



NCCDD
North Carolina Council on
Developmental Disabilities

Quarterly Council Meeting
November 1-3, 2017
Hilton Garden Inn
Cary, NC

*Improving the opportunities and lives
of North Carolinians with I/DD and their families
through advocacy, capacity building
and systems change*



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Hilton Garden Inn
131 Columbus Avenue
Cary, NC 27518

Phone: 919-377-0440

Fax: 919-377-0445



**NCCDD
STAFF ON CALL
JoAnn Toomey**

(919) 377-0440 - Hotel Front Desk

**Please call the hotel front desk
and ask them to call JoAnn Toomey.**



NCCDD

**North Carolina Council on
Developmental Disabilities**



2017 COUNCIL COMMITTEE MEMBERSHIP

EXECUTIVE COMMITTEE

Alex McArthur: Chair

Katie Holler: Vice-Chair

Wing Ng, M.D.: Vice-Chair

Anna Cunningham: Secretary

Amanda Bergen: Chair, Financial Asset Development

Kerri Eaker: Chair, Community Living

Nessie Siler: Chair, Advocacy Development

Individual with DD

Parent of Child with DD

Parent of Child with DD

Parent of Child with DD

Parent of Child with DD

Parent of Child with DD

Individual with DD

Staff: Chris Egan

FINANCIAL ASSET DEVELOPMENT COMMITTEE

Amanda Bergen, Chair

Karen Armstrong

Wayne Black; Alternate: Teresa Strom

Anna Cunningham

Bryan Dooley

Senator Valerie Foushee

Myron Michelle Gavin

William Hussey; Alternate: Dreama McCoy

William Miller

Tara Myers; Alternate: Jim Swain

Dave Richard, Deputy Secretary; Alternate: VACANT

Kelly Woodall

Paula Woodhouse

Parent of Child with DD

Public At Large

Agency: Div. of Social Services

Parent of Child with DD

Individual with DD

Other: Legislative (Senate)

Parent of Child with DD

Agency: Dept. Public Instruction

Individual with DD

Agency: Div. of Voc. Rehabilitation

Agency: DHHS

Individual with DD

Parent of Child with DD

Staff: Travis Williams

COMMUNITY LIVING COMMITTEE

Kerri Eaker, Chair

Katherine Boeck

Christina Dupuch; Alternate: Andrea Misenheimer

Joshua Gettinger, M.D.

Michael Groves

Brendon Hildreth

Aldea LaParr

Wing Ng, M.D.

Vicki Smith

James Stephenson

Peggy Terhune, Ph.D.

Sandra Terrell; Alternate: Deb Goda

Jason Vogler, Ph.D.; Alternate: Mya Lewis

Parent of Child with DD

Individual with DD

Non-Profit Agency

Parent of Child with DD

Individual with DD

Individual with DD

Individual with DD

Parent of Child with DD

Agency: Disability Rights NC

Parent of Child with DD

Local Non-Governmental Agency

Agency: Div. Medical Assist.

Agency: Div. of MH/DD/SAS

Staff: Philip Woodward

ADVOCACY DEVELOPMENT COMMITTEE

Nessie Siler, Chair

Eric Chavis
NaKima Clark
Mary Edwards; Alternate: Joseph Breen
Jason Faircloth
Katie Holler
Representative Verla Insko
Kelly Kimple, M.D.; Alternate: Danielle Matula
Joe Piven, M.D.; Alternate: Deborah Zuver
Cheryl Powell
Vacant
Vacant
Daniel Smith

Individual with DD
Individual with DD
Parent of Child with DD
Agency: Aging & Adult Services
Individual with DD
Parent of Child with DD
Legislative Representative
Agency: W/C Health
Agency: Carolina Institute on DD
Individual with DD
Parent of a Child with DD
Dept. of Public Safety
Parent of Child with DD

Staff: Melissa Swartz

STAFF

Chris Egan
Cora Gibson
Melissa Swartz
JoAnn Toomey
Yadira Vasquez
Shar'ron Williams
Travis Williams
Philip Woodward
Letha Young

Executive Director
Administrative Assistant
Systems Change Manager
Director of Operations
Business Officer
Business Services Coordinator
Systems Change Manager
Systems Change Manager
Office Assistant



Meeting: NC Council on Developmental Disabilities
Location: Hilton Garden Inn, Cary, NC

DRAFT
AGENDA
WEDNESDAY, NOVEMBER 1, 2017
BRADFORD D

- 1:00 - 1:30 PM **WELCOME & AGENDA REVIEW**.....Alex McArthur and Chris Egan
- 1:30 - 2:15 PM **MEMBER NETWORKING**
- 2:15 - 3:00 PM **COLLECTIVE IMPACT EVALUATION PRESENTATION**.....Linda Kendall Fields
- 3:00 - 3:30 PM **BREAK**
- 3:30 - 4:15 PM **EMERGENCY PREPAREDNESS FINAL REPORT**.....Director Mike Sprayberry
- 4:15 - 5:00 PM **SIBLING SUPPORT FINAL REPORT**..... Debby Torres
- 5:00 - 5:30 PM **BREAK**
- 5:30 - 8:00 PM **ADVOCACY & LEADERSHIP AWARDS RECEPTION***.....
.....Guest Speakers, Nicole and Ryan Rotundo

*Council meetings are open to the public. However, we are a federally-funded program and cannot reimburse individuals who are not Council members or invited guests for transportation, meals, lodging, etc. Meals that are included in the agenda are for Council members and invited guests and cannot be provided to members of the public due to budgetary constraints.



Meeting: NC Council on Developmental Disabilities
Location: Hilton Garden Inn, Cary, NC

DRAFT
AGENDA
THURSDAY, NOVEMBER 2, 2017
BRADFORD D

9:00 - 10:00 AM **WELCOME** (Continental Breakfast Provided)*

10:00 - 10:30 AM **NEW MEMBER AFFIRMATIONS**.....Supreme Court of NC, Justice Cheri Beasley

10:30 - 11:00 AM **BREAK**

11:00 - 12:00 PM **PUBLIC POLICY UPDATE & DISCUSSION**.....Erika Hagensen

12:00 - 1:00 PM **LUNCH** (Buffet Lunch Provided)*

1:00 - 2:30 PM **COMMITTEE DRAFT RFA DISCUSSIONS**

-I/DD Employment Collaborative and Informational Website.....Amanda Bergen

-Case/Care Management in a Managed Care Environment

-Shared Living

-Re-Post Transportation RFA.....Kerri Eaker

-NC ADA Network/Fiscal Intermediary

-NC Empowerment Network Update

-Leadership Development Training Efforts.....Nessie Siler

2:30 - 3:00 PM **BREAK**

3:00 - 5:00 PM **COMMITTEE MEETINGS**

Financial Asset Development.....Bradford C

Community Living.....Bradford B

Advocacy Development.....Bradford A

Dinner on your own

*Council meetings are open to the public. However, we are a federally-funded program and cannot reimburse individuals who are not Council members or invited guests for transportation, meals, lodging, etc. Meals that are included in the agenda are for Council members and invited guests and cannot be provided to members of the public due to budgetary constraints.



Meeting: NC Council on Developmental Disabilities
Location: Hilton Garden Inn, Cary, NC

DRAFT
AGENDA
FRIDAY, NOVEMBER 3, 2017
BRADFORD CID

8:30 - 9:00 AM	WELCOME, CONFLICT OF INTEREST & SAFETY AND PREPAREDNESS	Alex McArthur
9:00 - 9:10 AM	ROLL CALL	Anna Cunningham
9:10 - 9:15 AM	APPROVAL OF MINUTES	Alex McArthur
9:15 - 9:30 AM	DIRECTOR'S REPORT	Chris Egan
9:30 - 9:40 AM	FINANCIAL REPORT	Alex McArthur
9:40 - 10:00 AM	LEGISLATIVE UPDATE	
10:00 - 10:15 AM	PUBLIC COMMENT	Alex McArthur
10:15 - 10:45 AM	BREAK	
10:45 - 11:30 AM	COMMITTEE REPORTS	
	Executive Committee.....	Alex McArthur
	Financial Asset Development.....	Amanda Bergen
	Community Living.....	Kerri Eaker
	Advocacy Development.....	Nessie Siler
11:30 - 12:25 PM	NEW BUSINESS	
	Election: 1 Vice-Chair (2-year term)	
	Election: Secretary (2-year term)	
	Ad Hoc Committee Updates	
	Five Year State Plan	
	Communications and Member Development	
	DD Network Partners-Update	
	Disability Rights NC	
	Carolina Institute for Developmental Disabilities	
12:25 - 12:30 PM	OLD BUSINESS	
12:30 PM	ADJOURN	

*The North Carolina Council on Developmental Disabilities (NCCDD) is committed to offering members of the general public an opportunity to make public comments. NCCDD members who would like to comment during this period of the meeting must be recognized by the Council Chair and are limited to three minutes per speaker.

Council Minutes



NCCDD

North Carolina Council on
Developmental Disabilities



DRAFT
NC COUNCIL ON DEVELOPMENTAL DISABILITIES
www.nccdd.org

Quarterly Council Meeting Minutes
Hilton Garden Inn, Cary, NC

August 11, 2017

MEMBERS PRESENT: Karen Armstrong, Amanda Bergen, Teresa Strom (for Wayne Black), Eric Chavis, NaKima Clark, Anna Cunningham, Christina Dupuch, Bryan Dooley, Kerri Eaker, Joseph Breen (for Mary Edwards), Myron Gavin, Michael Groves, Brendon Hildreth, Katie Holler, Beverly Colwell (for William Hussey) Kelly Kimple, Aldea LaParr, Alex McArthur, Tara Myers, Wing Ng, Deb Zuver (for Joseph Piven), Cheryl Powell, Nessie Siler, Dan Smith, Vicki Smith, Sandra Terrell, Mya Lewis (for Jason Vogler), Paula Woodhouse

MEMBERS ABSENT: Katherine Boeck, Jason Faircloth, Sen. Valerie Foushee, Joshua Gettinger, Rep. Verla Insko, William Miller, Dave Richard, Clare Shocket, James Stephenson, Peggy Terhune, Kelly Woodall

STAFF PRESENT: Chris Egan, Cora Gibson, Melissa Swartz, JoAnn Toomey, Yadira Vasquez, Travis Williams, Philip Woodward, Letha Young

CONTRACTORS/GRANTEES PRESENT: Gordon O'Neill, Devika Rao

GUESTS: Jennifer Bosk, Karen Cook, Natalie Davis, Paula Coppola, Rene Cummins, Kathy Dooley, Darcy Hildreth, Renate Macchirole, John Marens, Douglas Stoll

WELCOME AND ATTENDANCE

Vice-Chairman Wing Ng welcomed the members and asked that any Council member with a potential conflict of interest regarding any item on the agenda to identify that conflict for documentation in the minutes and recuse, as necessary. He also reminded members of the emergency exits at the Hilton Garden Inn. Anna Cunningham then conducted the roll call.

APPROVAL OF COUNCIL MINUTES

Wing Ng asked for approval of the May 2017 Council meeting minutes. A copy of the minutes had previously been made available to Council members.

MOTION: Paula Woodhouse made a motion to approve the May 2017 Council meeting minutes. Amanda Bergen seconded the motion. The motion was approved by unanimous vote.

DIRECTOR'S REPORT

Chris Egan delivered his report to the members focusing on systems change and the evolution and nature of change. He used examples of early innovations and the process of building on early efforts

to set new goals for future systems change efforts, and referenced the literature on systems change theory. He described the importance of collaboration and shared vision in pursuing positive changes and opportunities for individuals with I/DD and their families, and to focus on what is possible. He included a brief update on the Council response to the Administration on Community Living regarding the possible future structure of Council's on DD and the importance of the funding that we receive. He concluded by welcoming Alex McArthur as the new Chairperson for the NCCDD.

FINANCE REPORT

Wing Ng reminded members to complete their reimbursement forms and submit them to staff. He gave a brief report on the financial status of the Council. A copy of the report had previously been made available and reviewed with Council members.

LEGISLATIVE UPATE/PUBLIC POLICY

Erika Hagensen and Jill Hinton had given a public policy update to the members the day before.

PUBLIC COMMENTS

Amanda Bergen made Council members aware of the accessibility feature in Microsoft Word.

John Marens with the DHHS Division of Vocational Rehabilitation Services, Client Assistance Program, introduced himself to new Council members and to make them aware of the program.

COMMITTEE REPORTS

Wing Ng requested presentation of committee reports. Please refer to the committee minutes for a detailed description of the committee's work, including motions made in committee.

EXECUTIVE COMMITTEE

The Executive Committee members met April 17, 2017, May 22, 2017, June 19, 2017 and July 17, 2017. Copies of the minutes were made available to Council members. Wing Ng asked members to review the minutes.

FINANCIAL ASSET DEVELOPMENT COMMITTEE

Committee chair Amanda Bergen presented the Financial Asset Development Committee report. She thanked all committee members and staff and gave a brief update on the discussions from the Thursday meeting. Updated information concerning initiatives was provided. The following motions were presented on the floor for Council consideration:

MOTION: Eric Chavis made a motion to grant NCCDD staff authority to release the Request for Applications (RFA) regarding the *Innovative Employment: Making Inroads to Long-Term Success through Apprenticeships, Pre-Transition Partnerships, and Post-Secondary Monitoring* initiative, in an amount up to \$100,000 per year with required minimum of 25% non-federal matching funds for Year 1 (of up to 3), beginning March 1, 2018 to February 28, 2019. Approval to fund will occur at the November 17, 2017 Council meeting. Anna Cunningham recused herself from the vote since she is aware of several agencies who may apply for the RFA. Vicki Smith seconded the motion.

Amanda noted that there were four additional bullets to be added to Component 3 by the committee. The motion was approved by unanimous vote.

