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**Draft Minutes**

Name of Organization: Nevada Statewide Independent Living Council (NV SILC)

Dates and Time of Meeting: Thursday, December 8, 2022

 2:00 p.m.

This meeting is open to the public and will be held at the following location:

Nevada Department of Health and Human Services

Aging and Disability Services Division

3208 Goni Road, Building I, Suite 181 , Carson City, NV 89706

And via video-conference:

The public may also observe this meeting and provide public comment on Zoom.

**To Join the Zoom Meeting**

<https://us02web.zoom.us/j/9299041434?pwd=NmM5Tk1Od3ltRzg1enhRYTU3WDdUZz09>

Meeting ID: 929 904 1434

Password: NVSILC (case sensitive)

+1 253 215 8782 US (Tacoma)

The number provided may incur long-distance telephone carrier charges, and is offered as a regional call-in number, only.

Meeting ID: 929 904 1434

Password: 707401 (if exclusively calling in; if accessing the meeting via *both* the audio and video feed, please use the *above* password *instead*)

Find your local number: <https://us02web.zoom.us/u/kdGvZ9R9O5>

Meeting Materials Available at: <https://www.nvsilc.com/meetings/>

\*Please note that beliefs and values held by our designated presenters may or may not align with those of the Council.

1. Welcome, Roll Call and Verification of Posting

Julie Weissman-Steinbaugh, Chair

**Members Present:** Havander Davis, Mary Evilsizer, Dee Dee Foremaster, Jennifer Kane, Kate Osti, Linda Vejvoda, Julie Weissman-Steinbaugh, Renee Portnell, Sabra McWhirter Vickie Essner,

**Members Excused Absent:** Obioma Officer

**Members Unexcused Absent:**,Cheyenne Pasquale, Ace Patrick,Raquel O’Neill,

**Guests:** John Rosenlund,Cindi Swanson, Catherine Nielsen, Cody Butler, Steven Cohen, Lisa Bonie, Peter Whittingham,

**CART Provider:** Becky Van Auken

ASL Interpreter: Val Sturm

Staff: Dawn Lyons and Wendy Thornley

1. Public Comment

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Cindi Swanson: She has been placed on the Olmstead Advisory group, representing Commissions serving persons with disabilities. She was surprised that there was no one to represent public education, higher education, or Vocational Rehabilitation.

She and her husband recently discovered that through a glitch with Social Security, their son is missing quite a lot of money that was mistakenly taken out of his benefits. Some providers knew about the glitch like Opportunity Village but consumers, like her son, were not notified.

She also has the following questions and concerns:

1.  What is the glitch in the system that is preventing Nevada Medicaid from paying the Medicare costs for recipients?

2.  What needs to take place to resolve the glitch?

3.  How long until the glitch is resolved?

4.  Why was this information provided to the state providers but not to the Nevada SILC, CSPD, or DD Council?

5.  Was this information provided to the individuals that this affects?  This could very well be a significant impact for a person living on SSDI with the current costs that are still rising.

6.  What is the plan to support those individuals if they are short for their monthly expenses?

7.  When will the agencies that exist to provide the services and supports, start engaging with the people they exist to serve?

These types of issues should not be found out by chance.  We must be able to trust the agencies that are entrusted to provide the services that have been established and for the purposes the services were established.    Many people would not be able to afford their housing, food etc. with this amount of money being withheld.

John Rosenlund: What was called the Governor’s Fiscal Recovery funds, which was some of the funding seen going out into some projects right now, you probably have seen or heard it mentioned.
There were some monies that were requested through this process to work towards eliminating the Assistive Technology for Independent Living program waitlist.
A lot of people saw that when it was going forward for approval, and the assumption by many people including him, initially was that all of those funds were going to eliminate the waitlist. That's not necessarily the case.

He addressed this at the last Council meeting. The portion that's going to be determined for the elimination of the waitlist will be decided by ADSD.
He does not know what that number is. He oversees the program, and works with community partners implementing it but everyone should know that as it goes forward.
He received information from leadership in ADSD that a portion of those funds will be used for a blind services pilot program.
The AT for Independent Living program has always had this ability of being a place to put out a pilot program, there's a lot going on in the lack of a services for individuals that are blind that are kind of in that in between the period of someone having the visual disability and then how to get to this next point without some of the services that no longer exist?
He wants to reach out to consumers that have been affected by this as they go forward with trying to build this pilot program and try to get some information from the people that are affected by these services.
His approach is not to jump to directors or organization agency heads, but to the people that are affected by these services who have missed out. That's who needs to be heard from. He asked people to reach out to him and gave his email: jrosenlund@adsd.nv.gov . He also wants people who have visual impairments or have experienced this or have connections to this, reach out, because as this moves forward he wants to establish and create platforms.
Perhaps the SILC would want to be a partner in collecting some information. There's bigger fish to go after and that's to nail down the services that have been eliminated since a portion of those were removed from Department of Employment Training and Rehabilitation (DETR) and Vocational Rehabilitation (VR) many years ago.
Let's use this as that opportunity and reach out to him and figure out what we can do to serve this process going forward. He does need to report back to the agency leadership the plan going forward but wants to start out by getting people together and having this discussion.

