eyeglasses /Vision Care								
% Needed this Service	30.1	33.6	33.4	32.8	35.5	33.1	33.3	32.8
% Did Not Receive Service	16.8	3.4	0.2	0.8	0	2.8	4.0	2.1
Number of Children with Unmet Need	413	144	12	55	0	48	474	289
Mental Health Care/ Counseling for child								
% Needed this Service	27.8	33.2	22.0	22.4	39.7	34.8	26.1	27.6
% Did Not Receive Service	27.0	7.5	8.7	11.1	5.6	6.3	15.0	9.9
Number of Children with Unmet Mental Health Need	614	312	432	558	67	117	1376	1143
Physical/Occupational/ Speech Therapy								
% Needed this Service	30.8	27.7	17.6	23.4	58.3	36.6	24.5	26.5
% Did Not Receive Service	5.9	4.9	11.4	10.2	22.5	21.7	11.9	10.2
Number of Children with Unmet PT, OT Need	149	169	454	538	399	422	1031	1129
Disposable Medical Supplies								
% Needed this Service	30.7	16.9	17.4	15.6	35.0	21.4	22.2	16.9
% Did Not Receive Service	2.2	0	1.0	4.5	0	3.9	1.1	2.9
Number of Children with Unmet Need for supplies	56	0	31	159	0	45	87	204

	Medicaid		Private		Both		TOTAL	
	2001 (N=8,191)	2005-6 (N=12,531)	2001 (N=22,613)	2005-6 (N=22,492)	2001 (N=8,191)	2005-6 (N=12,531)	2001 (N=22,613)	2005-6 (N=22,492)
Mental health counseling for family members								
% Needed this Service	14.1	20.0	11.2	10.6	28.8	21.6	13.7	14.9
% Did Not Receive Service	16.1	14.4	12.3	15.6	29.7	7.2	17.3	14.2
Number of Children with Unmet Need	186	360	312	370	259	82	833	881
Hearing Aids								
% Needed this Service	7.9	12.3	5.0	3.5	14.8	1.6	6.8	6.0
% Did Not Receive Service	6.7	0	2.6	0	0	0	3.0	0
Number of Children with Unmet Need	43	0	29	0	0	0	72	0
Genetic Counseling								
% Needed this Service	12.1	5.9	3.7	2.2	7.7	4.0	6.8	3.7
% Did Not Receive Service	23.4	29.7	4.4	8.7	53.8	23.8	18.4	20.3
Number of Children with Unmet Need	231	219	35	44	126	50	441	313
Home Health Care								
% Needed	6.2	8.3	3.0	3.1	21.1	8.6	5.6	5.2
% Did Not Receive	3.9	9.9	5.1	18.0	9.4	22.5	5.8	15.1
Number of Children with Unmet Need	20	102	34	123	60	102	114	327

	Medicaid		Private		Both		TOTAL	
	2001 (N=8,191)	2005-6 (N=12,531)	2001 (N=22,613)	2005-6 (N=22,492)	2001 (N=8,191)	2005-6 (N=12,531)	2001 (N=22,613)	2005-6 (N=22,492)
Mobility Aids								
% Needed this Service	5.7	8.5	3.6	5.0	12.3	8.3	4.7	6.3
% Did Not Receive Service	30.8	0	0	0	0	10.4	8.0	1.8
Number of Children with Unmet Need	125	0	0	0	0	45	125	45
Substance Abuse Treatment								
% Needed this Service	3.4	4.3	3.9	1.5	2.8	4.7	3.6	2.7
% Did Not Receive Service	61.1	10.4	4.1	0	0	0	14.5	4.9
Number of Children with Unmet Need	102	39	27	0	0	0	129	39
Communication Devices								
% Needed this Service	3.2	2.1	1.7	2.1	14.5	6.0	3.0	2.8
% Did Not Receive Service	31.0	0	0	0	47.9	30.4	25.9	10.4
Number of Children with Unmet Need	71	0	0	0	189	94	260	117

