NEVADA RARE DISEASE ADVISORY COUNCIL

MEETING MINUTES
Date: April 7, 2023
9:30 AM – 11:23 AM

Meeting Locations:
Pursuant to NRS 241.020(3)(a) as amended by Assembly Bill 253 of the 81st Legislative Session, this meeting was convened using a remote technology system and there was no physical location for this meeting.
Chair Annette Logan-Parker opened the meeting at 9:30 AM.

1) INTRODUCTIONS AND ROLL CALL

COUNCIL MEMBERS PRESENT:
Annette Logan-Parker (CHAIR); Gina Glass (Vice-Chair); Amber Federizo, DNP, APRN, FNPBC; Ihsan Azzam, MD, PhD; Jennifer Millet, DNP, RN; Valerie Porter, DNP, BSN, MBA; Kimberly Palma Ortega; Susana Sorrentino, MD; Nik Abdul Rashid, MD; and Christina Thielst (Quorum=9)

COUNCIL MEMBERS ABSENT:
Paul Niedermeyer (excused absence); Craig Vincze, M.D. (excused absence); Shirley Folkins-Roberts; Naja Bagner; Linetta Barnes, BSN, RN; Veneta Lepera

DIVISION OF PUBLIC & BEHAVIORAL HEALTH (DPBH) STAFF PRESENT:
Ashlyn Torrez, *Health Program Specialist I, Office of Public Health Investigations and Epidemiology (OPHIE), DPBH*; Sherry Stevens, Administrative Assistant III, Administration, DPBH; and Elizabeth Kessler, *Health Program Specialist II OPHIE, DPBH*; Kagan Griffin, *MPH, RD, Title V Maternal, Child, and Adolescent (MCH) Program Manager*, *DPBH*; & Cassius Adams, *MS, Title V MCH Children and Youth with Special Health Care Needs (CYSHCN) Project Coordinator, MCH, DPBH*

OTHERS PRESENT:
Pierron E. Tackes, *Senior Deputy Attorney General (DAG), Office of the Attorney General*

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 Logan-Parker opened the floor for public comment.

There was no public comment, so Chair Logan-Parker moved on to the next agenda item.

3) POSSIBLE ACTION: Discussion and possible action to approve meeting minutes from February 13, 2023. – *Council Members*

Chair Logan-Parker introduced the agenda item and asked if there was a motion to approve the meetings minutes.

Councilmember Jennifer Millet motioned to approve the meeting minutes from the prior council meeting dated February 13, 2023. Councilmember Nik Abdul Rashid seconded the motion to approve. There were no objections. A quorum voted to approve the prior meeting minutes.

4) POSSIBLE ACTION: Discussion and possible action to create two subcommittees, set expectations, and volunteers for a Needs Assessment Committee and Strategic Plan Committee. – *Council Members*

Chair Logan-Parker introduced the agenda item to formalize two subcommittees and recommended that the Council has two subcommittees that would be the Needs Assessment Committee that could be called something different such as the Data Collection and Analysis Committee, and the Strategic Plan Committee. Chair Logan-Parker continued The Data Collection and Analysis, or Needs Assessment Committee would agree to a possible additional meetings and few additional responsibilities to see that the Needs Assessment gets developed and deployed. Chair Logan-Parker added that the Data Collection and Analysis Committee or the Needs Assessment Committee would be responsible for organizing, reviewing and reporting the Council the status of the Needs Assessment and the results over time. Chair Logan Parker stated that the second subcommittee, Strategic Plan Committee would also have additional meetings suggested at once month and then moving to two meetings a quarter. Chair Logan-Parker added that the Strategic Plan Committee would be responsible for oversight of the development of the finalized document that will be presented for final approval and this Strategic Plan will be for the next two years. Chair Logan-Parker opened the floor to the Council for discussion or motion of approval.

