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Preface

This is a booklet about the strengths of families. All parents grow with their children, but parents of children with complex health needs develop an extraordinary array of new abilities as they immerse themselves in their child's care. Building collaborative relationships with home health care providers to enhance the ability of their children to participate as fully as possible in all aspects of family and community life is among the most important of these new skills.

This is also a booklet about a system. A home care system primarily structured to serve acutely ill adults that must operate within a bewildering maze of regulations in a highly competitive economic environment. Sadly, parents too often find themselves forced to struggle with arcane rules governing such things as eligibility and hours and restrictions they inevitably learn that they must assertively advocate for the services their child needs and that there is great value in joining with others to advocate for changes in policy that will reconfigure the system in family-centered ways.

A Parent's Guide to Home Health Care makes a powerful contribution to the families of Wisconsin by providing accurate and practical information about home health care. But perhaps more importantly, it also offers a compelling vision of the unique partnerships that can make home care successful. Parents are recognized as experts on their child and on the rhythm of life in their household; and home health workers are valued for the knowledge, sensitivity and perspective they bring into the home along with their direct care. This booklet emphasizes that they are essential allies, sharing responsibility for creating an environment of support that nurtures the well being of all- child, family, and care providers.

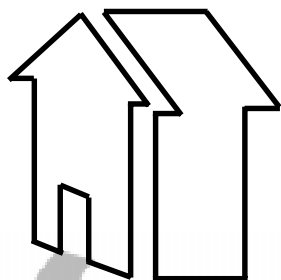
William Schwab, M.D.

University of Wisconsin
Department of Family Medicine
Parent of a child with special health care needs

For Charlie,
whose resiliency and inner strength
keep me learning and loving all along the way.



Introduction



We are living in a time when there are multiple demands on the American family. The two-parent family with a single wage earner is increasingly rare. Most families are stressed, overworked and struggle to make ends meet. Families who have children with disabilities are even more busy as they work to ensure that their children receive the appropriate support services. This journey of raising a child with special needs requires extraordinary time and energy, extending miles beyond “normal” parenting into a territory previously unknown. There is no doubt about this. Each parent must become a consumer of vast amounts of knowledge and information, learner of a whole new set of skills, master of a completely different language, and traveler on the emotional roller coaster of hope, despair and reward.

Given this, accurate information on home health care should be available to families, since it is one service that can alleviate some of the stress that families face. By utilizing home health care, a parent’s time and energy are more readily available. Home health care, an important service option when raising a child with a disability, is often unused or underutilized because of lack of accurate information or resources.

The home health care industry has primarily been built in response to an aging population and a decrease in lengthy hospital stays. Homemaker-home health aides are predicted to be one of the most rapidly growing occupations through 2006 (Occupation Outlook Handbook, 1998-99; HCFA, Health Care Financing Review, 1996; Department of Labor, Employment and Earnings, 1991-1995; U.S. Department of Labor, Bureau of Labor Statistics: Establishment Data, 1996). The industry is a combination of public and private organizations serving consumers by providing home health care typically billed to third party payers. Home health care is on the rise because it is often more economical to provide care at home instead of in a facility, and because people tend to do better emotionally and physically when they are in the comfort of their home (Buckingham, 1984). However, children with disabilities are an ever growing contingent of those in need of home health care.

Purpose and Use of this Guide

This booklet is intended as a primer for families who want to learn more or who want to enhance their skills as consumers of home health care for their children. While the information in the guide pertains to all families who want to use home health care, a large amount of the information focuses on home health care funded through the Wisconsin Medicaid Program. The reason for this is that Medicaid is the largest single payer for home care for children. Therefore, Medicaid regulations and terminology will be described and the term “home care” will be used to be consistent with the Medicaid language. This overview will address the following aspects of home care:

- ◆ Definitions of home care;
- ◆ Looking for home care;
- ◆ Seeking approval for home care;
- ◆ Making home care work for you;
- ◆ Recruitment, training, and retention; and
- ◆ Overall benefits and challenges.

This booklet will limit its focus to families with children under age 18, though many, if not most, of the issues, strategies and resources are applicable to a wide variety of individuals who require home care. The term “children” will be used to include: infants, toddlers, school-aged children, youth, and adolescents. The term “parent” refers to an individual in the primary caregiving role. Families are encouraged to learn more about home care and explore how it can enhance the quality of life for the entire family.

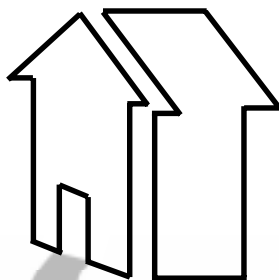
At the end of this booklet, three additional sections contain the following materials for families:

- ◆ **Tools and Tips:** Suggested approaches to sharing information through the creation of a home care book, medication log, sample schedule and range-of-motion description.
- ◆ **Reflections For Caregivers:** Words of reflection which may provide comfort to parents in the caregiving role.
- ◆ **References and Resources:** Full references for all materials cited in the booklet will allow further reading on the topic. In addition, other related materials are listed, including: a listing of advocacy agencies; excerpts from the Wisconsin Administrative Code; and a brochure on private duty nursing.

At the end of this booklet there is a blank note page for your personal thoughts and ideas. There is also a brief feedback form on the last page where you can comment on the usefulness of this booklet.



Defining Home Health Care



Home health care can broadly be defined as services intended to improve or maintain a person's quality of health primarily within the individual's home. Home health care may include assistance with the everyday activities of life, such as eating, dressing and bathing and can also include skilled assistance with life supporting devices. Hospice care and home-based therapies, often considered home care, will not be addressed in this booklet. Again, since Wisconsin Medicaid is the primary funder of home care, this section will focus on definitions from Medicaid.

How does Home Care Differ from Respite?

Home care differs from respite, though in some cases the actual worker may be the same person. Respite workers may not need any formal training to provide care for a child, whereas a home care worker is required to have the appropriate training corresponding to the child's care level. While respite can be provided in a setting outside of the home, such as a worker's home, or a community or recreational site, home care takes place primarily in the home.

Additionally, respite and home care are supported by separate funding sources and agencies. Medicaid, for example, does not pay for respite. While these differences do exist, many similarities abound, and the information on these pages may be relevant to both approaches when seeking and securing care for a child.

What are Primary Home Care Providers?

Medicaid home care providers include home health and personal care agencies, as well as independent nurses, all of which provide individuals with care where they live. Home health agencies can be public or private, licensed by the state's Bureau of Quality Assurance (BQA) and certified to participate in Medicare. Some home health agencies offer a variety of services including nursing, therapy, home health aide and personal care. A personal care agency can be a licensed home health agency, a county agency or an independent living center. Agencies differ widely in their philosophy, criteria and approach. It is wise for parents to research the agencies in their communities to determine which one(s) best matches their own style and need. Independent nurses may also be home care providers.

What are Home Care Services?

A wide variety of services can be provided by home care workers, depending on the individual's level of need. Licensed professionals include nurses and therapists who provide skilled care, such as intravenous injections, under the direction of a physician. Home health aides, personal care workers and homemaker assistants assist with activities of daily living, such as dressing and bathing. In addition to assisting with activities of daily living, a personal care worker may provide assistance with medically oriented tasks if delegated by a registered nurse. Home health aides assist with medically oriented tasks that are needed to maintain the child's health or treat a medical condition. It is important to emphasize that for all care levels, a registered nurse ensures supervision and coordination of the recipient's care. Below is a brief summary of the primary home care services within the context of Medicaid-funded home care, as defined by the Department of Health and Family Services:

Skilled Nursing Services Registered Nurse (RN) or Licensed Practical Nurse (LPN)

- ◆ Intermittent care (less than 8 hours a day)
- ◆ Private duty nursing (8 hours or more a day)
- ◆ Respiratory care services

Skilled nursing is divided into two categories, based on the number of hours of care a child receives. Home health skilled nursing, also called part-time intermittent nursing, is provided to recipients who require less than eight hours of direct skilled care per day. Private duty nursing is provided for individuals who require eight or more hours a day of skilled care. Both types of nursing tend to supplement the care provided by informal support systems, including other members of the child's family. Sections 107.11(1)(c), 107.11(2)(a) and 107.12(1)(a) of the administrative code define skilled nursing. The Reference and Resource section of this guide contains a detailed brochure from the Department of Health and Family Services on Medicaid private duty nursing.

Home Health Aide Services

- ◆ Medically oriented tasks, assistance with activities of daily living and specified household tasks.
- ◆ Basic training required is a minimum of 75 hours, including 16 hours in a clinical setting and 16 hours of classroom instruction. In-service training of 12 hours per year is also required.

The Wisconsin Administrative Code defines home health aide services as: "medically oriented tasks, assistance with activities of daily living and incidental household tasks required to facilitate the treatment of a recipient's medical condition or to maintain the recipient's health." (WI Administrative Code, HFS 107.11 (1)(b)).

Personal Care

- ◆ Primarily “hands on” assistance with a child’s physical needs by a personal care attendant.
- ◆ Assistance with eating, bathing, dressing or other activities of daily living.
- ◆ Training consists of a minimum of 40 classroom hours or six months equivalent experience.

Wisconsin Medicaid defines personal care services as: “medically oriented activities related to assisting a recipient with activities of daily living necessary to maintain the recipient in his or her place or residence in the community.” (WI Administrative Code, HFS 107.112(1)a).

The difference between a home health aide and a personal care worker is based primarily on training, responsibility, child’s complexity of care and level of medically oriented tasks. Home health aides are certified nursing assistants who have received a minimum of 75 hours of training and an annual in-service training. Personal care workers are required to have a minimum of 40 hours of training in the provision of personal care services. In general, a home health aide is prepared to carry out more medically oriented tasks such as gastrostomy-tube (g-tube) feedings and giving medications. A personal care worker focuses more on bathing, dressing and simple transfers. Licensed and certified home health agencies are required to comply with additional federal and state requirements that do not apply to personal care agencies. Home health aides often provide short-term visits to individuals transitioning from hospital to home. The important aspect for both categories of home care worker is the involvement of a nurse who delegates responsibility and supervises the care provided as often as necessary.

Clarifying the distinctions between home health aides and personal care workers is important for families to understand since it can be confusing and affects the care families receive. Each nurse and the associated agency provider decides what level of care it is willing to delegate to the direct home care worker. Some nurses and agencies will not delegate medically-oriented tasks to a personal care worker, while others will. The result is that any two parents with similar children receiving services from two different agencies may receive home care workers in different categories. In short, when a nurse delegates a task to a worker, her nursing license is on the line and this is one reason for the variability in home care service categories.

How is the Level of Care Decided?

A family's initial assessment will involve questions about the child's level of care and this information will help to determine the type of care needed (e.g., personal care versus skilled nursing) and the number of hours of coverage. Each child is evaluated individually. It is important to emphasize that Medicaid covered services are the same throughout the state of Wisconsin. The variation across the state as to what each child receives for home care appears to be contingent not just on the child's needs, but also on how the agency decides to assume responsibility for the child's care.

A covered personal care service, for example, is: "Meal preparation, food purchasing and meal serving," 107.112 (1)(b)11. One family comments:

"It takes my child so long to eat. Most kids eat lunch in 15 minutes, but it can take us easily an hour to feed Chris. To prepare his meal takes even more time because we have to buy special high-calorie items, then specially prepare the food, so he doesn't choke on it. If he doesn't get enough calories, he is likely to lose weight and get sick. And we have to hold him to feed him, since he cannot hold a spoon or sit up on his own and proper positioning is crucial so he doesn't choke or aspirate on his food. So there is a lot of pressure on us to feed him well in an uninterrupted, safe manner."

In this situation a personal care worker would be trained to purchase the appropriate foods, prepare the food and feed Chris. If a child's total meal time (preparation, feeding and clean-up) is one and a half hours, and the child eats three or five times a day, then potentially a personal care worker could be available for a total of five hours for feeding alone. Additionally, the child may need assistance with personal hygiene (bathing, tooth brushing, skin care, toileting) tasks that may require a total of another hour and a half each day. Now the family could potentially receive six and a half hours of personal care a day. Household chores that are incidental to personal care may account for one third of the Medicaid hours of care, but only certain tasks are allowed. Cleaning the kitchen after the child's meal preparation is permitted, for example, but doing the parents' laundry is not.

The cares described above could be met by a personal care worker. However, for children with serious medical conditions, skilled nursing care may be required. Airway care, for example, for a child with a tracheostomy, oxygen therapy and/or ventilator will require skilled nursing. Families may use creative approaches to supplementing Medicaid home care with other funding sources such as Medicaid waiver programs that have few restrictions on the medical necessity of the activities. For example a family may arrange for a personal care worker for meal time and then use Community Options Program (COP) funds to cover a trip to the mall.

“To tell you the truth, I don’t really know how our home care is paid for. We are on several county programs and I am really confused about how different things are paid for.”

How is Home Care Paid for?

Home care is expensive and typically paid for in one of several ways: private fee-for-service insurance or managed care plans; Medicaid/Medical Assistance; Community Option Program (COP), Community Integration Program (CIP); and out-of-pocket. Another option worth exploring is the Family Support Program in Wisconsin, a flexible funding source for families with children with disabilities living with their families. County programs which may help families are typically available through the county human services or community program agency. In the State of Wisconsin, most home care for children is funded through the Medicaid program. The Wisconsin Administrative Code (excerpts in reference section) delineates home care regulations, including a clear listing of covered and non-covered services. Parents will benefit from accessing a copy of this code from their public library, by ordering a copy of their own or by viewing it on the World Wide Web (see references). It is important to point out that each individual is initially assessed for home care eligibility and a level of care is determined before the care is authorized. In families where the child’s health fluctuates widely, it may be possible to have skilled nursing at times of extreme health risk and a personal care worker at times of relative stability.

What is Medicaid Prior Authorization?

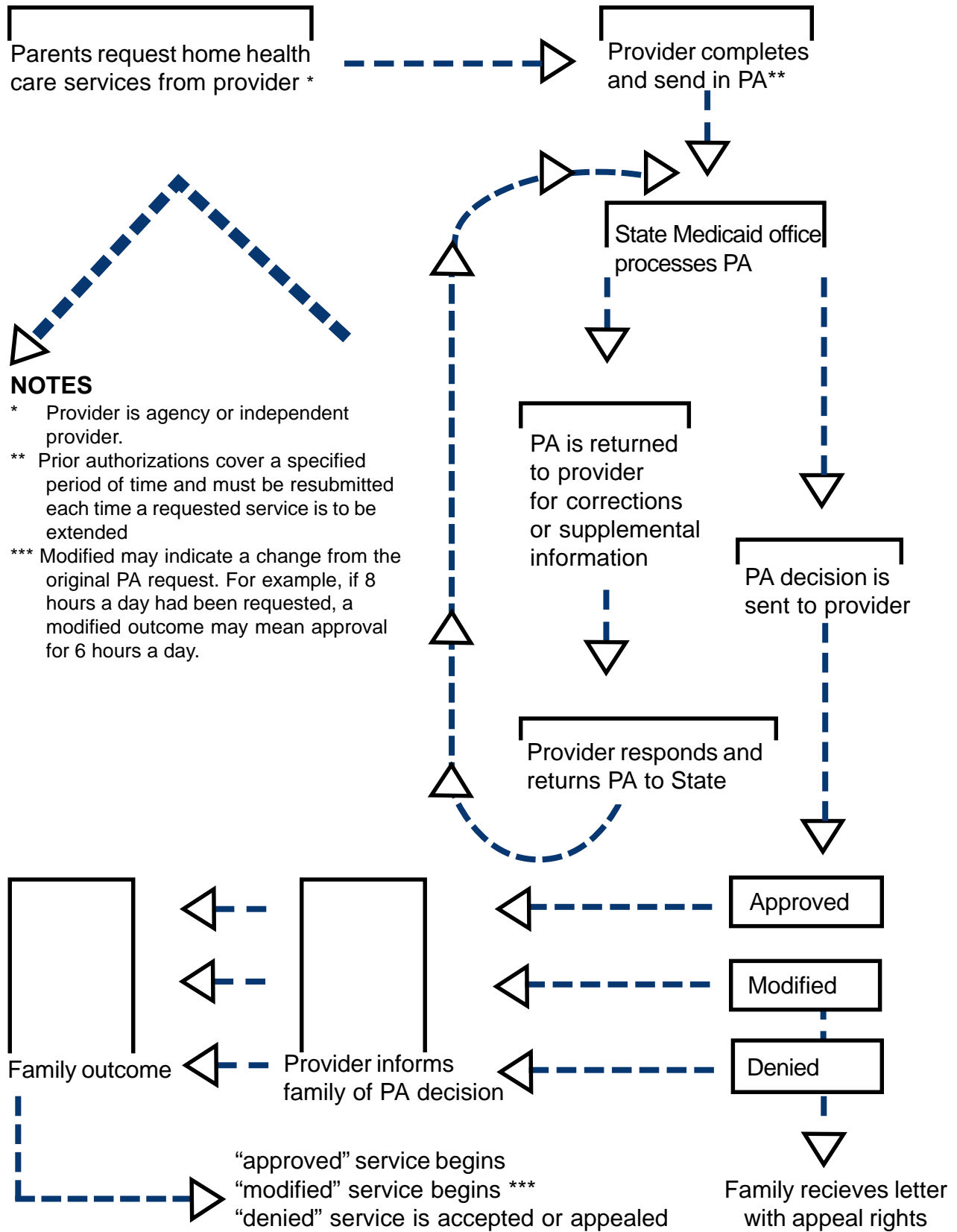
Home care provided as a Wisconsin Medicaid covered service requires a physician’s order and prior authorization. The Wisconsin Administrative Code offers the following definition:

“HFS 101.03(134) ‘Prior authorization’ means the written authorization issued by the department to a provider prior to the provision of a service.

