P.O. Box 33386

Las Vegas, NV 89133

nvsilc@adsd.nv.gov

<https://www.nvsilc.com/>

**Minutes**

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

Date and Time of Meeting: Monday, March 29, 2021

 1:00 p.m.

This meeting will be held via video-conference only:

In accordance with Governor Sisolak’s Declaration of Emergency Directive 006; Subsection 1; The requirement

contained in NRS 241.023 (1) (b) that there be a physical location designated for meetings of public bodies where members of the public are permitted to attend and participate is suspended.

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

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1. Welcome, Roll Call and Introductions

Patricia (Ace Patrick) Unruh, Chair

Members Present: Ace Patrick, Lisa Bonie, Dee Dee Foremaster, Sabra McWhirter

Members Excused Absent: Julie Steinbaugh

Guests: Mary Evilsizer, Stephanie Schoen, Lucy Wroldsen, Raquel O’Neill

1. Public Comment

Members of the public will be invited to speak; however, no action may be taken on a matter during public comment until the matter itself has been included on an agenda as an item for possible action. Please clearly state and spell your first and last name, if unique or otherwise unfamiliar to the Subcommittee. Public comment may be limited to 3 minutes per person, at the discretion of the chair. Agenda items may be taken out of order, combined or consideration by the public body, and/or pulled or removed from the agenda at any time. Pursuant to NRS 241.020, no action may be taken upon a matter during a period devoted to comments by the general public until the matter itself has been specifically included on an agenda as an item upon which action may be taken.

Ace Patrick: Thanked the participants for coming and is looking forward to the presentations.

Dawn Lyons: Stated that Julie Weissman and Sabra McWhirter were excused absent.

1. Approval of Meeting Minutes from 12/10/2020 **(For Possible Action)**

Patricia Unruh (Ace Patrick), Chair

Dawn Lyons motioned to approve the minutes. Ace Patrick seconded. Motion carried.

1. Presentation and Discussion Regarding Proposed Medicaid PCS Budgets for the Next Biennium.

Lucille Wroldsen, Social Services Program Specialist II, Division of Health Care Finance and Policy (DHCFP)

Kirsten Coulombe: They had their first budget hearing at the beginning of March.
They had that presented to the Human Services Subcommittee for Senate Finance and Assembly Ways and Means.
This group is looking at some of the changes they are making for PCS, the Governor did present to state agencies that they had to look at 12% budget cuts. That has come into some cuts to services..
For PCS, they are trying to identify areas for recipients that have the most need and looking at in terms of if there's some areas in their policy and on the functional assessment that could just be tightened up a little bit, that's how they look to have some of their cuts that were proposed.
For PCS it would be changing the functional assessment areas in terms of the eating, meal preparation, shopping, housekeeping, and then reducing laundry a couple of minutes, and then so in eating it's ‑‑ it would be in terms of cutting up food for individuals that would have that 15 minutes for cutting up..
A recipient has the option in those different categories to either score as independent in meeting those assistance with activities of daily living, might need minimal, moderate or maximum assistance. 0 for independent up to three for the maximum assistance.
They are currently proposing to adjust that scoring for individuals that have the eating on the ADL section for the 15 minutes to adjust that scoring for those that have that minimum assistance to combine that with the meal preparation.
There is also just a scoring for housekeeping, laundry and then the meal preparation.

And then the second proposal that they have is related to individuals that have live in caregivers the authorizations we would do for the instrumental activities of daily living like laundry, housekeeping, meal preparation, those types of things.
The current policy is that if someone has a Legally Responsible Individual, (LRI), they do not get that assistance with the instrumental activities of daily living because they have that legal relationship to do that.
To address the 12% budget cuts, they would be looking at those individuals that have live in caregivers that can help with those sort of common space areas in terms of housekeeping or laundry that would be for the whole household.
It wouldn't affect their bathing, dressing, grooming, transferring those kind of services buff the subset that's the instrumental.

That's the high level overview that they have currently proposed, hoping that along with everything else, additional funds will be determined.
But at the time that's what's proposed.

Stephanie Schoen: Her upcoming presentation addresses when people who are unable to direct their own care are living with legally responsible individuals or with a parent or family member of any kind whether they're the legally responsible person or not, there's a tremendous amount of burden that gets placed on those people for compliance with the State for financial outlay and to now tell them that they're not going to make their $10.25 an hour to help with someone's laundry where oftentimes they are also dealing with incontinence and with the additional type of laundry that goes along with a person who has these types of issues, they live paycheck to paycheck, and to them further and take away some of those minutes is going to be really hard.
People at the very lowest end of the income spectrum who are making, say, through consumer direct or one of the other PCAs agency are making the lowest income of any of us.
Most of these people have given up a career to care for their loved one.