Vice-Chair Gina Glass motioned to approve the formation of the two subcommittees, Needs Assessment or Data Collection and Analysis Committee and the Strategic Plan Committee. Councilmember Amber Federizo seconded the motion to approve. There were no objections. A quorum voted to approve the formation of the two subcommittees, Needs Assessment or Data Collection and Analysis Committee and the Strategic Plan Committee.

5) POSSIBLE ACTION: Discussion and possible action to build the platform of the Needs Assessment. – *Council Members*

Chair Logan-Parker introduced the agenda item that was updated from the last meeting by fixing typos, added a few more questions that was recommended from the last meeting. She continued once approved;

the Needs Assessment will be created into an online platform that will be a survey. Chair Logan-Parker commented that the online platform will be on the Nevada Rare Disease Advisory Council's website and the Council will promote marketing material. Chair Logan-Parker stated that Councilmember Dr. Ishan Azzam requested to consider drafting the Needs Assessment to be directed towards healthcare professionals as well. Chair Logan-Parker would like to purpose that the Needs Assessment gets done that will be geared towards the patients then would work out the kinks to establish a professional healthcare provider assessment. Chair Logan-Parker opened the floor to the Council for discussion.

Chair Logan-Parker asked Councilmember Dr. Azzam how he felt on starting with the patient needs assessment to work out the kinks and then replicate the needs assessment for the provider assessment.

Councilmember Dr. Azzam commented that the idea was wonderful and thanked Chair Logan-Parker.

Councilmember Amber Federizo wanted to suggest that for the demographic section to put non-binary or something similar instead of non-identified as non-binary is more in line with identification. Ms. Federizo suggested that the needs assessment should have the option of putting the patients' payers that the patients may be having problems.

Chair Logan-Parker thoughted that both suggestions were great with the Council's approval the suggestions by Councilmember Federizo will be incorporated.

Councilmember Dr. Rashid asked where the patient would put their insurance payer would go under which section.

Councilmember Federizo commented that there was a section that was for insurance and the section asked what insurance the patient is on.

Chair Logan-Parker agreed with Councilmember Federizo and added that the insurance section is vague, and the section does list out the different insurance types, but the needs assessment does not give an option on the commercial piece to indicate whether or not it is a commercial healthcare.

Councilmember Federizo commented that the specific names of the commercial insurance will say Blue Cross, Blue Shield however there are different types and if the individual filling out this needs assessment would not want to click on Blue Cross, Blue Shield because the issues would not be identified. Ms. Federizo continued that she would want to have the option to click on her insurer, such as Horizon Blue Cross, Blue Shield so that way the Council would have a better idea of which program is problematic as opposed to looking at the entire commercial insurer.

Chair Logan-Parker added that the needs assessment does indicate private insurance and there is a text box. Chair Logan-Parker added that the needs assessment can be updated to include the insurances seen in Nevada and include the 'other' with a text box as the needs assessment cannot include all the insurances seen in Nevada. Chair Logan-Parker continued with another possible suggestion of adding a comment in the needs assessment that asks the individual filling out the form to please indicate exactly what their insurance is. Chair Logan-Parker added that as a robust the needs assessment will have a drop down menu that will be in alphabetical order for ease of the individual filling out the needs assessment.

Councilmember Federizo agreed.

Chair Logan-Parker asked Dr. Rashid if her question was answered.

Councilmember Dr. Rashid commented that her question was answered.

Councilmember Dr. Ishan Azzam asked if the questions will be numbered and if the needs assessment will be in SurveyMonkey online.

Chair Logan-Parker replied that the needs assessment will be in a RedCap system that will be an entire platform that will have its own separate repository for data. Chair Logan-Parker stated that the reason for the RedCap option will be for ease of passing along the data to the State once the program gets up and running so that way the data will not be housed at the Cure4Kids Foundation server forever. Chair Logan-Parker added that the questions will be numbered and will have been sectioned with similar questions with drop menus to click on and move on to the next question.

Dr. Azzam asked how long the survey take for someone to complete. Dr. Azzam stated how long the survey will be for a person reading at high school level correlates with response rate. Dr. Azzam continued with a survey under ten minutes also has a high response rate and more the granular the needs assessment the better for analysis but that will make the survey longer.

