

MICROFILM DIVIDER

OMB/RECORDS MANAGEMENT DIVISION
SFN 2053 (2/85) 5M



ROLL NUMBER

DESCRIPTION

2330

2001 SENATE HUMAN SERVICES

SB 2330

2001 SENATE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. SB 2330-2331

Senate Human Services Committee

Conference Committee

Hearing Date February 5, 2001

Tape Number	Side A	Side B	Meter #
1	X	X	
2	X		
February 7, 2001 2	X		35.3
February 7, 2001 2		X	
Committee Clerk Signature <i>Carol Holodziejchuk</i>			

Minutes:

The committee was called to order by SENATOR LEE with all Senators present.

The hearing was opened on SB 2330 and 2331. The bills were heard together.

SENATOR MATHERN, sponsor of SB2330, introduced the bill with written testimony.

SENATOR MATHERN, sponsor of SB2331, introduced the bill with written testimony and presented proposed amendments.

DEB ISSACSON, speech pathologist, supports the bill. SENATOR LEE: What is the difference of evaluating the devices as medical or school. The physician recommends and prescribes. It is a team setting. Devices are used in schools and in community. Most school districts are good about allowing the device home at night or on the weekend. I can only speak for the school districts I am familiar with. If the device is covered by insurance it will be the child's. It goes with the child at all times.

SADY PAULSON, student using voice device, spoke through the device to the committee.

(Written testimony).

KATHY SCHULTE presented a letter from DR. KERSTIN SOBUS, Altru Health Services, Grand Forks, supports bill.

CONNIE LILLIARD presented testimony from parents in Wimbleton, who have a daughter using a device. They support the bill. DAVE and BARB BURSTEAD. (Written testimony)

SENATOR MATHERN: When someone has a device only at certain times, how does this affect the child? MS. LILLIARD: In school devices are used; they are not available at home and they must change communication patterns. It is potentially harmful.

ANNE ALBRIGHT, Anne Carlson Center, Jamestown, supports bill. The earlier you can get the child a device, the better. If only in school, the social, more motivating situations are outside of school and they don't have the communicating ability. What the children get is what they have on their shelves already and it is not the proper device for that child. The device should fit the child rather than the device fits the child's needs. Therapists do not know exactly what is out there and further assessment is needed. SENATOR ERBELE: What cost is there involved.

How many people need this in ND. MS. ALBRIGHT: The cost ranges from \$400-600 for low tech devices. We are trying to get a device funded just for our evaluation and that device is about \$9400. I'm not sure what the numbers are.

Opposition:

MICHELLE RAGAN, occupational therapist, urges amendments to include occupational therapists. (Written testimony)

This ended testimony specifically on 2330.

The chairperson called for testimony in favor of SB 2331.

SENATOR KILZER took the Chair position.

ERICA PELISHEK supports the bill (Written testimony)

JODI PELISHEK, mother, supports bill, (Written testimony)

ANNETTE KAIP, parent of a son with Cerebral Palsy, supports bill. (Written testimony)

Presented pictures to the committee.

HEATHER PHILLIPS, licensed physical therapist, supports bill. (Written testimony)

SENATOR KILZER: How long have you been practicing? MS. PHILLIPS: 2 years.

DEB HOUDEK, PA-C, Medcenter One, supports both bills. Written testimony on 2330 and 2331.

DR. KEVIN MURPHY supports bill in written testimony.

KEVIN VAN ECK, parent, supports bill. His family was denied several physical helps. My son needs to be strapped in chairs, walkers, standers.

MJ AJLOUNY, RN, BSN, supports bill, (Written testimony)

DR. MYRA QUANRUD, MD FAAP, supports bill (Written testimony).

LEON KELLER, Director of Rehabilitation Services at Medcenter One, supports bill. (Written testimony)

KAREN HIPSAK, supports bill in written testimony.

KATHY SCHMIDT read testimony from DONENE FEIST. (Written testimony)

COLLEEN STOCKERT, parent and employee of Dept. Of Human Services, supports bill.
(Written testimony)

DARLENE WEIGEL supports bill in written testimony.

KEVIN OLSON, parent, supports bill in written testimony.

RICK PELISHEK, Executive Director of the ND Disabilities Advocacy Consortium (NDDAC), supports bill. (Written testimony)

GRANT WILZ, Jordan's father, supports bill. Gave example of son's progress without therapy.

JON RICE, BCBS medical doctor, supports both bills with written testimony.

SENATOR LEE: How many children are covered in ND? DR. RICE: About 40% or 1.2

million per year. SENATOR KILZER: How long has language been in policy? DR. RICE: It

is an excision; the procedure is not denied. SENATOR MATHERN: Please explain. DR.

RICE: We will not cover because of it being an exclusion which means it is not medically

necessary. SENATOR KILZER: Does the Board at BCBS have any activity on the issue?

DR. RICE: No, I am not aware of any. SENATOR MATHERN: Is BCBS willing to cover part

of costs if the school board will cover part or what is meshing? DR. RICE: We are open to

considering that; there is some legal obligation to the school system to provide these devices. If

there is an opportunity to share these, what happens to the child who is uninsured, or the child

covered by Medicaid, who covers these devices better than we do at BCBS. SENATOR

MATHERN: Have you considered the possibility that schools might contract with you and the

families to provide this by each of you putting in part of it. DR. RICE: It may be considered. It

has not been a discussed item in the past.

Opposition:

DR. RICE, BCBS, opposes bill. (Written testimony on 2331). SENATOR MATHERN: Do you

make similar decisions about coverage as in the care of the heart? DR. RICE: Yes, we make

decisions. Adult medicine is different from kids. There are instances that are unallowable.

SENATOR MATHERN: Are these experimental? DR. RICE: There are not good studies and

that is one of the difficulties we have. How much therapy does a child need or how many

changes will take place. A lot of these things revolve around how often, how frequent, how long should we continue the therapy. What is maintenance and what is progress. Children change all the time. How much is due to the therapy or the growing and developing. SENATOR MATHERN: You talked about working together with groups. If you are able to offer more payment for more therapy; how would that impact your place in the market. Would it be useful in the Century Code so all insurance companies are treated the same. DR. RICE: You make a good point. Will it get financially out of hand? Employers would not be able to handle it. ARISA would not be affected. It is out of state, high risk.

ROD ST. AUBYN. BCBS, continues discussion. BCBS is providing for children. We need to go back. 92 cents goes for claims, 8 cents for administration. Expanded services are not objectionable. Subscribers are saying we can't afford it. We have to keep in mind 2331 would be millions of dollars. SENATOR LEE: What time frame do we need for working on problems.

MR. ST. AUBYN: You have established a 4 month time frame for a task force to work on this. DPI indicated they may do something about the speech devices to be with the child at home.

BRENDA BLAZER, Health Insurance Association of America, opposes 2330 and 2331 in written testimony.

The hearing was closed on SB 2330 and SB 2331.

February 7, 2001, Tape 2, Side A, Meter 35.4

The Human Services committee was called back to order. SENATOR MATHERN presented amendments to SB 2331. He explained these amendments are to correct the problem as to how these issues are dealt with by the Insurance Commissioners Office, and to eliminate the 70% issue of providers and narrow down the physical and speech therapy. Discussion followed. It was decided that the amendments would not make this a good bill.

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Senate Human Services Committee

Bill/Resolution Number SB 2330-2331

Hearing Date ~~February 5, 2004~~

2-7-01

SENATOR MATHERN moved the accept the amendments. SENATOR POLOVITZ seconded the motion. Roll call vote carried 6-0. SENATOR FISCHER moved a DO NOT PASS. SENATOR KILZER seconded the motion. Roll call vote carried 6-0. SENATOR LEE will carry the bill.

Discussion continued on SB 2330. SENATOR FISCHER present some amendments.

MR. GRONBERG, Dept of Education, explained the departments involvement with assistive technology devices or service. These serve communication as well as physical. The conjunction of school board and insurance would certainly contribute help to the parent needing the device for the child. A task force of the Department, insurance payer, insurance company, and not-for-profit organizations could come together to finance these devices. SENATOR FISCHER moved the amendments. SENATOR MATHERN seconded the motion. Roll call vote carried 6-0. SENATOR FISCHER moved a DO PASS AS AMENDED. SENATOR MATHERN seconded it. Roll call vote carried 6-0. SENATOR FISCHER will carry the bill.

Roll Call Vote #: / Date: 2/7/01

2001 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2330

Senate HUMAN SERVICES Committee

Subcommittee on _____
or
 Conference Committee

Legislative Council Amendment Number _____

Action Taken Amendments

Motion Made By Sen Fischer Seconded By Sen Mathern

Senators	Yes	No	Senators	Yes	No
Senator Lee, Chairperson	✓		Senator Polovitz	✓	
Senator Kilzer, Vice-Chairperson	✓		Senator Mathern	✓	
Senator Erbele	✓				
Senator Fischer	✓				

Total (Yes) 6 No 0

Absent 0

Floor Assignment _____

If the vote is on an amendment, briefly indicate intent:

Sen Fischer

Date: 2/7/01

Roll Call Vote #: 2

2001 SENATE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2330

Senate HUMAN SERVICES Committee

Subcommittee on _____

or

Conference Committee

Legislative Council Amendment Number _____

Action Taken Do pass as Amended

Motion Made By Sen Fischer Seconded By Sen Mathern

Senators	Yes	No	Senators	Yes	No
Senator Lee, Chairperson	✓		Senator Polovitz	✓	
Senator Kilzer, Vice-Chairperson	✓		Senator Mathern	✓	
Senator Erbele	✓				
Senator Fischer	✓				

Total (Yes) 6 No 0

Absent 0

Floor Assignment Sen Fischer

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE

SB 2330: Human Services Committee (Sen. Lee, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (6 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2330 was placed on the Sixth order on the calendar.

