



**Survey Findings:
Children with Special
Health Care Needs and
MaineCare Benefits**

April 30, 2004



**Survey Findings:
Children with Special Health Care
Needs and MaineCare Benefits**

Catherine Ormond
Prashant Mittal

Institute for Health Policy
Muskie School of Public Service
University of Southern Maine

April 30, 2004

Acknowledgements

We would like to thank the parents who took the time to participate in this survey; this report would not be meaningful without their candid responses and opinions. We are grateful for the leadership of Jude Walsh and Brenda McCormick at the Bureau of Medical Services (BMS) which guided the project at every stage. We would like to thank Al Leighton and the dedicated interviewers of the Muskie Survey Center who tested and administered the survey, Tina Gressani who was instrumental in the preparation of the survey sample, and Doug Thompson for his consultation regarding the weighting plan. Bob Keith served as data analysis advisor and Stuart Bratesman assisted with complementary claims data analyses. Alexa Halberg, of New England Serve, was extremely helpful in assisting us with obtaining the survey instrument and advising us on its use.

The survey and report were supported with funds from the Cooperative Agreement between the University of Southern Maine and the Department of Human Services. The views and opinions expressed in this report are the authors' and should not be attributed to collaborating organizations, funders, or the University of Southern Maine.

If you need additional copies of this report or need the report in an alternative format, please contact Catherine Ormond at:

(207) 780-4015 (voice)

(207) 228-8440 (TTY)

cormond@usm.maine.edu

Muskie School of Public Service

University of Southern Maine

P.O. Box 9300

Portland, ME 04104-9300

Table of Contents

Executive Summary	1
Purpose and Methodology	3
Purpose.....	3
Methodology.....	4
Target Population.....	4
Sample Design.....	4
Survey Instrument and Administration.....	6
File Construction, Data Analysis, Weighting.....	8
Study Limitations	8
Analysis and Presentation	9
Child and Family Characteristics	10
Children’s Health Status.....	10
Parents’ Health	13
Parents’ Education.....	14
Out of Pocket Expenses	15
Insurance Status	16
Findings	17
Primary Care and Specialty Services.....	17
Mental Health and Specialty Services	20
Access to Services.....	24
Emergency Room (ER) Use	25
Physical Accessibility.....	26
Mental Health Medication/Information.....	26
Quality.....	27
Care Coordination/Case Management	28
Written Care Plan	28
Perception of Coordination Among Providers.....	31
Care Coordinator/Case Manager.....	34
Community-Based Case Management.....	35
State Agency-Based Case Management.....	40
School Coordination	41
Unmet Needs.....	42
Medication Needs.....	47
Equipment, Assistive Technology, and Medical Supplies: Met and Unmet Needs.....	49
Final Word on Unmet Needs	50
Study Implications	52
Appendix: Telephone Survey Instrument	

Tables & Figures

Table 1:	Characteristics of Sample of Children with Special Health Care Needs	6
Table 2:	Organizations Delivering Care Coordination or Case Management	37
Table 3:	Percent of Children Served by Different Case Management Providers in 2002.....	39
Figure 1:	Age Distribution by Eligibility Category	9
Figure 2:	Primary Type of Disability by Eligibility Category	10
Figure 3:	Health Status of Survey Population (CSHCN) and Enrollees in Maine’s Children’s Health Insurance Program (SCHIP).....	11
Figure 4:	Health Status Report by Disability Type.....	12
Figure 5:	Health Status by Eligibility Type.....	12
Figure 6:	Parents Reporting their Health has been Affected by Caring for a Child with Special Needs.....	13
Figure 7:	Education of Respondents by Children’s Benefit	14
Figure 8:	Out-of-Pocket Expenses for Treatment or Medication	15
Figure 9:	Private Health Insurance Status (Excludes Foster Care).....	16
Figure 10:	Type and Location of PCP	18
Figure 11:	Parents’ Assessment of Factors of Care from PCP	19
Figure 12:	Mental Health Services Use by Eligibility Category	20
Figure 13:	Has Your Child Been Seen by a Specialist in the Last 12 Months?	21
Figure 14:	Distribution of Specialty Service by Eligibility Category.....	22
Figure 15:	Specialty Service Utilization by Children’s Age.....	22
Figure 16:	Specialist Most Often Seen	23
Figure 17:	How Often Do You Receive Help or Information from the Provider on the Phone?....	24
Figure 18:	Describe the Amount of Time It Took When Your Child First Needed a Specialist	24
Figure 19:	Primary Reasons for ER Visits.....	25
Figure 20:	Emergency Room Use by Survey Population (CSHCN) and Enrollees in Maine’s Children’s Health Insurance Program (SCHIP).....	26
Figure 21:	Rating of Overall Quality of Care	27
Figure 22:	Presence of Written Care Plan	28
Figure 23:	When Was the Care Plan Last Updated?	29

Figure 24: Percent of Children in Benefit Categories with Written Care Plans	29
Figure 25: Presence of Written Care Plan	30
Figure 26: Person Who Helped Develop the Care Plan.....	31
Figure 27: How Often is the PCP Involved in the Planning and Delivery of All of the Child’s Care?.....	32
Figure 28: Are Your Child’s Mental Health and Primary Care Services Coordinated?	33
Figure 29: Does Your Child’s Specialist Talk to the PCP About Your Child’s Care?	33
Figure 30: Presence and Need of a Case Manager (CM).....	34
Figure 31: Satisfaction with Community-Based Case Management Services	35
Figure 32: Satisfaction with Community-Based Case Management	36
Figure 33: Satisfaction with Case Management from Community Agencies	38
Figure 34: Satisfaction with Case Management Services by Provider	40
Figure 35: Health Care Coordination with Schools	41
Figure 36: Distribution of Children with Unmet Needs by Region	42
Figure 37: Distribution of Unmet Needs by Eligibility	43
Figure 38: Met and Unmet Needs	44
Figure 39: Distribution of Service Utilization by Region.....	45
Figure 40: Distribution of Service Utilization by Eligibility.....	46
Figure 41: Average Annual Number of MaineCare Prescriptions Filled per Child in 2002	47
Figure 42: MaineCare’s Annual Average Cost per Child for Prescription Medications in 2002	48
Figure 43: Children with Unmet Equipment Needs	49
Figure 44: Equipment/Supplies Utilization per Child.....	49
Figure 45: Equipment/Supplies/Assistive Technology Utilization.....	50

Executive Summary

This report presents findings from a random telephone survey of children with special health care needs who receive MaineCare services without the benefit of managed care. The sample was stratified to include children receiving benefits through adoption assistance, foster care services, the Katie Beckett eligibility option, the Title V program, and supplemental security income (SSI). Telephone interviews were completed with 1,251 parents or guardians between May and July 2003. This survey was commissioned by the Division of Health Care Management and Member Services of the Bureau of Medical Services of Maine's Department of Human Services to aid them in decisions about how to better meet the needs of these children.

Key findings of the survey interviews include:

- 99% of children with special health care needs receiving MaineCare benefits have a primary care provider (PCP), indicating that they have a medical home where they receive primary care services. 73% of these providers are described as a 'regular doctor,' 6% of parents describe their child's PCP as a nurse practitioner, and 20% describe the primary provider as a specialist. Ratings of these providers for continuity of care, access, and respect for the child and family are also very high. However, parents would like to receive more information from PCPs about their children's conditions and to help them understand their children's emotional needs.
- More than half of children with special needs receive services from a mental health provider. Parents are less satisfied with the quality of the mental health services their children receive, compared to services provided by other specialty or primary care providers. Respondents describe the time that it took to obtain the first appointment with a mental health provider as 'unacceptable' twice as frequently than for other specialty providers.
- More than half of children with special needs have a current written health care plan, the foundation for care coordination of services for children with complex needs. However, there is no clear indicator of why a child does not have a written health care plan; age, region, eligibility, and disability type do not appear to be influencing factors. Overall, 37% of the providers who assist parents with developing the plan of care are PCPs or specialists; 51% are case managers and the remaining plans are developed by school personnel.
- Children receiving MaineCare benefits through the Katie Beckett eligibility option and through SSI report a greater number of unmet needs, a lower satisfaction rating of services, and the highest utilization of services.
- There appears to be greater satisfaction with care and fewer unmet needs among children receiving services through the three eligibility categories that provide program supports - Adoption Assistance, Foster Care services, and the Title V program.
- The Title V program, which serves the fewest children with behavioral or mental health needs, has the highest satisfaction and fewest unmet needs of any eligibility category.

- Satisfaction with community-based case management lags behind coordination services provided by PCPs and specialty providers. Survey interviews reveal a high number of community-based organizations providing case management services to this population. Over 70 organizations were reported to deliver case management services to 686 respondents, indicating a proliferation of service providers and raising questions about oversight of these services.
- 9% of respondents report that they lack a case manager to help identify and obtain services; 43% report having one case manager; 19% report having more than one case manager. Children receiving services through SSI are most likely to lack a case manager.
- There is little regional variation among children with unmet needs; children in all three regions (southern, central, and north/east Maine) have similar rates of unmet needs. Overall, 34% report having two or more unmet needs. Behavioral health services and after-school services are the highest reported unmet needs, followed by dental services.
- Obtaining and managing medications are reported as needs that are largely being met. However, parents noted the importance of this benefit and expressed concern for continued funding.

This report is intended to inform policy makers and providers regarding consumer expectations and experiences. Survey responses demonstrate that children with special health care needs should not be treated as a homogenous group. Needs and perceptions vary considerably across this population. An important next step will be to assess state policy and priorities in light of survey findings.

Purpose and Methodology

Purpose

Children with special health care needs are defined as children and youth with special health needs who have or are at increased risk for chronic, physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type and amount beyond that required by children generally.¹ By assessing the experience and unmet needs of children with special health care needs we hope to inform the Bureau of Medical Services (BMS) of the Department of Human Services in their quality monitoring and improvement activities. While data on service use, expenditures, and service providers are available from MaineCare claims data for this population, BMS requested this survey to understand this information within the context of the experience, needs, concerns, and satisfaction from the family's point of view.

We tend to look at children with special needs as a single group, yet there are significant differences in their health status, the types of services they need, and their level of satisfaction with services. Understanding these differences is essential to state agencies and units of government with responsibility for their services.

The goals of the study are to:

- Differentiate the needs and experiences of subgroups of children with special needs in order to better target and focus resources,
- Better understand expectations of parents and guardians,
- Assess the performance of Maine's health care delivery system in meeting the needs of children with special health care needs, and
- Clarify the inter-dependence of the provider network in creating an effective service system for these children.

Of special interest in this study is to identify the types of care coordination and the providers of care coordination that Maine children are receiving. Since most children with special care needs are exempt from enrollment in the State's primary care case management program, policy makers have particular interest in examining how well the health care system is working from the perspective of those using the system.

The survey instrument was selected for its value in gauging the extent to which care coordination is taking place and understanding the relationship of care coordination to satisfaction and unmet needs. The survey instrument assesses access to primary care, specialty care, mental health services, unmet needs, environmental accessibility, equipment, and assistive technology needs of this population. Gaining a better understanding of the diverse needs of this population will be critical to designing effective systems and supports. Findings will inform policymakers as they work toward improving systems of care for children with special needs and their families.

¹ McPherson, M., et.al. A new definition of children with special health care needs. *Pediatrics* 102:137-40, 1998.

Methodology

Target Population

In 1997, the Balanced Budget Amendment allowed states to enroll Medicaid beneficiaries into managed care programs, but excluded certain populations, including children with special health care needs. The Health Care Financing Administration, now the Center for Medicaid and Medicare Services (CMS), defined this population as children under 19 years of age who receive services from foster care or adoption assistance (Title IV-E), Supplemental Security Income (SSI), Title V-funded care coordination services or services under a 1902(e) (3) option, known as the Katie Beckett option. Children with special needs include those with mobility, sensory, cognitive, emotional, and/or mental health impairments and those who are dependent on medical technology.

This survey examines the experiences and unmet needs of children in these populations who are living in the community and enrolled in MaineCare. Children who were enrolled at least eleven months in a particular MaineCare eligibility category were selected so that the survey would reflect the perspective of families with substantial experience under a particular benefit. If a household with more than one eligible child was selected to participate in the survey, one child from that household was randomly selected so that no family would be interviewed about the experience of more than one child. Only children living in households with a parent (birth, foster or adoptive) or guardian were included. A screening question, confirming that the identified child has a special need, was asked of each respondent. This study does not address the needs of emancipated minors, children in state care or children who reside in facilities or institutions in Maine or in other states.

Sample Design

The sample selection design included 1,200 completed interviews for children receiving MaineCare services through one of the following four eligibility categories:

- Adoption Assistance and Foster Care, supported by the Bureau of Child and Family Services,
- Katie Beckett eligibility option of MaineCare. This benefit is designed to support children who are eligible for an institutional level of care to live at home,
- Supplemental Security Income (SSI) for families with children with disabilities, or
- Title V Program for children with certain conditions, administered through the Bureau of Health.²

In order to understand any differences that may exist between children receiving adoption assistance and foster care, children receiving services through the Bureau of Child and Family services were over-sampled. Thus, 30% of the responses were collected from parents of children receiving these

² The Title V Program is funded by the federal Maternal and Child Health block grant and supports children with the following conditions: blood disorders, cardiac defects, childhood oncology, craniofacial anomalies, gastrointestinal disorders, metabolic disorders, ophthalmologic diseases, orthopedic, neurological neurosensory, neuromuscular, or respiratory conditions.

services. Overall, a total of 1,251 responses were collected. Table 1 displays the final sample sizes, ages, and geographic characteristics of the children included in the survey.

There is little variability in the demographic characteristics of the sample compared to the population of children with special needs. Despite random sampling, slightly more responses were collected from parents of children age 0-5 years (18%), compared to children of the same age in the MaineCare population (16%). Chi square tests show that these differences are significant at $P < .0001$. These differences were corrected in the weighting plan. Regional differences between the survey population and the MaineCare population are difficult to determine due to missing geographic information in 3% of the MaineCare population data; however, it appears that children in region three were slightly over-sampled (32%) in the survey, compared to children in MaineCare residing in region three (29%). The distribution of all Maine children from the 2000 census is also listed in Table 1 for comparison purposes to the general population.

Children in the survey population are primarily white (89%), 2% are African American or Hispanic and 2% are American Indians, and 6% are of mixed race or their race information was missing. Ninety-six percent of the children speak English as their primary language, 1% use American Sign Language and 2% are children older than two years old who are non-verbal or who use speech assistive devices. The remainder was reported to speak another language; among them were Farsi, Somali, Tagalog, and Russian.

Eighty-two percent of respondents were the child's parent or guardian, 3% were relatives and the remaining 15% were foster parents. Eighty-six percent of all respondents were female.

Table 1: Characteristics of Sample of Children with Special Health Care Needs (CSHCN)

Characteristic	Number and Percent in Survey Sample (N = 1,251)		Distribution of CSHCN in MaineCare (N = 7,794)	Distribution of all Maine Children 2000 Census (N = 318,835)
Age of Children				
0-5	230	18%	16%	26%
6-12	546	44%	42%	39%
13-18	475	38%	42%	35%
Gender				
Female	497	40%	39%	49%
Male	754	60%	61%	51%
Region				
Region 1	357	28%	28%	36%
Region 2	496	40%	40%	40%
Region 3	398	32%	29%	24%
MaineCare Benefit				
Adoption Assistance	188	15%	17%	n/a
Foster Care	186	15%	21%	n/a
Katie Beckett	312	25%	17%	n/a
SSI	283	23%	36%	n/a
Title V	282	22%	9%	n/a

- CSHCN in MaineCare (N = 7,794) are defined as children with special health care needs who were enrolled for at least 11 months in one of five MaineCare benefit categories.
- 3% of the CSHCN in MaineCare data (children in foster care) lacked geographic information and, therefore, were excluded from the distribution by region in the table above.
- The regions include the following counties: Region I (York and Cumberland counties), Region II (Androscoggin, Franklin, Kennebec, Knox, Lincoln, Oxford, Sagadahoc, Somerset and Waldo counties), and Region III (Aroostook, Hancock, Penobscot, Piscataquis, and Washington counties).

Survey Instrument and Administration

The telephone survey was adapted from the Family Survey in *"Identify...Collaborate ...Improve...Shared Responsibilities: Tools for Improving Quality of Care for Children with Special Health Care Needs,"* New England SERVE, Boston, MA, 2002. The instrument was thoroughly tested on a subset of the MaineCare population before being administered. Some questions, response choices, and probes were refined as a result of this testing. The instrument can be found in Appendix A of this report.

The survey questions generally included a 12 month recall of experiences in order to capture ongoing rather than short-term experiences. The exception to this was questions having to do with current met and unmet needs. We also asked respondents to exclude experiences in other states and only report on Maine-based services.

The instrument, protocols, and confidentiality procedures were reviewed by the University of Southern Maine's Institutional Review Board for human subject research and HIPAA compliance. Professional interviewers at the Survey Research Center at the Muskie School of Public Service in Portland, Maine administered the survey. All project staff are trained in HIPAA compliance and confidentiality protocols.

Survey Research Center interviewers were thoroughly trained prior to call administration. In addition to 15 hours of general interviewing techniques training, all staff also completed four hours of training for this survey instrument. Survey training included an explanation of the intent and objectives of all questions, practice interviewing with the instrument, and a final review of all survey questions on this instrument.

The survey was administered using a computer-assisted telephone interviewing instrument (CATI) developed by Muskie School staff to collect and enter data directly from respondents. Upon reaching one of the randomly selected households, the interviewers explained the purpose of the survey and offered to give the respondents the name and telephone number of a Department of Human Services contact to verify the validity of the survey. The interviewer asked to speak to the parent most knowledgeable about the child's needs.

Contact with 1,612 households yielded 1,364 respondents who agreed to participate in the interview. Interviewers then asked a screening question explaining that the survey was about children with special health care needs. A total of 188 respondents stated that their child did not have a special need or they were not sure. These respondents were disqualified yielding 1,251 parents who completed the survey. The interview took an average of 20 minutes; it was in the field from May 1st through July 15, 2003.

We calculated response rates for each of the subgroups. Parents whose children receive services through the Katie Beckett eligibility option had the lowest percentage of refusals (3%); parents of children receiving services through SSI and from the Bureau of Child and Family Services each had the highest (9%). Parents of children in SSI were the most difficult to reach for the survey; nearly 60% of the telephone numbers for this population were out of service, missing, or wrong numbers. Overall, the response rate for the survey was 80%. The final question on the survey asked parents if they would agree to be interviewed again on the same subject at a later date should the survey be repeated; 99% agreed. A number of interviewers noted that they had not conducted a survey in recent years in which respondents were generally so positive; many parents remarked to the interviewers that they were hopeful that improvements could be made as a result of their feedback.