Chair Logan-Parker commented that the needs assessment took her ten minutes to complete. Chair Logan-Parker felt that someone with less experience with the RedCap platform would take longer to complete the survey. Chair Logan-Parker added that having the subcommittee for the needs assessment will see the trends and any changes or adaptions needed can be brought to the Council so that way the Council is collecting data consistently. Chair Logan-Parker agreed with Dr. Azzam about having drop down menus to make the survey simple as possible for individuals taking the survey or needs assessment. Chair Logan-Parker asked if there was any other comments or suggestions.

Chair Logan-Parker clarified the vote will put the questions in the needs assessment into the RedCap platform with the two additions that Councilmember Federizo requested, the first being within the identification of self and the second being added additional drop down menus on the private or commercial insurance section.

Vice-Chair Gina Glass motioned to approve to build the platform of the Needs Assessment. Councilmember Dr. Nik Abdul Rashid seconded the motion to approve. There were no objections. A quorum voted to approve to build the platform of the Needs Assessment.

6) POSSIBLE ACTION: Discussion and possible action of the Strategic Plan for 2023-2024. – *Council Members*

Chair Logan-Parker introduced the Strategic Plan draft document that has a zebra theme throughout the document to get people to associate rare disease with zebras from a branding type of concept. Chair Logan-Parker stated that strategic plan document is conceptual and can be changed. Chair Logan-Parker added that the strategic plan was created based on the RDAC Council Member Survey that was

completed at the end of 2022 and presented during the February 2023 meeting. Chair Logan-Parker felt that the strategic plan would be able to clearly organize the focus of RDAC, and be able to share that focus with stakeholders to get involvement and support the Council. Chair Logan-Parker added that the strategic plan will outline current objectives and will be finalized by the subcommittee that will be presented to the Council at future meetings for possible action. Chair Logan-Parker continued that the strategic plan document provides a little history and then will go into detail on the specific areas of focus as assigned in Senate Bill 315. Chair Logan-Parker was hopeful that the strategic plan will clearly outline what the Council will be doing and will help the lawmakers and individuals understand. Chair Logan-Parker continued that the lawmakers and other individuals will take the RDAC more seriously and include the Council in important discussions as the State heads into the 2025 Legislative Session. Chair Logan-Parker added that the RDAC will get a positive reputation as an advocacy group for rare diseases and have more influence on the rare disease community as the State moves into the 2025 Legislative Session. Chair Logan-Parker continued that the subcommittee would work on an awareness and education campaign, the establishment of a comprehensive rare disease plan for Nevada Health Equity and Disparities. Chair Logan-Parker added that the objectives will address Nevada specific burdens and compare Nevada to other states. Chair Logan-Parker stated that each section will have three main objectives foreach category that will break up into pillars. Chair Logan-Parker opened up the floor to the Council for discussion and suggestions.

Councilmember Dr. Azzam thanked Chair Logan-Parker for drafting the strategic plan and suggested to leave the strategic plan into a word document for easier editing. Dr. Azzam added that he would like to see present and future work for the Nevada specific data collection and analysis. Dr. Azzam also suggested adding disease tracking and quality assurance to the strategic plan because the ultimate goal would be to improve quality of life, and the Council needs to know if their intervention is helping or hurting the patients and their families or if the intervention is not making a difference.

Chair Logan-Parker stated that the strategic plan will be in a word document format once the design are done. Chair Logan-Parker commented that having Councilmember Dr. Azzam on the subcommittee would be great to add his experience and insight of the process if Dr. Azzam has the time.

Dr. Azzam commented that he would love to be a part of the subcommittee but does not want to bite off more than he can chew. Dr. Azzam added that once the design of the strategic plan is complete to put track changes on the document to show accepted or rejected suggestions or edits.

Chair Logan-Parker added that Dr. Azzam's suggestion to turn on track changes is easy to do and the primarily document will be put on the RDAC website that will be available electronically.