Second problem is that conflating the difference between feeding and eating in a functional evaluation. A lot of the people in the community who need assistance with the cutting up of the food or puree of the food that's a good way to go there, that should be part of the meal preparation for these folks.
She is hoping they're also considering the idea that often times feeding is a completely different thing, feeding is the ability to put the food to the mouth and chew the food and swallow it and a lot of senior populations who need this level of assistance really need to have a person sitting right with them because it takes them extra time to consume their food in order to be safe.
She hopes that, in talking to the legislature and assembly people and senators, that they may not have as good a grip on ADL and IADL's who have worked in the field and lived this world for a long time.
She is concerned about the Legally Responsible Individual taking on responsibility for things they weren't expecting to take on in the first place.
They are expecting to sign for surgeries or sign time sheets, they were not expecting to take on some of this stuff. Her presentation is about not over-relying on the person who cares about an individual to also be the person who cares for the individual.

Kirsten Coulombe: Their policy already prohibits an LRI from being authorized for the IADL's unless there are certain circumstances where they can show  that care giving role there's certainly measures in place to be able to look in a case‑by‑case basis to do that.
The general thought is that person has that legal relationship already established to take care of that person, right or wrong, that's what the process is.
This would be looking at the living caregiver in terms of if they're already living in the home, they would be vacuuming for the whole household, essentially.

Stephanie Schoen: In some situations, the guardian does not live in and the guardian is a Legally Responsible Individual.
Sometimes the person directing care, it is not appropriate to have the male caring for an adult female who is not in a romantic situation and so there are exceptions to the rule.

Kirsten Coulombe: They submitted their budget well before session, in September they have to submit it to their director and the director sends it to the governor.
They would not be the ones to speak with the legislators and advocate. They answer questions through the process, but that is where that advocacy role would be more so from recipients, family members, stakeholders, entities such as this and other boards and commissions that feel strongly about what the Medicaid budget would be, that is that legislative process to be able to reach out.
They support the Governor's proposed budget would be but not saying there are not avenues for stakeholders and advocates to share feedback.

The next part of the process is to have a work session, it is not scheduled at this time.
That work session is when the subcommittee, she believes that the human services subcommittees would vote on their budget. That then gets sent to the full committee, which is also not scheduled yet. Their budget is not final.

In their process, they are making any policy changes, present their changes and proposals at a public workshop to get stakeholder feedback and make those changes and then they would have that at a public hearing before then their changes are effective. Because these are policy changes that are tied into their budget, they don't plan on doing that until it's approved because perhaps money can be found and these changes wouldn't move forward per se.
That process would happen after the legislative session ends depending on what the outcome is of their budget proposals.
That will still be coming, they welcome feedback.
It would just be a little bit challenging because it would be tied into their budget and areas that they can improve the process perhaps like data collection or the areas they have in their control of implementation of these measures, they will certainly take into consideration.

Dawn Lyons: Regarding SB 93, with Senator Settlemeyer, would CMS allow people getting reimbursement directly from Medicaid instead of it going to the PCA services?

Kirsten Coulombe: The bill has two distinct parts and had a senate finance hearing to talk about ‑‑ it had senate Health and Human Services policy hearing, senate finance since it has a fiscal note attached.
There's two separate pieces of it.
She is only familiar with the policy piece on the first part.
Although it says personal care services, and in the Medicaid world, personal care services are a state plan option which means it has different authority than what waiver services.
You can't self‑direct a state plan but you can certainly have self‑directed services, fiscal self‑directed services.
We have an intermediary service organization model under our personal care services, agency model or an intermediary service organization model.
ISO is more of ensuring all the paperwork piece is done but still the payment is still given to the intermediary service function.
They function as an intermediary.
Not a fiscal organization.
SB 93 is mandating us to do a fiscal self-direction, they do have that option for home and community based services.
A 1915c waiver or 1915I.
They understand the intent with the recipients that Senator Settelmeyer has referenced that this bill is a result of and Mr. Nagel presented his story as well kind of having that focus beyond the individuals on the physical disability waiver that have attendant care, and it's sort of an extension of state plan PCO for individuals that have a disability they need more hours than what we would authorize in state plan services.
So the attendant care on the waiver side is where they help and wrap and give more hours for PCS‑like services.
And so that's where our fiscal note speaks to what is focused on individuals on the physical disability waiver that attendant care and it speaks to us contracting with a fiscal intermediary, the fiscal intermediary would work with the recipient on a number of authorized hours and give them a budget and then they could decide how much they want to pay that caregiver.
Instead of having that set Medicaid rate that goes to the agency or the ISO that doesn't have that much flexibility, the fiscal intermediary oversees that process and works with the recipient specifically to manage their budget of their services.
Because we want to make sure a recipient doesn't spend all their budget in one service and they also have the need here so. It kind of just helps of them navigate that process.
It certainly is an option.
Would require us soliciting a request for information or might require a request for proposal to secure contract to have someone be a fiscal intermediary.

