



STATE INDEPENDENT LIVING COUNCIL

September 26, 2018

11:30 – 2:30 pm

Walker Building 1st Floor

21 South Fruit Street, Concord, NH

Present: Jeff Dickinson, Andrew Harmon, Dorine Pelletier, Rose Prescott, Marcia Golembeski, Susan Wolf-Downes, Bill Finn, Jennifer Beaulieu, Shellie Lemelin, Janet Bamberg, Joan Marcoux

Guest: Christopher Emerson, Gary Whitmarsh, Peter Marshall, Tobey Parch-Davies, Lorrie Ripley

Absent: Rose Prescott, Charles Saia, Erin Hall, Karen Sloper, Peggy Teravainen, Deborah Naumann-Lindsey

The SPIL Work Groups began work at 11:30.

The full SILC meeting was called to order by Chair Jeff Dickinson at 1:01 PM. Attendance was taken via introductions. Rose couldn't make it due to illness. Chuck and Erin Hall were busy. Lorrie came to fill-in for Chuck and Peter came in to fill-in for Erin. Karen has decided to resign from the SILC due to having too much on her plate. Jeff mentioned that Gary Whitmarsh has returned to the SILC. Janet mentioned that this is her last meeting and that Tobey will be taking on her role in developing and implementing the State Plan for Independent Living (SPIL).

Approval of Full SILC Minutes

Jeff asked if anyone had any comments on the June 27, 2018 minutes. Andrew commented that Jeff Donald's title of Director of COAST should be added next to his name. Joan mentioned that she should be listed as absent. Susan made a motion to approve the minutes which was seconded by Andrew. Joan and Andrew abstained. Motion carried.

SPIL Task Forces Updates

Goal 1: IL Services Expansion

- Jeff mentioned that due to only Dorine being present there may be no updates. Jeff asked if Dorine had comments. Dorine reported that she had none. Jeff said that he will defer for the next meeting any updates from this task force.

Goal 2: Transportation

- Andrew reported that in August the State Coordinating Council on Community Transportation (SCC) had an “unconference” which is an opportunity for the regional councils to discuss transportation issues. They talked about issues such as mobility management, which is how you handle the various structures and issues that come along with it for a fixed route versus door-to-door service. One huge issue is cross-state transportation largely due to communication issues. For example if a person needs transportation from Portsmouth to Lebanon, they may be able to get the ride but by the time its coordinated and everything, that person may have found another ride or organization. He said that he sent the minutes to Jeff and would send them to anyone who wants them. He mentioned that the SILC has been participating in the SCC monthly meetings and Regional Coordinating Councils (RCCs) organizations. The SCC on Community Transportation is looking to have more unconferences and Andrew will forward the dates to anyone interested.
- Marcia reported that Jeff Donald, an Executive Director of COAST (the public transportation system in the Seacoast area) is a member of the SCC. He is a strong advocate for people with disabilities. While other people at conferences and meetings say we should have more bridges or bike trails, Jeff Donald focuses on people with disabilities. Marcia further clarified how people with disabilities who can’t drive are stuck at home except for two trips a month in the state of NH.
- *Website Link to COAST:* <https://coastbus.org/>
- *Website Link to SCC:* <https://www.nh.gov/dot/programs/scc/>
- Andrew noted that Mike Acerno, who works for Home Healthcare Services (HCS), is partnering with the Community Volunteer Transportation Company (CVTC) to expand the rides in the more rural areas. It is the largest provider of non-emergency medical transportation in the Monadnock region and Sullivan County.
- *Website Link to CVTC:* http://www.cvtc-nh.org/about_cvtc_transportation_solutions.html
- Jeff mentioned that one of the objectives of the SPIL is for the SILC to become an active member of the SCC and to update the SILC membership on any updates from the SCC. Marcia, Shellie, and Andrew have done a very good job on that as noted by Jeff. He also noted that recently Bill went to an SCC Executive Committee meeting and mentioned that the SCC welcomes participation by the SILC to be there and provide input from the disability community.
- Bill noted that he is the Treasurer and Commissioner Representative for the SCC. He noted that right now they are working on their annual report.
- SCC meetings are held every month on the first Thursday at 1:30pm to 3:30pm.
- Shellie told her story of how she recently needed to go to the doctors. She used the UNH bus to go to the ER because she couldn’t use any of the area transportation. She noted that other providers either needed a week notice or 48 hour notice.

