

FULL COUNCIL MEETING

441 4th Street, N.W.
City-wide Conference Center
Room #1117
Washington, D.C.

October 11, 2013
3:00 PM

MINUTES

MEMBERS IN ATTENDANCE

Tina Campanella, Chair
Dr. Shearon Smith
Cathy Anderson
Kathy Gosselin

Ricardo Thornton
L. Thomas Mangrum, Jr
Tiffany Smallwood
Amber Koehane

STAFF

Mat McCollough, Executive Director
Denice McCain, Staff Assistant

Sudie Johnson, Program Analyst

OTHERS IN ATTENDANCE

Esme Grant, Public Policy Director
National Association of Council on
Developmental Disabilities

Christopher A. Stewart
DC Public Library/Adaptive
Services

Erin Leveton
Department of Disability Services

Trend Jenkins
Advocate

Dana Fink
Institute for Educational Leadership

Sarah Grime
SchoolTalk

Ron Smith
DC Advocacy Partner

Nahyo Smith-Nicolas
DC Advocacy Partner

Trudy Jones
Inclusive Research Institute

Elizabeth Akinola
Advocate

Sarah Roache
Student
Georgetown Law

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CALL TO ORDER

Tina Campanella, Chair, Developmental Disabilities Council (DDC) called the meeting to order. She then asked that everyone introduce him/herself and provide the name of the organization that he/she was representing.

REVIEW/APPROVAL OF MINUTES (July 18, 2013)

The Chair stated that everyone should have received a copy of the July 18, 2013 Minutes in their packet, and for those members who had not already done so, to please take a few minutes to review them. Following a brief review, a motion was made to approve the minutes. The motion was seconded and passed.

CHAIR'S REPORT

Significance of Disability Employment Awareness Month

The Chair began her report by reminding the membership that October is National Disability Employment Awareness Month. Every year there is a theme, and the theme for 2013 is "Because We Are EQUAL to the Task". She noted that employment has become a major issue and push. In addition, people with disabilities, especially developmental disabilities (because of the high incidence of unemployment among that group and the Developmental Disabilities Council's belief in the potential power of this group of people) could be employed and when they are employed could contribute to our communities. She went on to say that the roots of this go back to 1945, but remains as important today as ever given the 70% unemployment rate of people on a national basis. She encouraged everyone to share this information, put it on his or her tag line in emails, etc. and make sure that people are aware of the great, untapped resource out there (people with disabilities who are ready, willing and able to work). She then reported the following:

Quality Trust Fights for Justice: After more than a year, Jenny's home

Jenny Hatch who resides in Virginia was the subject of a guardianship proceeding one of which she did not ask for and thought she did not need. Although Quality Trust (QT) does not represent people in the State of Virginia on a regular basis, they were able and positioned to join this case (as co-counsel) to make sure that the issue around supported decision making and less restrictive options or support in decision making would remain available for people with disabilities. This is a huge issue not only in the District of Columbia for many people both young and as adults, to have their right to personal self-determination preserved and their right to access the least restrictive supports. Most importantly, they should have supports like anybody else for decision-making in his or her life and not have their own life decisions questioned simply because of an IQ score or a diagnosis.

Jenny Hatch won the right to make decisions for herself and QT was happy to share in that decision. In the ensuing weeks since this decision was made, QT has been hearing from a lot folks wanting to explore different options for themselves and QT asks that everyone stay tuned as they take on this issue here in DC on behalf of people with disabilities.

Other Thoughts

Congress approved legislation last evening to open up the Federal Government, which is going to divert any disaster around the DC. More importantly, the District of Columbia (DC) will escape

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any future potential fight around the budget that may happen in the beginning of the next year. A special provision was included in that legislation, which authorized DC to spend its own funds for Fiscal Year 2015 even if Congress does not pass an appropriations bill or continuing resolution.