File Construction, Data Analysis, Weighting

Muskie School staff reviewed the survey for response validity, coded open-ended questions, and imported the data into SAS software for analysis. It was not necessary to apply weights to data for benefit category analysis. (Many of the graphs in this report present distributions by the five benefit subgroups). However, we applied weights to aggregate data to ensure the population of children with special needs in MaineCare is represented most accurately. Weighting data compensates for irregular sample sizes and adjusts the aggregate findings to reflect the true distribution of this population. The weighting plan includes adjustments for age, gender and benefit group anomalies.

For example, children in the survey who receive benefits through SSI and Title V have equal sample sizes (23% of the survey population). These sample sizes allow for sufficient observations for analysis of each eligibility category. However, children in SSI actually represent 36% of the MaineCare population of children with special needs, while children in the Title V program represent 9%. Weighting compensates for these proportions and adjusts the observations to represent a greater, appropriate representation of children receiving benefits through SSI and a smaller representation is applied to the Title V program subgroup. Only aggregate data were weighted.

Study Limitations

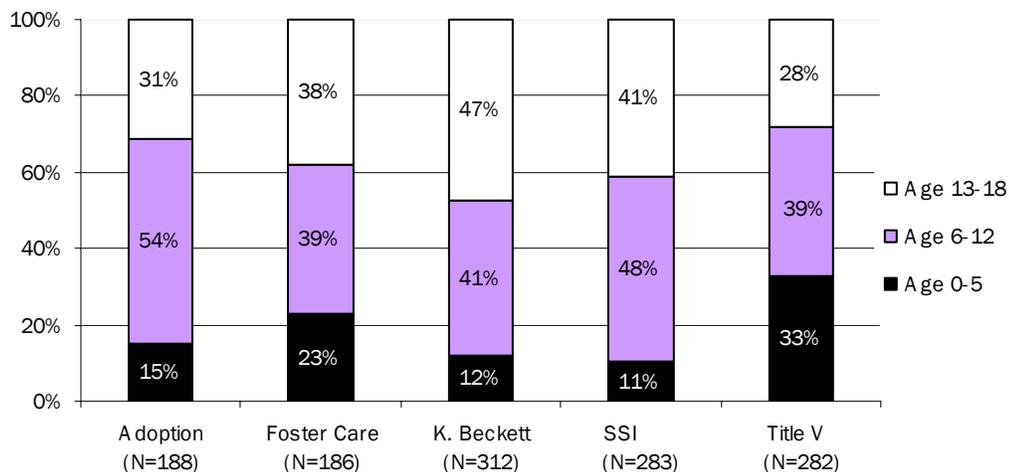
Because the percentages and counts contained in this report are based on samples of the population and weighted data, rather than direct responses from every parent of every child with special needs enrolled in MaineCare, they are estimates only. It should also be noted that the survey was administered to the adult in the household who reported on the health care use, needs, and services of the child with special needs. Therefore, the reliability of the responses is dependent upon the parents', guardians', or other family members' familiarity with all the child's needs and health care use.

Analysis and Presentation

We analyzed survey results by regional distributions, age groupings, children’s disability types, and by the benefit categories in which children receive MaineCare services and included in the report the analysis of the measure that offers the most variation. Most frequently this was the benefit category distribution. Though the eligibility group samples sizes are not equal, when displaying this information we distributed each benefit group to 100% to provide easier comparison among groups.

For example, Figure 1 shows the age distribution of the children in the five eligibility categories. The group with the smallest percentage of teens is the Title V program (28%); the Katie Beckett eligibility option contains the largest (47%). The denominator (N) is listed in the chart title as the number of respondents may vary depending upon the survey question. We note the number of respondents in the subgroups, particularly if they are less than the full cohort. Groups that do not add to 100% are due to rounding errors.

Figure 1: Age Distribution by Eligibility Category (N=1251)



The remainder of the report contains descriptive survey results on:

- Child and Family Characteristics,
- Primary Care and Specialty Services,
- Care Coordination/Case Management, and
- Unmet Needs.

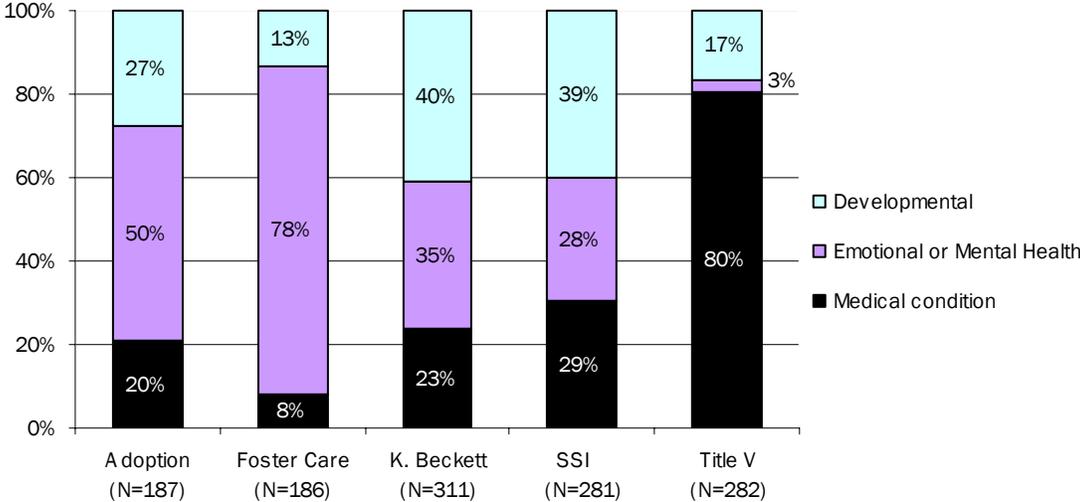
Child & Family Characteristics

Children’s Health Status

To analyze variances in satisfaction and unmet needs by disability type, we asked parents to characterize their child’s *primary* type of disability. Overall, 26% identified the disability primarily as a medical or physical condition, another 42% described it as an emotional or a mental health disability, and 30% said that it was developmental in nature. The remainder was uncertain how to characterize the disability. Many parents report that their children have serious secondary and tertiary conditions and that it was difficult for them to choose just one category.

Figure 2 shows the distribution by benefit groups of children in the survey population using these three categories of disability.

Figure 2: Primary Type of Disability by Eligibility Category (N=1247)



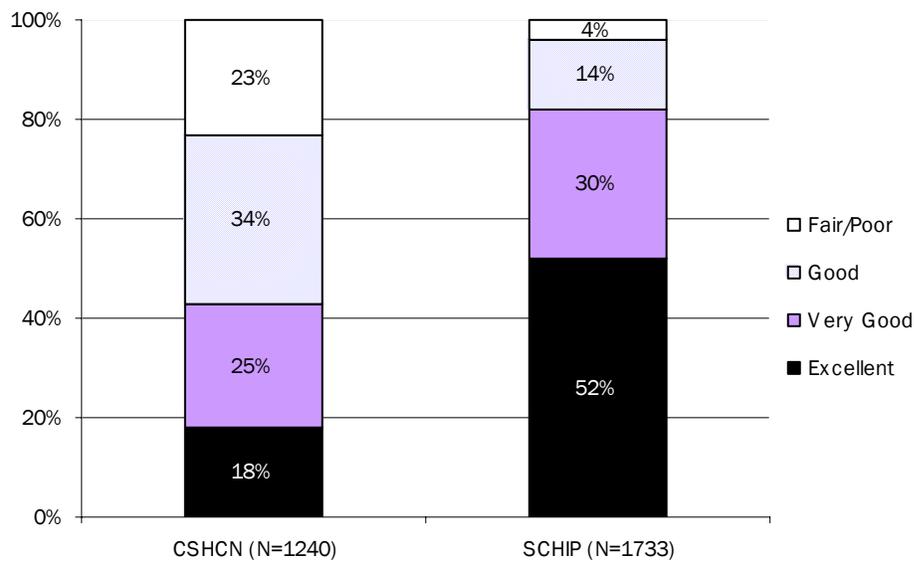
Children with developmental disabilities including autism, Asperger’s, pervasive developmental disorder and mental retardation are most likely to receive services through the Katie Beckett option or through SSI. Children with emotional or mental health needs are most likely to be receiving services through foster care (78%) and least likely through the Title V Program (3%). Eighty percent of children who receive services through the Title V program in the Bureau of Health have a medical or physical condition.

Several questions in the survey addressed physical access. Therefore, parents were asked if their child had a physical disability requiring accessible environments; 29% of the children in the survey population report that they did. Children with a physical disability are more likely to receive services through SSI than from any other benefit category.

Interviewers asked parents how they would describe their child’s current health status. Twenty-three percent report that their children are in fair or poor health. To understand how this rating differs from other children enrolled in MaineCare, we compared this to a recent satisfaction survey of children receiving benefits through Maine’s SCHIP program (States Children’s Health Insurance Program).³ Considered to be a generally healthy population, a quarter of the respondents in the SCHIP survey nevertheless reported that their child “...had an emotional, developmental, or physical condition that limits their ability to do what other children their age do.” Despite this large proportion of children with limitations, only 4% of children in the SCHIP survey were reported to have a poor or fair health status. Conversely, 23% of the children in the Special Health Care Needs survey are reported to be in fair or poor health - a more than five-fold difference from the SCHIP population.

More than half of the children in the SCHIP survey were considered to be in excellent health, compared to only 18% in the special health care needs population.

Figure 3: Health Status of Survey Population (CSHCN) and Enrollees in Maine's Children's Health Insurance Program (SCHIP)



³ Ziller, E., *Satisfaction with Children’s Health Care: Families’ Evaluation of Medicaid and the State Children’s Health Insurance Program (SCHIP)*, FY 2003. Muskie School of Public Service, November 2002.

Figure 4 shows that parents of children with medical or developmental disabilities rate their children’s health as excellent or very good at higher rates (46% and 47% respectively) than parents of children with mental health or emotional disabilities (38%).

Figure 4: Health Status Report by Disability Type (N=1226)

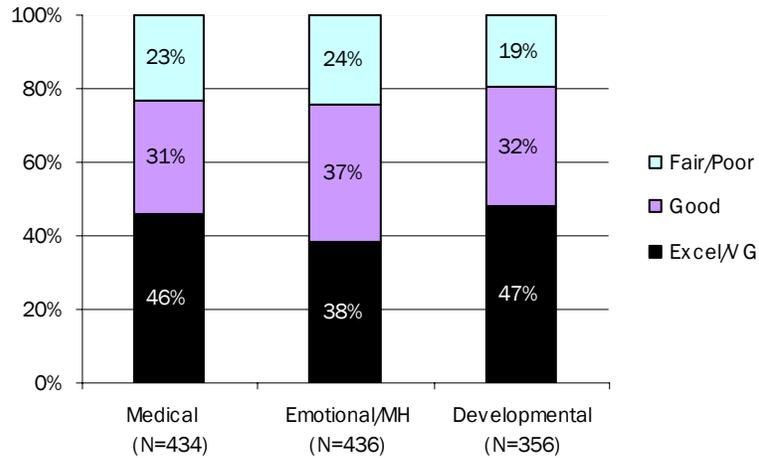
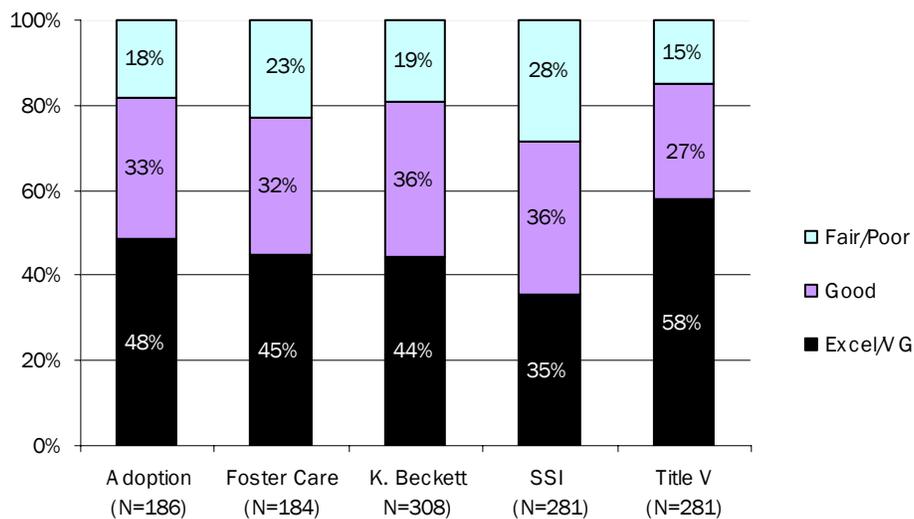


Figure 5 shows that children enrolled in MaineCare through SSI are more likely to have fair or poor health (28%), as reported by their parents, compared with children in Title V who are more likely to be in excellent or very good health (58%).

Figure 5: Health Status by Eligibility Type (N=1240)

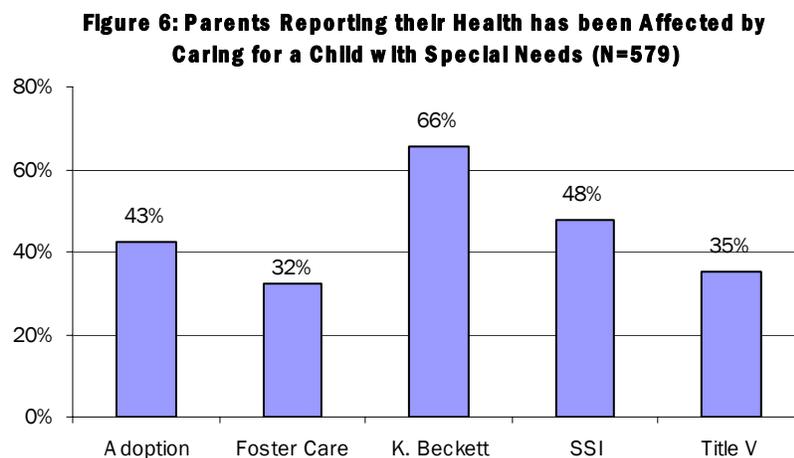


Parents' Health

The well-being of parents is inextricably linked to the well-being of their children and affects their ability to care for and coordinate multiple services their children use. To better understand the needs of the parents in addition to those of children, we asked parents about the affect on their own health and well-being of caring for a child with special needs.

Almost half of parents (46%) responded that their physical, emotional, and/or mental health was affected, with 90% of these parents reporting that their emotional health was adversely affected. In addition, 60% of these parents report that care-giving affects their physical health. When asked whether they had sought health care for themselves for these issues, 94% of parents said they had sought care within the last two years.

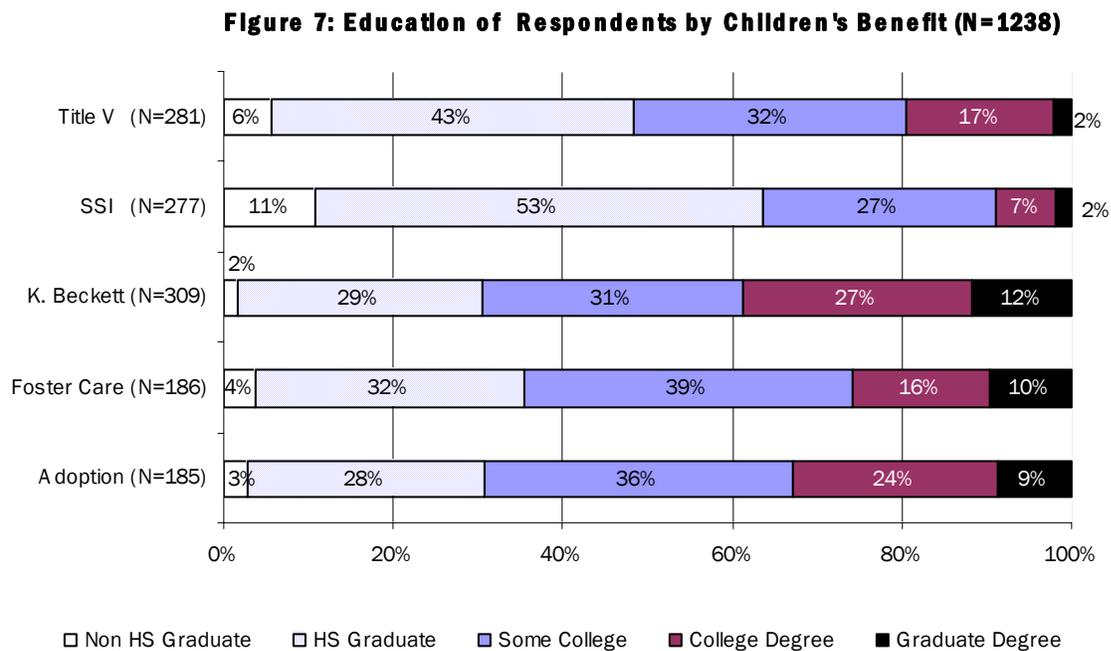
Figure 6 is a graph of the distribution of responses by eligibility group. Parents of children enrolled through Katie Beckett eligibility are most affected (66%) compared to foster parents (32%).



In addition, 3% of parents in the survey population responded to this question by saying that caring for a child with special needs has a positive affect on their health and well being.

Parents' Education

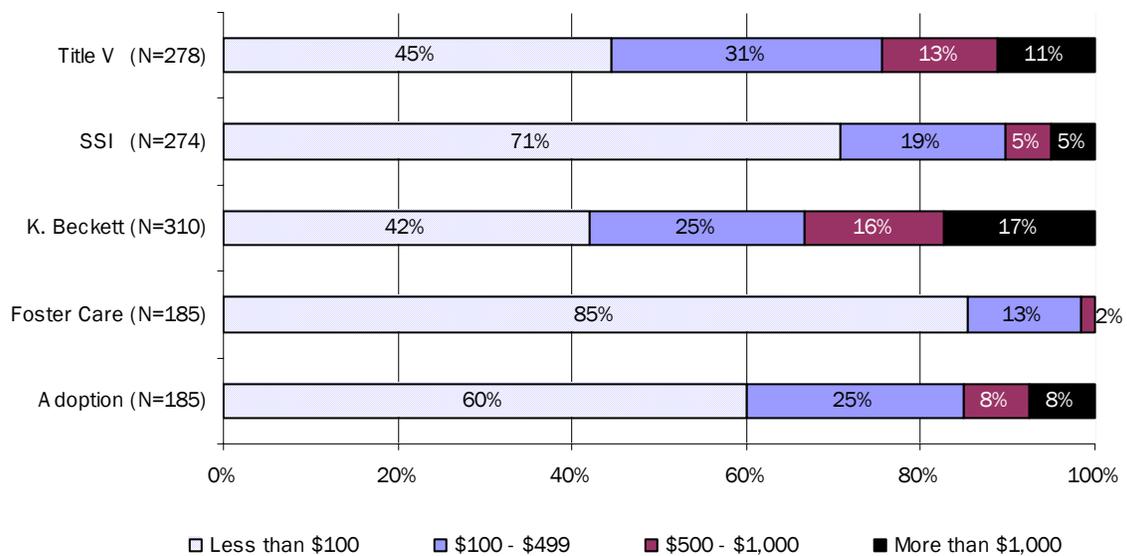
The educational status of respondents was collected as an indicator of socio-economic status. Figure 7 shows the distribution of education completed by respondents in each eligibility category. One-third of the parents of children receiving adoption assistance have undergraduate and graduate degrees and 39% of parents of children receiving MaineCare through Katie Beckett eligibility have this level of education. Parents of children in SSI and Title V are more likely to have completed their education with a high school diploma.



