



Building Bridges to Community

## North Carolina Council on Developmental Disabilities

Quarterly Council Meeting February 12 & 13, 2015  
Hilton North Raleigh, Raleigh, NC

*Promoting full lives in  
The community through...*

leadership & advocacy  
changing policy/changing practice  
building inclusive community



**Hilton North Raleigh, 3415 Wake Forest Road, Raleigh, NC 27609 ph 919-876-0890**

### **Directions**

From RDU Airport, Charlotte and all points west: take I-40 East towards Raleigh, take Exit #289 (Wade Ave) and follow until Exit 4B for I-440 North/Hwy 64 Rocky Mount, follow I-440 to Exit #10 (Wake Forest Rd). Make a Left at light off exit, the Hilton is ¼ mile North on the left.

From Richmond or all points North; Take I-95 South to I-85 South and follow to US 1 South at Henderson, NC. Follow this route 40 miles into Raleigh and take I-440 West. Follow I-440 West to Exit #10 (Wake Forest Rd) Make a right at light off the exit. The Hilton is 1/4 mile North on the left across from Duke Health Raleigh Hospital.

From Hwy 64, Rocky Mount, Greenville, NC and all point east: Take Hwy 64 West to exit for I-440 North at Tower Shopping Center. From I-440, take Exit #10 (Wake Forest Rd), turn right at the light off the exit. The Hilton is 1/4 mile north on the left across from Duke Health Raleigh Hospital.

“Hello,  
Council on  
Developmental  
Disabilities.  
How may I help you?”



**NCCDD STAFF ON CALL**  
**JoAnn Toomey**

**(919) 872-2323**  
**(Hotel Front Desk)**

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

## 2015 COUNCIL COMMITTEE MEMBERSHIP

### EXECUTIVE COMMITTEE

Ronald Reeve, Chair	Parent of Child with DD
Caroline Ambrose: Chair, Advocacy and Leadership	Individual with DD
Crystal Bowe, M.D.: Vice-Chair	Parent of Child with DD
Adonis Brown: Vice-Chair	Individual with DD
I. Azell Reeves: Chair, Community Capacity Building	Parent of Child with DD
Anna Cunningham: Secretary/Treasurer	Parent of Child with DD
Samuel Miller, Ph.D: Chair, Disability System Change	Parent of Child with DD

**Staff:** *Chris Egan*

### ADVOCACY AND LEADERSHIP COMMITTEE

Caroline Ambrose, Chair	Individual with DD
Karen Armstrong	Public at Large
Wayne Black; Alternate: Rick Zechman	Agency: Div. of Social Services
Lisa Byrd	Individual with DD
Michael Groves	Individual with DD
Mary Edwards	Agency: Div. of Aging & Adult Servs.
Lourdes M. Fernandez	Parent of Child with DD
Crystal L. Foreman	Individual with DD
Joshua Gettinger*	Parent of Child with DD
Katie Holler	Individual with DD
Cheryl Powell*	Individual with DD
Senator Tommy Tucker	Other: Legislative
VACANT	Parent/Individual with DD

**Staff:** *Melissa Swartz/Chris Egan*

\*Temporary Committee Assignments

### COMMUNITY CAPACITY BUILDING COMMITTEE

I. Azell Reeves: Chair	Parent of Child with DD
Amanda Bergen	Parent of Child with DD
Adonis Brown	Individual with DD
Anna Cunningham	Parent of Child with DD
Kerri Bennett Eaker	Parent of Person with DD
Representative Verla Insko	Other: Legislative
Nessie Siler*	Individual with DD
David White	Parent/Person with DD
Jim Swain; Alternate: Gina Price	Agency: Div. of Voc. Rehab.
VACANT	Parent of Person with DD
VACANT	Agency: Dept. Public Safety
VACANT	Agency: Dept. Public Instruc.
VACANT	Agency: Div. of W/C Health

**Staff:** *Shayna Simpson-Hall*

\*Temporary Committee Assignment

## SYSTEMS CHANGE COMMITTEE

Samuel Miller, Ph.D.: Chair  
Kelly Woodall Beauchamp  
Crystal Bowe, M.D.  
Courtney Cantrell; Alternate: VACANT  
Christina Carter; Alternate: Andrea Misenheimer  
Eric Chavis  
Robin Cummings, M.D.; Alternate: Deb Goda  
Wing Ng, M.D.  
Desiree Peterson  
Joe Piven, M.D.; Alternate: Deb Zuver  
Dave Richard, Deputy Secretary; Alternate: VACANT  
Vicki Smith  
Peggy Terhune, Ph.D.

**Staff: Steve Strom**

## STAFF

Chris Egan  
Cora Gibson  
Shayna Simpson-Hall  
Steve Strom  
VACANT  
Melissa Swartz  
JoAnn Toomey  
Yadira Vasquez  
Shar'ron Williams  
Letha Young

Parent of Child with DD  
Individual with DD  
Parent of Child with DD  
Agency: Div. of MH/DD/SAS  
Non-Profit Agency  
Individual with DD  
Agency: Deputy Sec., DHHS  
Parent/Person with DD  
Individual with DD  
Agency: Carolina Institute for DD  
Agency: DHHS  
AIDD Partner: DRNC  
Local Non-Governmental Agency

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



Meeting: NC Council on Developmental Disabilities  
Location: North Raleigh Hilton, Raleigh, NC

**DRAFT  
AGENDA**

**Thursday, February 12, 2015  
Salon D**

- 8:00 – 9:00 AM **NEW MEMBER ORIENTATION**.....Ron Reeve and Chris Egan
- 9:00 – 9:45 AM **WELCOME/INTRODUCTION OF NEW MEMBERS/COMMITTEE AGENDAS/  
AD-HOC COMMITTEE SIGN-UP/INTEREST**.....Ron Reeve
- 9:45 – 12:15PM **COMMITTEE MEETINGS:**  
Advocacy & Leadership .....Judicial  
Community Capacity Building .....Oakwood  
Disability Systems Change .....Sandalwood
- 12:15 – 1:30 PM **LUNCH BREAK (on your own)**
- 1:30 – 3:00 PM **COMMITTEE UPDATES/MEMBER MOTION REVIEW**
- 3:00 – 3:15 PM **BREAK**
- 3:15 – 4:15 PM **PUBLIC POLICY FORUM: MEMBER DISCUSSION**  
.....Beth Stalvey, PhD, Staff and Members
- 4:15 – 5:15 PM **COMMUNICATIONS INITIATIVE UPDATE/PRESENTATION**
- 5:15 – 7:30 PM **RECEPTION\***  
- WELCOME THE NEW MEMBERS!  
- OPPORTUNITY FOR PUBLIC POLICY DISCUSSION

**\*Heavy Hors d'oeuvre/Light Dinner Provided**



**Meeting: NC Council on Developmental Disabilities  
Location: North Raleigh Hilton, Raleigh, NC**

**DRAFT  
AGENDA  
Friday, February 13, 2015  
Salons D & E**

9:00 – 9:15 AM	<b>WELCOME/ CONFLICT OF INTEREST/ SAFETY AND PREPAREDNESS</b> ..... Ron Reeve
9:15 – 9:25 AM	<b>ROLL CALL</b> ..... Anna Cunningham
9:25 – 9:30 AM	<b>APPROVAL OF MINUTES</b> ..... Ron Reeve
9:30 – 9:50 AM	<b>DIRECTOR'S REPORT</b> ..... Chris Egan
9:50 – 10:00 AM	<b>FINANCE REPORT</b> ..... Anna Cunningham
10:00 – 10:10 AM	<b>PUBLIC COMMENT</b> ..... Ron Reeve
10:10 – 10:20 AM	<b>BREAK</b>
10:20 – 11:30 AM	<b>COMMITTEE REPORTS:</b> a) Executive Committee..... Ron Reeve b) Disability Systems Change Committee..... Sam Miller c) Community Capacity Building Committee..... I. Azell Reeves d) Advocacy and Leadership Committee..... Caroline Ambrose
11:30 – 12:00 PM	<b>OLD BUSINESS</b> ~Communications Initiative Update
12:00 – 12:30 PM	<b>NEW BUSINESS</b> ~Jean Wolff-Rossi Fund for Participant Involvement RFA Release Approval ~Public Policy In-House Funding Approval ~2016-2021 Five Year Planning Process
12:30 PM	<b>ADJOURN</b>

\*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





**DRAFT**  
**NC COUNCIL ON DEVELOPMENTAL DISABILITIES**

**Quarterly Council Meeting Minutes**  
**Hilton Garden Inn, Cary, NC**

**November 21, 2014**

**MEMBERS PRESENT:** Caroline Ambrose, Amanda Bergen, Crystal Bowe, Adonis Brown, Lisa Byrd, Eric Chavis, Anna Cunningham, Kerri Eaker, Michael Groves, Samuel Miller, Wing Ng, Desiree Peterson, Joseph Piven, Ron Reeve, I. Azell Reeves, Jim Swain, Vicki Smith, Peggy Terhune, Dave Richard, David White, Eric Zechman (for Wayne Black)

**MEMBERS ABSENT:** Courtney Cantrell, John Carbone, Christina Carter, Robin Cummings, Lourdes Fernandez, Wilson Finks, Crystal Foreman, Katie Holler, Representative Verla Insko, Senator Tommy Tucker, Kelly Woodall

**STAFF PRESENT:** Chris Egan, Cora Gibson, Shayna Simpson-Hall, Joshua Strasburg, Steve Strom, Melissa Swartz, JoAnn Toomey, Yadira Vasquez

**CONTRACTORS/GRANTEES PRESENT:** Jennifer Bosk, Karen Hamilton, Gordon O'Neill, John McCallum, Devika Rao, Beth Stalvey

**GUESTS:** Beverly Colwell, Renee Cummins, Barton Cutter, Mary Edwards, Renate Macchirole, Dreama McCoy, Pam Dickens

**WELCOME AND ATTENDANCE**

Chairman Ron Reeve asked that any Council member with a potential conflict of interest, in regards to the agenda, identify that conflict, so that it could be documented in the minutes and acted upon, as necessary. Mr. Reeve reminded Council members of the requirements of members to comply with the Statement of Economic Interest and Ethics Training. He also reminded members of the emergency exits at the Hilton Garden Inn. Anna Cunningham then conducted the roll call.

**APPROVAL OF COUNCIL MINUTES**

Ron Reeve asked for approval of the August 2014 Council meeting minutes. A copy of the minutes had previously been made available to Council members. Eric Chavis made a motion to approve the minutes. Lisa Byrd seconded the motion. The motion was approved.

## DIRECTOR'S REPORT

Chris Egan provided an overview of the meetings and conferences that he had attended in the last couple of months. He shared briefly the feedback that he has been getting since meeting with the non-agency Council members and that he would soon like to meet with agency Council members. Chris thanked all members, contractors and staff for their hard work over the past months.

## FINANCE REPORT

Anna Cunningham reminded members to complete their reimbursement forms and submit them to staff. Ms. Cunningham gave a brief report on the financial status of the Council. A copy of the report had previously been made available to Council members.

## PUBLIC COMMENT

There were no public comments.

## EXECUTIVE COMMITTEE REPORT

The Executive Committee members met September 15 and October 20, 2014. A copy of the minutes of each meeting has been made available to Council members. Mr. Reeve asked each member to review the minutes.

## COMMITTEE REPORTS

Mr. Reeve requested presentation of committee reports. Please refer to the committee minutes for a detailed description of the committees' work, including motions made in committee.

### DISABILITY SYSTEMS CHANGE COMMITTEE

Committee chair Samuel Miller presented the Disability Systems Change Committee report. Background information concerning the funding requests appears in the committee minutes. Following are the motions presented on the floor for Council consideration:

**Motion:** Samuel Miller made a motion that the NC Division of Aging and Adult Services be approved as the applicant selected for the NCCDD Guardianship initiative. Funding is approved for up to \$75,000 (level-funded) with a required minimum of 25% non-federal matching funds, for year one of up to three years beginning with the period of January 1, 2015 to December 31, 2015. Peggy Terhune seconded the motion. The motion was approved.

Vicki Smith recused herself because DRNC applied for this RFA. Dave Richard, Eric Zechman and Jim Swain recused themselves because they are DHHS employees.

**Motion:** Anna Cunningham made a motion to recommend the Executive Committee explore resources for strategic planning expertise that could be used for staff and Council member's growth and professional development to increase the likelihood of success in implementing the five year plan. Eric Chavis seconded the motion. Following lengthy discussion, motion was withdrawn.

**Motion:** Peggy Terhune made a motion that the Executive Committee review the potential of a strategic plan. Desiree Peterson seconded the motion. The motion was approved.

**Motion:** Samuel Miller made a motion to endorse the outcomes and expectations developed by the Stakeholder Engagement Group as outlined in their document and distributed in 2014. Peggy Terhune seconded the motion. The motion was approved.

#### **COMMUNITY CAPACITY BUILDING COMMITTEE**

Committee chair I. Azell Reeves presented the Community Capacity Building Committee Report. Background information concerning the funding requests appears in the committee minutes. Following are the motions presented on the floor for Council consideration:

**Motion:** Anna Cunningham made a motion to grant NCCDD staff authority to release the Request for Application (RFA) for the "NC ADA Network Fiscal Agent" for an amount up to \$35,000 (level-funded) for year one of up to three years beginning with the period of July 1, 2015 to June 30, 2016, with a required minimum of 25% non-federal matching funds. A recommendation was made to increase the allowable administrative costs to \$5,000 as part of the total contract of \$35,000. Eric Chavis seconded the motion. The motion was approved.

Desiree Peterson recused herself because she is on the board of the Alliance of Disability Advocates (the current contractor). Caroline Ambrose recused herself because she is employed with the current contractor and Renate Macchirole recused herself because the agency she works for may apply to the RFA.

#### **ADVOCACY AND LEADERSHIP COMMITTEE**

Committee chair Caroline Ambrose presented the Advocacy and Leadership Committee report. Background information concerning the funding requests appears in the committee minutes. There were no motions presented on the floor for Council consideration.

#### **NEW BUSINESS**

Ron Reeve discussed briefly the input from the public on the State Plan. Ron also reminded Council members to fill out there 2015 Committee Request Form and return them to staff.

**Motion:** Peggy Terhune made a motion for staff to assess individual accommodations for members to access Council communications. Eric Chavis seconded the motion. The motion was approved.

**Motion:** Anna Cunningham made a motion to approve the NCCDD Strategic Communications Plan presented by O'Neill Communications and in line with the development of the NCCDD strategic plan, to begin implementing elements of the initiative within the next three months. Desiree Peterson seconded the motion. The motion was approved.

**Motion:** Crystal Bowe made a motion to grant NCCDD staff authority to draft the Request for Application (RFA) for the "Jean Wolff-Rossi Fund for Participant Involvement Fiscal Agent and Program Manager" external initiative. Approval to release the RFA is planned to be requested at the February, 2015 Council meeting, but may be delayed until the May, 2015 meeting. Eric Chavis seconded the motion. The motion was approved.

#### ELECTION OF OFFICERS

In an open election on the floor of the Council, Crystal Bowe and Adonis Brown were re-elected Vice-Chairs and Anna Cunningham was elected Secretary/Treasurer. Committee Chairs are: Samuel Miller, Disability Systems Change; I. Azell Reeves, Community Capacity Building; and Caroline Ambrose, Advocacy and Leadership. Ron Reeve congratulated the returning elected officers.

A request was made to take a look at the election process and the length of office. Chairman Ron Reeve will consider forming a committee to review the by-laws in regards to the election process and length of terms.

Michael Groves made a motion to adjourn. Anna Cunningham seconded the motion. Meeting was adjourned.

Approved: \_\_\_\_\_

Anna Cunningham Secretary/Treasurer

Date: \_\_\_\_\_

# EXECUTIVE COMMITTEE



**NC Council on Developmental Disabilities (NCCDD)**  
**Executive Committee Minutes**  
December 19, 2014  
10:30 AM – 12:30 PM

**Present:** Carrie Ambrose, Crystal Bowe, Adonis Brown, Anna Cunningham, I. Azell Reeves, Ron Reeve

**Absent:** Sam Miller

**Others present:** Eric Chavis, Chris Egan, Yadira Vasquez, Melissa Swartz, JoAnn Toomey

**I. Approval of Minutes:**

The draft minutes of the October 20, 2014 Executive Committee meeting were discussed.

**MOTION:** Adonis Brown made a motion to approve the November minutes. Carrie Ambrose seconded the motion. The motion was approved.

**II. Financial Update:**

Yadira Vasquez reviewed the financial reports for the NCCDD. There was some discussion on the FFY balances and initiative expenditures. Ron Reeve asked the members if there were any further questions and there were none.

**III. Conference Funding Requests:**

**MOTION:** Anna Cunningham made a motion to fund two speakers for up to \$3,000.00 for the Autism Society of North Carolina's Annual Conference being held March 27-28, 2015 in Charlotte, NC. Carrie Ambrose seconded the motion. The motion was approved.

**MOTION:** I. Azell Reeves made a motion to fund two speakers for up to \$1,250.00 for the Arc of Davidson County's My Dreams, My Life: Third Annual Self-Advocates Conference being held March 28, 2015 in Clemmons, NC. Anna Cunningham seconded the motion. The motion was approved.

**IV. Process for Strategic Planning/State Plan:**

To follow-up the discussion and suggestions at the November Council meeting, Ron Reeve suggested that a "sequence of events" be sent out to all members the first week of January, 2015 so that they will be aware of

the timelines for the process of the Five Year Plan due in August, 2016. In addition, Ron reviewed a possible framework for strategic planning with four major cross-cutting areas within which current and future initiatives support the four areas. Ron will send EC members an outline of the areas.

**V. Potential Revision of By-Laws:**

A suggestion was made at the November Council meeting to re-visit the amendments to the NCCDD By-Laws. Ron Reeve will send the EC members the original and proposed NCCDD By-Laws that were put forth to members at a previous Council meeting in 2012.

**VI. Approval of Executive Committee Meeting Dates for 2015:**

The Executive Committee meets the 3<sup>rd</sup> Monday of each month (10:30 AM – 12:30 PM), except for the months where we have the full Council meetings. Members reviewed and agreed on the following dates:

Friday, January 23<sup>rd</sup> (9:00 AM – 11:00 AM) – Due to the holiday on Monday, January 19<sup>th</sup>  
Monday, March 16<sup>th</sup> (10:30 AM – 12:30 PM)  
Monday, April 20<sup>th</sup> (10:30 AM – 12:30 PM)  
Monday, June 15<sup>th</sup> (10:30 AM – 12:30 PM)  
Monday, July 20<sup>th</sup> (10:30 AM – 12:30 PM)  
Monday, September 21<sup>st</sup> (10:30 AM – 12:30 PM)  
Monday, October 19<sup>th</sup> (10:30 AM – 12:30 PM)  
Monday, December 21<sup>st</sup> (10:30 AM – 12:30 PM)

**VII. Other:**

Anna Cunningham let the EC members know that she is working with Beth Stalvey on the HCBS policy survey to offer all Council Members opportunity for feedback on the Home Community Based Services (HCBS) as input for DHHS workgroup and to determine Council position on these important rules. She asked for full EC support which was given. Crystal Bowe reminded members to look into the technology and accommodation issue for members.

**VIII. ADJOURN:**

Adonis Brown made a motion to adjourn. Members adjourned.

# ADVOCACY AND LEADERSHIP COMMITTEE





# North Carolina Council on Developmental Disabilities

## Advocacy and Leadership Committee Agenda DRAFT

February 12, 2015

9:45 a.m. – 12:15 a.m.

