



MINUTES

Health Insurance Mandate Review Committee

Wednesday, December 8, 2021

MEMBERS PRESENT

Senator Jason Schultz, Co-chairperson
Senator Sarah Trone Garriott
Ms. Angela Burke Boston
Ms. Stacie Maass
Ms. Liz Matney
Mr. Matt McKinney

Representative Shannon Lundgren, Co-chairperson
Representative Lindsay James
Ms. Sonya Sellmeyer
Mr. Dave Schutt
Ms. Marcie Strouse
Mr. Scott Sundstrom

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I. Procedural Business

Call to Order and Adjournment. The Health Insurance Mandate Review Committee was called to order at 10:02 a.m. on December 8, 2021, in Room 103, Supreme Court Chamber, State Capitol. The meeting was adjourned at 11:47 a.m.

Approval of minutes. The minutes of the November 3, 2021, meeting of the committee were approved as distributed.

II. Public Comment

Dr. Jason Kruse, DO, an internal medicine physician at Broadlawns Medical Center in Des Moines, and chair of the Department of Medicine, speaking on his own behalf, asked the committee to increase transparency into the pricing of insurance products and how mandates impact not only insurance premiums, but the total cost to consumers. He encouraged the committee to use a standardized template so all insurance companies are reporting comparable data; to request estimated profits for insurance companies; and to seek cost/benefit analyses of changes that affect consumers. He stated that insurance companies have the right to make a profit, but not by refusing to pay for services for lowans. He noted that without good data, there cannot be good policy, and asked that in the future the committee provide a seat at the table for members of the medical community and patient advocates.

Ms. Meredith Boesen acknowledged the difficult decisions legislators must make, and shared her family's experience with Pediatric Acute-Onset Neuropsychiatric Syndrome/Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANS/PANDAS). Her 10-year-old daughter, Annabelle, became ill, weighed only 40 pounds, and her body began to shut down. Doctors were unable, however, to provide a diagnosis and Annabelle was admitted to a treatment facility. The family was not allowed to see her and she was placed on a feeding tube. The cost of her care during a period between November and the end of January, for room alone, was \$179,520, which Wellmark covered. The family's out-of-pocket costs were \$16,300. Ms. Boesen recounted the situations of several other family members and members of the community whose children have the same symptoms; however, the parents do not have coverage for these treatments and are paying tens of thousands of dollars out-of-pocket. She stated that these families are making all of the right choices, are not living beyond their means, and are hard-working lowans, but they are struggling. There is a cure available for the children who, due to their illness, are at risk of suicide. Even when they do recover, it is difficult for these children to reenter the community and to develop friendships. Annabelle and her sister lost their childhoods. Annabelle does not know who to trust because she was told to trust the health care system and it failed her for a very long time. There is hope for these children but they need to have access to affordable treatment. Ms. Boesen read a statement from Dr. Cheryl Standings in support of intravenous immunoglobulin (IVIG) therapy and management of PANS/PANDAS through an interdisciplinary approach including general pediatrics, neurology, immunology, rheumatology, and psychiatry.

Mr. Duane Alpers, the father of a son with PANDAS, spoke about how PANS/PANDAS affects children and their families. IVIG treatments cost on average \$10,000 per treatment, and an average of five treatments is necessary. If a child is unable to receive appropriate treatment, the child may end up in a mental institution on psychiatric drugs. The cost of care in a mental institution is approximately \$10,000 per month, or \$120,000 per year. Without a proper diagnosis and treatment, this ineffective care may continue until the child ages out of the system. He compared the difference of the cost of care in a mental institution over a 10-year period at \$1.2 million per child versus the \$50,000 per child for proper treatment. There are over 450 parents on the PANS/PANDAS facebook site seeking help.



There is already a shortage of psychiatric beds in the state. He wondered how many of these beds are occupied by children with PANS/PANDAS who have been misdiagnosed. He asked that the committee support insurance coverage for PANS/PANDAS so these children receive the medical care they need and deserve, and parents get back the child they know. He reiterated that growing numbers of children with PANS/PANDAS commit suicide.

