

1997-98 SESSION
COMMITTEE HEARING
RECORDS

Committee Name:

Joint Committee for
Review of
Administrative Rules
(JCR-AR)

Sample:

- Record of Comm. Proceedings
- 97hrAC-EdR_RCP_pt01a
- 97hrAC-EdR_RCP_pt01b
- 97hrAC-EdR_RCP_pt02

➤ Appointments ... Appt

➤

➤ Clearinghouse Rules ... CRule

➤

➤ Committee Hearings ... CH

➤

➤ Committee Reports ... CR

➤

➤ Executive Sessions ... ES

➤

➤ Hearing Records ... HR

➤

➤ Miscellaneous ... Misc

➤ 97hr_JCR-AR_Misc_pt31a_Corr

➤ Record of Comm. Proceedings ... RCP

➤

MHO HOME HEALTH CARE

Memorial Hospital at Oconomowoc

March 17, 1995

Dear Personal Care Client,

We are writing to inform you that the State Budget Bill submitted by Governor Thompson on February 14, 1995, eliminated all funding for Medical Assistance Personal Care Services. This funding is what pays for your personal care providers. Unless these funds are reinstated, your personal care services will end beginning the first of next year. A determination will be made by July 1, 1995, regarding continuation of the Personal Care Program. At this point, it is up to the State Legislature.

It is very important for you and your families to contact your State Senators and Representatives, and the Governor to let them know how your life would be affected if you no longer would have personal care visits to your home. Tell them "Please don't take away personal care reimbursement." Only with your help can this provision be removed from the state budget and MA reimbursement preserved.

Better than anyone else in Wisconsin, you know the value of home health care and personal care visits. Better than anyone else, you can explain the impact this proposal will have on you and your family. Better than anyone else, you can communicate these facts to the State leadership. **Your own story is very, very important.**

We have enclosed a form letter for you use if you have difficulty writing. You need only to fill in your story and how the discontinuation of these services will affect you. Please feel free to write your own letters if you are able.

We will attempt to work with you in every way we can to win this battle. Please do not hesitate to contact us if you have any questions or concerns. Thank you.

Sincerely,



MHO Home Health Care

JOHN R. WILLIAMS

611 Mt. Snowdon, P.O. Box 100

Wales, WI 53183

(414) 968-4967

December 28, 1995

COPY

Oconomowoc Home Health
Ms. Sue Prime
125 Fowler Street
Oconomowoc, WI 53066

Dear Ms. Prime:

I am writing to seek your assistance in resolving a difficult problem concerning my son Drew and his care by Oconomowoc Home Health. I consider Oconomowoc Home Health and Barb Lemke fully liable for mismanagement, economic damage and harassment. They have forgotten how critically important their roles and responsibilities are to Drew's health and well being.

Drew was born with Spina Bifida but complications from symptoms of Arnold Chiari Syndrome and Arachnoiditis have made for an extensive care plan. The plan must address: seizures, reflux, swallowing problems, oxygen dependency, incontinence, apnea, lower body dysfunction, visual and hearing impairment, nystagmus, chronic asthma, latex allergies, hydrocephalus, and skin that is prone to breakdown. Excellent medical intervention involving over 30 surgeries has addressed the many critical problems as they have occurred.

A demanding routine care plan is performed daily. It starts at 5:30 AM. and continues until midnight. These cares are done at about two hour intervals and involve ten different medications, respiratory treatments and tube feedings in order to address the chronic problems. In addition there are diaper changes, suctioning, trach cares, monitoring alarms, and a variety of other things to do. At night a feeding pump, supplemental oxygen, apnea monitor, TES unit and Concha System help Drew through the night. Thanks in large part to the sensitivity and close monitoring of Drew by Dr. Leach, Dr. Rice and several nurses who have been involved in Drew's care for many years - Drew has become one of the oldest children surviving these complex problems.

When Drew was born we were unprepared for the rigorous medical cares he would require. We never realized how involved they could be or what advocates we could and would become for him. In many cases the greatest difficulty has been in dealing with secondary problems of his condition. Some hospital billing departments have found it easier to turn bills over to collection rather than to send them to the proper insurance carriers. Or the recovery room nurse who insisted that Drew's blue color and writhing pain was normal surgical recovery and not due to the bagging that blew out both his lungs. Or the Make a Wish person who insisted that Drew fly to Disney World despite the fact that he had a brain shunt, required oxygen and had Doctor's orders not to fly.

When the scooter issue came up, a meeting was held with Sue Loeffler. At the conclusion of that meeting Sue emphasized the need for better communications. Since that time the total dialog time with Barb Lemke and myself can be measured in seconds - not even minutes. Typically Barb calls, I answer the phone, Barb asks for the nurse, Barb leaves a message for us with the nurse, the nurse tells us Barb's message. The message is typically "there is no nursing coverage available for the next shift."

I find it curious that Barb Lemke has never administered any of Drew's cares or observed the nurses for verification of the proper procedure. She reviews the nurses for pay raises as if she did.

When a nurse worked her shift without feeding Drew, instead of informing the parents and taking corrective action, a meeting was held between Barb Lemke and the following shift's nurse for almost an hour to cover up the matter. During this meeting Drew was not monitored by either the nurse or Barb Lemke as required. Barb Lemke took no disciplinary action. This is selective enforcement of rules and ignoring liability.