This is good news. It is also good news that our federal programs will continue to be funded; and we can now pay our Medicaid bills. Congratulations to our leadership in DC, Mayor Vincent C. Gray, and our representative in Congress, Congresswoman Eleanor Holmes Norton.

EXECUTIVE DIRECTOR's REPORT

Mat McCollough, Executive Director, DDC provided the following report:

2013 Disability Mentoring Days Program

As previously mentioned by the Chair, DDC, October is Disability Employment Awareness Month and for the past four years the DDC has partnered with the Office of Disability Rights (Designated State Agency) to participate in the Disability Mentoring Days Program. The original concept of connecting students and job seekers with disabilities to employers came from the American Association of People with Disabilities and that concept continues in the District of Columbia and Metropolitan Area. The Executive Director (ED) advised that included in the packet (on green paper) was a breakdown of the partnerships that were made in terms of mentors and mentees. He provided a brief summary of that information and noted that because of the federal shutdown, they had to work on a smaller scale this year.

DDC Involvement

- i. The ED was asked by the Society for Public Health Educators to talk about the impact of the Affordable Care Act on people with disabilities. On July 30, 2013 he along with two other presenters gave a presentation on that topic. A copy of that presentation, with details of what was covered, is included in the packet.
- ii. The ED was also asked to do a presentation on "How to Develop an Effective Financial Literacy Program for Persons with Developmental Disabilities" by the National Association of Councils on Developmental Disabilities. He believes a part of why they asked was because the DDC is currently funding the Building Economic Strength Together Program. He also believes this was an opportunity to showcase the DDC's work. Ricardo Thornton, DDC Member also spoke during that September 26, 2013 webinar.
- iii. On October 1, 2013, the ED met with 30 high school students with disabilities from Stafford, VA on pre-employment skills. Part of the reason was because he went to that high school in Stafford, VA and because his mother asked him to. There are two resources included in the packet that were created and given to the students. One is "What do employers really expect of their employees with and without disabilities" and the other is a Volunteer Evaluation Sheet.

Summer/Fall Edition of the Herald

A copy of the latest DDC newsletter (the "Herald") is included in the packet.

Draft Article for Medical Textbook – Equitable Health Care for Persons with Disabilities

A draft of an article the ED was asked to write entitled "Equitable Health Care for Persons with Disabilities" is included in the packet. The focus of that article is people with disabilities being generally misdiagnosed and/or not getting the proper healthcare.

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Impact of Federal Government Shutdown on the District Government and the DDC

The DDC, like many other agencies that receive federal funds, was not allowed to use any of its funding to support people with developmental disabilities or their family members due to the federal shutdown. Now that the federal government has re-opened, the hope is that the DDC can once again start supporting people with disabilities and their families by sending some of our advocates and family members to the TASH Conference in Chicago, IL and by supporting the Transition Forum.

A copy of the letter that the Mayor of the District of Columbia, Vincent C. Gray, sent President Barack Obama, Congressmen John Bohner and Harry Reid explaining why Congress must pass and the President must sign emergency legislation exempting the District of Columbia from the federal government shutdown is included in the packet.

PROGRAM ANALYST REPORT

DDC Spending Report - Sudie Johnson, Program Analyst, DDC, informed the membership that a copy of the financial report could be found in the packet (on the golden rod paper) and that these are basically the preliminary numbers because the actual numbers have not been finalized. Also included in the report are the salaries as well. She then provided a summary of that report which covers the projected carryover funds along with the annual award, expenses incurred during FY 13, projected carryover for FY 14, total funds committed for FY 14 projects, and our uncommitted balance.

The Chair stated that over the course of the past three years since Mat has taken over leadership, the District had a significant amount of funds that were at risk of losing if we did not figure out how to use those funds as an investment in the citizens of the District of Columbia. She thinks that what we are seeing on the financial report is the result of a significant number of investments; including the graduation of two successful classes of the DC Advocacy Partners Program, which has the potential of being funded as long as we have the funds to continue doing it. The DDC is doing well with the allotment that we receive and making the kind of investments we want to make and she would like to thank the members of the DDC along with the staff and its leadership.

