

Steve Sisolak
Governor

Richard Whitley,
MS
Director



DEPARTMENT OF
HEALTH AND HUMAN SERVICES
DIVISION OF PUBLIC AND BEHAVIORAL
HEALTH

Helping people. It's who we are and what we do.



Lisa Sherych
Administrator

Ihsan Azzam,
Ph.D., M.D.
Chief Medical Officer

NEVADA RARE DISEASE ADVISORY COUNCIL
MEETING MINUTES
May 19, 2021
9:00am – 11:00am

Meeting Locations:

- This meeting was held via teleconference only. Pursuant to Governor Sisolak's March 22, 2020, Declaration of Emergency Directive 006, the requirement contained in NRS 241.023(1)(b) that there be a physical location is suspended in order to mitigate the possible exposure or transmission of COVID-19 (Coronavirus). Accordingly, all members of the public participated by using the web-based link and teleconference number provided in the notice.

Rex Gifford opened the meeting at 9:00 a.m.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:

Amber Federizo, DNP, APRN, FNP-BC (CHAIR); Kimberly Palma-Ortega; Shirley Folkins-Roberts; Annette Logan-Parker (Quorum = 3)

COUNCIL MEMBERS ABSENT:

Brinlyn Thornley; Valeria Porter, DNP, BSN, MBA

DIVISION OF PUBLIC & BEHAVIORAL HEALTH (DPBH) STAFF PRESENT:

Rex Gifford, Administrative Assistant III; Joseph Filippi, Executive Assistant; Jennie Belka, Administrative Assistant II; Melissa Yerxa, Student Intern

OTHERS PRESENT:

Isabel Bueso Barrera; Matthew Wright; William Gittinger; Jill Connor; Kelvin Yamashita; Paul Purdy; Brandon Yip; Cheryl Donahue

Roll call was taken and is reflected above. It was determined that a quorum of the Rare Disease Advisory Council (RDAC, the Council) was present.

2) PUBLIC COMMENT

Chair Federizo opened the floor for public comment. No public comment was made. This was verified by Rex Gifford and this item was closed.

- 3) POSSIBLE ACTION - Discussion and possible approval of finalized letter of support for SB 40 regarding the collection of certain data relating to health care and SB 175 with amendment, enacting provisions relating to lupus – Subcommittee Members

Chair Federizo motioned to approve the drafted letters as written for SB40 and SB175. Shirley Folkins-Roberts seconded the motion to approve as written. The Council voted unanimously to approve the letters as written.

- 4) POSSIBLE ACTION - Discussion and possible action to finalize letter of support for SB 420, relating to health insurance and SB 171, relating to drugs and the prescription of drugs – Subcommittee Members

Chair Federizo opened up the discussion and presented the possible action to support for SB 420. Chair Federizo reviewed the requirements for premiums to be 5% than the reference price, the gaps in addressing network adequacy, the anticipated administrative advisory portion, and its anticipated go live dates.

Subcommittee member Shirley Folkins-Roberts followed up with stating that her program is not very involved with insurance for families. Therefore, they are not as versed on the presented circumstances.

Chair Federizo revisits that it has been discussed with the state previously. A prior Senator suggested having Medicaid as an open option, however the administrative burden of that was a rough barrier because we are asking Medicaid to facilitate offering services as a Medicaid option – meaning that people would have to pay a premium to have Medicaid. As that was a previous iteration, this is the evolution trying to bridge that gap for patients in the program that slip in and out of coverage between the two due to income changes. The families who get caught in this gap are usually those whose job may offer them a raise and aren't under normal circumstances a cause of celebration. However, that raise may push them over the threshold of Medicaid but not yet fully subsidized off of the exchange plan, so that is one group that may access this. There is a lack of understanding of how big the group is and there is a lack of data, which provides hope for upcoming bills.