In the Spring of 1995 a care plan conference was requested by Barb Lemke. The conference included Dr. Leach, Dr. Rice, Barb Lemke, several nurses, my wife and myself at Children's Hospital. It was determined that Drew's oxygen could be eliminated when he was closely monitored during the day, oxygen was to be restored if it was found to be necessary. During the summer at around 3:00 AM the night nurse found that Drew was having some respiratory distress (Drew had a respiratory infection). She checked his oxygen saturation levels and decided to increase the oxygen flow from 2 liters to 4 liters per minute allowing Drew to get a good night's rest. For her conscientiousness the nurse was given a disciplinary notice by Barb Lemke. Apparently it's much more dangerous to give a child oxygen than to eliminate food from his diet.

I can't remember the last time Barb brought any new positive input into Drew's care plan. Bringing new ideas to a situation only requires a positive attitude, listening and caring. Drew, for several months, has wanted individual packets of peanut butter for a snack when he goes outside. I found that they were available through the local Kraft Food Distribution center. Barb could have called the Dietary Dept. at the hospital and determined their availability even more easily. It's a small thing but pretty important to Drew.

The most crass harassment is Barb Lemke's frequent calls to Dr. Leach and to the Katie Beckett Program in Madison asking them to reduce Drew's nursing coverage. She has stated to both that only "baby sitting" is being done and indicated that aides or the parents should do this work. This indicates a total lack of understanding of the case and of the family. It also shows a very low regard for the nursing profession. To use the term "baby sitting" only describes one's personal views and frustrations regarding their work - not the realities of the case.

If the airlines used Barb Lemke's logic they could eliminate those expensive pilots and just let a passenger fly the planes in good weather. After all the computers control all of the plane's functions.

Drew's condition is severe and chronic - there is no cure, only surviving. Drew's two friends who had similar conditions are both dead. They didn't have significant home nursing care - they no longer need it. Daily quality professional medical assessment and care keep him from being hospitalized in critical condition. Because his condition cannot be cured or completely corrected is no reason to deny him services and harass the people who care.

We have worked hard to provide Drew with a positive, loving and stress free home life. This has not been easy since two of his brothers also have problems. OCD and depression for one and ADHD for the other - both are on medications to treat the problems. Drew's mother has had surgeries for appendicitis, gall bladder, lower back tumor, skin cancer and surgery on both feet. Most recently she has had surgery for a vulvar malignancy. She uses a tens unit to control back and foot pain because of the tumor removal on her spine and also faces impaired mobility because of the recommended use of bilateral AFO's. Personally, my employer requires that I be on the road as often as 3 to 4 days weekly, making my wife virtually a single parent.

Oconomowoc has been addressing Drew's skilled nursing needs for more than 5 years. In recent years Drew's medical condition has had some improvements and some set backs but his abilities have improved dramatically. We give full credit for this to the commitment and caring of the nurses involved during this time.

Barb Haase set up care plans for training nurses and even made a video to demonstrate the nature and extent of Drew's cares. Nurses considering his case would be able to determine if this was a case to match their skills, objectives and personalities.

Since Barb Haase left the agency and was replaced by Barb Lemke we have seen a steady deterioration in the case management. Barb Lemke is simply not suited to this case. We expect good assessment skills, good judgment, positive attitudes, involvement and caring. Instead we receive no communication, selective rule enforcement, negative attitudes, inconsistent scheduling and harassment. Here are some examples:

The State of Wisconsin provided Drew with a battery powered scooter to allow him to be more independent and give him the same mobility his classmates with special needs enjoyed. Barb Lemke called the state police charging that this was a very dangerous vehicle, that it needed special licensing and that it should not be used when the nurses are around.

Drew's care plan has not changed significantly since Barb Haase's training video tape was made but it is no longer being used. The result is our time is wasted orienting nurses to a case they are not suited for and Oconomowoc wastes it's money paying the nurse for the time. This is mismanagement.

I contacted Barb Lemke in an effort to improve the quality and consistency of the nursing schedule. I was told if I didn't like it, she would give me the names of other Home Health Agencies to go to. Rather than address the problem, Barb chose to aggravate it. This is harassment and unprofessional.

When I met with Sue Loeffler to present a suggested longer term scheduling system for the nurses, she indicated that it should be given serious consideration. Barb Lemke rejected it stating that the nurses don't want consistency.

When we request that nurses be scheduled with consistency the result is always greater inconsistency. Nurses who want to work the case and increase their hours are pushed elsewhere, gaps occur between scheduled shifts and short shifts become the norm despite our requests. Nurses who ask to cover on school days are not scheduled on school days. When my mother passed away and the scheduled nurse canceled her shift - no backup was available to cover so my wife could attend her funeral.

Marge and I are parents not medical professionals. We have obligations to each other, to our children and to our employers - not just Drew. If Barb or any nurse fails to appreciate the value of their profession I suggest that they first get a new attitude and then find a new line of work. It is not their role to harass the parents and medical professionals who want to make life a little easier for the people they care about.