North Raleigh Hilton, Raleigh, NC

9:45 a.m. – 9:55 a.m.	<b>Introduction</b> <ul style="list-style-type: none"> <li>Welcome</li> <li>Completion of Financial Forms and Conference Requests</li> <li>Approval of Minutes</li> </ul>	<i>Caroline Ambrose</i>
9:55 a.m. – 10:35 a.m.	<b>Initiative Review</b> <ul style="list-style-type: none"> <li>Sibling Support</li> </ul>	<i>Bryce Coleman, Family Support Director, First in Families of North Carolina</i>
10:35 a.m. – 10:45 a.m.	<b>Fiscal Update</b>	<i>Yadira Vasquez, NCCDD</i>
10:45 a.m. – 11:00 a.m.	<b>Break</b>	
11:00 a.m. – 11:30 a.m.	<b>Initiative Review</b> <ul style="list-style-type: none"> <li>Partners in Policymaking</li> </ul>	<i>Deborah Whitfield, Executive Director, Advocacy Institute, Inc.</i>
11:30 a.m. – 11:45 a.m.	<b>Conference Funding Requests</b> <ul style="list-style-type: none"> <li>DRNC: Disability Advocacy Conference</li> <li>NCAPSE: Work Hard, Dream Big</li> <li>NC TIDE: Building Community Connections</li> </ul>	<i>Melissa Swartz, NCCDD</i>
1:45 a.m. – 12:10 p.m.	<b>Discussion of A&amp;L Staff Change</b>	<i>Chris Egan, NCCDD</i>
12:10 p.m. – 12:15 p.m.	<b>Wrap ups and Reminders</b>	<i>Caroline Ambrose</i>

### ADVOCACY AND LEADERSHIP COMMITTEE

Caroline Ambrose, Chair

Karen Armstrong

Wayne Black; Alternate: Rick Zechman

Lisa Byrd

Michael Groves

Mary Edwards

Lourdes Fernandez

Crystal L. Foreman

Joshua Gettinger\*

Katie Holler

Cheryl Powell\*

Senator Tommy Tucker

**Staff: Melissa Swartz/Chris Egan**

\*Temporary Committee Assignments

Individual with DD

Public at Large

DSS

Individual with DD

Individual with DD

DAAS

Parent of child with DD

Individual with DD

Parent of child with DD

Individual with DD

Individual with DD

Legislative Representative

**NCCDD**

**Advocacy and Leadership Committee  
DRAFT MINUTES**

Thursday, November 20th, 2014  
9:45am – 11:45am

**Members Present: Advocacy and Leadership Committee** – Caroline Ambrose, Adonis Brown, Michael Groves, Danielle Matula, Renate Macchirole, Katie Holler, Rick Zechman

**Members Absent:** Lourdes Fernandez

**Visitors:** Mary Edwards, Mike Mayer, Jonathan Ellis, Matthew Potter, Barton Cutter, David Taylor, and Sarah Potter

**Staff in Attendance:** Joshua Strasburg, JoAnn Toomey, Melissa Swartz, and Chris Egan

**Introduction:**

**Welcome:** Chairperson Caroline Ambrose welcomed all members and provided an opportunity for all to introduce themselves.

**Approval of Minutes:**

**MOTION:** Rick Zechman made a motion to approve the August 2014 Advocacy and Leadership committee meeting minutes. Mary Edwards suggested that the motion be revised to change her status in the August minutes from “member” to “guest” because the DAAS primary member has not been appointed yet. Adonis seconded the revised motion. Motion was carried.

**Initiative Review: NC Alliance for Direct Support Professionals**

Renate Macchirole provided an update on the activities of the NCADSP initiative as their first year comes to a close. She began with a brief review of the last year including highlights such as including all people receiving support services, not just people with I/DD. Renate explained that the NCADSP movement has support from every LME/MCO, including giving opportunities for presentations, hosting kick-off sessions for middle management, and supporting Direct Support Staff to attend the DSP conference, in which 108 DSP’s attended. Renate briefly discussed CMS’s core competencies for DSPs and how that can positively affect the profession. The NCADSP webpage wasn’t developed in the first year of funding as planned, however the initiative staff have set up a Facebook page to have a web presence.

**Fiscal Update**

JoAnn Toomey, NCCDD’s Director of Operations, gave an overview of the fiscal status of the organization. She provided Council members with information on each initiative housed in the Advocacy and Leadership committee.

### Initiative Update:

Mike Mayer and the Advocacy Ambassadors (Jonathon Ellis, Matthew Potter, and Barton Cutter) presented their final report with recommendations to the committee. Each committee member was given a copy of the final report to refer to during the presentation. Matt summarized four major issues that were reported frequently: infighting, conflicting personal agendas, lack of a cohesive vision, and lack of resources and support (both monetary and organizational support). As far as recommendations for strengthening the self-advocacy movement in NC, the three immediate areas of emphasis suggested by the Advocacy Ambassadors are technical assistance to current groups, communication and technology support for self-advocates, and leadership development for self-advocates.

### Wrap Up and Reminders:

Chairperson Caroline Ambrose reminded committee members to fill out their financial reimbursement forms, and to let Cora Gibson know as early as possible when there are conferences they would like to attend.

**MOTION:** Rick Zechman made a motion to adjourn the November 2014 Advocacy and Leadership Committee meeting. Renate Macchirole seconded the motion. The motion carried.

NOVEMBER 20, 2014



**FINAL REPORT TO THE  
NC COUNCIL ON  
DEVELOPMENTAL DISABILITIES**

**S. BARTON CUTTER, JONATHAN ELLIS, MONICA J. FOSTER & MATTHEW POTTER**

**N.C. ADVOCACY AMBASSADOR INITIATIVE IS A PROJECT FUNDED BY THE N.C. COUNCIL ON DEVELOPMENTAL DISABILITIES  
& ADMINISTERED BY MICHAEL MAYER, COMMUNITY RESOURCES ALLIANCE (CRA)**

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## EXECUTIVE SUMMARY

The N.C. Advocacy Ambassadors, in conjunction with the Community Resource Alliance (CRA), were charged with assessing the current state of self-advocacy within North Carolina under a 12 month grant from the North Carolina Council on Developmental Disabilities (NCCDD). The Ambassadors, individuals who themselves have disabilities, were recruited to reach out as a team to existing grass roots advocacy organizations across the state and determine the elements needed to ensure a robust self-advocacy movement in North Carolina.

The immediate goal of the N.C. Advocacy Ambassador Initiative team was to identify the specific strengths and weaknesses of the existing movement and to provide recommendations for rectifying weaknesses while bolstering existing strengths.

Two separate surveys and extensive stakeholder interviews were used to gather information. Results of the survey and interview process revealed that the current state of self-advocacy is tenuous at best and that major areas of concern need to be addressed to build a functional self-advocacy movement. Major emphasis needs to be placed on the following areas:

- *Education and training* in current advocacy issues, advocacy skills, group dynamics, collaboration, and communication
- *Technical assistance* for existing and emerging self-advocacy groups towards more regular, well-attended, well-governed meetings and connecting them with others and to address the other needs identified by the groups, such as using technology to support their efforts,
- *Identification of self-advocates with leadership potential* and the provision of training for them
- *Support* to state agencies and provider organizations to ensure access to processes and feedback that are accessible and self-advocate-oriented

### Stakeholder Perspectives (Section I)

Stakeholders were interviewed regarding their feelings about the status of self-advocacy in North Carolina. Stakeholders interviewed ranged from self-advocates, current and former heads of advocacy (including self-advocacy) groups,

representatives of provider organizations, disability rights advocates and attorneys, and state employees. The interviewees were guaranteed anonymity and thus, gave the most candid answers possible regarding the problems they saw facing self-advocacy.

The consensus among stakeholders is that the state self-advocacy movement is dysfunctional and ineffective due to:

- In-fighting
- Conflicting personal agendas
- Lack of a cohesive vision
- Lack of resources and support, both monetary and organizational

The picture of self-advocacy in North Carolina from the perspective of stakeholders is, at present, a dire one. However, stakeholders were united in the view that the situation could be vastly improved with adequate support provided by the right team.

### **Group Survey Analysis (Section II)**

During the initial phase of the Advocacy Ambassador Initiative, the Ambassadors encountered major hurdles in identifying pockets of active advocacy, both in group form and among unaffiliated individuals, despite reports to the contrary. Initially, the Advocacy Ambassadors began their exploration using the most recent membership lists from the Association of Self-Advocates of North Carolina. Yet, only a very small sample of member groups remained active in the wake of the only statewide self-advocacy organization's decline in 2009.

The responding organizations, although few, admitted needing and wanting outside assistance to:

- Continue a self-advocacy, person-first focus
- Grow their membership
- Remain viable as an organization

The low response speaks to both the low number of existing organizations and the poor communication, engagement, and collaboration among those that do exist.



The few responding leaders of these organizations generally believe they are working with a clear vision and mission and that the membership of their organization clearly understands their purpose for existing as a self-advocacy organization. However, if perceptions aligned with the current environment, the status of self-advocacy groups would be substantially better, demonstrating major outcomes for their constituencies. In short, the outcomes do not match the beliefs of the responding leaders.

### **Individual Survey Analysis (Section III)**

Of the 172,000 people with IDD in the state, the Ambassadors were able to make contact with approximately 500 self-advocates, nearly 300 of whom were communicated with directly by the AAI team, but of which only seventy-six people responded to the individual survey despite the well-coordinated attempt to disseminate, publicize, and encourage candid responses.

Such a low response rate does not allow for reliable and comprehensive patterns to be determined. The responses *do* reflect, however, a number of important issues:

- *Lack of understanding* of pertinent issues
- *Unwillingness to share* candid opinions and sentiments (suspected to be because of perceived pressure or fear of retribution)
- The need for *greater capacity to define personal support needs* among members of advocacy groups

### **Path Forward (Section IV)**

To address these current realities, the Advocacy Ambassador Initiative team feels that a multi-dimensional approach to strengthen and foster collaboration among willing and interested parties is required to ensure that the state self-advocacy movement becomes both unified and effective in its mission and objectives. This includes direct collaboration with allies, such as Disability Rights North Carolina. These efforts will also include the development of a self-sustaining business model to facilitate these goals on a long-term basis.

Initially, a strong emphasis will be placed on forging a cohesive infrastructure to:

- *Strengthen and expand* self-advocacy groups

- *Build communication* between groups across the state
- *Develop collaboration* among self-advocate leaders
- *Facilitate self-sufficiency* of the supports to sustain these efforts

To this end, our recommendations are that action be taken in four areas of most immediate need:

- *Technical assistance*
- *Communication and technology*
- *Leadership development and education*
- *Developing and implementing a working "business" model to continue to provide the above services and supports*

## Section I: Historical Contexts and Stakeholder Perspectives

### Introduction

The N.C. Advocacy Ambassador Initiative team asked 13 individuals (hereafter referred to as “respondents”) the same set of questions regarding their feelings on the state of advocacy in North Carolina. The respondents were guaranteed anonymity in their responses, and thus gave the most candid answers possible regarding the problems facing advocacy for people with disabilities. Respondents ranged from self-advocates with their own businesses to former heads of advocacy groups to disability rights attorneys to even state employees.

While the types of experiences and differences in vantage point were vast, the themes, issues, and solutions that emerged were generally very consistent. This is both distressing and encouraging; the picture of advocacy in North Carolina as of the time of this report is a dire one. However, it is clear based on what respondents told us that a better future is definitely possible.

### What Does an Effective, Statewide Advocacy Group Look Like?

Common themes for this section included an emphasis on things being run by advocates for advocates. While allies and others would be an important part of the process, their main function should be that of support.

Types of support frequently mentioned include financial supports, transportation support, and of course moral support. The establishment of an advocacy group across the state would facilitate the ability of individual groups to flourish (for example, specific disability sub-groups having places and ways to congregate about issues that are important to them) and it would discourage isolation and the jockeying for power between specific local or regional groups.

Rather, these individual groups would exist but also collaborate and support one another, to allow for simultaneous self-sufficiency and interdependence, and not strictly focus on “independence” from all other groups.

Other common themes include the need for frequent and accurate communication in ways that self-advocates could access and understand, the use of technology to facilitate communication, and the need for clearly defined visions, missions, and goals for advocacy groups and the means to attain these goals.

### Thoughts on the Current State of Self-Advocacy in N.C.

The responses we obtained were rather universal regarding the current state of self-advocacy in North Carolina.

While some respondents mentioned glimmers of effective self-advocacy through organizations such as The Arc, in general the descriptions of the current status were dismal.

Frequent terms used included "splintered", "no collaboration", "lack of support", and the potential for the image of a phoenix rising from the ashes. Several respondents hadn't heard of any ongoing efforts whatsoever, which is rather telling by itself and speaks to the "tenuous at best" picture painted by all 13 of our extremely knowledgeable respondents.

While many mentioned no support from providers and allies, others also mentioned the concerning issue of providers having "taken over" advocacy groups and co-opting their agendas for their own purposes.

### Current Rating of Self-Advocacy in N.C. from 1-10

Aggregating all of the 13 respondents, the average number for the current state of advocacy in N.C. was 3.3. The lowest number given was a 0, and the highest given was a 6. The majority of respondents rated the situation at a 3 or a 4. Obviously this indicates an incredibly fractured system of self-advocacy at best, and an utterly ineffectual and dysfunctional system at worst.

Unfortunately, the worst perspective was the one most frequently held. Clearly, interventions and assistance are needed.

### Thoughts on Some of the Biggest Problems Currently Facing the Self-Advocacy Movement in N.C.

Common themes in this section are very apparent. Discussions of lack of support, both financial and otherwise, were extremely common. Some talked about no support whatsoever, which left self-advocacy groups on their own in an environment in which they are unable to succeed.

Meanwhile, some respondents noted that, contrary to a lack of help, unfortunately and too often, those who try to help self-advocacy groups sometimes overstepped boundaries and pressed their own agendas on the groups they claimed to be assisting.

Transportation was another frequently mentioned barrier to effective self-advocacy.

Finally, a lack of cohesion is clearly a problem, and it is mentioned in both the context of egos and/or overpowering personalities among self-advocates, as well as a demonstrated lack of understanding about what is required for an effective self-advocacy group/effort.

### Thoughts on Possible Solutions to the Problems with Self-Advocacy in N.C.

In addition to the above comments, common responses in this section included assistance to help repair wounded relationships, support to connect the smaller groups together, and the use of technology as a means to overcome certain issues associated with transportation and a general lack of knowledge of the issues and how those issues affected individual self-advocates and the community as a whole.

Another common theme is the acknowledgment that individual agendas, and sometimes those issues unique to certain types of disabilities, are bound to exist and are essentially unavoidable, but that such things are only a problem when they overtake the collective agenda and goals that will benefit all.

It can be inferred by many of these suggestions (and was directly stated by some) that the creation of a body to advise, train, monitor, and link self-advocacy groups is very much needed and would be very much welcomed by those who have invested in the development of self-advocacy.

A "self-advocacy clearinghouse" is one possible option that was mentioned by several participants. It is important to remember, however, that steps would need to be taken to ensure that self-advocacy movements would remain "by self-advocates, for self-advocates", and that guidance and the training would not become overbearing and not usurp individual organizational goals nor creativity from local or regional self-advocacy groups.

#### What is the Ideal and Attainable Rating of Self-Advocacy in N.C. (from 1-10)?

The majority of respondents answered that the movement has the capability of being a 9 or 10 on this scale with the right supports in place.

The respondents who chose 9 were clear to indicate that the reason they did not say 10 was due to their desire to never suggest that there isn't room for improvement. Regardless, the potential increase was three times the current average score.

While a few respondents rated it as a 6 or 7, they were clear to indicate that that was meant to be more of a pragmatic answer with regards to what they actually believed *would* happen without concerted efforts such as the Advocacy Ambassador initiative, rather than a belief that things couldn't be better than that.

This is largely due to the need to manage many complex factors, including personalities/power struggles, funding, and the like. It is our belief that with proper interventions and activities, "the score" in the next couple of years could get up to an 8 or a 9.

### Thoughts on the Most Necessary Efforts/Resources to Bridge the Gap Between Current and Ideal Scores

Once again, it was the consistency among the multiple themes that emerged was notable. The most frequently mentioned resource mentioned as being needed was people who were capable and trustworthy.

Many respondents mentioned that the self-advocacy movement needs focused, dedicated leaders who will simultaneously take responsibility and maintain humility while being able to skillfully manage historically strong personalities to prevent a repeat of past efforts.

There were multiple inferences that people who are effective at keeping strong personalities and egos in check would be a highly valued resource. This is both a problem and a solution that is agreed upon by the Advocacy Ambassador Initiative team. Further, the solution cannot be "Raleigh Centric" as the need is literally in every corner of the state. Therefore, the solution needs to be statewide.

Other resources needed included technology (especially for improved communication), funds to cover the costs associated with managing such an effort (such as, training, communication), transportation, and "effective support systems". The need for intellectually accessible and effective training materials and education was frequently mentioned.

### Closing General Thoughts from Interviewees

The main themes in the closing thoughts were messages of support and approval of the Advocacy Ambassador Initiative, and the strong belief among the respondents that efforts to promote self-advocacy need to continue if there is any hope for truly effective self-advocacy in NC.

We have received strong messages of support for advancing self-advocacy from both individuals and advocacy organizations, such as The Arc, Disability Rights North Carolina, and North Carolina Partners in Policymaking, as well as other policy makers and implementers (such as LME/MCO's), and some of the most progressive providers.

The only other common theme in the respondent's closing messages was that those **trying to repair advocacy in N.C. will need to be very sophisticated in the management of personalities and in conflict resolutions** – and they must be careful to avoid repeating the historic problems mentioned above.



## Section II: Group Survey Analysis

### Context

The relationship between support staff and people with disabilities is typically viewed as one involving unequal power – with the staff having more power than the person with the disability. This can, and unfortunately frequently does, result in fear. That fear, at its core, comes from the invaluable nature of support staff. People with disabilities often fear the idea of saying something negative about supports that could jeopardize their supports, because without the supports, the people with disabilities feel helpless.

As a result, whether this fear is based in reality or not, the idea of being surveyed about quality of life, especially when some of the questions relate to supports, can be an extremely intimidating and frightening proposition for any person with a disability reliant on such supports.

Consequently, this fear often translates to self-advocacy groups which do not like being surveyed or questioned about their work for fear of revealing areas of weakness and the fear of having the group taken over by service providers who are not self-advocates themselves.

Surveying self-advocacy organizations proved to be a difficult task, but a small sample did respond to our effort. The surveys revealed that group leaders are hesitant to be examined, and yet do desire some support to grow and build long-term sustainability once they recognize a friendly, self-advocacy ally rather than an entity offering what they perceive as controlling direction.

### Dissemination Process and Challenges

During the initial phase of the Advocacy Ambassador Initiative, the Advocacy Ambassadors encountered major hurdles identifying pockets of active self-advocacy, both in group form and among unaffiliated individuals.

Initially, the Advocacy Ambassadors began their exploration using the most recent membership lists from the Association of Self-Advocates of North Carolina. Yet, as one might imagine, the information received from an organization that has been

effectively inactive since late 2009 was extremely outdated, and only a small sample of member groups remained active in the wake of the lead organization's decline.

Once this list of groups and members was exhausted as a source of potential survey participants, it became incumbent upon the Advocacy Ambassadors to utilize their personal and professional networks to uncover additional advocacy groups and individual advocates that existed outside of the old Association's membership.

Since this effort only yielded four additional self-advocacy organizations that are currently active being identified for survey purposes, the total study sample of active groups surveyed was far smaller than the 20-30 that had been anticipated.

In surveying those remaining, active groups, there were a variety of barriers encountered in gathering quality information:

- Out-of-date or incorrect group information
- Polarization and a hesitation to collaborate, especially among a few self-advocates that have historically been very active
- Challenges related to survey accessibility regarding the design of the questions
- Lack of trust among self-advocates, i.e. a fear of the misuse of information
- The attempt to skew the data by some family members and/or providers

## **Analysis of Findings**

### **Clearly Defined Vision & Mission**

Of the self-advocacy organizations that responded, all believe that for the most part they are working with a clear vision and mission, even if they could not articulate what these are beyond greater inclusion of people with IDD in the community through community activities and volunteerism. In other words, while the visions and missions of the groups are clear, the ability of many group members to clearly articulate their vision and mission requires significant effort.