Note: Some services are covered only if they are authorized by the department before they are provided. Some otherwise covered services must be prior authorized after certain thresholds have been reached.”

It is important for parents to realize that the Medicaid home care prior authorization (PA) procedure involves several steps and may result in a delay or denial in the start-up of home care. First, the home health agency must complete the PA paperwork in a timely manner and then submit it to the Department of Health and Family Services, Bureau of Health Care Financing, which reviews the request. The PA may be returned to the provider if it is incomplete or has clerical errors. The provider must make the necessary changes and resubmit the PA. This cycle can occur several times if the provider’s information is incorrect or absent. Ultimately, the request for service is either approved, modified or denied. If it is approved, the provider is notified and informs the family that services may begin. If it is modified or denied, the parents will receive a letter from the department with their appeal rights outlined. The term “modified” indicates that the PA is approved with changes from the original request. The term “denied” indicates that the entire request was not approved. *The Prior Authorization (PA) Process-Simplified* outlines the prior authorization process in a simplified version.

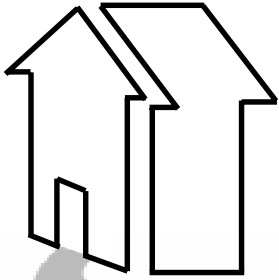
The Prior Authorization (PA) Process - Simplified





Looking for Home Care

Know Your Funding



Because of the high cost of home care, most families will rely on insurance to cover the cost. Before you begin the search for home care, it is wise to evaluate what insurance coverage you have for your child. A call to your private insurance company, if you have private insurance, will help to clarify what services they do or do not cover. Most private insurance companies do not provide long-term home care coverage. This information may also be available in the health insurance policy booklet.

Many children with disabilities qualify for Wisconsin Medicaid. Medicaid is “a state/federal assistance program that helps certain needy and low-income people pay their medical bills. It is also called Medical Assistance, Title 19, and T19.” (State of Wisconsin, 1999). Medicaid can be accessed in a number of ways and parents are encouraged to call Medicaid Recipient Services, (800) 362-3022, to learn more about how to apply. Medicaid is an invaluable resource for families as they seek home care.

In some situations, county programs such as COP, CIP and/or Family Support may supplement Medicaid services for the child’s non-medical needs. These county programs are not insurance yet might have funds to partially support home care depending on need and available funds. Parents can gain further information about programs in their counties by calling their local County Human Services office.

Identify an Agency

There are many ways to identify the home care agencies in your community. Below is a list of sources of information:

- ◆ Ask a parent of a child with complex health needs if he/she can recommend an agency.
- ◆ Ask your local community provider, (e.g., Family Support Program, Respite, Community Integration Program, Community Options Program), county human services and/or public health department.
- ◆ Look in the yellow pages of the phone book (e.g., listings under “nurses” or “home health services”).
- ◆ Call the State of Wisconsin, Department of Health and Family Services (DHFS), Division of Public Health, Wisconsin Maternal Child and Health Program (MCH) and ask for the contact information for First Step 1-800-642-STEP and the CSHCN regional resource centers 1-800-441-4576. DHFS’s Children and Families Services Section, (608) 266-7469, may also be able to assist families.
- ◆ Order the booklet from DHFS, Bureau of Quality Assurance, titled: *Licensed Home Health Agencies*. This booklet lists all of the Medicaid licensed home health agencies, alphabetically by provider or alphabetically by town/city, in the state of Wisconsin. This booklet lists the home health services (e.g., nursing, home health aide, personal care) each agency offers, a contact name and phone number. It costs \$5.00.
- ◆ Contact the Coalition for Independent Living Centers (see references) to determine if a personal care program is offered in your community.
- ◆ Contact disability-specific support groups (see references).

Contact the Agency

Families should identify and contact their local home health agencies and find out more about each program. Before calling, think about questions you would like to ask. Below is a sample protocol for your initial contact with a home health agency:

- ◆ Identify yourself and your reason for calling (to gather information on home care).
- ◆ Describe your child’s age, condition, and needs.
- ◆ Say: Our family has ____ insurance and my child has Medicaid coverage as a back-up.
- ◆ Let them know where you live.
- ◆ Ask: Could your agency provide home care for my child?

At this point, if the agency says they do not have available personnel to meet your needs, call another home health agency in your area. This may feel disappointing after the energy and time you spent preparing for this call. You can call other home health agencies or work with another program, such as the Family Support or Community Options Program to explore other ways to find home care.

If, however, the agency indicates that they may be able to assist you, consider asking the following questions:

Questions to Ask the Agency

- ◆ Do you bill private insurance and/or Medicaid?
- ◆ What are the usual steps and time line for signing up for home care services?
- ◆ Do you provide the home care workers or is it our responsibility to find care workers? or We have a person in mind who could provide excellent care, would you consider her as a potential worker?
- ◆ Is prior authorization necessary and how long does that process take?
- ◆ What is your agency's philosophy about serving families who have children with disabilities and/or special health care needs?
- ◆ Who is responsible for scheduling, training and supervision of the home care workers?
- ◆ How are your staff trained and what is their experience with children with disabilities?
- ◆ How long does a typical worker stay with your agency?
- ◆ How do you determine which home care workers come to our home?

Follow-up

The positive outcome of the phone call may be that a home visit is set up at a mutually agreeable time. This visit will most likely entail an hour or two of your time, during which you share information about your child's disability, care needs and other relevant information. You will also be asked to give the name, address and phone number of your child's primary physician so that a doctor's order can be obtained. The home care agency representative who does the assessment is usually a registered nurse.

A less desirable outcome from the phone call is the realization that you are not able to work with the agency. When this occurs it is best to begin again and search for alternative agencies or alternative plans. While this may feel discouraging, it is better to learn up front that an agency cannot meet your needs, rather than learn it a year down the road when a large amount of energy and time has been invested.

Nurses in Independent Practice

Medicaid-certified nurses, who are not affiliated with an agency, are an option for families with a child who requires eight or more hours a day of skilled nursing. If nursing services are not available to a family through a home health agency, then an independent nurse may provide the services.

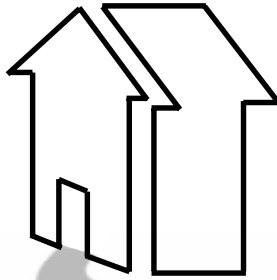
There are benefits and risks for families who hire an independent nurse. The benefits are that the agency as a third party is eliminated and therefore the communication is between the family and nurse alone. However, this also puts a burden on the family to be solely responsible for recruitment, background checks, training, supervision and a back-up plan. The level of risk to the family is magnified by the lack of outside support, especially if something should go wrong (e.g., poor performance, unethical behavior). Families need to consider the potential associated costs for unemployment and worker's compensation should a nurse be asked to leave or acquire an injury on the job. Parents are strongly encouraged to do their homework before hiring an independent nurse, asking many questions of the applicant and the references. Below are a few questions to consider:

Questions to Consider

- ◆ How long has the nurse been in independent practice?
- ◆ Is the nurse certified as a Medicaid provider?
- ◆ Is the nurse's license current?
- ◆ What other licenses or credentials does the nurse hold?
- ◆ Have any complaints been filed with the Department of Health and Family Services?
- ◆ Is confidentiality a priority within the nurse's approach to care?



Seeking Approval for Home Care



Prior Authorization

Upon completion of the agency's assessment for home care, there is a period of time when families must wait to hear whether or not the requested service has been approved. This process may take a few weeks and it may be hard to wait.

While Medicaid home care is a covered service in Wisconsin, the process of Prior Authorization is required as a quality control measure to evaluate the requested service and ensure the appropriate use of funds. When reviewing a provider's prior authorization request, the Department of Health and Family Services considers medical necessity, appropriateness, cost, frequency, quality, timeliness, alternatives and other related areas. Prior authorization is described in greater detail in the Administrative Code section HFS 107.02(3). A detailed handout from the Department, Private Duty Nursing, (see reference section) also describes in clear detail the prior authorization process as it relates to private duty nursing.

Advocacy

It is important that parents have accurate information about home care and the Medicaid requirements for prior authorization, covered and non-covered services. Families may also request copies of the prior authorization form and related materials from the home health agency so that they are "in the loop" of the process and will be better able to understand how the process progresses. The simplified prior authorization chart on page 9 shows how typically a parent requests a service and is generally then "out of the loop" until final notification is received. Many prior authorizations are returned to home health agencies due to clerical errors such as a missed digit in a number, a misspelling, or an unanswered question. A family may consider offering to review the document as a way to become better informed and to potentially catch minor clerical errors. Needless to say, parents need to consider how they asked to be involved so their interest is perceived as an offer of assistance and desire to be involved, as opposed to a suspicious assumption that the agency may have made mistakes. This point is especially important since the prior authorization process may be your first experience in working directly with the agency.

Complete and accurate information alone will not suffice, parents need to develop skills to advocate for their child when a request for prior authorization of a service is denied. Should a parent seek home care and be denied, there is a course of action to follow. Many families keep a notebook in which they log all phone calls, correspondences and meetings with providers and administrators. This is a useful tool to help you keep track of your efforts to seek home care and can be used to prepare your appeal. Other families have sought out the support of advocacy agencies to receive strategy advice or to get help in appealing. Still, other families have not kept records, nor contacted advocacy agencies and have independently worked with state administrators to build relationships. A parent's search for one person within the system who listens carefully and expresses sensitivity for and a willingness to look into the situation, may result in an improved outcome for the family. These different approaches may reflect the past experiences which individual parents have had and not the individual's ability to advocate positively.

"I could never have gotten the amount of nursing care I needed without the support from the advocacy community."

There are several agencies in the state to offer information and support, and some to offer legal services, to families with children with disabilities:

Advocacy Organizations

- ◆ Wisconsin Council on Developmental Disabilities
- ◆ Wisconsin Coalition for Advocacy
- ◆ ABC for Health
- ◆ Family Voices
- ◆ The Arc-Wisconsin

The References and Resources section contains detailed contact information for these agencies. There may also be additional advocacy organizations in local communities.

"In almost every benefits program and civil rights statute directed toward individuals with disabilities, Congress has included the right to individual appeal, first to a disinterested decision-maker and thereafter, if necessary, to the courts."

*- K. Seelman, Director
National Institute on
Disability and Rehabilitation Research*

In addition, Section HFS 104.01 of the Administrative Code outlines the “Recipient rights.” Section 104.01(5) “Appeals,” delineates the steps to a fair hearing. If a prior authorization is modified or denied, the parent always receives a letter explaining the reasons for the decision and the options a parent may pursue. The Department of Health and Family Services, Division of Health Care Financing recommends the following options:

A Parent’s Rights

- ◆ You may appeal a prior authorization decision by requesting a fair hearing before an independent administrative officer.
- ◆ Before beginning the appeals process, you should discuss the decision with your provider to make sure that the provider submitted all the necessary information in the prior authorization request.
- ◆ If additional information or corrections are needed, the provider may submit the prior authorization request for reconsideration.

From: Wisconsin Medicaid, Private Duty Nursing: *A Guide for Medicaid Recipients and Their Families*, POH 1122, April 1999.

Overall, families have benefitted from formal and informal advocacy routes by building positive relationships with advocates, home care agencies, and state administrators. Effective people skills, coupled with a strong knowledge base, enhance the ability to meet the needs of your child and family. The following suggestions are offered to parents:

Ways to Build Your Advocacy Skills

- ◆ Become familiar with the Wisconsin Administrative Code;
- ◆ Develop interpersonal skills to clearly state your needs in a positive constructive manner;
- ◆ Know what advocacy agencies can assist you should barriers arise;
- ◆ Network with other parents and advocates and share strategies;
- ◆ Attend conferences or workshops that will enhance your skills and knowledge base;
- ◆ Keep a record of phone calls, home visits and related correspondences with advocates, agencies and state administrators; and
- ◆ Look for opportunities to offer the parent perspective in policy development.

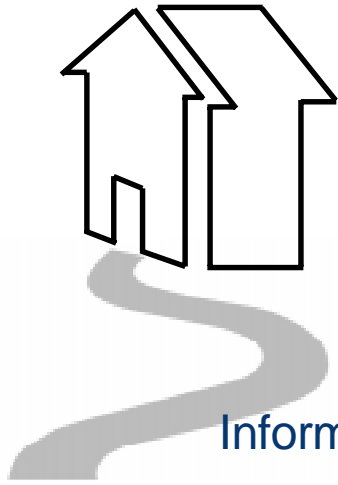


The following sections in this guide are based on the assumption that you have located a home care agency, received approval for funding and that you are now ready to get a worker on board.





Making Home Care Work for You



To prepare this booklet, information was gathered from written materials as well as interviews and focus groups providing input from families who are currently using home care for their children with special needs. Agency providers and state administrators also gave generously of their time and expertise. From this research, critical findings surface around four central themes: information, recruitment, training, and retention. This section reviews the findings and examines the challenges of these central themes as well as strategies to address the challenges.

Information

Increasingly, families are gaining information about home care and accessing it. The proven benefits of respite care, which is a more familiar program to families in Wisconsin, have paved the way for families' comfort with leaving their children in another person's care. However, there is a need for clear and accurate information to be made more readily available to families.

Families report that they have limited amounts of information about home care. Many do not know that the Wisconsin Administrative Code outlines covered and non-covered services for Medicaid recipients. Many say that they have never seen a copy of the administrative code. Many commented on a general feeling of confusion about which federal, state or local program funds their child's home care. Additionally, across the state there appears to be a wide range of "interpretations" of exactly what families are eligible for in terms of home care for their children. Clearly, information is variable across the state and parents are often told different things depending on whom they talk to. The age of the child seems to be an important criterion in some counties. For example, if an infant or toddler cannot typically dress him or herself, an agency may decide that the child does not qualify, citing "parenting" as a non-covered service. While it is true that all very young children require assistance with activities of daily living, a very young child with a disability may require care that far exceeds "normal" parenting. Parents are encouraged to seek the services, one of which may be home care, that will enable them to better meet the needs of all members of their family.

Still other families report that home care was available because both parents or a single parent work outside the home. The number of hours of service seemed to be connected to the parents' employment, though it is interesting to point out that the regulations for home care do not indicate

this variable as part of the eligibility criteria. This question stems from the definition of medical necessity HFS 101.03(96m), which states that Medicaid provides services that identify, prevent or treat a condition and that the service meets a set of standards for appropriate care. The Division of Health Care Financing states that parent availability and ability is considered in the approval process. For example, if a parent has a disability, this may allow for more home care for her child with a disability since she is restricted in her ability to provide care. For families, it is crucial that a lot of detailed information is given to the home health agency so that those reviewing the prior authorization process have a clear picture of the actual situation.

Recruitment

Finding quality workers to work in home care for a child with a disability is a common struggle for families. Several challenges and strategies are addressed below.

"I want people to see my child for who she is, not for her disability."

Challenges:

Families report that finding high quality, trustworthy people to work in home care is an overwhelming challenge. Many times, families are eligible for home care and yet may have either chronic or intermittent problems in finding care workers.

The Barriers to Finding Care Workers

- ◆ Lack of transportation or a bus route for workers in rural areas.
- ◆ Lack of choice from agencies with the burden falling on the family to find a care worker.
- ◆ Lack of pediatric experience and family-centered interest in the worker pool.
- ◆ Low wages and employee benefits.
- ◆ Competition from other employment opportunities including retail, food service, and residential centers.

Strategies:

While it can be a challenge to find home care workers whom you can trust and value, there are some successful strategies that families have shared. Families should consider how they find care workers. Is it out of your control or do you have a significant role to play? By taking an active role in choosing a home care worker, by investing time and energy up front, you are more likely to have a successful outcome.