If people asked questions and realized that there are no easy answers, attitudes might change. Is there a source of new information about Arnold Chiari? About Arachnoiditis? About the effects of diet? About living with Nystagmus? Are there any new developments in treating seizures? Where is research being done on Spina Bifida and Arnold Chiari? Why does Drew see Dr. Steinhaus? Is my wife's medical condition important? If I have to stay home from my work to cover a nurse's shift does it endanger my job, my medical insurance and my ability to pay our families' medical bills? The answers are important to everyone, not just Drew. Not asking only means not caring.

I expect that Barb watches to see that the nurse's CPR skills are refreshed regularly. When was the last time the parent's CPR skills were updated?

Drew and his cares are medical challenges. "Baby sitting" won't be tolerated - get involved! When Drew's case is again managed with a positive attitude, lines of communication opened and people who care are involved I'll go to Madison and to Washington to ask for improved programs and funding. Minimum levels are not acceptable.

If Barb still does not see the importance of quality medical care for Drew then I demand that Oconomowoc Home Health provide her with a challenging opportunity appropriate for her skills and interests elsewhere. I expect and demand that Drew's case be managed by a caring professional with a positive attitude who appreciates the value of good communications!

Sincerely yours,



John R. Williams

cc:M. Guthrick, Katie Beckett
cc:Dr. Leach, Physician
cc:S. Lowry, Attorney
cc:Dr. Rice, Pulmonary Physician
cc:Spina Bifida Center
cc:Dr. Splaingard, Rehabilitation
cc:Waukesha Human Services
cc:C. Wegner

JOHN R. WILLIAMS

611 Mt. Snowdon, P.O. Box 100

Wales, WI 53183

(414) 968-4967

January 17, 1996

Memorial Hospital of Oconomowoc
Ms. Sue Prime
125 Fowler Street
Oconomowoc, WI 53066

Dear Mr. Prime:

I am writing concerning my son Drew and his care by MHO Home Health. A copy of my letter to Sue Prime and the response from Sue Loeffler is enclosed for your review. The letter to Sue Prime is detailed because she has not had the opportunity to visit our home and meet Drew.

In short I don't understand why an institution established to care for people would now spend it's resources sending it's business away rather than doing it's job in the manner expected.

1. We have requested that Drew's case be truly managed by someone who cares about his well being. Someone who wants to be involved with the family and the medical professionals.

2. If the prospect of a case generating between \$50,000 and \$100,000 is no longer appealing after five years - Why not?

3. Most business's meet their objectives with efficiency and productivity leading to increased profitability - good involved management. What's different here?

It is not fair to the many quality nurses who have staffed this case for years to suddenly lose their income and benefits because the agency would not respond to a request for caring and improved communications.

It is not fair to MHO that they should be exposed to unnecessary liability due to the agency's selective enforcement of rules.

It is not fair to medical professionals to receive harassing phone calls.

It is not fair to the parents and their employer's that the scheduling of nurses be handled in such a short term haphazard manner.

It is not fair to Drew when he is disciplined because "someone" decided that he should change his own diapers.

Drew's case has been effectively managed in the past. I am simply asking that good communications be established and that caring be a case management priority.

Sincerely,

John Williams

August 27, 1997

Dear Chairman Grobschmidt and Grothman and
members of the Joint Committee for Review of
Administrative Rules,

As a taxpayer, I realize your ultimate goal
is to make sure that money is not wasted
on unnecessary medical care, but rest assured
that micro-management is not the answer. Of
course making sure that addicts don't cash state
checks to pay their bar-bills would make me
happy.

Remember that even a perfectly healthy
child's needs vary from hour to hour, day to
day, let alone month to month.

Knock off the intense scrutiny of non-
voting children and find the real waste.

Perhaps fewer pencil pushers and
more honest work is in order.

Bla Zymel W. on
behalf of Tony G.

Date: August 27, 1997

Dear Chairmen Grobschmidt and Grothman and members of
the Joint Committee for Review of Administrative Rules,

I am very concerned about the treatment of medically fragile children and how life has become so much more difficult for them and the families caring for them. This has come about in the way they are being treated by the Bureau of Health Care Finance.

At present the Bureau of Health Care Finance (BHCF) authorizes Private Duty Nursing (PDN) hours for the care of medically fragile and technology dependent children. These children have recently become the focus of the BHCF cut backs by taking away the nursing care ordered by the child's physician. They have also created arbitrary guidelines for the distribution of authorized PDN care. This might meet the needs of the BHCF, but it does not meet the needs of a medically fragile child being cared for at home.

It has become apparent that some very important items need to be addressed immediately. It is wrong that a program which is supposed to help children stay with their families is treating the child and family in such a irresponsible manner!

1. The drive to control the exact time per day of PDN does not treat the child and family with respect and dignity.
2. Informal policymaking by the BHCF should be stopped!
 - a. Informal policy changes occur to meet department needs and do not reflect the needs of the child recipient.
 - b. It is subject to the bias of individual interpretation, that interpretation may change at any given moment and may not take into account the quality of life for the child.
 - c. The life of the child and family gets thrown into turmoil when all the "rules" as they know change.
3. The BHCF should be required to establish policies for the department by formal administrative rule starting immediately!

