

SELF-DETERMINATION LOCAL ADVISORY COMMITTEE

Minutes

July 27, 2016

Present

Peter Mendoza, Chair

Jennifer Walsh, Vice-Chair

Eric Zigman, Executive Director, GGRC

Elizabeth Grigsby, Consumer Rights Advocate, GGRC

Anna Johnson, Assistant to Elizabeth Grigsby

Pilar Gonzales, Clients' Rights Advocate, OCRA

Sheraden Nicholau, Regional Manager, Bay Area Office, SCDD

Lili Byers, Parent Advocate

Connie Johnson, Parent Advocate

Anna – Community Member

Susan Pirmes, Administrative Assistant, GGRC

Call to meeting at 1:45pm. Conference Call line opened.

Peter informed everyone that the current meeting was being recorded for assistance purposes only in the preparation of minutes. Once the minutes for this meeting have been approved by the committee the recording will be erased.

At 2:10 pm, Anna, a community member, joined the meeting and all committee introduced themselves and their titles to her. Lili asked Anna how she learned about the meeting and Anna stated that she learned about it on the internet. Jennifer asked if Anna knew what Self-Determination was and Anna responded that she understands what it is.

Minutes and Agenda Approved

Pilar motions, Lili seconds, motion passed unanimously - Minutes of 6/22/16 meeting approved.

Connie motions, Eric seconds, motion passed unanimously - Agenda for today's meeting approved.

Chair's Report

Peter sadly reported the passing of colleague Laurie Hoirup. She was a highly respected disability advocate and award-winning author. A Celebration of Life will be held in her

honor on Saturday July 30, 2016 at 1:00 pm at The Old Sugar Mill Winery, 35265 Willow Ave, Clarksburg, CA 95612.

Peter reported that DDS's position is that it wants to move forward with Self-Determination Program (SDP) activities even though not all is yet worked out.

Peter believes that one of the committee's critical obligations is to provide information to the community regarding the SDP.

Recruitment and Outreach

Jennifer reported that, as a member of the workgroup created earlier this year, work on the Self-Determination webinar continues. Community Living Campaign and California Foundation for Independent Living Centers are very interested in helping to create a webinar. Jennifer emphasized that a plan must be in place before they will commit. She went on to say that the Golden Gate Self-Advocacy Conference may have a session on the SDP so it may be advantageous to record the SDP portion of the conference to determine what is needed for a webinar.

Pilar liked the idea of a webinar perhaps being part of a conference but stressed the need to have in-person conferences.

Discussions regarding organizing a conference in San Francisco were tabled to next meeting.

An updated draft for the SDP Outreach flyer was brought to the meeting. Further discussions and decisions about it were tabled to the next committee meeting. Pilar will prepare a suitable text version of the flyer. Connie and Lili suggested that it would be best not to distribute the flyer to anyone until the location of the committee meeting is firmly decided.

Old Business

Further discussions about scope of work of committee will take place at the next meeting.

Pilar will contact the CRA at Westside to obtain information about her experience in terms of committee development and scope of work.

Eric reported that he discussed the SDP at GGRC Board meeting in June with a focus on the agency's "Roadmap 2020" project. He will share a report with this committee.

Public Comment

None.

New Business

Sheraden reported on the Statewide Self-Determination Advisory Committee Meeting. It included discussions about ensuring that there is a focus on diversity as the SDP continues to be developed. As to next steps, several committees reported being stuck on deciding whether or not they should wait until finalized training modules are completed. Others are proceeding with what information is available despite its limitations. It was reiterated that while completion dates remain unknown, there is still some information available to all.

Eric reported on the amended language in Welfare & Institutions Code section 4685.9(t)(1) and (2), at which time Lili asked for clarification about what it meant. Eric reported that the practical implications of the language are to include family and consumer run organizations in getting information on the SDP out to constituents. These obligations exist but without any additional funding. He will report further on this issue at the next meeting.

