

**NEW YORK STATE DEPARTMENT OF HEALTH
2007 MEDICAID CARE AT HOME WAIVERS PARTICIPANT SURVEY**

EXECUTIVE SUMMARY

The New York State Department of Health (DOH) serves as the Medicaid (MA) Single State agency for five Care at Home (CAH) Medicaid waiver programs. Initiated in 1985, the program enables families to care for children with disabilities at home instead of needing, due to home care costs, to place them in an institution in order to receive Medicaid coverage for their required services.

The Department operates CAH I/II for children who require nursing home or hospital level of care; the Office of Mental Retardation and Developmental Disabilities (OMRDD) operates CAH III, IV and VI for children who require an intermediate care facility level of care. All CAH programs provide case management, respite and home and/or vehicle modification services; however, the total MA cost of the child's community based care must not exceed that provided in a nursing facility or other institution.

In January 2007, the DOH Office of Long Term Care surveyed the parents/guardians of the 1367 children enrolled in a CAH program on December 31, 2006. The purpose of the survey was to elicit information regarding satisfaction with the CAH services. The respondents were also asked to share their experiences with the program and to describe how the waiver services impacted their child or family.

Twenty-eight percent (387) of the surveys were returned, evenly representing each agency's programs. In summary, the survey provided the following information:

- Across all programs, most respondents (82%) found their case manager's work effective in addressing their child's needs. [Note: Case management is a mandated enrollee service assisting families with applications and access to prescribed services within a set expenditure budget.]
- Respondents generally acknowledged the benefit of home adaptation and vehicle modification services to their child's safety and access within the home and community. However, many (23%) reported that the length of time between application and project completion should be shortened. [Note: Current project completion time varies by geographic location and provider availability.]
- Most respondents (89%) indicated a need for home based respite services. [Note: Respite services may be provided in or outside the home to support parent/guardian caregivers. Thirty-five percent indicated they used other resources such as consumer-directed care, family members and nursing services to meet respite needs.]
- Many respondents (33%) indicated difficulty in acquiring the total approved number of hours of private duty nursing services for their child. [Note: Private duty nursing, a Medicaid State Plan service, is currently provided to 63% of CAH enrollees. The reported difficulty in achieving full nursing coverage reflects a statewide workforce shortage.]
- Sixty-six percent (66%) of CAH parents/guardians indicated they used private insurance to access prescribed medical services for their child.

2007 CARE AT HOME WAIVERS PARTICIPANT SURVEY RESULTS

Care at Home (CAH) is a Medicaid waiver program for children with disabilities. It is an alternative to institutionalization involving home and community based services. A waiver is a federally approved suspension of regular Medicaid rules to allow for a more cost-effective expenditure of Medicaid dollars. New York's CAH waivers suspend the eligibility rules for qualified children and provide access to Medicaid waiver services as well as necessary State Plan services. Waiver services under CAH are case management, home and vehicle adaptations and respite.

When the CAH waivers were first approved in New York State, there were a number of children receiving long term care services in hospitals, nursing homes and intermediate care facilities for the developmentally disabled. Some of these children could return to their own homes if the services they needed were available in the community and they could retain their Medicaid eligibility. The CAH waivers do just that. When a child is placed in a health care facility Medicaid eligibility is determined without parental income and it remains that way as long as the child remains institutionalized. Once a child is placed in a community setting Medicaid eligibility includes the parent's income along with the child's income, often making the child Medicaid ineligible. The CAH waivers allow New York State to suspend that Medicaid eligibility rule to allow children with significant health care needs living in the community access to Medicaid using just their own income.

There are multiple CAH waivers. CAH I/II enrolls children with physical disabilities. This waiver is directly administered by the New York State Department of Health (NYSDOH) and local Departments of Social Services (LDSS). CAH III, IV and VI enroll children with developmental disabilities who also have complex health care needs. These waivers are directly administered by the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) and local Developmental Disability Services Offices (DDSO). For the purposes of this survey evaluation, the CAH waivers are grouped by the agency that administers the waiver.