Out-of-Pocket Expenses

The survey asked parents about the amount of funds they used to supplement the services provided by MaineCare. Respondents with children in the Title V and Katie Beckett eligibility categories report a higher out-of-pocket expenditure compared to that of other parents. A third of parents of children enrolled through the Katie Beckett option spent more than \$500 for their child's treatment or medication in the previous 12 months; nearly a quarter of parents of children in the Title V program spent this level.

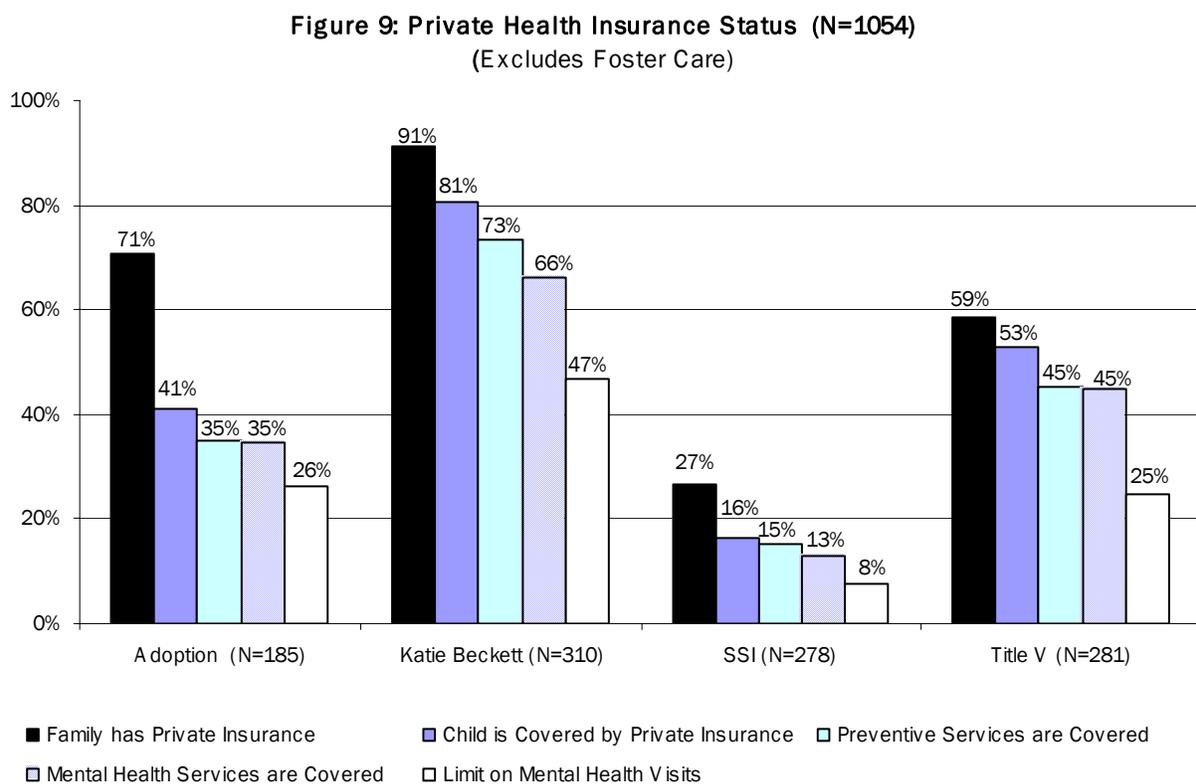
Figure 8: Out-of-Pocket Expenses for Treatment or Medication (N=1232)



Insurance Status

Overall, 798 or 64% of all respondents indicated that their family has private health insurance in addition to the MaineCare benefit that covers their child with special needs. Though children in foster care may be covered by their foster parents' private health insurance, none of the survey respondents indicated that they had this coverage. Therefore, for the purposes of the survey analysis, we excluded children in foster care. In the four remaining eligibility groups, 524 children, or 80% of the children in families with private health insurance, are covered by their family's private health insurance at the time of the interview. Figure 9 shows the distribution by eligibility group of the private insurance status of children in the survey population. Children enrolled in MaineCare through the Katie Beckett option or Title V are more likely to be covered by their families' private insurance than children enrolled in the other eligibility groups, 81% and 53%, respectively.

When asked to describe the private health insurance that covers their children, overall 89% (466) report that it covers preventive services and emergency room visits; 83% report that mental health services are covered. However, two-thirds of families with mental health coverage report that there is a limit on the number of mental health care visits reimbursed by their private insurance.



Primary Care and Specialty Services

A ‘medical home’, recommended for all children by the American Academy of Pediatrics, is particularly important to children with special health care needs. A medical home provider is one who is familiar with the child’s health history and health care needs. It is an approach to care in the primary care setting where the care is accessible, family-centered, continuous, comprehensive, compassionate, culturally competent, and coordinated with other specialty and community-based services.

Providing preventive services, regular checkups, and immunizations to children who may need accessible examination tables or more time on the part of clinicians due to behavioral issues pose additional challenges to PCPs with already heavy case loads. Anecdotal evidence suggests that the primary care of children with special needs may be neglected and become secondary to the increasing array of services and specialists needed by these children. Maine policymakers wanted to learn about the experience of children receiving services through MaineCare and to understand whether their primary health care needs are being met.

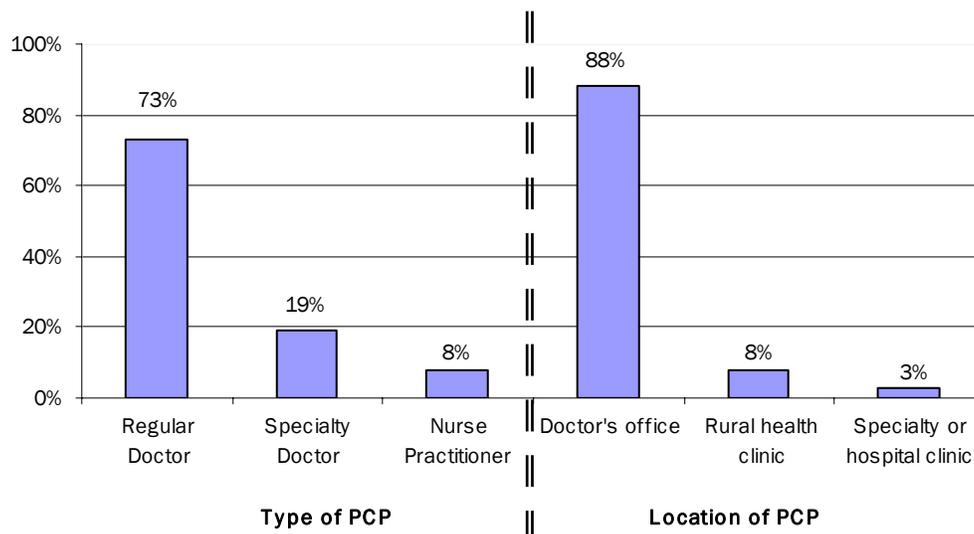
We asked parents a series of questions about their child’s primary care experience, including whether their child had someone they considered to be their PCP, the location where they receive their care, the frequency of seeing the same provider, whether the PCP treats them with respect and helps them understand their child’s needs and coordinates other aspects of their care. This series was designed to gauge the extent to which these children have a medical home. The results from this survey are consistent with results from the recent National Survey of Children with Special Health Care Needs conducted by the Centers for Disease Control (CDC). That survey, including children with special health care needs regardless of insurance coverage, found that nationally Maine has the second highest percentage of children who “receive services in an effective medical home.”⁴

⁴ Leatherman, S., *Quality of Health Care for Children and Adolescents: A Chartbook*, Commonwealth Fund, April 2004..

In our survey population, 99% percent of parents report that their child has a medical professional they consider to be their child’s primary care provider (PCP). This is a very strong finding considering that these children are not in managed care programs that require the assignment of a PCP and also considering the high specialty use of these children.

The graph below shows that of the 99% of children with a PCP, 73% describe the PCP as a ‘regular doctor’ and 19% describe the PCP as a specialty doctor. The remainder describe the PCP as a nurse practitioner. Eighty-eight percent of the parents describe the place where they take their child for regular check ups and primary care as a doctor’s office; 8% describe it as a rural health clinic and the remainder describe it as a specialist’s office.

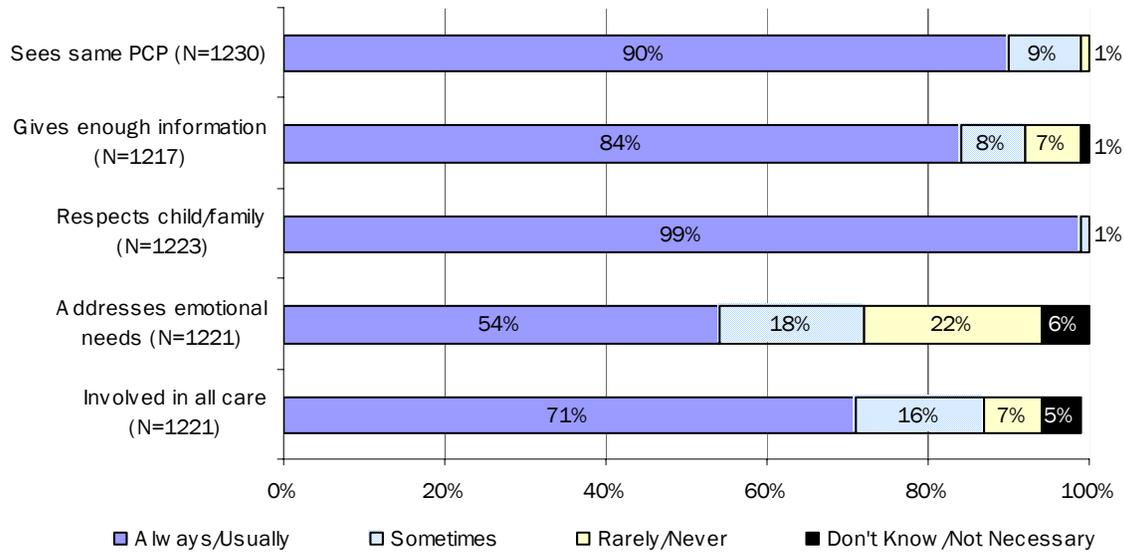
Figure 10: Type and Location of PCP (N=1239)



Children with special needs in MaineCare appear to have good continuity of care as evidenced by the high rate of parents who report that their child always or usually sees the same provider when they receive care (90%). They also believe that their PCP respects their family’s culture and ethnic background (99%). However, 15% of respondents report that their child’s PCP sometimes, rarely, or never provides them with enough information about their child’s condition and 22% report that the PCP rarely or never helps the parent understand the emotional needs of the child. Six percent of parents did not think this was necessary.

Twenty-three percent of parents report that the PCP is sometimes, rarely, or never involved in the planning and delivery of all of their children’s health care. Five percent did not think this was necessary. The PCPs’ involvement with care coordination is discussed further in the Care Coordination section of this report.

Figure 11: Parents' Assessment of Factors of Care from PCP

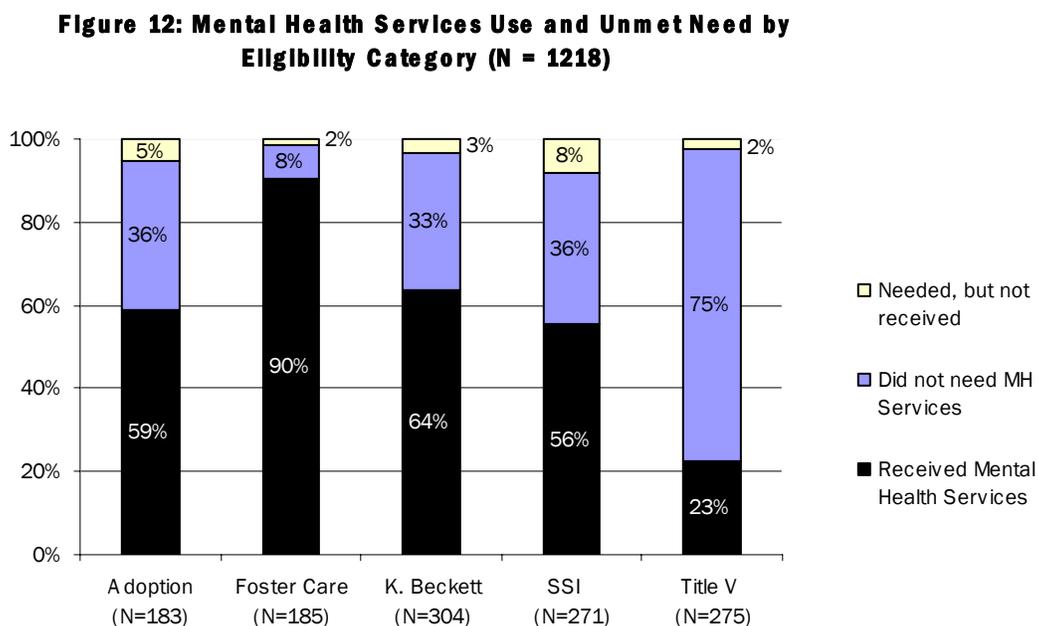


Mental Health and Specialty Services

Overall, 61% of the children in the survey population received mental health services from a psychiatrist, psychologist, social worker, or mental health counselor during the previous 12 months. Thirty-two percent of parents report that their child had not needed mental health services and 5% said that they needed mental health services but had not received any. The children who needed but did not receive mental health services are more likely to be receiving benefits through SSI eligibility.

Figure 12 shows the unmet need and service use of mental health services by children in the five eligibility categories. Ninety percent of children in foster care receive mental health services. Not surprisingly, the lowest mental health service utilization is by children receiving services from Title V, a benefit primarily for children with physical disabilities.

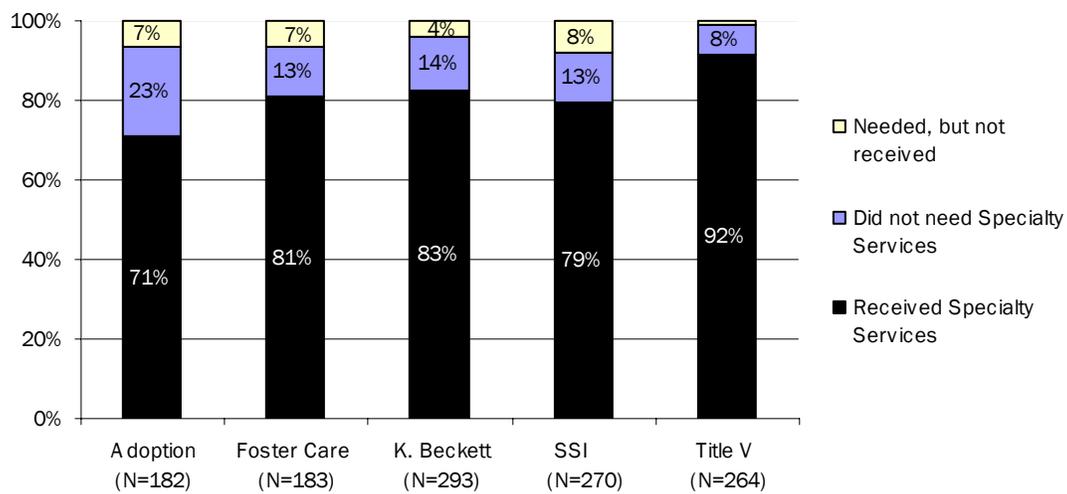
Eight parents report that they took their child to a mental health provider in another state; these data are excluded from the chart below.



Survey interviewers asked parents if their child had received any type of specialty care (mental health or medical) in the past twelve months. Overall, 77% of the survey population visited at least one specialist in the past year. Of the remainder, 13% report that specialty care was not needed, 6% report that they needed a specialist but had not seen one, and 3% report that they visited a specialist in another state.

Figure 13 shows that children in the Title V program receive more specialty services (92%) than children in other benefit groups; adopted children are less apt to need specialty care. Eight percent of children receiving SSI need, but have not received specialty services and 7% of children receiving adoption assistance and foster care services have unmet specialty care needs. Children visiting specialists in other states are excluded from the analysis in the chart below.

Figure 13: Has Your Child Been Seen by a Specialist in the Last 12 Months? (N = 1192)



Of the parents who reported that their child receives any specialty care, almost three quarters (74%) report that their child received care from the same specialist at least three times during the year. Parents were asked to describe that specialist. The majority of these providers are described as mental health care specialists (59%) and the remainder are a variety of other specialists. Figure 14 is the distribution by benefit category of the type of specialist children visited. In each category except Title V, a benefit designed to support children with medical needs, the majority of the specialists seen by children are mental health providers.

