
Health Care Needs of Rhode Island Children with Disabilities on Medicaid:

Comparison of 1997 and 2007 Survey Results

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I. BACKGROUND

In 1997, the Rhode Island Department of Health and the Department of Human Services (DHS) in collaboration with RI Family Voices conducted a baseline needs assessment survey to determine the health care needs of children with disabilities on Medicaid (1). In order to measure changes in access to health care for children with special health care needs from 1997 the Department of Human Services conducted a follow-up survey in 2007.

During that ten-year period, several new programs were implemented to address the unmet health care needs identified in the 1997 survey. These new programs include Comprehensive Evaluation, Diagnosis, Assessment, Referral and Reevaluation (CEDARR), RIte Care, Parent Consultants, Home Based Therapeutic Services (HBTS), Kids Connect and Personal Assistance Services and Supports (PASS) (See Appendix 1 for program and service descriptions). In both time periods the survey questions measured:

- Characteristics of Children
- Types of Disabilities
- Health / Functional Status
- Types of Disabling Conditions
- Utilization
- Satisfaction
- Barriers
- Unmet Need

(1) – Griffin J. Health Care Needs of Children with Disabilities on Medicaid: Results of Caregiver Survey, June 1998

II. METHODS

The sample for both the 1997 baseline survey and the 2007 follow-up survey was produced from the Medicaid Management Information System (MMIS). The sample was matched on the following criteria:

- Child on Supplemental Security Income (SSI)
- Continuously enrolled on Medicaid/RItE Care for one year
- Ages 1-17
- Living in the community

In 1997 there were 3,697 children who met the above criteria and in 2007 there were 3,949 children who met this criteria.

In both surveys a letter was sent to a random sample of parents/caregivers (see Appendix 2). Trained interviewers conducted phone interviews and completed 171 surveys in 1997 and 251 surveys in 2007 (see Appendix 3 for 2007 survey questionnaire). One interviewer was bilingual/bicultural and conducted interviews in Spanish. Survey questions were the same for both time periods.

III. RESULTS – CHANGES FROM 1997 - 2007

A. Characteristics of Children

Table 1 compares the characteristics of the children in the two survey groups. In 2007 the survey group was significantly more likely to be male and of minority race. The age distribution and health insurance coverage were the same in both surveys.

In 2007 about half (49.8%) of the respondents were in RItE Care and half (50.2%) were in Fee-For-Service Medicaid. Twenty-two percent (21.5%) of the children were enrolled in the CEDARR program.

TABLE 1: CHARACTERISTICS OF CHILDREN

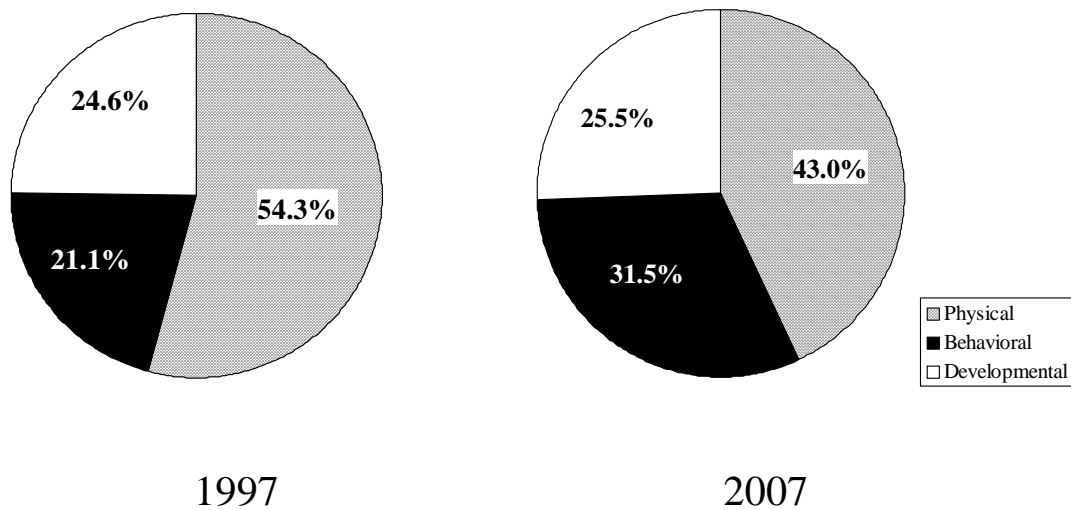
	<u>% in 1997</u> (n=171)	<u>% in 2007</u> (n=251)
Age		
1- 4	9.6	13.2
5- 11	47.5	45.8
12 -17	42.9	41.0
Race *		
White	65.5	52.1
Hispanic	25.5	27.9
Black	9.1	17.0
Sex *		
Male	57.9	68.9
Female	42.1	31.1
Has Other Health Insurance		
Yes	21.6	18.3
No	78.4	81.7
Medicaid Program Enrollment		
Fee-for-service	100	50.2
RIte care	NA	49.8
Enrolled in CEDARR		
Yes	NA	21.5
No	NA	78.5

