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Health Care Consumer Advisory Board

Report on Recommendations for a Complaint Resolution Process

January 14, 1998

HEALTH CARE CONSUMER ADVISORY BOARD MEMBERS

Bill Blom (Co-Chair)
Bloomington, Mn.
United Cerebral Palsy
Appointed by: Consortium for Citizens with
Disabilities (CCD)

Roger Clark
Side by Side Institute
Appointed by: Mn. House of Representatives

Andrea Everett
Minneapolis, Mn.
Appointed by: Minnesotans for Affordable Health Care

Linda Giersdorf
Mankato, Mn.
Region Nine Area Agency on Aging
Appointed by: Governor

Alvin Huff
Glenco, Mn.
AARP
Appointed by: Governor

Cindy Johnson
St. Paul, Mn.
Advocate
Appointed by: Consortium for Citizen with
Disabilities (CCD)

Roger Krantz
Duluth, Mn.
Appointed by: Minnesota Chamber of Commerce

JoAnne Korkki
Brooklyn Center, Mn.
Minnesota COACT
Appointed by: Health Care Campaign of Minnesota

Pete Ross
Bloomington, Mn.
Minnesota Senior Federation
Appointed by: Mn. Senate

Kate Stahl
Maplewood, Mn.
Appointed by: Mn. House of Representatives

Elizabeth Tucker
Bloomington, Mn.
Appointed by: Legal Services Advocacy Program

Joyce Shellhart Warner (Secretary)
Belle Plaine, Mn.
Multiple Sclerosis Society
Appointed by: Minnesotans for Affordable Health Care

Ellen Weiss (Co-Chair)
Mpls, Mn.
Health Care Campaign of Minnesota
Appointed by: Health Care Campaign of Minnesota

Margie Wherritt
Rochester, Mn.
Family Services Collaborative (FACES)
Appointed by: Mn. Senate

For Copies of this report, call Mark Meath (Mn. Dept. of Health) at 282-5615

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LEGISLATIVE DIRECTIVE

The Health Care Consumer Advisory Board was assembled according to the following mandate of the 1997 Legislature:

The Patent Protection Act of 1997

The Consumer Advisory Board "shall advise the commissioners of health and commerce on the following: (1) the needs of health care consumers and how to better serve and educate the consumers on health care concerns and recommend solutions to identified problems; and (2) consumer protection issues in the self-insured market, including, but not limited to, public education needs. The board also may make recommendations to the legislature on these issues . . . The commissioners of health and commerce, in consultation with the consumer advisory board and other affected parties, shall make recommendations to the legislature by January 15, 1998, on developing a complaint resolution process for health plan companies to make available for enrollees . . . The Consumer Advisory Board shall consider the use of physicians by utilization review organizations, including whether only Minnesota licensed physicians should be used for utilization review, whether appropriate types of medical practitioners are being used for utilization review, and whether Minnesota's utilization review statutes afford adequate consumer protection. The Consumer Advisory Board may report findings to the legislature prior to the 1998 legislative session."

Members of the board "must be public, consumer members who: (1) do not have and never had a material interest in either the provision of health care services or in an activity directly related to the provision of health care services, such as health insurance sales or health plan administration; (2) are not registered lobbyists; and (3) are not currently responsible for or directly involved in the purchasing of health insurance for a business or organization."

BACKGROUND

The board began meeting in October 1997, and set their first priority according to the timeline required by the Legislature for developing a complaint resolution process. The Department of Health, in consultation with the Board and other parties, is required to make recommendations to the Legislature by January 1998 on a complaint resolution process. The board, therefore, decided their first and only task between October and the end of the year 1997 was to develop their recommendations.

Two processes were used to develop the recommendations contained herein: one was facilitated by the Department of Health, and one was conducted independently. First, members of the board participated in the Department of Health's "facilitated process" which included several four-hour meetings with consumer advocates, health plan and insurance company representatives, other business and professional representatives, and representatives from state agencies. Board members were appointed to be liaisons for relaying information between the board and the group, and to bring back decisions under consideration by the group for board recommendations.

Secondly, the board conducted their own process, beginning with education on existing complaint resolution processes and legislation that the Legislature considered last year. Thereafter, it focused primarily on consumer testimony about how the complaint process was working. The board heard testimony from:

- roughly 30 consumers through approximately 5 hours of hearings and several written testimonies,
- health plans representatives – including Medica, the Minnesota Council of Health Plans, BHCAG, and Federated Insurance – many of whom also participated in the Department of Health's meetings,
- experienced ombudsmen about the role of an ombudsmen program in assisting health care consumers, and
- representatives from the Departments of Health and Commerce presented information at the beginning and near the end of this process, and were present throughout the process to answer questions.

There were some limitations to this process:

- The timeline was very tight. The board had little time to become established before digging into the issue of a complaint resolution process. As a result, six, four-hour long meetings, without breaks were held.
- The board is also operating with no budget. The lack of money has made it difficult to fully administer our work. The Consumer Protection Alliance provided help in establishing the board. After discussion, the Department of Health agreed to provide minimal administrative support. The Alliance and the Department of Health's assistance have been essential to its ability to carry out its responsibilities. The board thanks them for their assistance. Additional support, however, would have improved the board's ability to accomplish its tasks.
- In addition, the board has not yet been able to have a real presence outside the Twin Cities metropolitan area. Only a small number of consumers from greater Minnesota contacted the board, and as a result, the needs of health care consumers in greater Minnesota are not well known. Members of the board who live in greater Minnesota agreed to take responsibility for publishing information about the board in their area.
- Also, there has been no representation from communities of color. Board members have taken responsibility for working with appointing agencies who represent communities of color to encourage the making of those appointments.