Page 1, line 1, replace "create and enact a new section to chapter 26.1-36 and a new section to" with "provide for a legislative council study"

Page 1, line 2, remove "chapter 54-52.1 of the North Dakota Century Code."

Page 1, line 5, replace "A new section to chapter 26.1-36 of the North Dakota Century Code is" with "**LEGISLATIVE COUNCIL STUDY.** The legislative council shall consider studying, during the 2001-2002 interim, the coordination of benefits for children with special needs under the age of twenty-one among the department of public instruction, the department of human services, and private insurance companies, with the purpose of optimizing and coordinating resources and expanding services including augmentative communication devices and therapy services. The study, if conducted, must include reports from any private insurance company's task force concerning the coordination of these services. If the study is conducted, the legislative council shall report its findings and recommendations, together with any legislation required to implement its recommendations, to the fifty-eighth legislative assembly."

Page 1, remove lines 6 through 23

Page 2, remove lines 1 and 2

Renumber accordingly

2001 HOUSE HUMAN SERVICES

SB 2330

2001 HOUSE STANDING COMMITTEE MINUTES

BILL/RESOLUTION NO. SB 2330

House Human Services Committee

Conference Committee

Hearing Date March 12, 2001

Tape Number	Side A	Side B	Meter #
2	x		2404 to 3732
3	x		3620 to 3835
Committee Clerk Signature <i>Cornie Easton</i>			

Minutes:

Vice Chair Devlin: We will open the hearing on SB 2330.

Sen. Tim Mathern - District 11: SB 2330 is not a study resolution. It was introduced as a bill regarding mandated insurance coverage. In our state there is some confusion about the obligation of an insurance company and the obligation of a school district to pay for certain kinds of medative communication devices and therapy services. SB 2330 was introduced to clarify the responsibility of payment for those services. One of these medative devices might be a board with an alphabet on it or it might be a computer. There is a wide range of what would be covered under this matter, basically the Senate committee decided to amend this bill. Basically the bill as you have it before you in the house, is a study bill asking that the Legislative Council study the coordination of benefits for children of special needs under the age 21. Among the Department of Public Instruction, the Department of Human Services and the Insurance Companies. The goal of this study is to determine who is responsible for payment for these devices and therapies for

children of special needs. When public instruction in our Century Code seems to have some responsibility, when there seems to be some program eligibility in Human Services and when the family has some insurance coverage. So when you have those variables, the study would look at those variables and come to some recommendation to the next session as to some legislation. Like I say, the original bill would have been an insurance mandate, saying if you have coverage, the insurance company should pay for this. Then we heard testimony from the insurance companies and some other folks about the problems of that. We also learned that there is in fact a task group working between these groups, addressing this very issue. I believe these special needs children have the ability to learn and be productive citizens, but in order to build on that ability they need this equipment in the learning process. I ask that you support the study resolution in SB 2330.

Rod St. Aubyn - Blue Cross/Blue Shield of North Dakota: We are in support of this bill. (See written testimony).

Vice Chair Devlin: Questions for Mr. St. Aubyn. Further testimony in support of SB 2330.

Testimony against 2330. I will close the hearing on SB 2330.

COMMITTEE WORK:

CHAIRMAN PRICE: How about SB 2330 from this morning.

REP. CLEARY: I move a Do Pass.

REP. NIEMEIER: Second.

CHAIRMAN PRICE: Discussion?

REP. NIEMEIER: It does seem like it is something that needs to be worked out. Like

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House Human Services Committee
Bill/Resolution Number SB 2330
Hearing Date March 12, 2001

Mr. St. Aubyn said, a child might have one of these devices at school but then they aren't allowed to take them home. That is just one issue that could be resolved here as to ownership and availability of those devices.

CHAIRMAN PRICE: The clerk will take the roll on a **DO PASS**.

14 YES 0 NO 0 ABSENT CARRIED BY REP. PORTER

Date: 3-12-01
Roll Call Vote #: 1

2001 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. SB 2330

House Human Services Committee

Subcommittee on _____
or
 Conference Committee

Legislative Council Amendment Number _____

Action Taken DO PASS

Motion Made By Rep. Cleary Seconded By Rep. Niemeier

Representatives	Yes	No	Representatives	Yes	No
Clara Sue Price - Chairman	✓		Audrey Cleary	✓	
William Devlin - V. Chairman	✓		Ralph Metcalf	✓	
Mark Dosch	✓		Carol Niemeier	✓	
Pat Galvin	✓		Sally Sandvig	✓	
Frank Klein	✓				
Chet Pollert	✓				
Todd Porter	✓				
Wayne Tieman	✓				
Dave Weiler	✓				
Robin Weisz	✓				

Total (Yes) 14 No 0

Absent 0

Floor Assignment Rep. Porter

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE (410)
March 13, 2001 12:46 p.m.

Module No: HR-43-5455
Carrier: Porter
Insert LC: . Title: .

REPORT OF STANDING COMMITTEE

SB 2330: Human Services Committee (Rep. Price, Chairman) recommends DO PASS
(14 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2330 was placed on the
Fourteenth order on the calendar.

2001 TESTIMONY

SB 2330

**Senate Human Services Committee
Testimony on SB 2330
Monday, February 5, 2001
By Colleen Stockert, Parent**

Madame Chairperson, members of the committee, for the record, my name is Colleen Stockert. I am the parent of a child with cerebral palsy. I am also an employee of the Department of Human Services, and want to be clear that I am here testifying as a parent, in support of SB 2330, not as an employee of the Department. I am on annual leave this morning so I could be here to testify.

My six year old daughter, Nicole is here with me today. She has severe cerebral palsy and is unable to communicate verbally.

She is just learning how to use an augmentative communication device, an Alphatalker. She uses auditory scanning and a head switch to make her selections.

Communication touches all areas of a child's life. Since the argument could be made that a communication device is not "medically necessary", I would like to describe a situation that really occurred with Nicole to show that although communication affects all areas of her life, it definitely impacts on her medical needs.

Last year Nicole's daycare staff called me to tell me she was crying and had been crying for the past hour and a half. This is very unusual for Nicole and they were concerned that something was seriously wrong. I left work to pick her up. She cried all the way home and for another half hour at home before I decided to take her to the walk-in clinic. We tried everything we could think of at home to find out what was wrong, but nothing seemed to help.

While I was waiting for the pediatrician at the walk-in clinic, Nicole continued to cry. The ER nurse came over three times and strongly urged me to have her seen in the ER because it sounded like something was terribly wrong. So, after the third time the nurse came over, I agreed.

The ER doctor came in and Nicole was still crying. He started to talk about all the tests they may have to run to try to figure out what was wrong, including x-rays and blood tests. He also thought it may be necessary to run some more expensive tests if he wasn't able to figure out what was wrong with the initial tests.

Before any tests though, he wanted to check her out from head to toe. So, I undressed her, including removing her shoes and socks. The doctor and I noticed that her big toe was very red. It turned out that for the last three and a half hours her toe had been curled completely under in her shoe and she was in terrible pain as a result. If she had had a communication device, she

may have been able to tell us her toe hurt and we would have avoided that trip to the ER.

There are many other medical reasons that communication is important. She is unable to tell us that her stomach is upset. Since she has a g-tube, we control how much she eats, not her. Therefore, we usually find out that she's not feeling well after we feed her and it comes back up. If she could tell us that she wasn't feeling well we could adjust her diet until she felt better, which would make things easier on her and us.

Last fall my husband and I went to a Communication Aid Manufacture's Association convention in SD and learned about all the different devices available and what might work for Nicole. The cost of the devices she would need range from \$6,000 to \$8,000. We would be hard-pressed to come up with the money for a device, and currently insurance doesn't cover communication aids, so we would probably turn to Family Subsidy for assistance. We would be requesting assistance from the State to help us pay for her device, unless our insurance company would pay for some of the cost. Family Subsidy is a service available to families whose children qualify for developmental disability services. It is funded with 100% state general funds.

Nicole is already six years old and the window for learning communication skills is closing quickly. We are working with

the school system to teach her how to use a communication aid, but once she understands the concept of how to use the device, we will need to purchase one for her. The longer it takes us to do so, the more difficult it will be for Nicole to become proficient at communicating with the rest of the world. Please help us help her to be able to truly be a part of our world.

Thank you for listening to my testimony. I would be happy to answer any questions you may have.

Senate Bill 2330, Human Services Committee

I am Senator Tim Mathison from Fargo. I am sponsoring Senate Bill 2330 to address the problems parents have when trying to get certain adaptive equipment for their children who have disabilities.

The adaptive equipment in this bill is the "augmentative communication" device. These are used by a child who cannot speak. They enable the child to communicate with others.

Some devices are quite rudimentary, like a board with pictures on it. The child points to a picture or series of pictures to communicate a message. These devices are quite useful but they use only a very limited vocabulary. A child can progress to a device that provides a larger vocabulary and a greater variety of messages.

Some augmentative communication devices are more sophisticated. These allow a child to select individual letters to spell out words and to compose sentences from those words. Some devices use computer technology to read those sentences aloud so others can hear the child's message.

These devices are a marvelous stimulus to a child's intellectual growth and development. There are patients, parents, and professionals here to testify. They can give you a better idea of how important and useful augmentative communication devices can be.

These devices are prescribed for a child only when the child is otherwise unable to speak. This inability to speak is a result of a disability that is treated by a speech-language pathologist working together with a physician. These medical problems require medical treatment and an augmentative communication device is one means of medical treatment.

Many health insurance companies across the country cover augmentative communication devices when necessary for treatment of a child with a disability. This is the problem.

When a child needs an augmentative communication device in North Dakota, the child's local school district may have to purchase it --- with no help from the health insurance company. In other words, though an augmentative communication device is a medical expense, in North Dakota it often becomes an educational expense that is borne by the local school district.