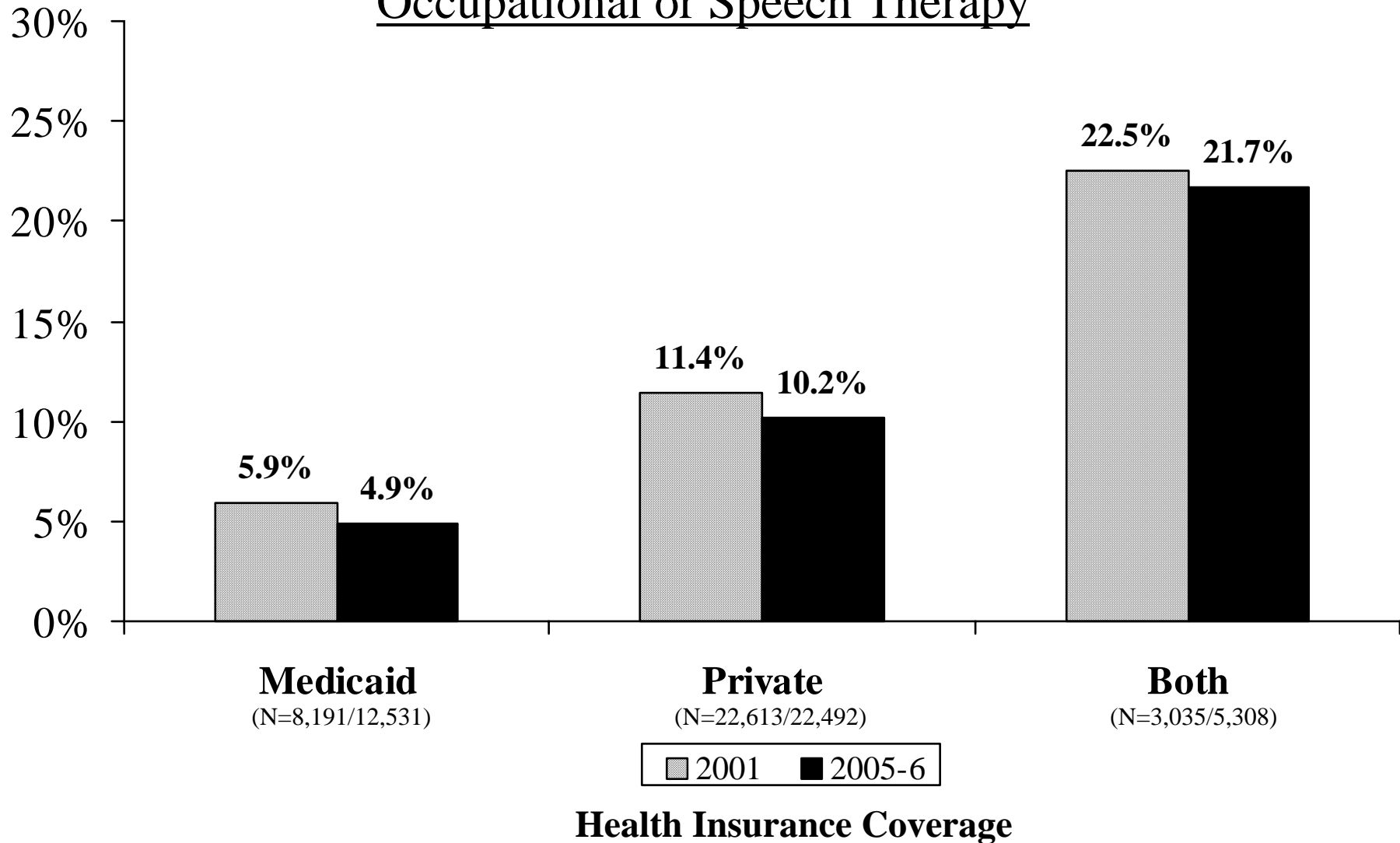
Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2001 (N=35,265, n=750) and 2005-06 (N=41,782, n=850).

**Figure 10: Percent of RI Children with Special Needs
Who Did Not Receive Needed Mental Health Care**



Data Source: National Survey of Children with Special Health Care Needs – Rhode Island Sample
 NCHS: CDC, 2001 (N=35,265) (n=750), CDC, 2005-6 (N=41,782) (n=850)
 Analysis – RI Medicaid Research & Evaluation Project

**Figure 11: Percent of RI Children with Special Needs
Who Did Not Receive Needed Physical,
Occupational or Speech Therapy**



Data Source: National Survey of Children with Special Health Care Needs – Rhode Island Sample
 NCHS: CDC, 2001 (N=35,265) (n=750), CDC, 2005-6 (N=41,782) (n=850)
 Analysis – RI Medicaid Research & Evaluation Project

Table 6
Ranking of Top Unmet Needs for All RI Children with Special Health Care Needs

2001		2005-06	
Listing of services with unmet need –shown in rank order for 2001	Number of RI children with special health care needs who need this care but do not get it	Listing of services with unmet need –shown in rank order for 2001	Number of RI children with special health care needs who need this care but do not get it
1st Any Dental Care	1,699	1st Any Dental Care	1,828
		Other Dental Care	1,352
2nd Mental Health Care/ Counseling for Child	1,376	2nd Mental Health Care/ Counseling for Child	1,143
3rd Physical/Occupational/ Speech Therapy	1,031	3rd Physical/Occupational/ Speech Therapy	1,129
4th Mental Health Counseling for Family Member	833	4th Respite Care	896
5th Care from Specialty MD	724	5th Mental Health Counseling for Family Member	881
6th Professional Care Coordinator	615	6th Care from Specialty MD	849
7th Prescription Drugs	567	7th Prescription Drugs	621
8th Respite Care	566	8th Routine Preventive Care	402
9th Routine Preventive Care	488	9th Home Health Care	327
10th Eyeglasses/Vision Care	474	10th Genetic Counseling	313

Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2001 (N=35,265, n=750) and 2005-06 (N=41,782, n=850).