OVERVIEW

Health plans currently have processes for handling consumer complaints. There is some debate between health plans and some consumers as to how many consumers' needs are going unmet through existing processes. The Minnesota Council of Health Plans, for instance, stated that a fraction of a percent of its enrollees register complaints. The board also noted the overwhelming numbers of consumers who testified that they had complaints, many involving serious and life-threatening concerns, that they never formally registered. The board believes that it is likely that the number of complaints registered is just the "tip of the iceberg" of the actual complaints that exist but never come to light. Regardless of how many consumers fall through the cracks of existing complaint processes, the board heard general agreement among health plans, state regulators, and consumers that the process should be improved in order to meet the needs of those who are poorly served by existing practices.

A good deal of information provided by consumers was instructive as to the problems with existing processes. Some of the problems appear to result from the process and others appear to be caused by other problems consumers face, such as the difficulty of dealing with an illness itself. Some of the common threads noted as the board heard from consumers included:

- consumers were not told of their rights to appeal decisions, including their rights to appeal directly to state regulatory agencies,
- the complaint process was too lengthy and too burdensome,
- consumers are ill, in some cases seriously, which makes it difficult for them to deal with anything other than their illness, including engaging in a formal complaint process,
- consumers were dissatisfied with the response from state regulatory agencies, and
- consumers have lost trust in their health plans, providers, as well as regulators.

SCOPE

The board considered both internal and external review processes, and looked at how complaints are handled for denial of claims as well as for quality of care issues. They considered the role of providers and utilization review in the denial of care, and the role of regulatory agencies and alternative processes for resolving complaints. The health care issues involved a wide range of problems, including denial of payment for diagnostic tests, medical equipment, specialist care, and treatment for a variety of illnesses. Some denials were formally provided in writing by the health plan, others were communicated by health care providers on the basis of their understanding of health plan policies as well as cost concerns in general. The board also considered the need to educate enrollees of federally-regulated plans to help them understand the complaint processes available to them.

ISSUES

Consumer Burdens

People are in a difficult position when they, or their family members, are ill. People described feeling vulnerable and emotionally drained from dealing with their illness or that of a loved one. In some cases, they were unable to question the authority of a provider or their health plan because of their illness.

In addition, some people have difficulty writing down their complaints. Some found it difficult to even write a brief, informal, one-page story for the board.

Lack of Information about Rights

Nearly every consumer who testified said that they were either not told of their right to appeal or were told by someone outside the health care system – a friend, relative, or consumer advocate. Many consumers described a dispute with a provider that was handled as a disagreement between the patient and their provider and not as a complaint so the complaint process was never triggered. Nevertheless, the consumer was unhappy with their care and therefore called the Board to discuss their problem.

In some cases, a Board member was the first to tell them about existing internal and external complaint processes. In addition, several consumers who had used, and in some cases exhausted, internal appeals processes were not told by their health plans that they could also file complaints with state agencies.

It is also unclear as to when denial of care begins. The board heard cases where denial seemed to have occurred in the doctor's office or hospital room. The role of utilization review and related standards in the denial of care were also of concern.

Lengthy and Cumbersome Processes

Some consumers described a bureaucratic process that required filing numerous appeals which took months to resolve. In some cases, the patient died during the time the family was involved in a complaint process within their health plan or with state agencies. Some consumers who used internal health plan processes described leaving messages that went unanswered, having to call back several times to get responses, not being given a representative's last name upon request, and having to appear before appeals panels that were intimidating and unhelpful. Consumers also described waiting for months for their complaint to be resolved through regulatory agencies.

There are also many entities with different appeals processes which makes it difficult to know who to complain to. For instance, you can use a health plan's internal process but you may also complain directly to state regulators, depending on the type of complaint you must direct it to either the Medical Practices Board, the Department of Commerce, or the Department of Health, or perhaps a combination thereof.

Regulatory Concerns

In general, most consumers don't realize that they can go to the Departments of Health and Commerce with complaints. Those who have used regulatory agencies described difficulty because they found the process to be lengthy and bureaucratic. In addition, there is some question as to the extent to which the Departments of Health and Commerce conduct independent investigations. Some consumers had the impression that state regulators only reviewed quality assurance files. Consumers also complained that they were not receiving adequate information about the findings of state regulators. Letters from the Department of Health cited data privacy laws that prevent them from sharing the information with the complainant. In addition, consumers questioned

the relationships between state regulatory agencies and private industry.

The Department of Commerce testified that they do independent investigations, will obtain information and interview whomever is required for an investigation, and will divulge their findings with the complainant. The Department of Health handles disputes about complaints involving HMO coverage of a service and has a right to inspect quality, appropriateness, and timeliness of services performed. They testified that they do not, however, have the resources to investigate complaints to the extent that is needed.

Loss of Trust

A common sentiment expressed by consumers was that they don't know who to turn to because they have lost trust. Some said they no longer trust their providers, their health plans, as well as regulatory agencies.