MOTION: Anna Cunningham made a motion to rescind the following motion from the May Council meeting:

MOTION: *Paula Woodhouse made a motion for staff of the Council to further research the potential of an in-house initiative regarding an I/DD Employment Resource Guide initiative in collaboration with Vocational Rehabilitation and other possible partnerships, for approval of funding at the August 11, 2017 Council meeting. Eric Chavis seconded the motion. The motion was approved by unanimous vote.*

Eric Chavis seconded the motion. The motion was approved by unanimous vote.

MOTION: Anna Cunningham made a motion for staff of the Council to have authority to draft the RFA regarding an I/DD Employment Resource Guide initiative in collaboration with Vocational Rehabilitation and other possible partnerships, in an amount up to \$75,000 per year with required minimum of 25% non-federal matching funds for a period of up to three years, for approval to release the RFA at the February 9, 2018 Council meeting. Alex McArthur seconded the motion.

Dan Smith suggested that the motion be amended. Discussion ensued. Anna Cunningham and Alex McArthur withdrew their motions.

MOTION: Anna Cunningham made a motion for the staff of the Council to have authority to draft a research report regarding an interactive, dynamic and regularly updated I/DD Employment Resource initiative in collaboration with Vocational Rehabilitation and other possible partnerships, for review at the Financial Asset Development Committee meeting at the November 2017 Council meeting. Eric Chavis seconded the motion. The motion was approved by unanimous vote.

COMMUNITY LIVING COMMITTEE

Committee chair Kerri Eaker presented the Community Living Committee report. Updated information concerning initiatives was given. She thanked all committee members and staff and gave a brief update on the discussions from the Thursday meeting. The following motion was presented on the floor for Council consideration:

MOTION: Mya Lewis made a motion to grant NCCDD staff authority to release the Request for Applications (RFA) regarding the *I Get Around – Improving Transportation Options* initiative, in an amount up to \$75,000 per year with required minimum of 25% non-federal matching funds for Year 1 (of up to 3), beginning March 1, 2018 to February 28, 2019. Approval to fund will occur at the November, 2017 Council meeting. Dee LaParr seconded the motion. The motion was approved by unanimous vote.

MOTION: Katie Holler made a motion to grant NCCDD staff authority to release the Request for Applications (RFA) regarding the *Using Natural Supports to Build Greater Community Engagement* initiative, in an amount up to \$75,000 per year with required minimum of 25% non-federal matching funds for Year 1 (of up to 3), beginning March 1, 2018 to February 28, 2019. Approval to fund will occur at the November, 2017 Council meeting. Anna Cunningham recused herself from the vote since she is aware of several agencies who may apply for the RFA. Eric Chavis seconded the motion. The motion was approved by unanimous vote.

MOTION: Anna Cunningham made a motion for continuation funding to The Arc of North Carolina for the From Planning to Action: Integrated, Collaborative Care for People with Intellectual and Developmental Disabilities (I/DD) initiative. Funding is approved for up to \$125,000 with a required minimum of 25% non-federal matching funds (\$41,667), for Year 2 (of 3) from January 1, 2018 to December 31, 2018. Eric Chavis seconded the motion. The motion was approved by unanimous vote.

MOTION: Alex McArthur made a motion for continuation funding to Vaya Health for the Supported Living: Making the Difference initiative. Funding is approved for up to \$100,000 (\$25,000 DD Funds, \$75,000 MFP/DMA Funds), with a required minimum of 25% non-federal matching funds (\$33,334), for Year 2 (of 3) from January 1, 2018 to December 31, 2018. Paula Woodhouse seconded the motion. The motion was approved by unanimous vote.

ADVOCACY DEVELOPMENT COMMITTEE

Committee chair Nessie Siler presented the Advocacy Development Committee report. Updated information concerning initiatives was given. She thanked all committee members and staff and gave a brief update on the discussions from the Thursday meeting.

NEW BUSINESS

Wing Ng reminded the members of the change of dates for the November, 2017 Council meeting and of the proposed Council meeting dates for 2018. The following motion was presented on the floor for Council consideration:

MOTION: Paula Woodhouse made a motion to approve the date change of the November, 2017 Council meeting to November 1, 2, 3, 2017, and to approve the 2018 meetings of the Council; February 8-9, May 10-11, August 9-10, and November 7, 8-9 be scheduled. The February, May and November, 2018 meetings will be held in the Raleigh area and the August, 2018 meeting will be held in the western region of NC. Katie Holler seconded the motion. The motion was approved by unanimous vote.

MOTION: Eric Chavis made a motion to rescind the following motions approved at the May, 2017 Council meeting:

MOTION: *Wendy Boyd made a motion for staff of the Council to research the creation of an in-house initiative regarding an "Access to Assets" Digital Lookbook initiative, or to include the digital lookbook in the NCCDD Communications initiative, in an amount up to \$50,000 with required minimum of 25% non-federal matching funds (match requirement only if included in an external initiative) for a period of one year, for approval at the August 11, 2017 Council meeting. Eric Chavis seconded the motion. The motion was approved by unanimous vote.*

MOTION: *Adonis Brown made a motion to approve funding for the NCCDD Communications initiative in an amount up to \$135,000 with a required minimum of 25% non-federal matching funds (\$45,000), for Year 1 (of up to 3) from October 1, 2017 to September 30, 2018. Kerri Eaker seconded the motion. The motion was approved by unanimous vote.*

Amanda Bergen seconded the motion. The motion was approved by unanimous vote.

MOTION: Anna Cunningham made a motion to approve the cost-extension of Year 3 of 3 funding to O'Neill Public Relations for the *NCCDD Communications* (including the Digital Lookbook) initiative in a total amount up to \$191,700 with a required minimum of 25% non-federal matching funds (\$63,900), from October 1, 2017 to September 30, 2018. Kerri Eaker seconded the motion. The motion was approved by unanimous vote.

AD HOC COMMITTEE UPDATES

Sandy Terrell gave an update on the Five-Year State Plan Ad Hoc Committee. A copy of the minutes from the August 4, 2017 meeting was provided to all members.

Amanda Bergen gave an update on the Communications and Member Development Ad Hoc Committee. A copy of the minutes from the July 20, 2017 meeting was provided to all members.

DEVELOPMENTAL DISABILITIES NETWORK PARTNERS-UPDATE

Vicki Smith congratulated the Council on the work they were doing and gave an update on the Disability Rights NC activities.

Deb Zuver gave an update on the Carolina Institute for Developmental Disabilities (CIDD) and their focus on research and that they are pleased to be a part of the NC Empowerment Network.

OLD BUSINESS

There was no old business.

ADJOURN

Wing Ng asked for a motion to adjourn the meeting.

MOTION: Amanda Bergen made a motion to adjourn the meeting. Eric Chavis seconded the motion. Motion was approved by unanimous vote and the meeting was adjourned.

Approved: _____

Anna Cunningham, Secretary

Date: _____

Executive Committee



NCCDD

North Carolina Council on
Developmental Disabilities



NC Council on Developmental Disabilities

DRAFT

Executive Committee Minutes

Date: September 18, 2017

Time: 10:30 AM – 12:30 PM

Members Present: Amanda Bergen, Katie Holler, Alex McArthur, Wing Ng, Anna Cunningham, Kerri Eaker, Nessie Siler

Staff Present: Chris Egan, JoAnn Toomey, Yadira Vasquez

Chairperson Alex McArthur presided over the Executive Committee meeting and welcomed the members calling in.

I. Approval of Minutes:

The draft minutes of the August 21, 2017 Executive Committee meeting were reviewed and considered for approval.

MOTION: Nessie Siler made a motion to approve the August 21, 2017 minutes. Kerri Eaker seconded the motion. Amanda Bergen and Katie Holler recused themselves since they were absent for the August meeting. The motion was approved.

II. Council Meeting/Member Survey Review:

Chris Egan reviewed the November draft agenda with the members. Several edits were suggested, including making time for the Emergency Preparedness and Sibling Support final reports on Wednesday and showing a video on Disability Employment Month during lunch on Thursday.

Chris also shared with the members that the article on the presentation at the August Council meeting on Opioid addiction in Highlights and Hot Topics received attention from Jennifer Johnson at the Administration on Community Living. Wing Ng, Anna Cunningham and Alex McArthur shared more thoughts on that topic during this time.

III. Conference Funding Requests:

Members reviewed a request from the North Carolina Providers Council for their 2017 Annual Conference titled, *Rising To The Challenges Ahead*, being held Wednesday-Friday, September 27-29, 2017 at the Sheraton Greensboro at Four Seasons. The request is to fund one speaker (fees & travel) for up to \$831.00.

MOTION: Anna Cunningham made a motion to approve the conference funding request from the North Carolina Providers Council for their 2017 Annual Conference titled, *Rising To The Challenges Ahead*, being held in Greensboro September 27-29, 2017 to fund one speaker's fee and travel expenses for up to \$831.00. Nessie Siler seconded the motion. The motion was approved.

IV. Personal Services Contract Review/Approval:

Chris advised the members that we entered into a Personal Services Contract with Lauren Borchert for the time period of September 15-December 31, 2017. Lauren is a co-coordinator of the in-house initiative, Inclusive Advocacy Leadership. Her services were originally secured through Temporary Solutions in early November, 2016. Because of the 31-day break that is required of Temporary Solutions employees, Lauren would have had to take the break in October which is a critical time in the conclusion of this in-house initiative. To prevent the loss of Lauren's time, DHHS approved a personal services contract through the end of this year. This did not involve any additional funds to be paid to Lauren from what was originally budgeted.

V. Council Members Attendance at Conferences:

Two additional members requesting participation at the Council of Community Programs Conference in December were discussed and approved.

VI. Ad Hoc Committees/Updates:

JoAnn Toomey updated the members that the Five-Year State Plan Ad Hoc Committee have scheduled their next meeting for Friday, September 29th and they are currently promoting member participation in the Language Access Plan (LAP) Workgroup.

Anna Cunningham updated the members on the Communications and Member Development Ad Hoc Committee that will meet again August 24th to discuss the November award nominations. There are currently 4 Hefner nominations to review and 11 Riddle nominations for review. The plan is for the recipients of the awards to be interviewed by O'Neill Public Relations to produce a video on each recipient to be shown at the awards dinner.

The ad hoc committee also shared with the EC members a Conference Attendance-Member Report Form. There was some discussion that it should be an on-line form on the NCCDD website so members would know what they would be asked after

attending a conference, and the form would also be included in the approval e-mail sent to them. Conference attendance by members will also be forwarded to O'Neill Communications for them to follow up with the member to ask the questions in an interview/video setting at Council meetings for conferences attended in the months between Council meetings. Alex McArthur made a few suggestions that will be incorporated into the final form.

MOTION: Anna Cunningham made a motion to approve the use of the Member Report form, with suggested additions. Amanda Bergen seconded the motion. The motion was approved.

VII. Other:

- Chris Egan updated the members that the deadline for submissions for our three RFAs was tomorrow, September 20th.
- Chris also discussed the need to draft a revision of the Conference Funding Policy to include other possible expenses that requestors could include, such as venue costs, to promote more interest in applying which would also promote the Council in their advertisement of supporters.

MOTION: Kerri Eaker made a motion to approve staff drafting a revision of the Conference Funding Policy, policy description section and the attached funding request form, to include other allowable expenses besides speaker fees and travel expenses. The procedures in this policy will not change. Anna Cunningham seconded the motion. The motion was approved.

- The Ideas Portal was discussed as a follow-up to the discussion and agreement by the EC in August. The process for submissions to the portal will be:
 1. Staff will review all information received through the portal.
 2. All information will be considered in conjunction with the Five-Year Plan and will be included as public input in the annual PPR.
 3. Staff will share with the EC if ideas received are in-line with the potential to apply for upcoming RFA releases, or

4. Staff will share with the EC if ideas received may be appropriate to be considered for sole-source review or for a new RFA release.
- The awards update was discussed previously in the ad hoc committee updates. However, since she was a member of that ad hoc committee, Chris Egan announced to the members that Clare Shocket has resigned from the Council, effective September 15, 2017. She will be moving to Singapore with her family in early October. Clare will be missed by all.
 - Boards and Commissions will be notified of Clare's resignation and vacancy of her parent/immediate relative position. Because there were recent recommendations forwarded for other vacancies in this category, they will again be sent to Boards and Commissions for their consideration.

VIII. Adjourn:

Alex McArthur asked for a motion to adjourn the meeting.

MOTION: Amanda Bergen made a motion to adjourn the meeting. Wing Ng seconded the motion. The motion was approved.

NC Council on Developmental Disabilities

FINAL

Executive Committee Minutes

Date: August 21, 2017

Time: 10:30 AM – 12:30 PM

Members Present: Wing Ng, Anna Cunningham, Kerri Eaker, Nessie Siler

Members Absent: Amanda Bergen, Katie Holler, Alex McArthur

Staff Present: Chris Egan, JoAnn Toomey

In the absence of the Chair, Vice-Chair Wing Ng presided over the Executive Committee meeting and welcomed the members calling in.

I. Approval of Minutes:

The draft minutes of the July 17, 2017 Executive Committee meeting were reviewed and considered for approval.

MOTION: Nessie Siler made a motion to approve the July 17, 2017 minutes. Kerri Eaker seconded the motion. The motion was approved.

II. Council Meeting/Member Survey Review:

Chris Egan reviewed the member survey responses from the August 10-11, 2017 Council meeting. Survey responses were very positive and complimentary of the agenda, discussions and the achievement of the objectives for the meeting. Several questions or observations included the lack of a morning break on Thursday, room temperature, length of the day on Thursday and a question regarding reasons for including the Opioid addiction presentation. Chris explained that the presentation on opioid addiction was included in the Thursday agenda to ensure members were aware that this crisis affects all communities in NC including people with I/DD and their families. The temperature in the room was also addressed and the thermostat can now be adjusted by Council staff instead of alerting hotel staff. Staff will continue to work to build in needed breaks and consider the overall agenda. The EC members agreed with a comment that we should encourage members to share their talents at the Council meetings and that there should be an agenda item for member development and/or team building.