Difference is Statistically Significant * p < .05 ** p < .01 *** p < .001

B. Type of Disabilities

Figure 1 below shows the changes in types of disabilities as reported by parents, for children on SSI from 1997 to 2007. The biggest change was the increase of the number of children with behavioral conditions. In 1997 21% of the children had behavioral conditions and in 2007 this proportion rose significantly to 32%. This represents an increase of one in five children with behavioral conditions in 1997 to one in three children in 2007. (Note: a complete listing of the individual diagnoses that make up the physical, behavioral and developmental conditions is found in Appendix 4).

Figure 1: Type of Disabilities *
for Children with Disabilities on Medicaid



* Parent self report

Table 2 below shows the ranking of the top ten disabling conditions that children had in the two time periods. The types and ranking of disabling conditions were similar. Attention Deficit Disorder with and without hyperactivity ranked first in both time periods. Asthma was in fourth place in 1997 and in 2007. In 1997 there were more developmental and physical disabilities such as cerebral palsy and downs syndrome.

TABLE 2: TOP TEN PRIMARY DISABLING CONDITIONS

	<u>1997</u> (n=171)	<u>2007</u> (n=251)
<u>Rank</u>		
1 st	Attention Deficit Disorder (14%)	Attention Deficit Disorder (21%)
2 nd	Cerebral Palsy (12%)	Learning Disability (14%)
3 rd	Learning Disability (9%)	Autism (9%)
4 th	Asthma (4%)	Asthma (7%)
5 th	Down Syndrome (4%)	Manic Depression/Psychosis (5%)
6 th	Prematurity (4%)	Prematurity (4%)
7 th	Emotional Problem (4%)	Cerebral Palsy (4%)
8 th	Spina Bifida (3%)	Emotional Problem (3%)
9 th	Heart Defect (3%)	Deaf (2%)
10 th	Seizures (3%)	Gastroschisis (2%)

TABLE 4: FUNCTIONAL STATUS

	<u>% in 1997</u> (n=171)	<u>% in 2007</u> (n=251)
Needs help with personal care needs? *** (eating, bathing, dressing etc...)	60.8	41.8
Limited in kind or amount of activity because of impairment or health problem?	73.1	61.0

Difference is Statistically Significant * p < .05 ** p < .01 *** p < .001

Table 4 shows the differences in the functional status between the two survey groups. The children in 1997 had significantly more functional limitations than the 2007 group. Sixty-one percent (60.8%) of the children in 1997 had limitations with activities of daily living (ADLs) whereas 41.8% of the 2007 cohort had these limitations. The higher rate of limitations in 1997 was due to the higher proportion of physical disabilities in this time period.

D. Utilization

Both emergency department (ED) utilization and hospital stays were reduced for children with special health care needs from 1997 to 2007. Table 5 shows that not only was the proportion of children who were hospitalized significantly reduced, but also the average length of stay was cut by more than half. In 1997, 28.8% of children had hospital stays and in 2007 this proportion reduced significantly to 17.1%. Average length of stay went from 25.6 days to 11.7 days. These reductions in ED and hospital use are due to efforts by RIte Care to improve access to primary care.

TABLE 5: UTILIZATION

	<u>1997</u> (n=171)	<u>2007</u> (n=251)
Used ED in Past Year		
Yes	56.2	48.6
No	43.8	51.4
Average ED Visits (range)	4.7 (1-110)	2.7 (1-20)
Hospitalized in Past Year **		
Yes	28.8	17.1
No	71.2	82.9
Average Hospital Days (range)	25.6 (1-120)	11.7 (1-70)

Difference is Statistically Significant * p < .05 ** p < .01 *** p < .001

E. Satisfaction

Table 6 shows that satisfaction with child's last doctor visit was very high in both time periods. Five of the seven satisfaction questions improved from 1997 to 2007.