DC SUPPORTING FAMILIES COMMUNITY OF PRACTICE PROGRAM UPDATE

Cathy Anderson, Director, Department on Disability Services/Developmental Disabilities Administration stated she would briefly introduce the Community of Practice and then let Ms. Leveton, who is the facilitator for the group; provide the update on the program. The Community of Practice held a large meeting but continues to have the core group meetings as well. They are also making plans for a meeting of the larger group again in December. She then turned it over to Ms. Leveton.

Erin Leveton, Legislative and Policy Analyst, Department on Disability Services (DDS) Developmental Disabilities Administration (DDA), provided the following update on the Community of Practice: Supporting Families throughout the Lifespan.

Since our last meeting, the Community of Practice (CoP) held its first State Team Meeting and about 50 people attended, many of whom were either parents or people with disabilities themselves. They came from different parts of the city and were ethnically diverse. The day was spent talking

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about what a CoP is, its nationally goal and talking with families about what a successful adulthood looks like and the supports people need to get there. Having a conversation about people in general, not just people with disabilities, because what we have found is, people have different definitions of success for people with disabilities and it should be the same trajectory towards a good adulthood.

Since this was CoP's first State Team Meeting, time was also spent talking about what success would look like in five-years (because this is a five-year CoP), what people hope would be different down the road in a new model, and who is not here that you wish were? What they are looking to do next is not only continuing the conversation with the big groups, but also going out into the community and organically growing a CoP by working with all of the resources that are already in place in the community. CoP has tried to identify all of the places where families already are so that we can go to them rather than expecting that they will come to us. The CoP is also working with their national partners on how we can take what was a day long discussion and break it down into a twenty or thirty minute uniformed conversation so as we collect data (around what people define as important) we can bring back, analyze and synthesize it, and have more than just an antidotal remembrance of the conversation.

A few tangible things already happening with CoP include parents who we have never met are coming to our community forums; we are receiving requests from different groups asking us to come out and talk to them; there is now a much better stakeholders list because we are reaching out and hearing back from people; and our stipend policy has been implemented in recognition of people's time.

CoP is planning on bringing the big group back together, hopefully in early December and they are also thinking about bringing in Michael Smull (the Person Centered Thinking guru) to work with the group using person-centered thinking practices and tools to look at these questions, "what's important to and what's important for their family members and themselves?" The core team will be meeting to start planning for year two of the CoP and Michael Smull will be included in that discussion to do some planning with them.

Following a brief discussion, the Chair stated she would like to underscore what everyone has just heard by saying this is an incredibly important initiative that has reflected a priority in this city for multiple decades. This is also a huge step towards having the Department on Disability Services and the Developmental Disabilities Council participating in a national project and providing leadership. Therefore, what we can do to support them is to continue to share information and get it out there beyond their networks so that more people connect up with them. Again, she thinks the younger folks are a real big plus to be a part of this because it just enlarges the conversations. She then thanked Ms. Anderson and Ms. Leveton for the update.

DDC COMMITTEE REPORTS

Building Economic Strength Together Project

The Executive Director, DDC provided a brief summary of the Building Economic Strength Together (B.E.S.T.) Project report that was included in the packet. The report covered training sessions that were held; survey findings measuring the impact of the project; and upcoming activities.

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Social Role Valorization Program

The Executive Director, DDC, provided a brief summary of the Social Role Valorization Program report that was included in the packet. The report provided a summary of activities conducted; the number of individuals impacted and description of the types of individual's participation; evaluation comments; and a summary of the next steps for the program.