Legislative updates were also discussed and suggestions were made on where they should be on the Thursday or Friday agenda.

The members reviewed the November draft agenda for the November Council Meeting. They made several suggestions for the awards dinner that included having the elevated platform and identifying sibling presenters as the guest speakers. They agreed that there needed to be a member development opportunity, along with a networking activity. A one sheet/page summary of intent and outcomes was suggested for each of the two advocacy leadership efforts. The elections will also be discussed during the welcome on Wednesday and Thursday, in preparation for the nominations to be made on the floor Friday.

III. Conference Funding Requests:

None at this time.

IV. Personal Services Contract Review/Approval :

None at this time.

V. Council Members Attendance at Conferences:

None at this time.

VI. Ad Hoc Committees/Updates:

JoAnn Toomey and Anna Cunningham updated the members on the Communications and Member Development Ad Hoc Committee that will meet again August 24th to discuss the November awards dinner/award nominations and member development opportunities. JoAnn also let the members know that the Five-Year Plan Ad Hoc Committee is in the process of identifying a date for their next meeting.

VII. Other:

Chris Egan let the EC members know that a New Member Orientation is in the process of being scheduled and a tentative date and location is October 4th at the Holiday Inn-Crabtree. Details will be coming soon.

Also, we were notified that the FFY 2017 award was increased by \$54,490 to \$2,070,454 due to a reallocation of Puerto Rico funds.

VIII. Adjourn:

Wing Ng asked for a motion to adjourn the meeting.

MOTION: Anna Cunningham made a motion to adjourn the meeting. Nessie Siler seconded the motion. The motion was approved.

NC Council on Developmental Disabilities

FINAL

Executive Committee Minutes

Date: July 17, 2017

Time: 10:30 AM – 12:30 PM

Members Present: Wing Ng, Amanda Bergen, Kerri Eaker, Katie Holler, Nessie Siler

Members Absent: Anna Cunningham

Staff Present: Chris Egan, JoAnn Toomey, Yadira Vasquez

Guest Present: Alexandra McArthur

In the absence of a Chair, Vice-Chair Wing Ng presided over the Executive Committee meeting and welcomed the members calling in.

I. Approval of Minutes:

The draft minutes of the June 19, 2017 Executive Committee meeting were reviewed and considered for approval.

MOTION: Amanda Bergen made a motion to approve the June 19, 2017 minutes. Katie Holler seconded the motion. The motion was approved.

II. Financial Report and Expenses/Match Update:

Yadira Vasquez reviewed the financial reports for the NCCDD. There was discussion on the 2015-2018 FFY balances and initiative expenditures. A detail report was also reviewed. Yadira pointed out to the members that that there is \$139,808 available for new initiatives in FFY 2017 that began October 1, 2016 and \$550,000 available for new initiatives in FFY 2018 that begins October 1, 2017. There will be \$689,808 available between FFYs 2017 and 2018.

The members reviewed the initiative report and noted that there were no match issues needing attention. Wing asked the members if there were any other questions or comments and there were none.

III. Council Meeting/Member Survey or Agenda Review

Chris Egan reviewed the draft August Council Meeting Agenda with the members and let them know that the suggestions from the June meeting had been taken into

consideration. The members agreed that with the topics, timing and flow of the agenda on Thursday and Friday. It is expected that we will have the new Chairperson appointed by the August meeting. Wing Ng and Katie Holler discussed their Vice-Chair roles during the August Council meeting and it was decided that Katie would assist the Chair on Thursday and Wing would assist on Friday.

IV. Conference Funding Requests:

None at this time.

V. Personal Services Contract Review/Approval:

None at this time.

VI. Ad Hoc Committees/Updates:

Chris Egan asked JoAnn Toomey to update the members about the Ad Hoc Committees. JoAnn shared with the members that the Communications and Member Development Committee will meet again on July 20th to discuss their review of the user-friendly version of the Council Bylaws and possible recommendation of approval to the Executive Committee.

The Five-Year Plan Ad Hoc Committee met June 28th and discussed the State Plan update process, along with the Collective Impact model which guides how the Council develops, implements, and evaluates the effectiveness of our initiatives. The next meeting is in the process of being scheduled.

VII. Other:

The members reviewed the proposed Council meeting dates for 2018: February 8-9, May 10-11, August 9-10 and November 7-9. There was discussion regarding the possibility of a meeting in the eastern or western parts of the state in either the May or August and it was decided to propose to the Council at the August meeting to have the August, 2018 meeting in the western part of NC.

There was discussion of the upcoming release of three RFAs. Chris Egan asked if Amanda Bergen or Kerri Eaker had received any feedback on the draft RFAs that were sent out last week. Amanda said she had received one inquiry so far and Kerri had not received any. Council members have

until July 24th to respond with any comments or questions. Discussion did occur regarding the Using Natural Supports to Build Greater Community Engagement RFA.

VIII. Adjourn

Wing Ng asked for a motion to adjourn the meeting.

MOTION: Nessie Siler made a motion to adjourn the meeting. Amanda Bergen seconded the motion. The motion was approved.

Financial Asset Development Committees



NCCDD

North Carolina Council on
Developmental Disabilities



North Carolina Council on Developmental Disabilities

Financial Asset Development Committee Agenda

November 2, 2017

3:00 p.m. – 5:00 p.m.

Hilton Garden Inn, Cary, NC

3:00 p.m. – 3:15 p.m.	Introduction <ul style="list-style-type: none"> • Welcome • Approval of August Minutes 	<i>Amanda Bergen, Chair</i>
3:10 p.m. – 3:25 p.m.	Fiscal Update	<i>Yadira Vasquez, Staff</i>
3:25 p.m. – 3:50 p.m.	Updates and Motion Items <ul style="list-style-type: none"> • RFA Discussion <ul style="list-style-type: none"> ◦ Innovative Employment... 	<i>Amanda Bergen and Travis Williams, Staff</i>
3:50 p.m. – 4:15 p.m.	<ul style="list-style-type: none"> • NDI Update on Expansion Activity 	<i>Michael Roush, National Disability Institute Donna Gallagher, The Collaborative</i>
4:15 p.m. – 4:25 p.m.	<ul style="list-style-type: none"> • Expansion of Employment Final Report 	<i>Pat Keul</i>
4:25 p.m. – 4:35 p.m.	Future Investments Discussion <ul style="list-style-type: none"> • NCDVR Employment Campaign 	<i>Jeanna Cullinan, NCDVRS</i>
4:35 p.m. – 4:55 p.m.	<ul style="list-style-type: none"> • Employment Collaborative and Website 	<i>Amanda Bergen and Travis Williams</i>
4:55 p.m. – 5:00 p.m.	Wrap Up and Reminders <ul style="list-style-type: none"> • Completion of Financial Forms • Reminder: February 8-9, 2018 Council meeting in Cary at Hilton Garden Inn 	<i>Amanda Bergen</i>

Financial Asset Development Committee

Amanda Bergen, Chair
 Karen Armstrong
 Wayne Black; Alternate: Teresa Strom
 Anna Cunningham
 Bryan Dooley
 Senator Valerie Foushee
 Myron Michelle Gavin
 William Hussey; Alternate: Dreama McCoy
 William Miller
 Tara Myers; Alternate: Jim Swain
 Dave Richard, Deputy Secretary; Alternate: VACANT
 Kelly Woodall
 Paula Woodhouse

Parent of Child with DD
 Public At Large
 Agency: Div. of Social Services
 Parent of Child with DD
 Individual with DD
 Other: Legislative (Senate)
 Parent of Child with DD
 Agency: Dept. Public Instruction
 Individual with DD
 Agency: Div. of Voc. Rehabilitation
 Agency: DHHS
 Individual with DD
 Parent of Child with DD

Staff: Travis Williams

**Financial Asset Development
DRAFT Minutes
August 10, 2017
3:00 P.M. – 5:00 P.M.
Hilton Garden Inn, Cary, NC**

Members Present: Karen Armstrong, Amanda Bergen, Teresa Strom (for Wayne Black), Anna Cunningham, Bryan Dooley, Myron Gavin, Beverly Colwell (for William Hussey), Alex McArthur, Jim Swain (for Tara Myers), Paula Woodhouse

Members Absent: Senator Valerie Foushee, Will Miller, Dave Richard, Kelly Woodall

Guests: Douglas Stoll

Staff/Contractors: Jennifer Bosk, Donna Gallagher, Pat Keul, Michael Roush (on the phone), JoAnn Toomey, Yadira Vasquez, Travis Williams

Introduction

Committee Chair, Amanda Bergen, welcomed the members and called the meeting to order. She asked the members to participate in an ice-breaker where each member was asked to think of a theme song to go with the FADC RFA.

MOTION: Anna Cunningham made a motion to accept the minutes from the May 11, 2017 committee meeting. Jim Swain seconded the motion. The motion was approved by unanimous vote.

The members were updated on the "Cross-Collaboration" recommendation from the May meeting. It was referred to the Communications and Member Development Ad Hoc Committee and staff were asked to draft an action item agenda for the next ad hoc meeting scheduled for August 24, 2017. They also were reminded to review the easy to read version of the NCCDD by-laws that was included in the mailout and to review the NCCDD Impact Statement that is in their committee folders. Anna Cunningham asked who to talk to about adding information to the Impact Statement. Travis Williams told her to let him know and he will get the information to Chris Egan. Chris did send the Impact Statement to the Administration on Community Living (ACL) and it is also on the NCCDD website.

She asked the members to participate in an ice-breaker where each member where each member was asked to think of a theme song to go with the FADC RFA.

Initiative Updates

Upward to Financial Stability Initiative

Michael Roush of the National Disability Institute (NDI) called in. Donna Gallagher of The Collaborative was present at the meeting. Donna said that The Collaborative is based in Raleigh. Donna passed out the hand-out for Michael to discuss with the members. Since the last time he shared information, he said it's very important to share the impact of the work from this initiative - trained over 490 individuals for train the trainer at this time. They have trained over 700 individuals – meaning over 1,000 people have been trained.

He had 88 people in attendance at the final webinar on August 3rd. Over 180 people have participated in the webinars. To continue the excitement, they are continuing to have calls for the trainer support network and have also created an on-line community. This is where the trainers can have discussions with other trainers and will also be able to share any events that might be coming up.

Michael Roush then discussed the lessons learned and potential next steps for the Council to address. This included the need for accurate benefits planning information and access to benefits counselors, more in-depth education on integrated services, enhancing the knowledge of NC ABLE with diverse partners, training additional Master Trainers, translating the curriculum into Spanish and increasing education and awareness on competitive employment. There will also be a four-part webinar series.

Donna Gallagher added that The Collaborative has already started outreach to the Latino community throughout the state. This is through Raleigh's Latino community and other community centers. This will hopefully provide them with better attendance at the next sessions where they will have Spanish materials. They have tentatively scheduled a FDIC Economic Inclusion meeting for November 6th at the World Center Conference Center but will let everyone know the place and time. Michael said that the work they have done with FDIC is to specifically look at people with I/DD and their saving behaviors and they have found that individuals may not be using the traditional venues but are more relying on pawn shops, pay day loan centers, etc.

Lengthy discussion occurred regarding this initiative and the members thanked Donna Gallagher and Michael Roush for their update.

Expansion of Employment Opportunities for People with I/DD Initiative

Employment Services Coordinator Pat Keul updated the committee with a progress report on the initiative. She has enjoyed the time working on this initiative that will be ending September 30, 2017.

Pat discussed paid apprenticeships and individuals that have started working in the feeding assistant program in the Charlotte and Marshal areas. She also shared with the members how this program started and how the Council has assisted in strengthening the program. She is also looking into the idea of I/DD Peer Mentor Apprenticeships. She did say there is not a lot of demand for it – yet. There will be meetings scheduled

in August and September regarding IT/Data Entry. Micro-breweries and senior services outreach is also being discussed.

Pat also discussed Project SEARCH– and how there will be continuation beyond NCCDD funding. There are now 14 Project SEARCH programs in NC. Wake County Schools are also in discussion to begin Project SEARCH in 2018. NC DVR will also participate with the Wake County Schools site schedule to start in 2018. Cincinnati Hospital will be doing more training in Asheville later this year. She also shared information about the State Employment Coalition/Partnership with Project SEARCH bringing "Thought Leaders" together to solve problems that are barriers to employment services and other new coalition focus areas.

She shared the slide with the quote by Steve Jobs: "Everyone here has the sense that right now is one of those moments when we are influencing the future." Pat said that she felt privileged to have been a part of this initiative.

The members thanked Pat Keul for her update.

Fiscal Report

Yadira Vasquez gave the fiscal report to the members and introduced a new, more detailed report on each initiative funded out of the Financial Asset Development Committee. Several questions were asked regarding the available funds and if there was a process for funding micro-enterprises. It was answered that there is – and it has been done in the past.

Draft RFA and Research Updates

Amanda Bergen asked the members to review and discuss the proposed release of the Innovative Employment RFA that was included in the May mailout in a sealed envelope. Anna Cunningham recused herself from the discussion and left the room. Jim Swain also recused himself and did not participate in the discussion or vote on the motion.

Lengthy discussion occurred regarding who could apply for the RFA and if any of the members knew of any agency or organization that might apply. They also discussed what could be done if there weren't any good candidates or qualified applicants for the RFA. There was a question from the presentation earlier in the day if there was going to be a concrete plan to engage in the community college system and if this would lead to some applicants coming with plans to include that system. Some of the wording in the RFA may need to be changed or moved around. Component 3 was discussed to be modified.