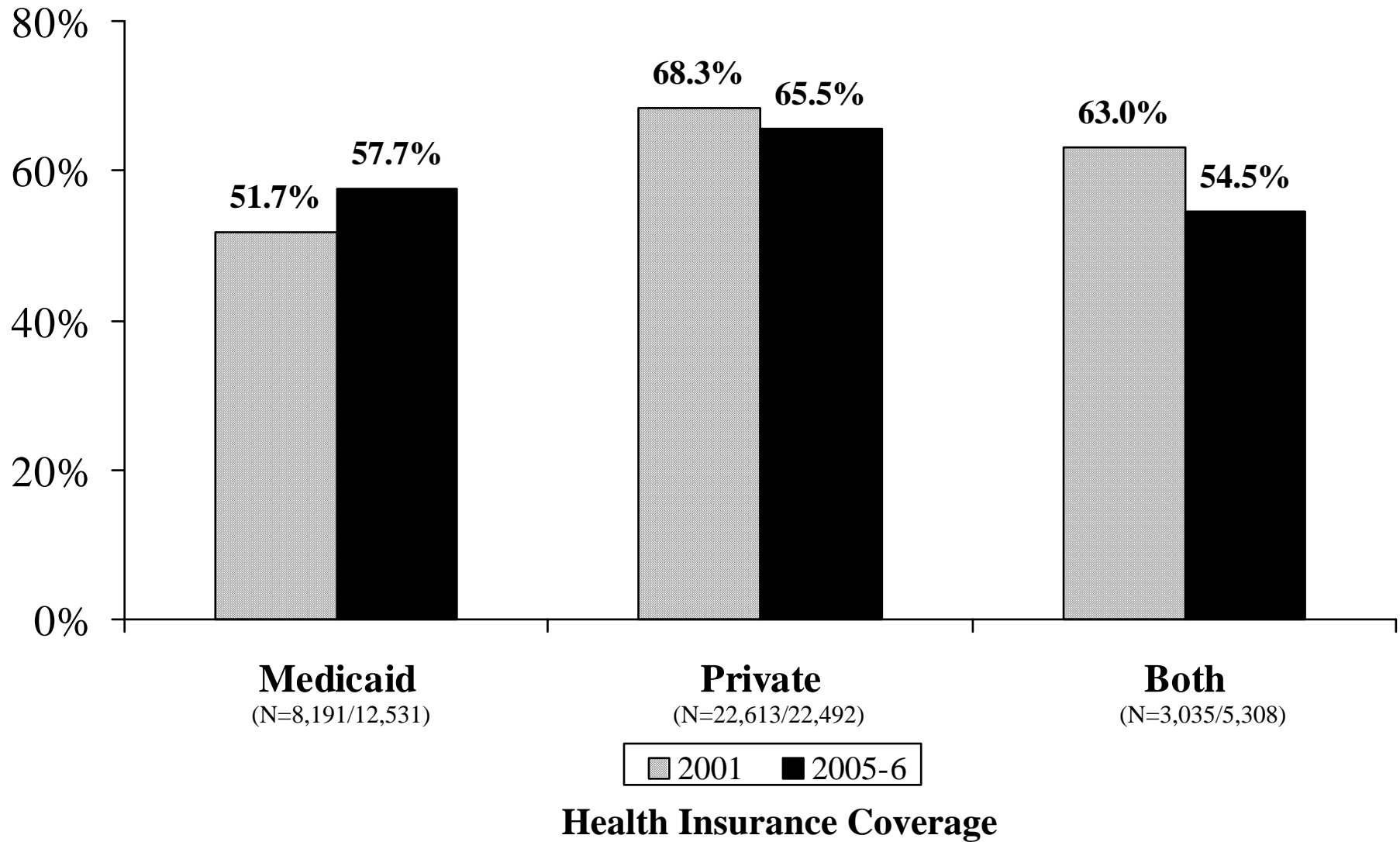
Satisfaction with Medical Provider

Table 7
Satisfaction with Health Care Provider by Health Insurance Coverage

	Medicaid		Private		Both		TOTAL	
	2001 (N=8,191)	2005-6 (N=12,531)	2001 (N=22,613)	2005-6 (N=22,492)	2001 (N=3,035)	2005-6 (N=5,308)	2001 (N=35,265)	2005-6 (N=41,782)
Percent doctor and other health care provider <u>always...</u>								
...spend enough time with child	51.7	57.7	68.3	65.5	63.0	54.5	62.6	61.7
...listen carefully to you	66.5	66.4	71.5	72.0	60.4	65.3	69.3	69.5
...are sensitive to family's values and customs	61.1	71.1	65.2	74.4	59.0	60.7	63.0	71.3
... get specific information you needed about child's health problems	56.6	63.6	57.3	60.9	35.6	44.0	55.3	59.5
... help you feel like a partner	62.4	73.3	72.6	75.7	54.1	59.6	68.9	72.7