Dr. Azzam thanked Chair Logan-Parker and expressed his gratitude.

Councilmember Christina Thielst commented that having a electronic version of the strategic plan would be great in terms of saving cost and easy to share with others.

Chair Logan-Parker agreed, and commented that having the strategic plan electronically can also add in links to send individuals to get more information. Chair Logan-Parker asked the Council for any other comments or suggestions, there was none.

Vice-Chair Gina Glass motioned to approve the Strategic Plan for 2023-2024. Councilmember Christina Thielst seconded the motion to approve. There were no objections. A quorum voted to approve the Strategic Plan for 2023-2024.

7) INFORMATIONAL: Review and discussion of Rare Disease Day 2023. – *Chair Annette Logan-Parker*

Chair Logan-Parker stated that Rare Disease Day was in February and the Council had good exposure. Chair Logan-Parker commented that Councilmember Christina Thielst had an article and Tweet outgoing formalizing the patient voice and rare disease and thanked her for representing the RDAC. Chair Logan-Parker added that her organization Cure4Kids Foundation had an interview on the Channel 3 News about RDAC and the work the Council is doing. Chair Logan-Parker added if Christina Thielst would like to add any insight on her experience.

Councilmember Christina Thielst added that the experience was great to showcase the Rare Disease Advisory Council, and was hopeful that the exposure will prompt other Rare Disease Advisory Council's in other states.

Chair Logan-Parker commented that Ms. Thielst article will be posted on the Nevada RDAC website under the News section for reference.

8) INFORMATIONAL: Review and discussion of Senate Bill (SB) 221 of the 82nd (2023) Legislative Session, revising provisions relating to Medicaid. – *Chair Annette Logan-Parker*

Chair Logan-Parker stated that Senate Bill 221 is co-sponsored by Senator Doñate and Senator Stone, and the goal of the bill is to expand the Medicaid Services Manual to include a new provider type under the current provider type 17. Chair Logan-Parker explained that each provider is assigned a provider type and then that provider type has a billing guide ands rate methodology associated with those provider types. Chair Logan-Parker continued that currently in Nevada there is provider type 17 that currently has 16 unique provider types in provider type 17 that includes Tuberculosis (TB) clinic, the outpatient birthing center, some HIV clinics, and other specialty clinics. Chair Logan-Parker added that provider type 17 is more specific disease type than provider type an example would be a TB clinic work on TB patients versus a provider, a pulmonologist are normally under provider type 20. Chair Logan-Parker stated that if the bill gets approved Medicaid would be required to create and provide an outpatient childhood cancer and rare disease clinics with a new billing guide and rate methodology associated with those types of practices. Chair Logan-Parked explained the main goal would be eliminate some the administrative burdens associated with pediatric hematologists, oncologists, and other rare disease physicians who qualify. Chair Logan-Parker commented the caveat to SB 221 would be that Medicaid designs what the qualifying criteria would be. Chair Logan-Parker explained an example would be when an outpatient clinic is giving nephrotoxic chemotherapy to a child and then the billing guide says the provider can only do one year analysis, but the provider will do a multiple year analysis during that time period to protect the patient. Chair Logan-Parker stated that the bill was passed anonymously and will continue on.

9) INFORMATIONAL: Review and discussion of SB 255 of the 82nd (2023) Legislative Session, revising provisions governing peace officers. – *Chair Annette Logan-Parker*

Chair Logan-Parker stated that there was a typo on the agenda, and the SB is 255 not 225, and is presented by Senator Kerry Buck. Chair Logan-Parker continued that if the bill passes will increase Medicaid fee for service by ten percent for pediatric specialists. Chair Logan-Parker added that Senator Buck is asking for suggestions and edits if the Council wanted to reach out to the Senator's office directly. Chair Logan-Parker commented that Senator Buck was hoping to influence more pediatric specialists to accept Medicaid fee for service patients because there is an access problem to specialty care for children with Medicaid Fee for Service. Chair Logan-Parker continued that there is a shortage of providers who provide that high level of expertise, but also very poor reimbursement. Chair Logan-Parker added that Medicaid has only increased their reimbursement rate by five percent over the last twenty years an with the cost of practicing medicine has increased more than the five percent. Chair Logan-Parker opened the floor for discussion to the Council.

