

**Developmental Disabilities Council
Full Council Meeting Minutes
September 20-21, 2018**

Members Present, September 20:

Julia Bell (Chair), Shamra Baez, TK Brasted, Maggie Craughan, Thanh Kirkpatrick, Anthony Nash, Mike Raymond, Ronnie San Nicolas, Adrienne Stuart, Donna Tiffan, Ryan Troyer, Michelle Hoffman, David Lord, Shannon Manion, Cassi Villegas (for Katie Mirkovich), Janice Tornow, Lisa Yanagida

Staff and Support:

Ed Holen, Donna Patrick, Linda West, Brian Dahl, Aziz Aladin, Emily Rogers, Kathy Easton, Jim Quatermass, Ashly Pfanenstiel, Josh Greathouse

Guests

Peter Tassoni

Call to Order and Introductions

Julia Bell called the meeting to order and Council members and others present introduced themselves.

Approval of the July 2018 Minutes

The minutes were briefly reviewed. One change was requested by Anthony Nash - that the minutes reflect that he abstained from the vote on the budget because it dealt with contracts and he might have a conflict of interest.

Motion: To approve the July 2018 minutes as with the change of noting Anthony Nash's abstention. Maggie moved and Mike seconded. The motion carried,.

Adjustments to the agenda

There were no adjustments to the agenda.

Chair's Remarks

Julia reviewed the goals for this meeting and outlined important parts of the agenda. She then discussed the results of the survey taken by Council members asking about interests and the things that they feel are important. The most common response was that members want information on the legislation affecting people with IDD and their families. As a result, there will be significant time at this meeting dedicated to public policy issues.

Members spent time at the last meeting discussing the various Council efforts and how they fit into the State Plan. A reading is provided detailing the results of that discussion.

Members also filled out a meeting evaluation. The results were mostly positive. Comments pertaining to the packets and making them easier to use were taken to heart. Council staff used a new format in putting together Council materials for this meeting and hope it better meets the needs of the membership. All comments are welcome.

Executive Director Report

Ed began by going over the Council staff activities report in the Council materials. The Council efforts fall into two categories:

- 1) Activities collectively done by staff and Council members; and
- 2) Contracted activities.

The activities report is a little different than it has in the past. Council staff are making an effort to align the activities with the State Plan. This is an on-going process and will be refined over the next few meetings. After reviewing the activities report, Ed went into more detail on a couple of other efforts.

Community Guides/Community Engagement

There is a waiver service that allows people to use contracted providers to help them access things and the community. A person receiving services under the waiver requests to have a community guide/community

engagement provider. The challenge at this time is that there are not enough trained providers. This is the focus of Council efforts. Ed and other Council staff have been going around the state providing training and resources to people who want to do this work. The Council is also trying to increase awareness of this service and connect providers for additional peer support and resources. To this point in time, Council staff have worked with about 130 contracted providers.

Local Leadership

The staff developed and disseminated a Request for Proposals (RFP) to solicit ideas from organizations to pursue local leadership activities. The deadline has passed and the responses have been received. The RFP covers 2019 and 2020, along with 2018. The next step is to have an independent committee score the proposals and make the awards. The Council will announce the results soon.

Retirement

After serving the Council for thirty-two years, Ed announced he will be retiring from his position as Executive Director at the end of June 2019. He picked this time so both he and the Council have time to prepare and make the transition.

Federal law states that the Council hires the Executive Director. It is not the staff or the Council Chair or the Department of Commerce who make this decision. Ed urged the Council members to plan for and engage in a thoughtful and extensive process in hiring his replacement. He also stressed he would walk with them through this journey.

Governance Policy Issues

Conflict of Interest

Since Filiberto, the chair of the Governance Committee, is providing technical assistance the Council in Puerto Rico, Ed took the lead on this agenda item. Ed presented a revised policy on "Conflict of Interest". The purpose of the policy is to outline potential areas of conflict Council members might face. As state officers, Council members are expected to perform their duties without conflict that leads to "personal gain or adverse effect on state government." Ed discussed in great detail to updated

aspects of the document and focused on the ethical responsibilities of each state officer of the Council. There was some discussion of ethical laws that are focusing on our emails and internet use and to use caution and be aware that there are discussions that are going through email that could constitute an open meeting.

Ed explained that Council members will have an opportunity to review the Conflict of Interest Document and vote tomorrow on approval of the document. Once it has been approved, DD staff will contact all members to sign the statement.

Council Member Travel Policy

This policy has needed to be updated for a while. Its purpose is to clarify the procedure of sending Council members to meetings, conferences and other events at the request of the Council or the request of individual members. It is also meant to provide greater transparency.

