



**New York City Individual/Family Advisory Board Meeting Summary**  
**104 W. 29<sup>th</sup> Street, 3rd Floor NY**  
**May 7th, 2019 from 10am to Noon**

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**Members Present**

Luz Diaz  
Linda Blumkin-via phone  
Joyce O'Connell  
Tondra Lynford  
Rachelle Kivanoski  
Alice Shulman  
Susan Hamovitch  
Jeanne Raichie  
Alem Blourt  
Rachelle Kivanoski

Terri Parker  
Khaquan Zafar  
Lisa Severino  
Jim Karpe  
Danny Shapiro  
Mary DiPerna  
Carol Dillon  
Elly Rufer  
Dana Barash  
Pauline Humphries

Danielle Lazzario  
Karel Karpe  
Joel Tan  
Janet Huang  
Gitel Blau  
Kitty Trvong  
Bin Feng  
Susan Angeles  
Imre Kovacs

**CDNY Staff Present**

Danielle Wiltsie, Director of Individual, Family & Self-Advocate Support  
Jim Moran, CEO  
Melisa Giuffra, Regional Director  
Ernie McNutt, AVP Care Management

**Members Absent**

Susana Montes  
Gail Siller  
Cindy Chen  
Riqi Lin  
Jackie Goldberg

Heather Piedmont  
Siem Yap  
Nyuk Siem Looi  
MaKhin Shwe Win  
Pat Lin Chan

Xinyne Wang  
Fiono Ho  
Debbie Chan  
Uly Ramos

**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 as some Board Members were present at the meeting and on the phone.

**Summary of Last Meeting:**

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

The Board discussed this Advisory Board has grown and the potential of two Board's developed, one being in Manhattan and the other either located in a location in Queens. The Advisory Board Members will be given a location for NYC and a location for Queens for the next Advisory Meeting. There has been interest in the Board Positions, Danielle will reach out to the Board Members who are interested in the Board Positions and discuss the process of discussing their interest at the next Advisory Meeting.

**Review of Handouts:**

Many of the families would like additional support with Food Stamps/HEAP etc. from there Care Manager. Danielle Wiltsie discussed with the Advisory Board Care Design has a very robust Benefits and Entitlements Department and will be available for individuals and families as well as Care Managers to do training.

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.

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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. Care Design agreed to discuss with vendor possible use of phone CAHPS survey to potentially broaden input.

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.

### **Discussion of Targeted Items:**

The Advisory Board would like to see actions items being worked on and follow up at the Board Meetings. The Board will work on action items identified in the next meeting to do during the summer months on various areas. The Board would like to work on and will form work group, one of the work groups that will be established is a Managed Care work group.

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The Board discussed that there are a variety of topics that they would like to focus on such as for example but not limited to: Managed Care, how to continue to facilitate relationship with OPWDD, Housing Navigator, Language Barriers, Benefits and Entitlements, Succession Planning and training availability/opportunities for families.

### **Summary of Meeting:**

- The meeting minutes to be sent out to all Board Members attended in person, phone or were unable to attend this meeting.
- 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
- A workgroup will be identified for Managed Care and information shared at the workgroup will be brought back to all Board Members.
- The Advisory Board will work on developing a job description for the Ombudsmen role.
- The next meeting will be scheduled for June 10<sup>th</sup> at 10:00 in NYC and 6:00pm in a Queens location. 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.

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