RECOMMENDATIONS

Consumer Advocacy Program

The board's recommendations center around an advocacy program which will address several of the issues raised. First, it will help consumers while they are experiencing problems rather than waiting until after the problem develops into a complaint. It will help consumers through complaint resolution processes, including helping them write complaints. The program will give consumers a place to go that is independent from health plans and state agencies, thus providing them with an advocate in the strictest sense. The advocates' first responsibility will be to the consumer. The program's independence will foster a greater sense of trust from consumers. The program will:

- be staffed by trained, experienced, independent advocates to help solve problems in a timely way,
- have a phone number that is given to all consumers and clearly posted where consumers can find it,
- be visible through outreach, education, and communication,
- be publicly accountable to the Consumer Advisory Board or another independent entity,
- be responsible for data collection, policy analysis, and advocating for health care system wide change,
- be accessible statewide,
- be fully funded through either an appropriation from the general fund or consumer funding through health plan enrollees annually. For example, one dollar per enrollee per year, or an amount to be determined by budget needs.

Consumer Education

There is some question as to how much responsibility consumers should bear for pursuing complaints, as well as for communicating their concerns in order to prevent the need for a formal complaint. Consumers should be encouraged to learn as much as they can about their coverage and to learn who to call when they have complaints. In addition, consumers need more help than is currently available, and health plans, regulatory agencies, the Consumer Advisory Board, the medical profession, and an advocacy program should all educate consumers about their rights.

Independent Appeals Process

Consumers need an appeals process that is neutral and is independent from state agencies and private industry. Such independence would increase consumer trust in the process. It should also be:

- easily accessible to consumers,
- publicly accountable to the Consumer Advisory Board or another independent entity,
- resolve complaints in a timely manner,
- and be fully funded.

Strengthen the Consumer Advisory Board

The board is mandated to provide information about the needs of health care consumers and to help educate consumers about the health care system. It is also mandated by the Patient Protection Act of 1997 to consider the use of utilization review practices and consumer protection needs in the self-insured market and report its findings to the legislature. The board will also work on the issue of the lack of patient trust of the medical profession and state agencies. In order to carry out its responsibilities, the board must:

- conduct research and analysis,
- hold public hearings,
- be able to communicate with the public across the state,
- and produce reports as well as educational materials.
- The board should also help develop and provide oversight for an independent appeals process and a consumer advocacy program and help to demystify the health care industry.

To carry out this work, the board must have full funding which would be used for office space, staff, mailings, copying, travel and per diem for board members, and incidentals.

Improving Health Plans' Internal Complaint Processes

The health plans' customer representatives need to be adequately trained so they can educate their enrollees about their appeal/complaint options.

Accessibility

All complaint processes, including internal and external offered by state regulators or other independent entities, must be accessible to people with disabilities, to people of diverse cultures, and to people who live in all regions of the state. The processes should also be able to take oral complaints.

Improving Departments of Health and Commerce Responses to Consumers

The Departments of Health and Commerce should conduct independent investigations whenever necessary and should report its findings to the greatest extent allowable by law to the complainant.

APPENDIX - CONSUMER TESTIMONY

The following summaries are taken from stories presented to the board through written and oral testimony. The consumers' experiences are important to understanding how the current system is working. The board thanks all those who shared their experiences.

Several quality of care issues were represented through these stories, including: doctors or other staff persons ignoring symptoms described by patients or their relatives, discharging patients from the hospital before they felt ready, discharging patients without giving them adequate information on their physical status and care that would be needed at home, lack of adequate and accessible follow-up care, and limited access to care in rural Minnesota.

Testimony 1

This woman was diagnosed with bladder cancer in December 1996. She received 12 chemotherapy treatments but the cancer spread and her health plan's doctor said she should see a particular doctor at the Mayo Clinic. She brought her x-rays and had four days of tests on May 20-23. The doctor wanted to remove her bladder immediately but she said she needed a few days to get things in order. She assumed her health plan doctor had checked the coverage before recommending the doctor at Mayo. At the last minute she found out that the Mayo doctor was not a network provider and her health plan would not cover the bill. She went ahead with the surgery anyway because of the urgency and now owes close to \$11,000. She appealed to her health plan in November 1997 and is awaiting a decision.

Testimony 2

This woman is a retired nurse who has had insulin dependent diabetes for 43 years. Her health plans' primary care physician ordered an EKG for baseline purposes. After the test he told her she had had a heart attack in the past. She replied, "not to my knowledge." Later she had a treadmill test and echogram. A cardiologist said she was just fine but her primary care doctor insisted she had had a heart attack. She chose to believe the cardiologist and asked for a new primary care physician. Her new doctor seemed confused about her diabetes so she left the plan and went to a community clinic.

In August, 1997 her new physician at the community clinic ordered an EKG and found evidence of a previous heart attack. An echogram and treadmill test found a damaged right ventricle with 40% blood flow to the heart. She speculates that the health plan's cardiologist didn't think she was worth treating since she is 64 years old and has had diabetes for many years. She had experienced extreme tiredness for some time but never knew the reason for it.

Testimony 3

A woman told the story of a friend who was 92 years old in 1995 when she fell on a rake in her garden and developed a painful upper leg. The elderly woman called 911 and was taken to a hospital. After several hours she was discharged without being x-rayed. Ten days later she asked to be taken back to the hospital due to pain in her upper leg. Again she was discharged without being x-rayed. About a week later she called 911 again because of severe pain in her leg and was taken again to the same hospital. They kept her for eight hours without x-raying her and then decided she should be transferred to a nursing home. The nursing home discovered a hip fracture and returned her to the hospital for surgery.