PDN hours that have been authorized by the BHCF should be distributed as deemed fit by the family of the recipient child. 24 hours of care in any day is acceptable for any reason providing it does not exceed the monthly allotment of hours. This supports the family in their ability to maintain the child's medical needs safely in the home along with the needs of the family as day to day needs can vary greatly. This is how PDN hours were distributed in the past and was more successful in meeting the needs of the medically fragile child being home with their family.

Sincerely,

① JoAnn H. Chack
116 Lakewood Gardens Lane
Madison, WI 53704

② Alan Fisher
46 E Jackson #5
HARTFORD WI 53027

③ Mark Beggan
46 E Jackson St.
Hartford, WI
53027

④ Catherine Meloy
2947 N. 53rd St.
Milwaukee, WI 53212

⑤ John A. Anbycht
3746 S. 60th St
Milwaukee, WI 53222

⑥ Paul C. Durgutz
2130 N 107th St
Milwaukee, WI 53226

Date: August 27, 1997

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Sincerely,

Theresa Zwaska
7930 Rogers Ave
Wauwatosa WI 53213
414 453-4429

SEP 05 1997

Date: August 27, 1997

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the Joint Committee for Review of Administrative Rules,

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Sincerely,

Thomas A. Coatt

402 S. 7th Ave
West Bend, WI 53095

Date: August 27, 1997

SEP 05 1997

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Sincerely,

Jean E. DeLander
7040 N. 60th St # 203
Milwaukee, WI 53223

Date: August 27, 1997

SEP 05 1997

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Sincerely,



Cedarburg, WI

SEP 05 1997

Date: August 27, 1997

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Sincerely,

Jane & William Craig
W67N804 Evergreen
Cedarburg WI 53012

Date: August 27, 1997

SEP 05 1997

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Sincerely,

Beverly A. Donald
275 Industrial Drive
Shredonia, WI 53021

Date: August 27, 1997

SEP 05 1997

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the Joint Committee for Review of Administrative Rules.

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Sincerely,

J. W. Schwenkel

Judy V. Schwenkel

9727 Cedar Creek Rd,

Cedarburg, WI 53012

Date: August 27, 1997

SEP 05 1997

Dear Chairmen Grobschmidt and Grothman and members of
the Joint Committee for Review of Administrative Rules,

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Sincerely,

Harmony Weissbach
778 NW 75 Wauwatosa Rd
Cedarburg, WI 53012

SEP 05 1997

Date: August 27, 1997

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Sincerely,

Jeanette Lindner

Cedarburg, WI 53012

SEP 05 1997

Date: August 27, 1997

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Sincerely,

Evelyn F. Klug
N91 W 5849 Rochester
Cedarburg WI 53012

Date: August 27, 1997

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Sincerely,

Sandra Floss RN
Barbara J. McComis RN
Julie Warren RN
Koryn Berland RN

Kristine Bloechl

CD 15 1997

Date: August 27, 1997

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Sincerely,

Barbara Green
1901 W. Pioneer Rd
MELQUON WI 53097

Date: August 27, 1997

SEP 05 1997

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the Joint Committee for Review of Administrative Rules,

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Sincerely,

Claw and Paul Krause
4824 W. Highland Rd
Mequon WI 53097

SEP 04 1997

Date: August 27, 1997

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the Joint Committee for Review of Administrative Rules,

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Sincerely,

Sandy Schneider
975 Garden St.
Lomira, WI 53048
(920-269-4932)

I am the mother of a medically fragile daughter. She is 17 yrs. old + has been 24 hr. ventilator dependent since birth with congenital central hypoventilation syndrome - CCHS. She needs 24 hr. care.

SEP 08 1997

Date: August 27, 1997

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Sincerely,

Lane E. Poulson

*Mother of Ventilator/Trach dependent
Child - Lara Burns*

** Please see extra notes attached*

Aug 28, 1997

Dear chairmen Grop Schmidt and Gouthman and
members of the Joint Committee of
Administrative Rules,

I have been a Private Duty Nurse
for over 5 years. Currently, I have 4 clients. 2 are
pediatric clients. Since I have known these
children and thier families for such a length
of time, and due to the nature of the business,
I've become very fond of them. Its hard to
see them have the added stress of the
restrictions BHCF has placed on them.

Most of us have families and know
sometimes are routine is complicated by things
that come up. We have the freedom to shift our
lives around if need be. These families should have
the same freedom.

If a family has x amount of hours
per month, its the same amount of money spent
whether they use the hours all at once or spread
out. I'm not saying being foolish with the hours,
just allow the families the freedom to use the
hours that fit them. Why should it matter to
BHCF? IT does matter to these families.

Thank you for taking the time to
read mu inout. sincerely,

August 30, 1997

Dear Chairmen Grobschmidt and Grothman and members of the
Joint Committee for Review of Administrative Rules,

The present treatment of the families with children with special medical needs must stop!! This Committee can help them by stopping the Bureau of Health Care Finance from making hardship "policies" that are for no ones benefit except for some power hungry official in Madison.

A so called policy was created for some crazy reason to take authorized Private Duty Nursing hours, for the care of children with special medical needs, and ration it out according to some power hungry official in Madison. This person or persons feels that the parents don't know enough to decided what is needed on any particular day for their child's needs, and too stupid to be allowed the responsibility to be given hours on a monthly basis so they can have some flex in how they run their individual family life.