MOTION: Teresa Strom made a motion to grant NCCDD staff authority to release the Request for Applications (RFA) regarding the Innovative Employment: Making Inroads to Long-Term Success through Apprenticeships, Pre-Transition Partnerships, and Post-Secondary Monitoring initiative, in an amount up to \$100,000 per year with required

minimum of 25% non-federal matching funds for Year 1 (of up to 3), beginning March 1, 2018 to February 28, 2019. Approval to fund will occur at the November 3, 2017 Council meeting. Myron Gavin seconded the motion. The motion was approved by majority vote.

MOTION: Paula Woodhouse made a motion to rescind the following motion from the May Council meeting:

***MOTION:** Paula Woodhouse made a motion for staff of the Council to further research the potential of an in-house initiative regarding an I/DD Employment Resource Guide initiative in collaboration with Vocational Rehabilitation and other possible partnerships, for approval of funding at the August 11, 2017 Council meeting. Eric Chavis seconded the motion. The motion was approved by unanimous vote*

Anna Cunningham seconded the motion. The motion was approved by unanimous vote.

NEW MOTION:

MOTION: Anna Cunningham made a motion for staff of the Council to have authority to draft the RFA regarding an I/DD Employment Resource Guide initiative in collaboration with Vocational Rehabilitation and other possible partnerships, in an amount up to \$75,000 per year with required minimum of 25% non-federal matching funds for a period of up to three years, for approval to release the RFA at the February 9, 2018 Council meeting. Teresa Strom seconded the motion. The motion was approved by unanimous vote.

The motion for staff of the Council to research the creation of an in-house initiative regarding an "Access to Assets" Digital Lookbook initiative, or to include the digital lookbook in the NCCDD Communications initiative, in an amount up to \$50,000 with required minimum of 25% non-federal matching funds (match requirement only if included in an external initiative) for a period of one year will be rescinded tomorrow at the Council meeting and combined with the revised NCCDD Communications initiative motion.

Wrap Up and Reminders

Myron made a motion to adjourn the meeting.
Amanda Bergen adjourned the meeting at 5:15 P.M.

Community Living Committees



NCCDD

North Carolina Council on
Developmental Disabilities



North Carolina Council on Developmental Disabilities

Community Living Committee Agenda

November 2, 2017

3:00 p.m. – 5:00 p.m.

Hilton Garden Inn Cary, NC

3:00 p.m. – 3:15 p.m.	Introduction <ul style="list-style-type: none"> Welcome Approval of August minutes Member Development 	<i>Kerri Eaker, Chair</i>
3:15 p.m. – 3:35 p.m.	Motion Items <ul style="list-style-type: none"> RFA Discussion <ul style="list-style-type: none"> Natural Supports Transportation 	<i>Kerri Eaker, Philip Woodward, Staff</i>
3:35 p.m. – 4:00 p.m.	<ul style="list-style-type: none"> Future Investment Priority Discussion <ul style="list-style-type: none"> Case Management in a Managed Care Environment Shared Living 	<i>Corye Dunn, Disability Rights North Carolina Kerri Eaker, Philip Woodward</i>
4:00 p.m. – 4:10 p.m.	Fiscal Update	<i>Yadira Vasquez, Staff</i>
4:10 p.m. – 4:30 p.m.	Initiative Updates <ul style="list-style-type: none"> Rethinking Guardianship: Building a Case for Less Restrictive Alternatives 	<i>Linda Kendall Fields, The Jordan Institute Kate Walton, Division of Aging and Adult Services</i>
4:30 p.m. – 4:50 p.m.	<ul style="list-style-type: none"> From Planning to Action: Integrated, Collaborative Care for People with Intellectual and Developmental Disabilities initiative 	<i>Karen Luken, The Arc of NC</i>
4:50 p.m. – 5:00 p.m.	Wrap Up and Reminders <ul style="list-style-type: none"> Completion of Financial Forms Reminder: Next Council meeting – February 8-9, 2018 in Cary at Hilton Garden Inn 	<i>Kerri Eaker</i>

COMMUNITY LIVING COMMITTEE

Kerri Eaker, Chair
 Katherine Boeck
 Christina Dupuch; Alternate: Andrea Misenheimer
 Joshua Gettinger, M.D.
 Michael Groves
 Brendon Hildreth
 Aldea LaParr
 Wing Ng, M.D.
 Vicki Smith
 James Stephenson
 Peggy Terhune, Ph.D.
 Sandra Terrell; Alternate: Deb Goda
 Jason Vogler, Ph.D.; Alternate: Mya Lewis

Parent of Child with DD
 Individual with DD
 Non-Profit Agency
 Parent of Child with DD
 Individual with DD
 Individual with DD
 Individual with DD
 Individual with DD
 Parent of Child with DD
 Agency: Disability Rights NC
 Parent of Child with DD
 Local Non-Governmental Agency
 Agency: Div. Medical Assist.
 Agency: Div. of MH/DD/SAS

Staff: Philip Woodward

Community Living Committee

DRAFT MINUTES

Thursday, August 10, 2017

3:00 p.m. to 5:00 p.m.

Hilton Garden Inn, Cary, NC

Members Present: Kerri Eaker, Mya Lewis, Christina Dupuch, Joshua Gettinger, Michael Groves, Vicki Smith, Brendon Hildreth, Katherine Boeck, Aldea LaParr, Alex McArthur

Members Absent: Peggy Terhune, Sandra Terrell, James Stephenson

Staff in Attendance: Philip Woodward, Yadira Vasquez

Guests: Karen Luken, Amanda Zaski, Jesse Smathers, Linda Kendall Fields, Darcy Hildreth (with Brendon Hildreth), Caryn Cook (ASL interpreter), Natalie Davis (ASL interpreter), Paula Coppola

Introduction:

Ms. Eaker opened the meeting welcoming the members and asking them to do an icebreaker where they state who they are, one strength, and one goal they have for their Council involvement.

Minutes from the May 2017 Community Living Committee meeting were reviewed.

MOTION: Dr. Gettinger made the motion to approve the minutes as read, and Ms. Dupuch seconded the motion. The motion was approved.

Fiscal Update:

Ms. Vasquez provided the fiscal report and reviewed the fiscal report forms in the committee folders. By request of the Council members, she added a sheet of definitions titled "Term Descriptions," which Ms. Smith complimented. Ms. Luken commented about receiving invoices from Duke being slow.

RFA Discussion:

Dr. Gettinger praised the RFA writing and called them inspirational. Ms. Smith commented that the review process made it more robust. The committee members had no further comments. Mr. Woodward explained that the RFA review process has a review committee that will be formed with Council members, stakeholders, and topic experts to come together for two meetings: an orientation meeting in September and a meeting to review the submissions in October. He said the Executive Committee will review the recommendations,

and then the Council will vote on them at the November meeting.

MOTION: Ms. Lewis made a motion to grant NCCDD staff authority to release the Request for Applications (RFA) regarding the *I Get Around – Improving Transportation Options* initiative, in an amount up to \$75,000 per year with required minimum of 25% non-federal matching funds for Year 1 (of up to 3), beginning March 1, 2018 to February 28, 2019. Approval to fund will occur at the November 3, 2017 Council meeting. Ms. Smith seconded the motion. The motion was approved by unanimous vote.

MOTION: Ms. Smith made a motion to grant NCCDD staff authority to release the Request for Applications (RFA) regarding the *Using Natural Supports to Build Greater Community Engagement* initiative, in an amount up to \$75,000 per year with required minimum of 25% non-federal matching funds for Year 1 (of up to 3), beginning March 1, 2018 to February 28, 2019. Approval to fund will occur at the November 3, 2017 Council meeting. Ms. Dupuch seconded the motion. The motion was approved by unanimous vote.

Future Investment Priority Discussion:

Ms. Eaker updated the members to let them know other two future investment priorities they voted on in May are now slated to have RFAs released in February 2018. Mr. Woodward further updated the members on the research he has done so far. He explained there is not enough knowledge in each area for the Council to move forward at this point, and more research is needed to inform the Council on how it can maximize its investment in each area.

Community Navigator and Targeted Case Management

Mr. Woodward referred to the discussion from May and said the Local Management Entity/Managed Care Organization (LME/MCO) system is still evolving. He mentioned the need for the committee to agree to clearly define terms like "community navigator," "community guide," and "care coordinator" in order to move forward in this area and invited the committee to discuss this topic further.

Ms. Smith said one perspective that was overlooked is: what works best? She asked for a definition of the service that works best and suggested that the committee come up with something to propose as a potential change down the road and discuss what needs to happen. Ms. Dupuch stated that many families are lacking something. Ms. Eaker mentioned the fear and frustration around the Adult Care Homes report.

Ms. Smith asked if the committee wants case managers to do advocacy? Ms. Dupuch said care coordinators have restrictions, and Ms. Smith asked, what does the word "management" mean? Ms. Dupuch asked for parent perspectives, and Ms. Hildreth said that as a parent, it's nice to have resources, but some

people don't know what to ask for. Mr. Hildreth observed that everywhere he goes, the services are different, and a person has to start over again each time he or she moves somewhere new. Ms. Smith commented that she is not sure "advocacy" is the right word. She offered a suggestion: between now and November, develop a questionnaire to send out to all Council members because we have a lot of resources on the Council. She also asked: how do we define "service?" Ms. LaParr said "service" won't always mean paid service; an example is support groups that provide community support and inclusion.

Ms. Kendall Fields asked to make a comment. She noted that two words popped up during this discussion: resources and advocacy. She believes these terms seem different than case management and noted that resources can be services or people. Mr. Smathers noted that he was once a case manager, and they are expected to know every resource in the community, which is impossible. He noted that there is a coordination aspect, and it is important to focus on what the person needs. He said care coordination and community navigator are not enough.

Ms. Lewis asked, what's missing? She said people know and understand the resources and understand there is some level of training involved in being a case manager, and she supports the idea of a survey for the members. Mr. Hildreth suggested dividing the state's services into three sections: west, central, and east.

Ms. Eaker asked what the committee should do next and if the committee should form a workgroup. Dr. Gettinger proposed doing what the Council is doing with its Rethinking Guardianship initiative: "Rethinking Case Management."

Shared Living

Ms. Smith said pockets in our state are doing shared living. Ms. Eaker mentioned four males with autism living together. Ms. Lewis asked if this arrangement is licensed and said North Carolina has AFL: Alternative Family Living. She said this concept changes the thinking. Mr. Smathers stated that shared living has a component that the person doesn't have to move if the service changes. Ms. LaParr asked if, with \$50,000, can we establish a database to assist with finding a match? Mr. Woodward provided a research update by giving the committee a definition of shared living and noting that other states have shared living programs, but there is not a lot of statewide guidance for such a program. He noted that shared living has cost savings over facility and group home living arrangements.

MOTION: Ms. LaParr made a motion to amend Priority #3 and Priority #4 from the May Council meeting's motion approving the Community Living Committee's prioritization of the future investment concepts to:

Priority #3: Staff of the Council will have authority to draft the RFA regarding a *Community Navigator and Targeted Case Management in a Managed Care Environment* initiative, in an amount up to \$125,000 per year with required minimum of 25% non-federal matching funds for a period of up to three years, for approval to release the RFA at the February 9, 2018 Council meeting.

Priority #4: Staff of the Council will have authority to draft the RFA regarding a *Shared Living* initiative, in an amount up to \$50,000 per year with required minimum of 25% non-federal matching funds for a period of up to three years, for approval to release the RFA at the February 9, 2018 Council meeting.

Ms. Boeck seconded the motion. The motion was approved by unanimous vote.

Initiative Updates:

From Planning to Action: Integrated Collaborative Care for People with Intellectual and Developmental Disabilities (I/DD)

Ms. Luken talked about the learning cohorts, and she echoed what Ms. Smith said in her introduction about the chance to bring together people from cross-disability categories. She said for the Duke pilot, Ms. Zaski's role involves resource coordination. Ms. Luken said the two pilot models will let us evaluate and see what works, and she asked the members to let her know if they know of a medical practice in North Carolina that might be interested. She said there will be some on-the-ground outreach.

The committee received a question from Council member Anna Cunningham: Please identify how self-advocates will be included in the formation and strategic plan. Ms. Luken said there are self-advocates on the advisory team, and there is a professional advocate at the Raleigh clinic. She will follow up with Ms. Cunningham. Dr. Gettinger asked about the TEACCH project and the three cohorts. Ms. Luken said each cohort will last four to six months, and then the initiative needs to make sure to move on to other cohorts.

Ms. McArthur said training is a component of having high expectations. Ms. Luken said she talked to Council member Deb Zuber, and primary care doesn't know about post-secondary education programs like Beyond Academics. She mentioned the need to address education during the consultation, and this comes back to the topic of navigation.

The guests left for the motion.

MOTION: Ms. Smith made a motion for continuation funding to The Arc of North Carolina for the From Planning to Action: Integrated, Collaborative Care for People with Intellectual and Developmental Disabilities (I/DD) initiative. Funding is approved for up to \$125,000 with a required minimum of 25% non-federal

matching funds (\$41,667), for Year 2 (of 3) from January 1, 2018 to December 31, 2018. Ms. LaParr seconded the motion. The motion was approved by unanimous vote.

Ms. Eaker asked if there was any further discussion. Mr. Gettinger asked, is it clear that we are thinking about the impact, and what do we want to be left with? Ms. Smith mentioned trying to integrate the model into the 1115 Waiver. Ms. Lewis said they will see what works and what doesn't work. Ms. Smith said there will be a lot of people who need some guidance. Dr. Gettinger clarified that he was asking about the shape of how we will influence things, and can we see it operating on a large scale? Ms. Dupuch said the elephant in the room is the scale: other funding is necessary to support this.