Parents across the state have discovered a creative assortment of recruitment strategies. One mother always selects a home care worker through word-of-mouth by someone she trusts who has recommended the individual. One family sends a personal letter to friends, asking if they know of anyone who might be interested in working with their child. Other parents

ask the home health agency for a few names and then initiate telephone screening and direct-contact interviews. Some parents have tapped into the availability of a close relative who would rather do meaningful work with a nephew than a shift job. Families living near colleges and universities have posted their personalized job announcements on bulletin boards in targeted departments (e.g., nursing, physical therapy, special education).

Recruitment may be out of a parent's control depending on the home health agency's policy. Yet even if there is no parental control over the recruitment process, it is important for each family to take some time considering what qualities they would like to see in a home care worker. Parents may benefit from asking themselves the following questions before they seek a worker:

Know What You Want

- ◆ Do I want the worker to be a relative or someone I already know in some way (e.g., cousin, aunt, church member, neighbor)?
- ◆ How long do I hope this person will work with my child (e.g., at least a year, for the summer)?
- ◆ What are the human resources in my local community (e.g., college students, W2 recipients, second income/part-time)?
- ◆ What are the qualities most important to me (e.g., honesty, trustworthiness, safety, good communicator)?
- ◆ How independent can the caregiver be (e.g., can I leave my child alone with the worker and not worry)?

For families who are in a position to search for their own home health workers, the following methods may be helpful: newspaper ads, student job center, church/community bulletin boards, and word of mouth. Families should ask the providing agency if there are restrictions on hiring (e.g., age, skill-level, citizenship).

What to Include in a Job Description

- ◆ Wage
- ◆ Hours/days
- ◆ Characteristics of applicant
- ◆ Expectations of job
- ◆ Location, transportation
- ◆ Specific contact information
- ◆ An indication of your family values uniqueness, interests, and what will be fun/rewarding about the job

Sample Job Description.

Home care worker, \$8/hr, 3-7 pm daily. Provide care in our home for our 8-year-old daughter with a physical disability. Looking for an energetic, thoughtful, sensitive individual to assist with activities of daily living (dressing, feeding, bathing). A great opportunity for those preparing for the "helping" professions. On bus line. Call Helen at 333-0409, evenings.

Once you have completed and posted the job description, phone calls will come. Or if an agency is pre-selecting care workers, you may still receive calls from a pool of potential care workers. (Note: some families may not be provided with input into this process through agency policy.) Being prepared for the calls with a telephone screening approach will make this process easier.

What to Ask During a Telephone Screening

- ◆ *Experience with individuals with disabilities:*
Could you tell me what experience you have had working with adults or children with disabilities?
- ◆ *Hours/days available:*
How many hours are you hoping to work?
What days are you available?
- ◆ *Purpose in seeking position:*
Can I ask why you are interested in this position?
- ◆ *Other commitments/responsibilities:*
Do you have another job or are you in school?
How long do you plan on being in this area?
- ◆ *Children:*
What experience do you have with children?
Do you enjoy interacting with children?
- ◆ *Transportation:*
Do you have a car or another way of getting here?
- ◆ *Physical strength:*
This job requires lifting my child who weighs _____ pounds.
Would you be able to perform this function?
- ◆ *Allergies:*
We have a cat, are you allergic to animals?
- ◆ *Ask them to problem solve:*
How would you handle the following situation _____?
- ◆ *Ask if they have questions:*
Do you have any questions?

Following the telephone screening, you may choose to interview potential home care workers. Invite applicants to your home to meet your family. Be sure you ask for the applicant's phone number and name in case you need to reschedule the visit. While some parents have very specific questions for applicants, others gain information through an informal discussion/conversation. Whichever technique you feel comfortable with, the following suggestions for the interview may help you begin to think about what information is helpful to you in this process.

What to Ask During an Interview

(Can be mixed into conversation or asked as discrete questions)

- ◆ *Determine length of commitment:*
When you think about this position, how long do you anticipate working here?
- ◆ *Examples of personality traits:*
Can you tell me about a time when you had to have incredible patience in order to do something? Can you tell me about a time when you had to be exceptionally energetic, playful or creative? Have you ever encountered a conflict in the workplace and if so, how did you handle it?
- ◆ *Knowledge about people with disabilities:*
Have you ever known a person with special needs; a neighbor, classmate, cousin?
- ◆ *Experience with children:*
Have you ever worked with children: baby-sitting, camp?
- ◆ *Hobbies, special interests:*
What do you like to do in your spare time: art, sports, garage sales?
- ◆ *General work experiences:*
What have your previous work experiences been?
What types of experiences have been the most difficult for you?
- ◆ *Qualifications:*
What sort of training, certification or licensure do you have?

During the interview, the parent should make sure that the applicant has complete information, so there is an understanding of what is involved in caring for his/her child on good and bad days. Families repeatedly emphasize the importance of being up-front with potential care workers, believing that if the worker chooses to stay knowing the full range of the child's situation, then the worker will be prepared and do a better job. If a child has episodic bouts with illness, self-abusive behavior, pain or other health conditions that come and go, it benefits all involved if these episodes are clearly addressed early on in the process. A parent may say to an applicant: *There will be days when my son cries almost all day and try as I may, I can't help him feel better. These days will be very frustrating and sad. There will also be days when he is feeling great, laughs out loud and wants to get involved in the world around him.*

Knowing your own values and how those relate to household practices is something to share as part of the interview process. For example, if television is restricted in hours or days this should be clear up-front. The parents' approach to discipline should be stated and an applicant needs to be comfortable in following through on the parents' approach, not their own. Religious beliefs are highly personal and parents may choose to ask the applicant about whether or not his/her religious beliefs will potentially be in conflict with the families approach to daily life. For example, in one family a child participates in yoga, and the personal care worker has refused to be involved in this due to her personal religious beliefs. The level of cleanliness in a home can at times conflict with an applicant's personal standards.

Again, addressing these issues in the very beginning and using the information gathered as part of the selection process can alleviate conflicts down the road.

Things to Look for During an Interview

- ◆ Individuals who show up on time as scheduled for an interview may indicate future punctuality, responsibility and reliability.
- ◆ An individual's ability to communicate his/her ideas and respond to your questions may indicate listening and speaking skills, and breadth of knowledge which may indicate an ability to respond to instructions/feedback, initiate communication, and articulate difficulties in an emergency.
- ◆ An individual's ability to interact with the children may indicate a genuine enjoyment of children, if children like the applicant, it may indicate a knowledge of age-appropriate behavior and language. Look for the way your child is addressed and/or included by the applicant through greeting, eye contact, and voice. Does the applicant talk directly to your child? Does the applicant speak more simply, slowly and loudly when addressing your child? Does the applicant say good-bye to your child upon departure?
- ◆ Individuals who have previous experience with children and/or at least one person (cousin, neighbor) with a disability are more likely to be comfortable and prepared to work in home care with children.
- ◆ Individuals who have career goals involving the helping professions and look at this experience as a stepping stone to their careers are more likely to be stable workers.
- ◆ An individual's body language and type of eye contact may lead you to think he/she is judgmental.
- ◆ Individuals who are athletes, lifeguards or have experience in manual labor may be more likely to have the necessary physical strength for the job.
- ◆ Individuals whose values are rooted in helping those in need may be strong candidates.

In the example provided earlier, where the parent shares that there are days when she cannot console her child, the parent understands that patience, an easy-going style and understanding are crucial characteristics for working with children who are medically complicated.

What to Think About During an Interview

- ◆ Do you have a gut feeling that this person would work out well?
- ◆ Are the applicant's interests similar to yours?
- ◆ What are his or her values and how well do those match yours?
- ◆ What is your hoped for outcome from the match and how does that blend with the applicant's hoped for outcome?
- ◆ Is this likely to be a mutually beneficial relationship; is there potential for reciprocity?
- ◆ Is there something about this person that makes you want to get to know her better?
- ◆ Is there something about this person that really annoys you but you cannot figure out what it is?

After you have interviewed the available workers, think about each one and try to envision him or her in your home and with your child. Ask your children what they thought of the applicants. While you ideally want the best qualified worker, parents report that there may be times when they have to “settle for less,” because the need for home care is so great that for a short-term solution, something is better than nothing. This is important because lack of home care may result in a parent’s need to stay home, creating a loss of employment. In the attendant guide *Working Together* (1998), the authors caution: “Beware of Being Too Choosy,” pointing out that part of the process of obtaining and securing home care is dependent on some compromises. It is crucial for families to identify those pieces of the puzzle they are willing to relinquish (e.g., exact hours preferred), and those that cannot be compromised (e.g., safety). A long-term lack of home care may also result in harm to the child, either through unavoidable neglect or general inability to provide quality care because of other competing commitments. A lack of long-term home care may also result in harm to the caregiver, whether through physical or emotional strain.

Follow-Up

Typically the home health agency will obtain references, yet you may also wish to ask the applicant for two references. You may want to say: *I really feel positive about the experience you bring to this position. I always ask applicants for two to three references just as part of this process. Could you provide me with references, perhaps including one person who has known you for a long time?* Some applicants will need to call you back with phone numbers and names. When you contact the reference, below are some sample questions to consider. Be sure to begin by clearly identifying yourself, your reason for calling, and ask if this is a good time to talk. Be sure to close by thanking the reference for his/her time and information.

What Questions to Ask a Reference

- ◆ How long have you known _____?
- ◆ In what capacity have you known _____?
- ◆ Can you speak to his/her strengths?
- ◆ Can you speak to his/her weaknesses?
- ◆ What do you think will be the most challenging to him/her about this job?
- ◆ Would you recommend _____ to work with a child?
- ◆ Is there anything else you’d like to tell me?

Orienting and Training the New Care Worker

Once a new home care worker is ready to take care of your child in your home, you need to consider how best to orient the worker. While home health agencies take some responsibility for this activity, many parents opt to be actively involved. The training may include highly individualized information not only about your child's condition, but also about where equipment, medications, and other supplies are kept within the home.

The home care notebook (in Appendix A), which many parents develop as a way to share information about their children, is a useful tool when explaining your child's needs. Often there is a large amount of information for the worker to learn at first and many people have trouble retaining volumes of information when it is given in a short period of time. Therefore, the book provides a written statement of need and can be referred to over time. The book is also a place to record ongoing changes and information.

Parents report they often engage the previous or existing home care worker in training the new worker. This strategy serves two purposes: it frees the parents' time to do other activities, and it offers the worker perspective to the new employee. For a new home care worker to hear the same information from two different perspectives will enhance his/her understanding and better prepare him/her for the job. This strategy may not be supported by the home care agency, in terms of paying two workers at the same time. A family could ask if they are allowed to use other funds, (e.g., COP, CIP, Respite), to pay one of the workers during the training period.

Parents emphasize the importance of being up-front with the new worker and sharing information openly. Working side-by-side with the new worker offers you a chance to create a conversational approach to training. You may demonstrate a procedure and then say, "Would you like to try now?" Ask how they think it went and then provide your feedback. After the new worker has demonstrated the ability to provide care, staying close by and available for the first few weeks will increase the quality of the training. Listening to the new worker and the child while at work in another room is a useful way to monitor the situation and also allows you to intervene when necessary. For example, many children will test a new worker, and the parent's role is to inform the care worker about what is acceptable behavior and what is not. Parents need to look for the quality of the worker's performance.

Ways to Evaluate Performance

- ◆ Is the child's safety a top priority?
- ◆ Is the follow-through on your training goals being carried out as instructed?
- ◆ Is the use of language age-appropriate and positive?
- ◆ Is the care worker demonstrating an effort to learn and do a good job in a conscientious manner?

Frequent and clear feedback during the orientation phase will likely improve the overall success of the match. It is a good idea to “check-in” at the end of each day during the initial orientation phase. Ask if the worker has any questions or concerns. It is harder to give critical feedback after the training phase. Below are several suggestions for developing your own role as a trainer of new home care workers.

How You Can Teach the New Worker the Job

- ◆ Recognize that you do have an influence on how the new worker perceives your child and his/her disability.
- ◆ Accept that the new worker is a new learner in this situation (your home) and will not know everything right away. Remember back to when you first learned caregiving skills, and demonstrate respect for that experience in others.
- ◆ Provide support to the new worker in a warm, instructional way. Acknowledge the new learner's abilities as they surface. Emphasize the positive.
- ◆ Model conscientious behaviors and thinking outloud to encourage the new worker to approach the work as you do. Model age-appropriate language and interactions.
- ◆ Practice and develop interpersonal skills as you create a learning environment that is interesting, clear and supportive.
- ◆ Nurture an approach of high expectations, coupled with forgiveness and understanding. Remember that this work can be very difficult emotionally and physically; home care workers need support.

Retention

Challenges:

Parents can play an active role in retention- the process of keeping a home care worker, working with your child. Retention is dependent on many variables, some of which are beyond the family's control. Being aware of retention issues can help you understand home care more clearly and give you a sense of what is within your control and what is not.

Situations may occur that have nothing to do with the family. For example, many parents report that an ongoing struggle with home care is that the direct care worker may be suddenly switched by the agency, resulting in a brand new worker showing up at the family's door. In this situation, families report feeling unwilling to leave their children with a stranger and feel frustrated by the poor communication flow between agency and family.

Retaining a home care worker also depends on what you as a family do to actively nurture the relationship and match. Once you have secured a worker, the need for close attention to the situation is critical to the success of the home care.

As a parent, you may want to monitor the care worker's satisfaction with the job. The following indicators may be signs that your worker is dissatisfied or otherwise questioning his/her job.

Some Common Signs of Job Dissatisfaction

- ◆ Is the care worker chronically late, does not show up, or cancels frequently?
- ◆ Does the care worker seem bored, overwhelmed or disinterested in the work?
- ◆ Has the care worker shown an interest in this sort of work, but now that he/she is actually doing it, sees that it is not what he/she wants to do?
- ◆ Does the worker spend more time following you around the house or sharing personal stories than spending time providing care for your child?
- ◆ Does the care worker spend more time cleaning dishes than interacting with your child?
- ◆ Does the worker need to earn a living, or is this a work-experience while pursuing another priority (e.g., education)?
- ◆ Does the worker need to earn a living and has another source of income with a higher wage?
- ◆ Is the care worker having personal difficulties preventing him/her from following through on life commitments in general?

If you feel that the match is not working out well, communication with the home care worker is crucial. When a family would like to let a care worker go after realizing that it is not a good match and/or the child's welfare is at stake, this can be done with the support of the home care agency.

When you lose a care worker, understanding why you lost him or her can help you to move past the feelings of disappointment and sadness you may experience.

Some of the greatest challenges faced by parents are found when workers suddenly, and often unexpectedly, leave the job. Sometimes they will provide notice, sometimes not. Sometimes a worker may simply not show up and that is the way you are informed of the resignation. This is often hard for families since parents may question themselves and perceive this as a personal failure. Children also may feel hurt when a care worker calls to resign, instead of coming to the home to say good-bye. Finding ways to talk about this with your children is also important so they understand that it was nothing that they did, and reassuring them that family will always love them and be there for them.

There is no way around the hurt feelings that naturally surface for many families when they suddenly lose a worker. Healing emerges from a careful review of what occurred and an objective understanding of why the worker left. Periodic self-evaluation of your own behaviors is important to the ongoing process of improving your own communication and management skills. And there are times when we all make regrettable mistakes. For many parents, there is comfort in understanding why a match did not work out. Many times it just was not a good match and no one is to blame.

Families may again refer to the Wisconsin Medicaid Administrative Code, which delineates rules about discharge. Agencies discharging clients have their own rules, yet also need to follow the code regarding giving notice, HFS 105.16(10)(f), 105.19(9) and 107.112(3)(b). In general, licensed Medicaid certified home health agencies must inform the parents if a service is discontinued and assist parents to find another agency for that same service. These guidelines are outlined in section HSS 133 of the Administrative Code and the Bureau of Quality Control governs this area. Families can file complaints if necessary and may begin by calling the Medicaid Recipient Hotline.

Strategies:

To ensure the success of the match, parents report that communication is the key. Some families keep a communication notebook, where all information is shared between home, school and community. This allows the home care workers to see the child as a complete person across environments. One family asks all workers to initial the notes after reading them to ensure that everyone stays in the information loop. Other parents develop “goals for the day,” or checklists that are updated daily to confirm that key activities are accomplished.

When families do encounter challenges to home care, the following approaches may help them address the problem before it results in an irreconcilable difference.

Ways to Address Concerns:

- ◆ Be direct, with a smile and friendly tone.
- ◆ Acknowledge that something is difficult to do and that it took you a while to learn how to do it, then demonstrate the correct way to do it.
- ◆ Model behaviors you want to see in them.
- ◆ Ask the worker how he/she is doing with a particular procedure and acknowledge the parts of the procedure that are going well and what needs attention.
- ◆ Determine if the difference is detrimental or just different and okay.
- ◆ Talk with a trusted friend and brainstorm about solutions.