Get Involved DC! Program

Trudy Jones, Project Manager, Get Involved DC! Program provided the following update for this program:

The Get Involved DC! Program ended as of September 30, 2013 and this will be her final report. The goal of the program for the first year was to train youth and young adults with developmental disabilities to independently find and attend community services and recreational events throughout the District of Columbia. During the first year, the group participated in a community service project, beautification of DC Public Schools. The participants were very enthusiastic about this community service project in addition to some of the other things in-which they participated. With all of the competition they had with Project Action! and the cross partnership the first year was a success!

In the second year, the group focused more on increasing participation and becoming independent. In this regard, a letter inviting participants to serve on a planning committee was developed and sent out. The idea of the planning committee was to serve and put together a schedule of events from their perspective versus having someone else putting it together. Of the ten individuals who responded, six formed a planning committee. The group met in December 2012 and activities were set up for the entire year. The meeting for January was supposed to be the kick-off but that was canceled due to inclement weather and re-scheduled for February. At the kick-off, which was held at TGI Friday's, they had discussions on what had already been done; things that would be done in the future; and got some more input from new people who had come on board. There were about 20 individuals at this kick-off. During discussions, the group went over the tentative schedule that was created and a decision was made, independently by the group, to do their recreational and community service in March. Individuals did community service on their own, some went on vacations on their own, and others did a combination of other events. Some also continued to recruit others to join the group. For April, the group decided to see a movie but because of the bombing in Boston that week and the heightened security and closure of Gallery Place Metro Center this event was canceled and rescheduled for a later date. During the month of May, individuals did activities on their own. A couple of individuals did a walk for Lupus, some participated in community clean-ups, and some donated and assisted in packaging food at a community food bank. Ms. Jones thinks that was great because again, we are moving on course with individuals making their own decisions independent of her telling them what to do. In the month of June, the participants went to the movie and also did a volunteer service event. In July they did another community service project helping people make terrariums. They were also going to go to the aquarium but it was extremely hot and they had to cancel. In August, they did the beautification clean-up at DC Public Schools--painting benches, helping teachers spruce up class rooms, etc.

A final celebration was held in September, which included a live DJ and food. Knowing that the grant was ending and not wanting to see things go astray, Ms. Jones decided to volunteer to

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mentor, advise or do whatever the group needs to continue this independence and decision-making process. This will include having at least two or three activities during the year. She will also encourage the group to collaborate with other groups like Project Action! with the hope that this group will be able to carry this program on independently.

DC Advocacy Partners Program

Dana Fink, Institute for Educational Leadership's (IEL) Center for Workforce Development, began her report by stating for those who aren't aware, the DC Advocacy Program is a free nine month leadership and advocacy training program for self-advocates and family members of people with intellectual and developmental disabilities. At the end of September 2013, the program graduated its second class of 21 individuals, which was an increase from the first graduating class. She thanked the DDC, Executive Director, and DDC Member Tiffany Smallwood for their outreach, which helped secure the participation of DC City Council members Jim Graham and Tommy Wells at the graduation ceremony. The Chair of the DDC and Laura Nuss, Director, Department on Disability spoke as well. The graduates provided a quick presentation of their final long-term project they worked on throughout the entire nine-month period. Some of those projects will be on going beyond the program itself and ranged from improving public transportation to trying to implement the disability history curriculum into DC Public Schools. Results are being seen beyond this point at the family and community level.

IEL is recruiting for the next year's class and included in the packet is some information about the program along with the contact information that she asked everyone to share with other individuals who may be qualified to participate in the program. The application for participation is due by November 18, 2013 and the first class will begin in January 2014.

Ron Smith, DC Advocacy Partners graduate, stated he would like to let the DDC know how valuable these programs are to the community. During the course of being able to participate in the DC Advocacy Program, he has learned a lot of advocacy skills and a lot of people in the community feel that the programs the DDC is sponsoring are really helping a lot, especially the young folks, and that is who we really want to try and reach more of .

The Chair stated the DDC could never hear that enough, especially directly from the participants and thanked Mr. Smith for sharing. The DDC really appreciates that.