CAH I/II enrollees must meet the following qualifications:

- Be younger than 18;
- Have had a continuous 30 day hospital stay or 30 days within a 90 day period;
- Be physically disabled according to standards in the Social Security Act where the disability is physical in nature;
- Be able to be cared for at home safely with support;
- Be ineligible for Medicaid in the community because the income and resources of responsible relatives would be deemed to them and be eligible when not deemed; and
- Be capable of being cared for at no more cost in the community than in the appropriate institutional setting.

CAH III, IV and VI enrollees must meet the following qualifications:

- Be younger than 18;
- Be developmentally disabled and have complex health care needs;
- Be able to be cared for at home safely with support;
- Be ineligible for Medicaid in the community because the income and resources of responsible relatives would be deemed to them and be eligible when not deemed; and
- Be capable of being cared for at no more cost in the community than in the appropriate institutional setting.

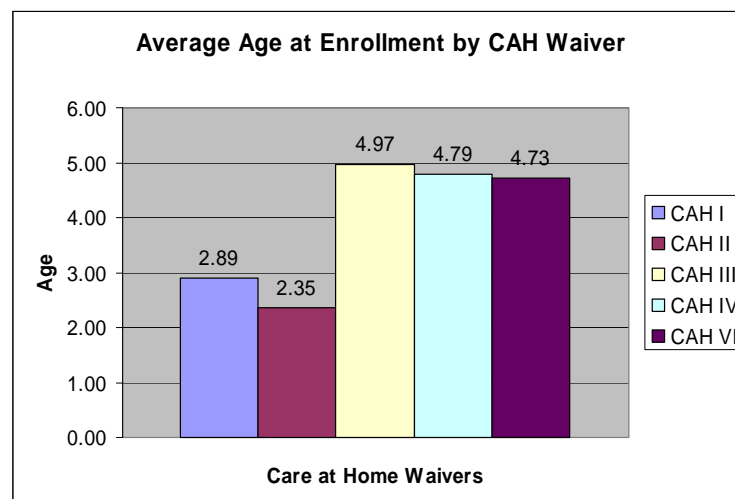
A survey was developed to discover if the CAH waivers provide services that parents need to keep their child home. In January 2007, a survey was mailed to 1,367 homes of those recipients using CAH waiver services on December 31, 2006. Of those who received the survey, 28% completed and returned it to the Bureau of Maternal and Child Health in the Office of Long Term Care (formally the Office of Medicaid Management). An additional three percent were either returned to sender or otherwise unusable (missing pages, not completed, etc.). Despite an early 2007 return date, completed surveys continued to come in through April 2007. Of the 387 usable surveys, 66% indicated the CAH waiver in which the child participated.

DEMOGRAPHICS

There were 1367 children participating in a CAH waiver on December 31, 2006. Of those responding, all enrollees had entered the program prior to age 15; twenty-eight percent (28%) joined the waiver within the first two years of life and eighteen (18%) entered after age 5. The majority (54%) live in the New York City metropolitan area. Fifty one percent (51%) of respondents were parents/guardians of girls.

Table 1 indicates the average age of enrollees by CAH waiver, based on responses where the waiver information was a clearly indicated response.

Table 1



CARE AT HOME WAIVER APPLICATION PROCESS

Parents/caregivers were asked to tell us where they first learned about the CAH waiver, how long they believed the application process to be and the ease of the application to complete. Thirty-two percent (32%) of the responses indicated they first learned of the CAH program from their child's hospital and an additional fourteen percent (14%) learned about it from a neighbor or friend.

Nearly half (46%) of the respondents learned about the CAH waivers from sources "other" than those listed on the survey. Most of the "other" responses were listed as the enrollee's school or preschool, a social worker or their Early Intervention Program. Two respondents searched the internet and found information about CAH there, one learned about the program from his/her wheelchair vendor and one even learned about it from a local car dealer.