Ms. Allison Stadtlauer, a sister of Ms. Boesen, also has two children who have been diagnosed with PANS/PANDAS. Her 15-year-old son was diagnosed by an expert in Washington, D.C. Her nephew received the necessary treatment and is thriving and her niece is also doing well; however, the situation has affected the whole family. Ms. Stadtlauer's oldest daughter will begin receiving IVIG treatment next week. There are ongoing issues as all four children have eating disorders and other complications. Families have gone bankrupt and children are dying. Children are ending up in psychiatric wards due to misdiagnoses. This could be avoided if the condition is caught early and the children are treated appropriately. These children desperately need support and their families are being destroyed by stress and financial burdens. Her family has financial support, but many families do not. All of these children deserve appropriate care.

Ms. Connie Beasley related that she has been active throughout her life in many philanthropic causes involving children's health. She is the grandmother of the children about whom Ms. Stadtlauer and Ms. Boesen spoke. Their family has the financial means to provide support for their family, but she has met people who are not as fortunate. Insurers and the state of Iowa need to do what is right, not what is easy. She spoke about her granddaughter, Annabelle, who was only allowed to go outside twice in two months and could not have visitors during her stay in the treatment center. Their family has started a fund to help other families with necessities such as gas and food to help defray costs and allow more families to have access to care. It is time for the government and insurance companies to stand behind these desperate families who have come before the General Assembly multiple times over the years. This is not just about patients, but their families and communities. It is about love and support and being there for those who need it.

Mr. Jeff Becker spoke in support of an insurance coverage mandate for PANS/PANDAS. Ms. Sarah Becker, his wife, submitted written comments that were distributed to committee members. Her comments included letters of support for the legislation mandating insurance coverage for PANS/PANDAS from Columbia University Department of Neurology, the Stanford University School of Medicine, the International OCD foundation, and ASPIRE. Mr. Becker read from the letter submitted by Dr. Dritan Agalliu, Ph.D., Columbia University, Department of Neurology, in support of the legislation. The letter noted that lack of insurance coverage for PANS/PANDAS further delays, and in some cases completely prevents, access to treatment. Insurers routinely deny coverage and a lengthy cycle of denials and appeals frustrates both health care providers and families. More importantly, the denials and appeals process prolongs patients' suffering and family trauma, and increases the risk of serious neurological and psychological harm, long-term disability, or even loss of life. While the cost of immunotherapies, particularly IVIG, is substantial, it is small in comparison with the cost of emergency interventions, in-patient psychiatric treatment, and/or pediatric hospitalizations for the complications of severe PANS/PANDAS. Delayed or denied care also carries a risk of long-term care for serious neurological, emotional, and behavioral disabilities. In addition to increased costs for medical care, untreated PANS/PANDAS also increases education-related costs, as children often require specialized, individualized instruction and significant accommodations for cognitive, neuropsychological, and psychological dysfunction. Dr. Agalliu and Iowa families ask that the committee alleviate the burdens placed on families, physicians, and other community members who strive to serve the critical needs of children with PANS/PANDAS, and to please enable their doctors to make appropriate medical



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decisions free from constraints posed by insurance company denials. He urged that Iowa join Arkansas, Delaware, Indiana, Illinois, Minnesota, and New Hampshire and require insurance coverage for PANS/PANDAS treatment to help Iowa children and families.

Following the public comments, Co-chairperson Lundgren expressed appreciation for the comments and advocacy, but clarified the purpose of the committee was to help the General Assembly evaluate requests for insurance coverage mandates going forward. She said the committee would not take action on any of the specific mandates that came before the General Assembly last session. With the committee's final report, however, the General Assembly will have some data to assist in analyzing future mandates. She added that Dr. Kruse made some valuable points about additional information that would be helpful to the General Assembly. The committee meetings and report are the start of the discussion. These issues are critical and cannot wait. But the easy way out is to pass a law and not know who it really helps, how it works, and whether the mandate is actually beneficial. There will be opportunities for those seeking mandates for various conditions to come before the General Assembly in the future to plead their case. The committee's work and report to the General Assembly will provide information to help future General Assemblies make informed decisions about whether to support a mandate. Co-chairperson Lundgren stated that she had the legislation written that established the committee to better understand how a mandate actually works. Everyone involved knows how complicated insurance is and the General Assembly needs the tools to make the right decisions and to know the decisions actually help people.