The leaders of these organizations generally believe that the membership of their organization clearly understands their purpose for existing as a self-advocacy organization.

### Responsive and Active Membership

Across the board, respondent organizations felt their membership is steady and active. Any barriers identified that might impede a member's regularity of participation are seen as external to the management of the organization and are equally spread among such reasons as work or school schedules, transportation, or health. For the most part, though, organizations have a very small group of regularly attending members participating in activities on a regular basis. This type of membership base, though, does not necessarily lead to growth in new membership.

### Size of Organization

Of the respondents, the number of active members was quite a diverse range. Two of the groups in smaller, rural communities have an average of five members participating on a regular monthly basis. More than 20 members participate in one self-advocacy organization's activities on a regular basis in a larger community area.

Yet another even larger organization in a major metro area reported gathering between 30 and 50 members monthly. This group benefits from a diverse array of transportation options, some independent drivers, carpooling, support staff providing transportation, county-provided para-transit, and participants that live within walking or a wheelchair's rolling distance of the accessible meeting site.

### Desired Involvement with Other Self-Advocacy Groups

A majority of respondents, while few, expressed interest in connecting with other self-advocacy groups across the state, while a small number were unsure or neutral about this. The neutral or uncertain response stems mostly from a concern that each community's organization retain its own identity, a need to

focus on solutions to the group's unique community concerns, and not wanting to dilute their local sense of camaraderie.

Respondents do acknowledge, however, that in advocacy a united voice of many is stronger than scattered voices. The mechanism of how to go about uniting groups separated by miles is a significant concern in a state with a very wide geography and where service types and focus, as well as transportation options/delivery are dramatically different.

Groups wonder what supports would be needed and potentially available for connecting groups across the state, such as technology, transportation, teleconferences, etc.

It is also acknowledged that **it is important that everyone understands broad self-advocacy issues well enough, with easy-to-follow and understand talking points, to enable them to speak up and advocate together as an organized voice rather than in a scattered way (or overly simplistic or highly individual ways)** that seems to lead to group frustration and leaves public officials further confused about what is important among their constituents with disabilities.

### Community Involvement of Self-Advocacy Organizations

All respondents agree that connecting with others is an important part of advocacy and building community. Again, it is a question of how.

A multi-pronged approach will be important in connecting self-advocates to advocacy issue information and forums. Approaches might include, but are not limited to:

- Social media engagement,
- Teleconferences,
- Newsletter articles,
- Op-ed pieces in the newspaper,
- Supporting in-person meetings at a mid-point between where current groups meet or switching between sites as accessibility, transportation and communication technology allow (teleconference ability, Wi-Fi access and high speed internet, etc.),

- Holding advocacy town hall-style meetings,
- Hosting self-advocacy refresher seminars and retreats, visioning, and planning strategy activities.

These diverse approaches must include advocates across a broad geography and wide spectrum of abilities and personalities.

All respondents polled said they believed they were well-connected and engaged with their communities where they live because they have community leaders come to their meetings to serve as presenters. As a result, respondents feel their membership can identify their community leaders and understand their job.

Still, transportation is key to getting out in the community rather than just having community contacts come to meetings. At least one of the three respondent groups has agency funded transport to get the membership out to do community service projects, and members do sometimes carpool with family or direct support professionals to events outside their home community, but more consistent accessible transportation is needed across the board.

### Working with Policymakers

All respondents strongly affirm that working with their local, county, and statewide policymakers is important in advocacy. Despite the above statement, virtually all expressed the need to better know who their local leaders are, and/or who to ask for support if they want to start an advocacy conversation or activity in their community.

Finding or compiling a current 'primer,' or easy-to-follow guide, for contacting officials would be helpful if it also included local/regionally-specific contact information, as well as models of letters and "scripts" that could be used to practice conducting a meeting with one or more officials. It also appears that it would be of benefit to provide information on how to converse on calls to local officials – again in self-advocate friendly terminology that they could use as a reference as needed. Of course, this will also need to be in multiple user accessible formats.

### Desire for Outside Assistance

While the written survey resulted in only one self-advocacy organization directly expressing a need for outside support, further conversation with the each of other groups clarified that they were uncertain how they would utilize this support, how deeply the support would/could be involved in their operations and how they could be assured of an exit strategy once the support has been given. Organizations clearly do not want to lose their local structure or focus as they connect to outside resources.

Eventually, as a result of these conversations the majority of **responding organizations want, and express a need for, outside assistance to help them continue with a self-advocacy, person-first focus, to help them grow their membership, or to stay viable as an organization, despite the lack of survey responses to this effect.**

### Funding Support

Two organization respondents receive financial support, and have designated meeting space through local service providers. One self-advocacy organization is attempting to be self-supporting with varying, and limited, results.

One of the respondent organizations desires more funding support so they can address the membership's transportation needs to and from meetings, in and around the community, and across the state to practice their self-advocacy skills and to heighten their voice on the state level.

The group further wants self-advocacy training in general, and specifically training and funding support for publicity and printing materials, membership growth, etc.

Further, individual discussions among self-advocate members led to the realization that virtually all of the responding organizations need some kind of financial support and training on how to develop funding streams to meet their future goals and objectives.

Some funding will need to be directed toward training local self-advocate organization leadership to learn how to better communicate among themselves and with their membership, in addition to helping their membership learn effective meeting participation skills, and how to support each other when there are communication and learning barriers. Finally, they will need training on how to proactively (rather than reactively) communicate with their sponsoring agency if one exists.

However, the single most serious issue among the self-advocacy organizations was transportation. Accessible, affordable and available transportation to and from meetings, to and from activities within the community and across the region and state, including conferences, training, and self-advocacy social events is of deep concern.

Once they know how to communicate effectively and establish group harmony, organizations will want to be more present in their respective communities and across the state to engage in self-advocacy activities.

Self-advocacy organizations want (and need) to clearly understand their funding supports and other resources they can access, as well as have a voice in how their organizational funds are spent. Gathering from responses and deeper discussion, agencies hosting or supporting the self-advocacy organizations typically distribute the funding for the self-advocacy organization to function and, as such, can control the agenda of the local organizations. Further, the self-advocacy organizations don't always know how much money is budgeted for them, or for what purpose. Self-Advocacy organization leaders and members desire more fiscal education and supportive control, rather than their perceived situation of no control or knowledge of their funding streams at all.

### Quality of Membership Communications

Responding organizations generally stated that they communicate with their membership at least in terms of reminders of monthly meetings. Two organizations further responded that communicating more frequently, and in different ways that others found more accessible, is always better.

Currently, respondents communicate mostly by phone, but some do use email, and most engage in impromptu conversations as members run into one another in their home community.

All agreed they want to figure out ways to communicate better as a group among the membership, as well as between their organization and other advocacy organizations. As of now, the communication between different self-advocacy organizations is poor to nonexistent. Organizations will need to iron out intra-organizational communication issues.

Organizations would greatly benefit from leadership communications training, how to effectively and safely use and access funding for U.S. postal mail, email, and social media platforms. Only once this learning and practice are solid can branching out to learn how best to communicate between groups take place.

#### Concluding Concerns Among Respondents

Respondents had several concerns they hope to address – and hope that the Advocacy Ambassador Initiative could assist with. These include:

- transportation
- better defining goals and objectives of the organization
- pinpointing funding resources
- remaining active, timely, and aware of national, state and local issues

Self-advocacy organizations want and need supports, but deeply want to develop and maintain their own identity outside the agencies supporting them. Responding organizations expressed a real desire to define who they are and want to be on their own terms without undue influence from an agency that does not share their goals and aspirations. **Self-advocacy organizations want, and need, a better idea of what their group defining goals and objectives are, beyond the identity of their hosting or supporting service provider.** Finally, they want to improve the drafting of their own agendas.

This is another area where leadership development and group communication needs more strength.



### Section III: Individual Survey Analysis

The overall approach to information gathering was built upon a combination of presentations to existing self-advocacy groups (a total of nine), mailings to known advocates across the state, presentations at conferences, and a variety of town-hall style, listening sessions. This effort resulted in the Advocacy Ambassadors ultimately engaging with over 500 self-advocates from the mountains to the Outer Banks, with 300 of these interactions being face-to-face. These included the connections made at conferences such as NC Self-Advocates Conference, Partners in Policy Making, and two presentations at the Carolina Youth Leadership Forum.

#### Survey Development

Two separate surveys were used for information gathering, one survey to assess organizational need and a second to understand individual perspectives on advocacy, both of which may be found in the Appendix 4 and 5 respectively (p. 62-75).

The intent of the Advocacy Ambassadors for the individual survey was to assess the thoughts and feelings of individuals who have disabilities related to self-advocacy, and to assist the Advocacy Ambassador Initiative of the N.C. Council on Developmental Disabilities to understand what matters most to self-advocates, and how to support people to obtain the assistance they need to have the lives they deserve through coordinated self-advocacy efforts.

The Advocacy Ambassadors also sought to ascertain a person's level of engagement with a self-advocacy group, and in what ways such engagement enhances individual advocacy skills. The final version included a set of questions pertaining to their understanding of the priorities of the NCCDD funded Stakeholder Engagement Group. Those questions (#14-29) relate to the outcomes of: no waiting lists, integrated employment, inclusive living, asset development, and an accountable system.

#### Dissemination Process and Challenges

As referenced in the previous section, the **Advocacy Ambassadors encountered many obstacles, as the vast majority of the remaining groups have become polarized in the absence of unifying issues that they felt they understood.** In some extreme cases the Advocacy Ambassadors were met with an overt unwillingness to collaborate. This has greatly affected both membership and individual self-advocacy.

Although in a small minority of situations the Advocacy Ambassadors were unable to circumvent these hurdles, in several situations relationships and trust were successfully re-tooled on the basis of a deeper understanding of the initiative's mission, purpose, and goals. When collaboration was successful, Advocacy Ambassadors were invited to speak at group functions, such as the 2014 North Carolina Youth Leadership Forum, Partners in Policy Making, and several smaller meetings of self-advocates throughout the state providing invaluable access to additional respondents for both the individual and group surveys.

### Analysis of Findings

Addressed below are the key findings drawn from the Advocacy Ambassadors' investigation that consisted of surveying individual self-advocates across the state of North Carolina. The vast majority of respondents to the individual survey came from those advocacy groups to which the Advocacy Ambassadors made presentations. Of the 172,000 people with I/DD in the state, the Advocacy Ambassadors were able to make contact with approximately 500 self-advocates, were able to talk directly with over 300 of them, however only seventy-six of them were willing to respond to the individual survey despite the well-coordinated efforts to disseminate, publicize, and encourage candid responses.

While such a low response rate does not allow for statistically valid comprehensive patterns to be determined, the responses *do* reflect a number of important issues across many people in virtually every area of the state.

These most significant of these issues are:

- **The lack of understanding of pertinent issues, particularly in relation to system wide advocacy;**

- **Unwillingness to share candid opinions and sentiments** in writing, either for fear of information misuse or because of overt influence by family or support personnel in answering questions (i.e. major discrepancies between survey results and anecdotal data from private conversations is evident), and;
- Individuals appear to be more capable of ascertaining their personal contentment or additional support needs rather than those not involved with such groups.

Despite an active effort to assure otherwise, it became readily apparent that the survey questions were not as intellectually accessible (understandable) to more of the self-advocates than had been anticipated from our trial rounds.

Thus, the Advocacy Ambassadors had to spend upwards of 70 hours explaining/translating the questions to over 110 individual participants who agreed to allow us to assist them (see below for further information).

The Advocacy Ambassadors received regular comments and questions regarding certain portions of the survey, and the final results showed that many of the same items questioned or commented upon in discussion were later skipped on the paper survey, implying that there were a number of respondents who were confused by some survey items (issues) but were not willing and/or able to verbalize their lack of understanding (not willing to self-advocate for the assistance they needed).

In an attempt to resolve this issue without rewriting the survey, which would have invalidated previous responses, the Advocacy Ambassadors used a variety of approaches, including leading entire groups through the questions one by one and holding discussions about the question's intent before giving people the opportunity to respond.

The Advocacy Ambassadors also reminded participants regularly that the Advocacy Ambassadors were readily available to answer any and all questions. At times the Advocacy Ambassadors sat with self-advocates to support their processing and understanding of each question of the survey.

The seeming lack of understanding among self-advocates related to disability system issues points to a natural inclination on the part of respondents to focus on personal needs and their immediate struggles (see below for further discussion). In fact, for some advocates believe that the fight for their *basic* needs may preclude their ability to collaborate with others under a unified vision of system change, resulting in further polarization in the absence of identified unifying issues that they can embrace.

Another significant factor that affected the quality of information acquired from the surveys was observed in those instances where respondents needed direct assistance to fill out questionnaires. While significant measures were implemented to mitigate any effects from outside assistance, such as promoting the use of the online survey and offering support directly from the Advocacy Ambassadors during survey completion, eliminating all external influences of the responses from support staff and/or family members proved difficult.

Over the course of the Advocacy Ambassador's listening process it became increasingly evident that **the barriers self-advocates faced were openly expressed in private conversations, yet survey responses showed vastly different results.** Of particular interest is the discrepancy between conversations around the ability for one to choose where he/she lives or works and the corresponding responses on the survey.

Though not always obvious to the casual observer, the Advocacy Ambassadors observed potential conflicts of interest between providing candid answers to some survey items and the fear of possible repercussions on an individual's care/support. Support personnel too frequently, though not necessarily intentionally, imposed undue influence on final responses.

Of major significance to the Advocacy Ambassador Initiative is the recognition from survey submissions that relatively few self-advocates exhibit a functional understanding of advocacy issues at the system level.

To address the gap in understanding of overarching advocacy issues, it will be paramount moving forward that a major emphasis be placed on education, both through leadership development of individual self-advocates and technical

assistance to self-advocacy groups in order to identify the key issues pertinent to their constituents and developing working agendas to effect change.

In defining a self-advocate driven agenda, the Advocacy Ambassadors expect to see a greater willingness for honesty and candor to emerge as self-advocates throughout the state begin to recognize and take ownership of a collective voice free from the influence of external priorities.

The survey results provides some insight into how currently engaged self-advocates view their support of others and themselves. This is especially true in relation to efforts to improve community engagement, individuals' living, work, and financial situations, as well as support/service needs. However, based on the answers directed at *"how successful have your advocacy efforts been"*, we find it is difficult to ascertain if anyone thought any efforts they may have made on behalf of others were successful or not.

The responses to the questions pertaining to system function and people's perception of it (question #20-23) revealed relatively little. We know from many discussions with advocates, including self-advocates, at all levels, that there is a belief that the system does not function in the best interest of the families and individuals it is expected to serve. Unfortunately, the formal responses to the survey questions generally do not reflect those same sentiments.

The same issues again arise:

1. Are the survey answers being distorted by external forces?
2. Are respondents avoiding answering negatively, and, if that is the case, why?
3. Are the individuals in this sample somehow significantly different than the larger population we have spoken with?
4. Is it possible that people we spoke with were giving us verbal answers they thought we wanted to hear but these conversations do not reflect their true opinions?
5. Finally, is it possible that the respondents simply do not understand these questions, even though most seem to understand the questions when we are in conversations with them?

Regardless of the reason, there is at least one advocacy issue that needs to be resolved (and probably several). These range from fear to lack of information to an unwillingness to appear in need of support to giving answers to please others.

For example: Results to the questions #1-13 would indicate that a majority of self-advocates feel confident with regard to personal control over where and how they live, work, and engage in the community, and yet anecdotal feedback from both self-advocates and industry professionals exposes several underlying contradictions. **When pressed, many advocates are actually unaware of their freedom to choose anything of substance.**

Further, **rarely are self-advocates aware of the scope of existing options, rendering them ill-prepared to make informed decisions.** Even in situations where self-advocates are sufficiently educated about existing possibilities, **they often feel resigned to their current situation in the face of what they perceive as overwhelming system barriers.**

Engagement with respondents also uncovered incongruities between observed responses and feedback from conversations specifically around employment opportunities and one's ability to readily engage in the community of their choosing. It was observed that **a lack of education regarding employment options** and the individual right to requisite compensation paralleled the education gap identified in other areas mentioned above. At the same time, additional external influences such as availability of transportation seemed to play a far more significant role in perception of free choice by the respondents.

One aspect that remained consistent between survey results and interview responses, conversations, and other accounts, was the **overwhelming need for increased opportunities for greater social and community engagement.** Within the survey itself, responses to questions pertaining to advocates' social lives and need for community engagement (#7 & #8) were virtually the same. Nearly 75% of respondents either *Strongly Agree* or *Agree* that they would like to know more about ways to be connected to their community and would welcome support in expanding their social lives. Given that the vast majority of the survey respondents are, to one extent or another, already involved with an self-advocacy group or are already identified as "strong self-advocates", it stands to reason that the broader I/DD population has an even greater need in this area.

## Findings and Observations

As survey responses, in general, frequently conflicted strongly with feedback from the meetings, discussions, and verbal interactions with those involved in self-advocacy groups, several conclusions may be distilled:

- Conflicting responses throughout the survey process point to an **overall state of disarray in the N.C. self-advocacy movement** that has operated without a cementing purpose or providing a force for change within the community;
- Continued influence of outside parties (service providers and/or family members or others) **interferes with defining agendas for collaboration as well as preventing a clear picture of the overarching needs of the I/DD community overall**;
- Social isolation and lack of connectedness persists as a barrier, even among the most outspoken advocates across the state;
- **Transportation continues to be a barrier for many** to becoming involved in a group or making changes in their lives for work/education, living arrangements, or expanding social contacts, and **many are effectively resigned to social isolation and minimal employment**;
- Survey results differ substantially from direct conversations about system accountability, service provision, and inclusion in system design, with conversations being far more negative/critical, and;
- **Much more education/training is required to close major gaps in most self-advocates' understanding of personal rights, housing options, employment, finances and asset building.**

## Proposed Response for Enhancing Individual Self-Advocacy

In light of the discrepancies between anecdotal observations (as an example, being told by self-advocates that professionals overtook their efforts) and documented survey results (which indicated they felt supported appropriately and not overwhelmed or overtaken by staff), and as a response to the knowledge gaps around such important issues as self-determination, employment, living situations, and system accountability, the Advocacy Ambassador Initiative team proposes a multi-faceted effort.

This would consist of at least the following approaches:

- Development of intellectually accessible modular "Leadership Development" curriculum and other related educational curriculums to be delivered to existing or "newly forming" self-advocacy groups and across the I/DD population, establishing a common reason for engagement;
- Development of an inter-group communication network founded upon identification of common needs and priorities across the state;
- Technical assistance to support the self-advocates' ability to communicate preferred life situations, including work and social engagement as well as where they call home, to provider organizations and other stakeholders;
- Development of invested self-advocates for leadership roles in existing and new/developing organizations and;
- Establishment of mechanisms to enable self-advocate led agenda design and infrastructure/support implementation.

The effect of these approaches would lead to lessening educational deficiencies while enhancing self-advocates' abilities to communicate their desires openly and in a productive manner that fosters collaboration in many different situations.

The detailed recommendations are outlined in Section IV.



#### Section IV: Recommendations for a Path Forward

Given the above observations concerning the state of self-advocacy in North Carolina, a multi-dimensional approach to strengthening and fostering collaboration among willing and interested parties is required to ensure that the self-advocacy movement within NC becomes both unified and effective in its mission and objectives.

Initially, a strong emphasis needs to be placed on forging a cohesive infrastructure that combines strengthening and expanding self-advocacy groups, the communication between groups across the state, and the development of self-advocate leaders committed to collaborating.

To this end, our recommendation is that emphasis be placed on three most immediate areas of need:

- Technical Assistance;
- Communication and Technology, and;
- Leadership Development

Additional consideration must also be given to the strategic design and formation of an infrastructure that can support and harmonize the evolution of the state's self-advocacy movement over the coming years by self-advocate leadership.