TABLE 6: SATISFACTION

	<u>% in 1997</u> (n=171)	<u>% in 2007</u> (n=251)
<i>Last doctor visit was very satisfied or satisfied with...</i>		
...length of time to get appointment	92.3	95.2
...doctor's personal manner	97.6	95.6
...doctor's knowledge of child's condition	89.7	92.2
...way doctor talked to you about child's condition	92.8	93.2
...your involvement in decision about child's care	96.3	96.8
...doctor's response to request for specialty care	93.7	94.1
...overall visit	96.3	95.9

Difference is Statistically Significant * p < .05 ** p < .01 *** p < .001

F. Barriers

Table 7 shows some barriers parents of children with disabilities face. The two greatest barriers faced by over 60% of parents, in both 1997 and 2007, were 1) feeling overwhelmed a lot of the time due to child's needs and 2) unable to work due to care taking responsibilities for child. Better access to transportation improved significantly from 1997 to 2007. In 1997 there were 21.9% of parents who were unable to get transportation to doctor and in 2007 this was almost cut in half to 12%.

TABLE 7: BARRIERS

	<u>% in 1997</u> (n=171)	<u>% in 2007</u> (n=251)
<i>Parent agrees with the following...</i>		
Unable to find childcare when child needs to see the doctor	37.5	35.1
Feel overwhelmed a lot of the time due to child's needs	60.9	59.4
Unable to get transportation to doctor **	21.9	12.0
Parking is not close to doctor's office	18.2	22.6
Parent is unable to work due to care taking responsibilities for child	60.4	61.5
Parent does not get support from family and friends regarding child's condition	29.6	26.3
Doctor does not provide information about child's care, diagnosis and services	17.2	12.0

Difference is Statistically Significant * p < .05 ** p < .01 *** p < .001

G. Unmet Need

Table 8 lists the 24 health care needs of children with disabilities that were asked of parents in both time periods. The table shows the percent of children who needed a particular service and the service was not available. There was a reduction of unmet need in every service. This reduction is due to improvements in Medicaid services over the past decade. The DHS engaged a large stakeholder group which guided policy and implementation of program improvements. These improvements included managed care, CEDARR Family Centers, Home Based Therapeutic Services, Kids Connect and Personal Assistance Service and Supports. The most significant improvements in access to services were:

- Behavioral health counseling
- Nutrition counseling
- Support group for parents
- Parent education classes
- Over the counter drugs.

Figure 2 shows the top ten unmet needs in 1997 compared to 2007. (Note: See Appendices 5 and 6 to see complete distribution of unmet need).