While communication around issues of the child's care is critical, parents have also found that personalized communication with the worker is needed. Developing a relationship between a parent and worker increases the prospects of a mutually beneficial outcome. First, you as the parent are in a better position to foresee difficulties if you have frequent conversations with the worker. Asking questions about the worker's life allows you to gain a sense of future plans, interests and strengths. You can then capitalize on any hobbies or special talents. This conversation also gives the worker the message that you care about him/her, that he/she is not just a person coming into your home to do a job. This mutual sharing and communicating is an essential component of an effective partnership.

Parents report that successful matches between parent and worker ultimately result in long-term relationships, a stronger bond between child and worker and increased trust and caring on both ends. Many families talk about a special worker who has stayed connected to their family for years. In these situations, the level of care sprouts from deep roots; parents use the word "love" to describe the relationship. Families say that some workers feel like members of the family, acting as role models to their typically developing children and as trusted advocates.

"Some of them fall in love with my son."

Acknowledging and demonstrating respect for workers is a key retention strategy according to families.

Ways to Acknowledge Workers

- ◆ Remember a card or gift on birthdays/holidays.
- ◆ Comment on specific actions you noticed and appreciate.
- ◆ Tell them of your child's fondness for them.
- ◆ Let them know that their own family should be their priority.
- ◆ Keep the refrigerator stocked with their favorite beverage.
- ◆ Listen to their personal stories.
- ◆ Share personal stories with them.
- ◆ Show flexibility.

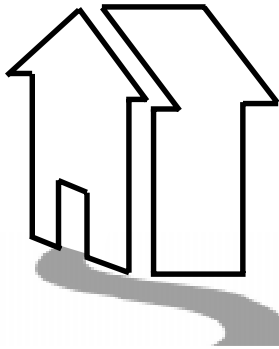
Ways to Show Respect for Workers

- ◆ Thank them as they leave each day.
- ◆ Provide specific and timely feedback when they do something well.
- ◆ Build a relationship; show interest in them as people.
- ◆ Be realistic about the energy it takes to care for your child and make sure your expectations are fair.

In addition, periodically self-evaluate your own behaviors. Are you showing the home care workers respect, flexibility and support? Are your expectations realistic? Remembering that possibly no one will ever do things as well as you, the parent, and letting go of expectations that the worker can read your child's every movement and cry is necessary for home care to work. If your home care experience is marred by frustration, tension and a chronic feeling of dissatisfaction, then it is time to step back and talk with a trusted friend or professional about the situation. Overall, home care should be an enhancement to your life; and if it is not, you should carefully review the issues.



Challenges and Benefits to Home Health Care



Challenges

Having another person to provide care for your child at home is unquestionably a benefit for many families. The benefit is countered by the challenge of the invasion of a very private zone, your home. Your home is probably the one place where you can totally be yourself and do things however you choose. Once you have home care in place, your home becomes more public.

“Be careful what you ask for; you may get it.”

In a sense families are used to this, since from early on we have frequently exchanged highly personal information for services. Home care is an extension of the many times we have opened up our lives to others in order to receive services. This opening is difficult for many families and consumes a lot of energy in terms of planning, monitoring and continuously improving the process. Parents say: “It takes a lot of energy having others in your house;” “It needs a lot of attention;” and it is “draining, exhausting, takes lots of emotional energy.”

Holidays can be difficult times for families, since it is common for workers to take personal vacations at this time. However, parents report this inconvenience as part of the “give and take” of the family-worker relationship.

Many families have experienced frustration with the home care agencies, especially around the issue of communication. Families have had concerns about the poor return on phone calls and responses to requests. One family member commented that she felt her family was not a high priority for the agency, which accounted for the poor communication. Another parent was devastated by an agency’s attempt to take her to court for alleged child negligence.

Another challenge is the availability or lack of home care workers and whether the parents are permitted to be involved in the selection of the workers. On the other hand, many parents have excellent experiences with their provider agencies, indicating that the quality of business etiquette and philosophical framework varies widely from one agency to the next.

“In my life, I don’t have anything that is confidential anymore. We have no privacy.”

Several families report that they stay with the same home care agency, despite dissatisfaction, because the thought of “start-up” with a new agency is overwhelming. The issue of start-up exists not only with switching agencies, but also with switching home care workers. Initiating the process of start-up consumes huge amounts of energy. Parents need to once again tell all the details of their child’s condition, explaining, requesting. And ultimately, many parents feel the burden falls on them to initiate, follow-up and ensure completion of the process. Building new relationships also takes energy and time.

In families where there are siblings, issues may arise that require further thought and action. Clearly, the covered service of home care is limited to individuals who are eligible. However, while in a family’s home it is often impossible to ignore the presence of siblings. Parents need to honor the fact that the home care worker is there for the child with special needs, yet there are ways to support sibling relationships. One example is seen at mealtime when the whole family and the worker are at the kitchen table. The worker may feed your child with a disability, yet your other children are there as well and this may be a time to model sibling interaction. Siblings may gravitate to a worker and compete for his/her attention. Parents can offer support by their presence and by intervening when appropriate.

Benefits

If securing home care for your child is difficult, why is there increasing interest and use of this service? Because in the overall balance of the equation there are net benefits. Parents report that the experience of receiving home care is highly positive because of the relationships that are built and the actual care that is provided. Families describe the incredible people who come into their lives, the role models for typically developing children and the feeling of satisfaction in the power of one person (your child) to create meaningful change in another person’s (care worker’s) life. Parents clearly see that home care allows them to go to work, get things done (e.g., errands, advocate, school meetings, other services), and spend time with their other children.

In interviews with parents of children in a Madison Medical Assistance personal care program, a study found: “Repeatedly when I asked parents what personal care meant to them, they stated ‘my sanity.’” (Van De Graaff, 1999). Further, parents report that home care allows them to maintain an “age-appropriate” relationship with their child, since typical development usually involves a gradual increase in independence, especially in personal care. Parents also stated that the care needs of their children are so extensive that it would be physically impossible to meet the child’s needs without help from another person.

With time, parents gain experience in how best to secure home care for their children. The process of obtaining home care is one that generally improves over time as you, a parent, become increasingly savvy and figure out how to meet the needs of your family. And there is a sense of satisfaction in this skill as it develops. This booklet is intended to share some of those strategies with families so that the wheel does not need to be continuously recreated. However, you alone will discover the nuances of home care and the details that work for you.

This booklet provides parents with the appropriate information and supports for their care giving roles, in the hope that they can exert more control over their choices and direction, thereby ensuring meaningful and fulfilling lives. Appendix B offers a few reflection pieces which may help parents think about their roles as caregivers. Home care for children with significant disabilities is one approach to supporting families so that parents maintain their health and success.

Parents' Perspectives: Areas of Concern

Parents who are receiving services expressed gratitude for the help they have received; they also recognized areas where the current system could be improved. A few of these key areas of concern and corresponding questions are summarized below:

Worker Categories of Care: While each home health agency or personal care agency follows the same Medicaid regulations for covered services, they have some latitude in deciding which level of care to request for a child with a long-term disability. This latitude is in part to allow the nurses to decide what tasks can be delegated to a worker, and consequently what the nurse can assume responsibility for. As a result, families with very similar children may be receiving different services (e.g., nursing, home health aide, personal care) depending on the agency they access. With many children surviving premature or traumatic birth experiences and living longer lives, there are more children with long-term needs who require skilled care for gastrostomy-tube (g-tube) feedings and medications, for example. These are the children who seem to receive greatest variability in the category of care.

Question: *Is this variability acceptable or does it cause families to feel like the quality and extent of the services they receive have to do less with their child's disability and more with where they live?*

Parenting versus Extraordinary Caregiving: A parent's care for a child with a disability is different from that of a worker in that typically it is fueled by an overwhelming sense of unconditional love. Yet the care that most children with significant disabilities require is extraordinary and can be distinguished from "normal" parenting by the amount of time and physical and mental energy it consumes. Medicaid regulations state that parenting is a non-covered service as part of the interpretation of the medical neces-

sity regulation. Yet medical services are sometimes denied based on an interpretation of these services as “parenting.”

Question: *Is there a need to establish the differences between “normal” parenting and the parenting of a child with a significant disability to ensure that the two are not perceived as the same?*

Care within the Home: Children with long-term disabilities have become increasingly involved in their local communities, participating in a wide variety of activities outside of the home, (e.g., parks, libraries, malls, business establishments, swimming pools, day cares). When these children leave the house to enter into community settings, their need for assistance (e.g., mobility, feeding, toileting, medications, suctioning) continues. The growing acceptance and push for community integration is inconsistent with the Medicaid regulations that largely limit personal care services to care within the home (with some exception).

Question: *Do the societal trends toward community integration require personal care guidelines to be updated to allow for flexibility of where the service is received or do families need to be encouraged to creatively patch together various funding resources to meet their needs?*

Allotment and Usage of Hours: Most families live highly dynamic lives that change with the time of year and the health of their children. While the home is the constant for families and the parents are the constant for their children, routines change with school schedules, hospitalizations and vacations. A child may be allotted eight hours of personal care a day. During the school year, an average of two hours a day is used. In the summer, however, the family needs ten hours a day if the parents work outside of the home and there is no summer school program.

Question: *Are families adequately informed of their right to request a new prior authorization process every time their needs change (e.g., change in recipient’s or family’s situation) or have the current prior authorization amended to provide greater flexibility as needs change?*

These questions indicate a need for future discussion between parents, workers and administrators on policy issues, especially around home care regulation. This booklet concludes with a call for future study, advocacy and quality assurance.



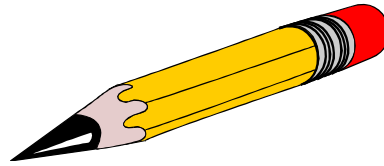


Appendix A

Tips and Tools



Create Your Own Home Health Care Book



Many families have created personalized home health care books for the providers who come into their homes. Here is a way to begin thinking about developing your own book.

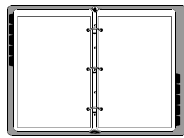
Getting Started



Make time to organize your thoughts and information and plan for the creation of a home health care book centered on your child.

You will need...

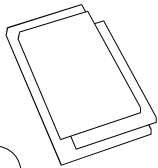
✓ 3-ring binder



✓ Plastic sleeves



✓ Paper



✓ Ideas



✓ Information



✓ Photos



Begin to collect and save articles, pamphlets, equipment guides and add them to the pocket of your binder (e.g., nebulizer, suction, Hoyer).



Creating Your Own Book

Following are some suggestions of what you may decide to include in your book.



◆ A “Snap Shot” of Your Child

Interests, likes, dislikes: Be sure to include information illustrating your child as an individual with his or her own personality. What are your child's favorite activities, books, movies and more?

Health status: You may choose to include recent reports summarizing your child's health or write an informal statement about how your child is doing these days.

Photos: Pictures of your child, important people in your child's life, and any other images that share information. For a child who is non-verbal, photos are an excellent method for promoting information exchange and story telling.

◆ Health Summary or Description of Your Child's Condition

This is where you may include specific information on your child's condition. Easy-to-read definitions and descriptions will enable a new learner to quickly grasp an initial sense of your child's disability. If your child does not have a diagnosis, you can still include information on specific aspects of the disability (e.g., asthma, hypotonia).



◆ Daily Schedule



A daily schedule will typically include waking and sleeping, information, times in and out of bed or using other equipment, times when food is given, times when the child is changed or bathed (a sample schedule is attached).

◆ Medications



For a child on medications, a clear description of each medicine, dosage, time given and purpose are critical. Many parents and agencies also require a careful logging system to ensure precision (see attached sample).

◆ Foods



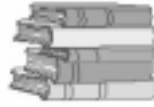
Many children have dietary restrictions for a variety of reasons, including weight, allergies, history of aspiration and more. Parents need to be clear about what foods are to be given, when and how. Some foods may need to be prepared ahead of time and instructions for this are helpful to a new provider. If your child has special likes and dislikes for particular foods, this is also useful information.

◆ Exercises and Therapies



If your child has specific exercises or therapies, the home health care book is a good place to keep the protocols. If a child requires range-of-motion exercises, a combination sketch or photo and description of the activity allows another person to follow-through (see sample).

◆ Articles/Booklets of Interest



Most parents have collected favorite articles, poems, and/or booklets that they have found helpful. Sharing these with providers is a wonderful way to enhance understanding about your child.

◆ Specialized Equipment



Many children have equipment (e.g., lifts, wedges, balls, standers, suction machines, ventilators, oxygen, nebulizers) in the home. Often when a piece of equipment is initially purchased, it comes with a pamphlet describing the item. Parents can 3-hole punch these pamphlets and put them in the home health care booklet. Or simply put the pamphlet in the binder's front or back pocket. You may choose to take a highlighter pen and highlight the main information in each pamphlet.

◆ Log Sheets



In addition to charting medications, some parents also like to keep track of all the child's activities of daily living. Log sheets can also be used intermittently as needed. For example, during and following a serious illness, a parent may want to closely track body temperature, respiration rate and frequency of coughs. Simple lined paper is also useful for the flow of open-ended information or story telling.

◆ Emergency Information



All new and existing home care providers should be absolutely clear on how to act in an emergency. A list of phone numbers or pagers and an order of whom to contact first is critical. Many parents carry pagers at all times so that they can be the first contact. A list of criteria for when to call 911 versus when to call a parent may also be delineated. In addition, this section should state where the fire extinguisher, flashlight and tornado-safety area are located in the event of a natural crisis.

Using Your Book



Your book may now be used to:

- ◆ Introduce applicants to child's needs
- ◆ Train incoming providers
- ◆ Offer ongoing support and information to providers
- ◆ Establish communication loop with providers
- ◆ Ensure your child's safety
- ◆ Make it easier for you to leave your child in someone else's care

A Sample Daily Schedule

Please note that this schedule is skeletal and is only to provide an example of what information is important. The schedule you create for your child would be much more warm, personal, refer to your child by name and include individualized details.

Welcoming the Day

Greetings and connecting

Wash face, hands

Brush teeth

Change Attend

Help, to choose new clothes and dress

Stretch arms, legs, feet

1 can of Ultracal, 2 ounces every 10 minutes

Ask: Would you like to move to your wheelchair?

Throw dirty clothes in wash, make bed

Clean glasses and put them on

Take a Break

Invitation to make choices about activities

Make sure face stays clean and dry, use lotion if needed

12 ounces fruit or vegetable juice, 4 ounces every 15 minutes

Check to see if a new Attend is needed

Make sure clothing is clean and dry, change as needed

Transfer out of chair

Range of motion exercises including hip rotation

Wash feeding items, keep area clean

Choices about activities, checking in on the day

Transfer back into chair

Lunch Time

Choice: Time alone or help while you prepare lunch

1 can of Ultracal, 2 ounces every 10 minutes

Wash up feeding items, keep area clean

Afternoon Rest and Relaxation

Invitation to make choices about activities

Make sure face stays clean and dry, use lotion if needed

12 ounces fruit or vegetable juice, 4 ounces every 15 minutes

Check to see if a new Attend is needed

Make sure clothing is clean and dry, change as needed

Transfer out of chair

Transfer back into the chair when ready

Closing the Day

Transfer out of the wheelchair

Assist with a large tub bath

Brush teeth

Examine skin for pressure areas

Range of motion exercises, including weight-bearing

Assist in choosing pajamas

Prepare dinner: 2 cans Ultracal, 2 ounces every 10 minutes

Straighten up room

Clean up from dinner

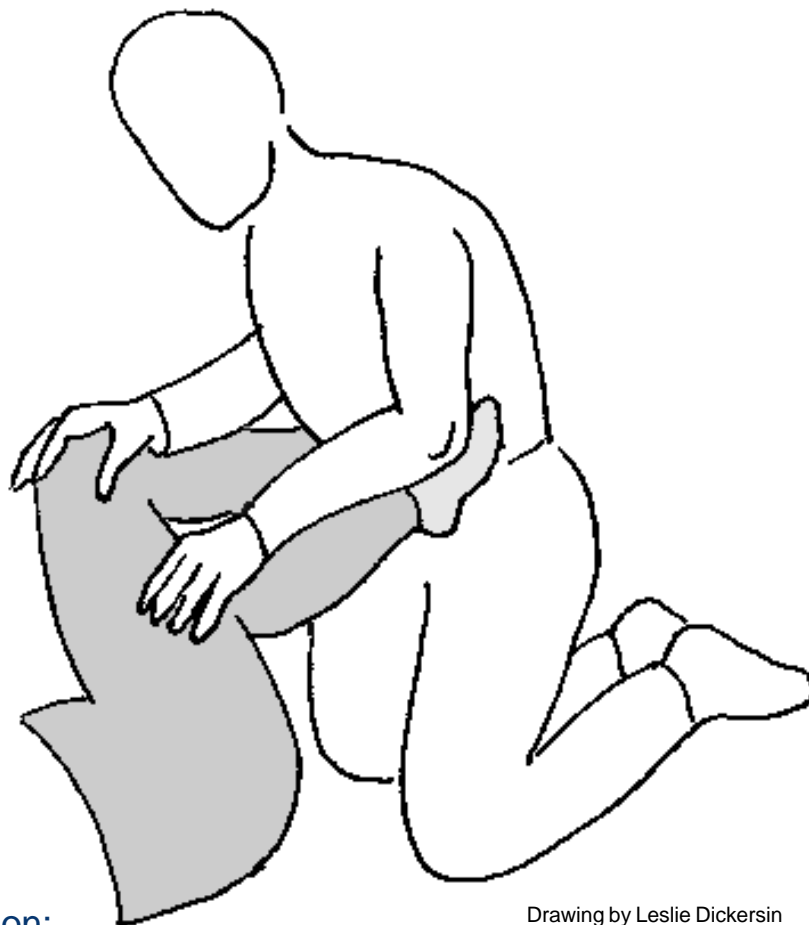
Pack up backpack and lunch box for the next day

Dress for bed

Cover with warm blanket

Range of Motion Exercises

Do the following exercises when she is out of her wheelchair lying on her back on the mat. (The shoulder flexion and head rotation exercises could also be performed while she is in her wheelchair.) Do each exercise for 10 repetitions; do them slowly and gently working towards the relaxation of her tone.