Her friend asked the doctor how this woman could have come to the emergency room three times without being x-rayed. She said the doctor looked at her coldly and stated, "Well, it doesn't matter now does it?" The elderly woman, who had been independent, is now permanently disabled and living in a nursing home.

Testimony 4

A woman told about her daughter who spent three months in a hospital that claimed to be treating her for anorexia. She received no bills for her daughter's care and kept questioning the hospital as she was worried about her insurance. The doctor kept telling her that she had very good coverage. After her daughter was released from the hospital this woman was told that she owed \$5,000. She was shocked and refused to pay. One day at church choir practice she told a friend about her dilemma and her friend suggested that she look into the Hennepin County Mediation Project. She did this and the insurance company ended up paying. No one else informed her of the mediation option.

Furthermore, she says, "our daughter to this day thinks the treatment at this hospital was a joke." Subsequent to her daughter's treatment at that hospital, she took her to the University of Minnesota hospital "who finally cured her of her anorexia. Our large boned, 5'8" daughter at 87 pounds was a week away from death when she entered the University of Minnesota hospital."

Testimony 5

This woman was seriously and extensively injured in a car accident when a driver ran a red light. She needed a lot of surgery and medication. She had a lot of hassles throughout this ordeal and paid some medical bills out of pocket. Her auto insurance coverage ran out but her health plan wouldn't pay because her injuries were auto related. She was sending some bills to her attorney when her health premium bill got mixed in and sent to his office by mistake. She didn't realize this until the plan cancelled her insurance. She can't work, has no insurance and no energy to fight. She gets anxiety attacks trying to write about her problem. An Advisory Board member told her about appeals options available to her, option she was unaware of.

Testimony 6

A woman testified that in August 1997 her father was diagnosed with prostate cancer. He was insured in Minnesota but was referred to a hospital in Fargo for a pellet procedure in which radioactive pellets are inserted into the prostate to kill the cancer cells. The daughter and her mother accompanied her father. They were told that he would stay in the hospital overnight because of his age. He is in his 70's. His clinic called and said that instead of staying in the hospital they would send him to a hotel across the street. He was given anesthesia and a spinal and 58 radioactive pellets were inserted in his prostate.

He was in recovery from 11am to 3:30pm. At 4:40 pm the daughter and her mother were told to get him dressed and take him to the hotel. He was still numb from the waist down, couldn't walk and had a catheter in place. The daughter and her mother were told to remove the catheter the next day and take the radioactive pellets out of the catheter bag and wrap them in foil. They received no detailed instructions on how to remove the catheter or how to handle the radioactive pellets. The daughter had to remove her father's catheter which was difficult to do, embarrassing, and painful for her father. Not having instructions as to what to do with the radioactive pellets, they put them in the wastebasket. In addition, the hospital had given her father codeine when his chart clearly stated "No codeine."

She says she feels there should be a board, not related to the medical field, to intervene in situations like this.

Testimony 7

A woman testified that in December 1996 her father, an active man in his 80's, went out to feed the birds and slipped on the ice. The next day he had a lot of pain. Family members brought him to a clinic where a leg wound was dressed and he was sent home. He began vomiting and had diarrhea. He couldn't get in and out of bed by himself so they had to get outside help. The next day he had an appointment with his regular doctor. It was cold outside but he refused to wear a coat because he was feeling very hot. The doctor said he had only a cracked rib and needed rest.

They got him home and into a chair where they had to leave him all night because they couldn't move him.

They began looking for a nursing home and they found one., but he died in the chair before they could get him there. The autopsy revealed six broken ribs and internal bleeding.

The family filed a complaint with the Department of Health. The Department thanked them for writing, said that they would look into the matter and that they would not be able to tell the family anything. The daughter asked, "What kind of complaint process is this? What is the purpose of filing a complaint?"

Testimony 8

This woman had major surgery at on a Wednesday in 1995 and was discharged on Friday even though she had pain, nausea, anemia, and a catheter that had malfunctioned in the hospital. At home on Saturday morning the catheter malfunctioned again and health plan sent her to an urgent care clinic across town. She spent over two hours shivering in an examining room that was freezing cold from air conditioning. Finally, a different catheter was inserted but, unknown to her, it had been taped incorrectly. When she got home she began having pain and spasms that made it impossible for her to sit or lie down. She had to travel back across town that evening to have the catheter repositioned.

On Monday she was nauseated, dehydrated, had a fever and vision problems. She called the clinic but the doctor who had done the surgery was not available. She waited for a prearranged call from a visiting nurse but no one called. Later she called her clinic but was not told to come in. She had to call again before being told to go back to Urgent Care where she was readmitted to the hospital for three days.

The day after she was discharged she phoned in a complaint to her health plan. They failed to send her a complaint form and over the next four months she said they stalled, ignored her, confused her and charged her a \$400 copayment for the second hospital admission. She complained again, in writing, protesting the copayment. They said she had received appropriate care and must pay the \$400. She appealed to the Department of Health and got the same answer. When she contacted a grassroots advocacy organization the case was re-investigated and her \$400 copayment was refunded, one and a half years after the incident.

Testimony 9

A woman told about a five year battle with her HMO to get her complaint heard and difficulty filing a complaint with the Department of Health. Recently, she had to sign a release of information form on two occasions because her case involved psychiatric records. She found this intimidating and was given no explanation. She had no contact person to talk to. Her HMO called her at work and said the release was not specific enough. They wanted to fax something to her at work. She told them it must be mailed to her at home.