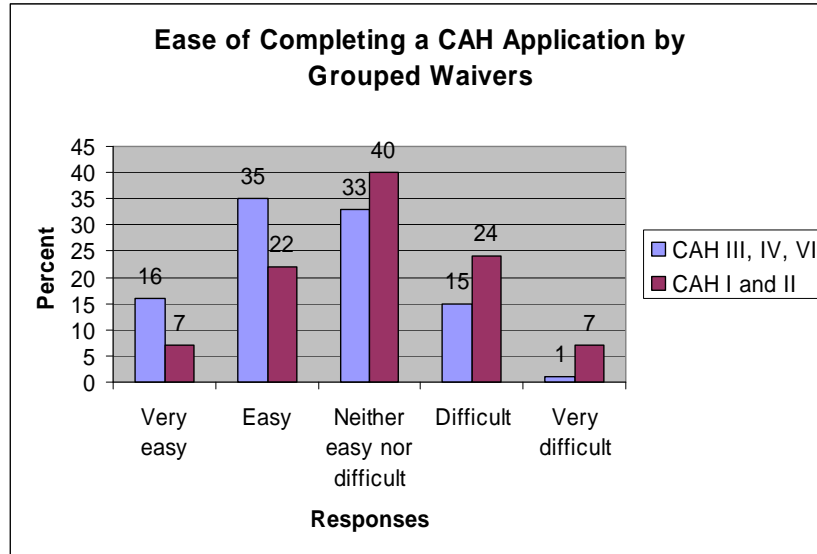
The CAH waiver application process includes completion of the following forms:

- Medicaid application
- Level of Care screen (CAH III, IV and VI only);
- Home Assessment Abstract (HAA);
- Pediatric Peer Review Instrument (PPRI, CAH I/II only);
- Disability determination;
- Physician orders;
- Care Plan; and
- Budget

Concerning the length of the application process, half the respondents thought the process was either long or too long. However, a sizeable number of respondents (38%) did not seem bothered by the application's length, saying it was neither long nor short. Many respondents mentioned that a case manager, a case management agency or nurses provided assistance in completing the application making the process much easier.

Despite the length of this process, 51% of respondents from CAH III, IV, and VI responded that the application was easy or very easy to complete. For CAH I/II, however, only 29% had this response. Nearly an equal amount of respondents in CAH I/II (31%) responded the application was difficult or very difficult. See Table 2.

Table 2



CARE AT HOME WAIVER SERVICES

Case Management

There were questions in two locations on the survey that dealt with case management services. Case management encompasses a wide range of activities whose objectives and functions include assisting children and their families in gaining access to Medicaid and other services provided in the community, assuring that the needs of the child are being met by the services requested, developing and participating in the plan of care, assuring that the services requested in the plan of care are accurate and being provided in a cost effective manner, and accessing private insurance for services. Case managers need to keep in regular contact with families.

Case managers are key to helping parents/guardians find the services they need for their child. They develop a strong, supportive working relationship with the child and family. Communication and mutual respect of parents, the child, service providers, vendors, and insurers is vital. Case managers need a thorough knowledge of individual and institutional services available in the community, as well as advocacy and brokering skills. CAH case managers assist and enable a child and family to access the full range of services and resources for which they are eligible.

Case managers are not “gate keepers” however; they are responsible for making connections between the parents and nurses, vendors, schools and other providers of services. Three percent (3%) of respondents indicated that they would first go to someone besides their case manager with questions regarding their child’s care.

It appears from the responses to the survey that there is regular contact between parents and case managers. On average, respondents called their case managers slightly more than twice a month. However, contrary to the CAH program’s design,

some respondents (2%) indicated they never initiate contact with their case manager, preferring to go directly to their LDSS or DDSO, or their child's physician. Ninety five percent (95%) of respondents indicated they had spoken with their case manager within the last two months with seventy-three percent (73%) indicating they had spoken to them in the last 30 days.

In ranking their child's case manager in successfully addressing the child's needs, eighty-two percent (82%) of respondents indicated their case manager was effective or highly effective. Eight percent indicated their case managers were ineffective or highly ineffective. One quarter of respondents indicated they had changed case management agencies. However, in many counties, there is only one agency providing case management services. At the time of the survey seven percent (7%) of respondents were considering changing case management agencies with exactly half residing in New York City or on Long Island.