Councilmember Dr. Ishan Azzam asked why the rest of the population was left out of the reimbursement increase because some individuals that have cancers and hematologic diseases.

Chair Logan-Parker commented that the Council has an opportunity to ask Senator Buck why the other populations were excluded. Chair Logan-Parker added that she does not want to speak for anyone, but the assumption Chair Logan-Parker has would be starting with children because of the large fiscal note attached to SB 255. Chair Logan-Parker commented that having SB 255 pass and change for at least that small percentage of the population then to build upon that change and include other populations.

Dr. Azzam thanked Chair Logan-Parker and felt that other providers will not take on Medicaid patients because of the complicated way of billing and poor reimbursement. Dr. Azzam believes that billing and poor reimbursement is not the only problem.

Chair Logan-Parker agreed with Dr. Azzam and reminded the Council to reach out to Senator Buck individually and not on behalf of the Council to give their insight.

Councilmember Dr. Nik Rashid asked if the bills can be emailed out to the Council.

Chair Logan-Parker stated that the bills and all supporting attachments were in the meeting invitation.

10) INFORMATIONAL: Sickle Cell Data Collection (SCDC) Grant update. – *Ashlyn Torrez, Health Program Specialist I, Office of Public Health Investigations (OPHIE), DPBH*

Chair Logan-Parker opened the floor to Ms. Ashlyn Torrez.

Ms. Torrez thanked the Council for their time and introduced herself. Ms. Torrez stated that the Division of Public and Behavioral Health (DPBH) gave permission to apply for the Sickle Cell Data Collection Grant that will allow the Division to establish and sustain a data registry for reporting data as it relates to sickle cell. Ms. Torrez continued that the SCDC Grant has two components A and B, and the Division will apply for Component B, Capacity Building. Ms. Torrez added that there is a requirement to establish a multi-disciplinary team and asked to Council to recommend any individuals with expertise in the following areas: clinical healthcare for children with sickle cell disease, clinical healthcare for adults with sickle cell disease, mental health care for people with sickle cell disease, community health care cu

has social work or patient investigation for individuals with sickle cell disease, health communications, government relations or policy, sickle cell disease community based organizations, an individual living with sickle cell disease, and an individual providing care for a person with sickle cell disease such as a family member. Ms. Torrez asked the Council to email her at atorrez@health.nv.gov for any recommendations the Council has and asked to also include a CV or resume. Ms. Torrez thanked the Council for their time and asked if anyone had any questions.

Chair Logan-Parker thanked Ms. Torrez and was hopeful that most individuals on the Council will want to participate in the multi-disciplinary team.

11) INFORMATIONAL: Nevada Cancer Registry Electronic Reporting Initiative for childhood cancer, non-hospital, reporters review and discussion. – *Chair Annette Logan-Parker*

Chair Logan-Parker introduced this agenda item and stated that she has been with Andrea who is the Cancer Registry Manager. Chair Logan-Parker added that Cancer Registry is working to implement an electronic automatic data interface that will eventually be a streamlined process. Chair Logan-Parker continued that Cancer Registry is understaffed by 20 percent and is working on identifying ways to have technology help make the data transfer in a simple and seamless ay where Cancer Registry receives the data in the format that is needed to validate and move the data on where it needs to go. Chair Logan-Parker was hopeful that what will be learned in this process with Cancer Registry will help the sickle cell data collection when the time comes. Chair Logan-Parker stated that a lot of good work is happening in Nevada and now it needs to be reported but first the bridge needs built between providers and data collection folks at the State. Chair Logan-Parker opened the floor for questions and discussion.

Councilmember Dr. Nik Rashid asked how the data is collected for the adult providers for cancer.