- Shellie also reported that she went to the Alliance for Community Transportation (ACT) meeting and discussed her story. Jeff asked about what the Alliance thought about Shellie's situation. Shellie said they were very supportive and surprised by her situation. Marcia responded that all of them were very concerned over the situation and were going to look into it. Jeff noted that the SILC should try to make clear to funders for these types of services that in the absence of transportation, one would be forced to call for an ambulance. Ambulances are expensive and would cost Medicaid more than accessible non-emergency transportation. Andrew noted that the whole point of the Managed Care Organizations (MCOs) was to cut down on ambulance rides but when they don't provide transportation to people who can't drive to medical appointments, people have to use the ambulance to get medical care.
- Chris mentioned that we need to be doing some advocacy with the Deaf community. He feels that strength in numbers will help. Dorine replied to him saying that we have tried to do that before. At first you have a bunch of people who get behind you but after a bit of time it fizzles out.
- Susan suggested that one way to advocate is to attend the forum of the Governor's Advisory on Diversity that will be held on October 4th in Concord.
- Susan noted that we could invite DOE Commissioner Frank Edelblut to the SILC because he should know about Shellie's story. Maybe he should be invited formally to one of the SILC meetings. She noted that this story should be put on the media and that it should go beyond this room and meeting. Marcia responded that that's how the people at the meeting felt.
- Andrew mentioned that not a single member of the Governor's Advisory on Diversity has a disability. Bill noted that the forum in Concord was targeted specifically to get input from people with disabilities. Gary asked if there was a way to get a member of SILC on the committee. Bill responded that it may be too late for that as membership is time-limited due to the task of the committee.
- Jeff mentioned that the autonomous vehicle bill passed by the legislature was vetoed by the Governor. The Governor felt that it didn't go in-depth enough about the different levels of autonomy of vehicles. Self-driving cars are on a level 4, the highest level of autonomy, but there are other levels the bill did not address. Jeff does think that there may be another bill either this year or next year.

Goal 3: Transition

- Susan reported that their group was doing very well. The group meets regularly. She mentioned that a number of items are on hold.
- Objective 1, Item A is meeting with NH Vocational Rehabilitation regarding the Implementation Plan for general and specialized services. It is currently on hold. Item B is meeting with all other community partners to coordinate efforts to help children and parents advocate for themselves. They feel that the Parent Information Center (PIC) already does education and the GCD advocates too, so no point in recreating that. Item C

is working with other community partners to develop a comprehensive guide for the state. She noted that they were tabling it because other organizations have already developed resource lists appropriate to their populations and the disability groups they serve. The task force would like to modify Item C to instead look at ombudsman options for consumers. Smaller agencies, like the SILC don't have one. She would like to add a note to the SPIL that SILC needs additional funding for an ombudsman.

- She mentioned that we should modify this document to reflect “people-first” language.
- Objective 2, Item A is collaborating with other agencies, which is done. Item B is meeting with PIC representatives to align efforts. This still is in-progress. They are waiting to get a specific name to be there and would also like to invite someone from PIC. The task force would like to invite them to share with the SILC and report on the actions that they are taking to support that goal.
- Objective 3 is identifying key collaborators and contacting each entity and is listed as done. Item B is contacting each entity and exploring ways to work together and define a role for SILC, and it is done. Jen will be adding this information.
- Objective 4, Item A is brainstorming ways to advocate for appropriate pay for personal care workers in collaboration with other identified key players. This item is on-going. Item B is to meet with GSIL to learn about their PCA program which is still being worked on and waiting to get a name. Once we have the name we will invite that individual to share with the group and talk about their experiences and why it's so very difficult to find people to fill those positions. Item C is recruiting a PCA to join the committee which like Item B, is a work in-progress.
- Susan reported that they are almost done with completing their tasks and that they might not be having long-term subcommittee meetings any longer unless Jeff feels they should.
- Jeff asked Susan if there would be benefits to producing a comprehensive guide of resources. Sort of like a directory that could be put on the website. Jen mentioned that we have something kind of like that on the website that contains links to website, names of the organizations, and contact information. She will be showing the list during the website presentation.

Membership

- Jeff noted that we are always looking for new members. Karen Sloper has stepped down from the SILC but Gary Whitmarsh will be appointed again as a member.
- Right now the Executive Committee is in the process of looking at where we are relative to appointment and reappointments. Right now, we are working on compiling that information so we could send something to the governor to make sure everyone's appointment is current. He

noted that members may hear from Jennifer asking for resumes, brief bios, or a copy of your appointment letter.

- Jeff mentioned that Tobey will be filling in Janet's shoes as far as advising SILC and helping with the development of the next SPIL.