Senator Trone Garriott stated that it was helpful to have public comment because the committee is so narrow in its focus on premiums and costs to insurers, but is not taking into account the significant out-of-pocket, financial, and personal costs to families. As a chaplain, she noted that the human cost cannot be discounted. She thanked the co-chairpersons for making it a priority to include public comment early on the agenda as those perspectives were not directly represented by the members of the committee and the human cost is so important to understand.

III. Insurance Overview

Ms. Angela Burke Boston, Insurance Division (division), reviewed the document produced by the division entitled "Iowa Total Health Insurance Coverage Chart for 2020," which provides information about the number and percentage of Iowans covered by insurance and is broken out by type of coverage. Ms. Burke Boston noted that the document was the same information presented at the first committee meeting. The document before the committee today presents that same information in a different format, including a pie chart. As to the data on existing mandates and proposed mandates, Ms. Burke Boston stated that the Federation of Iowa Insurers (federation) had provided information to the division and the division had reviewed the information late into the day on Tuesday. The division was unable to review the information thoroughly, however, so the federation would present the information.

IV. Presentation of Data Collected for Existing and Possible Future Mandates

Mr. Matt McKinney, speaking on behalf of the federation, provided background on the methodology used in collecting and compiling the mandate data. The committee had asked that data be collected for three existing and three proposed insurance mandates including, respectively, the costs or anticipated costs; increased utilization or anticipated utilization following implementation of the mandate; and the populations impacted by the mandate. The federation reached out to its members and provided a template to allow collection of the information on a uniform basis so the resulting document would be in an understandable and uniform format. The document was prepared by the federation and shared with federation members for their review.



Mr. McKinney first reviewed the information relating to the existing health insurance mandates for diabetes, autism, and biologically based mental illness, using the diabetes data as an example. He noted that the information on the per member per month (PMPM) impact was reported as a range and as an average to maintain confidentiality of the responding insurers. The footnotes on the document provide information as to the number of carriers providing responses for each condition. Mr. McKinney next reviewed which populations were subject to the mandate by insurer type. He explained that the self-insured public employee population refers to cities, counties, and school districts. The self-insured, uninsured, and those covered by Medicare are not included as those populations are not subject to state mandates. The federation used that information to determine the number of individuals impacted by the specific mandate. The next step was to take the average cost multiplied by the total number of lives subject to the mandate to arrive at the total cost impact on both a monthly and annual basis. The utilization figures were provided by the responding carriers. This same methodology was used to arrive at the results for both autism and biologically based mental illness.

Regarding the proposed health insurance mandates, Mr. McKinney stated that the federation used the legislation from the 2021 Legislative Session on PANS/PANDAS and on medically necessary foods as the bases for analysis of those mandates. For infertility, there was not legislation to use as a basis, so the federation used the current plan for the state of Iowa as a basis because that plan covers infertility benefits.

Senator Trone Garriott asked Mr. McKinney to define the PMPM cost impact and what was included in that cost. Mr. McKinney responded that the PMPM cost is broader than the premium. When actuaries determine the PMPM cost, they include everything that goes into the cost and break it down into a PMPM amount. This includes but is not limited to benefit and administrative expenses. This number is meant to be the total forecasted expenditure for care under each of the benefit categories. These costs are then wrapped into the premium. The type of coverage determines who is expected to actually pay the premium. For example, a small employer may be required to pay 65 or 70 percent of the cost of the premium. Co-chairperson Lundgren conjectured that looking at the PANS/PANDAS data, since the average cost impact is 35 cents PMPM on a total population of 821,797, and utilization is low, there would be a relatively small increase. Mr. Sundstrom and Mr. McKinney cautioned that it is difficult to predict how many patients would utilize the more expensive treatments and how many more patients would utilize the coverage if coverage were mandated. Mr. McKinney clarified that the description of utilization as "low" was not a reflection of the cost impact. Additionally, when a mandate is first implemented, the cost does not immediately increase. It takes time for a mandate to be implemented administratively, for members to understand that the benefit exists, and for the medical community to implement it. It is hard to forecast what the actual costs will be and insurers do not want to charge a premium to reflect the new coverage until the service is actually utilized. Often if utilization is very low, the impact is not immediate, but the impact will be reflected in future years as those benefits are utilized by that pool or population. Senator Trone Garriott noted that there might be more utilization and an increase in costs following enactment of a mandate, but asked if there is data to show a decrease in costs long-term as a result of people being provided appropriate treatment, preventive measures, or due to cost avoidance from reduced hospitalizations. Mr. McKinney responded that, unfortunately, for some of the existing mandates that were enacted long ago or that have been amended, that data is not available. Mr. Sundstrom provided the example of mandated coverage for education and supplies for diabetes, stating that the mandate reduces the costs resulting from complications from untreated diabetes, and noted that Wellmark supports this mandate. If supplies and education were not covered, he stated that costs probably would be higher. Senator Trone Garriott clarified that she was not trying to infer that insurers did not support the diabetes treatment coverage mandate. She stated, however, that there is data to demonstrate the increase in cost when diabetes is not controlled, including the average