This has to stop!!! It is destroying families that are already having a extremely hard time just due to their child being sick and needing nursing care.

This has to stop!!! It does not cost the state anything extra to go back to the way it used to be. Hours were authorized and it was up to the parents to schedule them throughout the month as needed for the individual needs of the child and family. Sometimes this meant 24 hours in a row for a few days, but later in the month not as many were used. Yes, sometimes the parents may actually stay over night away from the family to get some extra rest. This is needed so they can carry on with everything demanded upon them.

If these hardship "policies" don't change, it may actually, as time goes by, cost the state more as hospital admissions may increase due to long term effects of family care givers being stretched to their limit in caring for the child. There is the potential for more mistakes and also for the care giver to get ill themselves to the point that they can no longer care for the child.

It is stupid that something that could have been taken care of so easily has now had to come to this point. Talk about wasting money, a lot of time, effort and money has been spent to have the public hearing. While thankful for the public hearing to try to fight what has happened to these children and their families, someone has really dropped the ball in who is running the Bureau of Health Care Finance and wasting everyone precious time and energy. It is shameful that these families have been put through an unnessary and completely avoidable ordeal.

Thank you in advance for being the one to put an end to this madness!!

Sincerely,

Ruth Rebeck RN

September 2, 1997

Dear Chairman Grobschmidt and Grothman and members of the Joint Committee for Review of Administrative Rules,

I am sorry that I could not be at the public hearing on September 3, 1997 in person regarding the treatment of medically fragile children. Although I am not able to make it, this issue is very important to me and other families across the state.

My foster nephew is ventilator dependent and fed through a G-tube in addition to being cognitively delayed. He is the sweetest and greatest kid around and has brought my family and all those around him much happiness. It is through the hard work and dedication of my sister and brother-in-law that he is thrived and survived.

It is a disgrace that the Bureau of Health Care Finance now feels the need to dictate when families with medically fragile children can use nursing hours. These families are not asking for anything unreasonable by being able to schedule their own lives. Family situations and circumstances change daily especially when a family member has special medical needs. Flexibility in nursing hours allows these families that are already pushed to the limit to eliminate some of the chaos that is often a part of caring for a child who is medically fragile.

This issue is not an issue about money as these families are asking for flexibility in nursing hours, not more hours. I am asking that the Bureau of Health Care Finance use some common sense and give-up this mute issue of nurse scheduling inflexibility. The only people that suffer are the children and their families. Are these the goals of the Bureau's new and improved rules? I sure hope not!

Sincerely,



Dawn Richardson
1425 Underwood Ave. #6
Wauwatosa, WI 53213
(414) 453-8274

September 3, 1997

Dear Chairman Grobschmidt and Grothman and members of the Joint Committee for Review of Administrative Rules,

The Bureau of Health Care Finance has essentially brought us here today. Something so simple as allowing families to schedule their own life around the Authorized Private Duty Nursing hours for the child with special medical needs has been stopped. A daily and weekly allotment with daily limits is not in the best interest of my son but that is what has been imposed upon us. Caring for a child with complex medical needs requires one to be flexible.

If I am to be responsible to care for my child with life support needs am I not responsible enough to schedule his PDN to allow for proper care while also caring for the needs of my whole family.

I need to be given back the tools of having authorized number of hours per month to use as necessary. Some days that may mean 24 hours coverage and then doing with less on other days.

The BHCF is fearful that if there is potential for 24 hour coverage (even if the monthly total number of hours is not exceeded) the care giver may actually take a day or two away from the home. This is not a criminal act although families have been made to feel this way. Brief time is needed to care for one self so as to then be able to care for the family. The family should be commended for taking care of themselves, not condemned.

Being able to have time with 24 hours coverage also assists families to include their child with special needs into family functions. Without the nursing support throughout the day and possibly the next they would not have gone, as it takes so much out of you to coordinate the outing and recuperate from it as it can be quite exhausting.

These PDN hours are APPROVED HOURS, but at present it depends what phase the moon and stars are in as to if and how they can be used. This makes no common sense and is not in the best medical interest for my son. He must have alert competent care giver at all times. I cannot always be that person if not given the tools of flexibility to coordinate the PDN hours as deemed appropriate to maintain the health and safety of my son, myself, and the entire family.

Such a simple and cost neutral change can dramatically improved the quality of life for the children. I should think any department that can make such a positive outcome for the benefit and support of the family would do so willingly and could be proud of what they have accomplished. Please, members of the Joint Committee for Review of Administrative Rules, be proud of what you can do here today for the children and the families you represent.

Sincerely,



Kim Ann Greiveldinger
N48 W 16443 Lone Oak Lane
Menomonee Falls, WI 53051

JOHN R. WILLIAMS

611 Mt. Snowdon, P.O. Box 100
Wales, WI 53183

(414) 968-4967
jwilliams001@juno.com

9/3/97 Medical Assistance Testimony

When Drew reached the age of two it became apparent that his condition was more complicated than just his spina bifida birth defect. His voice sounded like Mickey Mouse one day and the Godfather the next, feedings stayed down only a matter of minutes and his eye balls virtually vibrated. According to Drew's neurosurgeon Dr. Kagen these were classic symptoms of Arnold Chiari and a serious decompression surgery would be needed immediately to address this life threatening condition. When we asked a prominent neurosurgeon for a second opinion, we were told there was nothing wrong with Drew and we should "take him home and stop wasting hospital bed space."