In addition to these three focus areas targeting the enhancement and rebuilding of a cohesive self-advocacy movement in North Carolina, continuing efforts must build on an established collaboration with the state through the Department of Health and Human Services and Division of MH/DD/SAS in order to enhance access to materials and information to self-advocate consumers.

Such collaboration could take the form of one or more contracts to provide the following:

- Evaluating current and newly designed materials for intellectual accessibility and ease of understanding
- Translating materials into consumer-friendly formats
- Obtaining consumer feedback
- Support with distribution of materials to self-advocates

- Providing information sessions and events throughout the state regarding consumer advocacy and other topics pertinent to self-advocates

### Recommendations for Establishing and Infrastructure

As noted earlier, our findings reveal a substantial need for Technical Assistance (TA), both among existing groups and among pockets of self-advocates interested in formalizing their activities. Activities within the realm of TA may include, but are not limited to the four areas below:

- Strategic development for existing groups, many of which currently operate without key components crucial for successful self-governance such as: published mission and vision, defined goals, by-laws, an identified leader/leadership, and effective Board dynamics
- Team building and communication skills
- Board development
- Incorporation and affiliation strategies for new groups

Technical Assistance efforts will also coincide with, and strive to reinforce, the other two primary focal areas, Communication and Technology, and Leadership Development. **This approach serves to foster sustainability, capacity development, and collaboration for both individual advocacy groups and the state-wide self-advocacy movement.**

### Immediate recommendations include the following:

- Support for unincorporated groups interested in formalization
- Formation of standardized and replicable incorporation processes for emerging groups
- Development of a modular curriculum on self-advocacy organization and Board governance to include visioning and course setting, by-law development, and Board function and operations
- Provide additional strategic development to self-advocacy groups as further needs are identified

A recurring theme throughout the investigation process, from conversations with leaders of organizations and individual advocates, was the barrier of maintaining long-term, meaningful engagement among groups and their membership.

Often, hidden beneath complaints of insufficient transportation or ineffective uses of technology, is the struggle to engage self-advocates in ways that fosters listening, collaboration, and respect, whether within the organization or between groups of advocates. This has caused further isolation among many self-advocates and groups across the state.

The second area of emphasis, Communication and Technology, would aim to address this through:

- Assessing the specific communication and technology needs of self-advocacy groups throughout the state, particularly those in which transportation is an identified barrier to the group's operations
- Fostering communication and collaboration among self-advocacy organizations across the state
- Identifying groups with aligned goals and interests
- Creating linkages between those groups to promote mutual support.

**Immediate recommendations include these items:**

- Develop a Communication and Technology needs assessment for existing self-advocacy groups
- Partner with local and state-wide technology resources to address barriers with innovative solutions
- Establish an inter-organizational liaison network to enhance conversation between groups
- Build inter-organizational alliances through joint training on topics of common interests

An essential aspect to assure positive and continued growth of self-advocacy within North Carolina, and a fundamental prerequisite toward making the impact of technical assistance and communication building efforts sustainable, is the identification and development of self-advocates with the potential to become

leaders within a unified movement across the state. These individuals must be recognized for their willingness to work effectively with diverse populations and toward common goals.

As highlighted in other sections, historical leadership by self-advocates has been rife with power struggles, personal agendas, and an overarching unwillingness to collaborate.

To address this, the third key area of emphasis, leadership development, will focus on enhancing the skills of cooperation and leadership for both current as well as up-and-coming self-advocates, through training that is not only self-advocate developed and led, but also holds at its core, the principles of inclusion, team building, and collaboration.

In addition to an identified historic unwillingness to collaborate across groups and individuals alike, our interviews and surveys reveal an extremely limited understanding of pertinent issues relevant to North Carolina self-advocates.

To address this, the approach proposed below for leadership development will also prove essential in educating self-advocates about the following priorities:

- Asset development
- Integrated employment
- Inclusive living
- Person-centered planning
- Self-direction
- Medicaid HCBS changes and options
- System accountability, etc.

Through supporting emerging self-advocate leaders with an understanding of how to integrate and advance these priorities within the self-advocacy movement, the results of these efforts will have positive effects throughout the state.

Immediate recommendations around leadership development include the following:

- Development of training focused on collaborative leadership/coalition building for self-advocate organizations to be replicated as a train-the-trainer model
- Creation of leader identification mechanisms and tools for supporting emerging self-advocate leaders
- Development of leadership/Board recruitment training curriculum for self-advocate organizations
- Development of a personalized leadership development program for emerging and established group leaders
- Ensure integration of principles outlined by the SEG into educational modules to be delivered in parallel with leadership and TA modular training

In addition to the above recommendations, it is crucial that consideration also be given to the most efficient and self-sustainable means of implementation.

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## National Picture Relative to N.C.

The National Leadership  
Consortium | on Developmental  
Disabilities

at the University of Delaware

### Best Practices in Self Advocacy Organizations:

In this report we provide a history of the self advocacy movement in the United States, a review of existing literature relevant to the self advocacy movement and the operation of self advocacy organizations and a discussion of research conducted to identify best practices, obstacles and, when known, paths to overcome obstacles to self advocacy organizations' ability to self-direct and achieve self-identified outcomes.

### History of Self Advocacy:

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*In 1968, self advocacy was first introduced as part of the civil rights movement in Sweden. Early writings by Bengt Nirje addressed the disparities that many people with developmental disabilities experience regarding self-determination, respect and dignity (Shapiro, 1993). Nirje called for action to support people to choose and control how they lived their lives, including "personal activities, education, independence, participation in decision making and information upon which to make decisions and solve problems (Ward, 2005, p. 108)."*

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In 1968, self advocacy was first introduced as part of the civil rights movement in Sweden. Early writings by Bengt Nirje addressed the disparities that many people with developmental disabilities experience regarding self-determination, respect and dignity (Shapiro, 1993). Nirje called for action to support people to choose and control how they lived their lives, including "personal activities, education, independence, participation in decision making and information upon which to make decisions and solve problems (Ward, 2005, p. 108)."

One of the earliest known self advocacy groups was started in 1868 in Stockholm as a social club for people who were deaf. The "Stockholm Deaf Club" still operates today (World Institute on Disability, 2005). This club's foundation and purpose are significant. It was the first non-medically related organization that offered people with similar disabilities to come together to speak about issues they experienced and participate in social and community activities.

The independent living and disability rights movement gained momentum in the 1960s, influenced by the social and political consciousness of other civil rights movements of the

period (Funk, 1987). Individuals with disabilities began relating their own oppression with that of other disenfranchised groups (Lehr & Taylor, 1986).

Ideologies such as normalization (Wolfensberger, 1969) encouraged self advocacy movements in the 1980s as "the drive for inclusion surfaced, criticizing 'home-like' and 'job-like' simulated programs (Pennell, 2001, p. 1)." Similarly, person centered thinking and planning models that recognized the right of the person using supports as an individual with unique needs, goals and desires aligned with the principles of self advocacy. These principles were further defined by People First in 1974 as members met to support one another and became active participants in decisions affecting their lives (Longhurst, 1994).

Most self advocacy organizations were born out of dissatisfaction with current policies or practices. Most addressed one or more of these major issues: the need to close institutions, end labeling, create legislation to prevent abuse in public institutions or group homes, address

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*There is considerable evidence demonstrating that when people with disabilities experience self-determination, including choice and control over their services and access to the communities of their choosing, they have better outcomes. The work of the Council for Quality and Leadership demonstrated that when people move from institutions to community settings there is no trade off in health and wellness, freedom from abuse, or safety.*

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stereotypes, change the criminal justice system to protect people with disabilities, assure that people with disabilities achieve employment and receive competitive wages, increase membership in local civic groups, and/or achieve inclusion in schools (Bullock, 2010).

The concept of self-determination is based on the shift of power from the system to the individual. The goal of self-determination is to offer people with disabilities opportunities to choose how they live and by what means they will be supported (Pennell, 2001). The overall goal of self-determination, explained by Martin and Marshall, is for people with disabilities to be 'knowing of their choice, by knowing what they want and how to get it' (Pennell, 2001). Four major principles on which self-determination focuses are freedom, authority, support and responsibility (Nerney, 2012).

There is considerable evidence demonstrating that when people with disabilities experience self-determination, including choice and control over their services and access to the communities of their choosing, they have better outcomes. The work of the Council for Quality and Leadership demonstrated that when people move from institutions to community settings there is no trade off in health and wellness, freedom from abuse, or safety. Community living results in better quality of life and social capital (Council on Quality and Leadership, 2008).



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*Historically however, well-accepted principles of self-determination have not translated to the social and economic support of self advocacy groups in the United States. In countries such as the United Kingdom, it is common for self advocacy organizations to receive direct funding from the government (Ramcharan, 2005). In the U.S., however, there is no federal source of on-going funding to self advocacy groups. Funding therefore is often provided sporadically and on a case-by-case basis. In some states, Developmental Disabilities Councils or other organizations will write self advocacy organizations into grants or other funding initiatives to both assure that the voices of self advocates are represented and to support the sustainability of self advocacy organizations.*

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Beginning in 1996, the Robert Wood Johnson Foundation provided \$5 million dollars to help states change their current systems to those that support self-determination. Additional grants have been provided to organizations and groups such as People First and The Arc of the United States to develop programs and trainings to promote and educate people about self-determination.

Historically however, well-accepted principles of self-determination have not translated to the social and economic support of self advocacy groups in the United States. In countries such as the United Kingdom, it is common for self advocacy organizations to receive direct funding from the government (Ramcharan, 2005). In the U.S., however, there is no federal source of on-going funding to self advocacy groups. Funding therefore is often provided sporadically and on a case-by-case basis. In some states, Developmental Disabilities Councils or other organizations will write self advocacy organizations into grants or other funding initiatives to both assure that the voices of self advocates are represented and to support the sustainability of self advocacy organizations. Adequate, on-going funding for self advocacy efforts has been and remains

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*According to Wolf (2002) barriers to forming a self advocacy coalition include: turf issues, failure to act, dominance by professionals, poor links to the community, minimal organizational capacity, funding, the failure to provide and create leadership, the costs of working together, and costs outweighing the benefits.*

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limited due to financial and social barriers (Pennell, 2001; Kardell, 2012).

An additional problem is that there has been a lack of inclusion and recognition of the self advocacy community in broader social institutions and efforts. Due to the marginalization of people with disabilities they have experienced great difficulty being recognized as having a legitimate and equal voice (Nussbaum, 2002). According to Wolf (2002) barriers to forming a self advocacy coalition include: turf issues, failure to act, dominance by professionals, poor links to the community, minimal organizational capacity, funding, the failure to provide and create leadership, the costs of working together, and costs outweighing the benefits.

Additionally, self advocates often identify as a barrier to effective achievement of their organizations' goals that they are not given enough time to execute activities and that they do not have sufficient funding to operate effectively. Often the lack of skill, training or support in the areas of leadership, group management, negotiation and ways to access resources are identified as barriers and limit self advocacy groups' participation or efficacy in policy and

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*Some research has addressed the relationships between self advocates and advisors. Trust and friendship are highlighted as important in a functional relationship between self advocates and advisors (Tilley, 2011). Advisor/self advocate relationships can fall along a continuum of "person-led" at one end, when the advisor provides support but self advocates are in full control of all decisions*

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advocacy-related efforts.

There has been little research about the structures and functions of self advocacy organizations or how they function in relationship to a larger organization which provides funding or under which they operate (umbrella organizations). Some research has addressed the relationships between self advocates and advisors. Trust and friendship are highlighted as important in a functional relationship between self advocates and advisors (Tilley, 2011). Advisor/self advocate relationships can fall along a continuum of "person-led" at one end, when the advisor provides support but self advocates are in full control of all decisions and "advisor-dominated" at the other end; when the advisor oversteps his/her role by influencing or dominating to too great a degree. Although there are anecdotal accounts of a wide range of relationships, from person-led to advisor-dominated, actual research is limited and necessary to understand how these relationships affect the function and operation of self advocacy organizations (Kardell, 2012).

Although we know that self-determination is related to better outcomes for people with intellectual and developmental disabilities and that limiting choice and control is detrimental to people's wellbeing, we have not successfully applied this knowledge in all instances to the successful function and operation of self advocacy organizations.

### Research Questions

To begin to address the gaps in knowledge related to the structural and operational supports and barriers to operating effective self advocacy organizations. Issues that were examined include the manner in which self advocacy groups operate; the relationships between self advocate leaders, advisors and representatives of funding or umbrella organizations; as well as structures within and outside of the self advocacy organization that either promote or hinder successful outcomes. This study focused on the following research questions:

- How do self advocate leaders, advisors and leaders of funding or umbrella organizations see their roles in the management and functioning of self advocacy groups? Specifically:

- What are the differences and similarities between self advocate leaders, advisors and leaders of funding or umbrella organizations as they see their roles?
- How do those differences and/ or similarities affect the functioning of self advocacy organizations?
- What are the operational and structural factors that support or hinder successful self advocacy groups? Specifically:
  - What are the similarities amongst successful self advocacy organizations?
  - What are the common barriers, concerns or challenges that self advocacy organizations face?

## Methodology

### Sample

To gather participants, researchers used purposive and snowball sampling techniques (Patton, 2002). First, an internet search for statewide self-advocacy organizations for people with intellectual and developmental disabilities was conducted using national disabilities-related websites. Emails were sent to contacts for statewide self advocacy organizations as well as contacts for each state's Developmental Disabilities CouN.C.il with a description of the project and a request for the person being contacted to either participate in an interview or send contact information for people who met the participant criteria. Follow-up phone contact was made with people who did not respond to email requests.

As contact information was gathered, each potential interview participant was sent an email containing a description of the project, a description of the participant role criteria and a request to participate and/ or identify potential interview participants. Potential participants were also sent a consent form explaining the purpose of the project, ensuring their confidentiality and indicating that the person could choose not to participate at any time. Each participant agreed to the consent form by signing and sending it back electronically or by consenting verbally during a recorded conversation.

As potential respondents agreed to participate, researchers clarified the person's role within the self advocacy organization or umbrella organization to ensure that each participant met the criteria. Criteria were as follows:

- **Self advocate leaders:** Identify as a self advocate and hold a position of leadership (preferably president) within the self advocacy organization.
- **Advisors:** Have a formal role and currently act as an advisor to the self advocacy organization.
- **Umbrella Organization Leader:** Holds a leadership position in the umbrella organization (definition below).
- **Umbrella Organizations:** Organizations under which self advocacy organizations operate. The self advocacy organization may receive funding from the Umbrella

Organization and operates under the auspices of the organization or as a program of the organization.

The final sample of individuals with whom interviews were conducted included fifteen self advocate leaders, eleven advisors and nine leaders from umbrella organizations. The sample included people from twenty-three states: New Jersey, Washington, Nevada, New York, Pennsylvania, Delaware, Texas, Kansas, Massachusetts, Indiana, Maine, Ohio, Alaska, Utah, The District of Columbia, California, Rhode Island, Vermont, Wisconsin, North Dakota, Colorado, Connecticut and Louisiana.

### **Semi Structured Interviews**

Researchers clarified each participant's role in order to accurately categorize responses and analyze the similarities and differences in responses between self advocate leaders, advisors and leaders of umbrella organizations. Each participant was interviewed over the phone or in person by trained interviewers.

Researchers created a semi-structured interview for each type of participant. Semi-structured interviews are useful when there are specific research questions but little is known about the interviewee. This approach allows the interviewee to respond to specific topics yet to answer in ways that are relevant and meaningful to them (Patton, 2002). Semi-structured surveys allow researchers to follow up with and clarify responses to ensure that they are truly capturing people's thoughts and experiences (Patton, 2002).

Each interview contained similar questions to allow researchers to triangulate responses and to assess the similarities and differences among the responses of self advocate leaders, advisors and leaders from umbrella organizations. Questions were worded to be relevant to each type of participant. (Survey questions are attached in Appendix A).

Each interview lasted approximately thirty minutes with the shortest interview lasting fourteen minutes and the longest lasting one hour and forty three minutes; this was an in-person group interview of four self advocate leaders from Delaware. Interviews were recorded and transcribed for analysis, however all identifying information, including name and organization was removed from the report to ensure confidentiality.

### **Analysis**

Responses were analyzed using thematic analysis, a method used to identify, analyze and report patterns within data (Boyatzis, 1998). Thematic analysis is a useful and flexible qualitative method that allows researchers to explore and organize data (Braun & Clarke, 2006). Braun and Clarke (2006) suggest a six-phase process that was used which includes:

- 1) Familiarizing yourself with the data,
- 2) Generating initial codes,

- 3) Searching for themes,
- 4) Reviewing themes,
- 5) Defining and naming themes, and
- 6) Producing the report.

Researchers reviewed the results from each interview and individually coded them for themes. Themes were discussed, recoded and renamed by a group of researchers to increase the reliability of the findings (Braun & Clark, 2006). Once themes were agreed upon, the results were organized by research question to ensure that each topic area was adequately addressed.

## Results and Findings

How do self advocate leaders, advisors and leaders from umbrella organizations see their roles in the management and functioning of self-advocacy groups?

Participants described their own roles as well as their perceptions of the roles of the advisors and umbrella organization leaders.

### Self Advocate Leaders

Self Advocate Leaders, by and large, described themselves as the leaders of their self advocacy groups using phrases such as, "I am in charge, I make the decisions." Leading, as described by the self advocates interviewed included tasks and responsibilities related to decision making, determining the group's goals, determining self advocacy initiatives and actions, defining roles among self advocate leaders and determining how the group's funds should be spent.

Self advocate leaders recognized that these were their roles, however many of them also recognized that their actual power and opportunities for decision making depended on the other members of their group, the support received from their advisors and their relationship with their umbrella organizations (where one existed). Many self advocate leaders described conflicts between members within the group and problems stemming from people having different goals or wanting to move in different directions. They indicated that sometimes the advisor was asked to (or did) step in to resolve conflict among members.

Self advocate leaders also identified conflicts between themselves and their advisors or umbrella organizations. They consistently described the role of an advisor as a support person to clarify and guide but not someone who should be making decisions. However, they recognized that sometimes "they (advisors) think they know what's best" and that sometimes the advisor did inappropriately share his/her opinions in a perceived effort to convince members to agree.

Self advocates were sometimes unclear of the role and relationship with their umbrella organization (if they identified one as existing). In some cases they stated that because the umbrella organization provided funding this sometimes led to a potential for conflict of

interest. One self advocate leader indicated that the umbrella organization funded group homes and also funded their self advocacy organization which spoke out in opposition of group homes. A few self advocate leaders described frustration with their umbrella organization because they "tell us what to do so that we can get funding."

In many cases, self advocate leaders recognized that in order to receive funding from their umbrella organization they had to provide a product or serve in a particular role such as providing training or support to an organization or Developmental Disabilities Council. Many did not feel that they had enough of a say in the product they were expected to produce or the role they were asked to play. For instance, one self advocate told the researcher that the Developmental Disabilities Council tells them what kind of training they need and pays them to provide training on that topic. While this person acknowledged that it was understood that funds are limited and only available to meet particular needs, the self advocate leader did not

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*One person indicated that there is often conflict among group members and that when this occurs the role becomes that of a buffer to address the issue before the group as a whole can move forward.*

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feel that it aligned with the principles of self-determination and self advocacy to be told what type of training was needed instead of being a part of the process to identify training needs.

#### Advisors

Advisors consistently described their roles as responsible for providing guidance, support and clarity but not to make decisions. Every advisor indicated that the self advocates were the ultimate leaders and decision makers in the group and that their job was to take a back seat and support the self advocates to be decision makers. Advisors did agree that this was sometimes a struggle and that they had to be very intentional in their roles. Some admitted to "overstepping boundaries every now and again," due to having more experience, knowing more about the situation and understanding the complexity and the context more clearly. They recognized that although they are passionate about the issues addressed by the self advocacy groups, they are not living the experiences of the self advocates and therefore felt that they sometimes needed to provide an objective voice to the discussion.

Advisors also indicated that their role sometimes became that of the peacemaker, either among self advocates in the group, or between the self advocates and the umbrella organizations. One person indicated that there is often conflict among group members and that when this occurs the role becomes that of a buffer to address the issue before the group as a whole can move forward.