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cost of hospitalizations relating to untreated diabetes. There is also data regarding the costs of weekly dialysis when an individual's kidneys are failing.

Mr. McKinney clarified that there are carriers that currently provide coverage for some of the proposed mandate conditions. He did not want to suggest that no treatments for these conditions were currently covered. However, some people want treatments covered beyond or in addition to those that are currently covered so it is not a zero-sum situation.

Co-chairperson Lundgren asked Mr. Sundstrom to describe the process to add coverage for certain conditions, based on, for example, United States Food and Drug Administration (FDA) approval, as an alternative to the General Assembly enacting a mandate. Mr. Sundstrom said that he was not an expert on Wellmark's process but to cover a drug, FDA approval is a baseline requirement. For coverage of a condition, the first step is for Wellmark's chief medical officer and his staff of doctors and other health care professionals to review the medical evidence and the efficacy of covering the condition. These experts review the medical literature annually and provide advice on medical policies as appropriate. The second step is for the experts to review customer demand. Larger employer groups have a greater ability to customize their benefit plans. Adding coverage of a condition as a benefit is always grounded in medical evidence and the efficacy in adding the benefit. The goal is to spend members' dollars wisely.

Representative James referenced the public comment in which other states were mentioned that have a mandate for coverage of PANS/PANDAS. Mr. McKinney said that the federation would look into the information from those states.

Senator Trone Garriott said that the premium is only one way of looking at the cost of a mandate and asked how to explain to a layperson the determination of the balance between premiums, co-pays, and out-of-pocket costs.

Mr. Sundstrom responded that under the Affordable Care Act (ACA), there are metallic plan tiers and there are requirements for premiums to be within a range for benefits and for out-of-pocket costs for the plans within each tier. With regard to drugs, there are drug formularies which are also tiered. The co-pays for lower tiers are less than the higher tiers. The insurer tries to align the economic incentives for consumers with the cost and the efficacy of a drug. Insurers are constantly reviewing options for plan designs. Some plan designs are more complex. All plans are designed to keep the product as affordable as possible while aligning incentives for covered individuals to use care efficiently.

Senator Trone Garriott asked, based on the low utilization projected for PANS/PANDAS, if an insurer might restructure out-of-pocket costs rather than increase premiums. Mr. Sundstrom replied that if coverage is expanded to include additional benefits, out-of-pocket costs will increase, premiums will increase, or both will increase as a counterbalance. If premiums increase, the insured can ask for a plan with higher deductibles; however, that makes care more expensive when it is actually utilized. Senator Trone Garriott noted there are many things in play for the insurer as well as for the insured. Mr. Sundstrom responded that one growing concern for Blue Cross Blue Shield (BCBS) is the issue of affordability. Under the ACA, a person can obtain coverage that has affordable premiums, but the out-of-pocket costs are very high. People might be able to obtain coverage, but they might not be able to afford to actually use it. BCBS has formed a national workgroup to start talking about federal policy.

Ms. Strouse added that everyone knows insurance is about risk, and an insurer has to look at all members in the pool when providing coverage. With a condition such as PANS/PANDAS that is hard to diagnose, the insurer needs to spread the risk across everyone in the pool. Since the ACA went into effect, out-of-pocket maximums continue to increase, and consumers are being priced out of the



market. Any time there is talk of a new mandate it will have an effect on everyone in the insurance pool. Insurance is complicated and there is only so much that can be done at the state level.