Drew had the decompression surgery and a shunt revision surgery and a gastrostomy feeding tube surgery and a tracheotomy surgery to prevent choking due to the paralysis of muscles in his throat. The simplest of these surgeries was the trach. Following this surgery we were invited into the recovery room where we found Drew writhing in pain and turning blue. The nurse told us this was just normal anesthesia recovery but we weren't convinced. Our loud comments brought Dr. Rice running. Three hours later we again got to see Drew. He looked much better now that his two collapsed lungs had been reinflated.

Before we could take Drew home from the trach surgery we needed to have home nursing care in place. This was when we learned how important good case management and caring was.

Before the first home care nurse could report for duty I found myself back in a hospital emergency room talking with a doctor about appendicitis surgery for my wife and keeping track of four boys under the age of seven. I also learned how gastrostomy tubing clamps can come loose and leave me covered with Drew's stomach contents.

When I called Vicki Hekkers (the case manager) she said "no problem"! Vicki not only picked up Drew but his three brothers too and said "stay with your wife as long as you need too". Vicki's caring and attitude really made a difference especially since she had not previously been in our home.

The next case manager was Barbara Haase who stayed with Drew for five years. At first she traveled from downtown Milwaukee to our home in Wales (about 30 miles each way) and later while working on her Master's degree at UW Madison she drove 60 miles each way to care for Drew. Barbara set up Drew's basic care plan that's still being used today, she worked with the doctors, her friends built Drew's fantasy playhouse complete with a ramp for accessibility, they built an oxygen carrier from a Tonka truck so he could be mobile despite his dependence on liquid oxygen. She made a two hour instructional video for new nurses unfamiliar with Drew and his complex cares, she even included Drew in her wedding party and taught him to dance in a wheelchair.

When Barbara left to accept a position at the University of Illinois Hospital, about two and a half years ago, a new case manager took over. It was obvious that she wasn't a hands on nurse. Drew and the case simply weren't important. She never used the instructional video on Drew's cares that Barbara had made or oriented any new nurses - that was the parents job.

Absenteeism increased, especially on critical days when both Marge and I were working. She couldn't find any nurses that could start more than a few minutes before Drew's school bus arrived and it was never necessary to talk to the parents.

When one nurse "forgot" to feed Drew for an entire day she sat with the nurse for an hour trying to figure out how to cover up the matter while ignoring Drew the entire time. When a nurse that had cared for Drew at night for five years increased his oxygen flow because of low oxygen saturation levels (within the Doctor's instructions) she wrote her up.

When I complained she told me "if you don't like the way the case is being run, I'll be happy to give you the names of other agencies you can go to." When one of Drew's favorite nurses (Kim Gibbs) asked to work a full 40 hour week with Drew instead of only 1 or 2 days she was then working, she was told by the agency that it wasn't possible. A few weeks later Kim resigned to work full time for a sister agency but even then our agency couldn't coordinate nursing coverage between the two agencies.

When Drew was eight we found that some nurses were following another of her directives. This time she had told the nurses that Drew should change his own diapers and that he should be given a time out if he didn't.

The agency Director wrote that anyone who was unhappy with the agency's service should contact the regional commission in Illinois. Within days a commission representative was in our home. The Director came along too but the case manager was nowhere to be seen. The Director concluded that communications really need to improve. It was the last time we saw or heard from her and the case manager continued her policy of not talking to the parents and reducing hours.

When my mother died and was to be buried on the last day of the month we knew that we could expect another 'Little Mary Sunshine' call informing us that our nurse wasn't able to work that day and the agency was soo sorry they didn't have any backup available.

When Drew was involved with Barbara Haase's wedding we asked for a long shift to allow for travel time and participation in the activities. One nurse had already said it was no problem and she had requested the shift. Instead the agency scheduled two short shifts with the shift change at the time of the ceremony.

When we requested monthly or quarterly nursing schedules the case manager said "nurses don't want consistent scheduling".

Last year we wanted Drew to attend school five full days a week but then learned that not enough hours were allocated for Drew to do this. Drew's nursing hours had been reduced because that's all that had been requested by the agency. The agency then blamed the State and the State said that's all that were requested. I was asked why I hadn't filed a protest - well, it seems that the State sends these protest requests to the agency, leaving the parents out of the system.

The last straw came when Marge and I arrived home a few minutes after the end of a nurses shift because we were tied up in traffic in Milwaukee. We were shocked to learn that the nurse had called the agency office and apparently was instructed to simply leave Drew without medical or adult supervision. Neither the nurse nor the agency ever called to find out if we had arrived home.

For this quality of care the State pays a premium of \$10 per hour for Registered Nurses. Since we fired the agency and went to Independent Nurses our absenteeism rate has dropped to almost zero and starting times of 7:00 AM, an hour before the school bus arrives have been no problem.