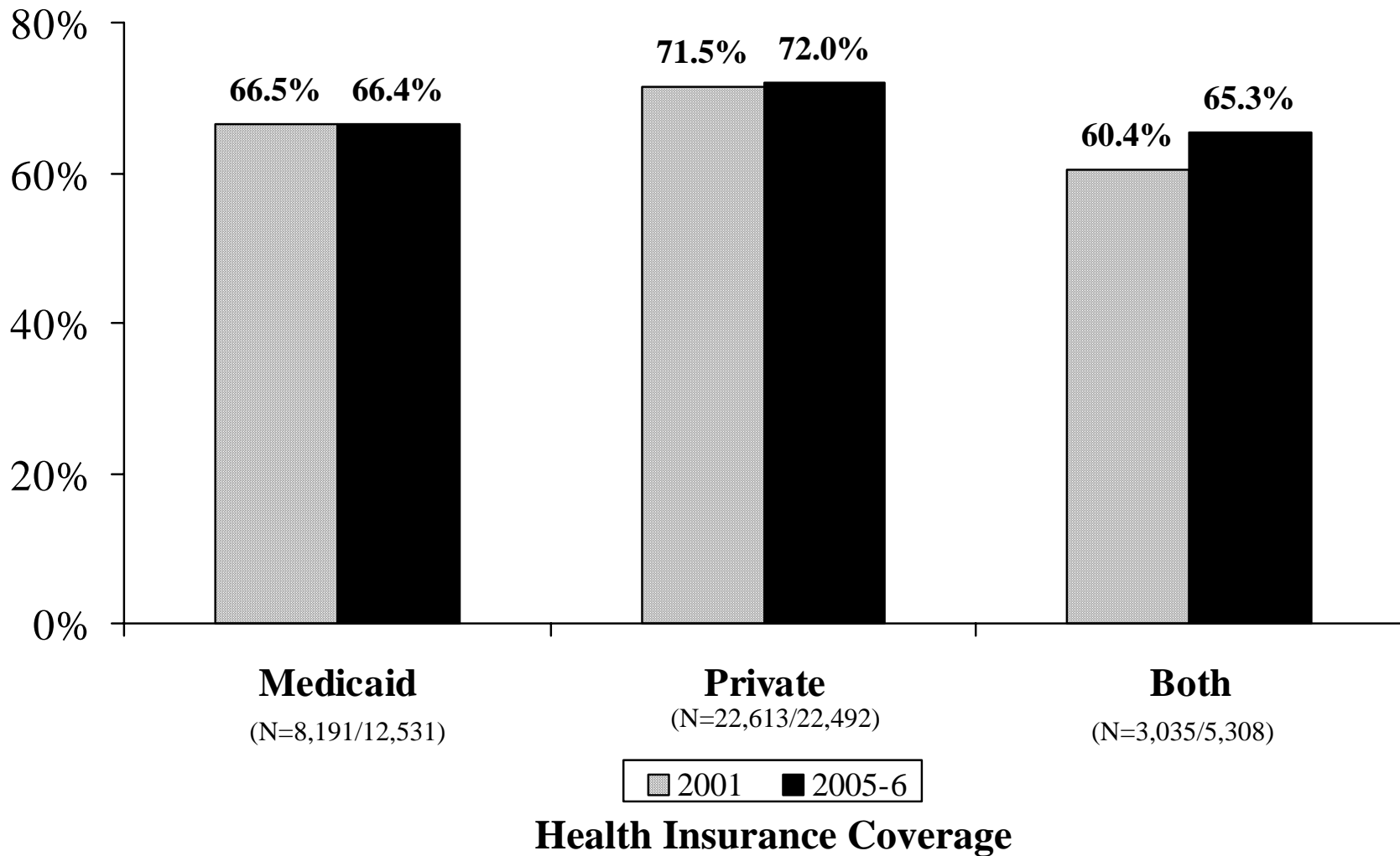
Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2001 (N=35,265, n=750) and 2005-06 (N=41,782, n=850).

Figure 12: Percent of Parents Who Say Doctor and Other Health Professionals Always Spend Enough Time with Child



Data Source: National Survey of Children with Special Health Care Needs – Rhode Island Sample
 NCHS: CDC, 2001 (N=35,265) (n=750), CDC, 2005-6 (N=41,782) (n=850)
 Analysis – RI Medicaid Research & Evaluation Project

Figure 13: Percent of Parents Who Say Doctor and Other Health Professionals Always Listen Carefully to Them