Home Adaptation and Vehicle Modification

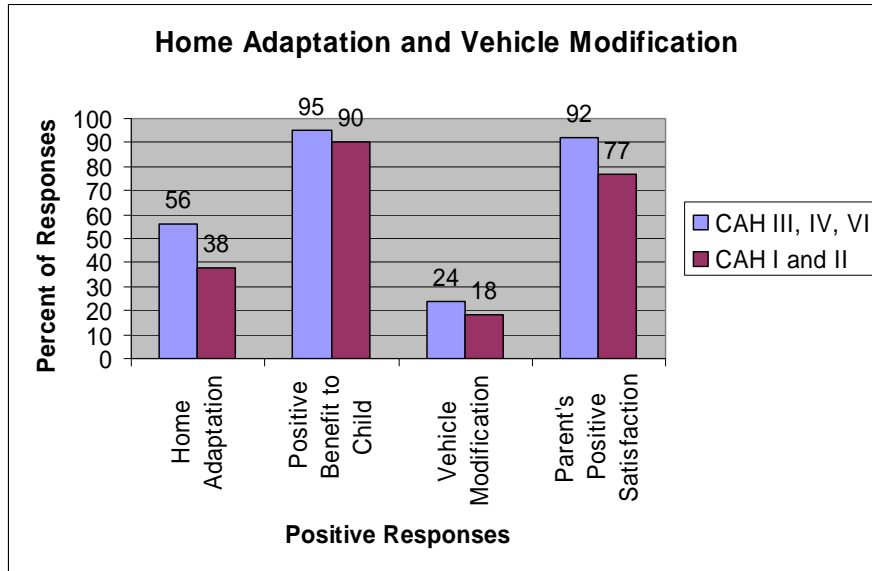
Often, to enable a child to return or remain at home, adaptations to that home need to be made. These changes are made to assure the child's safety, to permit the child to move about within the home, or to provide access for the child between home and community. Renters must get permission from their landlords and are encouraged to do this if living there is the long term plan. The cost of these adaptations must fit into the child's individual CAH budget and may not exceed \$20,000 per child for the duration of the child's participation in the CAH waiver.

Vehicle modifications are also a waiver service available to CAH enrollees. As with home adaptations, the cost of the vehicle modifications must fit within the child's individual CAH budget. Parents can have their child evaluated to determine the most appropriate vehicle to meet the child's needs. Families are expected to assume the cost of the basic vehicle and take advantage of equipment available from the dealer through factory installation. There are guidelines for purchasing a used vehicle available to families as well.

Vehicles must be evaluated by a Vocational and Educational Services for Individuals with Disabilities (VESID) evaluator who will provide modification recommendations. Following a three bid process, an approved VESID vendor must be used to complete the modifications. A vehicle modification may not exceed \$14,000 per child for the duration of the child's participation in the CAH waiver.

On average across all CAH waiver programs forty-seven percent (47%) of survey respondents indicated they have had a home adaptation, 38% in CAH I/II and 56% in CAH III, IV, and VI. Bathroom modifications, ceiling tracks, door widening and ramps for easier accessibility were the adaptations most often received by respondents, with an average of ninety-three percent (93%) of whom indicated that the adaptation benefited their child.

Table 3



When asked if changes needed to be made in the adaptation/modification process, more than half of the respondents agreed that the process needs to be simplified and made faster. Several found the process “cumbersome” and “time consuming”. Comments like “just make it easier” and “Simplify, simplify, simplify” were scattered throughout the 108 “yes” responses to changing the approval process.

Many respondents commented on the bidding process:

- “The three bid process was time consuming and difficult.”
- “It was hard to get three estimates for small jobs.”
- “We have been trying to get 3 estimates for ceiling tracking in our home. It’s been one year and we’ve only obtained 2 estimates even though 5 companies have been to our home.”