Sheraden stated that one way to advance the requirements of this language would be to put together training and invite community members to participate in that process. She believes that focusing specifically on reaching out to the community will result in including diverse groups of people. Further, she emphasized the need to ensure that there are continuing productive interactions between all counties.

Lili expressed her concerns that there is no information about what is actually going on and when relevant issues will be decided upon and completed. She believes this creates a lot of confusion and would prefer to proceed only after concrete information has first been provided and confirmed.

Sheraden offered her thoughts about sharing information: She believes that at this point it is safe to say that not much of the major topics of SDP information will dramatically change. An important part of the plan is to expose all to what has happened with the pilot programs.

Jennifer shared that she will be reporting on the status of the SDP at her next advocacy meeting.

Discussion regarding how to best embrace the spirit of the Bagley-Keene Act in light of current societal realities for the need for security at front entrances to buildings. Eric suggested that for any persons not wanting to identify themselves, the option of calling into the meeting via toll-free telephone line always remains available.

Peter reiterated that easy access and travel conditions are important factors to consider when choosing a location for committee meetings. Elizabeth confirmed that she experiences dangers when she must travel to certain locations. Consequently, these important factors need to be considered when choosing a location for committee meetings. For these reasons, Golden Gate Regional Center's (GGRC) San Francisco office was offered for future meetings.

Pilar asked if the Independent Living Center might be available for committee meetings.

Peter informed everyone that materials distributed at committee meetings are available both electronically and in paper. He suggested that committee members be mindful of informing Susan if they would prefer not to receive hard copies of materials at the meetings.

Regarding conference call with Maria Marquez:

Sheraden introduced Ms. Marquez as a past participant of a SDP pilot program who comes with a wealth of knowledge regarding the impact of the SDP in real life and insight into what has worked and what has not worked. Sheraden also outlined the general questions and topics that she had asked Ms. Marquez to address during her conference call with the committee.

Insights provided by Ms. Marquez included:

- Generally, her experiences with the SDP have been great.
- The first three years were difficult because she had much to learn about the process of budgeting, particularly through the IPP process. She did not know what her budget was until her meeting with the Regional Center regarding the SDP so it was necessary to learn how to budget very quickly. All aspects of the SDP activities had to be implemented by way of IPP.

- Examples of her experiences with the SDP:
 - She stated that she wanted a computer. She took computer training after which she was able to buy a computer. Having the ability to use a computer has provided her with opportunities to be employed in meaningful ways at meaningful jobs. She was a single parent with two children and so it meant very much to her to be an example to her children.
 - She asked for hand brakes for her vehicle. She was advised that if she did not know how to use them, they would be useless to her. That prompted her to research companies that sold hand brakes and learned that they would train her (12 sessions) on how to use the brakes. She also shopped around for the best prices. She was then able to buy the hand brakes through the SDP.
 - Under the SDP she was able to see what things cost and the impacts on her budget. However, she was not allowed to actually be given money to pay for the hand brakes directly. In some cases this could be an obstacle. However, as an example, Ms. Marquez addressed this with the hand brakes company and negotiated with it to vendorize it through her Regional Center. This company became a service provider because it was willing to go through the process including much paperwork.
 - Under the SDP she joined the YMCA. An added bonus was that, consequently, she was able to get discounts for her children to join. However, a drawback of purchasing anything out-of-pocket first was that the reimbursement process was very slow. Reimbursement took up to a few months.
 - She purchased a walker for herself.
- In some cases, Ms. Marquez ended up saving the Regional Center money because of her ability to shop around for best deals and obtain free training because of the freedom she had to negotiate with community resources.