During every legislative session we talk about crises in school funding, about ways to help local schools satisfy their budgets, about cutting local property taxes, about how to get more foundation aid to our schools. This session is no different.

We need to declare a state policy that augmentative communication devices and services are medical expenses, not educational expenses. Generally, augmentative communication devices are not a foreseeable expense. Insurance was devised to cover the risk of incurring this kind of expense. Some North Dakota health insurers are not covering even a tiny portion of the cost of augmentative communication devices and services. Without legislation, those same health insurance companies will continue to ignore these needs. Meanwhile, local school districts pick up the expense.

When a school district purchases an augmentative communication device for a student, the device belongs to the school district. I am told that in some instances, the school district does not allow a student to take the device home and the child can only use it in school. On the other hand, if the child's health insurance company covers the purchase of an augmentative communication device, the child can use the device at home, at school, and anywhere else.

I ask you to make a Do Pass recommendation for SB 2330 to the Senate. Thank you.

Proposed Amendments to SB 2330

Page 1, line 17, replace "individual is not responsible to" with "coinsurance may not exceed twenty percent."

Page 1, line 18, remove "pay more than twenty percent of the negotiated cost."

Renumber accordingly

Senate Bill 2330

Testimony of Deb Houdek, PA-C Medcenter One

Madam Chairman and members of the Senate Human Services Committee, my name is Deb Houdek, and I am testifying in support of Senate Bill 2330. This bill states that private payors provide for augmentive communication devices for children who are unable to communicate in any other form and the therapy services needed to assist the child in operating this device. An augmentive communication device is a battery operated machine that is small enough to be attached to the child's wheelchair and programmed so that the child can communicate his or her needs.

These children usually have some form of neurologic disorder such as cerebral palsy, muscular dystrophy, or other congenital anomaly that does not allow control of the muscles. When it affects their legs, we provide assistive devices to help the child with independent mobility such as wheelchairs, walkers, standers and crutches. When it affects their vocal cords and muscles involved in speech, we should provide assistive devices to help them communicate.

This needs to be done for two reasons. First, it is a matter of proper medical treatment. Communication is every bit as necessary as mobility. In fact, for these children, sometimes more necessary to their health. Second, patient communication is critical to the provision of medical services.

Because of this inability to form intelligible words, these children are unable to communicate any of the basic complaints that you or I are able to do such as headaches, stomach pains, nausea, pain in an arm or leg, or discomfort from sitting too long in one position. In a nonverbal child this could delay a diagnosis of a seizure, bowel obstruction, appendicitis or fracture, leading to serious consequences such as a massive infection or death.

Many insurance companies pay for these devices. Unfortunately, the predominant insurer in North Dakota, Blue Cross and Blue Shield, does not. It is the opinion of Blue Cross and some other third party payors that this is not a medical necessity.

I strongly disagree with this. As medical providers, if we are not able to

understand what is wrong and parents or guardians can only guess what the child is trying to tell us, we must delay a diagnosis. We can't treat what we can't diagnose.

The inability to form intelligible speech is a condition that is caused by these diseases. Third party payors agree that if the child can't walk because of their medical condition, a wheelchair or other assistive device for mobility is a medical necessity. If a child can't talk because of the same condition, an augmentive communication device is also a medical necessity that should be covered by these same payors.

I urge your support for this important bill. I'll be happy to try to answer any questions you may have. Thank you.

Senate Committee Testimony SB2330 and 2331 for 2/5/01

Committee Chair and Members,

My name is Donene Feist, from Edgeley, North Dakota. My apologies for not being present today and providing my own testimony, as I am home ill. I would like to make a few comments about SB 2330 and SB 2331.

I am pleased the Senate Committee is hearing testimony on these two very important bills for children with special health needs. I assist many families across the state find information that will assist them in the care for their child with special health needs. Many families for this population do not qualify for public insurance. For many families, whose children need augmentative communication, our private insurance considers this to be non-medically necessary. For many of these children it is medically necessary as this is their very means of communication, and further provides an avenue towards independence. How is a child to let a parent, physician, educational staff know that they are not feeling well if they have no means of communication?

Let us also examine medical necessity. For these children, it is extremely important in determining medical necessity and the services appropriate in the changing managed care systems. Existing definitions of medical necessity may lead to the denial of services required by children and youth with developmental disabilities, genetic disorders, serious mental health problems, or special health care needs. Presently, most definitions are those of which will improve health status. However many children with special health needs frequently need health and medical services that will maintain their health status. Hence, what is not understood is that if these children are denied many services to their day-to-day lives, it is very likely they may deteriorate and regress. We cannot place these children into a one-size fits all plan.

Another purpose for clearly defining medical necessity for this population is to distinguish it from rationing, or withholding of treatment on the basis of cost and outcome. Decisions about medical necessity should be based on a person's medical, health and family situation and not on cost. The key question should be "Does this person need this intervention to maintain or promote health?"

Many families have contacted me regarding the denials that they have incurred. Is this to say to them, that their children are not important? That they are too much of a liability and we have no provisions to assist you. Many of these families, once again, do not have public insurance to assist them. Nor should it matter whether premiums are self-pay or employer pay.

Medical necessity determinations must account for the reality that all situations with these children are different. Again, one size does not fit all. We should always keep in light with this population of children whether the service will help accomplish the child's overall health and functional goals.

With this vulnerable population of children it is also vital to have appropriate peer review. The plan should have in place, review that fully understands the issues of these children. You wouldn't want an OB/GYN to review something regarding Audiology or hearing concerns. You wouldn't want an Urologist to determine whether speech, physical, occupational therapy is appropriate. These children have very complex needs. The insuring provider should not scrutinize it whether the order that was written was appropriate. Our children utilize specialists and have the physicians they have for a reason. They understand the needs of these children! These specialists and physicians, write orders based on the needs of the child, and should be left in the hands of those writing the orders. Their therapies, medications, special diets, equipment, supplies and treatments have a vital purpose for the life of the child. I support the peer review provision added to this bill.

Additionally, there seems to be some confusion on "who these children are." We need to have a mechanism in place to identify these children, and provide quality assurance measures that they are receiving appropriate care. Many states have followed the Federal Maternal and Child Health Definition of children with special health needs. Which is **"Children with or at risk of disabilities, chronic illnesses and conditions and health related education and behavioral problems who require health and related services beyond that needed by most children."** This should be consistent in both the public and private service systems, to have consistency throughout the state. In our CHIP program, Medicaid, nor private insurance do we have this definition in identifying these children.

We have done a wonderful job identifying the needs of children in the general population, but we have missed a very important group with our children with special needs, and I hope this committee will do all that it can to correct this issue, by supporting these two bills.

Thank you

Donene Feist
PO Box 163
Edgeley, ND 58433
feist@daktel.com
493-2333

Testimony supporting SB 2330
Judy Lee, Chairperson
Senate Human Services Committee

Feb 5, 2001

Kevin L. Olson, parent
3141 Arizona Drive
Bismarck, ND 58503 Phone #255-5532

- I'm a parent of an 11-year-old boy named Bryce. Bryce has Cerebral Palsy. Bryce is intelligent and can talk a blue streak, the only problem is that there are very few words that I can really understand. It is often a guessing game trying to find out what he wants, or needs. Bryce is in a wheelchair and has limited gross motor and fine motor skills. He needs a communication device that can be activated with a switch.
- If your child could not talk, you would send him/her to a speech therapist. You would expect your insurance to cover the cost of the therapy. If the therapist said your child would never be able to talk, the insurance company would expect that you stop there. It doesn't matter what the child is capable of doing, you're on your own. We are in the 21st century, there are other options. Augmentative communication devices are as important to these children as your voice is to you.
- The question raised by this bill is how this augmentative device can be provided. If you look at other durable medical equipment, the insurance companies will pay for crutches, wheelchairs, and standers. These devices all help make the child a whole person. In the age of computers, we can help these children communicate their needs.

Brenda L. Blazer
Health Insurance Association of America

TESTIMONY IN OPPOSITION TO SB 2330
Senate Human Services Committee
February 5, 2001

The Health Insurance Association of America is an insurance trade association representing insurance companies who write accident and health insurance on a nationwide basis. The HIAA and its members strongly oppose SB 2330 mandating health insurance coverage for augmentative communication devices and services for children and capping any deductible or copay amount at 20 percent.

All health benefit mandates increase costs. Higher premiums affect the number of individuals able to afford health insurance and the number of employers able to offer health insurance as a benefit to their employees. At this time, health insurance benefits are generally not available for augmentative communication devices unless the child meets certain criteria such as demonstration that the patient has the ability to use the device and measurement of the effectiveness of the device in meeting the patient's communication goals. Coverage may then be subject to a maximum amount limit.

The mandated health insurance coverage for augmentative communication devices and services in this bill is without restriction or limit as long as it is prescribed by the patient's treating physician and speech-language pathologist. Unrestricted, mandated coverage for these communication devices and services will clearly increase health insurance premiums.

Health insurance cannot be all things to all people. Covered benefits should be determined by clinical effectiveness and outcomes. Statutorily mandated benefits does not allow a coverage analysis on whether the benefit has been proven effective.

HIAA asks the Committee to make a "do not pass" recommendation on SB 2330, which seeks to mandate health insurance coverage for augmentative communication devices and services.