The advisors also recognized the potential conflict of interest between the self advocacy groups and the umbrella organizations. They indicated that they sometimes felt pressure from the umbrella organizations to move the group in a particular direction in order to receive funding and felt conflicted when they felt pressure to influence the self advocacy group in this way. When this happened, a few people said that their role became that of an educator for the self advocacy group and as a liaison between the group and the umbrella organization. As educators they tried to help the self advocates understand the pressures the umbrella organization was under or the conditions of the funding. They attempted to help the self advocacy group understand the need for funding in order to succeed and tried to objectively present all sides and brainstorm possible outcomes with the group.

### Leaders of Umbrella Organizations

Leaders of umbrella organizations expressed sometimes conflicting values and described how they negotiate that conflict with the self advocacy organizations. Specifically, they recognized that as funders they have a level of power over the functioning and success of the self advocacy organization and that this power has the potential to be in direct conflict with the ideologies of

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*Techniques mentioned as being used to establish this collaboration included: consistent communication, collaboration on funding opportunities such as grants and state initiatives, involving the groups and leaders in the planning stages of projects and funding opportunities, and evaluation of their own motives and actions towards self advocate leaders and groups to ensure that their behaviors and funding opportunities are always in alignment with the values of the group and principles of self-determination.*

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self advocacy and self-determination. They described efforts to work collaboratively with self advocacy organizations and leaders rather than having power over them. Techniques mentioned as being used to establish this collaboration included: consistent communication, collaboration on funding opportunities such as grants and state initiatives, involving the groups and leaders in the planning stages of projects and funding opportunities, and evaluation of their own motives and actions towards self advocate leaders and groups to ensure that their behaviors and funding opportunities are always in alignment with the values of the group and principles of self-determination.

At the same time, the leaders from the umbrella organizations recognized that funds are limited and funding opportunities must meet the needs of a particular group, community, etc. They expressed frustration with the idea of funding solely for the sake of the operation of the self advocacy group if nothing was being produced that was of value to them as funders or their communities. A few umbrella organization representatives described a constant communication process that they have with the leaders of the self advocacy groups; they indicated that they sometimes need to remind the groups that funding is only available for

certain projects and that the sustainability of their group may depend on participating in a project that is not directly aligned with their interests and goals.

No umbrella organization representatives discussed any specific conflicts of interest regarding the values or practices of their umbrella organization and the values and goals of the funded self advocacy group. Because researchers were trying to ensure that participants were able to communicate openly and honestly, they were not asked directly to discuss these potential conflicts. However, it is important to note the differences in responses with regard to potential conflicts of interest between the self advocate leaders and advisors and the leaders from the umbrella organizations.

#### **What are the operational and structural factors that support or hinder successful self advocacy groups?**

The self advocate leaders, the advisors and the leaders from the umbrella organizations were all asked to identify the structures and systems that support or hinder the successful functioning of a self advocacy organization. Each group noted that any particular factor can have either a positive or negative effect on the successful functioning of a self advocacy organization. For example, each group identified the relationships among the three groups as the main factor that can either support or hinder the functioning of the self advocacy group. Relationships were described as either based on mutual respect and support or based on what self advocates perceived to be dictating activities and direction or an interest only in activities that met the umbrella organization's needs or that could be funded.

The successful functioning of a self advocacy organization was determined by the working relationships among the self advocates, the advisors and the umbrella organization representatives. Successful factors included relationships that were based upon respect, that honored the principles of self-determination and that made the goals of the self advocacy group a priority.

Interviewees from each group indicated that successful relationships incorporated some type of

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*Interviewees from each group indicated that successful relationships incorporated some type of professional and/or business model.*

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professional and/or business model. For instance, leaders from umbrella organizations said that when the self advocacy groups were formally involved in the planning and development of funding opportunities and were responsible for reporting their spending and outcomes to the funders, the level of respect between the parties increased. One umbrella organization leader noted that as work was accomplished to professionalize the relationship between the umbrella organization and the self advocacy group, the self advocacy groups felt and acted noticeably



more professionally in all areas, including in their meetings, their trainings and their presentations to the Developmental Disabilities Council.

Self advocates and their advisors agreed that when the umbrella organization treated them with respect as a legitimate and professional group, which included asking them to participate in the development of funding opportunities, involving them in planning processes instead of telling them what they will or will not fund, guiding and supporting them to find additional sources of funding, and training them in areas such as leadership, grant writing, public speaking, etc., they were more successful and able to better advocate and grow as a group.

Additionally, each group noted that it was important for each member to know his or her role and consistently act in accordance with that role. When advisors are able to consistently support, provide clarity and guidance without expressing their own opinions or acting in ways that could be interpreted as coercive, the self advocate leaders felt more empowered, were

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*Ultimately, there was agreement that the successful operation of self advocacy groups depends on a respectful relationship among all parties: the self advocate leaders, the advisors and the representatives of the funding or umbrella organizations. A mutual commitment to the self advocacy organization's right to determine and achieve its own goals was paramount. These findings align well with principles of self-determination, ideals related to person centered practices and supporting people with intellectual and developmental disabilities to have choice and control over every aspect of their lives.*

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more satisfied with the outcomes their groups achieved, and were better able to lead their groups with confidence. Similarly, when the leaders of the umbrella organizations were able to work with the self advocacy groups to plan initiatives or seek funding opportunities and were able to respect the group's decision to decline an opportunity or to address a conflict of interest between the two organizations, both groups viewed themselves as better able to build a collaborative relationship and be more successful. One leader from an umbrella organization described a collaboration process in which the Developmental Disabilities Council moved away from being the main funder of the self advocacy group and took on a different role, working together with the self advocacy group to advocate on mutually important issues across the state. This person described this new relationship as a collaborator rather than as a funder as ideal because it allowed the self advocacy group to operate more independently and allowed them to advise each other and provide a common voice on statewide issues.

Ultimately, there was agreement that the successful operation of self advocacy groups depends on a respectful relationship among all parties: the self advocate leaders, the advisors and the representatives of the funding or umbrella organizations. A mutual commitment to the self advocacy organization's right to determine and achieve its own goals was paramount. These findings align well with principles of self-determination, ideals related to person centered practices and supporting people with intellectual and developmental disabilities to have choice and control over every aspect of their lives.

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*A focus on both respectful relationships among representatives of all groups and business-like practices is the combination that has the best chance of assuring that self advocacy organizations enjoy both the autonomy and support needed to achieve their self-determined goals.*

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It is important to continually evaluate the practices and values of people who are in positions to advise and fund self advocacy organizations to ensure that adherence to these principles is consistently present. It is equally important that efforts are made to include self advocacy groups in all stages of funding development and to provide training and support so self advocate leaders understand the funding requirements under which their umbrella or funding organizations operate. A focus on both respectful relationships among representatives of all groups and business-like practices is the combination that has the best chance of assuring that self advocacy organizations enjoy both the autonomy and support needed to achieve their self-determined goals.

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## APPENDIX A

### INTERVIEW QUESTIONS

#### Questions for Self-Advocate Leaders

1. Can you describe the purpose and structure of \_\_\_\_\_? (name of organization or group)
  - a. *Prompts: why the group started (for what cause), what your goals are, what the group does, how often you meet, who the staff/ volunteers are, who the leaders are, how the organization is structured (who works with/ for who; whether the organization is under the umbrella of another organization and what organization that is)*
2. Can you describe your role as a self-advocate leader in \_\_\_\_\_? (Name of self advocacy organization/ group)
  - a. *Prompts: Description of job, major responsibilities, common/ day to day tasks*
3. Does the group have one or more advisors; people who help the organization to achieve its goals?
4. *(If applicable- question 3 is yes)* Can you tell me about your relationship with your group's advisor? Can you describe any challenges in working with the group's advisors?
  - a. *Prompts: how do you feel that the person is helpful or not? Can you describe the person's leadership role? How do you feel that the advisor takes on more or less of a leadership role than he or she should?*
5. *(If applicable)* Can you tell me about your group's relationship with \_\_\_\_\_? (Name of umbrella/ funding organization).
  - a. *Prompts: What is the best part about \_\_\_\_\_ as an umbrella for your organization? What are the problems or challenges with them being the umbrella organization?*
6. What are your greatest successes as a self-advocacy organization, and what supported you to succeed?
  - a. *Prompt: policies, organizational structures, specific people, relationships with other organizations, etc.*
7. What are the biggest barriers or problems that you think the organization has or needs to address?
8. What are the biggest barriers of problems that you face as a self advocate leader in your organization?

### Questions for Advisors:

1. Can you describe the purpose and structure of \_\_\_\_\_? (Name of organization or group)
  - a. *Prompts: why the group started (for what cause), what the organization's goals are, what the group does, how often you meet staff/ volunteers, organizational leadership structure (who works with/ for who)*
2. Can you describe your role as an advisor to \_\_\_\_\_? (Name of self advocacy organization or group)
  - a. *Prompts: Description of job, major responsibilities, common tasks*
3. Can you tell me about your relationship with the self-advocate leaders in your organization?
4. What challenges do you face as an advisor?
  - a. *Prompts: Can you describe circumstances in which it wasn't clear how to best advise the organization?*
5. (If applicable) Can you tell me about your groups' relationship with the \_\_\_\_\_? (Name of umbrella/ funding organization). Can you describe any challenges of which you are aware with the organization being under \_\_\_\_\_'s umbrella?
6. What are the self advocacy group's greatest successes as a self-advocacy organization, and what supported them to succeed?
  - a. *Prompts: policies, organizational structures, specific people, relationships with other organizations, etc.*
7. What are the biggest barriers that you face as an advisor to the organization?

### Questions for Leaders of Umbrella/ Funding Organizations

1. Can you describe your organization's role and relationship with \_\_\_\_\_? (Name of self advocacy organization or group)
  - a. *Prompts: funding structure, supervisors, management and oversight*
2. Can you describe the purpose and structure of \_\_\_\_\_? (name of the self advocacy organization or group)
  - a. *Prompts: why the group started (for what cause), what their goals are, what the group does, how often you meet with self advocacy staff/ volunteers, organizational leadership structure (who works with/ for who)*
3. What are the greatest successes of \_\_\_\_\_? (Name of self advocacy organization) and what supports them to succeed?

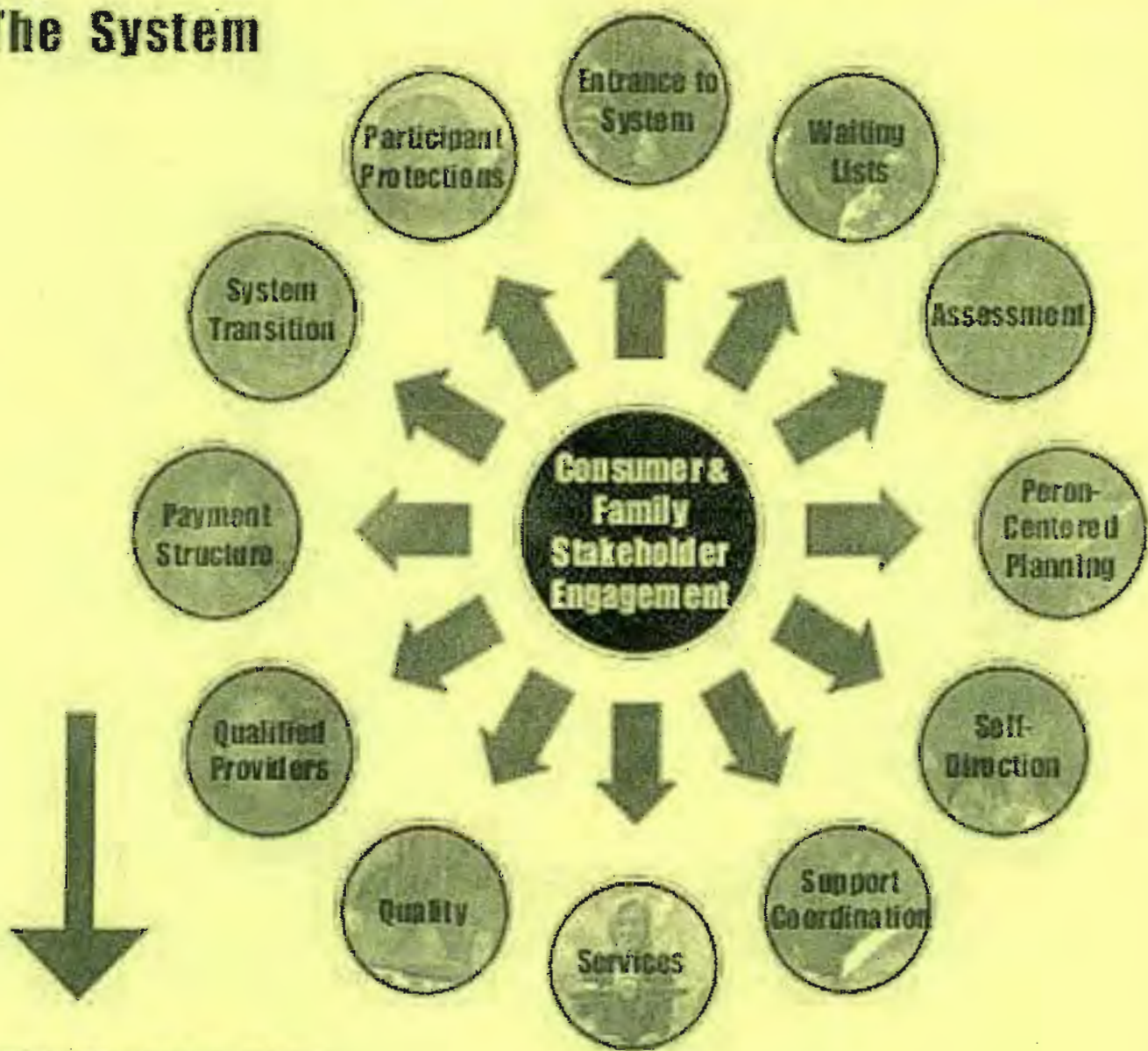
a. *Prompts: policies, organizational structures, specific people, relationships with other organizations, etc.*

4. What are the biggest barriers that your organization faces in relationship to \_\_\_\_?  
(name of self advocacy organization or group)

The SEG Way to a Healthy North Carolina

# A Consumer & Family Centered Approach for Managed Long Term Services and Supports Implementation

## The System



## The Outcomes

- No Waiting Lists
- Integrated Employment
- Inclusive Living
- Asset Development
- An Accountable System

For more information, contact Co-Chairs of the Stakeholder Engagement Group Michael Mayer, Ph.D., President of National Alliance on Mental Illness (NAMI-NC) at [mikem@nami.org](mailto:mikem@nami.org) or Ron Reeve, Chairman of the North Carolina Council on Developmental Disabilities (NCCDD) at [r7777@carolinasr.com](mailto:r7777@carolinasr.com)



### Questions for Representatives Historically Involved with State-Wide Advocacy

1. What has been your experience/involvement with self-advocacy in NC (local, regional, or statewide)?
2. Are you currently active in self-advocacy in NC (local, regional, or statewide)? If yes, how?
3. Can you describe in a sentence or two what you think effective state-wide self-advocacy in NC would look like?
4. Can you briefly describe the current state of self-advocacy in NC from your perspective?
5. On a scale of 1-10, how effective do you think state-wide self-advocacy efforts have been for people with IDD?
6. What do you think are the 5 biggest historic problems associated with state-wide self-advocacy in NC?
7. What would be your top 5 recommendations to correct these problems and/or establish effective state-wide self-advocacy in NC?
8. On a scale of 1-10, how effective do you think state-wide self-advocacy efforts COULD BE for people with ID/DD?
9. What potential resources do you envision being needed to achieve this outcome/score?
10. Any closing thoughts, issues, concerns, suggestions?
11. Can you help us reach organizations or leaders?

## Self-Advocacy in NC – A Personal Survey      PUBLISHED VERSION

This survey is about your thoughts and feelings related to self-advocacy to assist the Advocacy Ambassador Initiative of the NC Council on Developmental Disabilities to understand what matters most to self-advocates and how to support people to obtain the assistance they need to have the lives they deserve. This survey is confidential.

1. **Self-Advocacy Means To Me:** *(please check all that apply):*

- Helping people learn about my disability
- Speaking for people who cannot speak for themselves
- Talking or writing to people who make laws about issues that concern me
- Speaking up for myself when I am upset about the way I am treated
- Making new friends and working together with them
- Other (please explain) \_\_\_\_\_

2. **I feel free to have hopes and dreams:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

3. **I belong to a self-advocacy group that meets my needs and expectations:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

4. **I would like to be involved with a self-advocacy group/more self-advocacy groups:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

Self-Advocacy in NC – A Personal Survey      PUBLISHED VERSION

5. I feel I am able to change my living arrangements if I want to:
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know/Doesn't Apply
  
6. I feel I am able to change my work and/or school arrangements if I want to:
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know/Doesn't Apply
  
7. I would like to know about more ways to be connected to my community:
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know/Doesn't Apply
  
8. I would like help in finding ways to expand my social life:
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know/Doesn't Apply
  
9. I would like to change where I live:
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know/Doesn't Apply

**Self-Advocacy in NC – A Personal Survey**      **PUBLISHED VERSION**

10. I feel I get (or can change) the services and supports I really need:
- Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know/Doesn't Apply
11. I want to learn more about my personal rights:
- Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know/Doesn't Apply
12. I feel my personal rights are respected:
- Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know/Doesn't Apply
13. I feel empowered to make decisions about my life, including where and when I work, live, love, play, and relax:
- Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know/Doesn't Apply

Self-Advocacy in NC – A Personal Survey      PUBLISHED VERSION

Please tell us how much you agree with the following statements

1. I think that everyone who needs services and supports receives them (no waiting list).
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know
  
2. I believe everyone who needs services and supports should receive them without having to be on a waiting list.
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know
  
3. I live where I want to live
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know
  
4. I think everyone should work in integrated community employment at competitive wages, with the supports necessary to be successful
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know

Self-Advocacy in NC – A Personal Survey      PUBLISHED VERSION

5. Everyone should live inclusively in the community, *in housing that is not segregated by disability*, with people of their choice.
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know
  
6. Everyone should be able to develop personal and financial assets (like owning a home, having a savings account, and other things that will help prevent you from being totally dependent on others financially).
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know
  
7. The system currently involves consumers and families in the design, development, oversight, and evaluation of services and the system.
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know
  
8. The system is currently being continuously held responsible for their decisions, are open and honest about the services and system, and must answer to the public about if people feel they are doing a good job or not.
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know

9. The system should be involving consumers and families in the design, development, oversight, and evaluation of services and the system.
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know
  
10. The system should be continuously held responsible for their decisions, be open and honest about the services and system, and answer to the public about if people feel they are doing a good job or not.
  - Strongly Agree
  - Agree
  - Neutral/Maybe
  - Disagree
  - Strongly Disagree
  - Not Sure/Don't Know

Have you personally worked on any of the following items?

1. Have you helped yourself or another person receive services and supports they need?
  - Yes, quite a bit
  - Yes, Some
  - No
  - Not Sure/Don't Know
  
2. Have you helped yourself or another person find integrated community employment at competitive wages?
  - Yes, quite a bit
  - Yes, Some
  - No
  - Not Sure/Don't Know
  
3. Have you helped yourself or another person to live with people of their choice inclusively in the community?
  - Yes, quite a bit
  - Yes, Some
  - No
  - Not Sure/Don't Know

4. Have you helped yourself or another person to develop personal and financial assets?
- Yes, quite a bit
  - Yes, Some
  - No
  - Not Sure/Don't Know
5. Have you helped to make sure the system involves consumers and families in the design, development, oversight, and evaluation of services and the system?
- Yes, quite a bit
  - Yes, Some
  - No
  - Not Sure/Don't Know
6. Have you helped to make sure that the system is being continuously held responsible for their decisions, are open and honest about the services and system, and must answer to the public about if people feel they are doing a good job or not.
- Yes, quite a bit
  - Yes, Some
  - No
  - Not Sure/Don't Know

Things I wish you had asked me about or other comments....