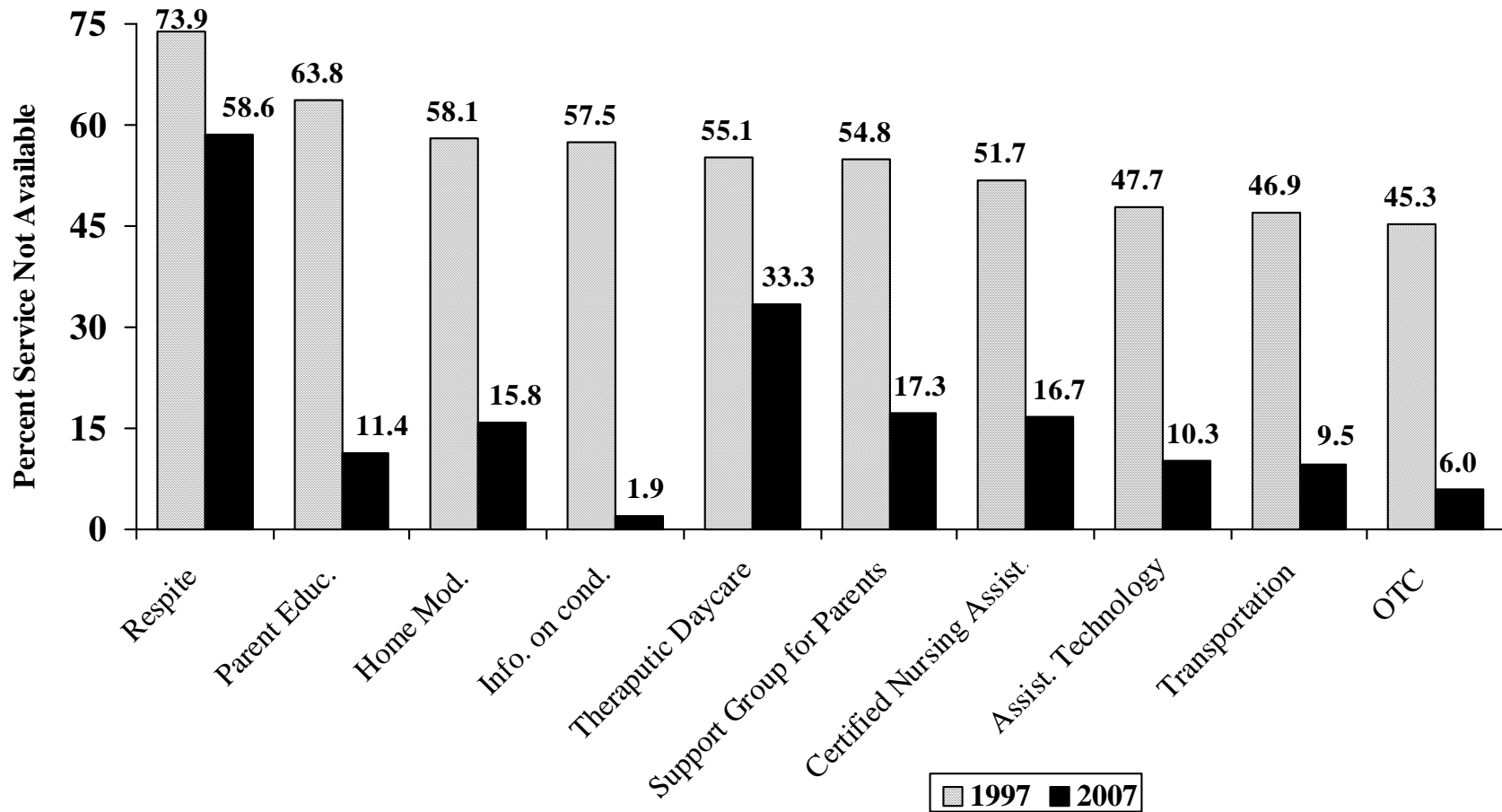
TABLE 8: UNMET NEED - CHILD NEEDS SERVICE AND SERVICE NOT AVAILABLE

	<u>% in 1997(n=171)</u>	<u>% in 2007 (n=251)</u>
Physical Therapy (SN)	14.3	0.0
Occupational Therapy (SN)	13.2	1.8
Speech Therapy (SN)	8.9	0.8
Respite Care	73.9	58.6
Skilled Nursing (4-8 hr shift) (SN)	24.2	11.1
Certified Nursing Assistant (CNA) (SN)	51.7	16.7
Behavioral Health Counseling ***	32.3	5.2
Case Management/Care Coordination (SN)	41.5	1.9
Nutrition Counseling ***	42.9	14.3
Support Group for Parents ***	54.8	17.3
Parent Education Classes ***	63.8	11.4
Information on Primary Condition (SN)	57.5	1.9
Prescription Medications (SN)	1.0	0.5
Over the counter drugs ***	45.3	6.0
Eyeglasses (SN)	14.0	4.6
Durable Medical Equipment (DME) (SN)	6.8	2.9
Assistive Technology (SN)	47.7	10.3
Home Modification (SN)	58.1	15.8
Disposable Medical Supplies (SN)	27.0	2.5
Transportation to health care appt. (SN)	46.9	9.5
Therapeutic day care, after school care *	55.1	33.3
Primary Medical Care (SN)	0.0	0.0
Specialty Medical Care (SN)	1.8	0.4
Dental Care *	11.7	5.5

Difference is Statistically Significant * p < .05 ** p < .01 *** p < .001
(SN) = small numbers - <5 cases in one of areas so unable to test significance

Figure 2: Top Ten Unmet Needs in 1997 Compared to 2007

Percent Service Not Available



Unmet Need = service not available for children who need service

IV. DISCUSSION

From 1997 to 2007 access and quality of health care for Children with Special Health Care Needs on Medicaid improved. Emergency department visits and hospital stays decreased and there was better access to most services. There was significant improvement in availability of behavioral health counseling, nutritional counseling, support groups for parents and parent education. Satisfaction with doctors remained high in both time periods and transportation barriers were removed.