As much as I would like to have Eric Nielsen, our Independent Nursing case manager, managing Drew's nutritional needs, bladder stimulation, physical therapy, and communicating with the many specialists that see Drew, his time is spent dealing with the fog of medical assistance paperwork and dealing with bureaucratic intimidation.

A year ago I brought Drew and Eric to Madison - we learned a lot. We learned that there is no communication between the people running the program and the people at EDS who process the paperwork. At the Medical Assistance office we heard "we've never seen the people we provide services for". At the EDS office it was obvious that they had no use for parents and would only talk

to the nurse. EDS insisted that a "486" form be completed but they didn't have any available and they had no idea where we could find one. EDS loves to delay and return paperwork with vague comments like "incomplete" and "wrong code". The recipient then gets to call their office, be put on hold and they're finally told the code should be '...' or the code has been changed to '...'. If they already knew the answer. Why did they waste everyone's time including their own.

Quotas for critical invivo products is life threatening to everyone of these children. Their lives are dependent on suction catheters. The lack of a suction catheter could easily result in brain damage and really raise costs. Meanwhile disposable syringes are available in plentiful quantities.

Requiring the cleaning Drew's trachs for reuse was another cost saving idea, except that it resulted in irritation of the trach site and almost hospitalization for Drew. It took me a lot of phone calls to find that the real problem was an allergic reaction to the detergent specified in the cleaning process. It was obvious that a great many people don't know the difference between cleaning and sterilizing.

What's the answer to this mess?

1. First, stop treating parents like second class citizens. Instead of complaining that they're not involved - start listening to them, they know far more about their children than they're given credit for. Let the parents network amongst themselves. A parent can learn more about a child's specialized needs in a few minutes on the Internet than Doctors can sitting in their offices for years.
2. Second, demand face to face interaction and hands on contact between supervisors and recipients. Working with these kids is fun and rewarding. Anyone who can't see that is in the wrong business and should get out!
3. Third, build flexibility into the system. Give the kids and the families what they really want. They'll probably give you a better system at lower cost than any high priced medical bureaucrat.
4. Fourth, work with the companies that manufacture the supplies and the equipment. Give them a fair profit for their products but demand efficient recyclable packaging, reliability, and appropriate quality.
5. Recognize people, organizations, and companies that provide exceptional care, innovative products, and great service.
6. Recognize that it's not just a child with a medical problem but a family with a problem. The stress of a child's medical condition results in too many single parents raising these children. It results in significant unemployment because companies all too often find ways of eliminating employees with high medical bills. It also results in stress and medical problems for other family members because they don't receive enough attention or can't adjust to the problems.
7. The Independent Nurses program has been an incredible blessing. It allows nurses who really care, to do so, rather than be caught up in agency politics. Why are they paid less money and no benefits while the agencies who have demonstrated that they don't want to do the job get top dollar for their services?

In conclusion I'd like to add a quotation that I think is appropriate: "Some of us are to blame but all of us are responsible."

Added after the testimony:

8. An advocate program. Many children and families misout on things because they must deal with misinformed, uninformed, or insensitive people. They also misout because they don't have the time, the energy, the knowledge or the skills to get corrective action.

JOHN R. WILLIAMS

611 Mt. Snowdon, P.O. Box 100
Wales, WI 53183

(414) 968-4967
jwilliams001@juno.com

September 4, 1997

SEP 05 1997

Senator Richard Grobschmidt
State Capitol
P.O. Box 7882
Madison, WI 53707-7882

J.R.W.

Dear Senator Grobschmidt:

In addition to the transcript of my testimony I am enclosing a two page letter we provide to people who don't have knowledge of Drew's medical complexities and a list of people who have been very special. Papers are also included that are used to document Drew's daily medical cares and orientation information for new nurses. Copies of documents sent to the nursing agency in an effort to resolve the earlier difficulties are also enclosed.

The MA program is a good one, it's simply the fact that it's real purpose has been forgotten and it's lost contact with the people it exists to serve. Home care is different from hospital care and adult care is different from pediatric care. I think the differences have been lost in this time of political correctness.

As many of the parents said - I'd like to extend an invitation to you and any committee members who would care to visit our home, meet Drew and see first hand the terrific progress that Drew has been making. We live just south of I 94 off exit #287 in case you have time on one of your trips through the area.

Sincerely,



John Williams

RR2 Box 1591B
Bays Mills, WI 54631
Sept. 4, 1997
% Kara Burns
Lore Poulin

Dear Chairmen Grobshmidt and Brothman;

I was able to testify at the open hearing 9/3, and I thank you for listening. I am the 'mom' who spoke 2nd, concerning my 17 years as a caregiver for my daughter, Kara Burns (who was present), the 1st child in Wisconsin to go home with a ventilator. I apologize for appearing to be in a hurry to leave the hearing - Kara and I had been up since before 5am and had a long drive for home ahead of us (and we were starving!)

I have a few points and suggestions I failed to mention in my testimony that I would like to address now. Actually it's to the other younger families that I am speaking. It's too late for me. My other, older daughters, thank fully, survived the family restrictions due to lack of nursing or inflexible nursing hours. They were restricted from after school/evening involvement in sports, plays etc. (and if they did go - I could not be there to watch) Priorities. I live by priorities. I've learned to be content just to have PDN's to cover my work hours. I am self supporting and pay for insurance. I consider myself fortunate to have nursing hours available for my necessities at this time.