She had some meetings with the Department of Health and began to feel good about this experience. Then she started getting calls at work from an HMO attorney and a paralegal came to her desk to have her sign a paper. She experienced anxiety, fear and was afraid to answer her phone. Recently she found out that the Department of Health had not begun investigating. The Department of Health couldn't work out anything with her HMO. Her complaint is at a dead halt because of questions regarding jurisdiction. She feels abandoned, that she is not receiving medically necessary services, that her health is deteriorating and she has feelings of hopelessness.

Testimony 10

This woman's husband received the initial diagnosis of a cancerous mass on his lung by his primary care doctor in a brief telephone conversation. When the family called back to ask more questions they were not allowed to speak to the doctor again, and the nurse incorrectly told them that there were two tumors. The patient began radiation treatments and was assigned a doctor who went on vacation after three days and was gone for three weeks. He had no assigned doctor during this time and had many problems with the radiation treatments. Another doctor, who filled in, suggested a change in the treatment plan but when the first doctor returned she would not change the treatment plan. The patient was not allowed to keep the second doctor.

After ten months of radiation and chemotherapy the oncologist mentioned that he had been treating this man for bladder cancer. This caused great fear, confusion and a trip to the Mayo Clinic where lung cancer was confirmed. He entered the hospital where he had been getting radiation treatment again on May 8 for I.V. medications. He received no attention for nausea and an inability to eat, was left in painful positions for hours and a bowel obstruction went undiagnosed until after he had been in unbearable pain for some hours. After an x-ray revealed the obstruction, treatment was delayed for three hours. He died one and a half hours later.

Eight days before his death his oncologist had said that he was stable and did not see him passing away anywhere in the near future. The man's wife commented, "We always kept a positive attitude. What happened? The system failed." As for complaining, she says, "we could have complained to our health care provider but unfortunately we did not have the 10-30 days needed [to go through the process] ... [he] died just ten days after he entered the hospital."

Testimony 11

This woman has a degree in public health nursing. In 1991, she developed dizziness, loss of appetite, abnormal blood pressure and pulse and had abnormal neurological findings. Her headache was so severe that no pain killer helped. A doctor in her health plan told her to take two Advil. Later, she saw a specialist but parts of her medical record were missing. She suspected she might have an infection and thought she should take an antibiotic. A neurologist kept her on aspirin for one year.

In 1992 they still had not figured out what was wrong with her and said it must be psychosomatic. Finally, she found out that her brain had been attacked by an infection. She believes the doctors protected each other when mistakes were made. She paid for her own care outside her plan and got the treatment she needed which was antibiotics, but she has permanent brain impairment, pain and grand mal seizures. She takes 12 different medications. She said, "I'm not the person I used to be."

She says that although nothing will help her now, she wants to prevent damage to others and feels that going public will be more effective than going to the Board of Medical Practice.

Testimony 12

This woman has to use health care regularly because of multiple chemical sensitivity and she ran into problems when she went to the emergency room. She had developed a severe migraine, her head was exploding with pain, she had double vision and vomiting. Her son called an ambulance. Her blood pressure was 186/130 and the paramedics thought she was having a stroke. At ER they gave her anti-nausea medicine and sent her home.

She had been assigned to UCare and was supposed to get approval for the ambulance. But in the confusion of the moment she didn't think about reading the information packet. She got a bill for the ambulance which she was unable to pay and had been taken to a hospital she was not assigned to. It took eight months to straighten this all out. She had to explain everything over and over. She doesn't know how the bill got paid. She said that is hard to understand the information packet. She had gone on medical assistance and said that she didn't know that she had lost the power to make decisions about her health care.

Testimony 13

A health insurer denied this woman's claim in 1995 for breast cancer surgery and rescinded her contract because of she did not understand that she had a fibrocystic condition at the time she applied for coverage. It subsequently developed into a growing lump. Even though it was recognized that this was not intentional misrepresentation, the Department of Commerce claims it has no statute upon which to overrule the insurer. She is now insured by MCHA, but has \$30,000 to \$40,000 of unpaid bills for her cancer treatment.

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Testimony 14

This woman's daughter, age 15, has cerebral palsy and uses a wheelchair. She had had ongoing problems getting medical services for her daughter. Her son, 17, is healthy and has no problems getting health care. Although she knows the system well, she still has a hard time getting her daughter's needs met. Recently, she needed a lift to get her daughter into the bathtub and onto the toilet. The only lift that fits into their home costs \$6,000 and her health plan would only pay for a \$900 lift. She lost repeated appeals. After 15 months she got the lift, but not through her health plan.

She spends hours and days working to get care for her daughter's needs. She has had to change health plans several times and is currently in the process of choosing a new plan. She says that it takes a lot of work to research which plan will best cover her daughter's needs. She is looking for a more responsive health care system. She says, "I can't handle eighteen more appeals."

Testimony 15

This woman has multiple sclerosis. In 1987 her provider, who is with a different health plan than hers, prescribed a scooter. Her legs and the right side of her body are weak. Last year her scooter broke down. Repair is too expensive to consider and her HMO denied a new one.

A therapist came to her home, evaluated her and recommended that she continue to use a scooter. Her HMO claimed the therapist had not recommended a scooter. She said, "All I could think of is, if the place burned up I would go with it."

She asked her plan for the criteria for denial. When she kept after them they finally agreed to pay \$2,000 toward the cost of a scooter. She has training in conflict resolution but says it is difficult to fight when you have chronic illness. She feels that people shouldn't have to fight like this. Her final comment was, "We need a fairer system."