Most respondents just want the process to be faster. Twenty three percent (23%) indicated the wait time from application for an adaptation/modification to full implementation should be shortened. In the responses received, this time frame ranged between six months and two years plus. One parent indicated that once the approval went through, three bids were obtained, and the paperwork was submitted, his child had already outgrown the initial requested adaptation/modification.

Respite

Respite services are temporary facility or in-home services which allow family members who ordinarily care for a child with disabilities, relief from these duties. Respite is one of three services available under the CAH waiver.

There are two locations where respite services can be provided, in-home where a nurse or other health care professional cares for the child while family members are out or in a

health care facility such as a hospital or skilled nursing facility. The length of time allotted for respite is approved in the child's plan of care.

Nearly all survey respondents (89%) indicated their preference for respite would be in the home. Twelve respondents wanted their child to be cared for outside the home but in a family-like setting. Several respondents mentioned the need for respite services for vacations and days off from school.

Almost one quarter of respondents (23%) have made use of respite services. Whether or not respondents would like respite services inside or outside the home, they indicated that the shortage of qualified nurses and lack of outside facilities hamper them from doing so. Of those responding that they had used respite services, 10 families from downstate indicated the use of out of home respite, possibly indicating a current lack of facilities for this service. Those who used in-home services used their nurses (16%), home health or personal care aides (12%) or accessed it through the Consumer Directed Program (17%).

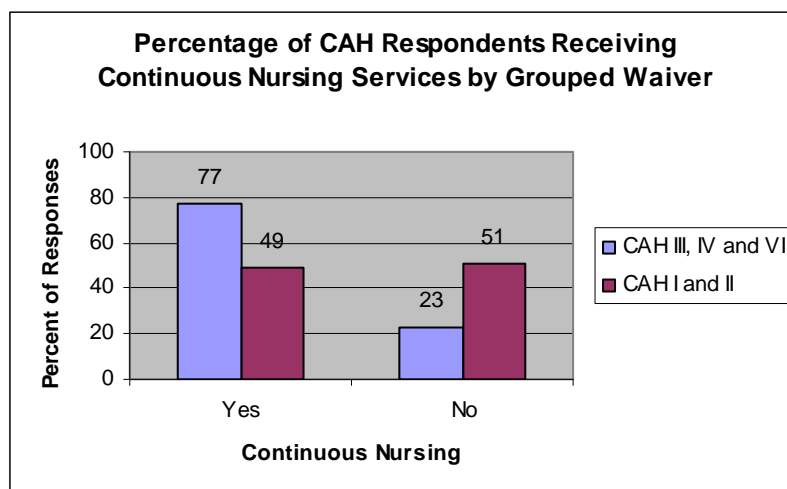
STATE PLAN SERVICES

Nursing Services

Nursing services are the most needed and, as noted by respondents, the most difficult services to fill in a child's CAH service plan. Continuous nursing services can be provided by a registered professional nurse (RN), a licensed practical nurse (LPN), or through a Licensed Home Care Services Agency. Nursing is a State Plan service available to all Medicaid eligible recipients when medically necessary.

On average across all CAH waiver programs, nearly two thirds (63%) of all respondents, 77% in CAH I/II and 49% in CAH III, IV and VI, indicated their child received continuous nursing services while participating in CAH as noted in Table 4.