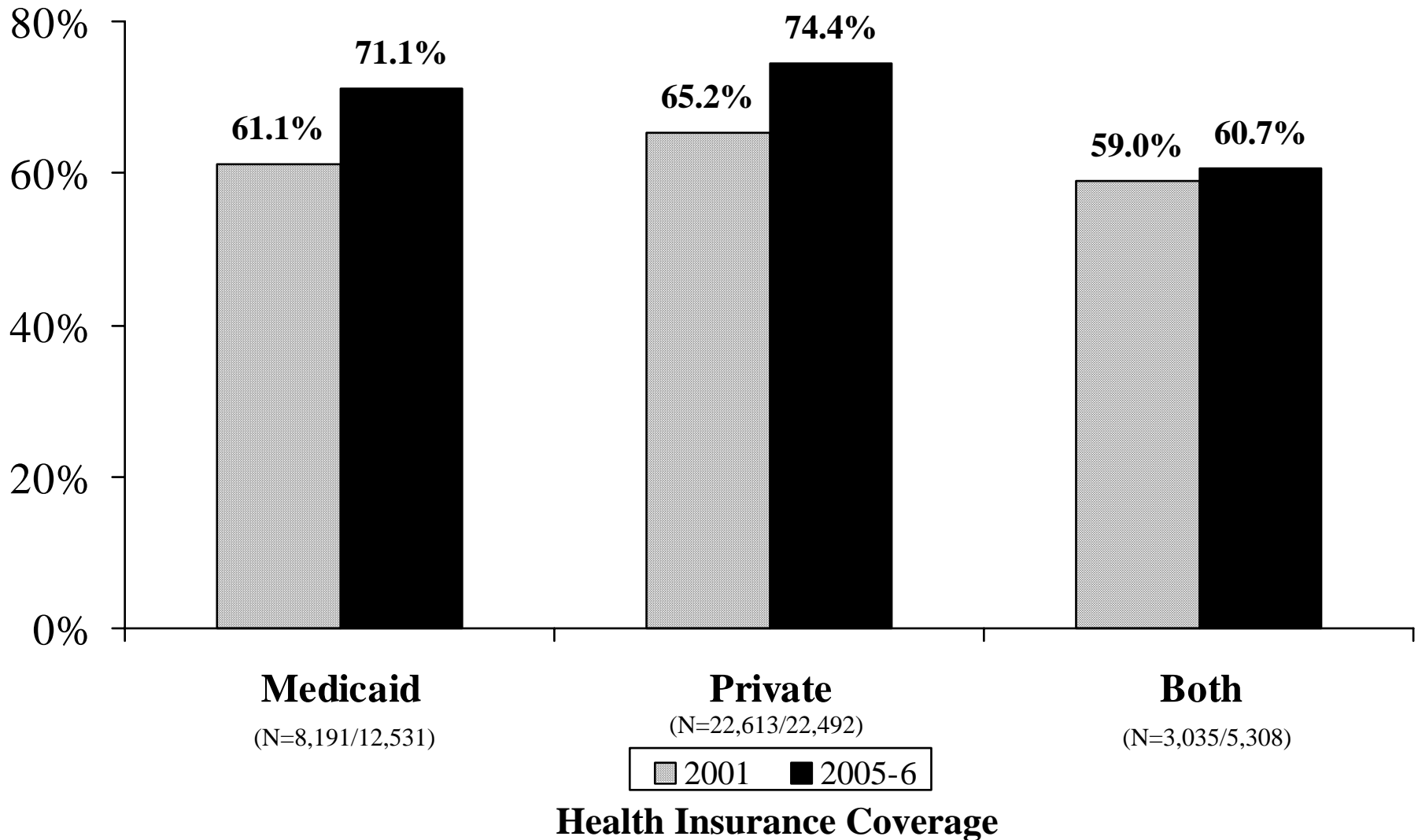


Data Source: National Survey of Children with Special Health Care Needs – Rhode Island Sample

NCHS: CDC, 2001 (N=35,265) (n=750), CDC, 2005-6 (N=41,782) (n=850)

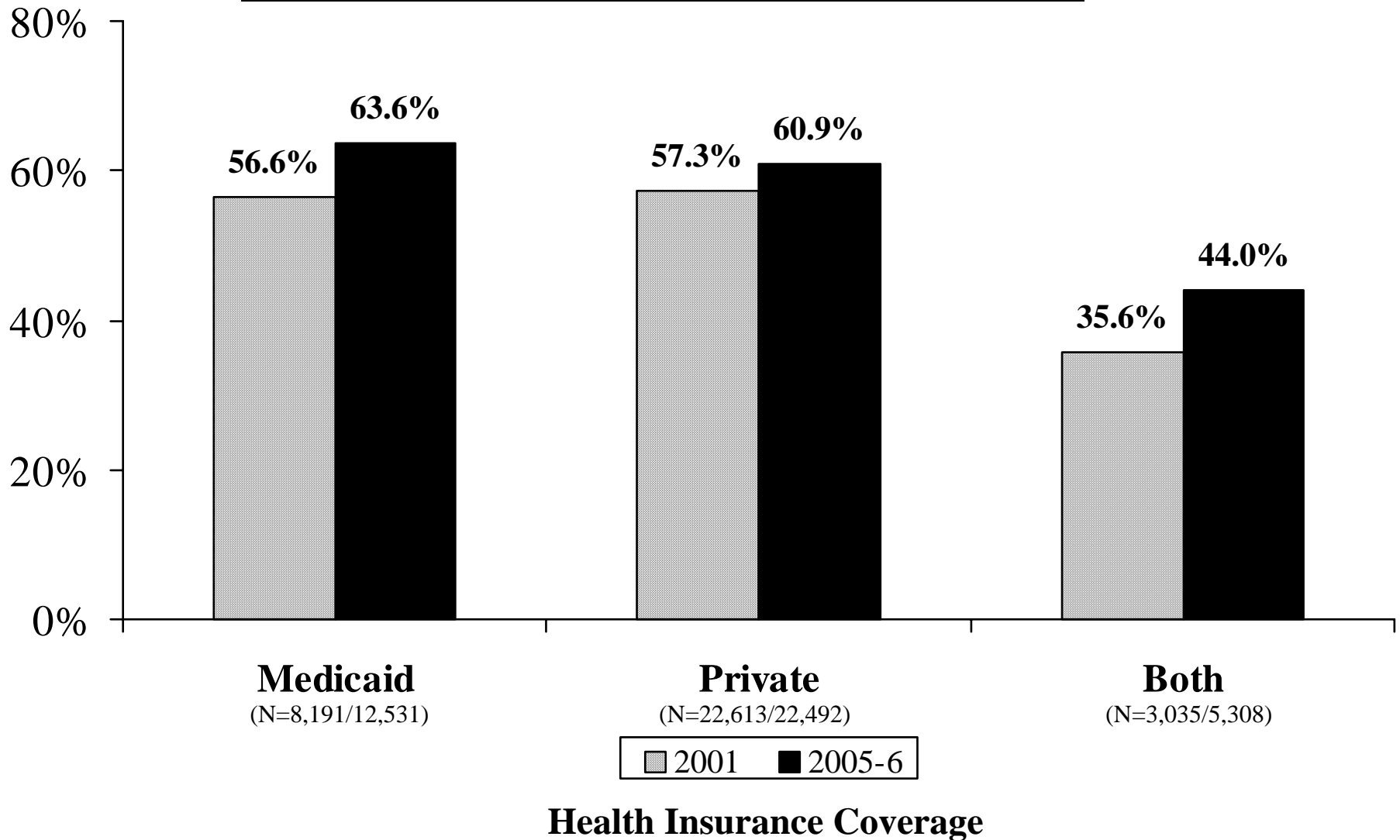
Analysis – RI Medicaid Research & Evaluation Project