Appendix 1: Program and Service Descriptions

Programs for Children with Special Health Care Needs in Rhode Island

CEDARR Family Centers - One stop information and referral centers for families who have a child on Medicaid with special needs. CEDARR stands for: Comprehensive Evaluation, Diagnosis, Assessment, Referral and Re-evaluation.

Home Based Therapeutic Services (HBTS) - Provides intensive home and community services to children on Medicaid with severe behavioral health, developmental or physical disabilities.

Kids Connect - Provides specialized health services delivered in licensed childcare centers so children with special needs can participate and play with typically developing peers.

Personal Assistance Services and Supports (PASS) – Provides specialized health services in a child’s home or community. Children receive help in performing activities of daily living, making safe and self-preserving decisions, and also participating in social settings.

For more information, see www.dhs.ri.gov under Children with Special Needs.

Appendix 2: Letter to Parents



STATE OF RHODE ISLAND AND PROVIDENCE PLANTATIONS

Department of Human Services
DIVISION OF HEALTH CARE QUALITY,
FINANCING AND PURCHASING
Center For Child and Family Health
600 New London Avenue
Cranston, Rhode Island 02920
Telephone: 462-3113 Fax: 462-6353

May 2007

Dear Parent,

The Rhode Island RItE Care/Medicaid Program is conducting a health survey to find out about the health care of children and teenagers with special health care needs. You have been randomly chosen to participate in this survey.

MCH Evaluation, Inc. is the health survey firm we have hired to conduct this survey. An interviewer will be calling you within the next few weeks to ask you to answer the survey questions. Your input is very important and will be used to decide how to provide better services to children and teens with special health care needs.

The phone survey takes about 15 minutes. All the information you give is confidential and those who participate will not be identified in any way. Your services or benefits will not be affected based on your answers or whether or not you chose to participate.

If you have any questions or would like to set up a particular interview time, please call MCH Evaluation at 431-6290 or toll free at 1-866-SURVEY6. Thank you for your help.

Sincerely,

Deborah Florio, Administrator
Center for Child and Family Health

Appendix 3: Survey Instrument

**HEALTH CARE NEEDS OF
CHILDREN**

WITH DISABILITIES

FOLLOW-UP SURVEY

May 8, 2007

Conducted by:

MCH Evaluation, Inc.
Center for Child & Family Health
Department of Human Services

HEALTH CARE NEEDS OF CHILDREN WITH DISABILITIES SURVEY

Parent/Caregiver's Name: _____

Phone: _____

Child's Name: _____

Child's Age: _____

Survey ID: _____

INTRODUCTION TO PHONE CALL INTERVIEW

Hello, this is _____ calling on behalf of the Medical Assistance/RItCare/Medicaid program. We sent you a letter a few days/weeks ago inviting you to answer survey questions about <NAME>. We are talking to parents and caregivers so we can improve services to children and teenagers with special health care needs.

Are you the person who is <NAME'S> main caregiver or who knows the most about his/her medical and health care? Did you receive the letter? (If not, may I read it to you?) Do you have any questions? The survey takes about 15 – 20 minutes. Do you have time now?

<Name> is currently ___ years old. Is this correct? I know you might have other children but today I only want to speak with you about <NAME>.

All the information you give in this survey is confidential and no one who participates in this survey will be identified in any way. You only have to answer the questions you feel comfortable with. There will be no effect on <NAME'S> services or benefits whether or not you participate and if you choose to participate, your answers will not affect <NAME'S> services or benefits.

1. Survey ID Number _____

2. MID Number _____

3. Survey Interviewer ID _____

1. Denise
2. Iris
3. Holly
4. Karin

4. Follow-up Status/Disposition: _____

1. Able to Contact - Completed Interview
2. Able to Contact – Declined Interview
3. Unable to Complete – Language Barrier
4. Unable to Contact (disconnected, wrong #, answering machine, not home, etc.)
5. Died
6. Moved Out of State
7. Other – No longer the caretaker, living in institutional setting, i.e., facility/group home
8. No attempt to contact.