Table 4

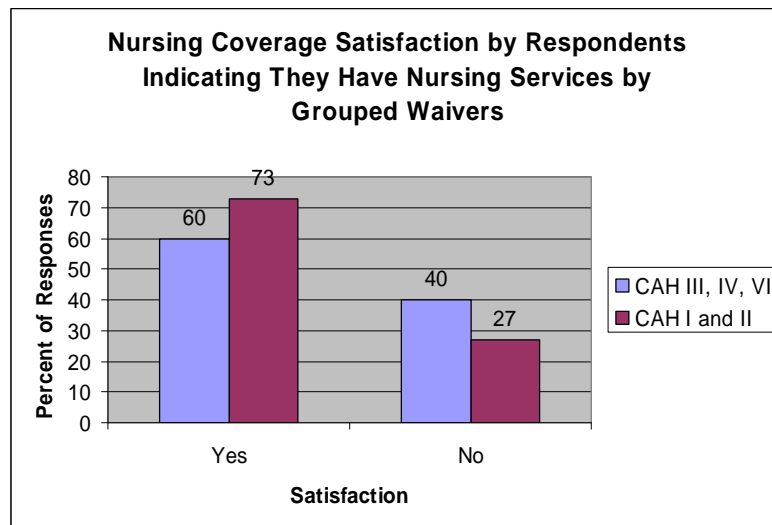


On average across all CAH waiver programs two thirds of those receiving continuous nursing care services indicated they were satisfied with the current services. Eighty-eight respondents left comments concerning nursing satisfaction. The following comment by one respondent illustrates a common theme throughout many of the responses:

“We are pleased and happy with the nurses we presently have but we are very, very tired of hearing the expression ‘We’re sorry we can not fill your hours – you know there is a nursing shortage’”.

The information in Table 5 indicates parent satisfaction with the current nursing services available to their child.

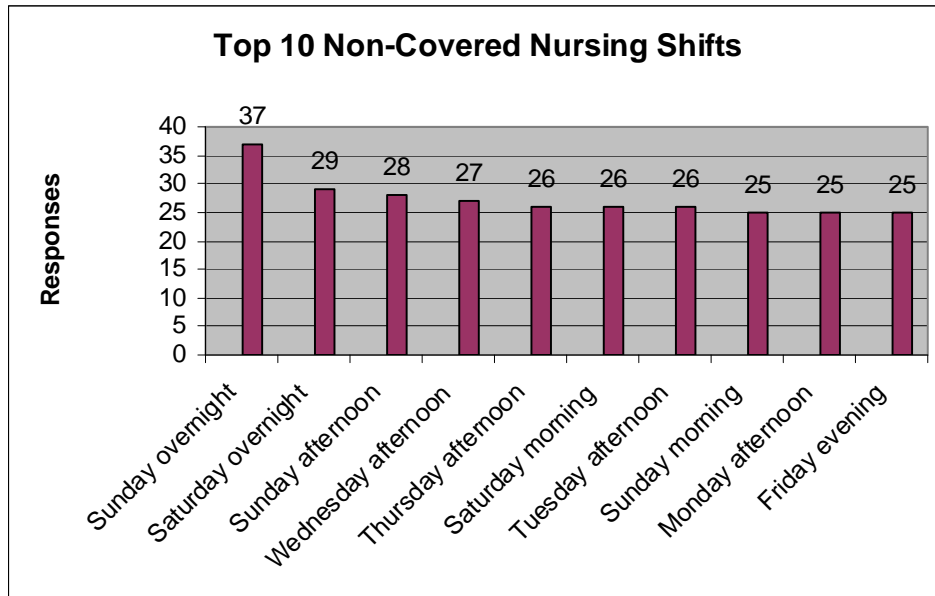
Table 5



When describing the process of obtaining nursing services, thirty-three percent (33%) of respondents used the word “hard” or “difficult” in their response. Some told of waiting as long as 2 years to obtain these services, sometimes utilizing home health aides and other similarly qualified individuals until finding a nurse. There were comments about nurses who were unreliable and had inconsistent attendance. Others mentioned rapid turnover, and their belief the nurses were underpaid. Often, respondents stated they went to the case manager for assistance in obtaining nurses.

Once a nurse is found, coverage during the parts of the day that are most crucial becomes a priority. Surveys indicated problems over all time periods, particularly Sunday nights. The top ten shifts encompassed twenty-one percent (21%) of all responses. They can be found in Table 6.

Table 6



The most difficult time or day to find nursing coverage is on Saturday and Sunday overnights. Afternoon shifts are also very difficult to fill, as most parents who need coverage at that time require it for just a couple of hours between the end of the child's school day and when they arrive home from work.

GENERAL QUESTIONS

CAH Handbook for Parents

The last set of survey questions involved the CAH Handbook, additional services respondents might like to see made available to enrollees and some general questions involving Medicaid.