Subcommittee member Annette Logan-Parker thanked Chair Federizo for the explanation of SB 420. Ms. Logan-Parker stated that she acknowledges that the subject is complex and that she personally, and for the Cure for the Kids Foundation, are in support of SB 420 as they have quite a few families that fall into the category of, what they refer to as, “the working poor,” where somebody will get a raise that bumps them out of the category of coverage. When dealing with families that have children with rare diseases that can be catastrophic to them and their family income based on that. Ms. Logan-Parker reiterates that it's a complicated subject and that it requires a lot of conversations. She states that it will be interesting to see how it is rolled out and how it's adjudicated, however, having that option for that category of community members is really important.

Chair Federizo responded that the perspective is shared and wanted to bring this up as an opportunity in case any council members might not have been well versed to be in support or choose that for their organization, so she is appreciative of everyone's responses.

Subcommittee member Kimberly Palma-Ortega shared that tomorrow is the Palsy Committee, so she will bring up this bill again. Ms. Palma-Ortega stated that across all boards are holding onto different options and that she is glad that the committee is holding onto this one. Ms. Palma-Ortega asked the committee if it is known whether this option is passed, if there will be any advocates in place to help

with the transitioning. For example, if there is a small difference, such as \$10, \$20 to \$100 that would kick them out of option through the state, is there an advocate who can assist, even if they were buy into the option, that Katie Beckett is still a follow up option for them. She followed up with if there is an understanding of the levels that are offered and if they did, at one point in time, have a buy-in option for Medicaid, does that include other areas of other plans that fall underneath Medicaid. Ms. Palma-Ortega stated that she can ask these questions to the IMAC Commission since they have a meeting coming up, as they may have some answers. Ms. Palma-Ortega continued asking that the families that fall in between being straight Medicaid, Nevada Check-Up, or different formats that may have different names, how does it change if more than one family member has a different plan. She followed up inquiring if the family has an option for siblings or children that don't necessarily have the straight version of Medicaid. She asked if there are options for families or if it's a "one options fits all" for one particular family.

Chair Federizo responded that subcommittee member Palma-Ortega asked great questions. She followed sharing that as [SB 420] is worded and as it is structured, it does have that structure in that they do realize that there is a need for an advocate and an executive design that supports the administration to ensure that there is a continuity of coverage. As of right now, people switch in and out of Medicaid coverage and there is a back and forth of what to be offered based on what they are qualified for with Medicaid. There is going to be a supportive section of [SB 420] in the development that should address some of the other issues that will come up in an administrative fashion. Right now, they are trying to get it passed and then have that section that currently encompasses that evolve into letting the advisory executive side to take over, like what would individual families be based on and offering the household that 5% reduction to apply to everyone and if there are any age restrictions or if they will follow the Affordable Care Act guidelines, which we anticipate most of those will likely still follow those exact same mechanisms. Chair Federizo stated that it is similar to how GovCHA was designed, which is the office of consumer health affairs in the state. Chair Federizo believes that they will be looking to tap into them, for more of a consumer-based – such as getting closer and connected. Knowing that there are a lot of patients that are not even aware of the GovCHA system that navigate these hurdles within the Nevada insurance system. So, there are these advocates and resources, but there is no executive administrative side within these insurances that necessarily assisting them to say 'here are your resources' and how can they assist you in making sure every individual in your family is continuously covered and what would that cost be for each person, if there is, and how would that potentially shift over time.

Chair Federizo stated that she anticipates that there will be some amendments coming forward that include other bills that may not be making it. With our committee, there was a similar bill that was put forward to assist patients to be continually eligible for up to one year for Medicaid. Surrounding the concern of continued paperwork, it will ensure that if someone is deemed eligible, they will remain eligible despite any changes that might accrue in a one year timeframe. Hopefully, those amendments will roll up to it. To address subcommittee member Palma-Ortega's point, there should be a development of a robust administrative side that will work closely with GovCHA to make sure that these things are identified on a more personal level and putting in a public option on a private side will create a best of both worlds. They don't usually do it with connecting with each other, so this is hoping to bridge a gap for this. That said, it could completely change between now and its passing. So that is always a possibility. Chair Federizo believes that it has promise, but thinks that perhaps it should have been introduced earlier for the session. Unlike some of the other bills that will become effective July 1st, they don't anticipate this rolling out robustly until May 26th, 2025 to get all of that formalized, so this isn't going to be an overnight thing by any means. It is at least a start because we have a bad habit with the state not getting started so it will move in that direction.