Figure 14: Percent of Parents Who Say Doctor and Other Health Professionals Always are Sensitive to Family's Values and Concerns



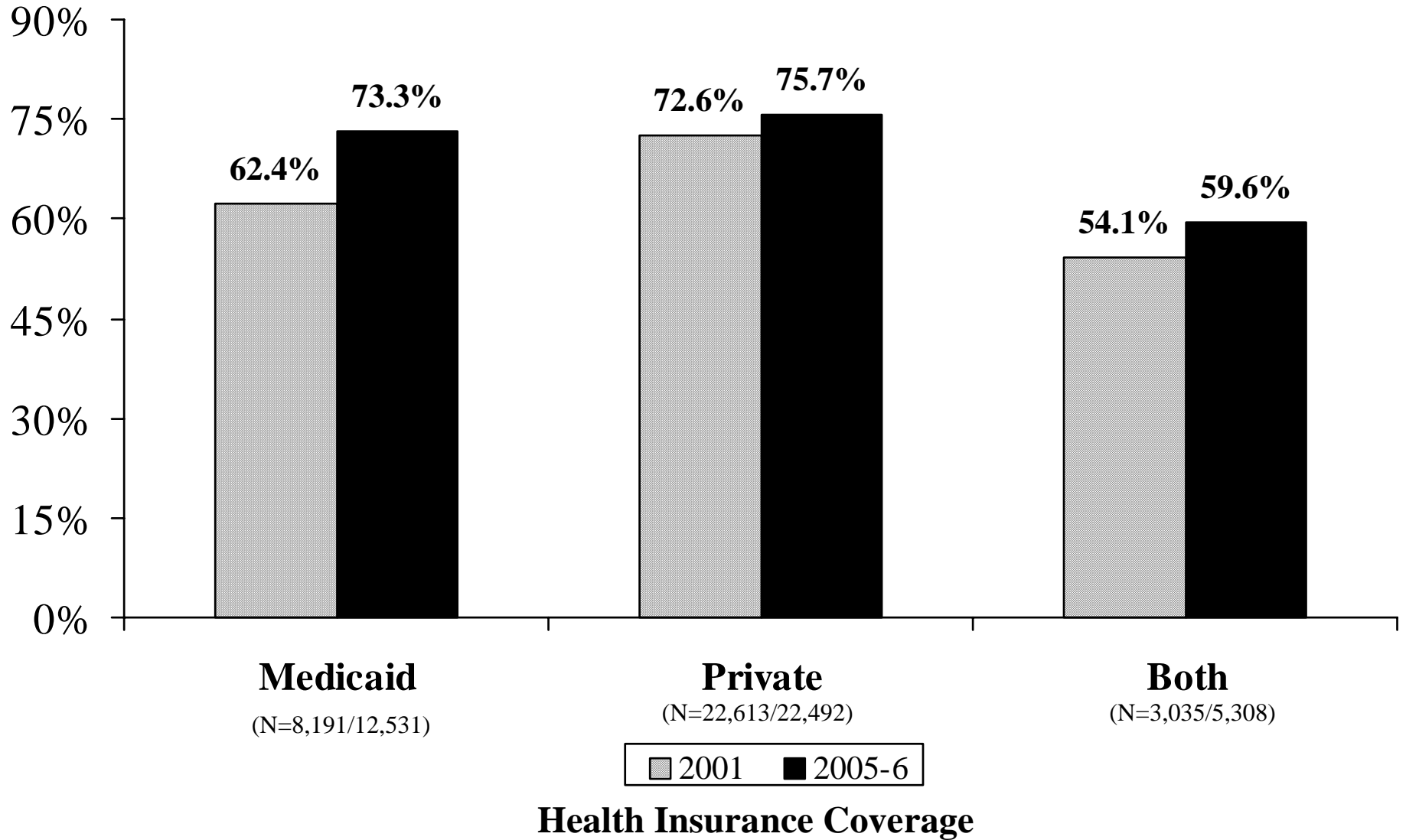
Data Source: National Survey of Children with Special Health Care Needs – Rhode Island Sample
 NCHS: CDC, 2001 (N=35,265) (n=750), CDC, 2005-6 (N=41,782) (n=850)
 Analysis – RI Medicaid Research & Evaluation Project

Figure 15: Percent of Parents Who Say Doctor and Other Health Professionals Always Get Specific Information You Need About Child's Health Problems



Data Source: National Survey of Children with Special Health Care Needs – Rhode Island Sample
 NCHS: CDC, 2001 (N=35,265) (n=750), CDC, 2005-6 (N=41,782) (n=850)
 Analysis – RI Medicaid Research & Evaluation Project