“Parents with Disabilities” Policy

Emily presented this policy to the Council. It has been a policy that has been worked on with the help of Susan Kas from Disability Rights Washington for about a year. The discussion began with the extensive history and details of the work that has been put into this policy. The biggest change discussed was in reference to the preservation of civil rights of those with DD when they become parents. Emily explained that this draft policy statement has been developed because of strong feelings that the Council should take a formal position on this issue.

The discussion on this policy was passionate and extensive. There was extensive discussion regarding which state programs would be involved in providing support to an individual with DD when he/she becomes a parent. (DDA, DCYF, and CPS). It was noted that this policy is to be able to state a vision regarding respect for what a person can do, and how the individual can be supported successfully in the future. It is a policy/belief statement which does not have any enforcement basis, but can reflect the Council's views as DCYF and DDA collaborate. It provides a clear statement to the public regarding the Council's position on this important topic.

Through the discussion several edits were suggested and incorporated into the document in real time.

Julia explained that all the proposed policies discussed will be voted on during the second day of this Council meeting.

Council Budget Update

Aziz provided an update on the Council budget, based on the latest available financial reports through the end of August, 2018. He began the discussion on the 2018 federal award and how the money was distributed and spent. There were several questions on the breakdown of expenditures. He went through all the items and answered the questions of the Council members.

Self-Advocacy Project

The one outstanding project from 2018 dollars in the money that was earmarked for self-advocacy. A proposal is being developed to use \$15,000.00 to continue the work began under the Equal Partners Interstate Congress project specifically dealing with the creation of a new DD Network Partner representing self-advocacy/civil rights. Brian reported that the Self-Advocacy Project is still in development.

Agency Updates

Aging and Long Term Support Administration (AL TSA)-Lisa Yanagida

Lisa reported on several things going on in the Administration, including legislation that AL TSA will be requesting. One piece of legislation addresses Adult Protective Services (APS) investigations of allegations of abuse, neglect, abandonment and financial exploitation of vulnerable adults. Problems have been identified with the offender registry. People who are put on the registry do not have the opportunity for review. Once a person has been placed on the registry, it is permanent. This means that there are people on the registry who may have been placed on it for one incident that occurred decades ago. According to current law, they have no recourse at any time. AL TSA and APS are looking into possible changes

that would allow some people to be removed from the registry based on specific criteria.

ALTSA is also working on:

- Changing the definition “willful” in abuse cases so it is clear that it means “showing intention or recklessness” or reasonable knowledge that the act would cause harm. This is in response to a court case that invalidated the definition currently being used;
- Changing the confidentiality laws to allow for acknowledging that an investigation is taking place to relevant parties;
- Proposing legislation to base billings on available data and align procedures with the requirements of CMS timelines;
- Negotiating for enhanced rates for travel providers to better serve tribes in the state;
- Creating legislation to initiate a supported living provider certification fee to pay for more investigators to oversee alleged abuse and neglect allegations; and
- Reworking the statute that requires people who not ambulatory to reside in the first floor of an adult family. The way the law is currently written it excludes some homes from being licensed because the architecture of some homes have different living spaces on different floors.

Disability Rights WA (DRW)-David Lord

David Lord reported that DRW reached a settlement in Trueblood vs. DSHS. As a result, there will be millions of dollars appropriated to provide services to divert people from jail in order to get mental health services.

The Administrative Offices of the Courts is going to ask more money from legislature to expand their Office of Public Guardianship, specifically to address alternatives to traditional guardianship. This will be particularly valuable for who do not have money or families. It is a big step and positive advancement for the Administrative Offices of the Courts.

Senator Peterson is looking at introducing legislation to make guardianship laws more consistent with the Uniform Guardianship Act. It remains to be

seen if this will be a good a bad thing. It is something the Council should monitor.

DRW is concerned that in order to avoid providing active treatment, the state is converting ICF's to nursing facilities. It is believed that the same level of treatment should be available regardless of the setting.

Lastly, the DD Ombuds has been working closely with the self-advocacy community to develop a Bill of Rights for people with developmental disabilities and it is hoped it will be passed by the Legislature and signed into law.

Developmental Disabilities Administration-Shannon Manion

Shannon shared that she and Aziz are serving on the Dementia Action Collaborative. One of the positive developments from this effort is the establishment of a staff position to be able to follow up on action items proposed by the collaborative. A person has been hired. Her name is Kim Boone and she should be reaching out to the Council soon.