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OPTIONAL (NOT REQUIRED):

Your Name: \_\_\_\_\_

Please give us information on the best way or ways to reach you:

Phone Number: \_\_\_\_\_

Email: \_\_\_\_\_

Home Address:

(Number) \_\_\_\_\_ (Street) \_\_\_\_\_

(City/Town) \_\_\_\_\_ (Zip Code) \_\_\_\_\_

If you are mailing this back to us -- please send it to:

CRA  
102 West Ruffin Street  
Mebane, NC 27302

Organization Name: \_\_\_\_\_

Organizational Representative: \_\_\_\_\_ Date: \_\_\_\_\_

Advocacy Ambassador: \_\_\_\_\_

1. Our group has a clearly defined vision and mission:

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

2. Our group has a dedicated, active membership:

- Strongly Agree
- Agree
- Neutral/Maybe/Not Sure
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

3. If you have a dedicated and active membership, how many members do you have? \_\_\_\_\_

4. Our group has a well-defined leadership structure:

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

5. We would like to be involved with other self-advocacy groups:

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

6. Our group thinks that connecting with others is an important part of advocacy:

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

7. Our group is actively engaged with various members of the community:

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

8. Our group thinks that working with lawmakers and policy people is an important aspect of advocacy:

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**9. Our group has well defined priorities:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**10. Our group feels confident in our ability to meet possible new members:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**11. Our group accomplished last year's goals:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

**12. Our group is stable and strong:**

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

13. Our group continues to get bigger, stronger, and more effective:

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

14. Our group has a clear vision for our future:

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

15. Our group could benefit from outside assistance:

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

16. Our group has the funding to support our organization:

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

17. Our group communicates well with our membership:

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

18. Our group would like to communicate better with our membership:

- Strongly Agree
- Agree
- Neutral/Maybe
- Disagree
- Strongly Disagree
- Not Sure/Don't Know/Doesn't Apply

19. Our biggest concerns are:

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20. I wish you had asked me about..../other comments:

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**THANK YOU VERY MUCH FOR YOUR HELP!**

Please give us information on the best way or ways to reach you:

Phone

Number: \_\_\_\_\_ Email: \_\_\_\_\_

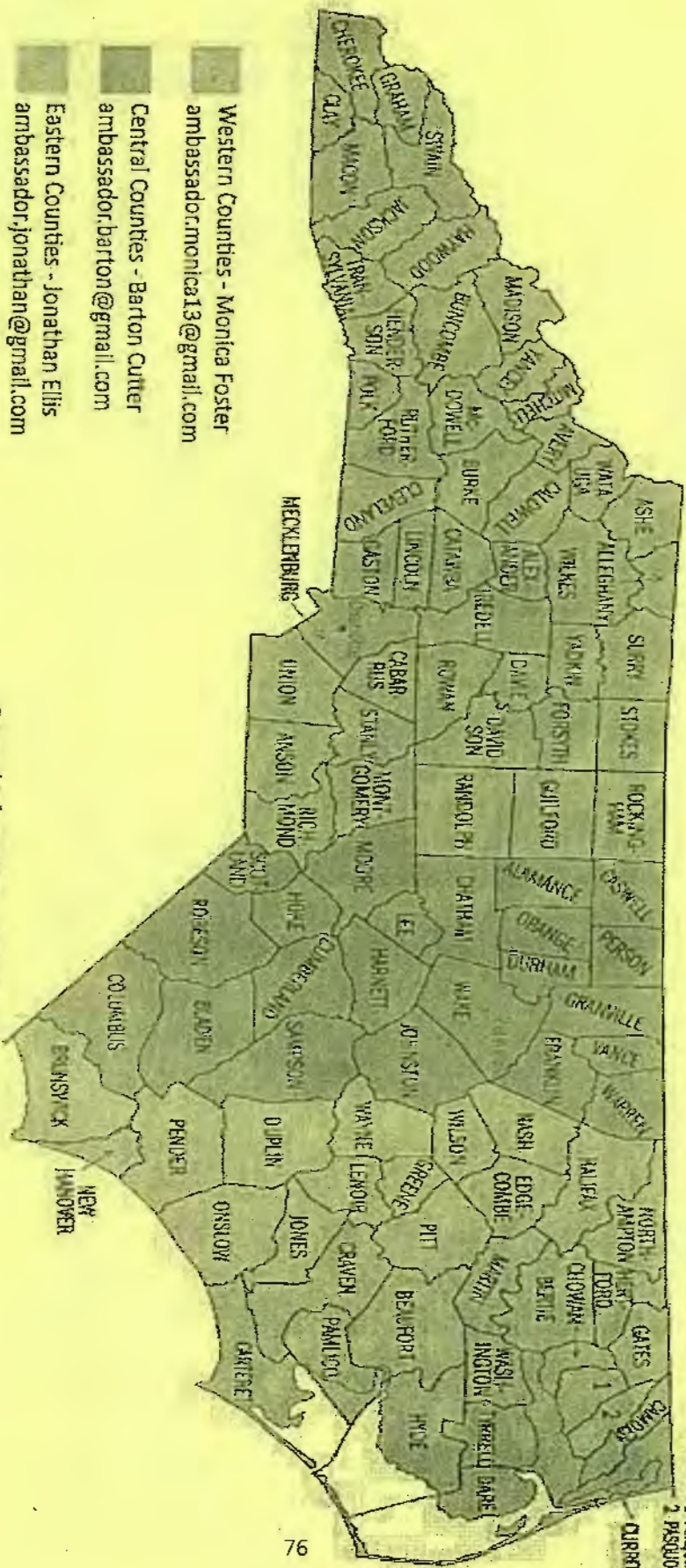
Home Address:

(Number) \_\_\_\_\_ (Street) \_\_\_\_\_

(City/Town) \_\_\_\_\_ (Zip Code) \_\_\_\_\_

If you are sending this back to us – please fax it to 888-542-8555 or mail it to:

CRA  
102 West Ruffin Street  
Mebane, NC 27302



General information – Matt Potter  
 ambassador.matt13@gmail.com

COUNTIES  
 1. PERKINS  
 2. PASQUON  
 CURRITUCK







**Monica J. Foster**  
Advocacy Ambassador  
Western N.C. Region

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Please Participate In Our Survey Here: <http://tiny.cc/c0t2cx>

This project is funded by the N.C. Council on Developmental Disabilities  
and coordinated by Community Resource Alliance



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Please Participate In Our Survey Here: <http://tiny.cc/c0t2cx>

This project is funded by the N.C. Council on Developmental Disabilities  
and coordinated by Community Resource Alliance



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Please Participate In Our Survey Here: <http://tiny.cc/c0t2cx>

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and coordinated by Community Resource Alliance



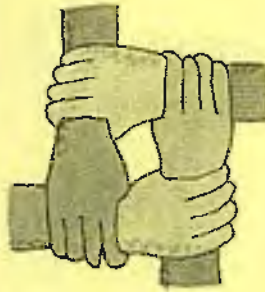
**S. Barton Cutter**  
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Central N.C. Region

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ambassador.barton@gmail.com

Please Participate In Our Survey Here: <http://tiny.cc/c0t2cx>

This project is funded by the N.C. Council on Developmental Disabilities  
and coordinated by Community Resource Alliance



PLACE  
STAMP  
HERE

**MEET YOUR  
ADVOCACY AMBASSADORS  
& ADVOCACY AMBASSADOR  
PROJECT ASSISTANT**

**Monica J. Foster**  
**Baron Coker**  
**Madal Fisher**  
**Jacqueline Eji**

**N.C. Advocacy Ambassador Initiative**  
W. Ruffin Street  
Mebane, NC 27302

**BUILDING  
Momentum in  
SELF-ADVOCACY  
ACROSS  
North Carolina  
TOGETHER**

*"Advocacy,  
Advocacy,  
Advocacy  
...and not necessarily  
in that order."  
~ Ed Roberts*



## What Are We Doing?

For a variety of reasons, self-advocacy efforts in North Carolina have been less than successful over the past several years. At present, there is no recognized state-wide self-advocacy organization.

However, there are a number of self-advocacy groups across the state - with maybe 7 active groups in each of the three regions of the state that may need support to continue to thrive with self-advocates' voices and intentions heard more clearly. Three self-advocates have been chosen as Advocacy Ambassadors to assess and support self-advocacy efforts in their home regions. (Please see the map).

We believe that there is potential for growth within each region - both within each group and through the development of new groups. There is also the potential for collaboration across groups, with self-advocates helping self-advocates, within and across the regions.

Advocacy Ambassadors will meet with all known self-advocacy groups in their region to discuss what self-advocacy means and doesn't mean to each group, and gather information, on whose support is most needed so North Carolina's self-advocacy groups can be stronger ever before.

We Need You!

## Which Region of North Carolina Do You Live In?



Contact Your Region's  
Advocacy Ambassador to  
Learn More

The N.C. Advocacy Ambassadors are working to visit all local self-advocacy groups in the state.

The goal of these visits is to find out:

1. Who are the members of the local groups, and what do the members want to do regarding self-advocacy?
2. What are the goals of the local groups and what are they currently doing?
3. What help do the local groups need to meet their goals?
4. What are some current positive working relationships and advocacy efforts?
5. Are there possible new and positive working relationships that can help meet these goals?

### Contact Us

**N.C. Advocacy  
Ambassador Initiative**  
102 W. Ruffin Street  
Mebane, NC 27302

Visit us on Facebook:  
[https://www.facebook.com/  
NCAdvocacy/AmbassadorInitiative](https://www.facebook.com/NCAdvocacy/AmbassadorInitiative)

Please Participate in Our  
Online Self-Advocacy Survey @  
<http://tiny.cc/p012cx>

## About the Team Members

### S. Barton Cutter

Barton is a professional leadership coach and mentor who uses his humor and uncompromising wit to empower organizational leaders, youth with disabilities, their families and professionals to discover a clear and powerful vision of their own independence within the communities of their choosing.

He combines his life experience of living with Cerebral Palsy and his professional background of leadership development to bring their vision to life through action steps that are both inspiring and practical.

After receiving his BA from The University of Arizona, Barton spent several years spearheading Youth Leaders in Action, an advocacy and leadership program for junior high and high school age youth with disabilities. Under his direction, Youth Leaders in Action developed a leadership curriculum to empower youth with disabilities to advocate for themselves. Further, he was a driving force behind a statewide conference focused on youth with disabilities and post-secondary education in which he united stakeholders with various interests under a common vision to achieve unified goals.

As the Co-Owner of Cutter's Edge Consulting, Barton has also served as the Communications Director for The North Carolina Council on Developmental Disabilities and Co-Coordinator for the Lifetime Connections Program with First in Families of North Carolina. Throughout 2011 and 2012, he was a monthly columnist for The News & Observer "Our Lives" column. Today, he continues his work with various organizations through speaking and training nationally while offering coaching to private clients.

### Jonathan Ellis

Jonathan worked for Easter Seals UCP of North Carolina & Virginia in Wilmington, North Carolina for seven years starting in April 2003. While he was there he served in two roles. One was a liaison between the companies that Easter Seals

worked with through their employment services. He also served as the Liaison between the Social Security Administration and the people who have disabilities, especially ensuring that their wages were reported in a timely fashion to Social Security.

Jonathan has served in many public service roles, including as a N.C. Council on Developmental Disabilities Board member from August 2005 through October 2013. In this role, Jonathan served as Chair of the Community Capacity Building Committee from November 2005 through November 2008. Jonathan also served on the Executive Committee as the Community Capacity Representative. He also served as the Vice Chair of the Council and on the Executive Committee from November 2011 through October 2013.

A well-known public figure and advocate, he has served on numerous other committees and workgroups, currently including the Stakeholders Engagement Group.

Jonathan holds a Bachelor of Arts in Communications with an emphasis in Public Relations from St. Andrews University in 1996, located in Laurinburg, North Carolina.

### Monica J. Foster

Monica is a well-known N.C. advocate and vibrant woman who also happens to live as an amputee on wheels, who was born with Spina Bifida and thrives in spite of a diagnosis of Depression.

She lives in Landis, N.C., located in Rowan County, with her husband, Bryan and their rambunctious cats, Annabelle and Poe, and own their wheelchair accessible home. Monica is founder and president of BUTTERFLYWHEEL® Motivation, Advocacy & Consulting, a personal and professional coaching and consulting business that combines her passions for self-determined, independent living, loving relationships, life coaching, energy work, disability access and inclusion. As a professional coach, speaker and consultant, she specializes but is not limited to working with people with disabilities, especially women and female disabled veterans. She is known for working hard to forge alliances among community and business leaders to build an ability conscious society.

Monica, a former two-term Governor's appointee to the N.C. Council on Developmental Disabilities and also a Governor's appointee to the N.C. Statewide Independent Living Council, is a professionally certified life coach, holding endorsements and certifications in life purpose, career, master vision board, with a Bachelor of Arts in English-Writing Studies from Pfeiffer University in 1995. She is also a N.C. Certified Peer Support Specialist through the UNC Behavioral Healthcare Resource Program.

Monica encourages clients and seminar attendees to lead lives 'beyond limits', as she calls living a life impacted by various challenges, especially disabilities, mental health issues, and chronic illness. She uses heart-based coaching activities that nudge clients over, around, and through the obstacles they encounter within themselves and in their communities. She encourages those she works with to shift obstacles into opportunities and challenges into new chances to uncover strengths and new ways to thrive.

Monica is also a nationally sought after speaker and consultant on various disability projects. For example, in just the past few months, Monica presented workshop sessions at the Atlanta Abilities Expo and the 40th Annual National Spina Bifida Association Conference in Anaheim, California. She provides trainings on self-advocacy, providing voluntary physical accessibility and disability sensitivity in the workplace, and inclusion and awareness in the community and schools. With a background in journalism, Monica regularly contributes to disability and self-advocacy focused publications nationwide

Monica is passionate about building self-advocacy opportunities, community collaboration, encouraging competitive employment and small business opportunities. She is also deeply invested in supporting safe, healthy relationships among people with disabilities as she spearheaded the N.C. Relationships Initiative, as funded by the N.C. Council on Developmental Disabilities and administered by Human Services Research Institute. She worked successfully to bring the wants and needs of self-advocates statewide together into one united voice and document called, "A Credo for Meaningful Relationships", which is now distributed nationally.

She currently serves on the Stakeholders Engagement Group, National Spina Bifida Association's Collaborative Care Network Planning Group, and is a founding member and advisory council member of the newly reorganized Spina Bifida Association of the Carolinas (SBANCSC).

### Matthew Potter

Matthew currently serves as the Assistant Director to the Advocacy Ambassador Initiative funded by NCCDD. He has been a public speaker and advocate for people with disabilities for his entire life, though it began in earnest during high school. Born with Cerebral Palsy, Matt decided very early on to rise above his challenges and help others to do the same. Matt graduated from Wake Forest University in 2009 with his BA in English.

He is a writer, speaker, Wake Forest sports fanatic, and part-time employee of the Wake Forest University Athletic Department. Matt also recently began work as a test evaluator for Measurement Incorporated in Greensboro. In speaking, Matt aims to make a positive emotional impact on audiences by telling his story and weaving it together with the stories of everyone listening.

Currently, Matt serves as a member of the Board of Directors of both CenterPoint Human Services and The Enrichment Center of Winston-Salem. He is also a former Vice-President of the Winston-Salem Mayor's Council for Persons with Disabilities, Chair of the CenterPoint Human Services Intellectual/Developmental Disabilities Advisory Committee, and a member of the CenterPoint Human Services Consumer and Family Advisory Committee (CFAC).

As an advocate with nearly ubiquitous presence, including his current service on the Stakeholder's Engagement Group and the MH/DD/SAS Medicaid Waiver Review Committee, Matt's dream is to do all in his power to bring together people of all disability service "silos," regardless of who they are representing the issues of intellectual/developmental disabilities, mental health, or substance abuse services, or physical disability, and in the process help create a better future for all through cooperation.



# COMMUNITY CAPACITY BUILDING COMMITTEE



# North Carolina Council on Developmental Disabilities

## Community Capacity Building Committee Agenda **DRAFT**

February 12, 2014

9:45 a.m. – 12:15 p.m.

North Raleigh Hilton, Raleigh, NC

9:45 a.m. – 9:55 a.m.	<b>Introduction</b> <ul style="list-style-type: none"> <li>• Welcome</li> <li>• Approval of Minutes</li> </ul>	<i>I. Azell Reeves</i>
9:55 a.m. – 10:15 a.m.	<b>Authority to Fund</b> <ul style="list-style-type: none"> <li>• NC ADA Network Fiscal Agent</li> </ul>	<i>Shayna Simpson-Hall, NCCDD</i>
10:15 a.m. – 10:45 a.m.	<b>Initiative Updates and Motion to Approve Continuation Funding</b> <ul style="list-style-type: none"> <li>• NC ADA Network</li> </ul>	<i>Karen Hamilton, NC ADA Network</i>
10:45 a.m. – 11:00 a.m.	<b>Break</b>	
11:00 a.m. – 11:35 a.m.	<b>Initiative Updates</b> <ul style="list-style-type: none"> <li>• Upward to Financial Stability</li> </ul>	<i>Michael Roush, Project Manager, National Disability Institute</i>
11:35 a.m. – 11:45 a.m.	<b>Fiscal Update</b>	<i>Yadira Vasquez, NCCDD</i>
11:45 a.m. – 12:00 p.m.	<b>Wrap Up and Reminders</b> <ul style="list-style-type: none"> <li>• Completion of Financial Forms and Conference Request</li> </ul>	<i>I. Azell Reeves</i>

### Community Capacity Building Committee

I. Azell Reeves: Chair

Amanda Bergen

Adonis Brown

Anna Cunningham

Kerri Bennett Eaker

Representative Verla Insko

Nessie Siler\*

David White

Jim Swain; Alternate: Gina Price

VACANT

VACANT

VACANT

VACANT

Parent of Child with DD

Parent of Child with DD

Individual with DD

Parent of Child with DD

Parent of Person with DD

Other: Legislative

Individual with DD

Parent/Person with DD

Agency: Div. of Voc. Rehab.

Parent of Person with DD

Agency: Dept. Public Safety

Agency: Dept. Public Instruc.

Agency: Div. of W/C Health

**Staff: Shayna Simpson-Hall**

\*Temporary Committee Assignment

Community Capacity Building  
DRAFT Minutes  
November 20, 2014  
9:45 a.m. – 11:45 a.m.  
Hilton Garden Inn, Cary, NC

**Members Present:** I. Azell Reeves (Chairperson), Desiree Peterson, Lisa Byrd, Larry Huggins (for John Carbone, M.D.), Wilson Finks, Amanda Bergen, Jim Swain and David White

**Members Absent:** Anna Cunningham and Senator Tommy Tucker

**Guests:** Beverly Colwell and Dreama McCoy (for Bill Hussey, NC Dept. of Public Instruction, appointment pending)

**Staff/Contractors/Council Chair:** Shayna Simpson-Hall, Karen Hamilton (NC ADA Network), Kim Corzine (Western Carolina University), Gordon O'Neill (O'Neill Communications), Abby Cameron (NC Dept. of Public Safety), Joanne Pierce (NC Dept. of Public Safety), JoAnn Toomey, Yadira Vasquez, Melissa Swartz and John McCallum

**Introduction:**

**Welcome:** Chairperson I. Azell Reeves welcomed all members and provided an opportunity for all to introduce themselves.

**Approval of Minutes:** Chairperson I. Azell Reeves asked for approval of August 14, 2014 Minutes.

**MOTION:** David White made a motion to accept the August 14, 2014 Community Capacity Building Committee minutes. Desiree Peterson seconded the motion. The motion passed.