Figure 14: Distribution of Specialty Service by Eligibility Category (N = 706)

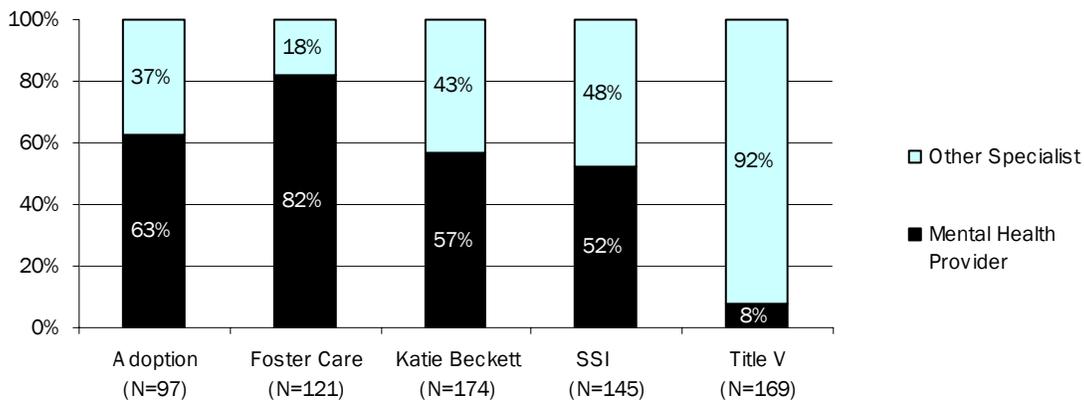
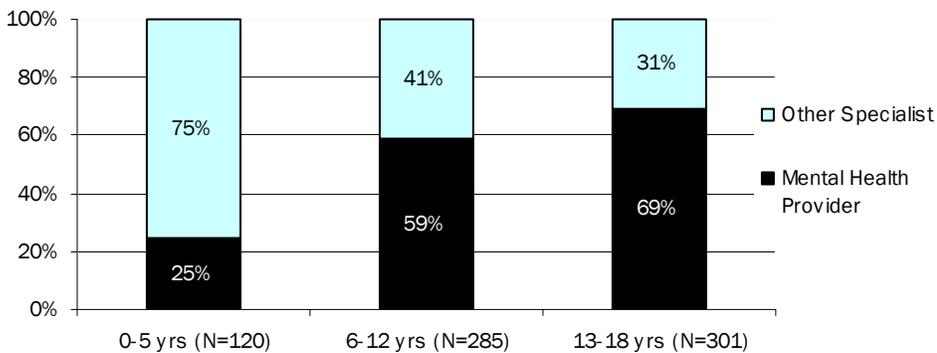


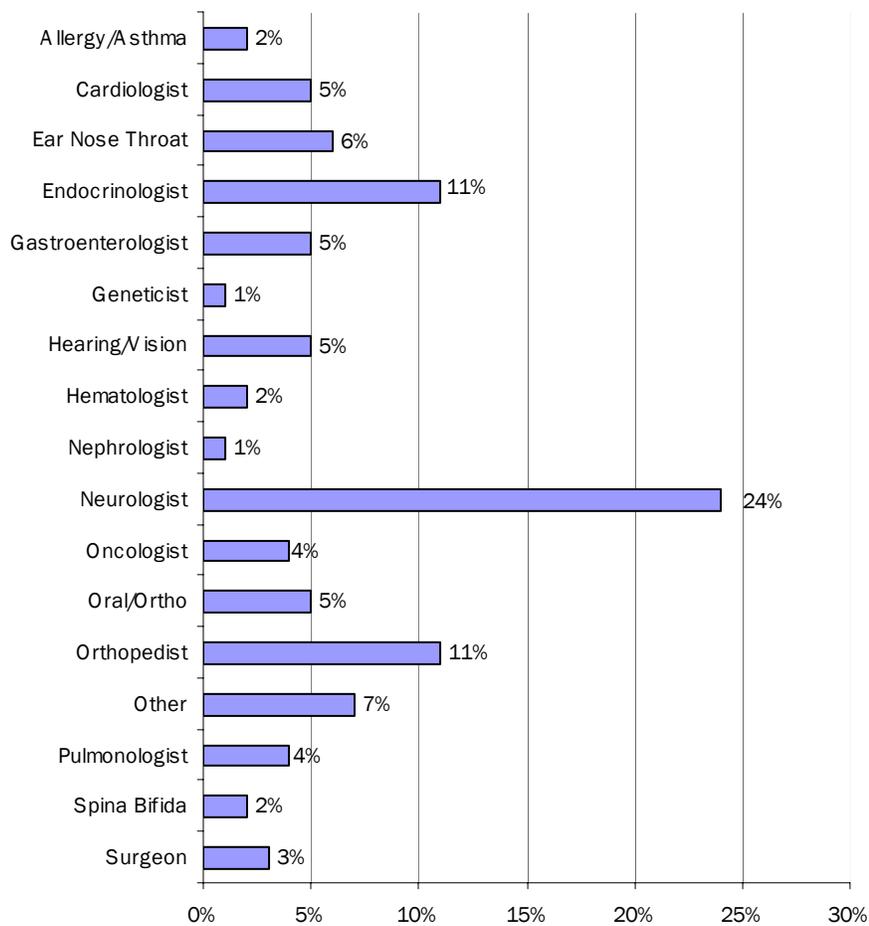
Figure 15 shows the distribution of specialty services by age groups and the increased reliance on mental health providers as children age.

Figure 15: Specialty Service Utilization by Children's Age (N = 706)



Parents report a vast array of non-mental health specialty providers who serve their children. Most frequently cited are neurologists, orthopedists, and endocrinologists. Approximately one quarter (24%) of children, who see a non-mental health specialist on a regular basis, see a neurologist. Figure 16 shows the distribution of non-mental health specialists the survey population utilized. The ‘Other’ category includes urologists, gynecologists, podiatrists, dermatologists, and a developmental pediatrician.

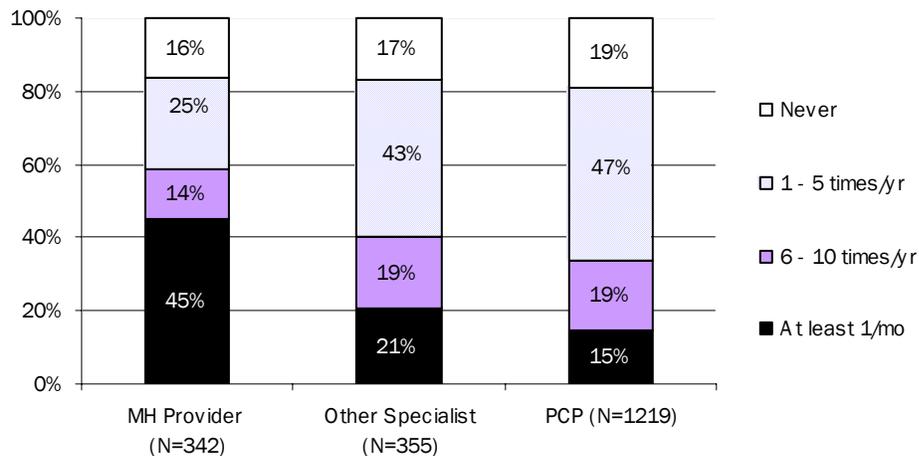
**Figure 16: Specialist Most Often Seen
(Other than Mental Health Provider) N = 355**



Access to Services

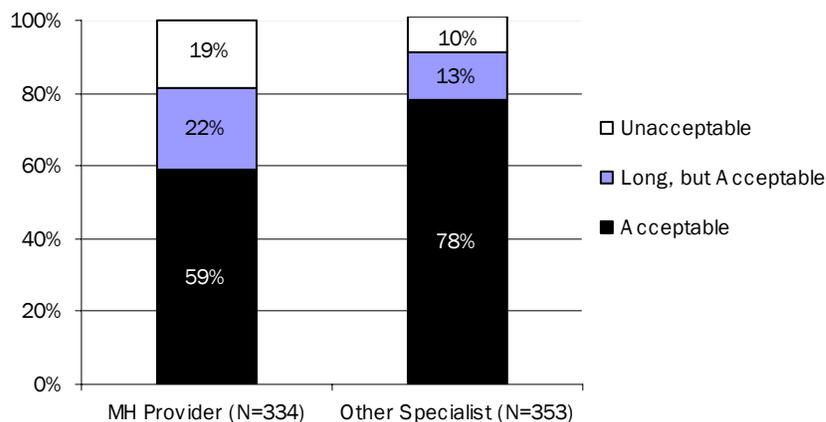
To gauge accessibility to care, parents were asked about the frequency of obtaining information from medical providers by phone or in writing and about the length of time it takes to obtain the first appointment. Parents appear to seek advice or information from mental health providers on the phone much more frequently than from other specialists or from their child's PCP. Twice as many parents of children receiving mental health services obtain information monthly from their child's mental health provider (45%) than parents who contact other specialists (21%). Only 15% of parents whose child has a PCP calls the PCP this frequently regarding their child's health care needs.

Figure 17: How Often Do You Receive Help or Information from the Provider on the Phone?



Obtaining the first appointment with a mental health provider appears to have taken longer, with parents describing the initial wait as 'unacceptable' at nearly twice the rate as parents seeking the services from other specialists, 19% vs. 10% as shown in Figure 18. Fifty-nine percent describe the initial wait for the mental health appointment as being acceptable, compared with more than three quarters of parents seeking other care (78%).

Figure 18: Describe the Amount of Time It Took When Your Child First Needed a Specialist (N=687)

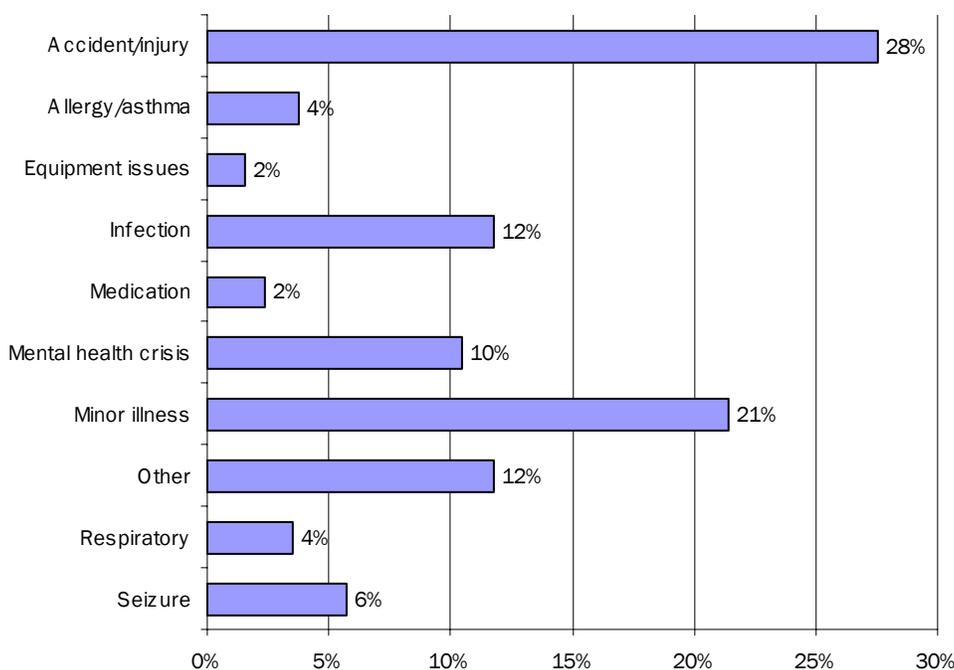


Emergency Room (ER) Use

Thirty-nine percent of children in the survey population visited the ER at least once during the previous 12 months. Approximately one half of the parents whose children visited the ER contacted their PCP or specialist to obtain advice or to visit the PCP prior to going to the ER. Reasons given for not contacting the usual source of care include inability to reach the PCP (50%) and not wanting to wait to see their PCP due to the nature of the emergency (35%).

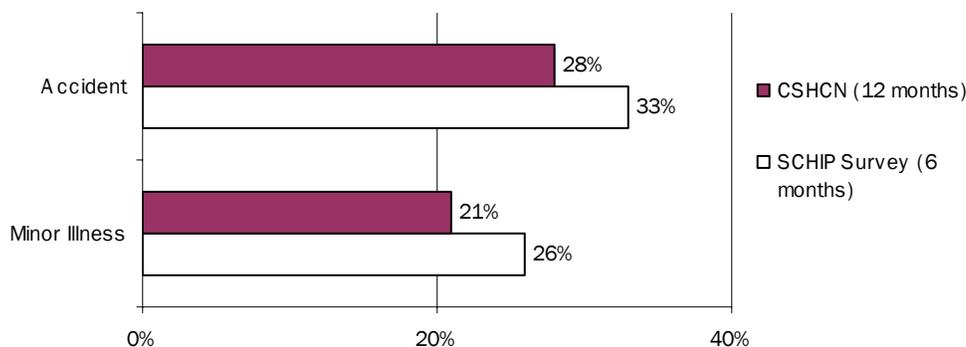
Of the 39% who reported visiting the ER, 9% visited the ER more than once during the previous 12 months. Figure 19 shows the reasons for the visits. Twenty-eight percent of the visits resulted from accident or injury, 21% were for minor illnesses, 10% of the visits were due to mental health crises, and 2% had to do with medication management. Parents referenced chronic illnesses such as asthma as disease-specific reasons for the ER visit; diabetes, included in the 'other' category, was mentioned to a lesser degree.

Figure 19: Primary Reasons for ER Visits (N=508)



Inappropriate emergency room use appears to be lower in this population compared to children enrolled in MaineCare through the SCHIP (States Children’s Health Insurance Program) benefit.⁵ Children with special needs tend to visit emergency rooms less frequently for minor illnesses during the 12 month recall period (21%), compared to children in the SCHIP population during a six month recall period (26%). Minor illnesses such as sore throats, colds, or ear aches are treated more appropriately by children’s usual source of care and considered to be inappropriate reasons for an ER visit. Children in the SCHIP population also reported a higher rate of ER visits for accidents and serious injuries during the six month recall period (33%) than did children with special needs over a 12 month period (28%).

Figure 20: Emergency Room Use by Survey Population and Enrollees in Maine's Children's Health Insurance Program (SCHIP)



Physical Accessibility

Interviewers asked a screening question to learn if the child had a physical disability requiring environmental accessibility. Twenty-nine percent of the survey population responded positively. These parents were then asked if the providers’ offices are “set up so that your child can get in and around easily, including examination tables, toilets, and entrances?” Six percent of children with physical disabilities receive services from their PCPs in environments that are not accessible; 2% of specialists’ offices are inaccessible, according to survey respondents.

Mental Health Medication/Information

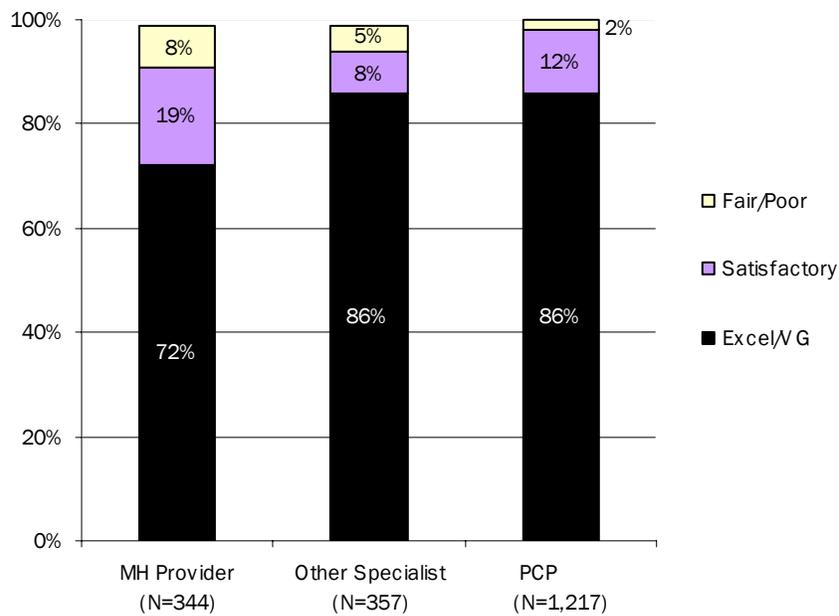
Sixty-four percent of the children who received any kind of mental health service during the reporting year said that their child had been prescribed medication for emotional or mental health needs. Of these respondents, 97% report that they received information about risks, benefits, or side effects of the medication. Two percent said they did not receive this information.

⁵ Ziller, E., *Satisfaction with Children’s Health Care: Families’ Evaluation of Medicaid and the State Children’s Health Insurance Program (SCHIP)*, FY 2003. Muskie School of Public Service, November 2002.

Quality

We asked parents to rate the overall quality of care their child receives from their primary care provider, mental health provider, and specialty provider. Parents rate their children's PCPs and medical specialists equally high; 86% are graded as excellent or very good. Ninety-one per cent of respondents rate the services provided by their children's mental health provider as satisfactory (19%) or excellent (72%).

Figure 21: Rating of Overall Quality of Care



Care Coordination/Case Management

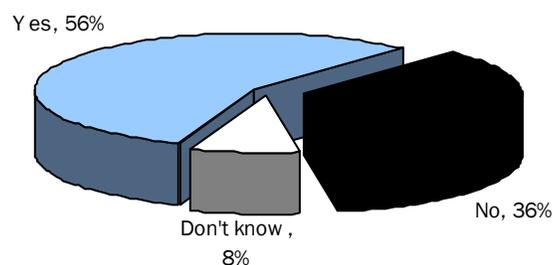
Nationally, the name of this service has recently evolved to ‘supports coordination.’ The term most often used in Maine is ‘case management;’ care coordination is used to a lesser degree. We use the latter two terms interchangeably in this report. In any case, this service can be defined as the coordination of both medically-based and community-based services. At least four elements constitute case management services: financial case management that attempts to reduce costs, administrative case management that provides referrals, family-centered coordination that focuses on the strengths and needs of the family, and systems integration that connects non-duplicative services to children and families.

This survey was designed to assess the extent to which care coordination is taking place and parents’ satisfaction with this service. The survey asks about parents’ perception of service coordination between their children’s PCP and specialty provider, whether or not they had someone or needed someone “to help coordinate their child’s care,” and how they would describe that person. Finally, we asked them to rate that service using a likert scale of excellent to poor. The purpose of this inquiry is to determine parents’ satisfaction with different types of care coordination providers. This service is becoming increasingly important with the growing number of children identified with special needs and the increasing types of services that require coordination. Understanding which systems are working well will inform policymakers as they work to improve and expand services.

Written Care Plan

The American Academy of Pediatrics recommends that each child with special health care needs have a written health care plan that serves as the cornerstone of care coordination. The plan should be updated annually and involve all the child’s providers. It typically includes goals for the year and the type, intensity, and duration of services. The presence of a written health care plan in Maine’s population serves as an indicator of the extent to which care coordination is taking place.

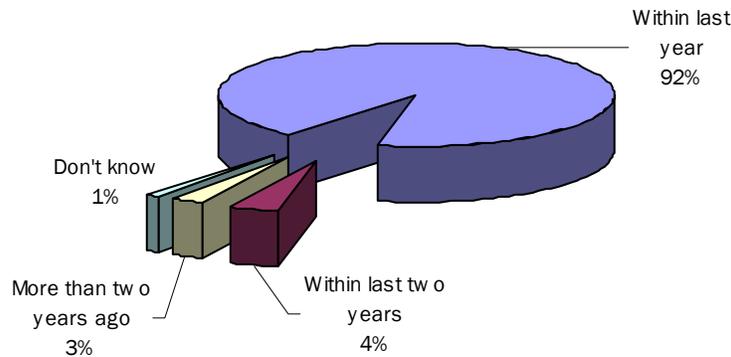
**Figure 22: Presence of Written Care Plan
(N=1241)**



Fifty-six percent of children (700) in the survey population have a written health care plan according to their parents and the majority (92%) of those plans were updated within the previous 12 months.

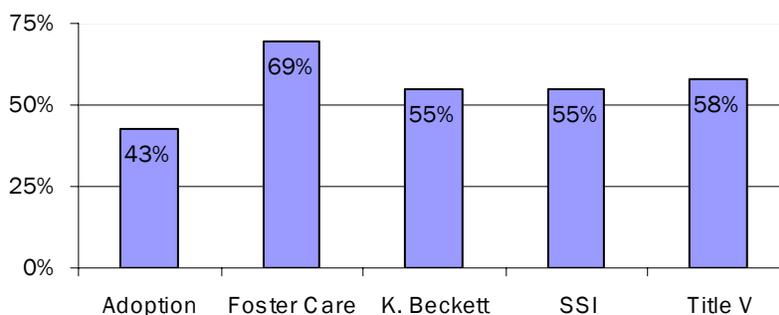
Of the parents whose children have a written care plan, 82% report that they have a copy of the plan. Thirty-six percent of the survey population do not have any written care plan in place and the parents of the remaining 8% were not sure whether a plan for their child exists.