Chair Logan-Parker commented that to her understanding the hospitals and labs are reporting well but there some holes in the data collection from the interface because of the handwriting the original forms and faxing in the to State. Chair Logan-Parker added that the cancer registry as a whole has some IT infrastructure that should help streamline reporting from the providers perspective. Chair Logan-Parker thought some challenges would be the original pathology might be identified through the lab interface reporting because the pathologist and the big national labs are already good at electronic interfaces but the long term care analysis that is challenging. Chair Logan-Parker was hopeful to influence more electronic reporting using the technology techniques to make it easier for providers and data collection efforts at the State and report to the CDC.

Ms. Brigette Cole commented that she is with Nevada Children's Cancer Foundation. Ms. Cole stated that some of barriers that has been identified in Northern Nevada especially in the rural areas of Nevada is that a lot of cancer patients go to Primary Children's in Utah, Oakland, UC Davis, and UCSF. Ms. Cole continued to say that collecting the data from those hospitals as well the patient population in Northern Nevada is a challenge and a huge barrier.

Councilmember Amber Federizo commented that one of the things that Ms. Cole could look into is having a more in-depth partnership with Healthy Nevada. Ms. Federizo stated that if the child's pediatrician are in Northern Nevada and has access to transmit data from their EHR into the Health

Nevada System and Healthy Nevada will aggregate that data to be used by the registry to be captured if their pediatrician ensures putting the diagnostic codes in the registry. Ms. Federizo added that the data would be transmitted in Healthy Nevada regardless of where the patient went for treatment.

Councilmember Dr. Ishan Azzam asked how many cancer patients are diagnosed outside of the state of Nevada. Dr. Azzam continued that if the lab is reporting every single cancer or dysplasia to Nevada then the State should be able to capture the total number of individuals who have cancer.

Ms. Cole commented on the patient population that her organization serves often is that the patient's family lives in Elko and the family goes to the hospital, but the hospital is not quite sure or suspects cancer. Ms. Cole continued that the family would be transferred to the nearest Children's Hospital that could be in Utah and that is where the child is diagnosed with cancer there. Ms. Cole thought that there is a continuity of care and that gap in communication often does not happen and could potentially fall through the cracks. Ms. Cole stated that the communication was that the patient was not receiving treatment such as radiation or chemotherapy in Nevada and all the patient's care is at that hospital.

Dr. Azzam confirmed that the problem is that even the patient was not diagnosed in Nevada, there still is not enough information on the continuity of care because not all provider report in the same way as some are still using fax machines and others are electronically reporting. Dr. Azzam expressed his frustration that the state of Nevada does not have the initial cases and how to get the cases from out of state and also after diagnosis.

Chair Logan-Parker added that from a regional perspective with cancer registry in the data collection process the home ZIP code of the patient at the time of diagnosis is collected. Chair Logan-Parker continued that every state runs into the problem of trying to meet the minimum threshold of reporting in order for report to be considered at the national level. Chair Logan-Parker added that at the national level when those cases are being abstracted the data will have the ZIP code of where the patient lived at the time of diagnosis and in theory the cases should come out. Chair Logan-Parker added that in the last few years expect for this last year Nevada did not meet that minimum threshold of reporting and there should be improvements in Nevada when it comes to reporting. Chair Logan-Parker commented that one of things she would like to work on for the 2025 Legislative Session in Nevada is to getting state funding to help physicians be able to afford the electronic interface for reporting to revolutionize Nevada's data collection efforts and be able to compare Nevada's data at the national level.

12) INFORMATIONAL: Nevada Medical Home Presentation – *Kagan Griffin, MPH, RD, Title V MCH Program Manager, Maternal, Child, and Adolescent Health Section, DPBH; and Cassius Adams, MS, Title V MCH CYSHCN Coordinator, Maternal, Child, and Adolescent Health Section, DPBH*

Chair Logan-Parker introduced Kagan Griffin and Cassius Adams.