5. Date of Actual Interview _____ / _____ / _____

6. In general would you say <NAMES> health is.... [READ ALL]

- Excellent 1
- Very Good 2
- Good 3
- Fair 4
- Poor 5

7. Please describe <NAME's> **primary disabling condition in the past 12 months**. (If more than one, select the one which requires most time spent with doctor/provider)

8. Does <NAME> have any other disabilities or medical conditions that require care or medication?

IF YES, how many? _____

List Conditions: _____

9. Primary Diagnosis: To be coded by Survey Manager [ICD-9]..... _____

10. Primary Diagnosis: To be coded by Survey Manager _____

11. Primary and Secondary Diagnoses: To be coded by Survey Manager _____

12. How many times has <NAME> been treated in a hospital emergency room in the past 12 months?..... _____
13. How many times has <NAME> been admitted to the hospital in the past 12 months? [If None, GO TO 15]..... _____
14. How many nights did <NAME> spend in the hospital for this (these) admissions?..... _____
15. Does <NAME> need the help of other persons with his/her personal care needs, such as eating, bathing, dressing, or getting around the house?
- No 0
- Yes 1
16. Is <NAME> able to take part at all in the usual kinds of activity done by most children his/her age? (<5 play, 5-17 school)
- No 0
- Yes 1
17. Is <NAME> limited in the kind or amount of activity he/she can do because of any impairment or health problem?
- No 0
- Yes 1

On <NAME'S> **last visit to the doctor** (or other provider) who takes care of <NAME'S> **primary condition** (as given in question # 6),

	<u>Not Very</u> <u>Satisfied</u>	<u>Satisfied</u>	<u>Very Satisfied</u>
how satisfied were you with...?			
18. Length of time it took to get the appointment.....	0	1	2
19. Doctor's personal manner.....	0	1	2
20. Doctor's knowledge of <NAME'S> primary condition	0	1	2
21. Way doctor talked to you about <NAME'S> primary condition	0	1	2
22. Your involvement in decision making about <NAME'S> care.....	0	1	2
23. <NAME'S> doctor's response to your request for specialty care?.....	0	1	2
24. Visit overall.....	0	1	2

<p>I am going to read you a list of medical and support services <NAME> may have needed or required in the PAST YEAR.</p> <p>In the PAST YEAR Did <NAME> NEED...</p>	<p>0 = No, does not need this service (go to next QUESTION)</p> <p>1 = Yes, does need this service (Go to next COLUMN)</p>	<p>Is service available and does it meet <NAME's> needs?</p> <p>0 = Service is not available</p> <p>1 = Service is available, but does not meet <NAME's> needs</p> <p>2 = Service is available and meets <NAME's> needs</p>
25. ...physical therapy	0 1	0 1 2
26. ...occupational therapy	0 1	0 1 2
27. ...speech therapy	0 1	0 1 2
28. ...respite care	0 1	0 1 2
29. ...skilled nursing (4-8 hr shift) (private duty nursing)	0 1	0 1 2
30. ...certified nursing assistant (CNA)	0 1	0 1 2
31. ...mental/behavioral health counseling	0 1	0 1 2
32. ...case management/care coordination	0 1	0 1 2
33. ...nutrition counseling	0 1	0 1 2
34. ... support group for parents	0 1	0 1 2
35. ... parent education classes	0 1	0 1 2
36. ... information on primary condition	0 1	0 1 2

<p>I am going to read you a list of medical and support services <NAME> may have needed or required in the PAST YEAR.</p> <p>In the PAST YEAR did <NAME> NEED...</p>	<p>0 = No, does not need this service (go to next QUESTION)</p> <p>1 = Yes, does need this service (Go to next COLUMN)</p>	<p>Is service available and does it meet <NAME's> needs?</p> <p>0 = Service is not available</p> <p>1 = Service is available, but does not meet <NAME's> needs</p> <p>2 = Service is available and meets <NAME's> needs</p>
37. ...prescription medications	0 1	0 1 2
38. ...over the counter drugs	0 1	0 1 2
39. ...eyeglasses	0 1	0 1 2
40. ...durable medical equipment (DME)	0 1	0 1 2
41. ...assistive technology	0 1	0 1 2
42. ...home modification	0 1	0 1 2
43. ...disposable medical supplies	0 1	0 1 2
44. ...transportation to health care appt.	0 1	0 1 2
45. ...therapeutic day care, after school care	0 1	0 1 2
46. ...primary medical care	0 <input checked="" type="checkbox"/>	0 1 2
47. ...specialty medical care	0 <input checked="" type="checkbox"/>	0 1 2
48. ...dental care	0 <input checked="" type="checkbox"/>	0 1 2