Low Back Rotation:

Drawing by Leslie Dickersin

Gently bring one leg up toward her chest keeping her leg parallel with her trunk. Hold the other leg straight on the floor. Then gently cross her flexed leg over her extended leg. Repeat for the opposite side.



Appendix B

Reflections for Caregivers



Take Time for Eight Matters of the Heart

by Ed Young



Take Time for Response
It is the germ of creation



Take Time to Read
It is the foundation of wisdom



Take Time to Think
It is the source of strength



Take Time to Work
It is the path to patience and success



Take Time to Play
It is the secret of youth and constancy



Take Time to be Cheerful
Valuing life brings happiness



Take Time to Share
Respect is the root of true happiness



Take Time to Rejoice
Joy is the Music of the soul

From *MATTERS OF THE HEART* by Ed Young. Copyright c 1997 by Ed Young. Reprinted by permission of Scholastic Inc.

Ten Tips to Take Charge of Your Life

- ✓ Choose to take charge of your life, and don't let your loved one's illness or disability always take center stage.
- ✓ Remember to be good to yourself. Love, honor and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
- ✓ Watch out for signs of depression, and don't delay in getting professional help when you need it.
- ✓ When people offer to help, accept the offer and suggest specific things that they can do.
- ✓ Educate yourself about your loved one's condition. Information is empowering.
- ✓ There's a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence.
- ✓ Trust your instincts. Most of the time they'll lead you in the right direction.
- ✓ Grieve for your losses, and then allow yourself to dream new dreams.
- ✓ Stand up for your rights as a caregiver and a citizen.
- ✓ Seek support from other caregivers. There is great strength in knowing you are not alone.

Reprinted with permission of the National Family Caregivers Association (NFCA). NFCA is a not-for-profit, national membership organization striving to make life better for all of America's family caregivers. For information on NFCA call: 1-800-896-3650.

The Common Bonds of Caregiving

What is caregiving and how do you define a family caregiver? What is the common thread that ties together those of us who care for spouses, children, parents, siblings, partners or friends who are chronically ill, frail, or disabled?

It certainly isn't the tasks of caregiving. They vary so much, from helping a developmentally delayed child learn new skills, to taking an aging parent to frequent doctors appointments, or suctioning a spinal chord injured spouse virtually every hour every day.

It surely isn't the number of years involved. Caregiving can last a few short months . It can last three to five years. At times, caregiving is a lifetime commitment.

Location varies from situation to situation. Although most caregiving goes on in the home, and most caregivers and recipients live under the same roof, talk to anyone whose parent is in a nursing home and you'll quickly learn that caregiving doesn't end when someone else is responsible for day to day care, or when caregiving takes place long distance.

If it isn't the responsibilities or tasks, and it is not the length of time, if it isn't the location - what is the essential bond of caregiving? What does caring for a spouse with multiple sclerosis have to do with caring for parents who are losing their independence, or a child with epilepsy.

In 1994, when the National Family Caregivers Association (NFCA) conducted its first caregiver member survey, we were seeking to find that common bond, to define the link between all caregivers. We found in no uncertain terms that the common bond of caregiving is its emotional impact. In 1997 when we surveyed our members again, we found the same thing.

The common bond of caregiving is the intense sadness we feel because someone we care about has suffered a brain injury, is losing their mobility, will never achieve normal life functioning. It is the sadness that comes from wanting the miracle of normalcy.

The common bond of caregiving is the upheaval of changing family dynamics that occurs because life has been turned upside down and because there is no set timetable for working through the painful stages of grief which caregivers and care receivers all experience in their own personal and private way.

The common bond of caregiving is the sense of isolation that comes from living outside the norm, from having everyday activities of life - dressing; walking; toileting; breathing, thinking clearly - that everyone else takes for granted, become such a big focus in your own life.

The common bond of caregiving is the frustration we all experience because it is so hard to get things done, because non-caregivers just don't understand, because healthy people park in handicapped parking spots, and because people who are supposed to have the answers often don't

The common bond of caregiving is the stress we feel because we don't have enough leisure or personal time, and the common bond of caregiving is unfortunately often the severe depression that so many of us suffer.

These are the common bonds of caregiving that tie us to one another, that develop in us an innate understanding of each other's pain, each other's lost dreams, each other's fears.

These shared emotions, these very difficult emotions, are the common bond of caregiving. But there is another common bond, another shared emotion, that we don't recognize as often as we should. It is the inner strength that most of us never knew we had.

It is the fortitude to go on despite the pain It is the wellspring of hope we always dip into. It is the power to make a difference. It is the clever way we solve a difficult problem. It is the knowledge that we have been tested by fire, and we have survived.

Our inner strength is the gift we have been given. It is the "pay back" for the pain, and although many of us would gladly trade it in for an easier life and our loved one's health and well being, we nevertheless ought to recognize its extraordinary value.

The problem is I don't think most caregivers do recognize it. I think most caregivers are so caught up in the act of caregiving that they don't step back and look at the extraordinary things they do. I think a great many caregivers don't even identify themselves as caregivers.

This is not surprising. The term caregiving does not exist in most dictionaries. Caregivers have not been counted in a US census and are therefore not officially recognized as a significant minority. Caregiving and caregivers, are invisible.

I wish it weren't so. I wish caregivers were given their just due. I wish caregivers themselves would recognize their value, acknowledge their individual achievements. Empowerment is an overused word, but it is the one that comes to mind when I think of what I want for caregivers.

Empowerment for me means a sense of self confidence, a belief in one's ability to have some control over situations, a sense of pride, a feeling of self respect and self worth. For the most part, we use our inner strength to help our loved ones and to get through difficult caregiving days. We need to begin to use it to take better care of ourselves, to feel proud, to experience the beauty of self love.

I received a letter recently, actually an e-mail, from a member of the National Family Caregivers Association. She said that NFCA had become a great solace to her. She said that we made her proud to be a caregiver.

Proud to be a caregiver. I mulled the phrase over in my mind for quite some time before I realized that the true definition of caregiving is buried in that phrase, in the understanding that caregiving is a role that tests our abilities, our faith, and our character.

What is caregiving? How do you define a family caregiver? I think I have the answer now - you define family caregivers by their emotions and their spirit, by the sadness in their eyes, but also by the determination in their hearts. Caregivers are very special people.

Reprinted with permission of the National Family Caregivers Association (NFCA). NFCA is a not-for-profit, national membership organization striving to make life better for all of America's family caregivers.
For information on NFCA call: 1-800-896-3650.



Appendix C

References and Resources



Books, Periodicals and Research Reports

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Videos

Family-Centered Home Health Services for Young Children (4 video set)

Produced by Judith L. Pokorni, Ph.D.

This video series was designed for home health staff and other personnel working with young children with special health needs. The series addresses issues in the areas of developmental needs, family concerns, and care coordination. Each video includes strategies for home health personnel and others working with families who have children with special health needs. Individual guides for each video include program objectives, a synopsis of the video content, supplementary information, related activities, and references. Closed captioned.

Responding to Families (24 min.)

In this video families receiving home health services describe some of the stress they experience from lack of privacy, disruption of normal family living, inconsistent nursing personnel, etc. In the second half of the video family members and home health personnel discuss important considerations for caregivers such as relating to the child as an individual, understanding the parent's role as primary caregiver and head of the house and working as a team. A supervisor's observations form in the guide includes a checklist of behaviors measuring responsiveness to families. The guide includes a checklist of specific behaviors for promoting communication and play skills.

Encouraging Communication and Play (20 min.)

This video describes strategies for integrating activities that promote communication and play skills into everyday care. The first half of the video discusses communication skills and shows strategies for encouraging communication during routine nursing care. The second half focuses on play and includes suggestions for engaging in interactive play and for using toys appropriately.

Encouraging Motor Development (16 min.)

This video illustrates the sequence of fine and gross motor skills that typically develop in the first few years of life. It also includes three basic principles for encouraging motor development: 1) positioning the child in the most stable and normal positions possible; 2) giving the child plenty of time in a variety of positions; and 3) providing many opportunities to use hands and fingers. Techniques for using each principle throughout caregiving routines are illustrated. A supervisor's observation form in the guide includes a checklist of specific behaviors for promoting motor skills.

Building Family-Centered Care Coordination (23 min.)

This video describes the role of care coordination in serving young children with ongoing health needs. The following four reasons for providing family-centered coordination for these families are discussed: 1) to insure a smooth transition from hospital to home; 2) to support the family in their role as caregiver; 3) to insure the child's optimal functioning with the family; and 4) to insure the transition to community-based services. Information on early intervention services within the community is included in both the video and the guide.

Governmental Resources

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Home Health Care Guides

Access to Independence, Inc. (1999). Working together: A consumer's guide to attendant management. Madison, WI:

Buckingham, Robert W. (1984). The complete book of home health care: A guide to understanding the practical alternatives to hospital care- from homebirth to home care of the disabled or dying, whether elderly or young- and how to make these beneficial ideas work for you. NY: The Crossroad Publishing Company.

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Children's Hospital and Regional Medical Center (1998). Care notebook. Seattle, WA: Children's Hospital and Regional Medical Center and Washington State Department of Health, Office of Children with Special Health Care Needs.

Community Enrichment Project (1993). Steps to independence: A guide to managing personal assistance. Edmonton, Alberta, Canada: Grant MacEwan Community College.

Wisconsin Advocacy Agencies for Families with Children with Disabilities

ABC for Health

152 West Johnson Street
Suite 206
Madison, Wisconsin 53703

(608)261-6939

ARC-Wisconsin

600 Williamson Street
Madison, Wisconsin 53703

(608) 251-9272

Coalition for Independent Living Centers

106 East Doty Street
Madison, Wisconsin 53703

(608) 251-9151

Family Voices

<http://kidshealth@familyvoices.org/st/Wisconsin.html>

Liz Hecht

E-mail: hecht@Waisman.wisc.edu

Web: <http://www.wfv.org>

(608) 263-5973

Wisconsin Coalition for Advocacy

16 North Carroll Street, Suite 400
Madison, Wisconsin 53703

(608) 267-0214

(800) 928-8778

Wisconsin Council on Developmental Disabilities

600 Williamson Street

P.O. Box 7851

Madison, WI 53707-7851

E-Mail: wiswcdd@dhfs.state.wi.us

Web Page: <http://www.wcdd.org>

Phone: (608) 266-7826

FAX: (608) 267-3906

Web Sites

Family Village

<http://www.familyvillage.wisc.edu/>

Family Voices

<http://www.ichp.edu/mchb/fv/>

The Internet Public Library

<http://www.ipl.org/ref/>

National Association for Home Care

<http://www.nahc.org/home.html>

National Family Caregivers Association

<http://www.nfcacares.org/>

State of Wisconsin Information Server, Badger

<http://www.state.wi.us/>

United States Health Care Financing Administration

<http://www.hcfa.gov/>

Wisconsin Department of Health and Family Services

<http://www.dhfs.state.wi.us/>

Wisconsin Department of Health and Family Services Administrative Codes

<http://www.legis.state.wi.us/rsb/code/codtoc.html>

<http://www.legis.state.wi.us/rsb/code/hfs/>

Wisconsin Families on Line

<http://www.waisman.wisc.edu/earlyint/wis-fam/index.htmlx>

QUESTIONS AND ANSWERS ABOUT PDN

IS IT POSSIBLE TO APPEAL A PRIOR AUTHORIZATION DECISION?

- You may appeal a prior authorization decision by requesting a fair hearing before an independent administrative hearing officer.
- Before beginning the appeal process, you should discuss the decision with your provider to make sure that the provider submitted all the necessary information in the prior authorization request.
- If additional information or corrections are needed, the provider may submit the prior authorization request for reconsideration.

WHAT IF CHANGES OCCUR IN YOUR NEEDS OR THE FAMILY'S ABILITY TO PROVIDE CARE AFTER THE PDN SERVICES ARE APPROVED?

- If changes occur, inform your PDN provider, who will then notify your physician and Wisconsin Medicaid.
- The Plan of Treatment can be modified and the PA Request may be amended with the approval of the Medicaid consultants.
- The Plan of Treatment must be re-evaluated and signed by your physician every 62 days, even if no changes occur.

ARE THERE LIMITS ON HOW MANY HOURS OF PDN CARE A RECIPIENT MAY RECEIVE?

Yes. PDN only covers the time spent by a licensed nurse performing skilled nursing tasks. If additional health care is authorized, family and PDN care may be supplemented by home health aides and personal care workers. Together, you, your family, and the PDN provider(s) should discuss how these hours will be coordinated.

CAN PDN RECIPIENTS USE THEIR AUTHORIZED HOURS FLEXIBLY?

Yes. You may use your authorized PDN hours flexibly over periods of time up to eight weeks in length. If you choose flexible scheduling, the provider(s) will indicate this preference in the prior authorization request or in an amendment to the existing prior authorization.

Flexible use of PDN hours allows most recipients to accommodate changes in family schedules, unscheduled provider absences, hospitalizations, or other unforeseen needs.

WHAT IF A PROVIDER CANNOT MEET A RECIPIENT'S NEED FOR FLEXIBLE HOURS?

If an agency or individual provider is unable to meet your needs for flexibility, you may wish to work with additional PDN providers to ensure coverage of all the PDN hours authorized. Providers should include a provision regarding flexible time in your service agreement with them.

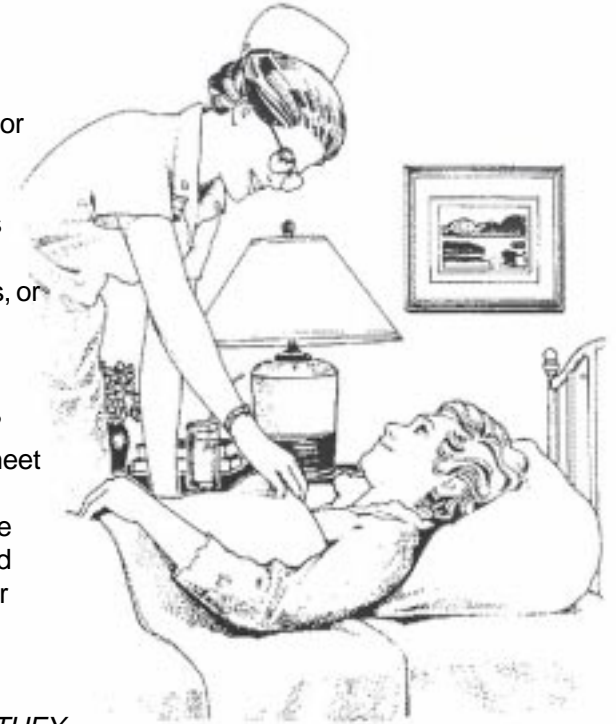
WHERE CAN RECIPIENTS GET MORE INFORMATION OR VOICE ANY CONCERNS THEY MAY HAVE ABOUT THEIR PDN CARE?

You can contact Medicaid Recipient Services by calling 1-800-362-3002 toll-free or 608-221-5720. Medicaid Recipient Services can:

- Answer questions about Medicaid coverage.
- Refer you to Medicaid-certified providers in your area.
- Refer you to state agencies that regulate the performance of home health care professionals.

Wisconsin Department of Health and Family Services
Division of Health Care Financing
POH 1122
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WISCONSIN MEDICAID



Private Duty Nursing

A GUIDE FOR
WISCONSIN MEDICAID RECIPIENTS AND
THEIR FAMILIES

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*Private Duty Nursing: A guide for Wisconsin Medicaid
Recipients and their Families*

ABOUT WISCONSIN MEDICAID PRIVATE DUTY NURSING

Wisconsin Medicaid covers private duty nursing (PDN) for recipients with medical conditions that require eight or more hours of skilled nursing care in a 24-hour period.