February 4, 2001

To: Members of the Senate Human Services Committee

I appreciate this opportunity to express my position regarding the direction of health care coverage for my son, Adam. Adam was born at 25 weeks gestation, weighing 1 pound 12 ounces. He surprisingly had few initial complications from this. However, due to his prematurity, general cares and size he remained in the hospital for 76 days. Within months, Adam's physician began to notice signs consistent with cerebral palsy (CP). Prior to his first birthday, CP became his official diagnosis. He began to receive both occupational therapy (OT) and physical therapy (PT) prior to his first birthday. Services continued one time each, per week until his third birthday. At the age of three, given his medical diagnosis of CP, Adam qualified for early intervention services through Fargo Public Schools. Part of his programming included PT/OT services when necessary to support his academic goals. Within one month of beginning school, Blue Cross Blue Shield (BC/BS) sent initial notification of intent to phase out PT/OT services. The reason given included "ROM (range of motion) was not a skilled service and past documentation shows minimal progress in trunk control and ADL's (activities of daily living)." We were informed that my wife and I would be trained in OT techniques in four sessions over the next three months and then OT would discontinue. From review of therapy progress notes, observation of interaction with his environment, and parental provision of ROM, it was clear that Adam was making slow but steady progress. Documentation from Adam's school based therapists identified that Adam's needs went beyond the scope of the academic setting. His physicians and private therapists also echoed this sentiment. Yet, these recommendations went unheeded. Since the denial of coverage was contrary to the therapeutic recommendations, this decision was appealed. The appeal/denial process began 5/12/00 and subsequently concluded 9/27/00. During the time of the appeal BC/BS asked for Adam's IEP. This was provided to them. We were later advised that due to his receipt of PT/OT at school his services would not be reinstated to their prior level.

We have experienced other lapses in service provision based primarily on the short coverage periods (windows). The therapy windows were designed for rehabilitative treatments from injury or some type of condition occurring after birth. Adam's condition requires a longer window period. Due to the paper reviews, shorter window periods have led to delays in services. Any delays in service could retard growth and development.

Other steps I have initiated: 1) I requested information on the qualifications of the case reviewers who grant or deny extensions or denials. I was advised that this was not available to me. 2) I have requested interactive meetings between Adam's therapists, physicians and BC/BS staff in order to articulate positions. I was told that this was not

a possibility. 3) After my son's initial denial for service coverage, I requested the criteria used in making this determination. I was advised that there were no written guidelines developed to govern this practice. I was advised that these guidelines would be developed within 6 months. This discussion took place in 5/00. I am unaware if these guidelines were developed.

BC/BS began a process (task force) on 1/24/01, intended to address some of the issues mentioned throughout the body of this letter. Prior to the initial meeting, BC/BS reinstated therapeutic services to all children at the level they were at from 12/00 thru 6/30/01. A moratorium was also instituted on denials of therapy until 6/01.

At the initial BC/BS task force meeting, I learned of the two bills now before you. Dan Ulmer, lobbyist for BC/BS, noted that these bills would likely go down to defeat. He identified that BC/BS was not equipped to handle these if passed. These are not new issues. However, they are only now coming to forefront in an official capacity due to organizational efforts of affected families, therapists and physicians each of who are stating that this practice cannot go on any longer. As regulators, you can send a strong message with your decision today. The passage of these bills will show your support for the basic needs of the most vulnerable children in our society. Thank you for your consideration of this material.

Respectfully,

Rick VanCamp



**NORTH DAKOTA PUBLIC EMPLOYEES
RETIREMENT SYSTEM**

For Information Call The NDPERS
Service Unit Without Charge:

Within ND 1-800-223-1704
Out Of State 1-800-874-2858
Fargo Local 282-1400



Underwritten By:

**BlueCross BlueShield
of North Dakota***

4510 - 13th Avenue S.W.
Fargo, North Dakota 58121-0001

PRIOR APPROVAL REQUEST

Provider : Deborah K. Isaacson, MS/CCC-SLP

Clinic/Facility : MedCenter One

Address : 300 North Seventh Street

City: Bismarck **State:** ND **Zip** 58506

Phone:

Subscriber Karen Hipsak

Address 515 W. Ave. A.

City: Bismarck **State:** ND **Zip** 58501

Phone ()

Benefit Plan # YQA502286120

Patient : Keith Hipsak

Birth Date: 2/28/91

Specific Procedure Planned : Extension of outpatient speech therapy benefits.

Signature of Provider

Diagnosis Code(s):

CPT-IV Code(s) :

Date

REPLY

Ref. # ND9926501064

The above procedure is **CONDITIONALLY** approved (see paragraphs below):

The above procedure is **PARTIALLY** approved (see paragraphs below & comments section):

Approval determinations are based on medical necessity provided coverage is in force for the patient and the provider is eligible for reimbursement at the time the services are rendered. Benefits for approved services are subject to the definitions, conditions, limitations and exclusions of this Benefit Plan. Please enclose a copy of this form with your claim submission. The subscriber has been sent a copy of this reply as well.

Upon receipt of this reply the subscriber must further verify benefits by calling the Customer Service phone number listed on the back of the insurance ID card. Providers can obtain benefit information by calling the Provider Service Department at 701-282-1090 or 1-800-368-2312.

Denial Explanation:

Comments: Approval is granted for 1 visit per week for 2 months to establish and update a home

Program The progress notes from January to present indicate minimal gains with no change in goals. This

Is considered maintenance therapy and not covered.

Provider, if you wish a reconsideration of this decision, it must be requested in writing. Please send your request letter to the Medical Management Department and attach further documentation to support the request.

Signature: *Julia Dumais*

Date: 10/1/99



medcenter one

Rehabilitation Center

Accredited by the Commission on Accreditation
of Rehabilitation Facilities

November 8, 1999

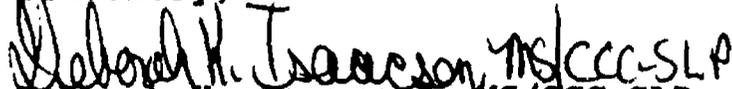
To whom it may concern:

This letter is written to justify continued speech therapy services for Keith Hipsak. Keith has been receiving direct speech therapy at Medcenter One Pediatric Therapies Department since February, 1999 to present. Recently, Blue Cross/Blue Shield decreased Keith's allowed speech therapy from three times per week to one time per week. Benefits are available at this frequency for only two months. It is important for Keith to continue direct speech therapy in order to increase his intelligible vocalizations and to provide alternative and augmentative communication systems. It is my professional opinion that it is very important for Keith to continue with therapeutic interventions in these areas so he can communicate his wants and needs to family and caregivers.

Keith has made progress with using sign language to communicate. He is able to respond to questions using sign language, which helps to communicate his needs to his listener. He has also made significant progress with using a picture system to communicate, in order to express sequence of activities, and items needed in order to complete a task.

If there are questions or concerns, please contact me at (701) 323-6198.

Sincerely,


Deborah K. Isaacson, MS/CCC-SLP
Speech/Language Pathologist

Medcenter One, Inc.

300 North Seventh Street
P.O. Box 5525
Bismarck, North Dakota 58506-5525
Telephone 701/323-6176

A health care
organization of



United to improve
America's Health™

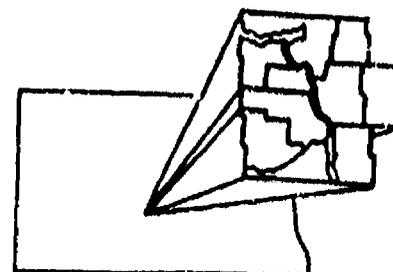


Edward T. Schafer
Governor

WEST CENTRAL HUMAN SERVICE CENTER

800 South 2nd Street, Bismarck, ND 58504
(701) 328-8888 FAX (701) 328-8900

North Dakota Department of Human Services
State Capitol, Bismarck, ND 58505
Carol K. Olson, Executive Director



Matthew W. Walsh
Regional Director

January 6, 2000

Karen Hipsak
Easter Seals
P.O. Box 1206
Mandan, ND 58554

Re: Keith Hipsak (DOB: 2/28/1991)

Mrs. Hipsak,

As you requested, I am providing a summary of my involvement with Keith and my recommendations regarding his current speech therapy needs. I have been providing behavioral and psychological consultation to Keith's treatment team since September of 1998. I have provided consultation regarding Keith's behavioral and psychological needs at home, school, speech therapy, and occupational therapy. As you know Keith has been diagnosed with Pervasive Developmental Disorder, NOS (PDD) which is characterized by a severe and pervasive impairment in the development of reciprocal social interaction skills, verbal and nonverbal communication skills, and a restricted range of interests.

The best prognosis for children with PDD is associated with the development of a functional communication system during childhood. Keith has been successfully using a limited amount of verbal communication, sign language, and augmentative communication for several years. It is obvious, however, that his communication skills are not entirely satisfactory at this time and would not be characterized as a functional communication system. Keith will require ongoing speech services if we are to maximize potential gains. A well known fact about problematic behaviors (e.g., head-banging, finger biting, scratching, kicking) is that they are frequently preceded by an inability to effectively communicate wants and needs. If Keith's communication skills do not continue to progress, it is likely that he will experience increasing levels of frustration regarding his inability to communicate. Frustration is often manifest as aggressive or self-injurious behaviors in children similar to Keith. Keith has already displayed a tendency to engage in self-injurious and aggressive behaviors. Therefore, I believe that it is of the utmost importance that Keith continue to receive speech therapy services including efforts to teach verbal communication and augmentative communication.

There has been some question regarding the appropriate role for augmentative communication systems in treatment. When children with PDD experience difficulty acquiring verbal communication, augmentative communication systems are typically recommended. The purpose of adding an augmentative system is to increase communication. An increase in communication, using augmentative devices, has been shown to increase speech and not impede it; therefore, initiating an augmentative system sooner rather than later will only help speech develop. The ultimate goal, however, is to fade the use of the augmentative system when verbal communication is sufficient. Augmentative communication should therefore be viewed as a tool that may help facilitate the acquisition of verbal communication skills.

Due to his diagnosis, Keith's progress in speech therapy will likely proceed more slowly than other children who receive speech therapy. His benefit from this service should be judged on an individual basis including an examination of his progress or lack of progress with specific areas of language acquisition. If a lack of progress is noted, then a careful examination of the reasons for the lack of progress should be conducted in order to determine if the problem areas can be addressed. It is recommended that Keith continue to receive speech therapy services targeting verbal communication and augmentative communication.