Supported Living: Making the Difference

Mr. Smathers shared success stories of a daughter moving into a home, two people from group homes now married and living together, and a person with autism living in a home the family set up. He mentioned that not all people see the flexibility benefit, and they need to find a way to maximize the cost of service. He noted that the J. Iverson Riddle Developmental Center presentation was well received. He said the first Learning Community webinar will occur on September 15th, and Kelly Friedlander will facilitate the Learning Community. He said Year Two will focus on developing some videos to share and noted that Vaya Health is committed to this model of service.

Ms. McArthur said part of the model is spreading the word and asked if there are best practices to share with other agencies? Mr. Smathers said the focus is on the outcomes, and he mentioned POM: Personal Outcome Measures. In response to a question about whether there is there a theme or a trend preventing individuals with I/DD from transitioning, Mr. Smathers said parents are concerned for safety; however, the biggest barrier is not just with parents but with care coordinators. Ms. Lewis said Vaya is bringing this information statewide to all of the LME/MCOs.

Ms. Eaker brought up one question/comment: we're excited to see how many people have transitioned. Mr. Smathers said supported living in North Carolina is not brand new – it's the reintroduction of an older concept.

The guests left for the motion.

MOTION: Mr. Hildreth made a motion for continuation funding to Vaya Health for the Supported Living: Making the Difference initiative. Funding is approved for up to \$100,000 (\$25,000 DD Funds, \$75,000 MFP/DMA Funds), with a required minimum of 25% non-federal matching funds (\$33,334), for Year 2 (of 3) from January 1, 2018 to December 31, 2018. Ms. Boeck seconded the motion. The motion was approved by unanimous vote.

Ms. Eaker asked if there was any discussion. Ms. Lewis commented on how much work it takes to place the 18 individuals for this initiative.

Wrap Up and Reminders

Ms. Eaker mentioned that the members will receive an update about the easy to read version of the NCCDD by-laws, and Mr. Woodward asked the members to look at and submit any feedback on the Impact Sheet.

Mr. Hildreth asked if we can use a name stamp to sign the conflict of interest form? Ms. Eaker and Mr. Woodward said yes, that is fine.

Ms. Dupuch motioned to adjourn. The meeting was adjourned by 5:10.



NC Council on Developmental Disabilities Case/Care Management in a Managed Care Environment

Request for Authority to Draft

GOAL 2: By 2021 Increase Community Living for Individuals with Intellectual and Other Developmental Disabilities (I/DD). Throughout their lifespan, more individuals will be fully included, respected, valued and supported in their communities.

OBJECTIVE B: Increase Health Access and Wellness Opportunities.

NCCDD 5 Year State Plan 2017-2021

Request for Authority to Draft
Anticipated Approval of Draft RFA
Anticipated Release of RFA
Anticipated Contractor Approval
Anticipated Start Date

November 3, 2017
February 9, 2018
February 14, 2018
May 11, 2018
October 1, 2018

Individuals with intellectual and other developmental disabilities (I/DD) and their families often need assistance in navigating the complex Medicaid system of long-term services and supports. In a traditional fee-for-service model, case managers typically assume the responsibilities of assisting individuals in gaining access to necessary care through assessment, person-centered planning, referral and linkages to community-based resources, monitoring, and follow-up. Case management, and "targeted" case management provided to specific populations such as those with I/DD, were designed to provide assistance with any services and supports needed to keep individuals at home and healthy.

As a result of the transition to the North Carolina Innovations Waiver, case management and targeted case management functions were replaced with Care Coordination and Community Guide services. Since the transition to managed care, there are still approximately 12,000 North Carolina citizens without an Innovations Waiver as identified on the registry of unmet needs who cannot access waiver services and may not be aware of supports that could be available to them while waiting for a waiver slot. Additionally, with nearly 200,000 individuals with I/DD living in this state, it is critical to have knowledgeable and experienced professionals to avoid directing individuals to the 'wrong' place in the service system, delaying necessary support to individuals and their families which will also impact the financial performance of the Medicaid program in North Carolina. Since the change from a fee-for-service system to a managed care model, provider roles and service definitions have created confusion for individuals and families. With over 40 definitions of care coordination services within the national system, providers themselves are often unclear of their specific mandate for service provision. In its final report to NCCDD on the work with the Adult Care Home Transitions initiative, Disability Rights North Carolina identified some of the issues facing individuals not receiving services such as the lack of access to a case manager as barriers to a successful transition to the community and made recommendations that promoted a targeted case management service.

To better understand how the current system is working for individuals with I/DD, NCCDD is implementing a survey for individuals with I/DD and family members to inform the Council on what works for them, what does not, and what the ideal system of services would look like. With the knowledge that there will not be enough public resources available to provide the number of waiver slots to eliminate the registry of unmet needs, NCCDD seeks to develop a Request for Applications (RFA) that will:

1. Fund an expert from a nationally accredited organization with scholarly research experience to examine North Carolina's current I/DD services system and provide recommendations for the North Carolina Department of Health and Human Services (DHHS). This direction would be similar to a past initiative such as the Reaching the Summit of Success initiative where the Institute for Community Inclusion at the University of Massachusetts Boston surveyed North Carolina's educational and employment landscape for people with I/DD and shared the findings in a final report titled *Creating Productive Futures for Youth and Adults with Intellectual and Developmental Disabilities* in September of 2015.
2. Produce recommendations for improved coordination and collaboration between care coordinators (Local Management Entities/Managed Care Organizations – LME/MCOs) and community guides (Providers).
3. Identify areas where targeted case management, care coordination, and community guides are used across the service system and make recommendations where these services can be utilized for individuals still on the waiting list.
4. Identify gaps in training and utilization of the services and make recommendations for closing those gaps to equip individuals and their families with the knowledge and resources needed to meet their unique needs.
5. Assess the possibility of using a targeted case management service within a managed care environment.

The successful applicant must collaborate with the key agencies within the NC Department of Health and Human Services (e.g., the Division of Mental Health, Developmental Disabilities and Substance Abuse Services; the Division of Medical Assistance), LME/MCO representatives, AND with individuals with I/DD and their families to gather relevant historical background information about the present system of services and supports, and data.

This initiative will provide a comprehensive final written report with detailed recommendations and the feasibility of further enhancements to meet the unique support needs of individuals with I/DD and their families. This initiative will be funded at \$125,000 per year for up to two years with a required match of \$41,667.

Advocacy Development Committees



NCCDD
North Carolina Council on
Developmental Disabilities



North Carolina Council on Developmental Disabilities

Advocacy Development Committee Agenda

November 2, 2017

3:00 p.m. – 5:00 p.m.

Hilton Garden Inn Cary, NC

3:00 p.m. – 3:10 p.m.	Introductions	<i>Nessie Siler, Chair</i>
	<ul style="list-style-type: none"> Welcome/Guide to Productive Meeting Approval of August Minutes 	
3:10 p.m. – 4:20 p.m.	Initiative Updates	<i>Nessie Siler</i>
	<ul style="list-style-type: none"> Inclusive Advocacy Leadership Development (IALD): Planning Year 	
3:20 p.m. – 3:40 p.m.	<ul style="list-style-type: none"> NC Empowerment Network 	<i>NCEN Members</i>
3:40 p.m. – 4:00 p.m.	<ul style="list-style-type: none"> Request to Draft RFA: Leadership Development Training 	<i>Chris Egan, E.D. IALD Co-Coordinators Brandon Matthews Lauren Borchert NCCDD Staff</i>
4:00 p.m. - 4:20 p.m.	<ul style="list-style-type: none"> Request to Draft RFA: ADA Network Fiscal Intermediary 	
4:20 p.m. – 4:35 p.m.	Future Investments Update	<i>Melissa Swartz, Staff</i>
	<ul style="list-style-type: none"> Outreach to Hispanic/Latino Communities <ul style="list-style-type: none"> RFA Responses NCCDD Language Access Plan Workgroup Accessible Recreation-May Discussion 	
4:35 p.m. – 4:50 p.m.	Fiscal Update	<i>Yadira Vasquez, Staff</i>
4:50 p.m. – 5:00 p.m.	Wrap Up and Reminders	<i>Nessie Siler Committee Members</i>
	<ul style="list-style-type: none"> Completion of Financial Forms Reminder February 8-9, 2018 Council meeting in Cary at Hilton Garden Inn 	

ADVOCACY DEVELOPMENT COMMITTEE

Nessie Siler, Chair

Eric Chavis

NaKima Clark

Mary Edwards; Alternate: Joseph Breen

Jason Faircloth

Katie Holler

Representative Verla Insko

Kelly Kimple, M.D.; Alternate: Danielle Matula

Joe Piven, M.D.; Alternate: Deborah Zuver

Cheryl Powell

Daniel Smith

Vacant

Vacant

Individual with DD

Individual with DD

Parent of Child with DD

Agency: Aging & Adult Services

Individual with DD

Parent of Child with DD

Legislative Representative

Agency: W/C Health

Agency: Carolina Institute on DD

Individual with DD

Parent of Child with DD

Parent of a Child with DD

Dept. of Public Safety

Staff: Melissa Swartz

Advocacy Development Committee
DRAFT MINUTES
Thursday, August 10, 2017 3:00 P.M. - 5:00 P.M.
Hilton Garden Inn, Cary, NC

Members Present: Alexandra McArthur, Joseph Breen, Eric Chavis, Katie Holler, Kelly Kimple, Cheryl Powell, Nessie Siler, Daniel Smith, Deborah Zuver

Members Absent: NaKima Clark, Jason Faircloth, Rep. Verla Insko, Clare Shocket

Staff in Attendance: Melissa Swartz, Yadira Vasquez

Guests: Renate Macchirole, Brandon Matthews

Welcome and Introductions:

Committee Chairperson Nessie Siler called the meeting to order, and welcomed all members, including new members, and guests.

Approval of Minutes:

Katie Holler made a motion to approve the May, 2017 Advocacy Development Committee minutes. Cheryl Powell seconded the motion. The motion was approved.

Initiative Update Inclusive Advocacy Leadership Development Initiative (IALD):

Brandon Matthews, co-coordinator and Melissa Swartz, staff provided a detailed update of the NCCDD In-House Inclusive Advocacy Leadership Development Initiative (IALD). The two primary activities of the IALD are developing a NC Self-Advocate Collaborative, now identified as the NC Empowerment Network (NCEN) and an Inclusive Leadership Curriculum, now identified as the Inclusive Leadership Development Training.

Brandon provided a NC Empowerment Network (NCEN) status update including transfer of responsibilities of the Association of Self-Advocates of NC (ASANC) 501c3 to NCEN, and NCEN subcommittee activities. The next meeting of the NCEN is October 6 and the primary business is re-engaging the PATH strategic planning process with facilitator Cate Weir, and graphic artist Tanya Richmond.

Brandon and Melissa provided the leadership development training exploration activity update. NC Partners in Policymaking and NC Advancing Strong Leadership graduates, participants, mentors, and program staff make up a core steering committee. The steering committee continued working on identifying a strategic exploration approach, drafting information gathering tools, and determining the platform for information gathering.

Information gathering tentatively scheduled for July and August was delayed for further development on the information gathering tools and reconsideration of the information gathering platform. The next meeting of the steering committee is tentatively scheduled for September.

Future Investments Discussion

IALD

Advocacy Development Committee members were reminded that their May future investments discussion involved the "No Cost Extension" for the Inclusive Advocacy Leadership Development Initiative and address of the Council's Targeted Disparity Objective involving outreach to the Hispanic/Latino disability community.

Outreach: Hispanic/Latino Developmental Disability Community

Melissa provided background information and a status update on address of the Council's 5-Year State Plan targeted disparity objective. Two of three RFA drafts in review by the Council include verbiage for outreach and inclusion of the Hispanic/Latino disability community. Also, the 5-Year State Plan Ad Hoc Committee (5YSP AHC) accepted the charge to facilitate the development of a NCCDD Language Access Plan (LAP). The LAP may include internal operations processes and coordinating information gathering opportunities to address the targeted disparity state plan goal objective, as well as the federally mandated targeted disparity requirement. Details of the proposed features and development approach and timeline of the Language Access Plan shared with the Advocacy Development Committee will be provided by Sandra Terrell, 5YSP AHC co-chair during the Council's New Business/Ad Hoc Committees report on August 11.

Fiscal Report

Yadira Vasquez, NCCDD Business Officer provided an overview of the Advocacy Development Committee initiative budgets.

Adjournment:

Motion to adjourn was made by Eric Chavis. The motion was seconded by Cheryl Powell. The motion was approved.



North Carolina Council on Developmental Disabilities

Inclusive Advocacy Leadership Development

Frequently Asked Questions – FAQs updated 8/28/17

General Information: Following federal approval of The North Carolina Council on Developmental Disabilities (NCCDD) new Five-Year Plan, the NCCDD is focusing attention on two leadership initiatives, including:

1. **Advocacy Organizing:** Supporting self-advocacy in NC.
2. **Leadership Development Training:** Structured leadership development education for self-advocates, parents, professionals and other stakeholders.

A Collaborative Effort: The NCCDD is currently gathering and is involved in planning regarding Advocacy Organizing and Leadership Development Training in partnership with other collaborators and stakeholders. These stakeholders include:

- NC Developmental Disabilities Network which includes the NCCDD, Disability Rights, NC and the Carolina Institute for Developmental Disabilities along with staff and board members of each of these organizations.
- Steering committees also include individuals with intellectual and other developmental disabilities, family members and professionals with historical involvement in leadership efforts of the Council and others interested to contribute.
- Previous graduates and staff of two specific leadership development initiatives that have been supported and funded by the NCCDD - Partners in Policymaking and Advancing Strong Leadership.