Please take exquisite care with the families at risk. We are very complex but, there aren't too many of us. My 1st suggestion would be to take each case separately and find out what is needed to help each family most. Keep PDN flexible - but Keep PDN's! I survived - and will continue to survive. But, I learned to be flexible, adaptable and clever enough to find alternative solutions to my nursing problems. I fought when I had to, but also adapted. I now take the path of least resistance on Non-crucial issues. I try to keep life as simple, normal and balanced as I can. I Dread being issued CHANGES from the state that could have a negative impact on our fragile way of life without recourse. I just don't have the time or energy to fight anymore - unless I have to.

(2)

% Tara Burns
Lane Poulin

Please understand - if home doesn't work there is no place to go with these kids. Even in the hospital ICU, parents don't leave these kids in their ^{hospital} care. These kids are beyond the skills of most hospital staff - including doctors. If these kids can't be home they go to a hospital ICU. There are very few nursing homes in the midwest that can handle a medically fragile, technology dependent child. I know of only one in Green Bay, WI - "Paddington Station" which has a long waiting list for its 12 or more beds. Plus, there is no possible way that a hospital or nursing home is more economical than home care. I know - I have researched this. However, there is an ugly reality that exists - we parents know - that if these kids do go to an institute for long term care, they will die. End of problem. And this is unacceptable to the families.

As I mentioned in my testimony 9/13, I believe the state originally years ago considered the cheaper home care in their decision to help get these kids home. I am also proposing that the state figured these kids would die at home - thus solving the problem. But these kids receive better care at home are happier and are NOT dying - so the cost goes on.

I drove 2 1/2 hours, and took off work to testify so that others without fragile children could possibly see a glimpse into our ever present, restricted, carefully balanced lives. Even so, we are happy.

I have a 2nd suggestion - an added response to a question from Rep. Gunderson at the hearing concerning a family member being reimbursed for caregiving for their child. I stated at the hearing I thought this would be a good and sometimes necessary consideration - It's not a total solution for each case. Some single parents need the added financial income this proposal would allot them due to their inability to work enough hours out of the home to support their family. Being eligible for SSI or state aid is not only unfeasible in many cases, but also undesirable due to its degrading and humiliating nature. Therefore, paying a family member for some of their caregiver hours would help in the financial issue of the family's problems.

3

To Lara Burns
Lane Poulin

There is still the issue of the Parents/caregivers' need to have dependable, flexible PDN hours to be able to get out of the House and restrictive environment for their sanity - at least! These PDN hours are, of course, necessary for work outside the home - but also to fulfill other family obligations such as sibling school functions, sports + recreation - and medical needs etc.

I only wish the BHEF could be more flexible with each of these children on a case by case fashion. I have been in contact with Peggy Bartels in the past, I spoke with her at the hearing 9/13 and she will be in contact with me in the future to review these issues more.

I apologize for these handwritten notes and thank you for allowing me to express my views. I sincerely hope this helps with your decisions. Wisconsin does provide well for their children - I want to assist Wisconsin to continue to do so. If we work together with open minds and hearts we will succeed. Feel free to contact me with any comments or questions. 608-872-2156.

Most Sincerely;

Lane E. Poulin
for Lara Burns

SEP 05 1997

Date: August 27, 1997

Dear Chairmen Grobschmidt and Grothman and members of the Joint Committee for Review of Administrative Rules,

I am very concerned about the treatment of medically fragile children and how life has become so much more difficult for them and the families caring for them. This has come about in the way they are being treated by the Bureau of Health Care Finance.

At present the Bureau of Health Care Finance (BHCF) authorizes Private Duty Nursing (PDN) hours for the care of medically fragile and technology dependent children. These children have recently become the focus of the BHCF cut backs by taking away the nursing care ordered by the child's physician. They have also created arbitrary guidelines for the distribution of authorized PDN care. This might meet the needs of the BHCF, but it does not meet the needs of a medically fragile child being cared for at home.

It has become apparent that some very important items need to be addressed immediately. It is wrong that a program which is supposed to help children stay with their families is treating the child and family in such a irresponsible manner!

1. The drive to control the exact time per day of PDN does not treat the child and family with respect and dignity.
2. Informal policymaking by the BHCF should be stopped!
 - a. Informal policy changes occur to meet department needs and do not reflect the needs of the child recipient.
 - b. It is subject to the bias of individual interpretation, that interpretation may change at any given moment and may not take into account the quality of life for the child.
 - c. The life of the child and family gets thrown into turmoil when all the "rules" as they know change.
3. The BHCF should be required to establish policies for the department by formal administrative rule starting immediately!

PDN hours that have been authorized by the BHCF should be distributed as deemed fit by the family of the recipient child. 24 hours of care in any day is acceptable for any reason providing it does not exceed the monthly allotment of hours. This supports the family in their ability to maintain the child's medical needs safely in the home along with the needs of the family, as day to day needs can vary greatly. This is how PDN hours were distributed in the past and was more successful in meeting the needs of the medically fragile child being home with their family.

Sincerely,

Kim & Al Anderson