In 2003 a "Care at Home Handbook for Parents" was created and distributed to all CAH I/II waiver enrollees and their families. This Handbook contains a description of the services offered through CAH I/II as well as instructions, application forms and other helpful resources. The initial response to this Handbook was well received. In early 2004, the Handbook was posted on the NYS Department of Health website.

The survey questioned current waiver parents/guardians if they had seen either the Handbook or the CAH website. One hundred thirty-nine (139) CAH I/II respondents indicated they had seen the Handbook and of those, only seven (7) did not find it helpful.

Additional Services

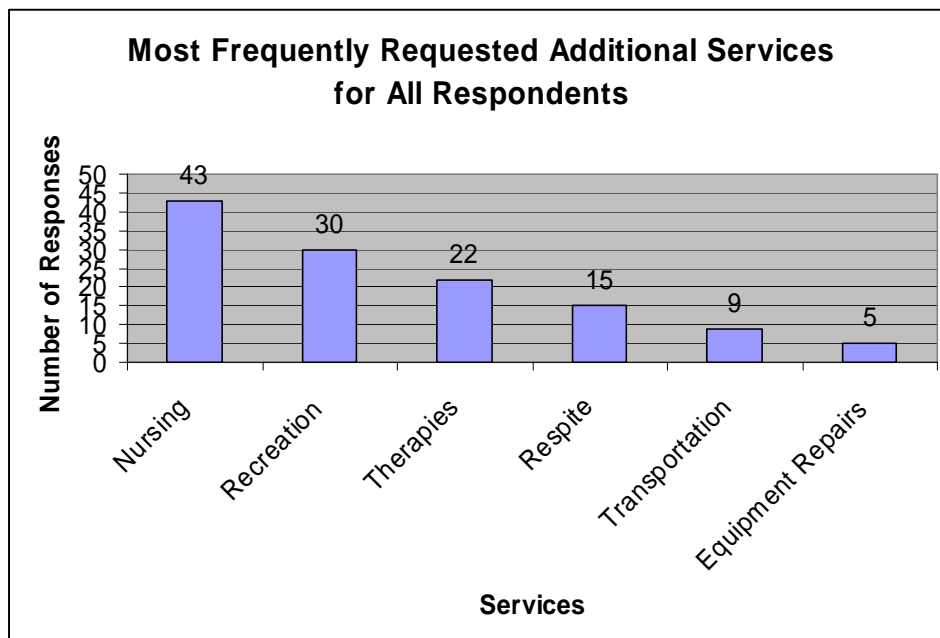
Children enrolled in the CAH waivers are eligible for Medicaid State Plan services as well as waiver services. They can be accessed by those financially qualified and in

need of services. Additionally, if a child is under the age of four, other programs such as Early Intervention may be available.

The responses to the question regarding needs not currently met was overshadowed by references to additional nursing services. There were 95 additional responses indicating a need for additional services. Therapeutic recreation (music therapy, hippo therapy, aquatic therapy) was the most frequent response, followed by alternative and regular therapies (OT, PT, Chiropractic and Speech) as seen in Table 7.

In addition, parents/guardians indicated a desire for day programs on weekends and after school settings where their child can socialize with children their own age. They would like day programs appropriate for their child's age, organized, and staffed by those with some training to care for children with medical needs.