Testimony 16

This woman has had multiple sclerosis for many years and has had many problems getting needed care. She had to fight to get a motorized wheel chair and now it needs new batteries. Her HMO will not pay for them because she doesn't use the chair all of the time. The exercise she gets walking around her house is good for her, but she needs the wheelchair to go other places because she tires easily. She cannot afford to pay for the batteries herself.

She went through an appeals process and has waited 75 days with no answer. Now she has to change health plans and will have to start over with the new plan. She is tired, frustrated and worn out by the system.

Testimony 17

This man, who has multiple sclerosis, was in a car accident and was taken to an emergency hospital that had no experience treating people with MS. He received three weeks of MS medication in one dose and nearly went into a coma.

He didn't know where to go to complain. He thought of legal action but feared consequences from his employer. He says he is nervous about possible future hospitalization and has no energy to keep fighting. Even though he is an employment manager he struggles with the system to get the care he needs.

Testimony 18

This woman's husband needed surgery. He is diabetic and this was noted in the chart, but no one addressed the fact and she said he did not receive proper treatment. Later, his blood sugar was very high and everyone at the clinic was "all excited" that he is diabetic. She has complained over the phone but has not filed a formal complaint because it concerns her husband's primary care doctor and he fears he may end up with a worse doctor.

Testimony 19

This man sustained a back injury at work in May 1993 and was treated by an orthopedist. A few months after receiving cortico-steroid injections he developed terrible pain in his left hip. He had no medical coverage at the time so he lived with the pain until he became eligible for medical assistance. He then went to a different clinic. Through his own research and a doctor at the clinic, he learned that his hip pain and deterioration was probably due to a bad reaction to the cortico-steroids. But this was not made clear to him until after the statute of limitations had expired for legal recourse. He was not told of the possible side effects of this drug before receiving the injections.

He characterized his current life as filled with pain and poverty, "a cripple" at age 36. He notified the Minnesota Board of Medical Practice last year. They replied that they reviewed his case and found no basis to take action. He is looking for someone to intervene in what he says is a "David and Goliath" situation.

Testimony 20

While driving his car, this man hit an open manhole in October 1997. He developed severe pain in his neck and throat where he has scar tissue from previous surgery. He made an appointment to go to his HMO three days later. By then he had swelling, difficulty swallowing, a headache and earache. He was seen by a nurse practitioner and told her about the previous surgery and how it was infected and treated with an antibiotic called ceftin. She said she thought he had a bug that was going around and prescribed erythromycin.

Three days thereafter, he was much worse and asked for a referral to the doctor who did the throat surgery three years prior. This was denied. His HMO said that he had to wait for the antibiotic to work. He waited another three days to see a doctor at his clinic for a referral. While waiting for this appointment he was in unbearable pain and couldn't swallow anything, including his own saliva. Finally, he was given a referral.

The next day he saw the doctor who performed his previous surgery and was admitted to the hospital with a severe infection, dehydration and weight loss. He required emergency surgery to relieve the infection and ceftin was prescribed. He commented, "They act like you're just a number or a pain in the ass when all you want is to be listened to and your illness treated properly."

Testimony 21

In 1979, this man had a tumor, called fibrous dysplasia, removed from the sinus above the right eye. It was causing headaches and sinus infections. The surgery was performed at Mayo Clinic and the symptoms disappeared. In 1994-1995 he again had headaches and sinus infections. In 1996 he hit his head in the shower and was taken to a hospital affiliated with his HMO.

A radiologist took a cat scan and determined that the tumor had grown back, almost obliterating his sinus and was entering his nose. His health plan refused to authorize surgery and refused to state the denial in writing. He said they kept making excuses for not authorizing surgery. Finally, after five months, he learned about an advocacy organization from a friend. After they demanded an explanation, his HMO authorized a visit to the Mayo Clinic and surgery was scheduled immediately. But his HMO continued to resist, forcing a cancellation of the surgery at the last minute.

When surgery finally took place, the sinus was found to contain pus equal to the volume of half a lemon and the tumor was at that point inoperable. The surgery took three hours and involved an incision over the top of his head from one ear to the other and pulling the skin down over his face. When he came out of the anesthesia he was told he must go home that afternoon. He believed his HMO made that decision. His doctor let him stay another day because he didn't feel up to traveling back to the Twin Cities on the bus. This man does not believe the five month delay caused the tumor to be inoperable but his HMO did refuse needed surgery and did not provide a written explanation of denial as required by law. He says his HMO did everything they could to make and appeal difficult.

Testimony 22

This woman had laproscopic surgery to remove her gall bladder in March 1997. Her surgeon had said she could stay overnight if she wanted. Six hours after the surgery the nurse asked her to get out of bed to sit in a chair but she was having a lot of pain and nausea and told the nurse she didn't want to. A shortwhile later, she got up to go to the bathroom and when she returned her bed was gone. She asked the nurse where her bed was and the nurse said they had a chair for her to sit in. The nurse then walked away, leaving her standing in the middle of the room in pain, tired, drugged, with an I.V. in her arm. Sitting down in the chair was very painful. A few minutes later the nurse told her that there was nothing more they needed to do for her.

Seven hours after surgery, at 2:30pm, she didn't think the nurses would do anything more for her and so decided to go home. She got into a wheelchair to leave the hospital and when it began to move she became nauseous and wanted them to stop but could not speak. The nurse asked if she was nauseous and she nodded yes. She said the nurse then "shoved" a bucket and paper towel in her hands and told her to use them if she needed and they wheeled her out.