Kagan Griffin thanked the Council for their time and introduced herself. Ms. Griffin stated that she and her co-presenter Cassius Adams will give a brief overview on Children and Youth with Special Healthcare Needs and Medical Home Portal.

Medical Home Portal and Title V presentation was shared and presented to the Council.

Chair Logan-Parker thanked Ms. Griffin and Mr. Adams for their presentation and asked how Medical Home is determined for the child and where is the data coming from at the national level.

Ms. Griffin stated that the data is coming from federally available data and there are different specifications of how the medical home portal is constituted. Ms. Griffin thought that there was six different factors that are contributed to the overall definition, and the apparent has to check that the apparent is meeting and can be little subjective, a lot of medical home portal is usual source of care. Ms. Griffin commented that if you want more information she can email that to the Council.

Council member Dr. Ishan Azzam asked to go back to slide 11 where the slide shows that Nevada is 44th in the national ranking and asked if the 44th rank means that Nevada has the lowest percentage of children with special needs who have medical home portal.

Cassius Adams confirmed.

Dr. Azzam asked how the number of children with special needs who have medical home portal be improved. Dr. Azzam commented that the Council heard in a previous agenda item that many provider's do not take Medicaid patients and how is the data being reconciled to increase the rate.

Ms. Griffin replied that a big part of the medical home portal is that it is metric and if there are not enough providers then by virtue of the way the data is being calculated there will not be reporting of their usual source of care in medical home. Ms. Griffin stated that on their end medical home portal is being promoted to help people find that usual source of care, and using family navigation to get at least children and youth with special health care needs more hooked into that medical home. Ms. Griffin commented that Maternal, Child, Adolescent Health program has had an issue with for years and will continue to work on to improve.

Ms. Griffin shared the components of medical home portal and the Maternal, Child, Adolescent Health Section Dashboard that comprises the data.

Ms. Griffin stated that the Dashboard is a little outdated because the federally available data was just released a couple days ago and the program is still working to update the dashboard. Ms. Griffin pointed out that the components are metric and if needed, the medical home is care coordination, referrals, family centered care reporting a personal doctor and nurse, and finally the reporting a usual source of care. Ms. Griffin stated that there are questions that are asked on the National Survey of Children's Health, and pointed out that Nevada does a pretty good job for usual source of care and family centered care. Ms. Griffin commented that even further down the Dashboard there is the care coordination section that is the head of dragging down the metric from the last 12 months.

Councilmember Dr. Rashid asked that the questions shown are collected from the patient not the providers.

Ms. Griffin confirmed that the questions are from the national survey of Children's Health data that is coming from the caregiver responses.

Dr. Rashid commented that might be a problem in terms of identifying someone with special needs such as a patient with chronic disease and most of those patients get their care from their chronic disease at a specialist center. Dr. Rashid added that with the patients general care such as vaccination and other forms of care that is occurring with their primary care physician there could be a discrepancy in that patients medical home with their care coordination.

Ms. Griffin stated that was good point and something that she will look into. Ms. Griffin added that in comparing Nevada to the other states the national survey of Children's Health data is asking the same questions and that provides a flattened sense of what is going on in Nevada.

Chair Logan-Parker commented that Nevada is constantly falling victim when being compared to other states. Chair Logan-Parker added that children living in Nevada access their special needs providers differently than other states because Nevada does not have a free standing academic based Children's Hospital and Nevada is being compare to those states that do. Chair Logan-Parker stated that providers at Cure4Kids Foundation are offered medical home and asked how people, or the parents are being asked to participate in the national survey of Children's Health.

Ms. Griffin stated that since the Children's Health is a national survey that is out of her program's hands but mentioned that the survey is funded by HERSA, the Maternal Child Health Bureau. Ms. Griffin stated that the survey uses telephone methodology which will not reach everyone. Ms. Griffin commented that she takes any national data with a grain of salt to see the trends.

Chair Logan-Parker appreciated that perspective and commented that from provider point of view is that most do have a medical home for their patients and there is a massive discrepancy between people collecting data and people doing direct patient care. Chair Logan-Parker commented that the bulk of medical home happens are the specialist level and not the primary care level, and the data from the survey is not truly representing Nevada.