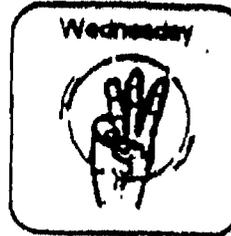
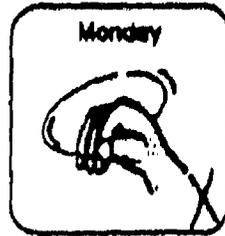
If there are questions or concerns, please feel free to contact me at 328-8835.

Sincerely,

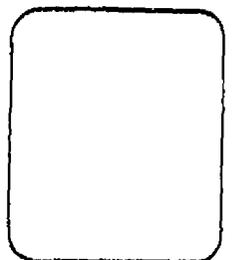
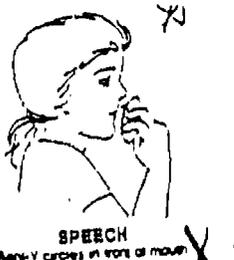
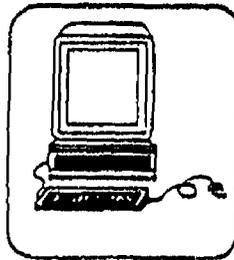
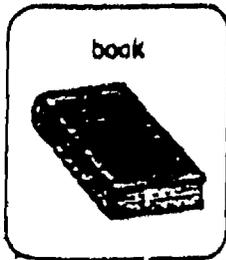
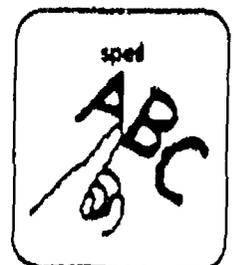
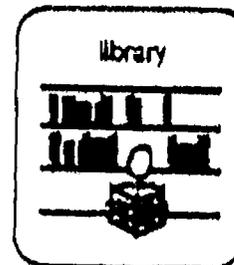
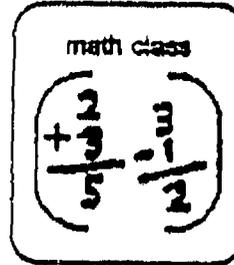
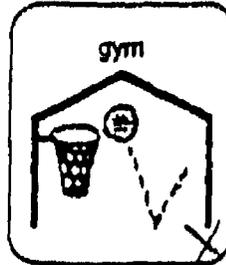
Richard E. Arndorfer, Ph.D.
Richard E. Arndorfer, Ph.D.
Psychologist II

Today is:

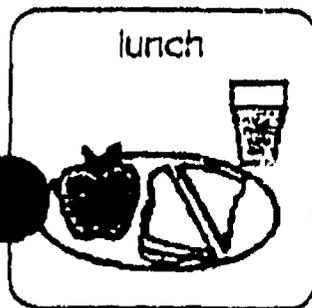
Oct 30, 2000



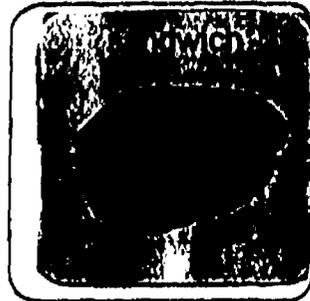
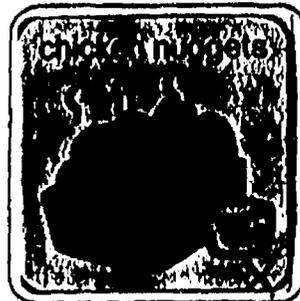
Today I had:



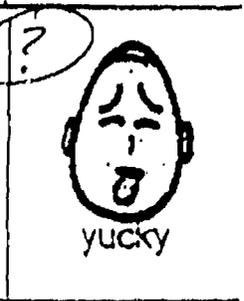
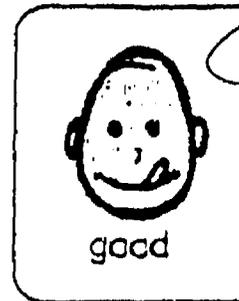
SPEECH
Sensory codes in front of mouth
(see MOUTH)



I ate

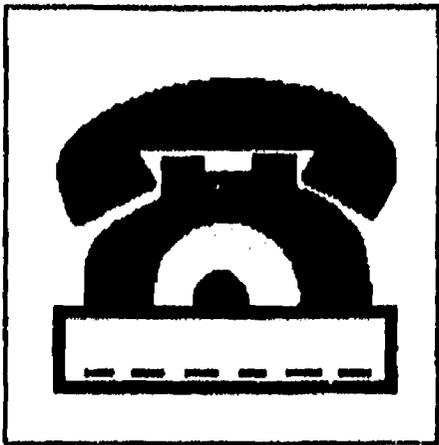


it was



Message from aide: There's a pre-conference survey question to be filled out & returned to school. Thanks!
Keith did not eat much lunch. Some peaches and milk. He laid his head down most of lunch time. He did go out and play at noon recess.

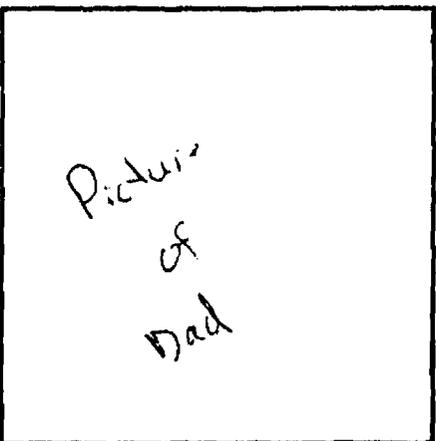
Message from home: You may notice Keith having some difficulties with chewing. 5 teeth were pulled on Friday. He has a big gap on his lower left hand side.
What does Keith need to bring for the Halloween Party? Are they having the parade again? yes
Have a good day.
How did it go with Keith choosing between food & snack?



224-8150



515 WAVE A.



DAD

SUPER SPELLER



Name: Heith Hipsar

9.

10.

11.

12.

1. Hati

2. Mom

3. home

100%

4. dad

5. 224-8150

6. Feb 28

7. Hipsar

w/ little help

8. 515th ave. A

had

13.

14.

15.

16.

17.

18.

19.

20.

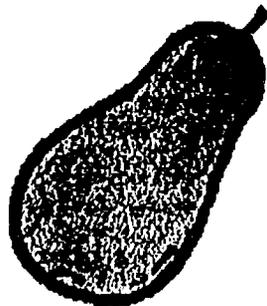
look at 3 times
card
I'm coming
along

SOUND BOARD (SOUNDS P B)