She complained to her doctor who said he should have been called if she was having that much trouble and that the nurse should have done a "u-turn" with the wheelchair. She has filed a complaint with the Departments of Health and Commerce and is awaiting a reply. She wants to know if there are rules about patients being discharged against their will and why her doctor was not involved in the decision. (Since giving this testimony, this woman has received a reply and is dissatisfied with the response. The Department of Health did not provide her with any details and when she called to ask what happened, they told her of the hospital's response which, she said, did not address the questions she asked.)

Testimony 23

A father testified about his son who was born with speech apraxia, a soft neurological disorder. After two years of school speech therapy his speech was still 85% unintelligible. His parents brought him to the University of Minnesota and he began receiving intensive therapy. Their HMO refused to pay for their son's treatment even though their policy read: speech therapy provided for "treatment to correct effects of illness, injury, or a medical condition." The father said that apraxia is a neurological disorder and deemed a medical condition.

They battled their HMO for two years, exhausting all internal appeals and the Department of Health said their HMO doesn't have to cover apraxia because it is not mandated by law. They learned that the HMO covered some apraxia cases and not others. The father described an intimidating appeal meeting at which their final appeal was denied. "My wife and I sat opposing the HMO board members occupying three long tables. This appeal was only a five minute courtesy." He also commented, "Today there is not help for those of us attempting to fight for health care for our family members. The appeals process is unclear. There is no place to go for advice. Your only hope is networking with others who have previously stumbled through the process."

Testimony 24

This woman has an 11 year old child who needs speech services for a neurological processing disorder. The child hears something different than what is said. Their health plan denied the services because the child was born with the condition. If it had occurred because of an accident the same problem would be covered. This policy conflicted with other information from the health plan.

She found it difficult to file an appeal because the process was ambiguous and she was given no guidance or guidelines. At the internal appeal she and one support person sat at a large table with 11 plan representatives who did not identify themselves and made no eye contact. They answered no questions and asked her no questions. After she made some statements she was told to leave. Her appeal was denied. She said she found this experience emotionally draining. She is an advocate in the field of education but those skills did not help her.

Testimony 25

This woman's mother had been seen for malnutrition, weight loss, dehydration from diarrhea and extremely low blood pressure. She said her HMO doctors saw her mother when those symptoms were not as severe as they eventually became, but they never looked for their cause.

As her mother's condition deteriorated rapidly she called the clinic in December 1996 but the triage nurse would not let her talk to her mother's doctor. She tried again six days later but the triage nurse would not let her through. She called the Department of Health and someone suggested they go to urgent care, which they did at 10:30am that day. At that time they did get to talk to a doctor but he did not examine her mother and said there was nothing he could do even though he realized she was very ill. He rejected the daughter's request that her mother receive TPN (nutrition that goes right into the blood stream).

The daughter said she would not leave the clinic until someone treated her mother. A security person was sent in and told her there was no need for her mother to receive treatment. Around 2:30pm they were allowed to see a doctor and around 4:30 they got an OK for her mother to be admitted to the hospital. Her blood pressure was so low they couldn't get a reading. It turned out that she was suffering from a rare disease called amyloidosis and would have died without special care. The daughter filed a complaint with the Department of Health and received a response that she calls a "joke." The Department said they had to keep all findings secret.

Testimony 26

This woman's mother had a breast lump for four years and she said her HMO told her mother not to worry about it, but it turned out to be cancerous. The family fought every step of the way to get care for their mother covered. After a mastectomy the cancer came back. She had three brain tumors and seizures. Her father stayed with her mother in the hospital 24 hours a day and intervened when overworked nurses made mistakes with medication.

After time, her mother developed pneumonia. The hospital said there was nothing more they could do and discharged her with an I.V. and feeding tube. She couldn't get out of bed and needed complete care. The family could not take care of her. No help was provided. There was no coverage for a hospice or home care or nursing home. Her dad said, "If we have to we'll sell the house." They brought her to a nursing home and it was a constant battle to get care covered. She said they were in an "emotionally awful" situation and needed an advocate. Their mother was delirious from all the medication. She didn't want to be so drugged but the doctor said it was up to each nurse to decide the dosage. Throughout this time the family felt they had no control.

Testimony 27

An advocate for multiple sclerosis patients told this story about a woman who is deceased. Her MS specialist recommended that she have an electric wheelchair because of the shoulder pain she experienced from using a manual chair. Her HMO denied the electric wheelchair and left the message on her answering machine. From continued use of her manual chair she developed a torn rotator cuff which required surgery and rehabilitation costing \$40,000. Still she did not get the motorized chair. She was able to go to work because her colleagues pushed her back and forth from the bus stop. But because she was working she no longer received rehabilitation center payments. After Doug Grove feature her story in a newspaper article her HMO said they would pay \$2,000 to \$10,000 for a chair. The community rallied and collected the rest of the money so she could get her chair.

Testimony 28

The patient wrote to the board about suffering a breast injury during a mammogram. The technician was new at the job and was in orientation but was allowed to work with her without supervision. She wrote that the technician continued to pull on her breast even after she told her it was painful. Her injury was so severe that it interrupted her normal life and required daily pain medication for over a year. It was uncomfortable to walk, sit, and lay down. A doctor she saw for the injury said she had a possible muscle tear and torn or damaged tissue.