The following statements have been said by the families and caregivers of children with special health care needs. Tell me if you agree or disagree with them:

	<u>Agree</u>	<u>Disagree</u>
49. I am able to find someone to watch my other children when <NAME> needs to see a doctor (or provider).....	1	0
50. I feel overwhelmed a lot of the time due to <NAME'S> needs.....	1	0
51. Transportation to <NAME'S> doctor (or provider) is available.....	1	0
52. Parking for doctor (or provider) appointments is close to office.....	1	0
53. I am not able to work as much as I want due to caretaking responsibilities for <NAME>.....	1	0
54. I get help and support from friends and family regarding <NAME'S> condition.....	1	0
55. The doctor (or provider) provides information about <NAME'S> care, diagnosis and available services.....	1	0

56. In the **past 12 months** did <NAME> have any other health insurance besides medical assistance/Medicaid/RIteCare (for example, private insurance, Medicare)?
- No 0
- Yes _____ 1
(Please Specify)
57. Are there any other issues you would like to tell me about <NAME’S> health care needs?

Thank you for your time and input. Your answers will help us improve health care for children with disabilities in Rhode Island.

58. **To Be Completed by Interviewer.** Interviewer’s Rating of Caregiver:
- Not knowledgeable about available services for child..... 0
- Knowledgeable but has a lot of difficulty accessing services..... 1
- Knowledgeable and has some difficulty accessing services..... 2
- Knowledgeable and has no difficulty accessing services..... 3

Appendix 4: Disabilities By ICD9 Groupings

**Appendix 3: Distribution of Primary Disabilities by ICD9 Code Groups
for Survey Respondents: Comparison of Two Years**

	ICD9 CODE	1997 (n=171)	2007 (n=251)
PHYSICAL DISABILITY			
Neoplasms	140-239		
Brain Tumor	191	1	1
Leukemia	204	1	
Other neoplasm	239		2
Endocrine	240-279		
Thyroid	240		1
Dwarfism	259		1
Metabolic	270	2	2
Cystic Fibrosis	277	3	1
DeGeorge syndrome	279		1
Blood Diseases	280-289		
Sickle Cell	282	4	
Hemophilia	286	2	
Nervous System	320-389		
Hydrocephalus	331	1	1
Cerebral Palsy	343	21	9
Paralysis	344	2	1
Epilepsy	345	4	1
Muscular Dystrophy	359	3	3
Blind	369	2	
Deaf	389	2	6
Hypertension	401		1
Other heart disease	429		2
Vasculitis	447		1
Respiratory	460-519		
Other respiratory	478		1
Pneumonia	487		1
Asthma	493	7	18
Tracheomalasia	519	2	
Digestive	520-579		
Short Gut	579		1
Genitourinary	580-629		
Kidney, kidney reflux	593	1	1
Other bladder	596		1
Skin	680-709		
Dermatitis	692		2
Psoriasis	696		1

	ICD9 CODE	1997	2006
PHYSICAL DISABILITY			
Musculoskeletal	710-739		
Torn achilles tendon	727		1
Muscular disorder	728	1	1
Osteochondropathy	732		1
Congenital Anomalies	740-759		
Anenaphalus	740	1	
Spina Bifada	741	5	1
Microcephalus	742	1	1
Eye anomalies	743		1
Heart defect	745	5	1
Cleft palate	749		1
Imperforated anus (digestive)	751	2	1
Bladder	753		1
Musculoskeletal	754, 755	3	
Gastroschisis (abdominal), Prune belly	756	1	6
Epidermolysis bullosa (skin)	757	1	1
Prader-Willi (chromosome), Fragile X syndrome, other congenital anomalies	759	2	3
Perinatal	760-779		
Prematurity	765	6	10
Respiratory distress - newborn	770		1
Ill - Defined	780-799		
Seizure Disorder	780	5	2
Nervous/musculoskeletal	781		1
Bulimia	783		6
Encopresis	787		1
Injury	800-999		
Traumatic Brain Injury	854	1	2
Lead poisoning	984		2
Near Drowning	994	1	
Child abuse	995		1

	ICD9 CODE	1997	2006
BEHAVIORAL			
Schizophrenia	295	1	
Manic depression/psychoses, BiPolar	296	3	13
Anxiety, OCD, Neurotic	300	1	2
Emotional/behavioral (dx unknown)	307	6	7
Post Traumatic Stress	309	1	1
Attention deficit disorder, ADD, ADHD (with/out hyperactivity)	314	24	53
DEVELOPMENTAL			
Autism	299	4	22
Learning disability, pervasive developmental disorder	315	15	36
Mental retardation	317	12	5
Down Syndrome	758	7	5
Speech Disorder	784	4	1
TOTAL		171	251