**Authority to Release RFA**

Desiree Peterson exited the room and recused herself from the discussion. Shayna Simpson-Hall reviewed aspects of the RFA including the objective which states that the Council will fund training, consultation and technical assistance for individuals to affect policies and practices that support integration, productivity, independence, and inclusion for people with intellectual and other developmental disabilities and their families. She also mentioned the activity which is to allocate funding that would support citizen action for voluntary compliance with the Americans with Disabilities Act. Specific activities shall include the following:

- 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 aids, interpreters, 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.

Karen Hamilton (NC ADA Network Coordinator) stated that the services provided by the current NC ADA Fiscal Agent is vital to 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. The members agreed that the services were essential. Prior to making the motion the committee requested that JoAnn Toomey, the NCCDD Director of Operations, give the group the fiscal perspective of increasing the administrative fee and if the Council had a cap on the amount of the administration fee which a contractor could bill. JoAnn explained the Council's guidelines on indirect cost and administrative fees. Following the discussion, the group decided that the administrative fee associated with this initiative should not exceed \$5,000.

**MOTION:** Wilson Finks and Amanda Bergen made a motion to grant NCCDD staff authority to release the Request for Application (RFA) for the "NC ADA Network Fiscal Agent" for up to an amount of \$35,000 (level-funded) for up to three years beginning with the period of July 1, 2015 – June 30, 2016, with a required minimum of 25% non-federal matching funds. Dreema McCoy seconded the motion with the recommended change that the amount of administrative fees shall not exceed \$5,000. The motion was approved.

Jim Swain stated that he was not comfortable with a flat administrative rate as opposed to a percentage.

#### Initiative Updates

Kim Corzine, Project Coordinator - Western Carolina University, Learning and Earning After High School: The Role of Transition Services in Raising Expectations and Attitudes for Students with Intellectual Disabilities. She began by reviewing the main objectives of the initiative which are:

- Raising expectations of students, families, teachers, administrators;
- Demonstrating possibilities of competitive employment, post-secondary education/training, and independent living options for youth with intellectual disabilities (e.g., highlighting success videos and stories across NC); and

- Providing teachers, families, and school districts with a web-based resource as a guiding blue print for preparing students with intellectual disabilities the opportunities for positive post-school outcomes.

She stated that the Advisory Teams met for the second time. Meetings were held in Catawba County (10/22), Harnett County (10/29), Graham County (10/24) and in McDowell County (10/21). All of the meetings were very well attended by students with I/DD, teachers, parents, employers, service providers, and administrators. Additionally, information was given on the focus groups which met in February, April, and May 2014. The group assessed the strengths, needs and identified barriers to implementation. Also, the website was unveiled and the group discussed design, content, and usability of website.

Ms. Corzine also informed the group of the information related to the Transition Survey. The survey was released in February 2014 to LEAs. It was sent to 270 stakeholders with a 55.9% response rate. It was disseminated to teachers, administrators, VR counselors, transition coordinators, job coaches, and families. She closed with the next steps of the initiative. The next steps are:

- RTLE.org is currently with LEAs; more videos, resources, lesson plans, and activities are being added;
- Conduct Evaluation (January, 2015) and Expectation surveys;
- Modify RTLE.org according to evaluation; and
- Expand RTLE.org to other schools and to NCDPI.

Following Kim's presentation, Joanne Pierce, Grant Coordinator - NC Dept. of Public Safety, Emergency Preparedness for People with I/DD initiative greeted the group. She began by providing the group with a review of the year one activities and highlights which were as follows;

- C-MIST committees meetings
- Technical plan and Blueprint
- Transportation survey
- ShowMe shelter communication tool
- ReadyNC updates
- MyPREP personal preparedness

She stated that on November 12, 2014 the kick off implementation meeting was held. Approximately, one hundred people attended the event. During this time the Technical Plan/Blueprint was released. The plan is inclusive with the whole community approach. The plan addresses the access and functional needs of people with I/DD. Moreover, the Blueprint is cross-functional, focusing on personal preparedness, local preparedness related to local infrastructure and emergency planning at the state level. Ms. Pierce then updated the members on next steps. The next steps for this initiative are:

- Implement C-MIST committees strategies;
- Review and update Blueprint as needed; and

- Emergency Preparedness Initiative Stakeholders' Meeting in October or November of 2015.

Cindy Thomas, Institute for Community Inclusion, UMass, Reaching the Summit of Success, joined the group by phone. She stated that over the past year the project focused on developing policy directions for employment with a particular focus on transition. The project team synthesized the findings from the summits that were held in September 2013 and used these as the foundation for a policy seminar that was held in June 2014. This seminar was well attended and included a range of stakeholders including state agency representatives, representatives from post-secondary education programs, educators, providers, family members and individuals. Seminar participants were briefed on the recently approved Joint Legislative Education Oversight Committee plan to study a range of issues related to vocational training for individuals with intellectual disabilities.

The seminar participants prioritized two recommendations:

1. The primary option for students after high school should be a competitive place of employment. *This process should start early enough to allow the student to attend college, if this is their choice.*
2. The DHHS (DMA, DMH/DD/SAS, DVR), community college system, DPI, UNC system and Department of Commerce shall assess policy barriers, identify revisions needed, set goals and advance coordinated policies and practices in regard to "Employment First" and post-secondary education for persons with I/DD.

The project team hosted a conference in September 2014 that was attended by over 100 stakeholders from throughout NC. The conference included a keynote presentation and breakout session by Teresa Grossi, a nationally known expert in the area of transition and employment, a state agency panel, a young adult panel, and a keynote presentation on the second day by Dave Richard.

Cindy also noted a challenge faced by the initiative. She stated that the advisory team was unsure on how aggressive the state is willing to be involved in transition to employment for people with I/DD and this has hindered their efforts. Also, she and other staff are unable to fully participate in the NC Employment First Work Steering Committee due to their inability to participate remotely. Cindy mentioned that she has reached out to the NC APSE to collaborate in their efforts to increase involvement and to leverage resources. Additionally, the project team is continuing to work with the Council to insure that the work of this project aligns and is integrated with the work being done on other projects including the SEG and SELN.

During the final year of the Reaching the Summit of Success initiative, three additional summits are planned for the upcoming year to be held in different parts of the state.

**Fiscal Update**

The Council's Business Officer, Yadira Vasquez, provided an update to the Community Capacity Building Committee of the current budget report and expenses by committee and the status of the three federal fiscal years.

**Wrap Up and Reminders**

Chairperson I. Azell Reeves reminded members to submit their financial forms. She asked that if members are interested, to please respond promptly when they receive notification from Cora about upcoming conferences or other events.

**Adjournment**

Wilson Finks and Lisa Byrd made a motion to adjourn the meeting. It was seconded by Desiree Peterson. Adjourned the meeting at 11:53 a.m.



## Project | SEARCH<sup>®</sup>

Project SEARCH Update Date: North Carolina Project SEARCH High School Transition Program is operated by Cincinnati Children's Hospital Medical Center with funding provided by NCCDD. It provides internship for youth with intellectual and developmental disabilities. Project SEARCH provides employment for youth and young adults with disabilities employment in an integrated setting. It is a unique, business led, one year school-to-work program that takes place entirely at the workplace. Total workplace immersion facilitates a seamless combination of classroom instruction, career exploration, and hands-on training through worksite rotations. Project SEARCH is an international trademarked and copyrighted program model. To ensure model fidelity and best practices, they require all Project SEARCH program sites to sign a licensing agreement with their national office. Currently there are 7 Project SEARCH sites on North Carolina. Three of which were developed and implemented with funding by the NCCDD. It is with great pleasure that we announce the addition of three new sites which would bring the number to 10! Below are the three new additions to the NC Project SEARCH family:

1. Greenville (Pitt County)
  - a. RHA-Howell
  - b. Pitt County School System School District, North Carolina Division of Vocational Rehabilitation, Greenville Office
  - c. East Carolina Behavioral Health
2. Lumberton (Robeson County)
  - a. Robeson Community College
  - b. North Carolina Division of Vocational Rehabilitation
  - c. Revelations Placement Service
  - d. Southeastern Health
  - e. Youth Employability Services of Robeson County, Robeson Community College & the Workforce Investment Agency Out-of-School Youth program
3. Monroe (Union County)
  - a. Union County Public Schools
  - b. North Carolina Division of Vocational Rehabilitation
  - c. InReach
  - d. Cardinal Innovations



# 2015/16 NC ADA Network: In-House Project Proposal

## Goal of Project:

Work with grassroots groups, led by people with disabilities, to conduct projects that increase compliance with the **Americans with Disabilities Act (ADA)** in local communities across North Carolina.

**Structure:** The NC ADA Network is collaborative project of the NC Council on Developmental Disabilities, Southeast ADA Center and a non-profit fiscal agent. Traditionally, the project is funded as follows:

- The NCCDD In-House Project budget covers the Project Coordinator and some other administrative costs;
- NCCDD also awards a small amount of funds to a non-profit to serve as a fiscal agent for funding local ADA Projects and participant travel/training expenses; and
- The Southeast ADA Center provided funds (\$15,000 in 2014), ADA materials, training and technical assistance to also support NC ADA Network activities.

**Objective 1:** Work with NC ADA Network local grassroots groups to conduct at least 15 local ADA Projects that result in improved ADA compliance in local communities across the state. (i.e., policy change, improved facility or program access, membership of people with disabilities on advisory boards, etc.)

**Objective 2:** Work with experienced ADA Network group leaders and other ADA experts to provide at least 5 events of ADA technical assistance to businesses or groups not covered by local ADA Projects. These technical assistance efforts will result in at least 5 improvements in identified ADA issues.

**Objective 3:** Work with at least 60 individuals with disabilities to participate in NC ADA Network Statewide Meetings and other state/regional meetings or trainings.

**Objective 4:** Expansion: Recruit at least 3 new grassroots groups, led by people with disabilities, to join the NC ADA Network and accomplish one or more of the following: conduct local ADA project; host an ADA training; and/or participate in NC ADA Network sponsored training. (23 grassroots groups, led by people with disabilities, participated in the NC ADA Network project in 2014/15.)

## 2015/16 NC ADA Network: In-House Project: Continuation Funding Request (7/1/15 – 6/30/16)

The following funding request will support the NC ADA Network: In-House Project for 12 months (7/1/15 – 6/30/16).

	NCCDD Funds	Description
Contracted Services - Staff	\$ 60,000	Contract expense for NC ADA Network Project Coordinator. (Note: the Project Coordinator expense is in-line with senior staff salary with 20% benefits)
<b>TOTAL</b>	<b>\$60,000</b>	<b>Funds Requested from NCCDD</b>

## NC ADA Network Outcomes over past 12 month:

### Counties Served (2014):

- 23 NC ADA Network grassroots groups, led by people with disabilities, conducted or hosted Americans with Disabilities Act (ADA) Projects/Activities serving **44 counties**.
- The NC ADA Network along with grassroots partners conducted or hosted ADA Trainings, distributed ADA publications/information, provided ADA technical assistance and conducted Public Awareness Events serving (people with disabilities, family members and businesses) representing **100 NC counties**. Summary of these 2014 ADA Activities include:
  - ✓ 25 ADA Trainings serving 707 people (254 people with disabilities, 80 family members and 373 business representatives);
  - ✓ 1801 ADA publications to 1209 people;
  - ✓ ADA Technical Assistance to 819 people (343 people with disabilities, 82 family members and 394 business representatives); and
  - ✓ 10 Public Awareness events, including ADA exhibits and presentations, reaching more than 300 people.

### Collaborators (2014-15):

- Southeast ADA Center – Atlanta, GA (provided technical assistance on the Americans with Disabilities Act and supplemental financial support)
- Alliance of Disability Advocates (fiscal agent)
- 23 grassroots groups, led by people with disabilities, from across North Carolina (these groups conducted or participated in ADA projects in their local communities)
- Other agency collaborators involved in supporting grassroots groups in promoting the ADA include but are not limited to: NC Office on Disability and Health, Department of Emergency Management, Disability Rights NC, local governmental agencies, etc.

### NC ADA Network – Local Projects and Outcomes (2014-15):

Over the past 12 months, grassroots group, led by people with disabilities, conducted local ADA projects addressing:

- Emergency preparedness,

- Public Transportation,
- Recreation trails,
- Sports stadiums,
- Service animals,
- Accessible Voting,
- Accessible Taxi service,
- Libraries,
- Restaurants, and
- Accessible parking

**Major outcomes (to date) resulting from these ADA Projects:**

- 2 restaurants updated policies/practices on allow service animals in business;
- 5 libraries and 1 courthouse made improvements to effective communication procedures;
- NC Lottery Commission updated policies/procedures related to serving people with disabilities;
- 25 businesses or local government entities added or improved accessible parking spaces, improved accessible route of travel to goods and services, and improved restrooms;
- Rowan Co. school changed policy to allow parents/guardian who are deaf to request interpreter for mandatory parent/teacher meetings;
- 2 apartment complexes added accessible parking spaces for tenants with disabilities, 3 landlords made accessibility improvements to leasing offices & apartment application process;
- Union County High School made accessibility improvements to Football Stadium;
- Tar River Transit updated policies & procedures affecting riders with disabilities and City of Charlotte added new accessible bus stop;
- 6 People with disabilities gained membership on statewide Emergency Preparedness Committees;
- 4 people with disabilities gained membership on local Emer. Prep task forces; and
- 3 people with disabilities gained membership on local transit advisory groups.

**Other Outcomes:**

Over the past 2 years, self-advocates from around the state have tested and helped write a new ADA Tool called "Starting the Conversation with Business." This Tool offers teams of people with disabilities a step-by-step guide to talking to businesses about the Americans with Disabilities Act and offering feedback on making programs and services more accessible. NC ADA Network representatives, including a self-advocate, will lead a session on this initiative at the National ADA Symposium in May 2015.

# DRAFT AND NOT INTENDED FOR DISTRIBUTION

The Roads to Learning and Earning (RTLE) website is for students in middle and high school. Here is what you can explore on this website.

- Go for a SPIN (Strengths, Preferences, Interests, Needs)
- Driver's Seat
- Road to Work
- Road to College
- Road to Community Living

Go through the map to success using a fun GPS. Click on the links to other places to learn more about what to do with your future!



Visit our Facebook page  
[facebook.com/RTLENC](https://www.facebook.com/RTLENC)

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# RTLE

Roads to Learning and Earning



Learning and Earning After High School  
The Role of Transition Services  
in Raising Expectations and Attitudes  
for Students with Intellectual Disabilities

# DRAFT AND NOT INTENDED FOR DISTRIBUTION

Our main purpose is to change attitudes & expectations of administrators, teachers, families, students, and community service providers with increased opportunities and more positive outcomes with individuals with intellectual disabilities.

Local Education Agency (LEA) Partnerships  
Graham, McDowell, Catawba, Harnett



The Roads to Learning and Earning (RTLE) website covers topics from middle school to high school, giving a variety of helpful resources in five domains:

Go for a SPIN (Strengths, Preferences, Interests, Needs) - transition assessments with students & families to reflect individual goals during and after school

*Driver's Seat - take charge of future goals and make appropriate plans during and after high school*

*Road to Work - work together to plan for successful employment after school*

*Road to College - work together in order to prepare for college*

*Road to Community Living - work towards successful independent living options after high school*

The easy-to-use links ensure that the site is appropriately used as an informative tool for students with intellectual disabilities, families, teachers, administrators, and community service agencies.

# DISABILITY SYSTEMS CHANGE COMMITTEE



# North Carolina Council on Developmental Disabilities

## Disability Systems Change Committee Agenda - DRAFT

February 12, 2015

09:15 a.m. – 12:15 p.m.

Hilton North Raleigh/Midtown

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9:15 a.m. – 9:30 a.m.	<b>Introduction</b> <ul style="list-style-type: none"><li>• Welcome</li><li>• Approval of Minutes</li></ul>	<i>Samuel Miller</i>
9:30 a.m. – 9:45 a.m.	<b>Fiscal Update</b>	<i>Yadira Vasquez</i>
9:45 a.m. – 10:10 a.m.	<b>Agency of Choice Model Intro Discussion</b>	<i>Beth Stalvey, NCCDD Contractor</i>
	<b>Presentation of Agency of Choice</b>	<i>Dakota Kirkland</i>
10:10 a.m. – 10:40 a.m.	<b>Initiative Updates/Requests</b> <ul style="list-style-type: none"><li>• Medical/Health Home</li></ul>	<i>Karen Luken, Easter Seals</i>
10:40 a.m. – 11:10 a.m.	<ul style="list-style-type: none"><li>• Adult Care Homes</li></ul>	<i>Cas Shearin, Disability Rights NC</i>
11:10 a.m. – 11:20 a.m.	<ul style="list-style-type: none"><li>• Break</li></ul>	
11:20 a.m. – 11:50 a.m.	<ul style="list-style-type: none"><li>• Communications Initiative - Council Cross-cutting initiative</li></ul>	<i>Samuel Miller</i>
11:50 a.m. – 12:10 p.m.	<ul style="list-style-type: none"><li>• Stakeholder Engagement</li></ul>	<i>Kelly Friedlander, NASDDDS</i>
12:10 p.m. – 12:15 p.m.	<b>Wrap Up and Reminders</b> <ul style="list-style-type: none"><li>• Completion of Financial Forms</li></ul>	<i>Samuel Miller</i>

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**Disability Systems Change Committee**  
**SYSTEMS CHANGE COMMITTEE**

Samuel Miller, Ph.D.: Chair  
Kelly Woodall Beauchamp  
Crystal Bowe, M.D.  
Courtney Cantrell; Alternate: VACANT  
Christina Carter; Alternate: Andrea Misenheimer  
Eric Chavis  
Robin Cummings, M.D.; Alternate: Deb Goda  
Wing Ng, M.D.  
Desiree Peterson  
Joe Piven, M.D.; Alternate: Deb Zuver  
Dave Richard, Deputy Secretary; Alternate: VACANT  
Vicki Smith  
Peggy Terhune, Ph.D.

Parent of Child with DD  
Individual with DD  
Parent of Child with DD  
Agency: Div. of MH/DD/SAS  
Non-Profit Agency  
Individual with DD  
Agency: Deputy Sec., DHHS  
Parent/Person with DD  
Individual with DD  
Agency: Carolina Institute for DD  
Agency: DHS  
AIDD Partner: DRNC  
Local Non-Governmental Agency

Staff: Steve Strom



**Disabilities Systems Change Committee  
DRAFT MINUTES**

Thursday, November 20, 2014

09:45 a.m. to 11:45 a.m.

Hilton Garden Inn, Cary, NC

**Members Present:** Samuel Miller, Kelly Woodall Beauchamp, Crystal Bowe, Eric Chavis, Kerri Bennett Eaker, Sandy Ellsworth (for Courtney Cantrell), Wing Ng, Greg Olley (for Joe Piven), Vicki Smith, Peggy Terhune

**Members Absent:** Christina Carter, Robin Cummings, Verla Insko, Dave Richard

**Staff in Attendance:** Steve Strom, JoAnn Toomey, Ron Reeve, Chris Egan, Jennifer Bosk, Yadira Vasquez

**Guests:** Beth Stalvey, Kelly Friedlander, Cas Shearin, Karen Luken, Brian Beauchamp, Monica Hamlin, Jim Jarrard, Dakota Kirkland and LeRoy Jarvis.

**Introduction:**

**Welcome:** Samuel Miller, chairman of the Disability Systems Change Committee, called the meeting to order, welcomed all members, and provided an opportunity for guests to introduce themselves.

Dr. Miller called for a motion to approve the August 2014 Disability Systems Change Committee minutes. Crystal Bowe made a motion to approve the minutes. Wing Ng seconded the motion. Motion carried.

**Fiscal Update:**

- Council Staff Yadira Vasquez presented the review of the Council administrative and program budgets and explained the details. Ms. Vasquez's fiscal update presented the budget summary spreadsheet of the three fiscal years from which all initiatives are funded and a one page initiative update that provided budget information in an easy to read and understand format on the initiatives, "*Adult Care Home Transition*", "*Medical and Health Home with IDD*", and "*Medicaid Reform Stakeholder Engagement*".