Figure 23: When Was the Care Plan Last Updated? (N=700)



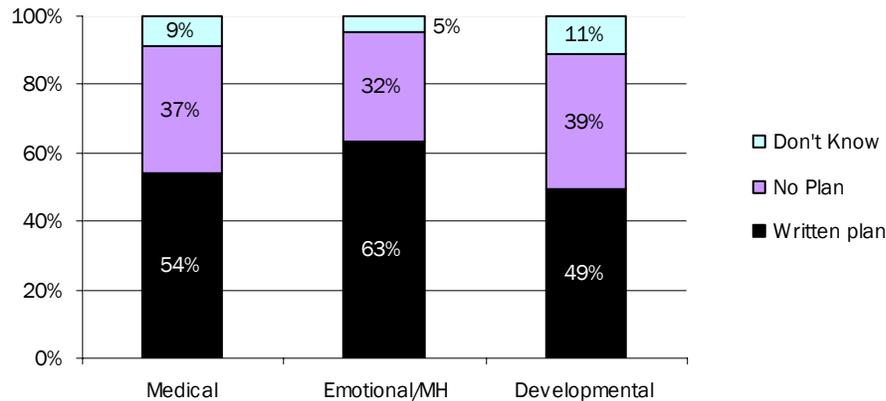
To understand why some children have care plans and others do not, we analyzed this variable by age groupings, regions, eligibility categories and disability types. The eligibility category analysis below (see Figure 24) shows the percentage of children in each benefit group with a written care plan. Slightly more parents of children in foster care report having a written care plan (69%); only 43% of children receiving adoption assistance have a care plan. The remainder do not have a care plan or they were not sure. Parents of children receiving SSI benefits were most likely to be unsure of whether their child had a care plan (12%).

Figure 24: Percent of Children In Benefit Categories with Written Care Plans (N=700)



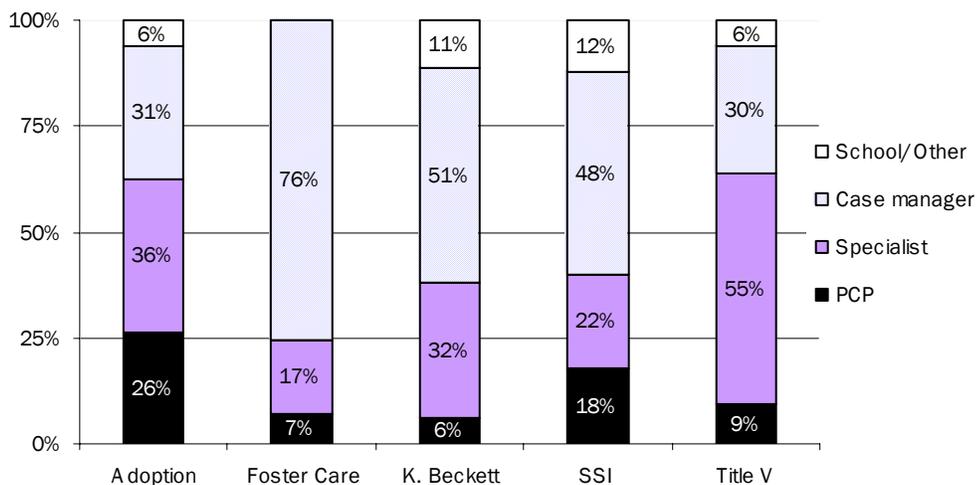
Children with emotional and behavioral needs are more likely to have a plan of care in place (63%) compared to other disability types, as seen in Figure 25.

Figure 25: Presence of Written Care Plan (N=1220)



The principle provider who works with parents to develop the care plan is seen in Figure 26. Overall, 37% of the providers responsible for developing the care plan are clinicians (PCPs or specialists) and 51% are described as case managers. Children in foster care are most likely to have their care plan developed by a case manager (76%), whereas children receiving services through Title V and adoption assistance are more likely to be served by a medical provider for this service (64% and 62% respectively).

Figure 26: Person Who Helped Develop the Care Plan (N=700)



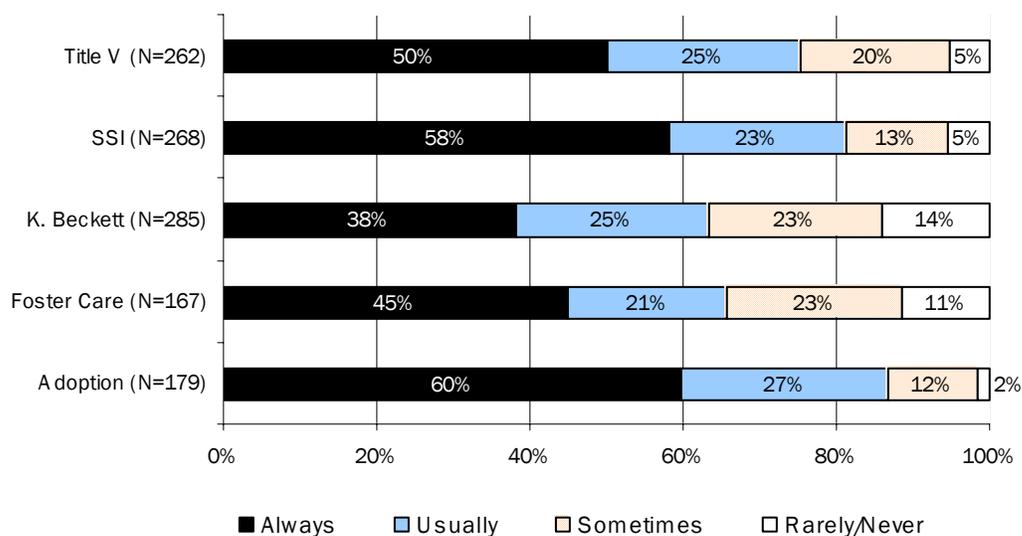
Perception of Coordination Among Providers

Though parents may not be fully aware of interactions between their child’s providers, they are aware of the amount of information that they must repeat or transmit from one provider to another. Therefore, their perception of the extent of coordination is a useful gauge of provider coordination, absent any other test.

We asked parents slightly different questions focusing on care coordination in various parts of the survey. In the section asking about the child’s primary care provider we asked whether their child’s PCP is involved in all health care planning and delivery. In the section on mental health services interviewers asked parents whether their mental health services are coordinated with their child’s primary care or other medical services. In the specialty section we asked if the specialty provider speaks with their PCP about the child’s care. Together, the responses to these questions illustrate the level of coordination of care among clinical providers.

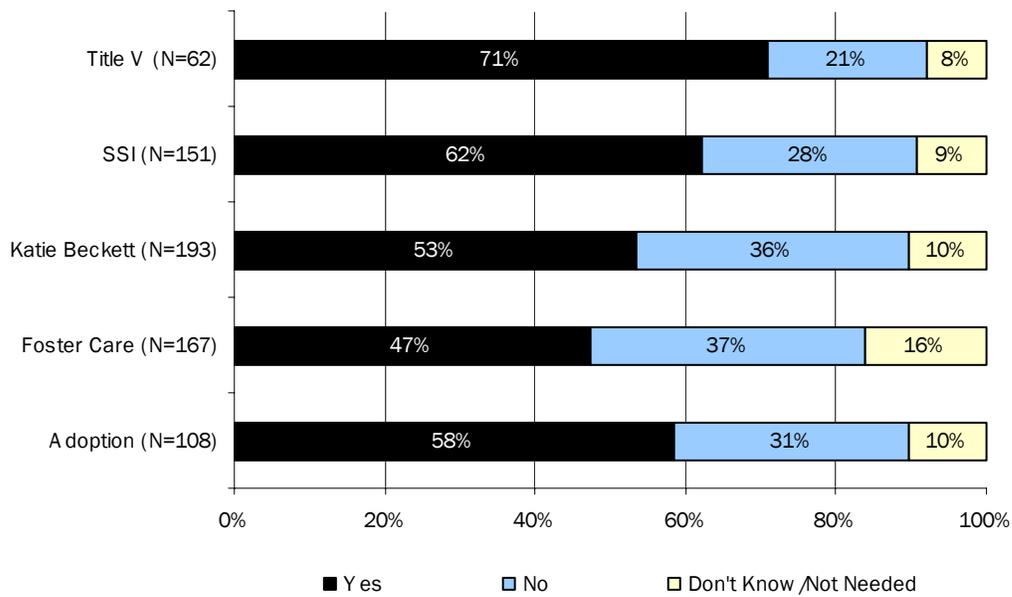
Figure 27 shows that parents of children receiving services through the Katie Beckett eligibility are less likely to believe that their child’s PCP is involved in all of their child’s care (37% report ‘sometimes’ or ‘never’) compared with parents of children receiving adoption assistance (14% report ‘sometimes’ or ‘never’).

Figure 27: How Often Is the PCP Involved In the Planning and Delivery of All of the Child's Care? (N = 1161)



The majority of parents (56% overall) believe that their child’s mental health and primary care services are coordinated. Figure 28 shows that parents of children in the Title V program are more likely to think that services are coordinated (71%) and parents of children receiving foster care services are least likely to believe services are coordinated (47%). However, note the variability of the numbers (N) of children receiving both PCP and mental health services reporting in each category.

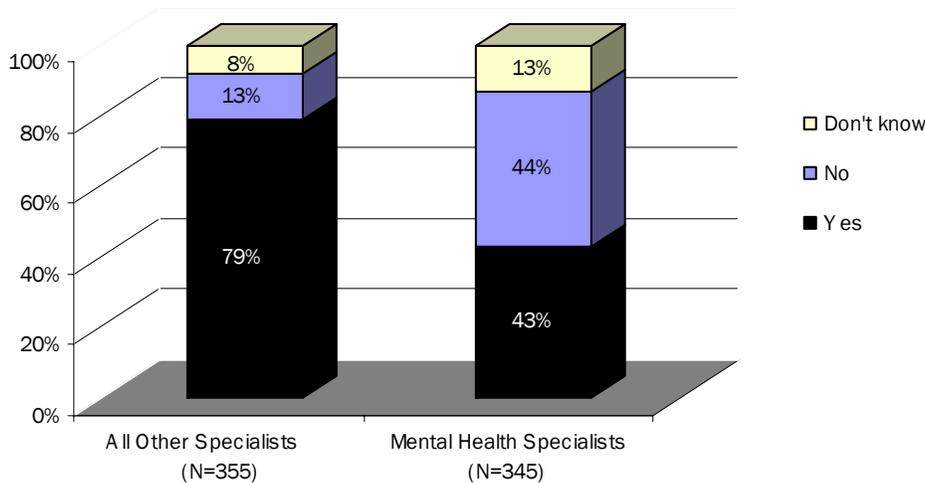
Figure 28: Are Your Child's Mental Health and Primary Care Services Coordinated? (N = 681)



Parents were asked about the coordination between specialty care services and primary care services provided by their child's PCP. Of the children who saw a specialty provider at least three times during the previous year, more than half (59%) describe the specialist as a mental health provider. Figure 29 shows that fewer than half (43%) of these parents believe that their child's mental health provider consults with their child's PCP about their child's care. An almost equal amount (44%) answered that they were sure their child's mental health provider did not consult with the PCP, and the remaining 13% reported that they were unsure of any communication.

Conversely, 79% of the parents whose children receive services from medical specialists believe that the specialists talk to the PCPs about their children's care. Only 13% were certain that their child's medical specialist did not talk to the PCP, and the remaining 8% were unsure about any consultation between providers.

Figure 29: Does Your Child's Specialist Talk to the PCP About Your Child's Care? (N = 700)



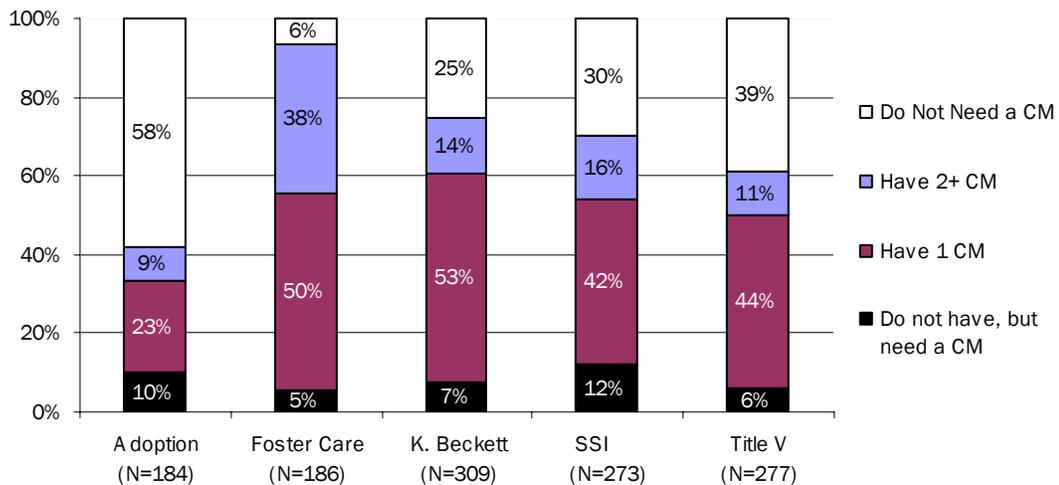
These responses may appear to contradict those of the previous question (*Are mental health and primary services coordinated?*). However, this question specifically asks whether the two providers talk to each other. It attempts to understand if the providers communicate about the child's progress versus other administrative, referral, or financial coordination that may be taking place.

Finally, parents were also asked whether their child's PCP provided information about family support services or parent-to-parent groups. Thirty-seven percent of parents had received this information from their PCP, 51% had not. The remainder did not remember if they had received this information or did not think this information was needed.

Care Coordinator/Case Manager

Survey interviewers first explained that a case manager is someone who “helps you to get and to coordinate services for your child’s care.” They then asked if the parents had this service, if they have one or more persons or agencies that help them, or if they need the services but do not receive them. In total, survey respondents report that they receive case management from over 70 community-based agencies, five state agencies, school, and medical providers.

Figure 30: Presence and Need of a Case Manager (CM) (N=1229)



Overall, 43% of respondents report that they had one case manager who assists them in coordinating their child’s care. Nineteen percent said that they have two or more case managers and 28% stated that they do not need a case manager. Nine percent report that they need a case manager, but do not have one. Of the children whose parents report that they need a case manager and do not have one, the largest group was children receiving services through SSI (12%), followed by children receiving adoption assistance, 10%. Parents of children receiving adoption assistance are also more likely to report that their children do not need a case manager (58%).

Children receiving foster care benefits are more likely to have more than one case manager (38%) than children receiving benefits from other sources. This is not surprising; each foster child is assigned a Department of Human Services (DHS) case worker/manager whose primary role is to represent the Department as the child’s legal guardian. In addition, foster children with high therapeutic needs may be assigned a community-based case manager whose role is to identify and coordinate behavioral health and other services the child may need.

Community-Based Case Management

Satisfaction with community-based case management, analyzed by age groupings and by region, shows little variation. Between seven and eight percent of parents in each region (see Table 1 for definitions of regions) rate their services as poor or fair. Ninety-two to 94% report these services to be satisfactory, very good, or excellent.

Figure 31: Satisfaction with Community-Based Case Management Services (N=686)

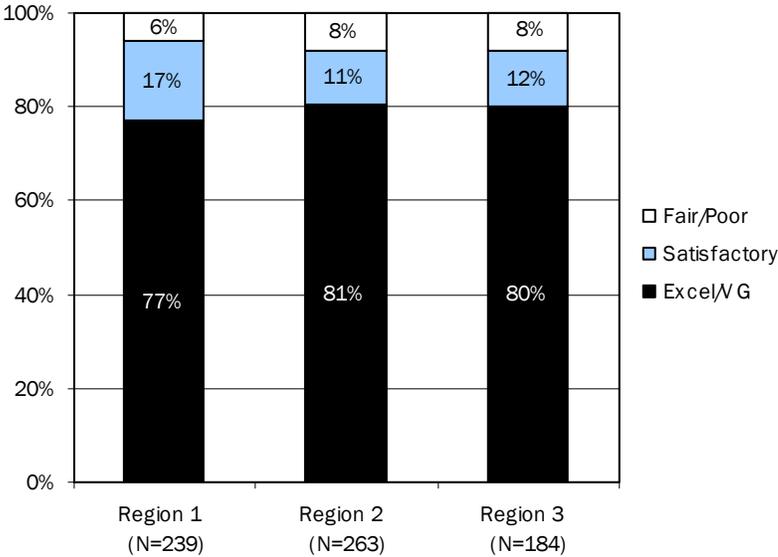
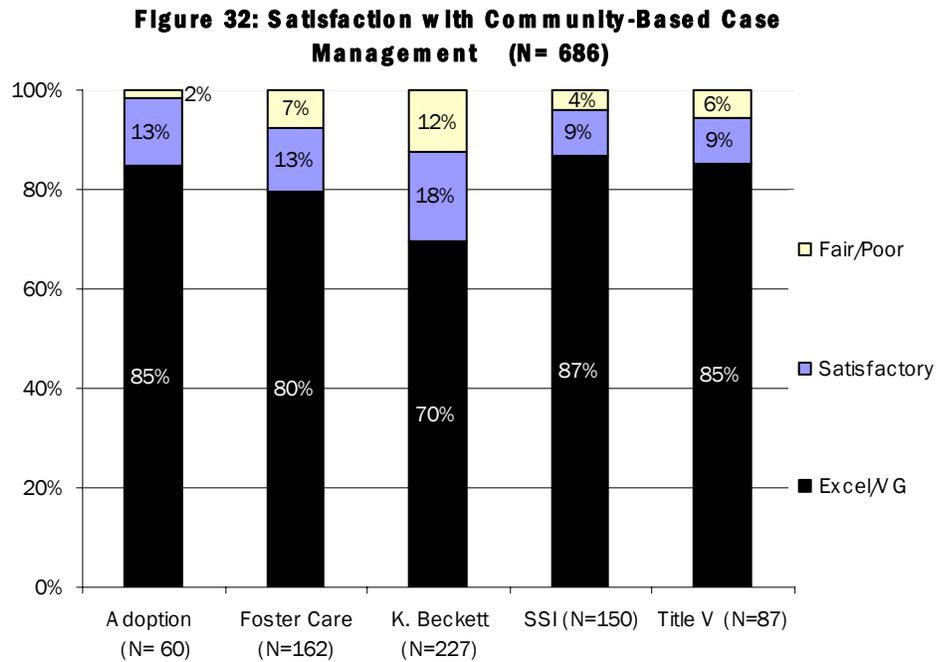


Figure 32 shows the differences in satisfaction among the children in the five eligibility categories. Parents of children enrolled in MaineCare through the Katie Beckett eligibility option are least likely to rank their child’s case management services as excellent or very good (70%) compared to parents with children in other eligibility categories. Respondents with children receiving services through other eligibility categories rate their case management services as excellent or very good between 80% and 87%.