This current planning initiative is supported by co-coordinators who facilitate and support the work of the steering committees involved in each of the two major elements of this initiative, as well as the administrative and operational responsibilities. *The co-coordinators do not direct the efforts of the steering committees, but support these efforts.*

Frequently Asked Questions (FAQs)

These FAQs are organized in three parts. This first section will answer general questions about the NCCDD. Section two will address questions regarding the Advocacy Organizing. The third section will address Leadership Training and Delivery.

Q is the Question

A is the Answer



General FAQs

Q: What organizations are part of the NC Developmental Disabilities Network?

A: The NC DD Network includes the NC Council on Developmental Disabilities (NCCDD), Disability Rights NC, and the Carolina Institute for Developmental Disabilities.

Q: Which NCCDD committee is the lead committee for the leadership development efforts?

A: The NCCDD has three standing committees that align with the three major goal areas of the federally approved Five-Year Plan <http://nccdd.org/the-council/five-year-plan.html> including a Financial Asset Development Committee, Community Living Committee and Advocacy Development Committee. These leadership development efforts are occurring within the Advocacy Development Committee.

Q: What is a planning initiative?

A: A planning initiative focuses on a specific systems change need, includes exploration of the issue, and brings together stakeholders to explore strategies and develop recommendations for consideration by the NCCDD.

Q: What is occurring during the planning year for these leadership initiatives?

A: Planning efforts are occurring in two specific areas:

- **Advocacy Organizing:** This systems change effort is bringing together self-advocate leaders of the NC DD Network boards, and other self-advocates and stakeholders to identify the pathway to strengthening organized self-advocacy efforts in NC.
- **Leadership Development Training:** This systems change effort is focused on future leadership development training options for individuals with I/DD, family members and professionals. Helping inform this effort are Partners in Policymaking and Advancing Strong Leadership graduates (and others). The NCCDD is exploring collaborative partnerships, sustainability and growth of leadership development training efforts.

The NCCDD approved in-house funding for a 1-year planning initiative until 12/31/17.

FAQ for ADVOCACY ORGANIZING

Q: Why did the NCCDD decide to fund the exploration of self-advocacy organizing in NC?

A: The NCCDD Five-Year Plan emphasizes the importance self-advocacy in NC. It is critical for self-advocates in NC to actively engaged in policy decisions occurring in the long-term services and supports systems and in local communities. A recognized state-wide organization will support local self-advocacy efforts and will serve as a connecting organization to increase the impact of self-advocacy in NC.

Q: What do you anticipate the long-term vision and goal are for a state-wide self-advocacy organization?

A: The long-term vision and goals of a state-wide self-advocacy organization are to strengthen the self-advocacy movement across the state of North Carolina. Self-advocates are active across NC but there



is not a state-wide coordinating organization. This initiative builds on the findings and recommendations of the NCCDD's Advocacy Ambassador report with two primary goals to (1) reestablish a recognized state-wide self-advocacy organization, and (2) expand the active efforts of self-advocates to represent the perspective of individuals with I/DD and families at local, state and national levels.

Q: How were the self-advocate leaders of the initial steering committee chosen?

A: The self-advocate leaders represent the organizations making up the NC DD Network. The DD Network is made up of three agencies: NCCDD, Disability Rights NC and the Carolina Institute for Developmental Disabilities. The steering committee also includes other interested self-advocates.

Q: How will the experiences of existing self-advocacy groups and leaders across NC be recognized?

A: The history of self-advocacy in North Carolina will inform the future. All who are currently participating in this initiative know that past leaders and currently active self-advocacy groups must be involved as engaged and committed partners.

Q: What is the role of the NCCDD funded coordinators in the self-advocacy organizing efforts?

A: The coordinators provide organizing and logistical support. Duties include meeting facilitation; logistical arrangements (e.g., scheduling, meeting location, space, participant support, etc.); and development, distribution, and updating of materials, including notes from stakeholder input, and steering committee sessions.

FAQ for LEADERSHIP TRAINING DEVELOPMENT

Q: Why is the NCCDD assessing and exploring options for leadership development?

A: For many years, the NCCDD has supported values-based leadership development and training through funding and support for two approaches:

Partners in Policymaking: Leadership development training for individuals with I/DD and family members.

Advancing Strong Leadership: Leadership development for professionals in the I/DD field.

The NCCDD is now considering several questions, including:

1. Is there value in the possibility of a combined (integrated) approach to leadership development? Or, could portions of these leadership development activities be combined?
2. Can technology be used to augment the training?
3. Will other partners share in the coordination and perhaps help support the cost of these efforts?
4. Can the leadership training efforts occur in areas of the state (not just in Raleigh)?
5. Can NC develop trainers to increase capacity for local training, growth and sustainability?
6. How can outcomes be tracked following graduation of participants?



Q: Will NC Partners in Policymaking and Advancing Strong Leadership graduates and mentors be involved?

A: Yes! In fact, graduates and participants of these leadership development efforts are among the most important resources in the exploration of leadership development training efforts.

- Graduates, mentors, participants, and program coordinators of these leadership efforts make up the steering committees who design the planning process and information gathering tools.
- Steering committee members will help strategize the best way to keep future participants and graduates of leadership development and training events connected, engaged, in position to respond to calls to action by the NC DD Network, and to share updates about personal activities using the leadership and advocacy training they received.

Q: Will existing leadership training programs be taken into consideration when developing a new one?

A: Yes! In fact, the reason graduates, mentors, participants, and program coordinators/staff make up the steering committee is to ensure that exploration and planning considers the primary outcomes desired for self-advocates, parents, stakeholders and both emerging and more seasoned professionals seeking to develop their knowledge and leadership skills.

Q: What happens if exploration finds the two separate training programs can or cannot be combined?

A: The NCCDD is committed to leadership development for self-advocates, family members, professionals and other stakeholders. Depending on this exploration process, it is possible that we will find that:

- a) Leadership development for individual and family members with professionals could be fully integrated; or,
- b) Recommendations may support a partially combined effort with a set of common objectives and outcomes along with unique objectives for individuals with I/DD and family members versus professionals.
- c) Recommendations could lead to maintaining separate leadership development training activities for individuals with I/DD and family members rather than having any overlap in the leadership development efforts with professionals.

Ultimately, this investment must achieve the desired outcomes for each participant.

Q: What is the role of the coordinators in the leadership training curriculum activity?

A: The coordinators are facilitators and provide information management support. Coordinator duties include meeting facilitation; logistical arrangements; and development, distribution, and maintenance of initiative materials including notes from stakeholder input, and steering committee sessions. The coordinators will contact graduates, mentors, participants, and program coordinators to help organize and participate in statewide focus groups to inform curriculum exploration and development.



NC Council on Developmental Disabilities North Carolina Empowerment Network Update

GOAL 3: By 2021, Increase Advocacy for Individuals with Intellectual and Other Developmental Disabilities (I/DD). More individuals with I/DD will lead and sustain self-directed lives through self-advocacy, family advocacy and stakeholder leadership.

OBJECTIVE A: As mandated by the DD Act, increase support to a statewide self-advocacy organization(s) through leadership development and coalition participation by: (I) establishing or strengthening a program for the direct funding of a state self-advocacy organization(s) led by individuals with I/DD; (II) supporting opportunities for individuals with I/DD who are considered leaders to provide leadership training to individuals with I/DD who may become leaders and; (III) participation in cross-disability and culturally diverse leadership coalitions.

Goal/Objective Measurement: More individuals with I/DD will knowledgeably advocate and take part in decisions that affect their lives, the lives of others and/or systems.

NCCDD 5 Year State Plan 2017-2021

Planning Year Approval	August 12, 2016
Planning Year Started	October 1, 2016
Planning Year Ends	December 31, 2017
Request for Sole Source Funding	February 3, 2017
Anticipated Start Date	March 1, 2018
Anticipated End Date	December 31, 2018



**NORTH CAROLINA
EMPOWERMENT
NETWORK**

Advocating for inclusive and equal lives for North Carolinians with intellectual and developmental disabilities throughout the state.

BACKGROUND. The NCCDD Inclusive Advocacy Leadership Development Initiative Activity I: Advocacy Organizing. The NCCDD, DRNC, and the CIDD maintained shared commitment and balanced support of twelve (12) self-advocate members of the NC DD Network boards engaging two "Planning Alternative Tomorrows with Hope" (PATH) strategic planning processes for the advancement of self-advocacy organizing in NC. The NC Empowerment Network is the chosen moniker of the self-advocate members.

The long-term vision and goals of the state-wide self-advocacy organization is to strengthen the self-advocacy movement across the state of North Carolina. Self-advocates are active across NC but there is not a state-wide coordinating organization. This initiative builds on the findings and recommendations of the NCCDD's Advocacy Ambassador report with two primary goals to (1) reestablish a recognized state-wide self-advocacy organization, and (2) expand the active efforts of self-advocates to represent the perspective of individuals with I/DD and families at local, state and national levels.

ACCOMPLISHMENTS. The NCEN Developed and implemented a strategic plan using the PATH process. Plan accomplishments to date include:

- Identified a Mission, Vision, and Branding Name
- Initiated development of membership core values
- Initiated steps to become and plan to maintain a 501(c)
- Expanding membership beyond NCCDD, CIDD, and DRNC board members

NEXT STEPS. On October 6, 2017, the NCEN engaged an advanced PATH strategic planning process, again facilitated by Cate Weir w/ graphic artist Tanya Richmond. This advanced facilitation was used to identify activities to sustain the organization's activities after planning year investments ends. Tentatively, future investment items *may* include:

- Marketing and recruitment travel for members for
- Growing the membership
- Website restructuring
- Technical Assistance and Development consultation to support a non-profit organization
- Presenting an investment proposal to the NCCDD in February 2018



NC Council on Developmental Disabilities
NC ADA Network – Fiscal Agent/Intermediary
Request for Authority to Draft

GOAL 3: By 2021, Increase Advocacy for Individuals with Intellectual and Other Developmental Disabilities (I/DD). More individuals with I/DD will lead and sustain self-directed lives through self-advocacy, family advocacy and stakeholder leadership.

OBJECTIVE B: Increase individual, family, public and system knowledge and engagement to provide system advocacy for the financial security and community living opportunities of individuals with I/DD; with additional specific emphasis to increase the knowledge and engagement of members of the NC Hispanic/Latino community.

NCCDD 5 Year State Plan 2017-2021

Request for Authority to Draft	November 3, 2017
Anticipated Approval of Draft RFA	February 9, 2018
Anticipated Release of RFA	February 14, 2018
Anticipated Contractor Approval	May 1, 2018
Anticipated Start Date	July 1, 2018

The NC ADA Network is an in-house project of the NC Council on Developmental Disabilities. The NC ADA Network works in partnership with a statewide network of grassroots groups, led by people with disabilities. These vital groups conduct projects and activities aimed at raising awareness of and increasing compliance with the Americans with Disabilities Act (ADA) in local communities across North Carolina.

A non-profit fiscal agent/intermediary is needed to distribute funds (cash advances, small ADA project reimbursements, and travel reimbursements) to people with disabilities and grassroots groups led by people with disabilities involved in the NC ADA Network initiative. Most of these individuals and small grassroots groups (including self-advocacy groups) do not have the funds or capacity to apply for funds to conduct ADA projects and activities in any other way.

The NC ADA Network – Fiscal Agent/Intermediary shall enable people with disabilities and small grassroots groups to access the funds they need to conduct and participate in advocacy activities that promote the Americans with Disabilities Act as follows:

- Provides cash advances for groups and individuals with disabilities with limited funds for travel and other ADA activities.

- Distributes funding for small ADA projects conducted by grassroots groups led by people with disabilities (\$250-\$1000). Many of these groups would otherwise not have the capacity to apply for NCCDD or other grant funds.
- Enables small grassroots groups to apply for funds and successfully conduct projects in their local communities that increase compliance with the Americans with Disabilities Act.
- Enables individuals with disabilities to serve on boards, committees, and task forces by providing funds for travel and accommodations such as aides, interpreters, alternate format, etc.
- Enables people with disabilities to participate in ADA trainings and events by providing funds for travel and training costs.
- Provides quick reimbursement for groups and individuals that have limited budgets (less than 15 business days).
- Provides technical assistance, as needed, to assist individuals with disabilities to complete forms and reports.

Having a fiscal agent/intermediary made many of these projects possible during 2016-2017:

- **ADA Publications:** Distributed more than 938 ADA publications to at least 540 individuals.
- **ADA Technical Assistance:** Provided ADA technical assistance to 429 individuals, including people with disabilities, family members, and businesses.
- **ADA Training:** Hosted or conducted 37 ADA trainings serving 570 individuals. 23 individuals completed an ADA Train-the-Trainer workshop in Burlington in May 2017 and conducted ADA trainings across North Carolina during the summer. Eleven NC ADA Network participants and other partners attended the National ADA Symposium in Chicago in May 2017.
- **Public Awareness Activities:** Conducted five ADA public awareness activities, including short ADA presentations, media events, and collaboration with other organizations on ADA-related special events.
- **Collaborative Efforts:** NC ADA Network members participated collaboratively in activities/events hosted by two Council initiative and four community organizations, including participating in emergency exercises, serving on committees/taskforces, attending trainings, and conducting research.
- **Examples of specific activities include:**
 - Disability Awareness Council – Chapel Hill Library hosted ADA training & resource fair for individuals with disabilities on 7/29/16 during ADA Anniversary Event. 21 people were in attendance (13 people with disabilities, 3 family members, and 5 others) receiving information on the following topic: "ADA Basics – 1 hour."
 - NC ADA Network delivered training to restaurant, lodging & tourism staff on 5/12/17 during Beech Mountain Visitors Bureau workshop. Seventeen people received information on the following topic: "ADA Title III including service animals."