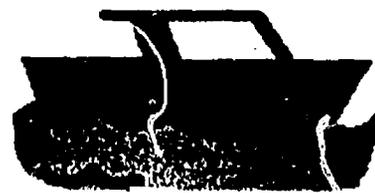
baby



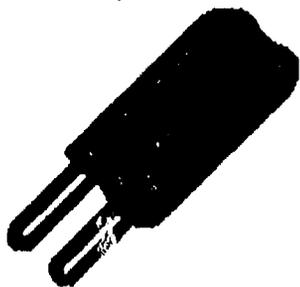
pear



boat



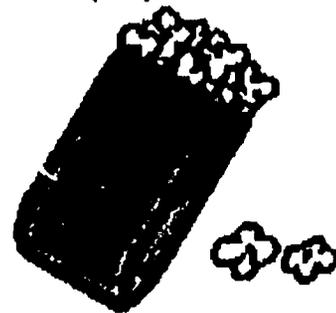
popsicle



bear



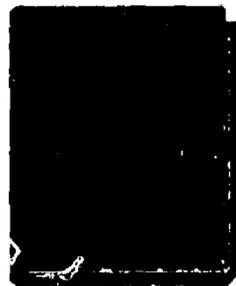
popcorn



pizza



book



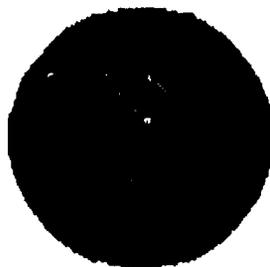
pineapple



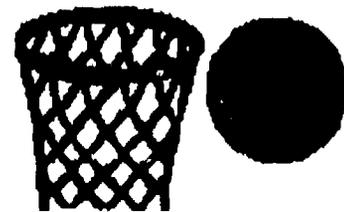
pajamas



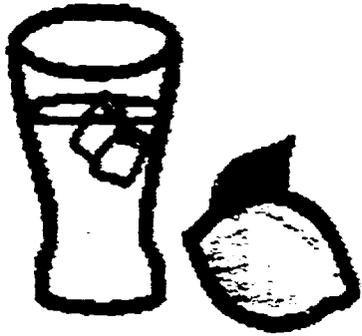
ball



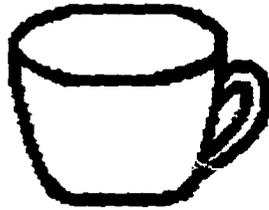
basketball



lemonade



cup



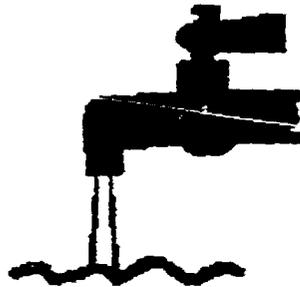
1 cup



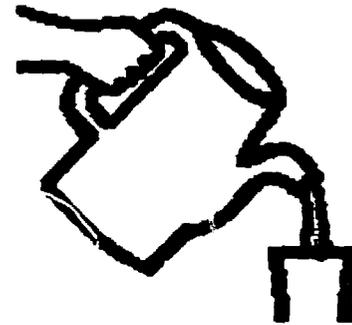
cooking spoon



water



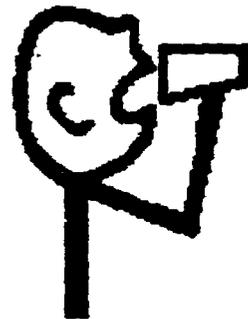
pour

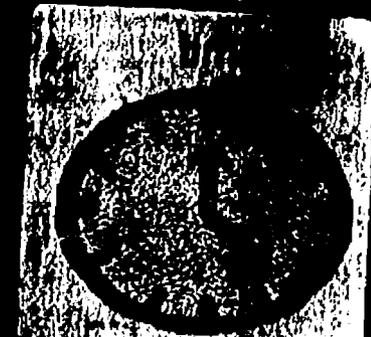


stir

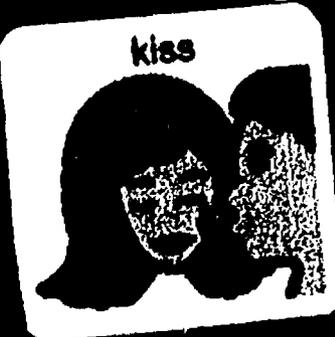


drink

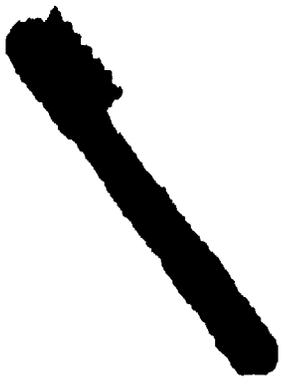




bed



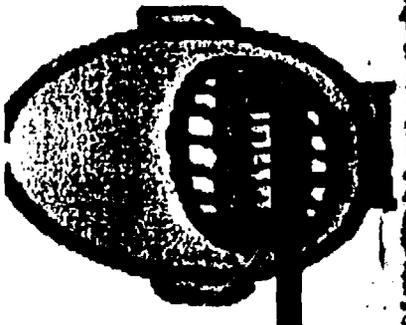
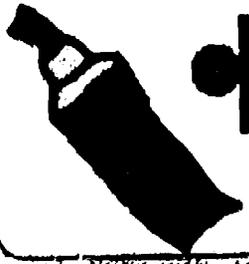
toothbrush



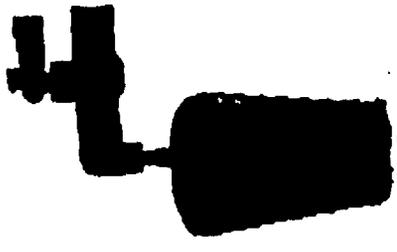
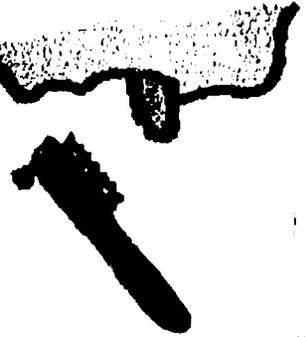
toothpaste



razor



tongue



Sen Fischer

Amendment for SB 2330

Page 1, delete lines 5 - 23

Page 1, line 1, add "SECTION 1. The legislative council shall consider studying during the 2001-2002 interim, the coordination of benefits for children with special needs under the age of 21 among the Department of Public Instruction, the Department of Human Services, and private insurance companies, with the purpose of optimizing and coordinating resources and expanded services including augmentative communication devices and therapy services. The study shall include reports from any private insurance company's task force concerning the coordination of these services."

Page 2, delete line 1 - 2.

Renumber accordingly.

February 5, 2001

To: Members of the Senate Human services Committee

From: Sherwin & Annette Kaip
307 Seventh St. NW
Mandan, ND 58554

Thank you for taking time to listen to our concerns. Our six year old son, Michael, has Cerebral Palsy. In May of 1999 Michael had a Selective Dorsal Rhizotomy. In this surgery, about 35% of the sensory nerves in his lower spinal cord were severed in order to reduce the spastic tone in his legs. He was hospitalized for 6 weeks. Michael walked before the surgery and we knew that his walking would eventually improve due to the rhizotomy. However, he had to start all over again. It took him three months before he could walk without a walker and is still working on improving his walk and all areas of physical mobility.

During the first six weeks following surgery, the pediatric neurologist prescribed physical therapy two times a day and occupational therapy once a day while he was in the hospital. He received the therapies prescribed and improved quickly. We returned to North Dakota. The pediatric physiatrist and pediatric neurologist both prescribed physical therapy five days a week for the first six months. Michael was learning to walk all over again. There were many variables that affected Michael's ability to improve his condition. This learning was "NEW" learning. His brain had already imprinted old patterns of movement that needed to be erased, while at the same time learning new patterns that he was now physically capable of because of the surgery. Due to the nature of the surgery and the recovery, Michael had not used his muscles for six weeks. They were very weak and took a long time to build up. Growth spurts changed the length of Michael's legs and muscles became tighter. Movements that may have been mastered once had to be re-taught and re-practiced due to these changes.

When coverage for the therapy was requested from BCBS, it was reviewed by a person who had no training or experience with pediatric rehabilitation and no understanding of what a selective dorsal rhizotomy is. Michael was treated as though he was an adult who underwent a minor knee surgery and fifteen days of therapy over a six week period were approved. We had no choice but to use the therapy up in 3 weeks and fight the insurance company. Letters from Shrine Hospital doctors and therapist as well as Med Center One were sent to the Insurance company. A detailed description of the surgery was also sent. Michael's therapist tried to reach the BCBS employee reviewing our request. Initially, she was denied the opportunity to talk with him and was not allowed to even know his name or have any contact with him. She was persistent and spent many hours trying to find a way to get the therapy approved. Eventually we were granted three months of therapy. Every three months therapy has to be re-applied for and re-approved. Every three months the therapist has to spend more time to get approval on therapy

that has been prescribed by pediatric doctors. It has been almost twenty months since the surgery. BCBS has reduced Michael to two sessions per week. His progression has slowed considerably. Recovery for the selective dorsal rhysotomy is approximately two years according to professionals in this field.

Michael also receives occupational therapy. He initially received OT once per week according to BCBS policy on his initial evaluation and follow-up therapy. After three months BCBS reduced OT to two times per month. Michael's progression slowed or stopped in most areas. Learning at this age requires repetition. A child with a disability requires more repetition for the same learning. With persistence and time, Michael's therapist was eventually able to convince BCBS to increase the therapy to once per week. His is once again progressing.

Insurance companies argue that therapy should be used for consultation and intense home programs should take the place of professional therapy. As the parents of a child with a disability, we want you to know that we love him very much and would not trade him for any kid in the world. But the reality is that everything we do, every activity, bath time, dinner time, outings, getting dressed, getting ready for bed, picking up toys, ...everything we do takes longer. We spend time almost everyday stretching Michael. We try to do as much of his home therapy program as we can. When we run out of time we feel guilty. Another reality is that a disability in a family puts more stress on everyone in that family. When the insurance company tells us that we have to take the place of the professional therapist, stress increases. What Michael really needs from us is time when his mom is just being his mommy and his dad is just being his daddy.

We strongly encourage you to support Senate Bill 2330 and 2331. This Bill will allow children to receive the services they need. It will also allow therapists and doctors to spend their time doing the jobs they were trained to do without having to constantly argue with insurance companies on what constitutes "medical necessity." It will unburden parents who are forced to take the place of the professional therapists when not adequately trained to do so. Please do everything you can to get these Bills passed. Thank you for your time.

SB2330 Testimonial

As an occupational therapist, I urge you to vote, "no" on Senate Bill 2330. Although I fully agree that augmentative communication devices should be covered by insurance plans, I do not agree with the wording of the bill that excludes occupational therapists as part of the team.

"Design, provision, and training in assistive technology," is included in the scope of practice set forth by the North Dakota State Board of Occupational Therapy Practice.

Although speech and language pathologists do address the cognitive and communication skills required in selecting and training in the use of augmentative communication devices, **occupational therapists** are involved in the physical skills required to use the device as well as the functional use of and access to the device.

Is the device easily used at home, at school, at daycare, and in other aspects of the community?

Is the individual physically capable of using the device?

Without an occupational therapist, these questions cannot be fully answered nor can the deficits be remediated or adaptations made to increase the independent use of the augmentative communication device by the recipient of the device.

I ask that you amend this bill to include occupational therapists.

Michelle Ragen

I am a pediatric speech therapist working with children with disabilities. Some of these children with disabilities cannot speak; some of these children may never speak. These children require a device to speak for them.

Many insurance companies do not cover these communication devices, nor do they pay for therapy services needed to teach the children how to use the devices.

The public schools do a wonderful job supplying communication devices to children who need them. My concern is that the school district has the responsibility to pay for the device and this may be difficult for the smaller rural school districts.

Real Alternatives

Real Alternatives is a non-profit, charitable organization committed to assisting women in crisis pregnancies by providing compassionate, practical, life-affirming alternatives to abortion.

Real Alternatives administers the state-wide alternatives to abortion program for the Department of Public Welfare. Real Alternatives exists to:

improve a woman's physical and mental well-being during her pregnancy and post-natal period.

improve the physical well-being of the unborn child and the newborn.

and encourage adoption as an option for women who are unable to parent.

There are 110 pregnancy centers, adoption agencies and maternity homes throughout Pennsylvania who can support you with your parenting or adoption decision. Over 37,000 women in Pennsylvania have turned to us for help since 1996. Give us a call!



1-888-LIFE-AID

Caring, Confidential & Free
Pregnancy, Adoption Services
for Women and Children

Real Alternatives
7810 Allentown Blvd.
Suite 304
Harrisburg, PA 17112

Administrative 717-541-1112
Fax 717-541-9713

www.realalternatives.org

Real Alternatives is duly registered as a charitable organization with the Commonwealth of Pennsylvania Department of State. A copy of the official registration and financial information of Real Alternatives may be obtained from the Department of State by calling 1-800-732-0999. Registration does not imply endorsement.