Table 7



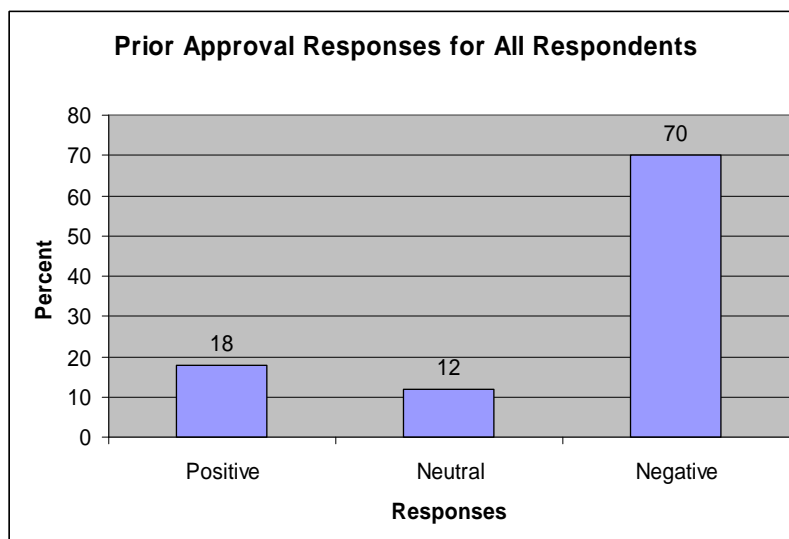
Private Health Insurance

Medicaid is always the payer of last resort. This simply means if a family carries private medical insurance and the child is included in that coverage, every effort must be made to access needed services through that private insurance. This can benefit the child by maximizing their individual CAH budget for other items. Sixty-six percent (66%) of respondents indicated they have utilized their private insurance to access medical services for their child.

Prior Approvals and Fair Hearings

The survey inquired about CAH parents/guardian's knowledge and use of the prior approval process. Sixty-four percent (64%) of respondents indicated they had experience with the prior approval process. More than two thirds of those provided comments about their experiences (See Table 8). Of the 153 comments made about the prior approval process, 18% were positive. Those satisfied indicated the process was "A painless experience and worth every penny", and "The staff was helpful and very pleasant." Other positive responses identified a person or an agency that provided extra assistance to get through the process.

Table 8



Of the seventy percent (70%) who responded negatively, forty-five percent (45%) commented on difficulty with the approval process and forty-one percent (41%) found the process too time consuming or stated the wait time was too long.

In Medicaid as well as CAH, there is a hearing process for denied, suspended or terminated services. Waiver enrollees can request a fair hearing at any time if they believe that their services are not adequate. Thirteen percent (13%) of respondents indicated they had requested a fair hearing while their child was enrolled on a CAH waiver.

Respondents were asked to comment on the experience of their fair hearing. There were both positive and negative comments and several comments that just said "I won/lost." or "They won/lost". Some respondents requested fair hearings with their private insurer because Medicaid would not cover the remaining cost unless their primary insurance covered the initial cost. Of the 33 who responded, sixty percent (60%) were granted the item or services they had requested but many found the process lengthy.

General Comments about the Care at Home Waiver

Parents/guardians provided a number of comments regarding general Medicaid State Plan services. For example:

- They are amazed at the cost the State is paying for diapers when they are “so much cheaper and better quality” in large box stores and supermarkets. (Note: Diapers are provided as durable medical equipment for children over three and are provided through a State contract.)
- Some parents/guardians would like to see family counseling or therapy as an added service. One parent indicated “My family has been having difficulty adjusting to our new circumstances”. (Note: Family counseling is a State Plan service available through the Office of Mental Health.)
- Another parent has had difficulty with obtaining medications for her child. She suggested having scripts written for three months, similar to private insurance to avoid gaps in service.

CONCLUSIONS

The Care at Home waivers provide an alternative to institutional care so that medically needy children with disabilities who are medically qualified. Most parents/guardians provided positive comments. The survey asked parents to provide any additional comments about the CAH waiver and how it has affected their child and family. While some respondents identified some problems with the waiver, it was always qualified with how much better their lives were because of Care at Home. For instance:

“We are so grateful to have the Care at Home program waiver for our daughter. Thank you for making caring for our daughter at home possible”.

“Thanks for this program!! Without it we would not have been able to carry on relatively ‘normal’ functions. My wife would have to quit her job, at the least, just to meet our son’s most basic needs”.

And finally,

“I want you, the DOH and Governor to know what a tremendous help the Care at Home program has been to our family. We are a family that is neither low income or wealthy, but as so many families we fall right in the middle. Without CAH and home and vehicle modifications program we would not have been able to afford the critical things that have allowed us to cope and adapt to the challenges of our son’s disability. His life would truly be one of disability instead of one of ability”.