NC Council on Developmental Disabilities

Outreach: Hispanic/Latino Communities Future Investment Discussion

GOAL 3: By 2021 increase advocacy for individuals with intellectual and other developmental disabilities (I/DD). More individuals with I/DD will lead and sustain self-directed lives through self-advocacy, family advocacy and stakeholder leadership.

OBJECTIVE B: Increase individual, family, public, and system knowledge and engagement to provide system advocacy for the financial security and community living opportunities of individuals with I/DD; with additional specific emphasis to increase the knowledge and engagement of members of the Hispanic/Latino community.

TARGETED DISPARITY STATEMENT: In collaboration with individuals with intellectual and other developmental disabilities (I/DD), their families and other stakeholders, the NCCDD will increase engagement and involvement of Hispanic/Latino individuals and families. The NCCDD will (minimally) focus on initiatives involving demographic areas in the state where larger numbers of individuals of Hispanic/Latino ethnicity live, including Mecklenburg, Wake, and Forsyth Counties. NCCDD initiatives in these areas will be expected to focus on accessibility of information and will recruit and include Hispanic/Latino collaborators and others concerned with inclusion and sustained participation of NC Hispanic/Latino (Spanish speaking) citizens with I/DD.

NCCDD 5 Year State Plan 2017-2021

Anticipated Start Date (Active initiatives/internal processes) October 1, 2017

Anticipated Start Date (New initiatives) January 1, 2018

Goal 3, Objective B is unique in that it specifies stakeholder knowledge and engagement in the other Council's goal areas. Also, this objective is unique because it addresses an Administration on Community Living (ACL) mandate related to targeted disparity. All councils on developmental disabilities' 2017 – 2021 five-year state plans must identify disparity among a subpopulation of the state's I/DD community and address that disparity. The NCCDD identified a barrier to services and supports for the Hispanic/Latino community caused by language access issues. Outreach to and collaboration with the Hispanic/Latino community to increase engagement and involvement is the Council's proposed intent.

This objective is partially addressed in the May 2017 Goal 1 RFA requests to draft for *"Access to Assets" Digital Lookbook*, and the *I/DD Employment Resource Guide*. These draft RFAs include a component for outreach and inclusion of the Hispanic/Latino community.

In addition to inclusion in RFA's addressing state plan objectives in Goal 1 and Goal 2, staff identified several opportunities to increase engagement and involvement of the Hispanic/Latino I/DD community through internal operations processes and inclusion of targeted disparity in all appropriate initiative (in-house and external) workplans.

Recommended internal operations processes (including but not limited to):

- Update RFA Processes:
 - Notice of Funding (NOFA) deliverables section will include standardized verbiage for outreach/inclusion of the Hispanic/Latino IDD community, including the workplan section of the DD Suite application.
 - RFA selection committee member position dedicated for Hispanic/Latino stakeholder, partner, topic expert.
- The next continuation funding processes for active initiatives will include a Hispanic/Latino I/DD community outreach/inclusion strategy in the workplan of DD Suite application.
- Develop and maintain a Hispanic/Latino resources list.
- Internal telephonic interpretative services*.

*Research efforts for Goal 3, Objective B revealed that Spanish interpretation and translation costs varied but are consistently expensive. Addressing this objective and the targeted disparity mandate require funding discussions. For example, initiative contract budgets must include a line item for outreach/inclusion of the Hispanic/Latino I/DD community, as will the NCCDD administrative budget for translator and written translation services.

To address the above recommendations and consider additional strategies, staff propose the development of an NCCDD Language Access Plan (LAP) for people with low/limited English proficiency. The plan could be drafted by staff, Council members, and stakeholders with oversight by the 5-Year State Plan Ad Hoc Committee (5YSP AHC), or a workgroup of the ad hoc committee. Plan areas for consideration related to funding might include eliciting ideas/input from the NC Hispanic disability community via listening sessions, time-limited think tank, or a learning community.

5 Year State Plan

FFY 2016-2021

Year I: Oct. 1, 2016 thru Sept. 30, 2017



Listen. Gather. Act.





2017 – 2021 Five Year State Plan Goals and Objectives

The NCCDD will advance the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) expectations of self-determination, independence, productivity, integration and inclusion in community life for individuals with intellectual and other developmental disabilities (I/DD) and their families.

GOAL 1: By 2021, INCREASE FINANCIAL SECURITY THROUGH ASSET DEVELOPMENT FOR INDIVIDUALS WITH INTELLECTUAL AND OTHER DEVELOPMENTAL DISABILITIES (I/DD)

Increase financial asset development for individuals with I/DD so that they and their families have greater opportunities for choice, self-determination, independence and productivity.

OBJECTIVE A: Increase financial asset development and security by increasing knowledge, developing financial plans and implementing the plan's goals

Measurement: More individuals with I/DD will have a financial plan, leading to greater security.

OBJECTIVE B: Increase integrated competitive employment and careers

Measurement: More individuals with I/DD will have integrated, competitive employment and careers through collaboration which will include education, workforce development, employment supports, employer engagement and barrier reduction.

OBJECTIVE C: Increase educational expectations for employment and careers

Measurement: More individuals with I/DD will have educational expectations and education regarding employment and career goals, as will their families and other stakeholders through increased knowledge and meaningful collaborations.



2017 – 2021 Five Year State Plan Goals and Objectives

GOAL 2: By 2021, INCREASE COMMUNITY LIVING FOR INDIVIDUALS WITH INTELLECTUAL AND OTHER DEVELOPMENTAL DISABILITIES (I/DD)

Throughout their lifespan, more individuals with I/DD will be fully included, respected, valued and supported in their communities.

OBJECTIVE A: Increase community housing and transportation

Measurement: More individuals with I/DD will choose where and with whom to live in their community and will have transportation options to support community living and employment.

OBJECTIVE B: Increase health access and wellness opportunities

Measurement: More individuals with I/DD will have access to, and continuity of healthcare and wellness opportunities through individual and family education and provider capacity building.

OBJECTIVE C: Increase healthy community relationships

Measurement: More individuals with I/DD will have healthy relationships and positive community connections that will support personal choice and decision making.



2017 – 2021 Five Year State Plan Goals and Objectives

GOAL 3: By 2021 INCREASE ADVOCACY FOR INDIVIDUALS WITH INTELLECTUAL AND OTHER DEVELOPMENTAL DISABILITIES (I/DD)

More individuals with I/DD will lead and sustain self-directed lives through self-advocacy, family advocacy and stakeholder leadership.

OBJECTIVE A: As mandated by the DD Act, increase support to a statewide self-advocacy organization(s) through leadership development and coalition participation by:

(I) establishing or strengthening a program for the direct funding of a state self-advocacy organization(s) led by individuals with I/DD,

(II) supporting opportunities for individuals with I/DD who are considered leaders to provide leadership training to individuals with I/DD who may become leaders and,

(III) participation in cross-disability and culturally diverse leadership coalitions.

Measurement: More individuals with I/DD will knowledgeably advocate and take part in decisions that affect their lives, the lives of others and/or systems.

OBJECTIVE B: Increase individual, family, public and system knowledge and engagement to provide system advocacy for the financial security and community living opportunities of individuals with I/DD; with additional specific emphasis to increase the knowledge and engagement of members of the NC Hispanic/Latino community

Measurement: More individuals with I/DD and their families will knowledgeably advocate and take part in decisions that affect their lives, the lives of others and/or systems; with additional specific emphasis to produce accessible communication so more Hispanic/Latino individuals with I/DD will lead and sustain self-directed lives through self-advocacy, family advocacy and stakeholder leadership.

OBJECTIVE C: Increase professional development to improve expectations and supports for individuals with I/DD

Measurement: More I/DD professionals, other professionals and community leaders will receive leadership development to support collective impact to advance the financial security and community living opportunities of individuals with I/DD.

1. The first part of the document discusses the importance of maintaining accurate records of all transactions.

2. It is essential to ensure that all entries are supported by appropriate documentation and receipts.

3. Regular audits should be conducted to verify the accuracy of the records and to identify any discrepancies.

4. The second part of the document outlines the procedures for handling disputes and resolving conflicts.

5. It is important to establish clear communication channels and to address any issues promptly and fairly.

6. The third part of the document provides information on the various services and products offered by the organization.

7. These services are designed to meet the needs of our customers and to provide them with the highest quality of service.

8. We are committed to continuous improvement and to providing our customers with the best possible experience.

Committee or Venue	State Plan ID	Activity Description
MEMBER DEVELOPMENT SESSION		
	All Goals	Opioid Addiction-Public Health Presentation
	All Goals	Collective Impact Evaluation Presentation
	2C	Emergency Preparedness Initiative Final Report
	3B	Sibling Support Initiative Final Report
	All Goals	Advocacy & Leadership Awards Reception
POLICY UPDATE		
	All Goals	Public Policy Update
MEMBER DEVELOPMENT SESSION		
		Committee Draft RFA Discussions
	1A	I/DD Employment Resource Portal
	2B	Community Navigator and Targeted Case Management in a Managed Care Environment
	2A	Shared Living
	2A	RFA Re-Post: I Get Around-Improving Transportation Options
	3B	ADA Network/Fiscal Intermediary
	3A	NC Empowerment Network Update
	3A	Leadership Development Training Initiative
ADVOCACY DEVELOPMENT		
	3A	Initiative Update: Inclusive Advocacy Leadership Development (IALD) Planning Year
	3A	NC Empowerment Network
	3A	Request to Draft: Leadership Development Training Initiative
	3A	Request to Draft RFA: ADA Network Fiscal Intermediary
	3B/ Targeted Disparity St. PL Section	Outreach to Hispanic/Latino Community via accessible communications. Language Access Plan
	n/a	Accessible Recreation-May Discussion

COMMUNITY LIVING

- 2C Funding Recommendations: Using Natural Supports to Build Greater Community Engagement
- 2A RFA Re-Post: I Get Around-Improving Transportation Options

Future Investments Discussion

- 2A Shared Living
- 2B Case Management in a Managed Care Environment
- 2C Rethinking Guardianship: Building a Case for Less Restrictive Alternatives
- 2B Update: From Planning to Action: Integrated, Collaborative Care for People with Intellectual and Developmental Disabilities initiative

FINANCIAL ASSET DEVELOPMENT

- 1B Funding Recommendations: Innovative Employment: Making Inroads to Long-Term Success through Apprenticeships
- 1A Update: Upward to Financial Stability/NDI Expansion Activities
- 1B Update: Expansion of Employment Opportunities for People with I/DD Initiative
- 1B/1C NCDVR Employment Campaign
- 1A Employment Collaborative and Website

FULL COUNCIL MEETING

New Business

- All Goals** 2015 NCCDD Ad Hoc Committee Updates:
 - Five Year State Plan
 - Member Recruitment
 - Communications and Member Development
- All Goals** NC DD Network Partners' Updates
 - Disability Rights North Carolina
 - Carolina Institute for Developmental Disabilities

Ad HOC Committees



NCCDD

North Carolina Council on
Developmental Disabilities



NC COUNCIL ON DEVELOPMENTAL DISABILITIES

Communications and Membership Development Ad Hoc Committee Meeting

August 24, 2017

Members Present: Amanda Bergen, Anna Cunningham, Mary Edwards, Clare Shocket

Staff Present: Chris Egan, Melissa Swartz, JoAnn Toomey, Travis Williams

Travis Williams opened the tele-conference meeting by welcoming the members. Travis reviewed a general agenda for the meeting which included a brief overview from Chris Egan on proposed changes to the Hefner and Riddle awards. Changes involved incorporating short video clips to highlight recipients during the awards ceremony. Chris also described the timelines necessary to produce videos for the upcoming awards scheduled for our November Council meeting. The call for nominations will be posted on the NCCDD website tomorrow (8/25/17) and the deadline to submit will be September 18th. Ad Hoc committee members will review the nominations, along with those submitted last year, at the next meeting on September 21st. Staff will send the members the nominations the morning of September 19th so they will have time to review them before their meeting. Everyone agreed that it will be a good idea to include videos if there is time and gave their approval for changes.

Under other agenda items, the following was discussed:

- Amanda Bergen was nominated by Clare Shocket to serve as vice chair for the ad hoc committee. Amanda accepted the nomination.
- Ideas presented to promote engagement at Council meetings and to promote participation of members included time reserved on Council agendas, specifically for ice breakers and networking activities.
- To encourage Council members attending conferences to share and highlight information gathered, the committee suggested developing a form for members to fill out to highlight their major take-aways from conference presentations and their thoughts on the potential implications for the I/DD community.
- Including O'Neill Communications to discuss videos of in-person reflections of members sharing what they learned after attending conferences (idea put forth was to post on NCCDD website, allowing other Council members and public to view them).

Travis Williams' assignments for the next meeting included:

- Develop a form template for Council members to use to document what they learned at conferences, their impressions, and possible implications for the Council or I/DD community.
- Collaborate with O'Neill Communications concerning reflection videos.

Other meeting dates are scheduled for 09/21/2017 and 10/12/2017- all times are set for 11am to 12pm.

Staff thanked those in attendance for their input. Meeting adjourned.

NC COUNCIL ON DEVELOPMENTAL DISABILITIES

Communications and Membership Development Ad Hoc Committee Meeting

September 21, 2017

Members Present: Amanda Bergen, Anna Cunningham, Mary Edwards

Staff Present: JoAnn Toomey, Travis Williams

Travis Williams opened the tele-conference meeting by welcoming the members. Travis reviewed a general agenda for the meeting which included discussion of the Hefner and Riddle award nominations. Co-Chairs Anna Cunningham and Amanda Bergen facilitated discussions. For the Riddle award Amanda Bergen made a motion that Mr. Tony Dalton receive the award for this year. Mary Edwards seconded the motion, there were no objections. Regarding the Hefner award, Anna Cunningham made a motion to nominate Sherry Paul as this year's recipient. Mary Edwards seconded the motion. There were no objections.