Peter Whittingham: He is the Board Chair for the Down's Syndrome Organization of Southern Nevada. He thanked the SILC members and team, especially Julie for attending and supporting the Buddy Walk event held on October 16th in Las Vegas.
They had over a thousand people there, Julie, and her team played a great role. He also thanked the SILC and the Executive Director, Dawn Lyons for the donation that was made towards the event. He sees his organization as part of the SILC’s extended collaboration with local agencies who serve members of the Disability Community.
He appreciates on behalf of the board and their members, for the public attention and to the Assisted Living (IL), team. especially locally, Lance, as they are having a public awareness event on Saturday.
All this is happening is because of their association with SILC and he wants to make sure everybody knows how much the members of the Down's Syndrome organization really appreciate this collaborative partnership.

1. Discussion and Approval of Response to Letter from the Director of Nevada Health and Human Services **(For Possible Action)**

Julie Weissman-Steinbaugh, Chair

Dawn Lyons: The one and only agenda item other than the regular public comment items and the regular open meeting law details, and the reason why this meeting was called, was because the SILC

received a letter from the Director about the letter the SILC had sent him regarding Aging and Disability Services and some of the issues that the SILC had with the Public Health Workforce money.
At the time Ace Patrick said that she felt like he didn't address all of the issues in the response.
Hopefully everyone had a chance to read that response, and she has written a draft that she hoped they all also read. She would like to get some feedback and some ideas if they think it's a good letter. She wished that Ace was present to get her feedback because it was her public comment at the last meeting that she wanted to have this as an agenda item because she didn't feel like all her concerns were addressed.
Dawn trusts that the members knew where Ace was coming from because they voted on the letter. Cody sent Dawn a suggested change to the letter to change the sentence that says quote, “The SILC is the only council that is made up of a majority of people with disabilities and, therefore, is technically the only qualified council to provide feedback and receive these reports in order for us to create an effective state plan for Independent Living as mandated federally.” Cody said that it would probably be good to change it to something like, “The SILC is a council that's made up of a majority of people with disabilities and therefore is uniquely qualified to provide feedback and receive these reports in order for us to create an effective state plan for independent living as mandated federally.”

Dawn agreed with his suggested change after Cheyenne who is also not in this meeting, on a personal level, reached out to Dawn about that one sentence and said that sounds like we're excluding everyone else from that qualification and so Dawn thought that was a good way to change it.
 She read the letter out loud, “Dear Mr. Whitley,

Thank you for responding to our letter of concern regarding ADSD’s handling of federal funding for Public Health Workforce that was supposed to come through Title VII, Part B. We appreciate the opportunity to discuss our concerns with Administrator Schmidt. We do understand the loss of funding was not intentional, and that leadership discussed corrective action for future funding opportunities; although, it is still unclear what assurances are in place to prevent it from happening again. The idea that it was discussed is encouraging, at least.

During our discussion with Ms. Schmidt, several other concerns of ours were expressed, including the concern about disability services diminishing with the merging of Disability Services Unit into the Planning, Advocacy and Community Services Unit. When Ms. Schmidt asked what could be done to ensure improved communication moving forward, the response was a resounding “nothing about us without us” and to please ensure that people with disabilities are consulted when planning new services or changing existing services for people with disabilities. As you may be aware, this is specifically defined in NRS 427.040 and further clarifies the Agency shall report on the progress of their strategic plan annually. The SILC is the only Council that is made up of a majority of people with disabilities, and, therefore, is technically the only qualified Council to provide feedback and receive these reports for us to create an effective State Plan for Independent Living, as mandated federally.

Although this concern was not specifically addressed in your response to our initial letter, we are optimistic that ADSD will begin to follow the above mentioned NRS based on the additional concerns we expressed to Administrator Schmidt. We hope that you will continue to monitor this, as well, and deeply appreciate the time you took to address our concerns.

Respectfully,

The Nevada Statewide Independent Living Council”

Julie Weissman Steinbaugh: Thinks that the letter is very politically correct. And that the SILC needs to be included in a lot of the decisions that are being made and ‑‑ or ignored. Her main concern is that the disability community has just been forgotten.
And Aging Services has gone on to provide lots of and pay attention to lots of needs of the senior population, but have completely and totally ignored the disability community.
They swooped in and, again, picked up all of the transportation moneys, which will be funneled to people 60 and older and not even a second thought of people with disabilities who mostly have less income than the seniors, and don't have a way to buy a bus pass with the cost of rent and food.
That wasn't even brought into consideration with the transportation board. They just swooped in and took all the money.
She has a lot of concerns that the disability community is getting left in the back of the classroom to say the least.

Mary Evilsizer: Thinks the letter looks fine.
She didn't get a chance to go back and compare this letter to the original letter and was wondering, on the paragraph during the discussion with Ms. Schmidt, several of the SILC’s concerns were expressed, including the concern about disability services diminishing the merging of the Disability Services Unit into the Planning, Advocacy, and Community Services Unit.
In the original letter, did we place that dialogue?
Her recommendation was going to be if it wasn't expressly in the first letter, this is really an important issue, and might warrant opening up a dialogue if this is the primary issue, not going back to something that was discussed just when you met regarding the original issue about the state not applying for Title VII, Part b funding. Cody’s recommendation on that one particular sentence was good.

