



Long Island Individual & Family Advisory Board Meeting Summary
1 Michael Avenue Farmingdale NY
May 7th, 2019 from 6:00pm to 8:00pm

Members Present

Ralph Warren Jr.
Edward Levine
Lisa Fleisher
Doreen & Ken McIlwaine

Joseph Gerardi
Susan Platkin
Denise Ginther
John Jahng
Luna Fang

Carol Sholl Ostiwski
Steve Fleisher
Suzanne Valls

CDNY Staff Present

Jim Moran, CEO
Danielle Wiltsie, Director of Individual, Family & Self-Advocate Support
Luisa Eusse-Roché, Regional Care Manage Director
Ernie McNutt, AVP Downstate

Members Absent

David Ng



Welcome:

Care Design NY (CDNY) welcomed all self-advocates and family members for attending the meeting.

Introductions:

The Advisory Board Members introduced themselves along with CDNY Employees.

Summary of Last Meeting:

Review of the Meeting Minutes from the previous meeting. The Board Members approved the previous meeting minutes.

Review of Handouts:

Review of development of the Chairperson and Secretary Job Description: The Job Descriptions for the two Chairpersons and the Secretary were reviewed. The Regional Advisory Board Members were given a chance to review the job description prior to the meeting. There was a discussion on having two Chairpersons to share the role and work and possibly having sub-committees that will work on different topics in between the meetings. The Advisory Board agreed on these three options.

The Board Members who were interested in the positions shared information with Advisory Board prior to the meeting. At the meeting the Board Members who were interested in a Board Position spoke to the Board as to why they were interested in on serving on the Board. The Advisory Board completed a silent vote at the meeting.

After the Advisory Board Meeting the two Board Chairpersons and Secretary was announced. The two Board Chairperson for the Long Island Region are Susan Platkin and Lisa and Steve Fleisher. The Advisory Board Secretary is Carol Sholl Sholl-Ostrowski. Congratulations to the Board Members who will be serving in these positions and those that also applied for the positions.

Discussion of Targeted Items:

Danielle Wiltsie shared with the Board in response to the feedback of self advocates and families discussion of trainings being provided to them Care Design will begin a series of trainings. Self Advocates and Families have asked for training on various of topics on Benefits and Entitlements. The Advisory Boards were given a survey outlining six topics that are encompassed in Benefits and Entitlements. After reviewing the feedback from the survey, the first Workshop will be on Transition Planning. The Workshop will focus on how eligibility for



benefits and entitlements like Medicaid, Supplemental Income, Social Security Disability and SNAP Benefits chase as a child become an adult. The Advisory Board Members will have the opportunity to participate in a preview of the training and offer feedback prior to the scheduled Workshops.

The Workshops will be scheduled in various locations in each region and the Benefits and Entitlement Staff will be present in the region they work in. Self Advocates and families will have the opportunity to meet the staff and ask questions after the Workshop. The first Workshop will be in June. The information regarding the Workshops will be shared via mail and Care Design's Website. All individual and families are encouraged to attend. There will be additional Workshops scheduled for the following months on various Benefits and Entitlement trainings.

At the previous Advisory Board Meeting, the Advisory Board reviewed a drafted survey for feedback on Care Management Services. Care Design was looking for Regional Advisory Boards to review with input, comments and feedback. Care Design is looking for feedback on Care Management Services received, the is very important to Care Design as a growing agency. Danielle Wiltsie discussed with the Board the feedback that is being received from each Advisory Board has been reviewed. After listening to the Advisory Boards and the suggestions offered Care Design has decided to look at outside vendors for this process.

The Advisory Board reviewed a DRAFT of a Consumer Assessment of Healthcare Providers and Systems (CAHPS) Home and Community Based Waiver (HCBS Waiver) survey that addressed some concerns identified by the Advisory Boards around measuring satisfaction. The CAHPS offers a scientifically validated reliable questions and methods to most accurately reflect the individuals and family's satisfaction. It is scientifically researched, validate and proven reliable in measuring satisfaction in healthcare. This will allow CDNY reliable measures of itself as a support and allows for comparison among other organizations using the same standard tool. The next steps would be for Care Design NY to meet with vendors regarding the process and align the content to be developed by the Advisory Boards. All the updates with this process will be shared with the Advisory Boards and input from the Advisory Board is welcomed. This is the first survey that will be sent out to self advocates and families, this will be used to determine a baseline of quality of services.

Danielle Wiltsie shared with the Advisory Boards the forms that were created with the support and feedback from each Advisory Board. Self Advocates and Families asked for Frequently Asked Questions and Answers. This form will be mailed and shared on the Care Design Website for self advocates and families.

Danielle Wiltsie shared with the Advisory Board information regarding a Self Direction Work Group that has been established at Care Design. The Work Group has met three times and have been working on increasing training and knowledge for Care Managers in Self Direction. Danielle Wiltsie shared with the Advisory Board the documents that the Work Group has created. Danielle Wiltsie asked for the Board Members to review the documents and offer



feedback. As the Self Direction Work Group continues to meet they will be working on outlining the topics to train Care Managers on as well as self advocates and families. Danielle Wiltsie asked for the Advisory Board to offer any feedback they have in this area to ensure we are focusing on the areas they would like to see more information on.

The Advisory Board discussed Managed Care and what this would look like for services moving forward especially with individuals receiving Self Direction. Danielle Wiltsie discussed with the Board that she will look at developing a focus group with a few members and discuss the process of moving forward with Managed Care and the focus group can bring the information back to the Advisory Board Members.

During the meeting the Advisory Meeting there was discussion of talking points for the next meeting. Members have asked to discuss: the creation of a sub-committee to work on Quality Measures for CCOs – including: OPWDD required quality measures its using to evaluate CCOs; DOH performance measures for I/DD health homes and DOH/OPWDD work group progress on I/DD quality measures that will be used in Value-based Payments.

The Advisory Board had a discussion regarding CFCO and its relationship to assessments and service planning for OPWDD Com. Hab. OPWDD has information on their website regarding Home and Community Based Waiver Services and a timeline for individuals and families to provide comments and feedback to OPWDD.

This Advisory Board discussed the frequency of the meetings, location and time. The Long Island Advisory Board would like to have the meetings every other month at the 6:00 PM time. The meeting will be held in June due to the busy months of July and August there will not be any meetings, but work will be completed and followed up on in between.

Summary of Meeting:

- The meeting minutes to be sent out to all Board Members attended in person or were unable to attend this meeting.
- Danielle Wiltsie distributed the job descriptions for the positions of the Advisory Board; the two Chairpersons and Secretary. The Board Members completed a silent vote for the Board Positions. The Board Members will be notified who is fulfilling those positions once the Board Members not present at the meeting today complete their votes.
- The Board Members received a draft of a survey regarding services provided by the Care Manger to review. The Board discussed the Survey and talked about feedback at the Advisory Meeting. Updates will continue as more information is identified.
- The Advisory Board to list out priorities for the next 4-6 months and discuss who will volunteers to chair committees to lead those.



- The Advisory Board will work on developing a job description for the Ombudsmen role.
- The next meeting will be scheduled for June. Danielle Wiltsie will be sending out the location, day and time of the next Board Meeting to ensure that it accommodates all Board Members. The meeting will be in June as the Advisory Board decided to not have a meeting in the months of July and August.