- PDN supplements the care families and other health professionals are able to provide in the home.
- PDN services are generally provided in a recipient's home. However, PDN may also be provided outside the home if the recipient's normal activities, like school or work, require him/her to leave home.
- Recipients may use their authorized daily hours of PDN care flexibly over periods of time up to 8 weeks in length.
- The number of PDN hours covered daily is based on medical need and must be prior authorized by Wisconsin Medicaid medical consultants.
- Only Medicaid-certified home health agencies or independent nurses may provide Medicaid PDN.

GUIDING RECIPIENTS THROUGH THE PROCESS

If it appears that you, the Medicaid recipient, may qualify for PDN services, the PDN provider will work with you and your physician to help you get the care you need.

If you do not require eight or more hours of skilled nursing care in a day, the PDN provider can refer you to providers of part-time intermittent skilled nursing care.

PLAN OF TREATMENT

The PDN provider will work with you and your physician to develop a Plan of Treatment, sometimes called a Plan of Care. A Plan of Treatment includes:

- A medical assessment.
- Medication and treatment orders.
- Treatment goals.
- Methods of care to be used.
- Plan for care coordination by nurses and other health professionals.

FAMILY SUPPORT

The PDN provider will ask questions about your family support needs, including:

- Your family's ability to provide medical care.
- Daily schedules — including hours of work, school, sleep, and care for other family dependents.

GUIDING RECIPIENTS THROUGH THE PROCESS (CONT.)

REQUEST FOR PRIOR AUTHORIZATION

Based on the Plan of Treatment and the family support information, the provider will:

- Prepare a written prior authorization request.
- Obtain a signed statement from you or a responsible family member saying that you or he/she has read both the Plan of Treatment and the Prior Authorization Request.
- Submit the Prior Authorization Request and the Plan of Treatment to the Medicaid medical consultants who will review the request.

APPROVAL OF PDN

Medicaid medical consultants will review a request for prior authorization of PDN services within two weeks after it is received.

- If the information is not complete, the Prior Authorization Request will be returned to the provider.
- If the information is complete, the request will be approved, modified, or denied.
- If the request is modified or denied, you will receive a letter explaining the reason for the decision and what further steps you may take about Wisconsin Medicaid

How to Read and Understand the Wisconsin Administrative Code

The next several pages contain excerpts from the Wisconsin Administrative Code, which delineate and describe the home care services supported by the Wisconsin Medicaid Program. This document may seem overwhelming, yet it is quite simply a listing of definitions, exactly what is and is not a covered service and under what conditions. It is important to point out that these services are contingent upon the prior authorization procedure, which may limit some services based on individual need and circumstances.

The Administrative Code contains the following definitions, which may be of use as you read the excerpts:

HFS 101.03 Definitions

(35) “Covered service” means a service, procedure, item or supplies for which MA reimbursement is available, provided to a recipient of MA by an MA-certified provider qualified to provide the particular service, procedure, item or supplies or under the supervision of a certified and qualified provider.

(103) “Non-covered service, item or supply for which MA reimbursement is not available, including a service for which prior authorization has been denied, a service listed as non-covered in ch. HFS 107, or a service considered by consultants to the department to be medically unnecessary, unreasonable or inappropriate.

(134) “Prior authorization” means the written authorization issued by the department to a provider prior to the provision of a service.

Note: Some services are covered only if they are authorized by the department before they are provided. Some otherwise covered services must be prior authorized after certain thresholds have been reached.

Note: The following excerpts are reprinted with permission from: HFS.107.11-107.122, Wisc.Admin.code.

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- (g) Personal hygiene items such as tooth paste and cotton balls;
 - (h) "Patent" medicines such as drugs or other medical preparations that can be bought without a prescription;
 - (i) Uneconomically small package sizes;
 - (j) Items which are in the inventory of a nursing home;
 - (k) Drugs not listed in the medicaid index, including over-the-counter drugs not included in sub. (3) (h) and legend drugs;
 - (L) Drugs included in the medicaid negative drug list main-tained by the department; and
 - (m) Drugs produced by a manufacturer who does not meet the requirements of 42 USC 1396r-8, unless sub. (2) (e) or (3) (j) applies.
 - (n) Drugs provided for the treatment of males or females for infertility or to enhance the prospects of fertility;
 - (o) Drugs provided for the treatment of impotence;
 - (p) Drugs, including hormone therapy, associated with transsexual surgery or medically unnecessary alteration of sexual anatomy or characteristics;
 - (q) Drugs or combinations of drugs that are administered to induce abortions, when the abortions do not comply with s. 20.927, Stats., and s. HFS 107.10(3)(L).
 - (r) Food;
 - (s) Infant formula, except when the product and recipient's health condition meet the criteria established by the department under sub. (2) (c) to verify medical need; and
 - (t) Enteral nutritional products that do not meet the criteria established by the department under sub. (2) (c) to verify medical need, when an alternative nutrition source is available, or that are solely for the convenience of the caregiver or the recipient.
- (5) DRUG REVIEW, COUNSELING AND RECORDKEEPING.** In addition to complying with ch. Phar 7, a pharmacist shall fulfill the requirements of 42 USC 1396r-8 (g) (2) (A) as follows:
- (a) The pharmacist shall provide for a review of drug therapy before each prescription is filled or delivered to an MA recipient. The review shall include screening for potential drug therapy problems due to therapeutic duplication, drug-disease contraindications, drug-drug interactions, including serious interactions with non-prescription or over-the-counter drugs, incorrect drug dosage or duration of drug treatment, drug-allergy interactions and clinical abuse or misuse.
 - (b) The pharmacist shall offer to discuss with each MA recipient, the recipient's legal representative or the recipient's caregiver who presents the prescription, matters which, in the exercise of the pharmacist's professional judgment and consistent with state statutes and rules governing provisions of this information, the pharmacist deems significant, including the following:
 1. The name and description of the medication;
 2. The route, dosage form, dosage, route of administration, and duration of drug therapy;
 3. Specific directions and precautions for preparation, administration and use by the patient;
 4. Common severe side effects or adverse effects or interactions and therapeutic contraindications that may be encountered, including how to avoid them, and the action required if they occur;
 5. Techniques for self-monitoring drug therapy;
 6. Proper storage;
 7. Prescription refill information; and
 8. Action to be taken in the event of a missed dose.
 - (c) The pharmacist shall make a reasonable effort to obtain, record and maintain at least the following information regarding each MA recipient for whom the pharmacist dispenses drugs under the MA program:
 1. The individual's name, address, telephone number, date of

- birth or age and gender;
- 2. The individual's history where significant, including any disease state or states, known allergies and drug reactions, and a comprehensive list of medications and relevant devices; and
- 3. The pharmacist's comments relevant to the individual's drug therapy.
- (d) Nothing in this subsection shall be construed as requiring a pharmacist to provide consultation when an MA recipient, the recipient's legal representative or the recipient's caregiver refuses the consultation.

History: Cr. Register, February, 1986, No. 362, eff. 3-1-86; am. (3) (h), Register, February, 1988, No. 386, eff. 3-1-88; emerg. am. (2) (e) and (f), (4) (k), cr. (2) (g),(3) (j) and (k), (4) (L), eff. 4-27-91; r. and recr. Register, December, 1991, No. 432,eff. 1-1-92, r. and recr. (2) (c), am. (2) (d) and (e), cr. (2) (f) and (g), (3) (L) and (4)(n) to (t), Register, January, 1997, No. 493, eff. 2-1-97.

HFS 107.11 Home health services. (1) DEFINITIONS. In this section:

- (a) "Community-based residential facility" has the meaning prescribed in s. 50.01 (1g), Stats.
- (b) "Home health aide services" means medically oriented tasks, assistance with activities of daily living and incidental household tasks required to facilitate treatment of a recipient's medical condition or to maintain the recipient's health.
- (c) "Home health visit" or "visit" means a period of time of any duration during which home health services are provided through personal contact by agency personnel of less than 8 hours a day in the recipient's place of residence for the purpose of providing a covered home health service. The services are provided by a home health provider employed by a home health agency, by a home health provider under contract to a home health agency according to the requirements of s. HSS 133.19 or by arrangement with a home health agency. A visit begins when the home health provider enters the residence to provide a covered service and ends when the worker leaves the residence.
- (d) "Home health provider" means a person who is an RN, LPN, home health aide, physical or occupational therapist, speech pathologist, certified physical therapy assistant or certified occupational therapy assistant.
- (e) "Initial visit" means the first home health visit of any duration in a calendar day provided by a registered nurse, licensed practical nurse, home health aide, physical or occupational therapist or speech and language pathologist for the purpose of delivering a covered home health service to a recipient.
- (f) "Subsequent visit" means each additional visit of any duration following the initial visit in a calendar day provided by an RN, LPN or home health aide for the purpose of delivering a covered home health service to a recipient.
- (g) "Unlicensed caregiver" means a home health aide or personal care worker.

(2) COVERED SERVICES. Services provided by an agency certified under s. HFS 105.16 which are covered by MA are those reasonable and medically necessary services required in the home to treat the recipient's condition. Covered services are: skilled nursing services, home health aide services and medical supplies, equipment and appliances suitable for use in the recipient's home, and therapy and speech pathology services which the agency is certified to provide. These services are covered only when performed according to the requirements of s. HFS 105.16 and provided in a recipient's place of residence which is other than a hospital or nursing home. Home health skilled nursing and therapy services are covered only when provided to a recipient who, as certified in writing by the recipient's physician, is confined to a place of residence except that intermittent, medically necessary, skilled nursing or therapy services are covered if they are required by a recipient who cannot reasonably obtain these services outside the residence or from a more appropriate provider. Home health aide services may be provided to a recipient who is not confined to the home, but services shall be performed only in the recipient's home. Services are covered only when included in the written plan

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of care with supervision and coordination of all nursing care for the recipient provided by a registered nurse. Home health services include:

(a) Skilled nursing services provided in a recipient's home under a plan of care which requires less than 8 hours of skilled nursing care per calendar day and specifies a level of care which the nurse is qualified to provide. These are:

1. Nursing services performed by a registered nurse, or by a licensed practical nurse under the supervision of a registered nurse, according to the written plan of care and accepted standards of medical and nursing practice, in accordance with ch. N 6;
2. Services which, due to the recipient's medical condition, may be only safely and effectively provided by an RN or LPN;
3. Assessments performed only by a registered nurse; and
4. Teaching and training of the recipient, the recipient's family or other caregivers requiring the skills on an RN or LPN.

Note: For a further description of skilled nursing services, refer to the Wisconsin Medical Assistance Home Health Agency Provider Handbook, Part L, Division II.

(b) Home health aide services are:

1. Medically oriented tasks which cannot be safely delegated by an RN as determined and documented by the RN to a personal care worker who has not received special training in performing tasks for the specific individual, and which may include, but are not limited to, medically oriented activities directly supportive of skilled nursing services provided to the recipient. These may include assistance with and administration of oral, rectal and topical medications ordinarily self-administered and supervised by an RN according to 42 CFR 483.36 (d), ch. HSS 133 and ch. N 6, and assistance with activities directly supportive of current and active skilled therapy and speech pathology services and further described in the Wisconsin medical assistance home health agency provider handbook;

2. Assistance with the recipient's activities of daily living only when provided on conjunction with a medically oriented task that cannot be safely delegated to a personal care worker as determined and documented by the delegating RN. Assistance with the recipient's activities of daily living consists of medically oriented tasks when a reasonable probability exists that the recipient's medical condition will worsen during the period when assistance is provided, as documented by the delegating RN. A recipient whose medical condition has exacerbated during care activities sometime in the past 6 months is considered to have a condition which may worsen when assistance is provided. Activities of daily living include, but are not limited to, bathing, dressing, grooming and personal hygiene activities, skin, foot and ear care, eating, elimination, ambulation, and changing bed positions; and

3. Household tasks incidental to direct care activities described in subds. 1. and 2.

Note: For further description of home health aide services, refer to the Wisconsin Medical Assistance Home Health Agency Provider Handbook, Part L, Division II.

(c) 1. These are services provided in the recipient's home which can only be safely and effectively performed by a skilled therapist or speech pathologist or by a certified therapy assistant who receives supervision by the certified therapist according to 42 CFR 484.32 for a recipient confined to his or her home.

2. Based on the assessment by the recipient's physician of the recipient's rehabilitation potential, services provided are expected to materially improve the recipient's condition within a reasonable, predictable time period, or are necessary to establish a safe and effective maintenance program for the recipient.

3. In conjunction with the written plan of care, a therapy evaluation shall be conducted prior to the provision of these services by the therapist or speech pathologist who will provide the services to the recipient.

4. The therapist or speech pathologist shall provide a summary of activities, including goals and outcomes, to the physician at least every 62 days, and upon conclusion of therapy services.

(3) **PRIOR AUTHORIZATION.** Prior authorization is required to review utilization of services and assess the medical necessity of continuing services for:

- (a) All home health visits when the total of any combination of skilled nursing, home health aide, physical and occupational therapist and speech pathologist visits by all providers exceeds 30 visits in a calendar year, including situations when the recipient's care is shared among several certified providers;
- (b) All home health aide visits when the services are provided in conjunction with private duty nursing under s. HFS 107.12 or the provision of respiratory care services under s. HFS 107.113;
- (c) All medical supplies and equipment for which prior authorization is required under s. HFS 107.24;
- (d) All home health aide visits when 4 or more hours of continuous care is medically necessary; and
- (e) All subsequent skilled nursing visits.

(4) **OTHER LIMITATIONS.** (a) The written plan of care shall be developed and reviewed concurrently with and in support of other health sustaining efforts for the recipient in the home.

(b) All durable medical equipment and disposable medical supplies shall meet the requirements of s. HFS 107.24.

(c) Services provided to a recipient who is a resident of a community-based residential facility shall be rendered according to the requirements of ch. HFS 83 and shall not duplicate services that the facility has agreed to provide.

(d) 1. Except as provided in subd. 2., home health skilled nursing services provided by one or more providers are limited to less than 8 hours per day per recipient as required by the recipient's medical condition.

2. If the recipient's medical condition worsens so that 8 or more hours of direct, skilled nursing services are required in a calendar day, a maximum of 30 calendar days of skilled nursing care may continue to be reimbursed as home health services, beginning on the day 8 hours or more of skilled nursing services became necessary. To continue medically necessary services after 30 days, prior authorization for private duty nursing is required under s. HFS 107.12 (2).

(e) An intake evaluation is a covered home health skilled nursing service only if, during the course of the initial visit to the recipient, the recipient is admitted into the agency's care and covered skilled nursing services are performed according to the written physician's orders during the visit.

(f) A skilled nursing ongoing assessment for a recipient is a covered service:

1. When the recipient's medical condition is stable, the recipient has not received a covered skilled nursing service, covered personal care service, or covered home visit by a physician service within the past 62 days, and a skilled assessment is required to re-evaluate the continuing appropriateness of the plan of care. In this paragraph, "medically stable" means the recipient's physical condition is non-acute, without substantial change or fluctuation at the current time.

2. When the recipient's medical condition requires skilled nursing personnel to identify and evaluate the need for possible modification of treatment;

3. When the recipient's medical condition requires skilled nursing personnel to initiate additional medical procedures until the recipient's treatment regimen stabilizes, but is not part of a longstanding pattern of care; or

4. If there is a likelihood of complications or an acute episode.

(g) Teaching and training activities are covered services only when provided to the recipient, recipient's family or other caregiver in conjunction with other covered skilled nursing care provided to the recipient.

(h) A licensed nurse shall administer medications to a minor child or to an adult who is not self-directing, as determined by the

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physician, to direct or administer his or her own medications, when a responsible adult is not present to direct the recipient's medication program.

(i) Services provided by an LPN which are not delegated by an RN under s. N 6.03 are not covered services.

(j) Skilled physical and occupational therapy and speech pathology services are not to include activities provided for the general welfare of the recipient or activities to provide diversion for the recipient or to motivate the recipient.

(k) Skilled nursing services may be provided for a recipient by one or more home health agencies or by an agency contracting with a nurse or nurses only if the agencies meet the requirements of ch. HSS 133 and are approved by the department.

(L) RN supervision and administrative costs associated with the provision of services under this section are not separately reimbursable MA services.

(m) Home health aide service limitations are the following:

1. A home health aide may provide assistance with a recipient's medications only if the written plan of care documents the name of the delegating registered nurse and the recipient is aged 18 or more;

2. Home health aide services are primarily medically oriented tasks, as determined by the delegating RN, when the instability of the recipient's condition as documented in the medical record is such that the recipient's care cannot be safely delegated to a personal care worker under s. HFS 107.112;

3. A home health aide visit which is a covered service shall include at least one medically oriented task performed during a visit which cannot, in the judgment of the delegating RN, be safely delegated to a personal care worker; and

4. A home health aide, rather than a personal care worker, shall always provide medically oriented services for recipients who are under age 18.