ANNOUNCEMENTS

Sarah Grime, Conflict Resolution Specialist, announced on behalf of School Talk DC, that they are hosting the Fifth Annual Moving Forward Together Secondary Transition Fair and Community Forum. The Transition Fair will be held on Friday, October 25, 2013 for the schools and the Community Forum will be held on Saturday, October 26, 2013 for the community. Information is included in the packet for Saturday's community event and Ms. Grime asked that everyone help get the word out and encourage those who are interested to attend this community forum. Both events will be held at the Martin Luther King, Jr. Memorial Public Library, 901 G Street, NW.

Tiffany Smallwood announced that Brainy Camps, a transition program for DC teens and youth with Epilepsy, is offering a free weekend Transitioning Youth Forward Program at Trinity College, November 15-17, 2013. This information was included in the packet and she asked that it be passed on to those who are interested in attending.

RESOURCES & OTHER UPCOMING EVENTS

The Executive Director advised that other information on the following resources and other upcoming events were included in the packet. He asked Ms. Esme Grant if she would provide a brief update on the Affordable Care Act:

- a. NACDD Information about the Affordable Care Act (ACA)
- b. Field Notes – Focus area: Emergency Preparedness
- c. A Path to Preparedness Handbook: Publication from DC Department of Health & Office of Disability Rights

Esme Grant stated that as the new Director of Public Policy for the National Association of Councils on Developmental Disabilities located here in Washington, DC her role in the national office is as a resource on national policy for all of the state and territory DD Councils. One thing she has done since being in this role is to issue an Affordable Care Act (ACA) Summary Sheet of which she provided the following brief summary: The Healthcare Insurance Marketplace also called Exchanges opened October 1, 2013 and one issue a lot of them are having (especially ones that are federally run) is that people are having difficulties signing up for health plans. There are people working on this to make it a lot easier to sign-up. Some good news is that all signs point to ACA being positive for people with developmental and other disabilities. A major plus is that none of the plans offered through the exchanges can deny coverage because of a pre-existing condition, nor a health issue related to a disability. We will also see Medicaid expansion and that will definitely affect people with developmental disabilities significantly. On the back of the ACA summary information sheet is a link to healthcare.gov website (which is being worked on) and multiple other links to ACA resources detailing such things as what the ACA is, why it is important, facts about the implementation, etc.

The Chair advised that the District jumped on this early and they now have their own internal Health Benefits Exchange. Grant proposals for in-person assisters were put out and those individuals have been trained and are on the ground as October 1, 2013. Quality Trust (QT) was awarded one of those grants with QT's focus and expertise being helping people with disabilities, family members and healthcare service workers to get the information about the Affordable Care Act, and if necessary, help walk them through the process of enrollment. She further advised that if anyone needed to get access to that information, the Health Benefits Exchange is on-line and if they are in doubt and need help, they can call Quality Trust.

GOOD NEWS AND ANNOUNCEMENTS FROM COMMUNITY MEMBERS

Ron Smith announced that he would be getting in touch with everyone very soon to invite them to his niece's (Meka Flowers who is a breast cancer survivor) upcoming book signing party in Washington, DC.

The Executive Director shared that the brand new publication "A Path to Preparedness," which was included in the packet was produced by the Department of Health in partnership with Office of Disability Rights.

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ADJOURNMENT

Before adjourning the meeting, the Chair advised that this is our final meeting for the year and again she would like to say thank you to the community members. The DDC does this work for the benefit of the community members. By virtue of you being here to hear the information we share and give us feedback is important. It really helps us to know that we are on the right track. We really appreciate your participation and thank you for supporting our programs. A motion was then made to adjourn the meeting. The motion was seconded and the meeting was adjourned.

NEXT MEETING

The next meeting date is January 16, 2014, 3:00 pm – 5:00 pm. Location to be determined.

Respectfully submitted,

Denice McCain
Staff Assistant