Co-chairperson Lundgren asked if, for example, an FDA-approved drug became available to treat PANS/PANDAS, how would an insurer determine whether to include the drug in its formulary and how would the insurer perform the cost benefit analysis?

Mr. Sundstrom responded that drugs are unique and that Wellmark, like all insurance companies, has a pharmacy and therapeutics (P and T) committee. Wellmark's P and T committee is made up entirely of practicing physicians and pharmacists with a range of specialties. The P and T committee meets at least twice a year to review all drugs, including new drugs and new studies related to drugs. The P and T members are not Wellmark employees, but advise Wellmark on what to include in the formulary based on medical science, practice, and evidence. The P and T committee's decisions are binding. With IVIG treatment, the committee would determine whether clear medical evidence exists related to the use of IVIG for treating PANS/PANDAS. Mr. Sundstrom said that he would take the information provided to the committee about IVIG back to Wellmark's P and T committee for evaluation. If the committee finds clear medical evidence, Wellmark would cover IVIG for PANS/PANDAS. Co-chairperson Lundgren asked if the General Assembly mandated coverage for PANS/PANDAS and required IVIG to be a covered treatment, even if the Wellmark P and T committee did not agree that there was enough evidence to cover it, would Wellmark cover it? Mr. Sundstrom replied in the affirmative.

Mr. Sundstrom provided the example of the new class of Hepatitis C drugs that were approved a few years ago. When the drugs were first approved they were very expensive. Wellmark immediately decided to cover them, even though one employer group did not support inclusion due to the cost, because the drugs were so much more effective than prior treatments. Following initial coverage, there was a huge spike in costs due to increased utilization. As demand leveled out the costs decreased. Even though the drug was very expensive, the P and T committee decided it was highly effective and Wellmark covered it. Senator Trone Garriott added that the drugs were probably less costly than alternatives such as a transplant, and Mr. Sundstrom agreed.

Co-chairperson Lundgren asked what sources Wellmark relies on for proof of efficacy of a treatment, and if a specific treatment were not approved for a specific condition, how consumers could advocate for the treatment to be considered under the insurer's treatment approval process? Mr. Sundstrom responded that Wellmark utilizes multiple sources, and in certain specialties there are specific authoritative sources. One source is the American Academy of Pediatrics Redbook which is published every four years. The most recent Redbook was published in 2021. The 2021 Redbook section on PANS/PANDAS concludes there is insufficient evidence to support the use of IVIG for treatment of the condition. But as medical science evolves, more studies are conducted, and the evidence accumulates as to the efficacy of the treatment, Wellmark could change its coverage decision based on the science. Doctors also use a source called "up-to-date" which aggregates studies on various conditions. "Up-to-date" also does not currently support coverage of IVIG for the treatment of PANS/PANDAS. As to information about coverage of other conditions, Wellmark.com provides medical policies for many conditions along with the support for those policies.

V. Closing Comments

Co-chairperson Schultz thanked the committee members for their work and for educating him in particular. He said the committee is not an oversight committee and he hoped the members did not feel as though they were being interrogated.



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Ms. Matney stated that even though Medicaid was largely carved out of the conversation on mandates, Medicaid also has a P and T committee on the pharmaceutical side. Medicaid covers FDA-approved and rebatable drugs, and the P and T committee reviews new drugs and the medical science on an ongoing basis. For medical services, there is a clinical advisory committee to which the public may submit recommendations for new treatments as they develop.

Representative James shared that she reviewed a study that indicated consumers spend 12 million hours per week on the phone with insurance companies. One public commenter had spoken of the time spent on repeated denials and appeals. She stated that no one likes a mandate, but the General Assembly has an obligation to these families who would not have to come before the committee if they were getting what they need. She said while she is not an expert on health care, she has spent her life as a chaplain and feels a deep commitment to those who are marginalized and vulnerable. She did not understand why someone should have to pay \$76,000 to keep their child alive, especially when they have insurance coverage. Legislators have to weigh the total costs, including not just the premiums, rates, and bottom lines, but the human costs. She expressed that she was dissatisfied with how the issues presented by the families were being addressed.