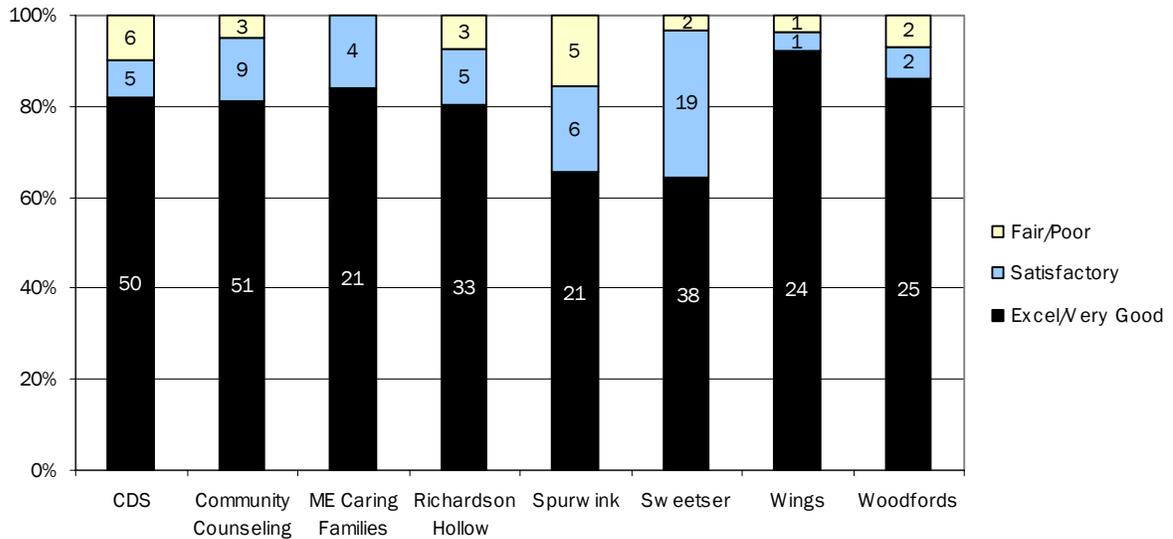
Though respondents were asked specifically about their children’s case management or care coordination services, parents reported receiving these services from a wide variety of organizations. Table 2 shows a list of the agencies reportedly providing case management services; note that parents cited some agencies that provide home health services, while others provide counseling or even residential services (Heritage House). In the case of the latter, Heritage House is operated by Youth Alternatives; it may be this organization that is providing case management services.

Table 2: Organizations Delivering Care Coordination or Case Management Services (N=686)

Addison Point	Living Innovations
Androscoggin Home Care	Maine Caring Families
Aroostook Mental Health	Maine Children’s Cancer Program
Assistance Plus	Margaret Murphy Center
Atlantic Home Health	May Center for Autistic Children
Care and Comfort	Merry Meeting
Casa	Micmac Council
Casey Family Services	Midcoast Mental Health
Catholic Charities	Mobius
Charlotte White Center	MST
Children's Center	NE Occupational Exchange
Children's Development Services	New England Health Care
Choices	New England Rehabilitation Center
Community Concepts	OHI Family
Community Counseling	Penquis CAP
Crisis and Counseling	Pine Tree Society
Counseling Services, Inc.	Port Resources
Day One	Project Peds
Donegal Town	Providence
Elmhurst, Inc.	Richardson Hollow
ESM	Spurwink
Exuberant Living	Sunrise Community Workshop
Family Focus	Support Solutions
Gentiva	Sweetser
Harland Turner Center	Tri County Mental Health
Healthy Families	UCP
Heritage House	Waban Projects
Independence Association	Waldo County Family Services
Jason Program	Washington County Services
John Murphy Homes	Wings
Katahdin Friends	Woodfords Family Services
Kennebec Valley Mental Health	York Community Action
Kidney Foundation	Youth & Family Services
Kids Peace	Youth Alternatives

Only eight community-based service agencies provided case management services to 25 or more children in the survey population, according to parents' reports. The majority of community-based case management service providers shown in Table 2 serve between one and 24 children in the study population. Figure 33 shows parents' ratings of the case management services they receive from the eight agencies serving the greatest number of children. Note that due to the low number of responses, we use the actual number of parents' reporting, rather than percentages.

Figure 33: Satisfaction with Case Management from Community Agencies (N>25 in each agency)



To understand the extent to which children in MaineCare receive case management services from more than one community-based provider, we conducted a separate analysis. We reviewed claims submitted by all community-based providers for children enrolled in the five subgroups of MaineCare during 2002. State agency-based case worker claims were excluded from this analysis.

Table 3 shows that, according to claims data, 45% of children enrolled in these benefit groups for 11 months do not have any case management provider. Forty percent of the children in this population had claims submitted for their case management by one community-based provider agency. Overall, 12% of the children had claims submitted on their behalf from two provider agencies and three percent had claims submitted by three different agencies.

Table 3: Percent and Number of Children Served by Different Community-based Case Management (CM) Providers in 2002 (N=7,892)

	Number of Case Managers							Total
	No CM	1 CM	2 CM	3 CM	4 CM	5 CM	6 CM	
Adoption	75.8%	18.9%	4.9%	0.4%	0.0%	0.0%	0.0%	100%
Foster Care	10.0%	67.0%	17.6%	4.4%	0.7%	0.2%	0.1%	100%
K. Beckett	32.8%	48.9%	15.4%	2.7%	0.2%	0.0%	0.0%	100%
SSI	47.6%	36.0%	12.6%	3.1%	0.6%	0.1%	0.0%	100%
Title V	78.7%	13.8%	5.8%	1.3%	0.4%	0.0%	0.0%	100%
Total	44.9%	39.7%	12.2%	2.7%	0.4%	0.1%	0.0%	100%

	Number of Case Managers							Total
	No CM	1 CM	2 CM	3 CM	4 CM	5 CM	6 CM	
Adoption	965	240	63	5	-	-	-	1,273
Foster Care	162	1085	285	71	11	4	1	1,619
K. Beckett	444	661	209	36	3	-	-	1,353
SSI	1,382	1,045	365	91	16	2	-	2,901
Title V	587	103	43	10	3	-	-	746
Total	3,540	3,134	965	213	33	6	1	7,892

Children receiving foster care services have more than one case manager at a slightly higher rate than children in other subgroups; 17.6% have two case managers and 4.4% have three. However, the numbers of children in SSI with two or more case managers are higher (365 children with two case managers, 91 children with three) than the numbers of foster care children with multiple case managers (285 children with two case managers, 71 children with three).

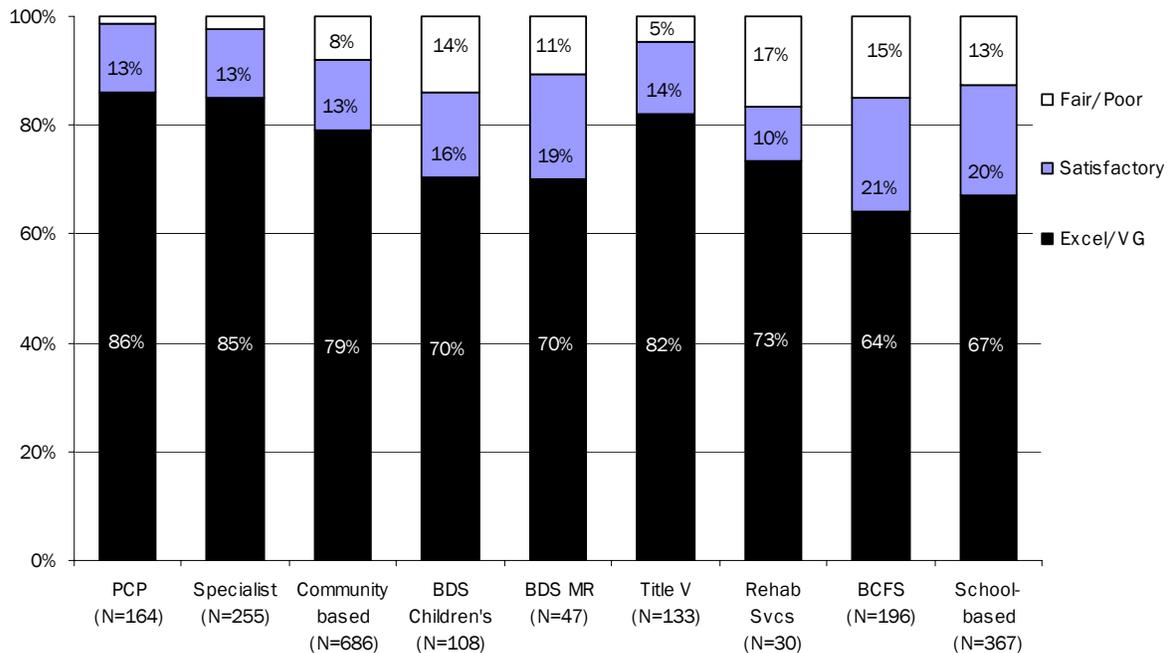
State Agency-Based Case Management

In addition to community-based case management services, parents reported receiving case management services from the following state agencies:

- Department of Behavioral and Developmental Services (BDS) – Children’s Services
- Department of Behavioral and Developmental Services (BDS) – Mental Retardation (MR) Services
- Department of Labor - Bureau of Rehabilitation (Rehab) Services
- Bureau of Child and Family Services (BCFS)
- Bureau of Health - Title V - Children with Special Health Care Needs Program

Figure 34 shows parents’ satisfaction with these care coordination services. Also included are ratings of care coordination from school-based and medically-based sources. Note the variance in the numbers (N) of parents reporting in each category; children receiving case management through school-based providers total 367, while only 30 children in the survey were reported to be receiving case management through the Bureau of Rehabilitation Services in the Department of Labor. The latter should be interpreted with caution.

Figure 34: Satisfaction with Case Management Services by Provider (Respondents reported more than once)

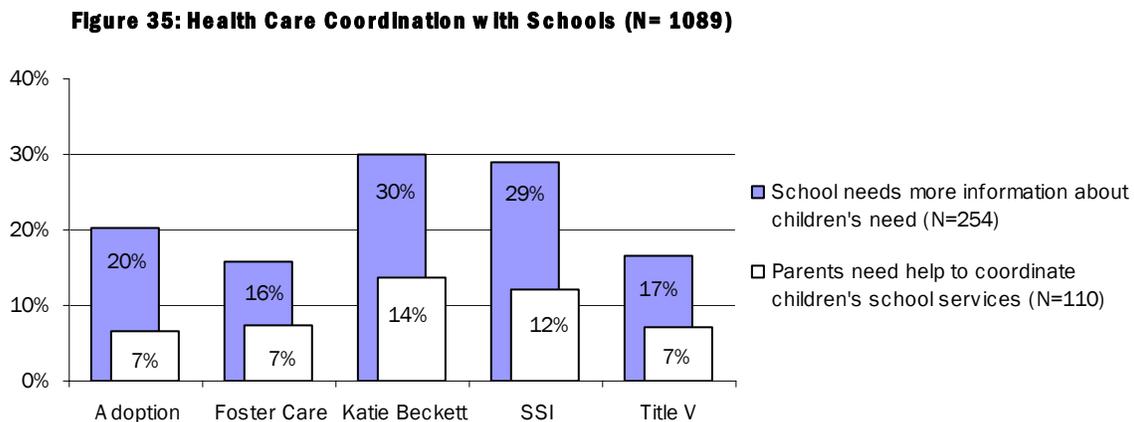


Parents whose children receive care coordination or case management through a PCP, specialist, or through the Title V program rate these service providers the highest, reporting excellent or very good 86%, 85%, and 82%, respectively.

The restructuring and reductions in payment rates to foster parents begun two months prior to the survey field work may have had a negative effect on the foster parents' report of satisfaction with services received through the Bureau of Child and Family Services (BCFS). Services provided through this bureau are dissimilar to those of other bureaus; they include foster co-parenting, with the BCFS functioning as the legal guardian) and oversight of the home environment, including addressing the recent requirement of smoke-free foster and adoption homes.

School Coordination

Although Figure 34 shows that the majority of parents rate their child's school-based care coordination as excellent, very good (67%) or satisfactory (20%), more believe that their school would benefit from having more information about their child's particular health care needs. When asked whether their child's school or day care needs more information, 30% of parents of children receiving benefits through Katie Beckett eligibility and 29% of parents of children receiving SSI benefits responded positively. Sixteen to twenty percent of children in the three remaining eligibility categories report this need. (See Figure 35.)



When asked about the coordination of health care services and school-based services for their children, 14% percent of parents whose children receive services through the Katie Beckett eligibility option report that they need help to coordinate their child's special needs with their school or day care. Twelve percent of parents with children enrolled in SSI report this need, while only 7% of children in the remaining eligibility categories report this need.

Unmet Needs

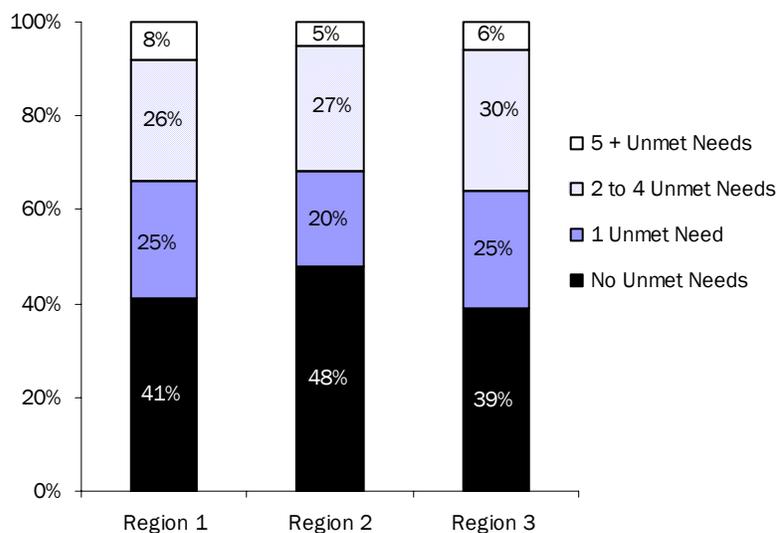
Survey interviewers asked respondents about the services their children need and receive and those that are needed, but not received. Services that are age-specific, such as transition and early intervention, were asked only for children of appropriate ages, all other questions were asked of all 1251 survey respondents. The following is a list of services included in this series of questions:

After school services	Mental health services
Behavioral health	Mental health diagnosis
Dental services	Nutrition counseling
Early intervention	Physical or occupational therapy
Genetic services	Special day care
Hearing services	Special education
Home nursing	Speech therapy
In-home services	Substance abuse
Medication	Transition planning
Medication management	Vision services

Parents were asked about other unmet needs that were not on the list; to this parents added respite, recreational therapy, developmental therapy, and mentoring that their children received or needed. These services are included in the analysis in the “other” category.

There was little variation among the three regions, with approximately one third of the population in each region having two or more unmet needs. There appear to be more children in region two with no unmet needs (48%) than in southern or northern parts of the state.

Figure 36: Distribution of Children with Unmet Needs by Region (N= 1251)



Looking at unmet needs of children distributed by MaineCare eligibility categories in Figure 37, we see that children receiving services through both the Katie Beckett eligibility and SSI have the greatest proportion of unmet needs. These groups show that 41% and 44% of their population have two or more unmet needs, respectively. Later in the report, survey data show that these two groups also have the highest utilization of five or more services (See Figure 40, *Distribution of Service Utilization by Eligibility*).

The combined adoption assistance and foster care group below shows that approximately one quarter of these children have two or more unmet needs. Children who receive services through Title V have the highest percentage of no unmet need (61%) and the lowest percentage of two or more unmet needs (18%). The service utilization graph later in this section reveals that 9% of this population report they do not need any services, the largest proportion of children without services among these subgroups. This may be partially attributed to the fact that these children have primarily medical, rather than behavioral or mental health needs.

Program support provided by the Title V program, foster care, and adoption assistance includes services that assist parents with identifying and accessing services. It is worth noting that of the five eligibility categories, the two that do not have such programmatic support, Katie Beckett and SSI, report the greatest number of unmet needs and also the highest utilization of services.