(5) NON-COVERED SERVICES. The following services are not covered home health services:

(a) Services that are not medically necessary;

(b) Skilled nursing services provided for 8 or more hours per recipient per day;

(c) More than one initial visit per day by a home health skilled nurse, home health aide, physical or occupational therapist or speech and language pathologist;

(d) Private duty nursing services under s. HFS 107.12, unless the requirements of sub. (4) (d) 2. apply;

(e) Services requiring prior authorization that are provided without prior authorization;

(f) Supervision of the recipient when supervision is the only service provided at the time;

(g) Hospice care provided under s. HFS 107.31;

(h) Mental health and alcohol or other drug abuse services provided under s. HFS 107.13 (2), (3), (3m), (4) and (6);

(i) Medications administration by a personal care worker or administration by a home health aide which has not been delegated by an RN according to the relevant provisions of ch. HSS 133.

(j) Skilled nursing services contracted for by a home health agency unless the requirements of s. HSS 133.19 are met and approved by the department;

(k) Occupational therapy, physical therapy or speech pathology services requiring only the use of equipment without the skills of the therapist or speech pathologist;

(L) Skilled nursing visits:

1. Solely for the purpose of ensuring that a recipient who has a demonstrated history of noncompliance over 30 days complies with the medications program;

2. To administer or assist with medication administration of

an adult recipient who is capable of safely self-administering a medication as determined and documented by the RN;

3. To inject a recipient who is capable of safely self-injecting a medication, as described and documented by the RN;

4. To prefill syringes for self-injection when, as determined and documented by the RN, the recipient is capable of prefilling or a pharmacy is available to prefill; and

5. To set up medication for self-administration when, as determined and documented by the RN, the recipient is capable or a pharmacy is available to assist the recipient;

(m) Home health services to a recipient who is eligible for covered services under the medicare program or any other insurance held by the recipient;

(n) Services that are not medically appropriate. In this paragraph, "medically appropriate" means a service that is proven and effective treatment for the condition for which it is intended or used;

(o) Parenting;

(p) Services to other members of the recipient's household;

(q) A visit made by a skilled nurse, physical or occupational therapist or speech pathologist solely to train other home health workers;

(r) Any home health service included in the daily rate of the community-based residential facility where the recipient is residing;

(s) Services when provided to a recipient by the recipient's spouse or parent if the recipient is under age 18;

(t) Skilled nursing and therapy services provided to a recipient who is not confined to a place of residence when services are reasonably available outside the residence;

(u) Any service which is performed in a place other than the recipient's residence; and

(v) Independent nursing services under sub. (6).

(6) UNAVAILABILITY OF A HOME HEALTH AGENCY. (a) *Definition.* In this subsection, "part-time, intermittent care" means skilled nursing services provided in a recipient's home under a plan of care which requires less than 8 hours of skilled care in a calendar day.

(b) *Covered services.* 1. Part-time, intermittent nursing care may be provided by an independent nurse certified under s. HFS 105.19 when an existing home health agency cannot provide the services as appropriately documented by the nurse, and the physician's prescription specifies that the recipient requires less than 8 hours of skilled nursing care per calendar day and calls for a level of care which the nurse is licensed to provide as documented to the department.

2. Services provided by an MA-certified registered nurse are those services prescribed by a physician which comprise the practice of professional nursing as described under s. 441.11 (3), Stats., and s. N 6.03. Services provided by an MA-certified licensed practical nurse are those services which comprise the practice of practical nursing under s. 441.11 (4), Stats., and s. N 6.04. An LPN may provide nursing services delegated by an RN as delegated nursing acts under the requirements of ss. N 6.03 and 6.04 and guidelines established by the state board of nursing.

3. A written plan of care shall be established for every recipient admitted for care and shall be signed by the physician and incorporated into the recipient's medical record. A written plan of care shall be developed by the registered nurse or therapist within 72 hours after acceptance. The written plan of care shall be developed by the registered nurse or therapist in consultation with the recipient and the recipient's physician and shall be signed by the physician within 20 working days following the recipient's admission for care. The written plan of care shall include, in addition to the medication and treatment orders:

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- a. Measurable time-specific goals;
- b. Methods for delivering needed care, and an indication of which, if any, professional disciplines are responsible for delivering the care;
- c. Provision for care coordination by an RN when more than one nurse is necessary to staff the recipient's case;
- d. Identification of all other parties providing care to the recipient and the responsibilities of each party for that care; and
- e. A description of functional capabilities, mental status, dietary needs and allergies.

4. The written plan of care shall be reviewed, signed and dated by the recipient's physician as often as required by the recipient's condition but at least every 62 days. The RN shall promptly notify the physician of any change in the recipient's condition that suggests a need to modify the plan of care.

5. Drugs and treatment shall be administered by the RN or LPN only as ordered by the recipient's physician or his or her designee. The nurse shall immediately record and sign oral orders and shall obtain the physician's countersignature within 10 working days.

6. Supervision of an LPN by an RN or physician shall be performed according to the requirements under ss. N 6.03 and 6.04 and the results of supervisory activities shall be documented and communicated to the LPN.

(c) *Prior authorization.* 1. Prior authorization requirements under sub. (3) apply to services provided by an independent nurse.

2. A request for prior authorization of part-time, intermittent care performed by an LPN shall include the name and license number of the registered nurse supervising the LPN.

(d) *Other limitations.* 1. Each independent RN or LPN shall document the care and services provided. Documentation required under par. (b) of the unavailability of a home health agency shall include names of agencies contacted, dates of contact and any other pertinent information.

2. Discharge of a recipient from nursing care under this sub-section shall be made in accordance with s. HFS 105.19 (9).

3. The limitations under sub. (4) apply.

4. Registered nurse supervision of an LPN is not separately reimbursable.

(e) *Non-covered services.* The following services are not covered services under this subsection:

1. Services listed in sub. (5);
2. Private duty nursing services under s. HFS 107.12; and
3. Any service that fails to meet the recipient's medical needs or places the recipient at risk for a negative treatment outcome.

History: Cr. Register, February, 1986, No. 362, eff. 3-1-86; r. and recr. Register, April, 1988, No. 388, eff. 7-1-88; am. (3) (d) and (e), cr. (3) (f), Register, December, 1988, No. 396, eff. 1-1-89; emerg. r. and recr. eff. 7-1-92; r. and recr. Register, February, 1993, No. 446, eff. 3-1-93; emerg. cr. (3) (ag), eff. 1-1-94; **correction in (6)(b) 1. made under s. 13.93 (2m) (b) 7., Stats., Register, April, 1999, No. 520.**

HFS 107.112 Personal care services. (1) COVERED SERVICES. (a) Personal care services are medically oriented activities related to assisting a recipient with activities of daily living necessary to maintain the recipient in his or her place of residence in the community. These services shall be provided upon written orders of a physician by a provider certified under s. HFS 105.17 and by a personal care worker employed by the provider or under contract to the provider who is supervised by a registered nurse according to a written plan of care. The personal care worker shall be assigned by the supervising registered nurse to specific recipients to do specific tasks for those recipients for which the personal care worker has been trained. The personal care worker's training for these specific tasks shall be assured by the supervising registered nurse. The personal care worker is limited to performing only those tasks and services as assigned for each recipient and for which he or she has been specifically trained.

(b) Covered personal care services are:

1. Assistance with bathing;
2. Assistance with getting in and out of bed;
3. Teeth, mouth, denture and hair care;
4. Assistance with mobility and ambulation including use of walker, cane or crutches;
5. Changing the recipient's bed and laundering the bed linens and the recipient's personal clothing;
6. Skin care excluding wound care;
7. Care of eyeglasses and hearing aids;
8. Assistance with dressing and undressing;
9. Toileting, including use and care of bedpan, urinal, commode or toilet;
10. Light cleaning in essential areas of the home used during personal care service activities;
11. Meal preparation, food purchasing and meal serving;
12. Simple transfers including bed to chair or wheelchair and reverse; and
13. Accompanying the recipient to obtain medical diagnosis and treatment.

(2) **SERVICES REQUIRING PRIOR AUTHORIZATION.** (a) Prior authorization is required for personal care services in excess of 250 hours per calendar year.

(b) Prior authorization is required under par. (a) for specific services listed in s. HFS 107.11 (2). Services listed in s. HFS 107.11 (2) (b) are covered personal care services, regardless of the recipient's age, only when:

1. Safely delegated to a personal care worker by a registered nurse;
2. The personal care worker is trained and supervised by the provider to provide the tasks; and
3. The recipient, parent or responsible person is permitted to participate in the training and supervision of the personal care worker.

(3) **OTHER LIMITATIONS.** (a) Personal care services shall be performed under the supervision of a registered nurse by a personal care worker who meets the requirements of s. HFS 105.17 (3) and who is employed by or is under contract to a provider certified under s. HFS 105.17.

(b) Services shall be performed according to a written plan of care for the recipient developed by a registered nurse for purposes of providing necessary and appropriate services, allowing appropriate assignment of a personal care worker and setting standards for personal care activities, giving full consideration to the recipient's preferences for service arrangements and choice of personal care workers. The plan shall be based on the registered nurse's visit to the recipient's home and shall include:

1. Review and interpretation of the physician's orders;
2. Frequency and anticipated duration of service;
3. Evaluation of the recipient's needs and preferences; and
4. Assessment of the recipient's social and physical environment, including family involvement, living conditions, the recipient's level of functioning and any pertinent cultural factors such as language.

(c) Review of the plan of care, evaluation of the recipient's condition and supervisory review of the personal care worker shall be made by a registered nurse at least every 60 days. The review shall include a visit to the recipient's home, review of the personal care worker's daily written record and discussion with the physician of any necessary changes in the plan of care.

(d) Reimbursement for registered nurse supervisory visits is limited to one visit per month.

(e) No more than one-third of the time spent by a personal care worker may be in performing housekeeping activities.

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(4) **NON-COVERED SERVICES.** The following services are not covered services:

- (a) Personal care services provided in a hospital or a nursing home or in a community-based residential facility, as defined in s. 50.01 (1), Stats., with more than 20 beds;
- (b) Homemaking services and cleaning of areas not used during personal care service activities, unless directly related to the care of the person and essential to the recipient's health;
- (c) Personal care services not documented in the plan of care;
- (d) Personal care services provided by a responsible relative under s. 49.90, Stats.;
- (e) Personal care services provided in excess of 250 hours per calendar year without prior authorization;
- (f) Services other than those listed in subs. (1) (b) and (2) (b);
- (g) Skilled nursing services, including:
 - 1. Insertion and sterile irrigation of catheters;
 - 2. Giving of injections;
 - 3. Application of dressings involving prescription medication and use of aseptic techniques; and
 - 4. Administration of medicine that is not usually self-administered; and
- (h) Therapy services.

History: Cr. Register, April, 1988, No. 388, eff. 7-1-88; renum. (2) to be (2) (a), cr. (2) (b), am. (3) (e), Register, December, 1988, No. 396, eff. 1-1-89; r. and recr. (2) (b), r. (3) (f), am. (4) (f), Register, February, 1993, No. 446, eff. 3-1-93; emerg. am. (2) (a), (4) (e), eff. 1-1-94.

HFS 107.113 Respiratory care for ventilator-assisted recipients. (1) COVERED SERVICES. Services, medical supplies and equipment necessary to provide life support for a recipient who has been hospitalized for at least 30 consecutive days for his or her respiratory condition and who is dependent on a ventilator for at least 6 hours per day shall be covered services when these services are provided to the recipient in the recipient's home.

A recipient receiving these services is one who, if the services were not available in the home, would require them as an inpatient in a hospital or a skilled nursing facility, has adequate social support to be treated at home and desires to be cared for at home, and is one for whom respiratory care can safely be provided in the home. Respiratory care shall be provided as required under ss. HFS 105.16 and 105.19 and according to a written plan of care undersub. (2) signed by the recipient's physician for a recipient who lives in a residence that is not a hospital or a skilled nursing facility. Respiratory care includes:

- (a) Airway management, consisting of:
 - 1. Tracheostomy care: all available types of tracheostomy tubes, stoma care, changing a tracheostomy tube, and emergency procedures for tracheostomy care including accidental extubation;
 - 2. Tracheal suctioning technique; and
 - 3. Airway humidification;
- (b) Oxygen therapy: operation of oxygen systems and auxiliary oxygen delivery devices;
- (c) Respiratory assessment, including but not limited to monitoring of breath sounds, patient color, chest excursion, secretions and vital signs;
- (d) Ventilator management, as follows:
 - 1. Operation of positive pressure ventilator by means of tracheostomy to include, but not limited to, different modes of ventilation, types of alarms and responding to alarms, troubleshooting ventilator dysfunction, operation and assembly of ventilator circuit, that is, the delivery system, and proper cleaning and disinfection of equipment;
 - 2. Operation of a manual resuscitator; and
 - 3. Emergency assessment and management including cardiopulmonary resuscitation (CPR);
- (e) The following modes of ventilatory support:
 - 1. Positive pressure ventilation by means of a nasal mask or mouthpiece;
 - 2. Continuous positive airway pressure (CPAP) by means of

- a tracheostomy tube or mask;
- 3. Negative pressure ventilation — iron lung, chest shell or pulmowrap;
- 4. Rocking beds;
- 5. Pneumobelts; and
- 6. Diaphragm pacing;
- (f) Operation and interpretation of monitoring devices:
 - 1. Cardio-respiratory monitoring;
 - 2. Pulse oximetry; and
 - 3. Capnography;
- (g) Knowledge of and skills in weaning from the ventilator;
- (h) Adjunctive techniques:
 - 1. Chest physiotherapy; and
 - 2. Aerosolized medications; and
- (i) Case coordination activities performed by the registered nurse designated in the plan of care as case coordinator. These activities include coordination of health care services provided to the recipient at home and coordination of these services with any other health or social service providers serving the recipient.
- (2) **PLAN OF CARE.** A recipient's written plan of care shall be based on the orders of a physician, a visit to the recipient's home by the registered nurse and consultation with the family and other household members. The plan of care established by a home health agency or independent provider for a recipient to be discharged from a hospital shall consider the hospital's discharge plan for the recipient. The written plan of care shall be reviewed, signed and dated by the recipient's physician and renewed at least every 62 days and whenever the recipient's condition changes. Telephone orders shall be documented in writing and signed by the physician within 10 working days. The written physician's plan of care shall include:
 - (a) Physician orders for treatments provided by the necessary disciplines specifying the amount and frequency of treatment;
 - (b) Medications, including route, dose and frequency;
 - (c) Principal diagnosis, surgical procedures and other pertinent diagnosis;
 - (d) Nutritional requirements;
 - (e) Necessary durable medical equipment and disposable medical supplies;
 - (f) Ventilator settings and parameters;
 - (g) Procedures to follow in the event of accidental extubation;
 - (h) Identification of back-ups in the event scheduled personnel are unable to attend the case;
 - (i) The name of the registered nurse designated as the recipient's case coordinator;
 - (j) A plan for medical emergency, to include:
 - 1. Description of back-up personnel needed;
 - 2. Provision for reliable, 24-hour a day, 7 days a week emergency service for repair and delivery of equipment; and
 - 3. Specification of an emergency power source; and
 - (k) A plan to move the recipient to safety in the event of fire, flood, tornado warning or other severe weather, or any other condition which threatens the recipient's immediate environment.
- (3) **PRIOR AUTHORIZATION.** (a) All services covered under sub. (1) and all home health services under s. HFS 107.11 provided to a recipient receiving respiratory care shall be authorized prior to the time the services are rendered. Prior authorization shall be renewed every 12 calendar months if the respiratory care under this section is still needed. The prior authorization request shall include the name of the registered nurse who is responsible for coordination of all care provided under the MA program for the recipient in his or her home. Independent MA-certified respiratory

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therapists or nurses in private practice who are not employees of or contracted to a home health agency but are certified under s. HFS 105.19 (1) (b) to provide respiratory care shall include in the prior authorization request the name and license number of a registered nurse who will participate, on 24-hour call, in emergency assessment and management and who will be available to the respiratory therapist for consultation and assistance.

(4) OTHER LIMITATIONS. (a) Services under this section shall not be reimbursed if the recipient is receiving respiratory care from an RN, licensed practical nurse or respiratory therapist who is providing these services as part of the rental agreement for a ventilator or other respiratory equipment.

(b) Respiratory care provided to a recipient residing in a community-based residential facility (CBRF) as defined in s. 50.01(1g), Stats., shall be in accordance with the requirements of ch. HFS 83.

(c) Durable medical equipment and disposable medical supplies shall be provided in accordance with conditions set out in s. HFS 107.24.