Subcommittee member Kimberly Palma-Ortega stated appreciation for Chair Federizo taking the additional step further because unfortunately when the exchange first came, everyone was excited, like climbing up a hill and as soon as we got people plugged in, there were the different offers and changes, causing so many questions. Not everyone was familiar or have that background of understanding, a lot of people felt like it fell off a cliff. Ms. Palma-Ortega stated that she believes that for this community and this council with different abilities across, it will be beneficial for families to have options. It will allow them a chance to grow in knowledge and not just take the basic options that are given. Such as moving between different jobs and constantly having a transition in life that impacts the quality care for yourself and your children. This will help solidify some of the issues that families will see, especially in the medical community. With the other bill regarding prescriptions, Ms. Palma-Ortega asked if we know, in regard to the insurance piece, with different plans having different options for prescriptions, dental, etc., if this bill has any verbiage in relation to insurance options or is based on health care. If so, will they introduce specifics later on.

Chair Federizo responded by noting that as of right now, SB420 approaches with the same requirements as the Affordable Care Act, to provide essentially the same elements which is provided from the exchange from the pharmacy standpoint, so there could still be structures within the exchange. The biggest difference is that the premium cost for families is required to be 5% lower than the reference price – the biggest difference is that they might have to pay if they are not eligible for the subsidy with the exchange, it would be 5% lower cost from that.

Chair Federizo continued stating that SB171, the other bill open for discussion, may not make it out of Senate finance, and the economic form reported that our state deficit is not likely to be as low as anticipated. Chair Federizo followed up that this is a blessing, as the Medicaid 6% reduction from AB3 will no longer be implemented. This makes it so no clinics or hospitals will have to change their reimbursement structures because they will not get hit with cost reduction by 6%. Which was fortunate, but occurred during an inopportune time with being in the middle of the legislative session. Hopefully, fiscal notes that we were under consideration before that announcement. People are more conservative and now we are late in the game. The timing was bad, although the news was good. SB171 may not make it out of Senate finance committee, but that bill does look at the pharmacy side of things. Its intent does not mandate that patients are required to obtain their prescription from a mail order pharmacy. Mail order pharmacies intent originally was to create convenient access for patients and perhaps reduce the cost by accessing larger distribution sites and reducing costs, which was a benefit on the parent side because they were paying less and benefit on the patient side because then they have a choice to get a 90-day supply at the cheaper rate or decide whether they want to go to a retailer at the higher rate.

However, overtime that convenience factor for the patients was moved from an option to being mandatory. So now we have several insurances who are mandating mail only as your only option for all of your medications. For example, if you are admitted to a hospital and your insurance plan requires that you utilize mail order only, you may have to wait to be discharged until your mail order can confirm that it will be shipped. One of the biggest issues that came up this last year, especially with the VA, was that they had significant issues because of what was going on with the postal service at the time. This caused a lot of veterans to encounter delays because they are very heavily reliant on mail order, so there has been many patients who did not receive their medications and who may be been potentially hospitalized as a result. The same kind of issues were happening because of the weather issues that we faced last year. When there was freezing weather and we had a distribution line mess up, you can imagine that everything that was on its way to Nevada was delayed and, unfortunately, the access to distribution within the state for these medications were pretty limited. Most of the pharmacy benefits managers

managed their medications in the Midwest or in Southern California. In terms of having access to them here, it can be a problem.