Dawn Lyons: To address Mary’s concern, originally when Dawn checked the posting, there was an accessible copy, of the director's original letter was posted on the materials.
There might be a technical issue with the original, accessible copy appearing on the website. Wendy will make sure that it is posted, because this was what Ace was actually giving public comment about at the last meeting.
In the draft minutes from the last meeting, Mary could review that to see where Dawn had read aloud the actual letter from the director and where that would address that, it is important.
Ace who had the complaint, wanted to make sure that the SILC was responding in a timely manner to the response to the SILC.
However, the SILC wanted to make sure that that door remained open so that the Director knows that the SILC does not feel it's necessarily resolved yet, and that issues still may come up.
That is why the SILC is asking him to monitor the situation as well. That allows the SILC to possibly write another letter down the line to him if something else does come up or if issues aren't resolved in a satisfactory way.

Mary Evilsizer:
She has a copy of the letter and was looking and comparing the two and there is a point where it says, “as federal funding for ADSD services are critically needed in Nevada opening up the communication” ‑‑ so that's what they were addressing, “the communication regarding state plan funding issues.”
In the response, it identifies NRS 427.040, and asks that individuals with disabilities and the disability community remain open in communication.
So I'm comparing those two points and thinking that what you're saying is addressing the previous point.

Havander Davis motioned to approve the letter with the changes that Cody suggested and sent to the appropriate people. Sabra McWhirter seconded, the members voted unanimously, and the motion passed.

Dawn Lyons will send the letter out with the changes.

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Havander Davis: Thanked everyone for coming for this special meeting and doing all the advocacy work to make things better for persons with disabilities.

Dawn Lyons: She seconded Havander's appreciation to this group and thanked those who attended including those who are not regular SILC members, and for their public comments.
She appreciates all their information and assistance with what the SILC is trying to do here.
She will reach out to John Rosenlund later.

John Rosenlund: Thanked the SILC for taking on this issue, “Nothing about us without us” is more than a slogan. It is something that is very near and dear to him. He brought it up at the conference with the SILC. It truly is more than a statement and what we carry around and say. If organizations are not at the table in providing this information to the Nevada SILC, then who are they?
Why are they not providing it is always the question, right?
It's supposed to be at the front of the table. That's why there's designated state entities that are partners with the SILC. He has been involved with SILC and independent living for almost 20 years. He commended the group for taking it to task. It's not always easy to be involved in something where you're bringing up negative feedback or ‑‑ kind of putting somebody on the spot.
When the AT Council sent a letter to the governor regarding the inaccessibility of websites, it caused quite a stir, but one must stay vigilant. You're here to speak up and you're here to hold people accountable for those things.
These things aren't negative. These are just calling out the things that need to be called out because everybody should be given the respect to provide the information and be part of the decision making.
Also, a shout to Cindi Swanson for bringing that issue forward. His understanding is this is another issue where bringing that issue out into the open through the Nevada SILC or the CSPD or these avenues, why is that information not being carried forward to the people with disabilities?
It's not appropriate and it's not right that they find out about this information after the fact whether it be a glitch in the system or something was messed up.
Give people the respect to respond and to take care of what they need to take care of.
If someone is $130 short, and currently he is not in that position but at one point in his life he was.
If there would have been $100 missing out of his monthly check, he would have been missing rent, that would have been a whole trigger of things that end up leading to being homeless. It triggers a series of events that would have dramatically impacted somebody with a disability if that Medicare premium isn't covered. So, hats off to Cindi and the SILC.

Dee Dee Foremaster: Expressed the extreme need for the SILC’s vigilance regarding being ignored in the future.
Nobody is going to speak up for us. We must do it ourselves, and John is right. If we're not there to advocate to make things better for the disabled community and to insist that we are not invisible, nobody else is going do it but us. Please stay vigilant in your communities.
And thank you, and for everybody's hard work

Julie Weissman Steinbaugh: Thanked everyone for making time to attend this meeting.

1. Adjournment

 Julie Weissman-Steinbaugh, Chair

Meeting adjourned at: 2:45 pm

**NOTE:** We are pleased to make reasonable accommodations for members of the public who have disabilities and wish to attend the meeting. If special arrangements for the meeting are necessary, please notify Wendy Thornley as soon as possible and at least five days in advance of the meeting. You may email her at wthornley@adsd.nv.gov According to NRS 241.020, supporting materials for this meeting is available at: 3416 Goni Road, #D-132, Carson City, NV 89706 or by contacting Wendy Thornley by email at wthornley@adsd.nv.gov.

***Agenda Posted at the Following Locations:***

Notice of this meeting was posted at:

Nevada Department of Health and Human Services

Aging and Disability Services Division

3208 Goni Road, Building I, Suite181, Carson City, NV 89706

and on the Internet: <https://www.nvsilc.com/meetings/> and <https://notice.nv.gov> and <https://www.nvsilc.com/>