Kirsten will let Dawn know when that work session is coming up. She mentioned their budget being in NELIS and for individuals to give input to the legislators in advance.

Ace Patrick: Is interested in how the different times for completing tasks is done. The hours of service that she is allotted, do not cover her needs.

Stephanie Schoen: Feels that assessments done in her home are not accurate for time to complete tasks.

Kirsten Coulombe: Agrees that assessments need to be thorough and mentioned that COVID has temporarily stopped in-person assessments in the home.

1. Discussion Regarding In-Home Nursing Care and Services for Higher Medical Need.

Stephanie Schoen, Guest

Stephanie Schoen: Wanting to address living in the community in Nevada as it applies to people who have high levels of care need. People who are medically fragile, medically complex, as well as the inability to direct their own care.
Those who because of some underlying conditions, whether everything from dementia, TBI, stroke, autism, or some sort of intellectual disability are not able to direct their own care. Families want their children to be able to stay at home. Once that child is an adult, the parents need additional supports.
She made a list of the services that currently do not work under the state of Nevada, the gaps.

Most of the respite programs don't provide skilled care.
People who would otherwise be living maybe not even in a skilled nursing facility but perhaps even in a hospital or long‑term hospital setting where their hospital needs are intense.

People on ventilators is one example of the level of care that's needed and the nursing homes aren't staffed for this level of care.
If they weren't cared for by family in the home, they would live in an intensive care unit at a hospital. They need staff that are trained in tube feedings, medications, catheters, and IVs. That’s the population that she is wanting to address.

Because of that there's something called “under skilled” under PCA services but in order to do that there's a lot of paperwork and it can happen, but you don't know to ask for it.

Somebody has to identify you, they don't advertise that they have it.
It's not easy to get.
There are day programs or workshops, but they are for people with dementia, people who are just senior and need a place to go and for people who have intellectual and developmental disabilities. None provide nursing the whole time.
Daybreak programs are not age appropriate for younger adults.

Private pay nursing is cost prohibitive, starts about $45 per hour, which cannot be used if an individual is getting nursing through Medicaid. The family ends up covering whatever Medicaid does not cover on those nursing programs.
Not everyone has extended family living nearby.
Not every family is willing or even up to the task of providing that level of care.
And sometimes the family themselves are impaired.

Ace Patrick: Multi-generational housing where people “Share the care”, is a possibility to help with the shortage of care professionals for general household tasks and the high cost of in-home care.

Stephanie Schoen: Acknowledged people not asking for extra help form their care providers to preserve the hours they are allotted through the system.

Dee Dee Foremaster: Mentioned people beginning to use small buildings in their backyards to house college students or retired nurses to assist family members needing care. These buildings are sometimes called “Granny flats.” She also mentioned pods, where people who have disabilities live in a pod or in an environment where there is one person or two or three people keeping an eye on the other people who are there in the home with disabilities.

Lisa Bonie: Getting the number of people in Nevada, who need these services would be very helpful in helping the state know what kind of funding is really needed.

Dawn Lyons: Feels that this group is the appropriate place to brainstorm for this population and to help start possible case study research programs to gather data on the numbers of people in Nevada needing these types of services. This would be helpful in getting grant funding. She proposed coming up with a list of interested parties that could be invited into this conversation and develop a plan for moving forward.

1. Discussion and Information Regarding Life Coaches.

DeeDee Foremaster, Workgroup Member

Dee Dee Foremaster had sent a one-page summary of the work that she and the Rural Center for Independent Living Center (RCIL), have been doing for the disability community in the rural areas of Northern Nevada.

She has 25 years of experience in this field. RCIL serves the rural areas. .
Our center started out as a traditional Center for Independent Living, they started focusing on homeless individuals that have significant disabilities that are on the streets. RCIL started a day drop-in center which drew many people needing that service. This developed into a peer support and networking group.

Due to COVID, they have not been able to open anything back up.
They do a lot of work helping people regain skills needed to live successfully in housing after being homeless for large amounts of time. They try to place these people in housing near each other to provide support.