Pregnant?

Worried?



There is help

► Caring,
confidential &
free
services

Real Alternatives

Program funded through PA
Department of Public Welfare

...are pregnant, or you think you
...can be pretty scary. You didn't
...you're not sure how your
...boyfriend, or other people in
...react. Maybe you're scared
...feeling like you're alone. But
...There are people who understand
...They'll take the time to listen
...and they'll give you the help and
...support you need.

Will you tell anyone?

If you're not ready to tell anyone that you're pregnant, that's okay. Everything is confidential! Our counselors will listen to you, not judge you, and they'll be with you every step of the way during and after your pregnancy.

If you are eligible, all services are free! Project Women In Need (WIN), is a program set up by the government to help pregnant women and their babies in Pennsylvania who are living below 185% of the poverty level. Counselors at our

centers, however, will help everyone who is experiencing an unplanned pregnancy. Do you have a PA Access Card? You're automatically eligible to receive free assistance!

If you call us toll-free, a counselor will put you in touch with a local center that can help you.

- If you're not sure if you're pregnant, we can provide you a PREGNANCY TEST KIT.
- COUNSELING is available to you, so that you can talk about your situation and get the help that you need, whether you choose to parent your child, or to make an adoption plan. The choice is yours.
- If you don't have a place to live and you are eligible, your counselor can search for a TEMPORARY APARTMENT for you- a safe place where you can live before and even after your baby is born.
- Your counselor can REFER YOU TO OTHER RESOURCES (FINANCIAL) for health

insurance, public assistance, WIC, and any other help you need to care for your baby.

- There's a lot more your counselor can help you with, like maternity & baby clothing, food, and furniture...whatever you need to keep you and your baby healthy.

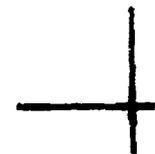
How can I find you?

Finding us is as easy as picking up the phone! There are over 100 Project WIN centers in Pennsylvania.

Call us toll-free at 1-888-LIFE-AID. We'll put you directly in touch with a counselor and get you and your baby the help you need and *deserve* right away. Or check out our website www.realalternatives.org for a complete list of all of our centers.

Call to talk to women who care...

 **1-888-LIFE-AID**





Mission Statement

The NDDAC will advocate for public policy that ensures all people with disabilities and their families are fully integrated into the mainstream of society. We will work to:

- ▶ Improve the quality of life through greater independence, empowerment, and self determination.
- ▶ Guarantee the freedom to exercise rights and responsibilities as citizens of North Dakota.
- ▶ Promote universal accessibility and inclusion in all aspects of community life.
- ▶ Uphold the values of the Americans with Disabilities Act

To Accomplish its Mission NDDAC will:

- ▶ Identify and research public policy issues, develop testimony and policy recommendations, and encourage innovative solutions to public policy concerns.
- ▶ Educate legislators in an effort to improve public policies and programs for individuals with disabilities.
- ▶ Encourage people with disabilities and their families to advocate for themselves and coordinate grass roots efforts to support them.
- ▶ Advocate for a consumer-friendly service delivery system.

NDDAC Member List

Dakota Center for Independent Living
Mental Health Association in ND
The Arc of Cass County
North Dakota Family Voices
ND Statewide Independent Living Council
The Arc of Bismarck
Bismarck Public Schools
ND Federation of Families for Children's Mental Health
People First of ND
ND Center for Persons With Disabilities
Friendship INC.
ND Protection & Advocacy Project
Options Inc.
North Dakota IPAT
ND Association of the Deaf
Freedom Resource Center for Independent Living Inc.
United Voices

and growing.....



FACTS SHEET Re: SENATE BILLS 2330 AND 2331

Reason for Action

Senate Bills 2330 and 2331 were written in response to the inappropriately justified authorization of insurance benefits for children in North Dakota with special needs as related to augmentative communication devices, therapy services, and medically necessary equipment.

Purpose of Legislation

Senate Bill 2330 will require insurance companies of North Dakota when deemed medically necessary by a child's physician and therapist to provide coverage for augmentative communication devices and the speech therapy required to use them.

Senate Bill 2331 will require insurance companies of North Dakota when deemed medically necessary by a child's physician and treating therapist to provide therapy service and equipment for a child under 21 years of age.

Current Problems

1. If a child cannot speak, BCBS of ND has a zero payment policy for purchase of an augmentative communication device and the speech therapy service to learn utilization of the device.
2. Of a multitude of different private and public insurance organizations identified by our task force, including Medical Assistance of North Dakota, BCBS of ND remains the only one with a zero payment policy on augmentative communication.
3. BCBS of ND has no documented definition of medical necessity as it pertains to children with special needs.
4. BCBS of ND is consistently denying therapy services and equipment to children with special needs when the treating physician(s) and therapist(s) have recommended the services.
5. BCBS of ND has no consistent peer review process for children with special needs. Because of this, adult health care providers with little pediatric specialty experience often deny therapy services and equipment determined medically necessary by the pediatric based treating physicians and therapists.
6. BCBS of ND has implemented inappropriate episodes of therapeutic treatment for children with special needs often based from an adult model.
7. BCBS of ND has recently demonstrated a "cook book" type of approach when authorizing benefits for therapy services for children with similar diagnoses but very different levels of functioning. The focus, thus, is on diagnoses versus the individual medical needs preventing the child from reaching his or her maximal functional ability.
8. BCBS of ND has on several occasions, when reviewing the need for medically based services, requested information regarding current educationally based services to justify their authorization of benefits, even though medical instead of educational needs have been justified by the treating physician and therapist. In compliance with the IDEA Act, this information is completely separate and should in no way affect their ability as North Dakota citizens to obtain medically based services through a private insurer.

Senators:

1. Chairperson – Judy Lee (R) – West Fargo, ND
2. Vice Chairperson – Ralph L. Kølzer (R) – Bismarck, ND
3. Robert S. Erbele – (R) – Lehr, ND
4. Thomas Fischer – (R) – Fargo, ND
5. Tim Mathern – (D) – Fargo, ND
6. Michael Polovitz – (D) – Grand Forks, ND

RE: Senate Bill #2330 & Senate Bill #2331

- Introduced by Senator Tim Mathern (D) – Fargo, ND; Senator Russell Thane (R) – Wahpeton, ND; and Representative Gail Fairfield (D) – Eldridge, ND

My name is Leon D. Keller, I am the Director of Rehabilitation Services at Medcenter One. One of the areas that I manage is the Pediatric Therapy services to include physical therapy, occupational therapy, and speech therapy. I am supporting these two pieces of legislation, because I believe that insurance companies of North Dakota have not implemented the appropriate insurance coverage for children with special needs. As manager, I have seen the tremendous amounts of documentation that the therapists have to submit to Blue Cross Blue Shield of North Dakota (BCBS) in order to get extensions for services and/or pre-authorization for services. This documentation is required because BCBS of North Dakota consistently denies services and equipment for children with special needs even though the treating physicians and therapists have recommended the services as medically necessary.

It appears to me the reasons for the denials of services stem from the fact that BCBS of North Dakota has:

1. No documented definition of medical necessity as it pertains to children with special needs;
2. And, no consistent peer review process for children with special needs. Because of this, the adult health care consultant will deny services and equipment that the pediatric specialist has found to be medically necessary.

Other reasons for requiring this documentation is that BCBS of North Dakota has implemented inappropriate episodes of therapeutic treatments for children with special needs often based upon an adult model at BCBS. Recently, BCBS of North Dakota has demonstrated a "cookbook" approach when authorizing benefits for therapy for children with similar diagnoses but very different levels of functioning. The focus is on the diagnosis versus the individual's medical needs, which prevents the child from reaching his or her maximal functioning ability.

When the therapists have to spend time writing letters, faxing, and re-faxing notes to BCBS, it takes time away from providing services to the children. This is time that would also be spent on developing new programs that could possibly educate parents and prevent disabilities. It also takes time on BCBS's part to review all of this information. This is a gross inefficiency of time for the therapist, and I would suspect for BCBS of North Dakota as well.

As a manager who is also a physical therapist, I have always believed that the physician working with the patient and therapist must determine the medical need of the patient. The mainstay of both of these bills relies on the determination of medical necessity by a pediatric specialist and the peer review process by a similar pediatric specialist.

SB 2330
TESTIMONY
SENATE HUMAN SERVICES COMMITTEE
FEBRUARY 5, 2001

Good morning Chairwoman Lee and members of the Human Services Committee. My name is Jon Rice. I am a Medical Director at BCBSND. It is my pleasure to appear before you and discuss senate bill 2330 and provide some recommendations as to how this bill should be handled.

Historically, BCBS benefit plans have specifically excluded augmentative communication devices. Under exclusions in our standard contract language is the following exclusion, "electronic speech aids, robotization devices, robotic prosthetics, myoelectronic prosthetics, customized cutaneous dermal protective covers, endolite prosthetic systems, or artificial organs." Those with a historical background believe that the origins of this type of exclusion were from the fact that many of the services in the electronic speech area were related to school activities and covered in schools. An additional exclusion in our contracts exists relating to services performed in schools. That exclusion reads, "services when benefits are provided by any governmental unit or social agency, except for Medicaid, or when payment has been made under Medicare Part A or B. Medicare Part A and Part B will be considered the primary payor with respective benefit payments unless otherwise required by federal law." Because of concerns that have risen over the past year and that were brought specifically to our attention in the community forums that were held around the state, BCBSND is working with a task force of interested parties in an effort to better supply necessary services to children with special healthcare needs including OT, ST, and PT. This task force includes physicians, parents, occupational, speech and physical therapists as well as members from the Department of Public Instruction and Department of Human Services. One of the efforts of this task force is to avoid duplication of services and unwarranted duplicative services to our members.