(d) Respiratory care services provided by a licensed practical nurse shall be provided under the supervision of a registered nurse and in accordance with standards of practice set out in s. N 6.04.

(e) Case coordination services provided by the designated case coordinator shall be documented in the clinical record, including the extent and scope of specific care coordination provided.

(f) In the event that a recipient receiving services at home who is discharged from the care of one respiratory care provider and admitted to the care of another respiratory care provider continues to receive services at home under this section, the admitting provider shall coordinate services with the discharging provider to ensure continuity of care. The admitting provider shall establish the recipient's plan of care as provided under sub. (2) and request prior authorization under sub. (3).

(g) Travel, recordkeeping and RN supervision of a licensed practical nurse are not separately reimbursable services.

(5) NON-COVERED SERVICES. The following services are not covered services:

(a) Parenting;

(b) Supervision of the recipient when supervision is the only service provided;

(c) Services provided without prior authorization;

(d) Services provided by one individual in excess of 12 continuous hours per day or 60 hours per week;

(e) Services provided in a setting other than the recipient's place of residence; and

(f) Services that are not medically appropriate.

History: Cr. Register, February, 1993, No. 446, eff. 3-1-93;

correction in (4) (c) made under s. 13.93 (2m) (b) 7., Stats.,

Register, April, 1999, No. 520.

HFS 107.12 Private duty nursing services. (1) COVERED SERVICES. (a) Private duty nursing is skilled nursing care available for recipients with medical conditions requiring more continuous skilled care than can be provided on a part-time, intermittent basis. Only a recipient who requires 8 or more hours of skilled nursing care and is authorized to receive these services in the home setting may make use of the approved hours outside of that setting during those hours when normal life activities take him or her outside of that setting. Private duty nursing may be provided according to the requirements under ss. HFS 105.16 and 105.19 when the written plan of care specifies the medical necessity for this type of service.

(b) Private duty nursing services provided by a certified registered nurse in independent practice are those services prescribed by a physician which comprise the practice of professional nursing as described under s. 441.11 (3), Stats., and s. N 6.03. Private duty nursing services provided by a certified licensed practical nurse are those services which comprise the practice of practical nursing under s. 441.11 (4), Stats., and s. N 6.04. An LPN may pro-

vide private duty nursing services delegated by a registered nurse as delegated nursing acts under the requirements of ch. N 6 and guidelines established by the state board of nursing.

(c) Services may be provided only when prescribed by a physician and the prescription calls for a level of care which the nurse is licensed and competent to provide.

(d) 1. A written plan of care, including a functional assessment, dedication and treatment orders, shall be established for every recipient admitted for care and shall be incorporated in the recipient's medical record within 72 hours after acceptance in consultation with the recipient and the recipient's physician and shall be signed by the physician within 20 working days following the recipient's admission for care. The physician's plan of care shall include, in addition to the medication and treatment orders:

a. Measurable time-specific goals;

b. Methods for delivering needed care, and an indication of which other professional disciplines, if any, are responsible for delivering the care;

c. Provision for care coordination by an RN when more than one nurse is necessary to staff the recipient's case; and

d. A description of functional capability, mental status, dietary needs and allergies.

2. The written plan of care shall be reviewed and signed by the recipient's physician as often as required by the recipient's condition, but not less often than every 62 days. The RN shall promptly notify the physician of any change in the recipient's condition that suggests a need to modify the plan of care.

(e) Drugs and treatment shall be administered by the RN or LPN only as ordered by the recipient's physician or his or her designee. The nurse shall immediately record and sign oral orders and shall obtain the physician's countersignature within 10 working days.

(f) Medically necessary actual time spent in direct care that requires the skills of a licensed nurse is a covered service.

(2) PRIOR AUTHORIZATION. (a) Prior authorization is required for all private duty nursing services.

(b) Private duty nursing for which prior authorization is requested is limited to 12 continuous hours in each 24 hour period and no more than 60 hours in a calendar week for the number of weeks care continues to be medically necessary, when provided by a single provider for all recipients combined who are receiving services from the provider. A prior authorization request for 2 consecutive 12-hour periods shall not be approved.

(c) A request for prior authorization of private duty nursing services performed by an LPN shall include the name and license number of the registered nurse or physician supervising the LPN.

(d) A request for prior authorization for care for a recipient who requires more than one private duty nurse to provide medically necessary care shall include the name and license number of the RN performing care coordination responsibilities.

(3) OTHER LIMITATIONS. (a) Discharge of a recipient from private duty nursing care shall be made in accordance with s. HFS 105.19 (9).

(b) An RN supervising an LPN performing services under this section shall supervise the LPN as often as necessary under the requirements of s. N 6.03 during the period the LPN is providing services, and shall communicate the results of supervisory activities to the LPN. These activities shall be documented by the RN.

(c) Each private duty nurse shall document the nature and scope of the care and services provided to the recipient in the recipient's medical record.

(d) Services performed in two consecutive 12-hour periods under sub. (2) (b) are not reimbursable.

(e) Travel time, recordkeeping and RN supervision of an LPN are not separately reimbursable services.

(4) NON-COVERED SERVICES. The following services are not covered services:

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- (a) Any services not included in the physician's plan of care;
- (b) Any services under s. HFS 107.11;
- (c) Skilled nursing services performed by a recipient's spouse or parent if the recipient is under age 21;
- (d) Services that were provided but not documented; and
- (e) Any service that fails to meet the recipient's medical needs or places the recipient at risk for a negative treatment outcome.

History: Cr. Register, February, 1986, No. 362, eff. 3-1-86; emerg. r. and recr. eff. 7-1-90; r. and recr. Register, January, 1991, No. 421, eff. 2-1-91; emerg. r. and recr. eff. 7-1-92; r. and recr. Register, February, 1993, No. 446, eff. 3-1-93.

HFS 107.121 Nurse-midwife services. (1) COVERED

SERVICES. Covered services provided by a certified nurse-midwife may include the care of mothers and their babies throughout the maternity cycle, including pregnancy, labor, normal childbirth and the immediate postpartum period, provided that the nurse-midwife services are provided within the limitations established in s. 441.15 (2), Stats., and ch. N 4.

(2) LIMITATION. Coverage for nurse-midwife services for management and care of the mother and newborn child shall end after the sixth week of postpartum care.

History: Cr. Register, January, 1991, No. 421, eff. 2-1-91.

HFS 107.122 Independent nurse practitioner services.

(1) COVERED SERVICES. Services provided by a nurse practitioner, including a clinical nurse specialist, which are covered by the MA program are those medical services delegated by a licensed physician by a written protocol developed with the nurse practitioner pursuant to the requirements set forth in s. N

6.03 (2) and guidelines set forth by the medical examining board and the board of nursing. General nursing procedures are covered services when performed by a certified nurse practitioner or clinical nurse specialist in accordance with the requirements of s. N 6.03 (1). These services may include those medically necessary diagnostic, preventive, therapeutic, rehabilitative or palliative services provided in a medical setting, the recipient's home or elsewhere. Specific reimbursable delegated medical acts and nursing services are the following:

- (a) Under assessment and nursing diagnosis:
 1. Obtaining a recipient's complete health history and recording the findings in a systematic, organized manner;
 2. Evaluating and analyzing a health history critically;
 3. Performing a complete physical assessment using techniques of observation, inspection, auscultation, palpation and percussion, ordering appropriate laboratory and diagnostic tests and recording findings in a systematic manner;
 4. Performing and recording a developmental or functional status evaluation and mental status examination using standardized procedures; and
 5. Identifying and describing behavior associated with developmental processes, aging, life style and family relationships;
- (b) Under analysis and decision-making:
 1. Discriminating between normal and abnormal findings associated with growth and development, aging and pathological processes;
 2. Discriminating between normal and abnormal patterns of behavior associated with developmental processes, aging, life style, and family relationships as influenced by illness;
 3. Exercising clinical judgment in differentiating between situations which the nurse practitioner can manage and those which require consultations or referral; and
 4. Interpreting screening and selected diagnostic tests;
- (c) Under management, planning, implementation and treatment:
 1. Providing preventive health care and health promotion for

- adults and children;
- 2. Managing common self-limiting or episodic health problems in recipients according to protocol and other guidelines;
- 3. Managing stabilized illness problems in coloration with physicians and other health care providers according to protocol;
- 4. Prescribing, regulating and adjusting medications as defined by protocol;
- 5. Recommending symptomatic treatments and non-prescription medicines;
- 6. Counseling recipients and their families about the process of growth and development, aging, life crises, common illnesses, risk factors and accidents;
- 7. Helping recipients and their families assume greater responsibility for their own health maintenance and illness care by providing instruction, counseling and guidance;
- 8. Arranging referrals for recipients with health problems who need further evaluation or additional services; and
- 9. Modifying the therapeutic regimen so that it is appropriate to the developmental and functional statuses of the recipient and the recipient's family;
- (d) Under evaluation:
 1. Predicting expected outcomes of therapeutic regimens;
 2. Collecting systematic data for evaluating the response of a recipient and the recipient's family to a therapeutic regimen;
 3. Modifying the plan of care according to the response of the recipient;
 4. Collecting systematic data for self-evaluation and peer review; and
 5. Utilizing an epidemiological approach in examining the health care needs of recipients in the nurse practitioner's caseload;
- (e) Physician services described under s. HFS 107.06 that are under protocol;
- (f) Services under s. HFS 107.08 performed for an inpatient in a hospital;
- (g) Outpatient hospital services, as described in s. HFS 107.08 (1) (b);
- (h) Family planning services, as described in s. HFS 107.21;
- (i) Early and periodic screening, diagnosis and treatment (EPSDT) services, as described in s. HFS 107.22;
- (j) Prescriptions for drugs and recipient transportation; and
- (k) Disposable medical supplies, as described in s. HFS 107.24.
- (2) PRIOR AUTHORIZATION.** (a) Services under sub. (1) (e) to (k) are subject to applicable prior authorization requirements for those services.
 - (b) Requests for prior authorization shall be accompanied by the written protocol.
- (3) OTHER LIMITATIONS.** (a) No services under this section may be reimbursed without a written protocol developed and signed by the nurse practitioner and the delegating physician, except for general nursing procedures described under s. N 6.03 (1). The physician shall review a protocol according to the requirements of s. 448.03 (2) (e), Stats., and guidelines established by the medical examining board and the board of nursing, but no less than once each calendar year. A written protocol shall be organized as follows:
 1. Subjective data;
 2. Objective data;
 3. Assessment;
 4. Plan of care; and
 5. Evaluation.
 - (b) Prescriptions for drugs are limited to those drugs allowed under protocol for prescription by a nurse practitioner, except that controlled substances may not be prescribed by a nurse practitioner.
- (4) NON-COVERED SERVICES.** Non-covered services are:

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- (a) Mental health and alcohol and other drug abuse services;
- (b) Services provided to nursing home residents or hospital in-patients which are included in the daily rates for a nursing home or hospital;
- (c) Rural health clinic services;
- (d) Dispensing durable medical equipment; and
- (e) Medical acts for which the nurse practitioner or clinical nurse specialist does not have written protocols as specified in this section. In this paragraph, "medical acts" means acts reserved by professional training and licensure to physicians, dentists and podiatrists.

History: Emerg. cr. eff. 7-1-90; cr. Register, January, 1991, No. 421, eff. 2-1-91; correction in (1) (e) made under s. 13.93 (2m) (b) 7., Stats., Register, April, 1999, No. 520.

HFS 107.13 Mental health services. (1) INPATIENT

CARE IN A HOSPITAL IMD. (a) *Covered services.* Inpatient hospital mental health and AODA care shall be covered when prescribed by a physician and when provided within a hospital institution for mental disease (IMD) which is certified under ss. HFS 105.07 and 105.21, except as provided in par. (b).

(b) *Conditions for coverage of recipients under 21 years of age.* 1. Definition. In this paragraph, "individual plan of care" or "plan of care" means a written plan developed for each recipient under 21 years of age who receives inpatient hospital mental health or AODA care in a hospital IMD for the purpose of improving the recipient's condition to the extent that inpatient care is no longer necessary.

2. General conditions. Inpatient hospital mental health and AODA services provided in a hospital IMD for recipients under age 21 shall be provided under the direction of a physician and, if the recipient was receiving the services immediately before reaching age 21, coverage shall extend to the earlier of the following:

- a. The date the recipient no longer requires the services; or
- b. The date the recipient reaches age 22.

3. Certification of need for services. a. For recipients under age 21 receiving services in a hospital IMD, a team specified in subd. 3. b. shall certify that ambulatory care resources do not meet the treatment needs of the recipient, proper treatment of the recipient's psychiatric condition requires services on an inpatient basis under the direction of a physician, and the services can reasonably be expected to improve the recipient's condition or prevent further regression so that the services will be needed in reduced amount or intensity or no longer be needed. The certification specified in this subdivision satisfies the requirement for physician certification in subd. 7. In this subparagraph, "ambulatory care resources" means any covered service except hospital inpatient care or care of a resident in a nursing home.

b. Certification under subd. 3. a. shall be made for a recipient when the person is admitted to a facility or program by an independent team that includes a physician. The team shall have competence in diagnosis and treatment of mental illness, preferably in child psychology, and have knowledge of the recipient's situation.

c. For a recipient who applies for MA eligibility while in a facility or program, the certification shall be made by the team described in subd.

5. b. and shall cover any period before application for which claims are made.

d. For emergency admissions, the certification shall be made by the team specified in subd. 5. b. within 14 days after admission.

4. Active treatment. Inpatient psychiatric services shall involve active treatment. An individual plan of care described in subd. 5. shall be developed and implemented no later than 14 days after admission and shall be designed to achieve the recipient's discharge from inpatient status at the earliest possible time.

5. Individual plan of care. a. The individual plan of care shall be based on a diagnostic evaluation that includes examination of the medical, psychological, social, behavioral and developmental aspects of the recipient's situation and reflects the need for inpatient psychiatric care; be developed by a team of professionals

specified under subd. 5. b. in consultation with the recipient and parents, legal guardians or others into whose care the recipient will be released after discharge; specify treatment objectives; pre-scribe an integrated program of therapies, activities, and experiences designed to meet the objectives; and include, at an appropriate time, post-discharge plans and coordination of inpatient services with partial discharge plans and related community services to ensure continuity of care with the recipient's family, school and community upon discharge.

b. The individual plan of care shall be developed by an inter-disciplinary team that includes a board-eligible or board-certified psychiatrist; a clinical psychologist who has a doctorate and a physician licensed to practice medicine or osteopathy; or a physician licensed to practice medicine or osteopathy who has specialized training and experience in the diagnosis and treatment of mental diseases, and a psychologist who has a master's degree in clinical psychology or who is certified by the state. The team shall also include a psychiatric social worker, a registered nurse with specialized training or one year's experience in treating mentally ill individuals, an occupational therapist who is certified by the American occupation therapy association and who has specialized training or one year of experience in treating mentally ill individuals, or a psychologist who has a master's degree in clinical psychology or who has been certified by the state. Based on education and experience, preferably including competence in child psychiatry, the team shall be capable of assessing the recipient's immediate and long-range therapeutic needs, developmental priorities, and personal strengths and liabilities; assessing the potential resources of the recipient's family; setting treatment objectives; and prescribing therapeutic modalities to achieve the plan's objectives.

c. The plan shall be reviewed every 30 days by the team specified in subd. 5. b. to determine that services being provided are or were required on an inpatient basis, and to recommend changes in the plan as indicated by the recipient's overall adjustment as an inpatient.

d. The development and review of the plan of care under this subdivision shall satisfy the utilization control requirements for physician certification and establishment and periodic review of the plan of care.

6. Evaluation. a. Before a recipient is admitted to a psychiatric hospital or before payment is authorized for a patient who applies for MA, the attending physician or staff physician shall make a medical evaluation of each applicant's or recipient's need for care in the hospital, and appropriate professional personnel shall make a psychiatric and social evaluation of the applicant's or recipient's need for care.

b. Each medical evaluation shall include a diagnosis, a summary of present medical findings, medical history, the mental and physical status and functional capacity, a prognosis, and a recommendation by a physician concerning admission to the psychiatric hospital or concerning continued care in the psychiatric hospital for an individual who applies for MA while in the hospital.

7. Physician certification. a. A physician shall certify and re-certify for each applicant or recipient that inpatient services in a psychiatric hospital are or were needed.

b. The certification shall be made at the time of admission or, if an individual applies for assistance while in a psychiatric hospital, before the agency authorizes payment.

c. Recertification shall be made at least every 60 days after certification.

8. Physician's plan of care. a. Before a recipient is admitted to a psychiatric hospital or before payment is authorized, the attending physician or staff physician shall document and sign a written plan of care for the recipient or applicant. The physician's plan of care shall include diagnosis, symptoms, complaints and

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