Under other agenda items, the following was discussed:

- Jo Ann Toomey gave an update on edits made to the conference feedback form per Chairperson Alex McArthur's request.

Travis Williams' assignments for the next meeting included:

- Continue to collaborate with O'Neill Communications concerning reflection videos.

Next meeting date scheduled for 10/12/2017- all times are set for 11am to 12pm.

Staff thanked those in attendance for their input. Meeting adjourned.

FYI



NCCDD

**North Carolina Council on
Developmental Disabilities**



FISCAL TERMS/DESCRIPTIONS

TERM	DESCRIPTION
FEDERAL FISCAL YEAR	This term is defined as the fiscal year for the federal government which begins on October 1 and ends on September 30.
FEDERAL AWARD	This term is defined as a financial grant for any federal program, project, service, or activity provided by the federal government that directly assists domestic governments, organizations, or individuals in the areas of education, health, public safety, public welfare, and public works, among others.
ENCUMBER PERIOD (2 Years)	This term is defined as a two year time period to budget and record expenses.
SPEND BY YEAR 3	This term is defined as all funds from a federal award that need to be spent by year 3 end date of the award.
APPROVED CONTRACT or ANTICIPATED BUDGET	These terms are defined as the contract amount approved to fund a program under a federal award. An anticipated budget is the best estimate of the funds needed to support the work described in a contract.
CURRENT EXPENSE	This term is defined as ongoing business expenses that are accounted for as they occur.
CURRENT UNEXPENDED BALANCE	This term is defined as the actual remaining balance of budgeted funds.
IDENTIFIED PENDING COUNCIL APPROVAL	This term is defined as the initiative dollar amounts that have been identified to propose to the Council for approval.
AVAILABLE FOR NEW INITIATIVES	This term is defined as funds available to seek new in-house initiatives or RFAs.
TOTAL PENDING & AVAILABLE BALANCE	This is the sum of the identified pending Council approval and the funds available for new initiatives.

BUDGET CATEGORIES/DESCRIPTION

CATEGORY	DESCRIPTION
SALARIES	Salaries only for staff hired by the applicant organization to work specifically on the initiative. This may include professional staff, interns, paraprofessionals, and/or part-time/hourly employees.
FRINGE BENEFITS	Fringe Benefits only for staff hired working on the initiative and may include FICA, Unemployment, Worker's Compensation, Health Insurance and/or Retirement Benefits.
SUPPLIES	Supplies may include consumable items that are essential to the program. Examples of allowable supplies include office supplies, computer supplies, medical supplies, furniture, directories and/or journals.
TRAVEL	Travel costs only for staff hired as identified in the budget that is deemed reasonable and necessary to conduct project activities. Examples of travel include staff mileage relating to program operations, lodging, air fare, conference registration fees and meals.
RENT/COST OF SPACE	The Rent/Cost of Space may include rent or lease of office space, equipment, furniture, vehicles, and meeting or conference space cost to be used specifically for the program.
EQUIPMENT	Equipment should possess both of the following characteristics: it is not consumable or expendable and has an expected useful life of longer than one year. Examples of allowable equipment include communication, computers, laptops, iPads, printers, office, assistive technology, medical, vehicles, scientific, and others.
SUB-CONTRACT	Sub-Contract may include essential services which cannot be met by other program staff which specifically relate to the work of the program. Examples of Sub-Contract may include consultants/contractors, photocopy services, consultants/contractors travel and fiscal services. The Sub-Contract line item must be itemized based on the subcontract agreement. The Council must provide approval prior to grantee entering into any contracts. A copy of the contract must be included.

BUDGET CATEGORIES/DESCRIPTION

CATEGORY	DESCRIPTION
OTHER	The Other category may include audit services, service payment such as stipends, costs incurred for conferences, postage/mail, internet, printing/copies, training/meetings, cleaning/janitorial, license fees, incentives, participants insurance and bonding and any other services or expenses that will not fit into another category.
INDIRECT COST	Indirect Cost rates negotiated with the Department of Health and Human Services Regional Comptroller or other similar federal agency may be used to compute allowable indirect costs. Expenditures included as indirect costs may not be duplicated elsewhere in the budget. A copy of the Negotiation Agreement must be included with the grant application. Indirect/overhead costs may not exceed 15% of the total project cost or \$20,000, whichever is less.
UTILITIES	The cost associated with water, electricity, gas, telephone, and services.
MEDIA/COMMUNICATIONS	The cost incurred for advertising, audio visual presentations, multimedia, tv, radio presentations, logos, promotional items, publications, public service announcements and ads, reprints, text translation into another language, websites, and web materials.
DUES/SUBSCRIPTIONS	Dues includes approved dues for company memberships in professional organizations and subscriptions includes the cost of subscriptions to newspapers, magazines, and periodicals.



NACDD
National Association of Councils
on Developmental Disabilities



“Nothing About Us Without Us”
Best Practices to Support Statewide Self-Advocacy Organizations
User Feedback Survey Summary
August 2017

Dear DD Council Network,

In 2016, the “Nothing About Us Without Us” Best Practices for Supporting Statewide Self-Advocacy Organizations was developed by NACDD’s Self-Advocacy Committee (SAC) and numerous self-advocate leaders from advocacy organizations around the country. The resource document includes an executive summary of the self-advocacy survey completed by DD Councils in 2014 and a list of best and promising practices that NACDD believes will result in the growth and sustainability of effective self-advocacy organizations.

If you have not reviewed the resource, it can be found on the NACDD website under the [Advocacy/Self-Advocacy and Leadership](#) tab and on ITACC website under the [Other Resources](#) tab.

In August of 2017, NACDD/ITACC disseminated a follow-up survey to assess the use and usefulness of the resource and compile recommendations to share on how it is being used. A brief update on the status on self-advocacy was also collected to assess the current statewide self-advocacy movement, determine how Council efforts are impacting advocacy, compile a list of self-advocacy organizations involved directly with Council work and offer suggestions for additional resources and topics of interest.

Please see the summary below as we hope it will inspire you and your Council to use the resource for the first time or provide ways to continue sharing it with Council members, colleagues and advocate leaders in your state and territory.

Resource User Feedback Survey Summary

- 1) The resource user portion of the survey was answered by 18 people representing 15 State/Territorial DD Councils. Half of the respondents did not know the resource was available. The remaining respondents stated that they use other resources and materials for self-advocacy or did not have enough time to address the issue.

Summary/recommendation:

To address the number of people who responded that they did not know about the resource, NACDD/ITACC may utilize social media announcements (FB & Twitter), website postings, events/trainings/teleconferences and "reminders" on list serves to advertise future resources. This will better inform the DD Council network and ensure that they know of the valuable resources that are being provided for their use.

- 2) Below is a summary of how respondents used the resource.
 - To support Council members who are self-advocates - 50.00% (3)
 - To support self-advocacy organizations - 83.33% (5)
 - To address self-advocacy through our RFP process - 16.67% (1)
 - We have shared and posted this information for others in our state/territory. - 16.67% (1)
 - We have disseminated this document via e-mail, or in hard copy at meetings & conferences. - 16.67% (1)
 - We have discussed this document at Council meetings. 16.67% (1)
 - Comments from respondents:
 - We will begin using this resource in upcoming trainings.
 - We will eventually use it to support self-advocacy organizations.
 - We anticipate sharing and using this resource with our SA organization training workshops.
 - Information in the resource supported the Councils approval for funding the initiation of a statewide self-advocacy group that included board and advisory members from the DD network...the group will review the recommendations of this report, acknowledge aligned activities and consider adding activities...

Summary/recommendation:

The responses suggest that the resource was mostly used to support self-advocates and self-advocacy organizations. NACDD/ITACC may forward this resource to other advocacy organization leaders across the states and territories for posting on their websites, list serves and social media. This added exposure will increase the usability of the resource and reach more advocates.

3) Of all the strategies listed in the resource, the following were the most helpful to respondents. Overall, the most helpful strategies centered around leadership and skill building of advocates and increasing diversity.

- Increase membership of self-advocates on the Council. 25.00% (2)
- Increase leadership of self-advocates in key Council roles. 75.00% (6)
- Use plain language in all documents. 62.50% (5)
- Use people first language and self-identification preferences of self-advocates. 50.00% (4)
- Increase diversity by including people of all ages, religions, races, ethnicity and sexual orientation in leadership development opportunities. 62.50% (5)
- Promote participation through addressing transportation needs of diverse members. 62.50% (5)
- Promote access and participation by making print materials accessible to diverse learner abilities. 37.50% (3)
- Promote access and participation by addressing accessibility issues including physical access and bus line/public transportation access. 25.00% (2)
- Provide people with intellectual and developmental disabilities the training and support they need to serve as paid staff/leaders in the statewide self-advocacy organization. 25.00% (2)
- Facilitate access to financial support so that the self-advocacy organization is an independent organization. 25.00% (2)
- Provide information, support and skill building to people with I/DD so that they can participate in addressing key policy issues. 62.50% (5)
- Build collaborations and partnerships with other groups that may share the same issues and concerns. 50.00% (4)
- Use technology and social media to help spread the word about the self-advocacy organizations, grow their membership and share information. 37.50% (3)

4) The following stats reflect whether or not NACDD's creation of the **Nothing About Us Without Us Best Practices to Support Statewide Self-Advocacy Organizations** resource was useful to states/territories in further developing and supporting self-advocacy.

Yes, 85.71% (6) – No, 14.29% (1)

Summary/recommendation:

The majority of the respondents found the resource useful within their state/territory to further leadership among self-advocates and to strengthen their support of self-advocacy organizations.

NACDD/ITACC will continue to explore the needs of states/territories with regard to supporting SA on many levels and provide training, technical assistance and tools that support those needs.

If you have any additional information to share about the resource or questions about its use, please contact Angela Castillo-Epps at acastilo-epps@nacdd.org or call 202-506-5813, ext. 100

This report is supported through AIDD's contract (#HHSP233201600068C) with NACDD to provide technical assistance to the national network of DD Councils

Status of Self-Advocacy in Your State/Territory Feedback Survey Summary

The status on self-advocacy portion of the survey was answered by 10 respondents.

The following four questions provided NACDD with general feedback on the current status of self-advocacy in states and territories.

1) As a result of your Council efforts, how has self-advocacy changed in your state/territory?

Five respondents answered question one and all stated that the following changes have occurred due to Council efforts.

- The self-advocacy organization has grown in membership.
- Our state/territory offers more training and leadership opportunities for self-advocates.
- Our council has more self-advocate members. Our council has more self-advocates in leadership roles.
- The self-advocacy organization is now an independent organization.
- More self-advocates are active in policy discussions, public input and influencing policy decisions.

2) What state or local self-advocacy group(s) is your DD Council most involved with?

Twelve respondents answered question 2. See list.

- People First
- MA Advocates Standing Strong Statewide Independent Living Council
- Speaking for Ourselves of Colorado
- People First Wisconsin
- Self-Advocates in Action Organization
- NC Empowerment Network was established because of NACDD involvement. Credit is shared with DD Network Partners: Carolina Institute for Developmental Disabilities and the Disability Rights of NC.
- Oklahoma Self-Advocacy Network (But we also have Oklahoma People First, lesser involvement, but still financial support provided.)
- The Statewide Self-Advocates Network
- Self-Advocates United as one; Speaking for Ourselves; Pennsylvania Autistic Self Advocacy Network, etc.
- People First of Alabama
- Peer Power Alaska statewide self-advocacy organization
- Advocates as Leaders Self-Advocacy Speakers Network and Next Chapter Book Club.

3) How would you describe the current statewide self-advocacy movement presence within your state or territory?

Twelve respondents answered question 3.

- Well organized 33.33% (4)
- Strong advisors empower self-advocates to lead 41.67% (5)
- New leaders are emerging 75% (9)

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- Issues related to changing interests of younger advocates not relating to older advocate issues 33.33% (4)
- Not well organized 8.33% (1)
- Non-profit status (501c3) 58.33% (7)
- Participates/ is active in local or state policy making decisions 66.67% (8)
- Participates/ is active in the local or state political process 50.00% (6)
- Allies/ advisors (people without disabilities) are the leaders 16.67% (2)
- Maintains a system of statewide chapters 41.67% (5)
- Involved in local or state issues that are not disability related 8.33% (1)
- Involved with cross population advocacy (e.g. aging, LGBT, racial/ethnic minority populations) 33.33% (4)

Though the responses were limited, it appears that the majority of respondents feel strides are being made with regard to new leaders, people active in policy and policy making decisions, and self-advocacy organizations acquiring non-profit status.

4) Please share with us any additional resources for self-advocacy you would like NACDD to provide to the DD Council Network.

Three respondents answered question 4.

- More examples of what other states and territories have done.
- Resources on accessible language, fund raising and how to acquire in-kind resources.
- The last respondent offered to share trainings with Councils.

NACDD/ITACC will continue to keep an open dialogue with the DD Council Network and utilize a diverse set of strategies, which include but are not limited to list serves for information sharing, the Leadership Circle, the Self-Advocacy Committee (SAC), CEO Awards, resource page on nacdd.org website, DD Awareness Month Campaign, Civic Engagement, and Close UP to support the work of Councils, advocate leaders and self-advocacy organizations across each state and territory.

Council Meeting Dates

Please mark your
calendars! We want
to see you there.



February 8 & 9, 2018

May 10 & 11, 2018

August 9 & 10, 2018*

November 7-9, 2018



Locations: Hilton Garden Inn

131 Columbus Ave, Cary, NC 27518
919-377-0440

*Hilton Garden Inn, Asheville NC

309 College Street, Asheville, NC 28801
828-255-0001