Chair Federizo stated that these are issues that come to say that while it has been a cost effective avenue, those cost reductions haven't quite migrated down to the consumers either. So there has been a cost-saving mechanism for the medical plan or the pharmacy plan, those savings haven't quite always been transparently seen by the patients. So, the patients are still either seeing high prices or high coinsurance or high deductible despite the fact that they are willing to wait for mail order and are willing to go in this manner. It is a step to make sure these mandates are going towards a cost-effective version for the plan, but maybe health-effective. Or both the hospital that has to maintain them until they can get these prescriptions or until the patient can actually obtain them. The VA had to stop going from submitting 90-day supplies down to 30 because their ability to distribute them became disrupted. When veterans were planning on going anywhere to see family, they had three to four medications that were on different days for renewal, they would go without them because they wouldn't be home when they were gone. Despite it not being mandated, patients may find themselves required to use the mail order process to access their medications instead of through the clinic. This highlights that side of it, or the other side of it, that you brought up that it was also intended to prohibit use of accumulator program. There are many patients who are reliant on copay coupons from manufacturers because of the high cost involved with several drugs. When you start to get into diseases where there is no generic autoimmune disorders, these are the things where this cost is pretty high. To offset them, the only way to get adherence for those patients is to use those programs. Copayment accumulator programs were instituted to shift medications to generics, which is great and we understand the intent of that, however, when you don't have that option, copayment accumulator programs prohibit you to use alternative forces of payment to assist you in paying for those. Both of those were established for safeguarding and protecting patients access to their medication and how they obtain them. The structures that were in place have become barriers more than they have become cost saving mechanisms, so that bill has those provisions. Chair Federizo stated that if it doesn't make it out of committee this time, they will join together and in the next session, with a lot that will happen in the interim, there will be a lot to watch and see how it goes. This has been on the SB171 side of it, if you do encounter or have issues in that manner for your own organization this is maybe an opportunity to suggest to them that that bill continues to move forward. There is a slight chance that the session, since we are getting near to the end, that it can at least be an ongoing conversation for the next session.

Subcommittee member Kimberly Palma-Ortega followed up stating that, as a parent or one who works with individuals who are in our community, she hopes that the bill does merge. It would be huge, especially with families that are veterans and that have social needs, with different components. Subcommittee member Palma-Ortega used her personal experience of a family member in the hospital for over a week, relating the need to leaving the hospital and the mental state of needing medication, which these instances would impact mental health. Ms. Palma-Ortega reiterates her support for the bills to merge to provide leeway and flexibility to families and individuals that are trying to maintain their care.

Chair Federizo concluded the open discussion about SB 420 and SB 171. She opened it up if there is anyone else who has thoughts or need any additional information or wish to submit anything on behalf of their organization. Chair Federizo offered assistance to help with understanding the information. She noted that she brought it up, as it does relate to the council and that these bills can vastly impact what the council does and also the community in the capacity encounter very soon.

Chair Federizo opened up the floor for additional discussion on Agenda item four. No additional comments were made.

5) POSSIBLE ACTION: Discuss and determine future agenda items – Subcommittee Members

Chair Federizo noted that, with the subcommittee's permission, as it is late in the legislative session and the letters have been finalized, she suggested that future items will include monitoring and surveilling what goes through and what evolves with SB 40 or SB 175. The subcommittee can reconvene and find a date that works to meet. Chair Federizo suggested rolling the subcommittee's tasks over to the larger council meeting for the presentation at the July meeting. She opened it up to the subcommittee if there are any other future agenda items that should be addressed prior to transitioning to the larger council meeting.

Subcommittee member Kimberly Palma-Ortega agreed with Chair Federizo's suggestion. Since the subcommittee is at a standstill to see how the everything happens, Ms. Palma-Ortega supported moving what has been done with this subcommittee to the larger committee until the committee can determine what else is going to pan out. This will allow the subcommittee to digest what's to come with the bills and to bring it back to the full council.

6) POSSIBLE ACTION: Discuss and schedule future meeting dates and times – Subcommittee Members

Chair Federizo tied in what was established in Agenda Item five, that the next meeting will be with the RDAC council meeting in July, to present what has been already discussed. At that time, the additional bills would have made it through would be added as an agenda item for discussion by the entire council to see how the final decisions will impact any other recommendation made in the future for the annual report.

7) PUBLIC COMMENT

Chair Federizo opened the floor for public comment. Rex Gifford asked if there was anyone from the public on the line and that they would have three minutes to make any discussions of topics discussed. No members of the public made a comment. This was verified by Rex Gifford and this item was closed.

8) Adjournment – Chair

Chair Federizo moved to adjourn the meeting at 9:34 AM. She wished everyone the best and thanked everyone who joined together for the meeting. She stated to let her know if anyone needs anything and wished the attendees a great afternoon.