Shannon spoke about the decertification of the Residential Habilitation Centers (RHCs) at Rainier and Fircrest. She explained that the federal rulings were the result of site visits that determined that residents were not receiving Continuous Aggressive Active Treatment, which is a required service in Intermediate Care Facilities (ICFs) like those at Rainier and Fircrest. Some individuals living at Rainier were also determined not eligible for ICF level of care, either because they are unable to participate due to health reasons or they are simply refusing to participate.

Shannon reported that an outside consultant is being used to review everyone who is living at Rainier School and determine who will need to be relocated, based on ineligibility for ICF level-of-care. Julia mentioned that she has learned through her participation in the RHC Task Force that approximately 60 individuals who are current residents of "PAT A", who of the residential living groups, will be leaving Rainier and moving into nursing facilities or community-based settings.

Council Member Homework Assignment

Members reported on their interactions with people in their communities, during which they talked about the Council.

Public Policy Issues

Julia reported on the initial selection of public policy priorities illustrated by the “dots exercise” that Council members participated in during the lunch break. Members were asked to vote with sticky dots on the top three public policy issues posted around the room. The top priorities order were:

Health Care
Special Education funding/CAP;
Guardianship/Decision making; and
Unserved

After some initial discussion, Council members were asked to work in small groups at their tables to expand on their choices of public policy priorities. Julia asked them to use two handouts they were provided to review the current status of public policy issues which may affect persons with developmental disabilities, and to develop recommendations for future Council activities related to those topic areas.

After the small group discussions, the groups reported back on their discussions. While the initial list of topic areas was lengthy, the discussion groups had each found ways to bundle them together to suggest that all of the issues need to be addressed. Julia suggested that the Public Policy Committee will have the challenge of determining how to break the topic areas down into manageable units for future Council presentations and other efforts.

Town Hall Preparation

Members prepared for the town hall meeting that evening.

Council Meeting recessed until Friday morning.

September 21, 2018

Members Present

Julia Bell (Chair), Shamra Baez, TK Brasted, Maggie Craughan, Thanh Kirkpatrick, Anthony Nash, Mike Raymond, Susanne Searles, Pat Shivers, Adrienne Stuart, Donna Tiffan, Ryan Troyer, Michelle Hoffman, David Lord, Shannon Manion, Cassi Villegas (for Katie Mirkovich), Mark Westenhaver

Staff and Support:

Ed Holen, Donna Patrick, Linda West, Brian Dahl, Aziz Aladin, Emily Rogers, Kathy Easton, Jim Quatermass, Ashly Pfanenstiel, Josh Greathouse

Guests:

Peter Tassoni

Call to Order and Introductions

Julia Bell called the meeting to order.

Adjustments to the agenda

There were none.

Town Hall Meeting Discussion

There was a recap of the Town Hall meeting. Julia summarized a few notes she took from the meeting. Topics that were discussed at the meeting included Adult Family Homes, transportation in rural areas or lack of bus routes, jobs and housing. The Council heard other concerns about residential supports, respite providers and recreation opportunities.

There was discussion about different kinds of outreach to people throughout the state, quality of life measures and different opportunities the individuals with DD have.

Council Items for Approval

Conflict of Interest Statement

Motion: to approve the conflict of interest statement. Maggie moved and Ryan seconded. The motion carried.

Training and Travel Policy

Motion: to approve the travel and training policy. Pat moved and Anthony seconded. The motion carried.

Parents with Disability Policy

Before a vote, there was discussion about a few technical revisions to the policy that were highlighted in red. The need for wording to identify appropriate protocols for competency evaluations was discussed.

There was also discussion about creating possible workgroup or task force to address the protocols used to assess individuals. Ed volunteered to bring this information to the DD Network Partner meeting to solicit input and insight from DRW, the UCEDD, and Allies.

Motion: to approve the amended policy statement. TK moved and Thanh seconded. The motion carried with Shannon abstaining.

Council Project Reports

Ed reported on the final reports from the Informing Families/Community of Practice and the Smart Living Project.

2019 Meeting Dates and Format

The Council discussed potential options for Council meetings in 2019, and selected the following dates for the 2019 meetings:

January 17 – One day council meeting
April 18 & 19 – one and a half day meeting
July 18 & 19 – one and a half day meeting
Oct. 17 & 18 – one and a half day meeting

Motion: to approve the 2019 meeting structure. Adrienne moved and Mike seconded. The motion carried.

Public Comment

There was none.

November Council Meeting Agenda

There was some discussion around the meeting agenda for November.

- The election of the second Vice Chair
- Election of 2nd vice chair
- State plan update
- Self-advocacy project proposal

Council Adjournment

Motion: to adjourn the meeting. Mike moved and Maggie seconded. The motion carried.