Figure 16: Percent of Parents Who Say Doctor and Other Health Professionals Always Help You Feel Like a Partner



Data Source: National Survey of Children with Special Health Care Needs – Rhode Island Sample

NCHS: CDC, 2001 (N=35,265) (n=750), CDC, 2005-6 (N=41,782) (n=850)

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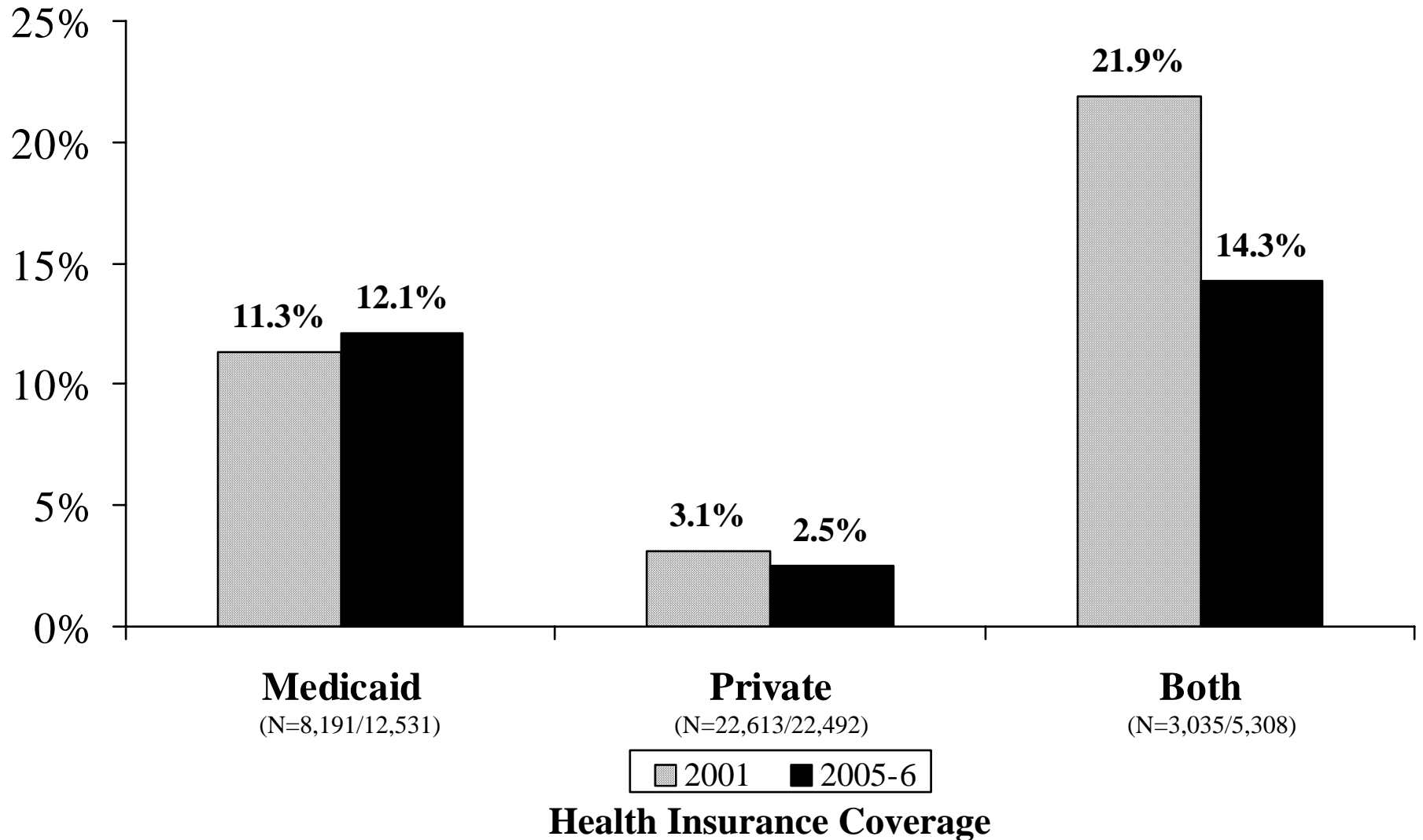
Impact on Family

Table 9**Impact on Family of Having a Child with Special Health Care Needs by Health Insurance Coverage**

	Medicaid		Private		Both		TOTAL	
	2001 (N=8,191)	2005-6 (N=12,531)	2001 (N=22,613)	2005-6 (N=22,492)	2001 (N=3,035)	2005-6 (N=5,308)	2001 (N=35,265)	2005-6 (N=41,782)
Hours per week spent arranging/coordinating care								
% < 2 hours	61.1	62.4	83.0	83.3	57.1	48.5	75.4	71.8
% 2 - 4 hours	18.7	15.1	13.5	9.3	9.5	23.3	11.9	13.3
% 5 -7 hours	1.7	3.0	1.3	3.5	6.3	3.9	1.8	3.4
% ≥ 8 hours	11.3	12.1	3.1	2.5	21.9	14.3	7.0	7.0
% Don't know	7.3	7.4	2.0	1.3	5.3	9.9	3.7	4.5
% of families who provide health care at home for child								
	47.5	40.8	45.0	40.5	70.6	52.8	47.3	42.3
% of families reporting child's health condition has caused financial problems for family								
	26.4	12.8	8.2	12.7	25.0	20.6	14.8	14.0
% of families that need additional money for child's medical expenses								
	15.2	9.7	6.5	9.7	35.2	10.9	11.1	9.9