Co-chairperson Lundgren reiterated that the purpose of the committee was to determine where the system is broken. She asserted the system is broken at the federal level, and the state is limited in what it can do and what it can force insurance companies to do. The General Assembly needs to understand these limitations. Insurers also have processes for determining which benefits are covered. She shared that as the aunt of a child who has been suicidal, she is very sympathetic to what families go through. Everyone wants Iowans to be healthy and have access to what they need to remain healthy. But the purpose of the meeting is to determine what the barriers are, and many of them are at the federal level.

Commissioner Ommen thanked the committee for allowing the division to engage in the process and he committed to working with the committee and the General Assembly going forward.

Mr. McKinney expressed his appreciation for being able to provide information from the members of the federation to the committee. He shares the concern that there are needs in the state. As far as the obligation to fix the issues, if an insurance company covered the specific treatments discussed, other policyholders would ask why the company was using their premium dollars to cover a treatment that is not approved by the Redbook or other medical sources. Insurers are trying to be good stewards of policyholders' dollars. They manage the dollars that are available so that members get the coverage they need at a premium that is affordable while limiting out-of-pocket costs that would make coverage inaccessible.

Co-chairperson Lundgren reiterated that the General Assembly receives requests for coverage mandates for many different conditions and the committee's conversations do not mean that the General Assembly will not go forward with passing legislation. Based on the work of the committee, the General Assembly will now have the necessary information and understand the nuances of health insurance coverage to make educated decisions.

Representative James stated that she would like to learn more about the insurers' process because doctors have told her that IVIG treatment works. That is why it is important that doctors and others are included in the discussion, not just insurers. She said she looked forward to more follow-up conversations.

Ms. Strouse said that as an insurance agent, she can help insureds file appeals and work through the process because she works for the consumer, not the insurance company. If someone is trying to manage the process on their own it can be overwhelming. No matter what type of insurance a person



has, the agent is there to help, and consumers have a right to have an insurance agent. The cost of an agent is already included in the premium cost. An agent can also relay conversations with consumers to an employer or an insurer on the consumer's behalf. As a parent of children with special needs, she understands the challenges and offered her assistance as an insurance agent.

Ms. Maass shared that Iowa Total Care relies on FDA approval and utilizes an advisory panel in making decisions about drugs. She also noted that as medical science changes and evolves, coverage changes and evolves.

Senator Trone Garriott said that evaluating insurance mandates is complex and other voices need to be included in the process. The committee reviewed the costs to insurers, but the costs to individuals and the community, as well as personal costs, also need to be evaluated. Premiums and out-of-pocket costs as well as other factors like profit should be considered. As a legislator, she has been involved in advocating for her constituents on insurance issues. It would be beneficial to make the insurance process more accessible and easier for individuals to navigate on their own so they do not have to rely on a legislator to advocate for them. The hope is that people in the insurance industry are acting as advocates for consumers, but that is not always the case.

Co-chairperson Schultz said that the legislation specified the issues the committee should address. The membership of the committee reflected the expertise necessary to address those specific issues. The committee meetings were very helpful and as the General Assembly goes forward, legislators will not have to ask members of the lobby the questions they have repeatedly asked in the past, because the committee has answered those questions. Co-chairperson Schultz thanked everyone again for spending their time educating the committee members.

Co-chairperson Lundgren added that the General Assembly passes a lot of bills, but the General Assembly is not doing its job if the legislators do not ask questions and understand how their constituents are going to be affected. As to the reliance on sources like the FDA in making decisions, she noted the examples of drugs that were not approved by the FDA for use against COVID-19 being touted by doctors as being effective against COVID-19. The FDA is a reliable data source. Through personal experience she knows that people will do anything to help their children. There will be further discussions and additional questions, but at least the committee has consistent answers to the foundational questions moving forward. She expressed her appreciation to the members and to those providing public comment. The committee will file its final report with the General Assembly and the work will continue.

VI. Materials Filed with the Legislative Services Agency

The following materials listed were distributed at or in connection with the meeting and are filed with the Legislative Services Agency. The materials may be accessed from the link on the committee's website www.legis.iowa.gov/committees/meetings/documents?committee=36638&ga=ALL:

1. Iowa Total Health Insurance Coverage Chart for 2020 submitted by the Insurance Division.
2. Existing and Proposed Health Insurance Mandates Compilation submitted by the Federation of Iowa Insurers.