So having a life coach for the first few weeks that they get into housing helps people to be able to establish a routine and be able to live a more productive life. Sometimes someone is needed to come into the actual home to assist with daily living skills, sometimes the support is sporadic. Many of the life coaches that she works with, are volunteers.

Dawn Lyons asked Mary Evilsizer if the SNCIL had any programs like the drop-in center.

Mary Evilsizer: SNCIL works with housing vouchers in Las Vegas. They assist people with the organization and paperwork to obtain these vouchers. Other skills needed to get through the interviewing process, fingerprinting, background checks, criminal history checks, transportation, appointment making and keeping, are all taught. SNCIL assists with finding housing that accepts the vouchers and working with the management. Once housing is attained, SNCIL assists with acquiring food and household goods, like towels, bedding, dishes, etc. They do not provide coaching on things like laundry or cooking.

Dee Dee Foremaster: RCIL’s priority is to get people into housing and then start coaching in life skills. She shared her contact information if anyone had any more questions or input.

She wanted to let everyone know about assembly bill 317 that has to do with housing vouchers and the fact that you cannot discriminate against people who have housing vouchers, it is coming up in the assembly, and it is vital that we get it through.
That would stop people from blocking the section eight vouchers.

1. Discussion and Make Recommendations to Distribute a Survey to Personal Care Assistant (PCA) Provider Organizations, Employees, and the Consumers they Serve **(For Possible Action)**

 Patricia Unruh (Ace Patrick), Chair

Tabled till after the Legislative Session.

1. Discussion and Information Regarding Other States’ Successes.

Deanna Gay, Workgroup Member

Tabled till next meeting.

1. Discussion and Approval of Letter of Support for Senate Bill 93 to Senator Settlemeyer Based on SILC IL Services, Diversion & Transition from Institutions Position Statement **(For Possible Action)**.

Patricia Unruh (Ace Patrick), Chair

Lisa Bonie: Gave suggestions for changes to the letter.

Dawn Lyons: She will make the changes. She reminded everyone that the SILC did vote to go ahead and allow this subcommittee to go ahead and endorse things the SILC has already approved as far as their position statements go.

Dawn Lyons motioned to move forward with the letter. Sabra McWhirter seconded. Motion carried.

1. Approve Next Meeting Agenda Items and Next Meeting Date **(For Possible Action)**

NV SILC TWG to be discussed.

Patricia Unruh (Ace Patrick), Chair

Tabled agenda items

Continue discussion about higher needs and medical care for home services

Peer cooperative care

Drop-in centers (Dee Dee Foremaster)

Waiver numbers discussion

what potential this group has to incorporate professional alive coaches in this model

Swedish senior/disability nursing facilities

Peer Cooperative systems/Professional life Coaches (Mary Evilsizer)

1. Public Comment

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Dee Dee Foremaster: Wanted to bring up Assembly Bill 317 that stops discrimination in housing. Dawn Lyons will send out the video.

1. Adjournment

 Patricia Unruh (Ace Patrick), Chair

Meeting adjourned at 3:01 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 at (775) 687-0551 as soon as possible and at least five days in advance of the meeting. If you wish, 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 at (775) 687-0551 or by email at wthornley@adsd.nv.gov.

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

Notice of this meeting was posted on the Internet: <https://www.nvsilc.com/meetings/> and <https://notice.nv.gov>

**In accordance with Nevada Governor Sisolak’s Declaration of Emergency Directive 006 there will not be a physical location for the** **Nevada Statewide Independent Living Council (NV SILC) Legislative Subcommittee.**

· As per Nevada Governor Sisolak’s Declaration of Emergency Directive 006; Subsection 3: The requirements contained in NRS 241.020 (4) (a) that public notice agendas be posted at physical locations within the State of Nevada are suspended.

· As per Nevada Governor Sisolak’s Declaration of Emergency Directive 006; Subsection 4: Public bodies must still comply with requirements in NRS 241.020 (4)(b) and NRS 241.020 (4)(c) that public notice agendas be posted to Nevada’s notice website and the public body’s website, if it maintains one along with providing a copy to any person who has requested one via U.S. mail or electronic mail.

· As per Nevada Governor Sisolak’s Declaration of Emergency Directive 006; Subsection 5: The requirement contained in NRS 241.020 (3)(c) that physical locations be available for the public to receive supporting material for public meetings is suspended.

· As per Nevada Governor Sisolak’s Declaration of Emergency Directive 006; Subsection 6: If a public body holds a meeting and does not provide a physical location where supporting material is available to the public, the public body must provide on its public notice agenda the name and contact information for the person designated by the public body from whom a member of the public may request supporting material electronically and must post supporting material to the public body’s website, if it maintains one.