Figure 37: Distribution of Unmet Needs by Eligibility (N=1251)

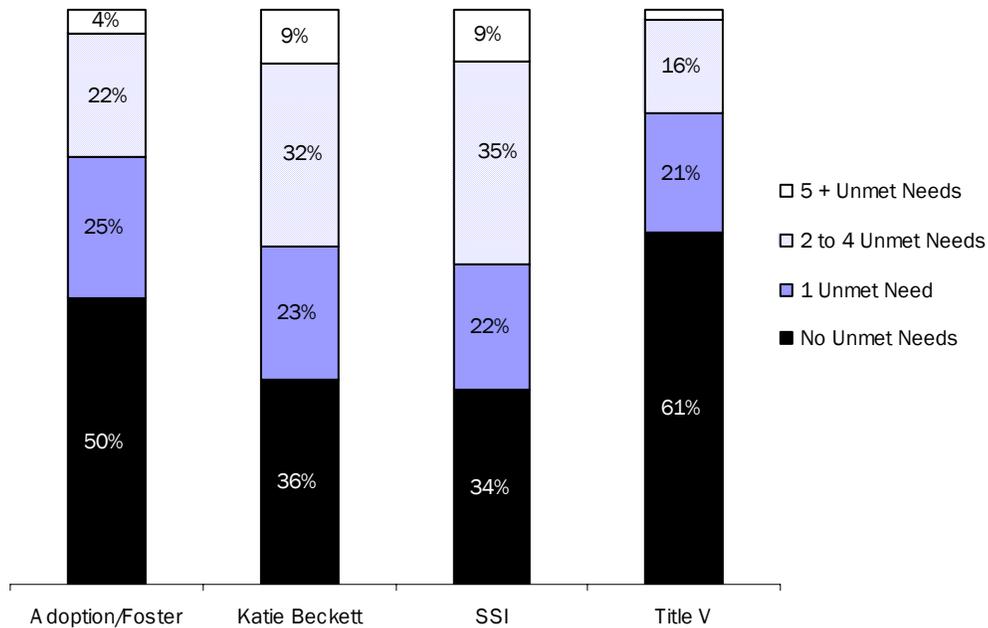
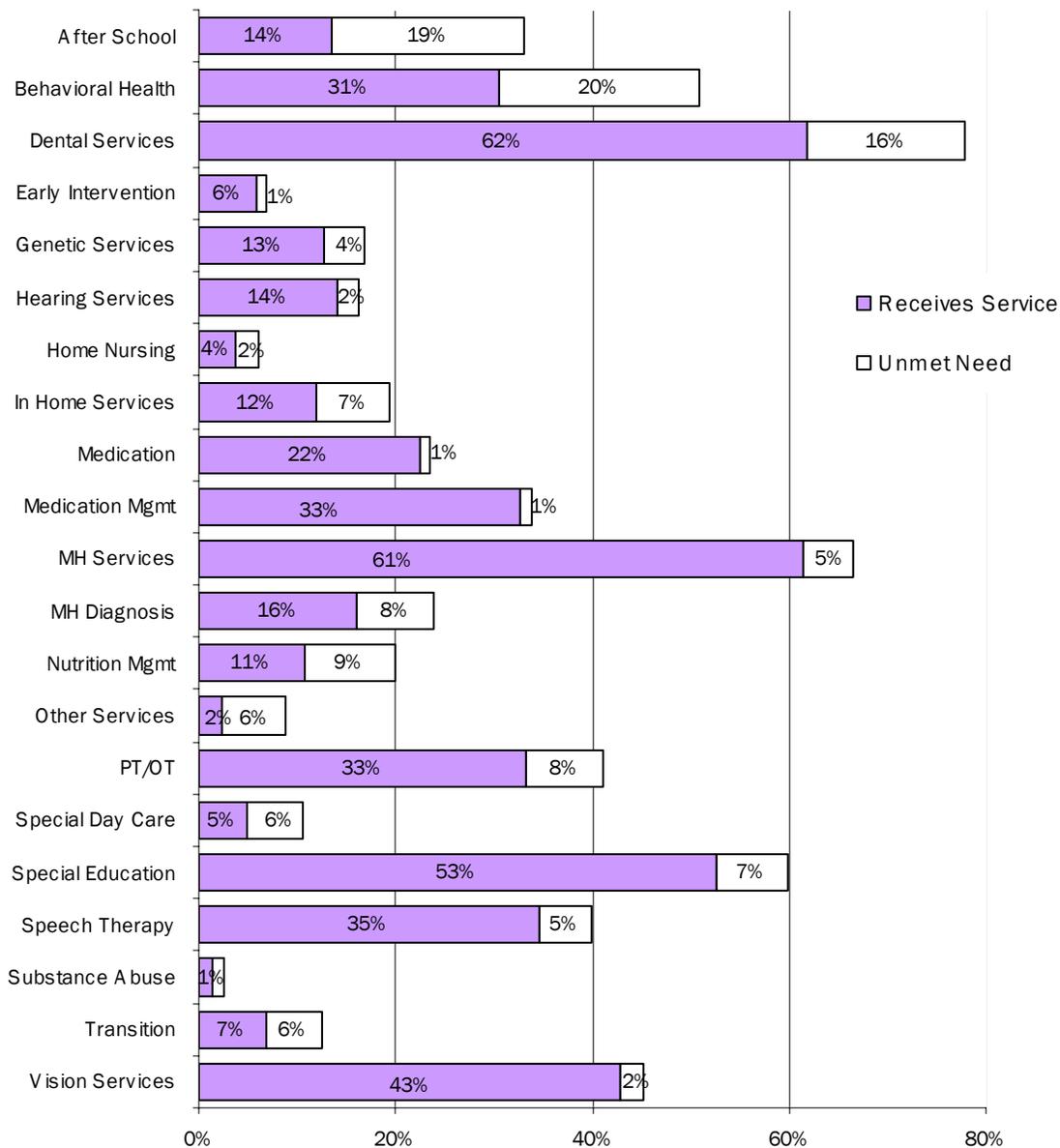


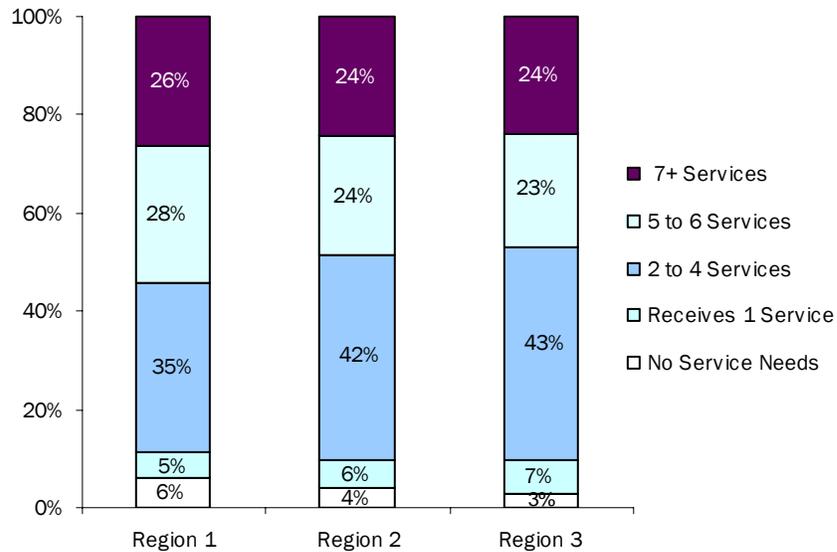
Figure 38 shows the proportion of met and unmet needs by the specific service identified in the survey. Fifty-one percent of the survey population state that their children have behavioral health needs; 31% receive these services, the remaining 20% of these children lack needed behavioral health services. The second highest unmet need is after-school programs; 19% of the respondents report that they need this service. Sixteen percent of children lack dental services. Eight percent lack a definitive mental health diagnosis, the first step in identifying effective services and developing the child’s care plan and goals. Note that ‘Other’ includes services that parents volunteered including respite, recreational therapy, developmental therapy, and mentoring, among others.

Figure 38: Met and Unmet Needs (N=1251)



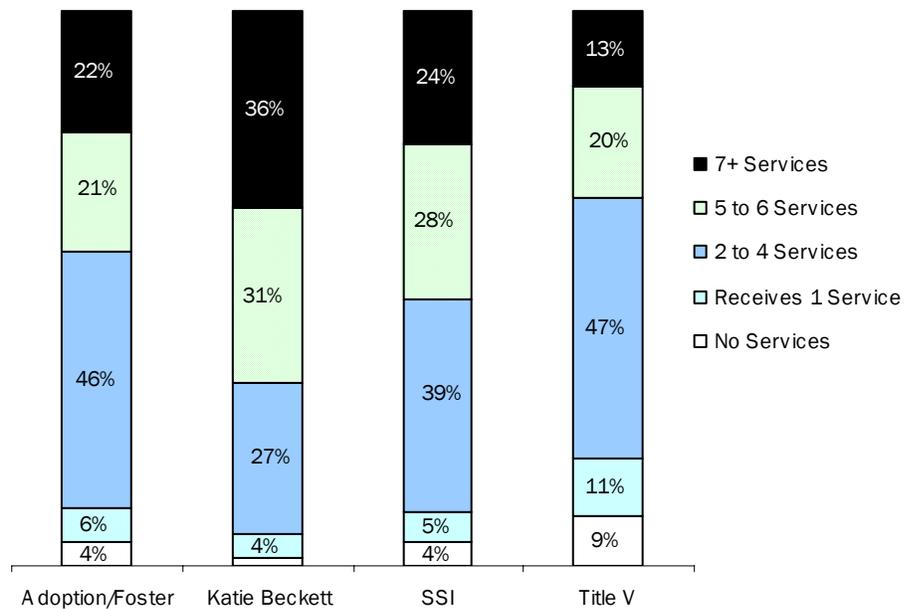
In addition to unmet needs, interviewers asked about the services their children receive. Figure 39 shows a uniform distribution of services received by children in the three regions of the state. Five to seven percent use one service; 35-43% use two to four services, 23-28% of the children in each region use five to six services and approximately a quarter of this population uses seven or more services. Three to six percent of children, across the three regions, have no service needs.

Figure 39: Distribution of Service Utilization by Region (N= 1251)



Analysis by eligibility category (Figure 40) shows that children receiving services through the Title V program are more likely than children receiving services through other benefits to require no services (9%) or only one service (11%). Two-thirds of children receiving MaineCare through the Katie Beckett option receive five or more services, the highest proportion of service utilization of the eligibility groups. More than 50% of children with SSI benefits receive five or more services. Children in these two groups also were previously reported to have the highest unmet needs (see Figure 37, *Distribution of Children with Unmet Need by Eligibility*), indicating the complexity of needs of these children.

Figure 40: Distribution of Service Utilization by Eligibility (N = 1251)

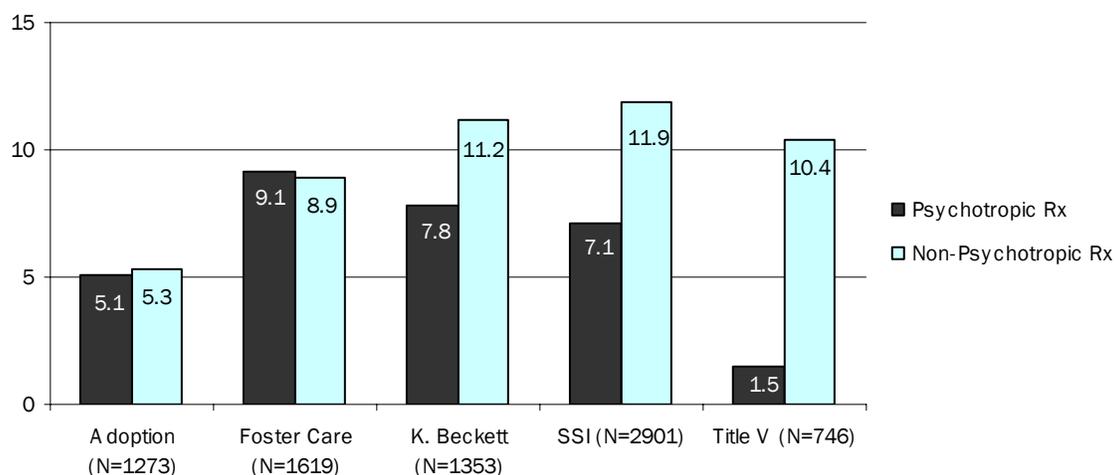


Medication Needs

The need for medication and medication management was reported uniformly by respondents in each eligibility category. Although these needs are largely being met, many parents commented in the open-ended question section of the interview on their concern for continued funding for medications. Therefore, to learn the extent to which children rely on medications and to review the cost of these drugs, we analyzed de-identified MaineCare pharmacy claims.

Figure 41 shows the number of prescriptions that were filled for children in 2002 according to MaineCare claims records. For example, children who receive benefits through SSI have an average of 19 prescriptions filled per year (usually a thirty day supply per prescription). An average of twelve (11.9) prescriptions for non-psychotropic medications were filled for children in this group during the reporting year. Fewer prescriptions, 7.1, were filled for psychotropic medicines for this group. Children in the Title V program rely the least on psychotropic medications (1.5) compared with children in foster care who use these medicines the most (9.1).

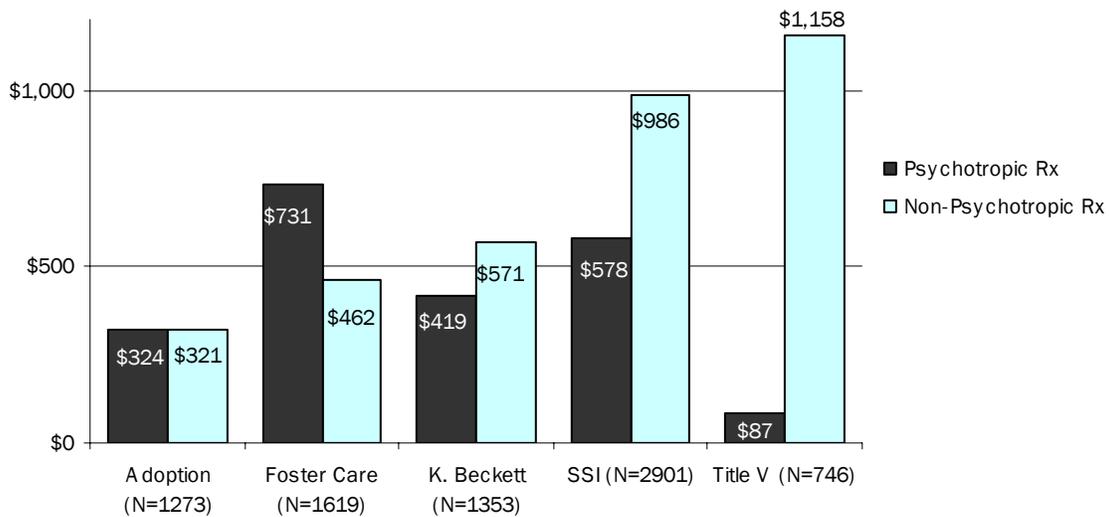
Figure 41: Average Annual Number of MaineCare Prescriptions Filled per Child in 2002 (N = 7,892)



Psychotropic medications include anti-anxiety agents, antidepressants, anti-psychotics, hypnotics, stimulants/anti-obesity/anorexiant, and miscellaneous psychotherapeutic and neurological drugs.

These figures include only MaineCare–funded prescriptions obtained from non-hospital pharmacies. Private health insurance may have covered additional prescriptions for these same groups of children. The cost of prescriptions, seen in the graph below, varies greatly, with non-psychotropic medicines needed by children in the Title V program costing an average of \$1,158 per child per year. The average yearly cost of non-psychotropic medicines for children receiving services through adoption assistance was \$321.

Figure 42: MaineCare's Annual Average Cost per Child for Prescription Medications in 2002 (N=7,892)



Equipment, Assistive Technology, and Medical Supplies: Met and Unmet Needs

Parents were also asked about their children’s unmet equipment and supply needs. These included obtaining, repairing, and adjusting needed medical equipment, such as wheelchairs or hearing aids and medical supplies such as gloves, needles, and syringes. Adaptive equipment (including ramps and other environmental adjustments) and assistive technology for home or school and training for this equipment were also included in this series of questions.

Overall, 24% of the population, or 299 children, report that they use or need these services. Of this group, 17% report having at least one unmet need. Thirty-six children (12% overall) report having one unmet equipment or technology need and seventeen children (5.7%) report having two or more unmet needs. Figure 43 shows the number of children with unmet equipment needs in each of the three regions.

Figure 43: Children with Unmet Equipment Needs (N=299)

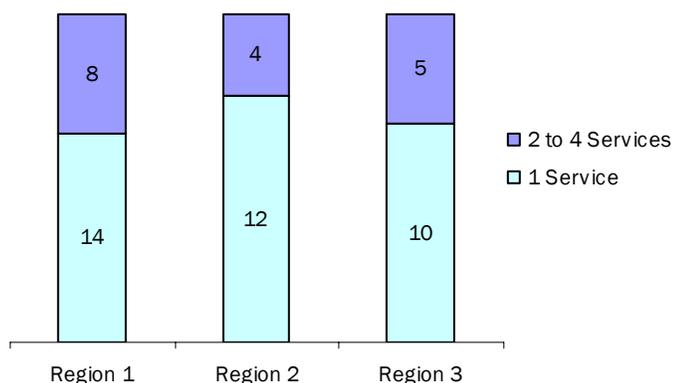
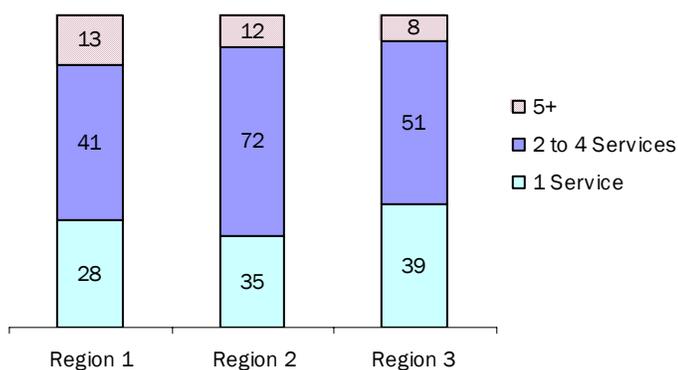


Figure 44 shows the number of children who use equipment and supplies and the number of services they use. Slightly more children in region two (119) require these forms of adaptive or assistive equipment or supplies, compared to children residing in region one (82) or region three (98). Overall, thirty-three children in the survey population use five or more equipment-related services.

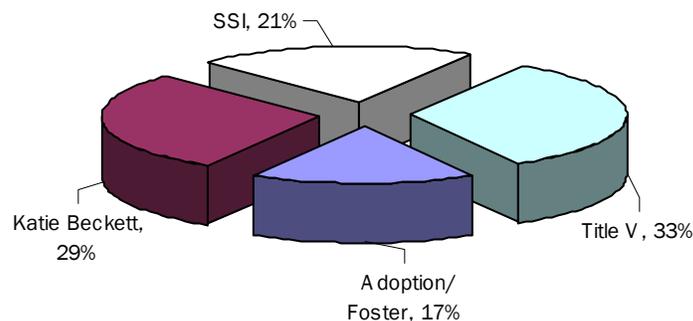
Figure 44: Equipment/Supplies Utilization per Child (N=299)



Of the 17% of children with equipment/technology unmet needs, children receiving services through the Katie Beckett option have the largest proportion, 9%, followed by children receiving services through SSI, 4%, children in Title V, 3% and children receiving adoption assistance or foster care services, 1%.

Children with equipment and assistive needs are found in each eligibility category (Figure 45). One third of these children receive services through the Title V program, 29% receive MaineCare through the Katie Beckett option, 21% receive SSI, and the remaining 17% receive adoption assistance or foster care services.

Figure 45: Equipment/Supplies/Assistive Technology Utilization (N=299)



Final Word on Unmet Needs

The penultimate question on the survey asked “*What do you consider to be your child’s greatest health care need?*” This was an open-ended question intended to give parents an opportunity to express any need or concern not already covered during the interview. The majority of parents responded to this question by indicating the need for more services designed to support children with a specific condition, such as autism, asthma, or brain injury.

Many indicated a need for “continuing maintenance”, ongoing support, or other indications of preventive services from both specialists and their PCPs. They also expressed concern for the future, referencing the child’s needs and wondering how they would have the necessary supports when their children become adults. Below are some examples of concerns parents expressed in the interview:

- “Identify what his primary diagnosis is; no commonality with diagnoses – makes treatment very difficult.”

- “He has been losing the use of his legs; need to find out the cause.”
- “Her depression and anxiety...you never know when it’s going to hit.”
- “Needs Medicaid for his prescriptions - that he really needs.”
- “He is recovering from Hodgkin’s disease and he needs help with medication and follow-up appointments.”
- “Not sure...needs constant care, she can’t walk...she can’t see.”
- “He needs support for all his activities – everything he does.”
- “Neuro-sensory assessment...he’s dysfunctional at times. He could burn himself and he wouldn’t know it.”
- “His mental health issues and lack of insurance for that.”
- “He was born addicted to a drug, so he takes a lot of meds...he also has ADHD, OCD and PTSD.”
- “Metabolic management – must eat continuously.”
- “Deteriorating hearing – how he can provide a living for himself in the future...his communication skills.”