- She confirmed that when she was a participant, she was not required to have a broker but feels the current potential requirement for a financial manager will make things easier for participants.
- As part of her participation, she was required to attend many meetings where she was taught the meaning of the SDP including how the SDP supports Freedom, Authority and Responsibility.
- Since her SDP involvement, she has been asked to participate in many presentations regarding the SDP through DDS and other entities. To answer Pilar's question, Ms. Marquez confirmed that even though she is no longer in the SDP, she continues to be involved in training and sharing her experiences with audiences. In fact, she stated that she will be the keynote speaker at the People First Conference in Sacramento.
- Her involvement with the SDP has been very helpful to her but she emphasized that it should also be understood that it is a lot more responsibility to have greater freedom of choice.
- She believes that when the pilot programs roll out, SDP participants will be able to routinely pick and choose services from established providers available through the Regional Centers and/or other independent non-vendored resources.
- She confirmed that she is no longer a participant in the SDP because of a move she made to another catchment area.
- Ms. Marquez firmly believes that she was much better off in the SDP.

Questions and comments from committee members and guest:

Anna asked Ms. Marquez if she had to first justify her choices before she could proceed with making those choices. Ms. Marquez stated that to some degree yes but that for her it was a positive because it inspired her to make thoughtful decisions like learning how to use a computer before purchasing one.

Elizabeth stated that it sounded like Ms. Marquez was saying that, when she was in the SDP, she had more input into what she wanted and how to obtain that, but also importantly, input into what she did not want.

Sheraden added that, under the SDP, participants are also allowed to access generic types of services/products that might be less expensive or more desirable.

Peter stated that the SDP sets up competition in the marketplace amongst service providers which will create better services.

Ms. Marquez commented that in the existing Regional Centers procedures, there are times when services providers are assigned to consumers who have no idea about how to do what is required of them. Peter further opined that while there are similarities to Supported Living Services, the SDP allows for more control over choices thereby affording the same dignity for Regional Center consumers that is afforded to other people.

Sheraden added that there exists a level of anxiety with current service providers regarding the impact the SDP will have on them.

Jennifer asked if Ms. Marquez ever had a conflict between Department of Rehabilitation (DOR) funds and SDP funds. Ms. Marquez said it was never an issue for her and that all actions made by her were determined in her IPP.

Peter added that his experience with DOR has been more in the area of employment and that the Regional Center is there for other services. Furthermore, existing law states that DOR and Regional Centers are required to work together.

Sheraden informed that under the SDP a consumer will be allowed to move up to 10% of available funds into different areas when a consumer identifies a desire to focus more of his/her budget to one area. Also under the SDP, unplanned events or emergencies can be accounted for with flexibility in the consumer's budget.

Jennifer asked Ms. Marquez what were the main services she was able to get under the SDP that she did not have prior to the SDP. Ms. Marquez identified the following: 1) A Personal Assistant (PA) of her choosing; 2) A computer and training; and 3) Hand brakes for her car and training.

As her final remarks, Ms. Marquez stated that PCT language and its use is very important and that the most important thing that the SDP provided to her was the authority to choose.

Peter thanked Ms. Marquez for her time and all of the valuable information she generously shared with the committee. He also hoped that Ms. Marquez would make herself available again for further discussions in the future.

Sheraden reported that under the SDP, there is a process in place that deals with conducting criminal background checks and fingerprinting of all potential Financial Management Services (FMS) and others as identified by the consumer and FMS representatives.

Peter suggested that as to the material distributed at this meeting, he asked that committee members read them to prepare for discussions about them at the next committee meeting.

Announcements

Golden Gate Regional Center will be hosting its 20th Annual Self-Advocacy Conference on Thursday September 29, 2016 at Milton Marks Conference Center located at 455 Golden Gate Avenue, San Francisco, CA from 9:30 am – 3:00 pm. Further information about the conference is available on the GGRC website at ggrc.org.

Sheraden suggested that perhaps committee members could participate in SDP presentations at this conference which could be taped and put on YouTube for future viewing. Elizabeth added that the agenda for this conference is very packed.

Meeting Adjourned.

Next Meeting

August 24, 2016

1:30 pm – 4:00 pm

Support for Families

1663 Mission Street, 7th Floor

San Francisco, CA

Submitted by Susan Pirnes