Data Source: The Health Care Needs of Children with Disabilities on Medicaid Parent Phone Survey, RI Medicaid Research & Evaluation Project, 1997 & 2007

Appendix 5: Availability of Services & Unmet Need - 1997

Appendix 4: Unmet Need - 1997
Availability of Services for RI Children/Adolescents with Disabilities

Medical and Support Services	% of Children Who Need This Service (as reported by caregiver)	Of those children who need service....		
		...% service is not Available	...% service is available, does not meet child=s needs	...% service is available, meets child=s needs
Physical therapy	49.1	14.3	23.8	61.9
Occupational therapy	53.2	13.2	20.9	65.9
Speech therapy	60.2	8.9	22.8	68.3
Respite care	40.4	73.9	8.7	17.4
Skilled nursing care (4-8 hr shift)	18.1	24.2	6.1	69.7
Certified nursing assistant (CNA)	17.0	51.7	13.8	34.5
Behavioral Health counseling	36.8	32.3	8.1	59.7
Case management/care coordination	38.0	41.5	15.4	43.1
Nutrition counseling	33.3	42.9	7.1	50.0
Support groups for parents	49.1	54.8	11.9	33.3
Parent education classes	27.5	63.8	12.8	23.4
Information on primary condition	46.8	57.5	15.0	27.5
Prescription medications	55.0	1.0	7.3	91.7
Over the counter drugs	49.7	45.3	22.1	32.6
Eyeglasses	28.7	14.0	26.0	60.0
Durable medical equipment (DME)	34.5	6.8	18.6	74.6
Assistive technology	25.2	47.7	15.9	36.4
Home modification	18.1	58.1	22.6	19.4
Disposable medical supplies	36.8	27.0	14.3	58.7
Transportation	47.4	46.9	14.8	38.3
Day care, after school care	40.4	55.1	4.3	40.6
Primary medical care	99.4	0.0	6.5	93.5
Specialty medical care	95.3	1.8	7.4	90.8
Dental care	90.1	11.7	13.6	74.7

Data Source: Caregiver Survey, 1997 (n=171)

Appendix 6: Availability of Services & Unmet Need – 2007

Appendix 5: Unmet Need - 2007
Availability of Services for RI Children/Adolescents with Disabilities

Medical and Support Services	% of Children Who Need This Service (as reported by caregiver)	Of those Children Who Need Service....		
		...% service is NOT available	...service is available, does NOT meet child's needs	...% service is available, meets child's needs
Physical Therapy	36.8	0.0	16.5	83.5
Occupational Therapy	45.8	1.8	17.5	80.7
Speech Therapy	54.6	0.8	16.4	82.8
Respite Care	11.2	58.6	13.8	27.6
Skilled Nursing (4-8 hr shift)	7.2	11.1	22.2	66.7
Certified Nursing Assistant (CNA)	7.2	16.7	5.6	77.8
Behavioral Health Counseling	46.4	5.2	30.2	64.7
Case Management/Care Coordination	41.0	1.9	19.2	78.9
Nutrition Counseling	22.7	14.3	16.1	69.4
Support Group for Parents	20.3	17.3	28.9	53.9
Parent Education Classes	17.6	11.4	11.4	77.3
Information on Primary Condition	42.2	1.9	17.0	81.1
Prescription Medications	80.5	0.5	5.5	94.0
Over the counter drugs	60.0	0.0	6.0	94.0
Eyeglasses	26.7	4.6	9.1	86.4
Durable Medical Equipment (DME)	28.0	2.9	11.4	85.7
Assistive Technology	11.6	10.3	31.0	58.6
Home Modification	7.6	15.8	15.8	68.4
Disposable Medical Supplies	16.3	2.5	5.0	92.5
Transportation to health care appt.	17.1	9.5	23.8	66.7
Therapeutic day care, after school care	13.3	33.3	27.3	39.4
Primary Medical Care	100	0.0	2.4	97.6
Specialty Medical Care	100	0.4	6.7	92.9
Dental Care	100	5.5	17.5	77.0

Data Source: Caregiver Survey, 2007 (n=251)