She contacted an attorney who told her to go to the hospital to pick up a patients' bill of rights. She also complained to the hospital but they denied that her injury was caused by the procedure, though when she talked to a technician and asked if she was the one who injured her, the technician said she probably was and apologized several times.

She wrote that she feels the hospital is responsible for what happened and that they, therefore, should pay for her treatment. She has considered getting legal help several times. At no time was she told of a way to file a formal complaint. She also had to negotiate continually with her insurance company to get coverage for the therapy treatments.

Testimony 29

This woman wrote to the board about her husband who had radiation treatments for rectal cancer in 1990. A colostomy was performed in 1994 and a severe infection developed. He had endless problems and severe pain. A different doctor performed a second colostomy which was then changed to an ileostomy. He requires ongoing home health care and pain medication.

The patient's wife wrote this, "Many comments have been made to us by other professionals that [the doctor] may not have been knowledgeable about the colostomy procedure and this in turn has caused [my husband] needless pain and suffering and a lesser quality of life." The family wants an investigation into this doctor's credentials to prevent other patients from suffering. The statute of limitations has expired for legal action.

Testimony 30

This woman wrote about problems she has had with her health plan resolving a problem with her premium payments. She is 60 years old, and finds it difficult to get into a plan. Her plan said she missed a payment and threatened to terminate her. After three months of discussions about the problem, a friend helped her get together copies of all of her checks. They faxed the copies to the health plan and after another month they agreed that she had paid. She felt she deserved an apology and wrote them a note but received no response. Then, in September she decided to change to a lower cost deductible plan and did not get a bill for September. She called in October and they said they made a mistake and would send her one in December. She wrote that "I suppose next summer I would get a bill for the whole thing or they would cut me off. I do use the insurance quite a bit, maybe they wish I would terminate."

Testimony 31

A woman writes about complaints she has with "participating provider" networks. She says the health care providers decide who she can or cannot see and whether she has had enough care or if benefits should be cut off. But, she says, patients pay such high premiums that they expect to get a good amount of coverage and they are surprised to find out that when they ask for care there are limitations. She writes, "Once we need to use the coverage for an illness or accident, it is too late for the truth of being told we are breaking the rules and [being] cut off from coverage because we aren't seeing who they think we should. That's not fair to us either -- we pay twice -- first the premium and then for the continued care we have to pay on our own."

Testimony 32

A woman writes that the brochure for her insurer's Medicare plan does not describe the term of a benefit period in the same way her contract does. She called the 1-800 number on her policy but the person answering did not know if 60 days was a benefit period and whether she would have to pay the deductible again after 61 days. The consumer has worked for a legal service for ten years and is now "in the volunteer health insurance counseling program and feels these are things that need to be worked out before one needs to hire a lawyer ... should one need to collect on our insurance."

Testimony 33

Two people wrote on behalf of a health care clinic in rural Minnesota about the problems their clinic has serving their patients. They say that insurance plans tell consumers that their clinic would be their primary care network in order to get the consumer to buy the policy but their clinic had not signed a contract with the plan. They feel that "this is a tactic that the insurance plans have used to get providers to sign cut-rate contract by putting the providers at odds with their patients. In small communities patients are not just patients, but our friends, neighbors, relatives." Furthermore, they write that patients cannot just switch plans after discovering the problem. In rural communities there may be only one primary care clinic in a county and one local hospital with specialty care. They write, "if the insurance plans continue to try to shove cut-rate contracts down our throat the inevitable will happen. WE WON'T BE HERE TO PROVIDE HEALTH CARE!!" Consumers will then have to travel 60-75 miles for routine and emergency care.

They add that their patients have trouble getting access to specialty care. Specialists who come to the local hospital may not participate with the patients' insurance plan. The clinic is obligated to refer patients to specialists within the network which may mean the patient will have to travel two and a half to three hours to see a specialist. In addition, state employees who are selecting health insurance for 1998 find that the least expensive option did not allow them to use the local health care system. They conclude, "access to health care in the rural communities is shrinking and the ultimate payer in this will be the patient (our friends, neighbors, parents, children)."

Testimony 34

A woman writes that her dental plan will not pay for a porcelain crown that she had received this summer. They say that because she took out new coverage on her husband, who retired from his company and lost his coverage, her coverage started over and she had to fulfill her deductible again. She writes, "I feel this is totally unfair. Not only am I paying three times the amount of payment for family coverage ... but I am not receiving the benefit of the coverage!" She has requested that this matter be raised with the Attorney General.

Testimony 35

A woman who coordinates a health insurance counseling program in rural Minnesota writes on behalf of her clients. She writes, "Although I believe [a complaint resolution process] to be a real need throughout Minnesota; it is just the tip of the iceberg when trying to deal with the myriad of problems facing rural health care delivery. The problems go much deeper than a complaint process. As an advisory board, you have the opportunity to impact and facilitate lasting change that needs to take place if consumers are to be assured of reasonable access to affordable health care in the future.

She gives an example of a woman with three children who had seen her doctor for 25 years and was happy with her care. In 1997, she was asked to select one of three plans. Because of her low income, she selected the one that was lowest cost. Later she learned that her doctor is not a participating provider and there are no physicians at her community clinic on the participating provider list.

The woman also describes having to travel 27 miles to a clinic, and the difficulties doing that in bad weather. She has had to keep her child at home for three days while waiting for winter weather to improve in order to make the trip. She writes that "We will have succeeded when what makes sense for the health plan's pocket book also makes sense for the consumer."