It has been particularly difficult in the area of speech therapy to separate the roles of the Department of Public Instruction and the insurance companies in regard to speech therapy and augmentative communication devices. It is our understanding that the school system is required to supply these devices for students that need them. It is also our understanding that, as a general rule, these devices are not allowed to go home from the schools with the students. If that in fact, this is the case, a mandate such as we are looking at could conceivably provide students who are insured and in the public school systems with two devices. We feel that we need to carefully mesh the public entitlements, the role of the public school system, and the role of the insurance industry as we care for individuals that may need this type of assistance.

Specific concerns about the bill include the fact that the language in the bill stating that the individual is not responsible to pay for more than 20% of the negotiated cost. This language bypasses current deductibles and copay rules as well as allowances for durable medical equipment. Also, there is not, within this bill, a definition of an augmentative communication device. These devices may run from simple signboards or simple electronic devices at a price of \$50 to \$100 up to computer-assisted devices that may run in the \$5,000 to \$10,000 range.

It is important to assist children with difficulties in communication. We do not think a mandate for this coverage is appropriate for three reasons: 1) All children will not be covered by the insurance mandate and ERISA plans specifically are excluded from this service, 2) There is a task force at work attempting to redefine the insurance role and to try and integrate the roles of the education system and the Human Service system in these situations, and 3) If this policy-making body determines that specific action needs to be taken, more appropriate action would be to study the roles of the Department of Public Instruction, school system, Department of Human Services, and the private insurance industry and how their roles can be integrated together to provide comprehensive and non-duplicative services to these children.

I thank you for your attention and would be happy to respond to questions to the best of my ability.

Prepared testimony for the hearings related to Senate Bills 2330 and 2331

As a mother of a developmentally delayed child with the diagnosis of "microcephaly", translated into lay terms as "small head", I come here today seeking a resolution for all children. I am not a stranger to health care, I have been a registered nurse for over twelve years now. The information that I present here today was obtained by my own personal experiences and is my own perception of the issues at hand.

The disillusionment faced by parents of children with disabilities is partially caused by the disbelief that this is happening to them as a family but more prevalently by the red tape involved in the procurement of services for their children. I have never been blind to the needs of compromised children having worked in maternal child areas most of my career, however prior to my own experiences I have been guilty of seeing the world through rose colored glasses. In January of 1997, with the birth of my daughter Bryce the glasses came off. I was awakened to the struggle of parents dealing with meeting the needs of their compromised children. **The most debilitating aspects of our circumstances as parents of these children is our inability to fight for their rights with insurance companies.** I was completely ignorant in my understanding of insurance and the role it would play in the quality of life for my child. My mistake in all this was the trust I placed in the fact that I was insured and therefore felt I was protecting and guarding my family from any health misfortunes that may occur. I could not have imagined or anticipated the amount of time and energy that would be required in battling for services my daughter Bryce would need to achieve the best quality of life possible. Services that physicians directly involved in my daughter's care deemed medically necessary for her to achieve the best quality of life possible. Since her birth, Bryce who is now four years old, has seen the same pediatrician, the same pediatric neurologist, the same pediatric physiatrist and the same pediatric ophthalmologist. They have all said verbally and in written documentation that she needs and would subsequently substantially benefit from various therapies. Yet, my insurer BCBS of North Dakota in numerous letters of response to letters of appeal for denied services, without ever laying a hand or eyes on Bryce continued to dictate medical necessity for services. One of their standard responses: **PLEASE KEEP IN MIND THAT BENEFITS ARE ONLY AVAILABLE FOR MEDICALLY APPROPRIATE AND NECESSARY SERVICES.** In my mind these services were medically indicated according to the experts that had worked with Bryce throughout her short life. Finally after numerous phone calls and persistent resubmittance of documentation from these health care professionals a second statement: **PLEASE KEEP IN MIND THAT BENEFITS ARE ONLY AVAILABLE FOR MEDICALLY APPROPRIATE AND NECESSARY SERVICES, SUBJECT TO THE CONDITIONS, LIMITATIONS AND EXCLUSIONS OF THE PATIENT'S BENEFIT PLAN.** The reality of all this came down to one conclusion, having medical insurance means absolutely nothing if the insurer continues to deny claims first under the premise that the service is not medically indicated and second when the letters of appeal continued to surface under the exclusion of the patient's benefit plan. In your consideration of the issues at hand, please consider the level of frustration in dealing with this absurd paradigm. My belief is that when it comes to children medically appropriate and necessary services should never be subject to the conditions, limitations and exclusions of the patient's benefit plan. Insurance companies **should and could** formulate a product that meets the needs of these children. Our children should never face a day where they are denied an opportunity for best quality of life possible on a slight technicality, oh by the way it's not covered!

Who sold us, through our employers these insurance plans anyway! Insurance companies spend a great deal of man power and resources on denials of claims, would these dollars benefit children more by using these funds to create a product that genuinely cares about children all children! As a parent I ask myself this question daily... If I do not act as a voice for my child and the numerous other children who will? At this point that is why we as parent's are here today, to act as advocates for our children and the children of future generations. We need to emphasis that insurers must sell a product that is in the best interest of these children. The reality is that these services are expensive to supply but these children do benefit from these services and the focus must always be on giving them every opportunity humanly possible to grow, survive and thrive in the community. Insurance companies need to develop a suitable product that adheres to the inherent needs of children with disabilities. It is so disheartening to see parents struggle continuously for the rights of their most precious commodities. The struggles are day in and day out for most of these families, if we can alleviate any of the stress, trials and tribulations then we are obligated to do so. If we here today do not act in these children's best interest who will? If those of us who are able do not educate the general public on the lack of services covered in these plans who will? If we do not articulate the needs of the innocent children affected who will? If our elected officials do not remove the obstacles and barriers these families face with the appropriate legislation who will? **We can no longer allow the public to be lulled into a false sense of security by thinking, no problem we're insured.**

Respectfully Submitted By: M.J. Ajlouny, R.N., BSN.
February 5, 2001.

Blue Cross Blue Shield Proposal for Compromised Children

A. Medical Necessity: Any service is medically necessary if it is deemed necessary by a medical physician who has seen and evaluated a patient and renders the decision that a patient would benefit from a service to improve the patient's potential for normal growth and development hence enabling the patient to achieve the best quality of life possible.

B. Services: Services can be defined by the physician and can be but are not exclusive to referral to another physician, professional therapies, devices which are proven tools to assist in the goal of best quality of life possible.

C. Insurance: Insurance is a product that is formulated, this product in the provision of services to infants/children should include full and non-restrictive criteria based on medical necessity, to aid in obtaining the goal of best quality of life possible. At no time should medical necessity be the decision of the insurer, they are not the physician who has been working directly with the patient nor have they seen and evaluated the patient.

D. Case Managers: One qualified case manager should work in conjunction with the professionals working with the patient on obtaining the goal of best quality of life. At no time should a child have multiple contact individuals. The child needs to be evaluated in his or her totality to maintain expert decision making to obtain the goal. These case managers should be live individuals who are readily assessable and have knowledge of the services offered the child. One or two case workers assigned to a facility may be an option and in all probability be advantageous to all parties. At no time should resources be wasted in the pursuit of discrediting the contribution that each party is able to provide in reaching the goal of best quality of life provided. A mutual relationship of trust and collaboration will be expected in order to render positive impact on quality of life.

~~2/23/00~~
2/23/00

Members of the Senate Human Services Committee,
My name is Sady Paulson.

I am an Eighth grade student at Wachter Middle School
in Bismarck.

I need an augmentative communication device in order
to speak. When I use a computer like this to speak, the
people I talk to realize that I only have a physical
disability. I really am just as smart as any other eighth
grader.

This is the third communication device I have used in my
school career. I need access to augmentative
communication devices and services in order to do my
school work and communicate with my peers.

Thank you

**Testimony for SB 2330
House Human Services Committee
March 12, 2001**

*Legislative
Study*

Madam chair and committee members, for the record I am Rod St. Aubyn, representing Blue Cross Blue Shield of North Dakota. When SB 2330 was first introduced it would have mandated insurance coverage for augmentative communication devices. It was introduced along with SB 2331, which would have mandated coverage for any services or equipment for children with special needs under the age of 21. Both of these bills were heard in the Senate Human Services Committee. Dr. Rice, one of our Medical Directors, explained the problems with both bills as they were originally drafted. We had informed the committee about a task force BCBSND had developed in response to concerns heard during one of our Town Hall Forums held around the state last year. This task force is comprised of parents of children with special needs, occupational therapists, physical therapists, speech therapists, a representative for DPI for special education, a representative for Human Services for the Development Disabilities Department, and representatives from BCBSND. A facilitator was hired to coordinate the task force. The idea of the task force was to explore the issues of the augmentative communication devices and therapy services for children with special needs. Planning for the task force began in the end of October. It was our intent that the task force would complete its tasks by the end of April, so that the proposals could be considered during our insurance contract re-write, which would be completed by the end of June or early July, 2001.

One of the issues to be considered is the coordination of services between DPI, the Department of Human Services, and private insurance companies. Duplication of services needs to be minimized if at all possible. That is one issue being explored by our task force. Our task force met toward the end of January. Four subcommittees were established and each of those met at least two different times before the full committee's second meeting at the end of February. Much progress has been made during these meetings. It is hoped that recommendations will be made at the March 29th full committee meeting for benefit changes in our policies.

This bill was changed to a study by the Senate Human Services Committee, with the intent of studying the coordination of benefits among the departments of public instruction, the department of human services, and private insurance companies. A report from our task force will be supplied to this study committee. We are in support of this study. Much progress has already been made in our task force, but I would also expect many other benefits if a complete study should be completed during the interim. BCBSND stands ready to participate fully in this study.

Madam chair and committee members, we strongly support this study and I would be willing to answer any questions you may have.

Rod St. Aubyn
Blue Cross Blue Shield of North Dakota