Study Implications

In addition to the survey findings highlighted in the Executive Summary, this report reveals a range of system improvement activities to explore. Many of our findings are consistent with those from recent national studies and reports on children's disability issues and identify areas where state agencies could improve supports and services for children with special needs.⁶

- **Information/Resources.** Findings suggest that not being enrolled in a managed care benefit does not have an adverse affect on having a medical home and maintaining continuity of care for these children. However, parents would like to receive more information from their children's PCPs about the children's conditions and emotional needs. This may be an opportunity for assessing providers' needs and assisting in developing useful information and education resources for parents and children.
- **The locus of care coordination.** Parents of children who receive care coordination from medical or specialist providers, rather than from community-based organizations or state agencies, are more satisfied. This distinction warrants further investigation to understand these differences. Focus groups with parents receiving services from different sources would provide a deeper understanding of factors contributing to greater satisfaction.
- **Ombudsman.** Services for children enrolled through SSI and the Katie Becket option appear to be less efficient and less satisfactory as evidenced by higher rates of both unmet needs and utilization. Children with very complex needs in these groups could benefit from an ombudsman charged with ensuring that case management for these children is in place and effective.
- **Case management.** These services are provided by a vast array of community-based agencies. Children with complex needs and co-occurring secondary and tertiary conditions need case managers who can identify services to support all needs including medical, behavioral, school-based, and community-based services. It is important to ensure that these critical services are uniformly defined and that quality is monitored to ensure that all needs, physical as well as mental health needs, are being met.
- **Feedback from Parents.** Given the breadth and depth of information provided by parents in this study, service system development and improvement initiatives would benefit from ongoing feedback from parents, guardians, and other stakeholders.

⁶ Dougherty Management Associates, Inc., *Children's Mental Health Benchmarking Project: Third Year Report*, July 2003. Van Dyke, P., *Presentation for DataSpeak on the National Survey of Children with Special Health Care Needs*, HRSA. May 2003. Bethell, C. et. A., *Partnering with Parents to Promote the Health Development of Children Enrolled in Medicaid: Results from a Survey*, Commonwealth Fund, September 2002. President's New Freedom Report, *Policy Options: Subcommittee on Children and Family Promoting, Preventing, and Restoring Children's Mental Health*, February 5, 2003. www.mentalhealthcommission.gov/subcommittee/Sub_Chairs.htm. Leatherman, S. *Quality of Health Care for Children and Adolescents: A Chartbook*, Commonwealth Fund, April 2004.

- **Feedback to Providers and Staff.** Concomitantly, providers, case managers, and front line state agency staff might find abbreviated versions of these survey data useful to understanding the perspectives from the families they serve.
- **Identification in MaineCare.** Proper identification and early assessment of needs is critical to obtaining appropriate care. In addition to assessments of children in these five population groups, other children enrolled in MaineCare may have special needs that are not being met. Results from a screener question, added to the MaineCare application and renewal form, could be used to alert PCPs and direct appropriate services to the child and family.
- **Mental Health.** The President's New Freedom Initiative on Mental Health identified nine areas in which states can improve children's mental health services.⁷ Maine has already taken steps to reduce fragmentation by re-organizing critical departments supporting children; other areas identified in that report may be useful to explore.

These survey results demonstrate the value of obtaining feedback from parents about their children's services, needs, and experiences. Together with data available through claims, utilization, and other sources, these findings reveal a more complete picture of the needs and expectations of this population and identify for policymakers areas where systems and supports can be buttressed to improve the lives of these children.

⁷ President's New Freedom Report, *Policy Options: Subcommittee on Children and Family Promoting, Preventing, and Restoring Children's Mental Health*, February 5, 2003. www.mentalhealthcommission.gov/subcommittee/Sub_Chairs.htm

Telephone Survey Instrument
Children with Special Health Care Needs Receiving MaineCare Benefits
May 15, 2003

*Adapted from Family Survey in "Identify...Collaborate...Improve -Shared Responsibilities:
 Tools for Improving Quality of Care for Children with Special Health Care Needs."
 New England SERVE, Boston, MA, 2002.*

Introduction

Hello, may I speak with _____? My name is _____, I'm calling from the University of Southern Maine. We're calling to survey parents of children with special needs in order to identify services that need to be improved. Your participation is voluntary; your benefits will not be affected whether you do the survey or not. Your answers will be combined with those of all respondents so your answers will not be associated with you. All answers will be kept strictly confidential. The Bureau of Medical Services in the Maine Department of Human Services asked us to do this survey and you can call them to verify that this is the case. Our questions will only take a few minutes. Is now a good time to do the survey?

Interviewer: Offer phone number of Brenda McCormick at Bureau of Medical Services.

Probe: If it would be better for me to call back, could you tell me when?

START TIME: _____

1. I'd like to speak to the person who is most knowledgeable about _____ (child's name) health care...How are you related to the child?
 - Mother or father
 - Grandparent
 - Aunt or uncle
 - Older brother or sister
 - Other relative
 - Legal guardian
 - Foster parent
 - Other
 - DK/NA

2. This survey is about children with special health care needs. Does your child have a special health care need?
 - Yes
 - No ⇒ **Probe**
 - Don't know ⇒ **Probe**

*Probe: a special health care need is one that is expected to last at least 12 months as a result of an emotional, behavioral and/or medical condition.
 If still No – go to close.*

3. For this survey, if you have more than one child with special health care needs, please answer all of the questions with only CHILDS NAME in mind. In general, how would you rate (child's name)'s overall health now? Would you say it is ...
- Excellent
 - Very good
 - Good
 - Fair
 - Poor
 - DK
 - NA
4. How would you best describe CHILD'S NAME needs? Please choose only one...is his/her needs primarily the result of a...
- Medical condition
 - An emotional or mental health condition
 - Developmental condition

When answering the following questions on this survey, please only refer to services that have been provided in Maine. If your child has received services in another state, please do not include that experience in your answers.

Primary Care Services

The next questions are about the primary care your child received during the last 12 months. Primary care includes shots, regular check ups, and care when your child has a minor illness such as a sore throat or an ear ache.

5. Does CHILD'S NAME have a medical professional you consider to be his/her primary care provider (PCP)?
- Yes
 - No
 - Not sure
6. Where do you take CHILD'S NAME for regular check ups and primary care?
- Doctor's office
 - Rural health clinic/center
 - Specialty clinic or hospital clinic
 - Emergency room
 - Child only receives specialty care
 - Other: please describe: _____
7. How often does CHILD'S NAME see the same medical professional when he/she visits. Is it...
- Always
 - Usually
 - Sometimes
 - Never

If "NO" response to Q5, skip the following questions and go to Mental Health Services section.

8. How would you describe CHILD'S NAME PCP (primary care provider) Is he/she a:
- Regular doctor such as a general practitioner or internist
 - Specialty doctor
 - Regular nurse
 - Specialty nurse
 - Not sure
9. In addition to office visits, how often do you get help or information from CHILD'S NAME primary care provider on the telephone or in writing:
[read response choices:]
- Weekly
 - At least once a month
 - 6-10 times a year
 - 1-5 times a year
 - Never
10. How often does CHILD'S NAME primary care provider or nurse give you enough information about your child's medical condition?
[read response choices:]
- Always
 - Usually
 - Sometimes
 - Rarely
 - Never
11. How often does CHILD'S NAME primary care provider respect you, your family's culture and ethnic background?
[read response choices:]
- Always
 - Usually
 - Sometimes
 - Rarely
 - Never
 - Not needed
12. How often is CHILD'S NAME primary care provider involved in the planning and delivery of all your child's health care?
[read response choices:]
- Always
 - Usually
 - Sometimes
 - Rarely
 - Never
 - Not needed
13. How often does CHILD'S NAME primary care provider help you to understand your child's emotional needs?
[read response choices:]
- Always
 - Usually
 - Sometimes
 - Rarely
 - Never

- Not needed
14. Has someone at CHILD'S NAME primary care site given you information about parent-to-parent or family support services?
- Yes
 - No
 - Not needed
15. If CHILD'S NAME has a physical disability, is the primary care office your child visits set up so that your child and his/her equipment can get in and around easily...this includes exam tables, toilets, entrances?
- Yes ⇒ **Skip next question**
 - No
 - Don't know ⇒ **Skip next question**
 - Not needed ⇒ **Skip next question**
16. Using the categories Excellent, Very Good, Satisfactory, Fair or Poor, please rate the overall quality of the primary care CHILD'S NAME received in the last 12 months.
- Excellent
 - Very Good
 - Satisfactory
 - Fair
 - Poor

Mental Health Services

The next questions are about the mental health services CHILD'S NAME may have received.

17. Has CHILD'S NAME received mental health services from a psychiatrist, psychologist, social worker, or mental health counselor during the last 12 months?
- Yes
 - No ⇒ **Go to Specialty Care**
 - Child needs services, but has not been able to get them ⇒ **Go to Specialty Care**
 - Not needed mental health services ⇒ **Go to Specialty Care**
18. Do you feel that CHILD'S NAME mental health services are coordinated with his/her primary care or other medical services?
- Yes
 - No
 - Not needed
 - Don't know
19. Has CHILD'S NAME primary care provider or mental health provider(s) prescribed medication to treat his/her emotional or behavioral needs in the last 12 months?
- Yes
 - No ⇒ **Go to Specialty Care**
 - Not sure ⇒ **Go to Specialty Care**
20. Have you received information about the medication prescribed for CHILD'S NAME, including risks, benefits or any possible side effects?
- Yes
 - No
 - Not needed
 - Not sure

Specialty Care Services

The next questions ask about the specialty care your child may have received over the last 12 months. A specialist or specialty care provider has training in a specific medical area. Examples are: heart doctor, neurologist, orthopedist, spina bifida clinician, ophthalmologist, or endocrinologist. DO NOT include your experience with physical therapists, social workers, occupational therapists or nutritionists for these questions.

21. Has CHILD'S NAME been seen by a specialty care provider in the last 12 months?
- Yes
 - No ⇒ **Go to Care Coordination**
 - No, he/she needed one, but hasn't seen one ⇒ **Go to Care Coordination**
 - Don't know ⇒ **Go to Care Coordination**
 - Not needed ⇒ **Go to Care Coordination**
22. Please answer the following questions thinking of one specialist that CHILD'S NAME saw three times or more during the last year, even if your child sees many specialists. What type of specialist will you be talking about?
- _____
 - Has not been to any ONE specialist three or more times
23. In addition to office visits, how often do you usually receive help or information from CHILD'S NAME specialty care provider on the phone or in writing:
[read response choices:]
- Weekly
 - At least once a month
 - 6-10 times a year
 - 1-5 times a year
 - Never
24. When CHILD'S NAME first needed specialty care services, was the amount of time it took to get the first appointment with your child's specialty care provider:
[read response choices:]
- Acceptable
 - Long, but acceptable
 - Unacceptable
 - Don't remember

Skip next question for responses to Q5 – no PCP.

25. Does CHILD'S NAME specialty care provider talk with your child's primary care provider about your child's care?
- Yes
 - No
 - Don't have a PCP
 - Don't know
26. If CHILD'S NAME has a physical disability, is the main site where your child receives specialty care set up so that your child and his/her equipment can get in and around easily...this includes exam tables, toilets and entrances?
- Yes
 - No
 - Not sure
 - Don't know/Refuse

27. Using the categories Excellent, Very Good, Satisfactory, Fair or Poor, please rate the overall quality of the specialty care CHILD'S NAME received in the last 12 months.
- Excellent
 - Very Good
 - Satisfactory
 - Fair
 - Poor

Care Coordination

28. Does your child have a written health care plan? (*A written health care plan describes the medical care and all health services your child needs.*)
- Yes
 - No ⇒ **Skip to Q32**
 - Don't know
29. If yes, when was the care plan last updated?
- Within the last year
 - Within the last two years
 - More than two years ago
30. Who worked with you to develop the plan? Was it CHILD'S NAME
- PCP
 - Specialty doctor or nurse
 - Case Manager
 - School personnel
 - Social worker
 - Other: _____
31. Do you have a copy of the written health care plan that was developed for CHILD'S NAME?
- Yes
 - No
 - Child does not have a written care plan.
 - Don't know

The next questions ask about the help you receive or may need to **get and to coordinate services for** your child's care. Sometimes the people who provide this service are called "case managers."

32. Do you have someone or need someone to help you coordinate CHILD'S NAME services?
[read response choices:]
- Yes, have someone
 - Yes, have more than one person
 - Need, but don't have
 - Don't need
 - Not sure

33. I am going to read a list of offices that may work with you and your child on a regular basis. As I read through the list please say "Yes" if someone from that office helps you to coordinate your child's care. Say "Yes" to all that apply.
 [Probe: do not include one-time help]

We also want to know how you rate the quality of the care coordination or case management from these offices. The ratings are: Excellent, Very Good, Satisfactory, Fair or Poor. Did your child receive care coordination or case management services from...[If yes] And how would you rate that service? *Repeat response choices if needed.*

		Yes/No	Excellent	Very good	Satisfactory	Fair	Poor
1	Your child's PCP (primary care provider) office						
2	Your child's specialist or specialty clinic						
3	Title V program, (sometimes called the Program for Children with Special Health Care Needs in the Bureau of Health).						
4	Community service provider: _____						
5	Children's Services in the Department of Behavioral and Developmental Services (BDS)						
6	Mental Retardation Services in the Department of Behavioral and Developmental Services (BDS)						
7	Dept of Voc Rehab (Vocational Rehabilitation in the Dept of Labor)*						
8	Bureau of Child and Family Services (BCFS) in DHS						
9	School-based services						
11	Other: _____						

* Also includes Division of Blind and Visual Impairment and Division on Deafness.

34. Do you need help to coordinate CHILD'S NAME health care with his/her school or day care? *[read response choices:]*

- Yes, I need it but don't get it
- Yes, already receive help
- Not needed
- Not sure

35. Do your child's school and / or day care providers need more information about his/her special health services and needs?

- Yes
- No, already receive information
- Not needed
- Not sure

36. The next question asks about finding services for your child and whether you need help. As I read through a list of services, please tell me if you need help in finding that service for your child.

	Do you <u>need</u> the service?		Do you <u>get</u> the service?		Do you need <u>help finding</u> the service?		Not sure
	Yes	No	Yes	No	Yes	No	
1. Early Intervention (< 6 years)							
2. After school programs (>age 6)							
3. Special Education (> age 6)							
4. Speech therapy							
5. Diagnosis (or confirmation of diagnosis)							
6. Special day care							
7. Physical/occupational therapy							
8. Home nursing services							
9. Other In-Home services							
10. Medical equipment							
11. Mental health services (counseling, therapy)							
12. Behavioral health services (life skills, social training)							
13. Substance Abuse Services (> age 12)							
14. Getting Medication							
15. Managing Medication							
16. Transition Services (ages 14-20)							
17. Dental care							
18. Nutrition counseling							
19. Genetic counseling and testing							
20. Vision related services							
21. Hearing related services							
22. Other _____							

Emergency Services

36. Has CHILD'S NAME gone to the Emergency Room or used any emergency services in the last 12 months?
- Yes
 - No ⇒ **Go to Medical Supplies**
 - Not needed ⇒ **Go to Medical Supplies**
37. What were the two primary reasons for visiting the Emergency Room in the last 12 months?
(Interviewer: OK to accept only one response)
- Need for Medication or medication management
 - Infection
 - Seizure
 - Mental health crisis
 - Equipment problems
 - Sore throat/cold/chest infection or ear ache/fever
 - Broken bones/injury
 - Other _____
 - Other _____
38. Did you contact your child's PCP or specialist to get advice or try to see him/her before going to the emergency room?
- Yes ⇒ **Skip next**
 - No
39. Why did you not contact your child's PCP or specialist?
- PCP or specialist told me to go to the emergency room
 - Could not reach PCP or specialist
 - Could not wait to talk to PCP or specialist
 - Could not get an appointment with PCP or specialist on time
 - Other

Medical Supplies or Equipment

The next question asks about medical supplies and equipment that your child may have received during the last 12 months.

40. Please let me know if your child needed any of the following:

	Did he/she <u>need</u> ...		Did he/she <u>get</u> it?			If <u>No</u> or <u>Some</u> , why?		
	Yes	No	Yes	No	Some	Funding	Couldn't Find	Other
Disposable medical supplies (<i>such as: gloves, syringes, needles, catheters, diapers</i>)								
Durable medical equipment (<i>such as: wheelchairs, braces, hearing aids, nebulizers</i>)								
Repairs or adjustments to durable medical equipment (<i>such as: wheelchairs, braces, hearing aids, nebulizers</i>)								
Adaptive equipment or assistive technology at home (<i>such as: ramps, communication devices, feeding and bath aids</i>)								
Adaptive equipment or assistive technology for school (<i>ramps, physical modifications, adapted keyboards, software, etc</i>)								
Training on how to use specialized equipment								

Additional Information About Your Child and You

The next questions are about you and your family.

41. What is your child's primary language?

42. What is your child's racial/ethnic background? (*please check one*)

- White
- Black/African American
- Hispanic
- Asian/Pacific Islander
- Southeast Asian
- American Indian
- Mixed Racial
- Other: _____
- Refused

43. Regarding your own health care, do you think that caring for your child with special needs has affected your own health and well being?
- Yes
 - No
 - Don't know
43. Has it affected your physical, emotional and/or mental health? *[check all that apply]*
- Physical
 - Emotional
 - Mental Health
44. When did you last visit a doctor for this issue or for a regular check-up?
- In the last 12 months
 - More than 2 years ago
 - More than 5 years ago
 - More than 10 years ago
45. Does your family have any private insurance coverage?
- Yes
 - No
 - Don't know
- a. If yes, is your child covered under this policy?
- Yes
 - No
 - Not needed
46. Does this insurance cover....*[check all that apply]*
- Only Hospitalization
 - Catastrophic events
 - Emergency room visits
 - Preventive health care visits
 - Comprehensive care
 - None or limited number of mental health visits
 - Limited preventive coverage
47. Please estimate how much money you have spent out-of-pocket in the last 12 months for medical treatments, services, equipment or medications for your child.
- 0 - \$99
 - \$100 - \$499
 - \$500 - \$1,000
 - More than \$1,000
49. What is your education level?
- Less than high school graduate
 - High school or technical school graduate
 - Some college
 - College graduate
 - Graduate degree
48. Finally, what do you consider to be your child's greatest health care need?

Thank you for your time to answer these questions; we really appreciate it.



EDMUND S. MUSKIE SCHOOL OF PUBLIC SERVICE educates leaders, informs public policy, and broadens civic participation. The School links scholarship with practice to improve the lives of people of all ages, in every county in Maine, and in every state in the nation.

EDMUND S. MUSKIE SCHOOL OF PUBLIC SERVICE
96 Falmouth Street
PO Box 9300
Portland, ME 04101-9300

TELEPHONE (207) 780-4430
TTY (207) 780-5646
FAX (207) 780-4417
www.muskie.usm.maine.edu