Cassius Adams commented that the implication that there are more children with medical home than what the data from the national survey is showing is great news. Mr. Adams stated that the medical home is as work in progress and getting to the providers and access to that data to be presented in a appreciable way is what Medical Home is trying to do.

Dr. Azzam asked does one child have two medical homes.

Mr. Adams replied that the medical home encompasses more than one provider, for example if there is one child who sees five different specialists and if those five specialists are coordinating services together and all encompass medical home there would be one medical home for all those providers.

Dr. Azzam commented that the rate of children with a medical home could be better but when compared to other states that are more densely populated state, Nevada always will be hindered.

Ms. Griffin thanked the Council for their thoughts and will bring everything discussed back to our leadership. Ms. Griffin added that her program has to use the federally available data with the Title V Blocker that is provided to her program. Ms. Griffin continued with the pre-blocker is pre-populated

with the data shown on the Dashboard and was interesting to see the discrepancies and nuances. Ms. Griffin stated that she would try to see what can be done on her programs side to show that Nevada is unique and there are different factors that need to be taken into consideration and the national data does not show. Ms. Griffin expressed her sympathy that the whole story of Nevada is not being told.

Chair Logan-Parker asked if the Maternal, Child, Adolescent Health program has the grant funds the phone calls that asks the other person to complete the survey.

Ms. Griffin stated that the Title V part of the Maternal, Child, Adolescent Health is not funded with the calls and that all is done at the national level.

Chair Logan-Parker asked where the original data comes from, who picks the people that are being called.

Ms. Griffin commented that the data comes from HERSA that complies different data sources. Ms. Griffin added that the medical home portal question is captured in the National Survey of Children's Health but the Title V program at Nevada is receiving data on a variety of other performance metrics such as the national vital statistics systems, National Immunization Survey, and others. Ms. Griffin continued that she could send over the specific outline methodology over email if the Council was interested.

Chair Logan-Parker expressed her interest in receiving the outline methodology.

Ms. Griffin commented that there will be a five year assessment that is sort of similar to a needs assessment of the community, providers, and different priority measures to focus on. Ms. Griffin added that her program is working on a proposal for finding a vendor that will help with the assessment.

Councilmember Amber Federizo commented a good opportunity would be to work with Medicaid because Medicaid submitted a grant to create a new provider type in Nevada that came about in the last two years working with the Council. Ms. Federizo added that once the new provider type is created then the data can dramatically improve in Nevada by allowing the clinics to be identified in that provider type that will be able to go to this specific information and ask within the provider's patient population.

Chair Logan-parker thanked Ms. Federizo for her comment. Chair Logan-Parker informed the Council that Dr. Capurro is no longer with the Division of Health Care Financing and Policy or Medicaid, and mentioned that Dr. Capurro' s work will continue with who fills her shoes. Chair Logan-Parker thanked Ms. Griffin and Mr. Adams for their time and asked if anyone else had questions.

Hearing none, Chair Logan-Parker moved on to the next agenda item.

13) INFORMATIONAL: Council member information sharing announcements. – *Council Members*

Chair Logan-Parker asked the Council if there was anything to share.

Councilmember Dr. Azzam shared that Dr. Capurro moved on from Medicaid and Dr. Malinda Steward is the new replacement in Medicaid.

Chair Logan-Parker thanked Dr. Azzam and asked if there was anyone else who would like to share anything.

Hearing none, Chair Logan-Parker moved on to next agenda item.

14) PUBLIC COMMENT:

Chair Logan-Parker opened the floor for public comment.

There was no public comment, so Chair Logan-Parker moved to adjourn the meeting.

15) ADJOURNMENT – *Chair Annette Logan-Parker*

Chair Logan-Parker moved to adjourn and expressed appreciation for everyone on the council.

Chair Logan-Parker moved to adjourn the meeting at 11:23 am.