Website

- Jen presented the website to the full SILC. She showed them the different items on the menu such as the accessibility icon and the resource page. The menu contains items such as About Us, SILC meetings, The CIL, IL News and Politics, the CAP, and Resources. The accessibility bar allows people to enlarge text, change the color of the background, remove style, stop animations, invert, grayscale, underline links, highlight links, control by keyboard, and change to a more readable font. The resources section contains information and resources on advocacy, transition, state disability organizations, and federal disability organizations. Andrew mentioned that the CIL should be spelled out in the menu. Joan noted that the federal and state disability resource page section on nervous system disorders and sensory disorders should be separated into different categories. Susan agreed with her.
- Jen noted that the SILC Facebook presence is going well and is being updated regularly. The Facebook site has five likes but it is still new so that could be why. Twitter is doing a lot better. We have 24 followers, and many different organizations like Pathways, NHDPH, ABLE NH, and more are retweeting our tweets.

SPIL

- Jeff reported that the next SPIL needs to be done by March. He mentioned that we need to have a public input period to get input on what the SPIL should be focused on. The public sessions should be between now and the end of the year so we would have enough time to write the SPIL. Tobey noted that at the last Executive Committee meeting she gathered some input and that one of her tasks is to develop mechanisms to get the word out as much as possible through multiple channels.
- Tobey mentioned that we should live-stream the forums on the SPIL for people who can't make it but are still interested in listening. As noted by her, the mostly important task is figuring out where the meetings will be? What should the dates be? What the format will be? With this data, we could start on advertising when they will be and who needs to be in the room from the SILC. She thinks that the meetings should be in different areas of the state with three in total.
- Jeff mentioned that it was tried in the past but there needs to be more from the membership to facilitate them and go to the meetings because the Executive Committee can't do it alone.
- Janet mentioned that last year we had public input sessions in Concord, Portsmouth, and Littleton. This didn't help people in Keene or people in the South. In the past, we had five of

these forums in one year. We also tried to piggyback on existing meeting that some of our SILC members have and that seemed to work.

- Gary noted that we should see if there is a way we could coordinate something through New Hampshire Employment Security, use their offices, and reach out to all of the sections of the state. If we could coordinate with the Commissioner maybe we could get employers in the area to come as well as potential employees.
- Andrew noted that they could have the meetings at the Vocational Rehabilitation buildings.
- Bill noted that we should go to where people meet to obtain input in addition to the forums. He mentioned the peer support groups of the Sight Services for Independent Living program (SSIL) as one example of where we might get input that can be used to develop the SPIL.
- Bill mentioned that he hears about many issues while listening in to the task force conversations in the morning and these should be captured to be put into the SPIL.
- Janet mentioned that partnering with other agencies via social media is important. She also mentioned that there should be a planning committee to help Tobey and Jen with all this work.
- Tobey asked if there have been any press releases done for these events. Jeff responded that just the minimum of paper flyers. Andrew noted that he remembers it being in one press release that got circulated a couple times by the Concord Monitor but it didn't get many hits. Tobey asked about community TV stations. Bill mentioned that representatives Lynn Ober and Mariellen McKay are going to have a TV show on Nashua Community Television called Double Trouble which may be an opportunity.
- Tobey mentioned that once the SPIL is drafted there is a responsibility to have it churned back out again to see what the public thinks of it before it is submitted to ACL.
- Andrew asked if there ever were any state representatives or senators to come to any of those public forums because it might help boost awareness or attendance. Dorine responded by saying they had opened an invitation to a few of them before but none showed up.

Mission/Vision

- Jeff mentioned that this item has been on the agenda for a long time now and keeps being deferred to the next meeting, but that it needs to be talked about before the next SPIL comes out.
- He thinks that maybe we should modify the agenda for the next meeting to replace the task force work with the mission/vision piece, or we should schedule a separate meeting to discuss it.

DSE Update

- Bill reported that the three Part B contracts are scheduled to be approved by the Governor and Council (G&C). The G&C has approved the Northeast Deaf and Hard of Hearing Contract (NDHHS). The Commissioner of Education is looking at all of the contracts and asking good, helpful questions.

- He noted that VR is still in an Order-of-Selection but on Monday they were able to move 100 people out of delayed status.

Other Business

- Lorrie reported that it has been a busy season. Right now the GCD is trying to get the word out about Stable NH. She also reported that CAP is going well.
- Susan noted that the NDHHS will be having their Working Together Conference coming up soon. It will be on October 12, 8:30pm to 3:00pm.
- Jeff thanked Janet for all her service to the SILC. Today was her last SILC meeting.

Jeff asked for a motion to adjourn. Andrew made the motion to adjourn the meeting and Marcia seconded. All were in favor. None opposed. Motion carried. The meeting was adjourned at 2:32 PM.

NEXT SILC MEETING: Wednesday, November, 14 2018.

Recorded by Jennifer Beaulieu