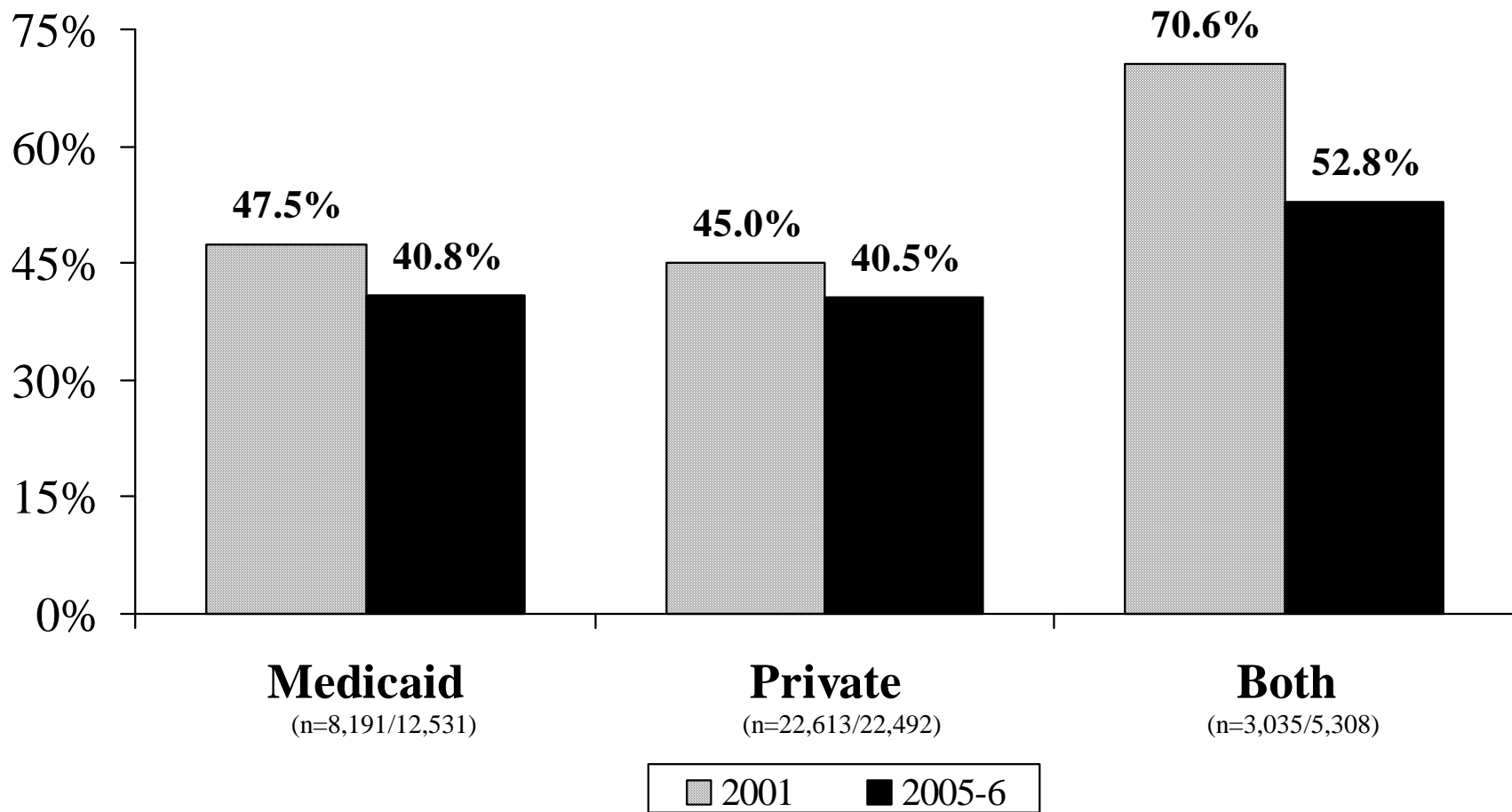
Data Source: Centers for Disease Control and Prevention, National Center for Health Statistics, National Survey of Children with Special Health Care Needs, 2001 (N=35,265, n=750) and 2005-06 (N=41,782, n=850).

Figure 17: Percent of Family Members Who Spend
>= Eight Hours a Week Coordinating/Arranging Care
 for Child with Special Health Care Needs



Data Source: National Survey of Children with Special Health Care Needs – Rhode Island Sample
 NCHS: CDC, 2001 (N=35,265) (n=750), CDC, 2005-6 (N=41,782) (n=850)
 Analysis – RI Medicaid Research & Evaluation Project

Figure 18: Percent of Family Members Who Provide Health Care at Home for Child with Special Health Care Needs



Data Source: National Survey of Children with Special Health Care Needs – Rhode Island Sample
 NCHS: CDC, 2001 (N=35,265) (n=750), CDC, 2005-6 (41,782) (n=850)
 Analysis – RI Medicaid Research & Evaluation Project