During the fiscal presentation, a discussion began on the new communications initiative and the opportunity to develop a strategic plan. Vicki Smith made the motion to authorize the Executive Committee to explore resources and expertise to train both Council members and staff on strategic planning. Crystal Bowe seconded the motion. Motion carried.

Dr. Miller and members thanked Ms. Vasquez for her presentation on the fiscal details of each project.

#### Recommendation for Funding from Selection Committee:

- Dr. Miller asked anyone who had a conflict of interest in discussing the recommendations from the selection committee and any guests to wait outside the committee room. Jim Jarrard, Monica Hamlin, and Vicki Smith exited the room during the discussion. Crystal Bowe presented the update on the selection committee meeting. Following the presentation, Dr. Miller called for a motion to accept the recommendation from the selection committee. Kerri Eaker made a motion that the NC Division of Aging and Adult Services be approved as the applicant selected for the NCCDD Guardianship initiative. Funding is approved for up to \$75,000 with a required minimum of 25% non-federal matching funds, for year one of up to 3 years from January 1, 2015 to December 31, 2014. Kelly Woodall Beauchamp seconded the motion. Motion carried.

#### Initiative Updates:

- Kelly Friedlander, contractor for NASDDDS, provided an update on the current initiative, "Medicaid Reform Stakeholder Engagement". The SEG has met two additional times since the August Council meeting and is preparing the members for the new year when the General Assembly reconvenes in 2015. Dr. Miller requested that all Council members be added to the e-mail distribution list for all SEG correspondence. Crystal Bowe made a motion to forward the SEG report to the full Council for formal approval and endorsement. Vicki Smith seconded the motion. Motion carried. Dr. Miller thanked Ms. Friedlander for her presentation.
- Cas Shearin, Disability Rights NC, provided an update on the "Adult Care Home Transition" initiative including stories of two individuals who have been identified as candidates to move into the community along with the challenges and barriers each face to transition into the community. Following a question and answer session, Dr. Miller thanked Ms. Shearin for her presentation.
- Karen Luken, contractor for Easter Seals UCP, provided an extensive update on the "Medical/Health Home" initiative. Ms. Luken has been active in the past three months conducting community outreach and partner meetings. The information gathered is important to inform the Department on the importance of integrated medical and behavioral health and will be gathering stories from families and individuals to write up the consumer profiles that highlight challenges and barriers to accessing healthcare. Dr. Bowe and the members thanked Ms. Luken for her presentation.

**Agency of Choice Model and Discussion:**

Following up on a discussion from the May Disability Systems Change Committee, Kerri Eaker brought her son, Dakota Kirkland and his direct support professional, LeRoy Jarvis, to talk to the Committee about the "Agency of Choice" model for providing supports and services. Mr. Kirkland talked to the committee members about how this model has helped him have greater choices to participate in his community. Mr. Jarvis presented the benefits of less paperwork and greater support of the individual. Dr. Miller thanked Mr. Kirkland for his presentation. Council Staff, Steve Strom, invited Mr. Kirkland back for the February Council meeting due to time running out for a full presentation.

**Wrap Up and Reminders:**

Dr. Miller thanked the members of the Disability Systems Change Committee for their work during the meeting and adjourned the meeting.

**Medical and Health Homes for People with Intellectual and Other Developmental Disabilities: Coordination, Collaboration and Community**

**For the Year Two Contract (October 1, 2014 – September 30, 2015)**

(Amendment will begin March 1, 2015 – September 30, 2015)

Funding Request (\$20,000)

Support establishment of a NC chapter of the Developmental Disabilities Nurses Association. The chapter goal is to foster the growth of nursing knowledge and expertise about optimal care of persons with I/DD, thereby improving their care, services, and quality of life.

- Consultation with national organization and existing state chapters
- Identify NC nurses engaged in providing care to persons with I/DD: LME MCOs, DD provider agencies, academic programs, AHEC, medical practices, NC Nurses Association, etc.
- Convene regional meetings with partners

In partnership with stakeholders convene a statewide “Summit on Medical Health Homes for People with I/DD” that focuses on models, policies, and practices that support medical homes and health homes for people with I/DD within a managed care environment.

- Identify national subject matter experts
- Develop summit agenda
- Identify NC audience and extend invitations to key stakeholders and partners
- Convene summit and develop state action plan.

Promote the integration of oral health as part of medical health homes for people with I/DD by ensuring that state initiatives and activities addressing access to dental care reflect the needs of people with I/DD and their families.

- Identify and review data sources that address needs and gaps related to access to dental care, health outcomes, and cost.
- Identify resources that address an integrated plan of care that includes dental health.
- Recruit 2 dental practices (local health department clinic, ECU community clinic, community health center, and/or private dental practice) and identify priority educational and resource needs.

- Provide educational resources to dental professionals, DSP, individuals with I/DD and families on strategies that promote dental health.

#### **Budget Outline**

**Project team:** \$1,550

**Supplies:** \$250

**Contracted services:** \$14,800

**Project Director:** \$4,800 plus \$450 travel = \$5,250

**Nursing consultant:** \$3,900 plus \$450 travel = \$4,350

**Summit speakers:** \$5,200 (honorarium and travel)

**Other:** \$3,400 (Summit costs of \$1,750 for meeting space, working lunch, and materials. \$1,650 for purchase of educational resources (curricula, books, DVDs) and materials used in community meetings and educational events (refreshments, folders, pens, CDs)

**NCCDD funds:** \$20,000

**Match provided by Easter Seals/UCP:** \$6,667

**Project total:** \$26,667.

# State Plan

Year 1: Oct. 1 2011 thru Sept. 30 2012

Year 2: Oct. 1 2012 thru Sept. 30 2013

Year 3: Oct. 1 2013 thru Sept. 30 2014

**Year 4: Oct. 1 2014 thru Sept. 30 2015**

Year 5: Oct. 1 2015 thru Sept. 30 2016



Committee or Venue	State Plan ID	Activity Description
<b>Member Development Session</b>		
	5.5	New Member Orientation New Member Introduction Ad Hoc Committee Interest Solicitation
<b>ADVOCACY AND LEADERSHIP</b>		
	2.2	Partners in Policymaking
	4.4	Sibling Support Initiative
	5.6	Conference Funding Requests
<b>COMMUNITY CAPACITY BUILDING</b>		
	2.12	Authority to Fund: ADA Network Fiscal Agent
	1.5	Continuation Funding: ADA Network Initiative
	2.1	Upward to Financial Stability Initiative
<b>DISABILITY SYSTEMS CHANGE</b>		
	2.5	Agency of Choice Model Discussion Medical and Health Homes for People with Intellectual and Other Developmental Disabilities: Coordination, Collaboration and Community
	2.5	Bridging Practice and Policy: Transitions from Adult Care Homes
	2.3	
	5.3	NCCDD Communications and Marketing Initiative Enhancing Disability Stakeholder Engagement in Managed Long-Term Services/Supports and Primary/Acute Care Systems Coordination
	2.7	
<b>PUBLIC POLICY FORUM</b>		
<b>Member Discussion</b>		
	5.2	Catalyst for Change – Be the Change Public Policy Initiative
<b>Member Development Session</b>		
	5.3	NCCDD Communications and Marketing Initiative

**FULL COUNCIL MEETING**

**Old Business**

5.3

NCCDD Communications and Marketing Initiative

**New Business**

5.4

Request to Release Request for Application: Participant  
Invovlement Fund Administrator

5.2

Continuation Funding: Catalyst for Change – Be the Change  
Public Policy Initiative

5.1

2016 - 2021 Five-Year State Plan Development Process



NCCDD 2011 - 2016 Five Year State Plan  
Goals, Objectives, Activities and Timelines

**GOAL 1: TRANSITION**

Advocacy, capacity building, systems change efforts of the Council will give people with I/DD and their families more access to the services and supports they need to make life transitions.

Objectives	Implementation Activities	Timeline
<p><i>Not Awarded</i></p> <p>1.1 Council will provide funding/resources so that individuals with I/DD will have more opportunities for choice in post-secondary education. <i>Post-Secondary Education (not awarded)</i></p>	<p>1) Develop Request for Application for stakeholder group to assist in the assessment of policy barriers to post-secondary education (PSE) options for students with I/DD. 2) Select grantee(s) and negotiate grants. 3) Council will participate in Carolina Institute on Developmental Disabilities Post Secondary Education (PSE) Alliance stakeholder group to assist in the assessment of policy barriers to PSE options.</p>	<p>1) By 05/31/2012 2) By 06/30/2012 3) By 06/30/2012</p>
<p><i>Not Awarded</i></p> <p>1.2 Council will provide funding/resources so individuals with I/DD will have more post-secondary education opportunities in the community college system. <i>Post-Secondary Education: Standing on the Shoulders of Success (not awarded)</i></p>	<p>1) Develop Request for Application for transition to community college/post-secondary education. Identify and convene stakeholder group to assist in the assessment of policy barriers to Post-Secondary Education (PSE) options for students with I/DD. 2) Select recipient(s) of funding and enter into contracts(s). 3) Provide technical assistance to enhance the effectiveness of advocacy/systems change efforts. 4) Promulgate findings and target selected strategies for advocacy/system change.</p>	<p>1) 07/01/2012-12/31/2013 2) 07/01/2012-12/31/2013 3) 07/01/2012-12/31/2013 4) By 12/31/2013</p>

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<p><b>1.3</b> Council will provide funding/resources to increase access in the community to economic opportunities, inclusive of competitive employment for people with I/DD.  <i>NC Alliance for Full Participation Employment First Policy Initiative (Institute for Community Inclusion)</i></p>	<p>1) NCCDD adopts "Employment First" Policy; 2) NC Alliance for Full Participation (NCAFP) delegation attends the National AFP Summit; 3) Educate policymakers and general public, in collaboration with stakeholders, about benefits of securing Employment First legislation. 4) Develop, in partnership with stakeholders, strategic policy/practices and social agenda in support of full participation for people with I/DD in integrated employment at a competitive wage; 5) Implement strategic policy/practices and social agenda in support of full participation for people with I/DD in integrated employment at a competitive wage; 6) Assess effectiveness of the implementation of the strategic policy/practices and social agenda in support of full participation for people with I/DD in integrated employment at a competitive wage; 7) Council will provide funding/resources for public awareness of transition to work and integrated employment initiatives.</p>	<p>1) 10/01/2011 - 09/30/2013 2) 10/01/2011 - 09/30/2013 3) 10/01/2011 - 09/30/2013 4) 10/01/2011 - 09/30/2013 5) 10/01/2011 - 09/30/2013 6) 10/01/2011 - 09/30/2013 7) 10/01/2011 - 09/30/2013</p>
<p><b>1.4</b> Council will provide funding/resources to advance strategies that support family capacity to leverage the family's resources to achieve the life goals of an individual with I/DD.  <i>Supporting Families: Coming of Age (First in Families of NC)</i></p>	<p>1) Identify and promote policies and practices that support family capacity to leverage the family's resources to achieve the life goals of an individual with I/DD.</p>	<p>1) 01/01/2011 - 09/30/2016</p>

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<p>1.5 Started 9/01/2013</p> <p>Council will provide funding/resources to increase access in the community for economic opportunities, inclusive of competitive employment for people with I/DD.</p> <p><i>"Transition to Success" Learning and Earning After High School: The Role of Transition Services in Raising Expectations and Attitudes for Students with Intellectual Disabilities (NC Dept. of Public Instruction, Exceptional Children's Services)</i></p>	<p>1) With Department of Public Instruction (DPI), identify three Local Education Agencies (LEAs) to participate in developing and testing a model, beginning at the Middle School level, for improving transition outcomes for students with intellectual disabilities (ID).</p> <p>2) Create a paper prototype that provides a transition-focused curricula and outcomes for students with ID between 12 and 21 and for all levels of support needs and conduct evaluation.</p> <p>3) Develop initial, web-based version of the model and field-test, and conduct evaluation in 6 original schools and 12 additional schools in 3 partner LEAs.</p> <p>4) Present the results of the initiative to date to one or more state conferences for LEA Exceptional Children's directors.</p> <p>5) Create a management environment for the system that will allow it to be used within LEAs on a fee-for-service basis.</p> <p>6) Use outreach from DPI to incorporate outcome data from pilots and to promote the system within LEAs.</p>	<p>1) 9/1/2013-8/31/2014 2) 9/1/2013-8/31/2014 3) 9/1/2014-8/31/2015 4) 9/1/2015-8/31/2016 5) 9/1/2014-8/31/2015 6) 9/1/2014-8/31/2015</p>
<p>1.6 Started 10/01/2011</p> <p>Council will provide funding/resources that shall bring together state Developmental Disability agencies for sharing, educating and providing guidance on practices and policies around employment to its members.</p> <p><i>State Employment Leadership Network (Institute for Community Inclusion, National Association of State Directors of Developmental Disabilities Services)</i></p>	<p>1) The State Employment Leadership Network (SELN) staff will conduct an in-state assessment, in collaboration with the Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMH/DD/SAS).</p> <p>2) Assist DMH/DD/SAS to analyze employment policies and practices and potential options for change.</p> <p>3) Implement policies and practices across DMH/DD/SAS that advance competitive employment of people with disabilities in integrated, community workplaces.</p>	<p>1) 10/1/12-9/30/16 2) 10/1/12-9/30/16 3) 10/1/12-9/30/16</p>

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<p>Started 9/30/2013</p>	<p>1.7 Council will provide funding/resources to implement a high school transition initiative which is a business-led, one-year, school-to-work program that combines classroom instruction, career exploration, and relevant job-skills training through strategically designed internships for students with I/DD.  <i>Project SEARCH (Cincinnati Hospital)</i></p>	<p>1) Increase the number of licensed Project SEARCH program sites in North Carolina by adding 6 new programs. 2) Encourage family involvement in Project SEARCH through Family Involvement Curriculum implementation in existing 4 Project SEARCH sites. 3) Collect data on all Project SEARCH program sites on student enrollment, job placement and job retention during funding cycle. 4) Convene at least one statewide meeting(s) to bring together representatives from all North Carolina Project SEARCH program sites for training and sharing innovations and best practices. 5) Promote and deliver course offerings of the Project SEARCH Training Institute.</p>	<p>1) 9/30/13-9/30/16 2) 9/30/13-9/30/16 3) 9/30/13-9/30/16 4) 9/30/13-9/30/16 5) 9/30/13-9/30/16</p>
<p>Started 10/01/2012</p>	<p>1.8 Council will provide funding/resources to assist families and students with I/DD in understanding options and opportunities for work and post-secondary education through a series of regional and statewide summits presenting best practices and policies.  <i>Reaching the Summit of Success (Institute for Community Inclusion)</i></p>	<p>1) Development of a statewide steering committee. 2) Literature review of evidence-based transition and competitive employment practices. 3) 3 strategic planning summits in 3 different regions of the state. 4) Develop preliminary, strategic plan including implementation strategies that will lead to enhanced employment and post-secondary education outcomes for youth and young adults with I/DD. 5) Hold a statewide conference, in partnership with the Post-Secondary Education Alliance, to continue to expand the knowledge base among parents, students and education professionals.</p>	<p>1) 10/1/12-9.30.13 2) 10/1/12-9/30/16 3) 10.1.12-9/30/13 4) 10/1/12-9/30/15 5) 10/1/13-9/30/14</p>

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Goals, Objectives, Activities and Timelines

**GOAL 2: SYSTEM RESPONSE TO PEOPLE'S NEEDS**

Advocacy, capacity building and systems change efforts of the Council will improve the ability of service delivery systems to respond to the needs of people with I/DD and their families.

Objectives	Implementation Activities	Timeline
<p>2.1 Council will fund training, consultation and technical assistance for organizations to support the development of policies and practices that advance integration, productivity, independence, and inclusion for people with I/DD and their families.  <i>Real Relationships (Human Services Research Institute)</i>  <i>Child and After School Care (Southwestern Child Development Commission, Inc)</i></p>	<ol style="list-style-type: none"> <li>1) Allocate funding to identify barriers to the development of healthy, safe relationships for people with I/DD;</li> <li>2) Convene stakeholder group to make recommendations re: the development of policies and practices that advance healthy, safe relationships for people with I/DD;</li> <li>3) Target selected strategies for advocacy/capacity building/systems change;</li> <li>4) Assess effectiveness of advocacy/capacity building/systems change efforts;</li> <li>5) Allocate funding to identify barriers to the inclusion of children and youth with I/DD in typical child and afterschool care settings or programs;</li> <li>6) Convene stakeholder group to make recommendations re: the inclusion of children and youth with I/DD in typical child and afterschool care settings or programs;</li> <li>7) Target selected strategies for advocacy/capacity building/systems change;</li> <li>8) Assess effectiveness of advocacy/capacity building/systems change efforts.</li> </ol>	<ol style="list-style-type: none"> <li>1) 10/01/2011 - 12/31/2011</li> <li>2) 10/01/2011 - 09/30/2012</li> <li>3) 10/01/2011 - 09/30/2012</li> <li>4) 10/01/2011 - 09/30/2012</li> <li>5) 10/01/2011 - 06/30/2012</li> <li>6) 10/01/2011 - 06/30/2012</li> <li>7) 10/01/2011 - 06/30/2012</li> <li>8) 10/01/2011 - 06/30/2012</li> </ol>

Ended: 12/31/11 & 06/30/2012

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<p>On-going</p> <p>2.2</p> <p>Council will fund training, consultation and technical assistance for parents and self-advocates to affect policies and practices that support integration, productivity, independence, and inclusion for people with I/DD and their families.</p> <p><i>Partners in Policymaking (The Advocacy Institute, Inc.)</i></p>	<p>1) Allocate funding for Partners in Policymaking™ program</p>	<p>1) 10/01/2011-06/30/2016</p>
<p>Started 9/01/2013</p> <p>2.3</p> <p>Council will provide resources to support the development of policies and practices for people with I/DD to have more options for living in the community, including living in a home that they or their families rent or own.</p> <p><i>Bridging Practice and Policy: Transitions from Adult Care Homes for People with I/DD (Disability Rights NC)</i></p>	<p>1) Locate individuals with I/DD living in adult care homes in North Carolina who may be eligible for Home and Community Based waiver services, state-funded services, or any available Medicaid State Plan (i) option.</p> <p>2) Provide advocacy, support to individuals with I/DD living in adult care homes to facilitate their transition from adult care homes to homes in community settings.</p> <p>3) Assist at least six (6) individuals with I/DD in transitioning from an adult care home to home in the community.</p> <p>4) Identify and assess barriers to community living for individuals with I/DD.</p> <p>5) Develop a "blueprint" to close the front door of adult care homes to people with I/DD and ensure the successful transition for people with I/DD who wish to live in the community.</p>	<p>1) 9/1/2013-8/31/2014</p> <p>2) 9/1/2014-8/31/2015</p> <p>3) 9/1/2014-8/31/2016</p> <p>4) 9/1/2014-8/31/2015</p> <p>5) 9/1/2015-8/31/2016</p>
<p>2.4</p> <p>People with I/DD have transportation options that are affordable, accessible, reliable, flexible and safe.</p>	<p>1) Promote the participation of people with I/DD on local transportation boards to ensure local, state, and federal policy implementation.</p>	<p>1) by 09/30/2016</p>

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<p>Started 9/01/2013</p>	<p>2.5 People with I/DD will have access to the full range of needed primary and specialized health care services. <i>Medical Health Home for People with I/DD (Easter Seals UCP of NC and VA)</i></p>	<p>1) Engage stakeholders in 6-7 information-gathering sessions. 2) Develop 6 data-informed, consumer profiles to improve the knowledge base on understanding the population, needs, utilization, costs and outcomes. 3) Identify process, cost and outcome data available and analytic options to improve the knowledge base re: relevant data. 4) Establish Community-Academic-Provider Consortium to support policy entrepreneurs in promoting quality assurance and sustainable system change. 5) Identify I/DD Medical and Health Home competencies necessary to the development of social strategies that contribute to robust professional expertise, enhanced practice support and educational requirements. 6) Develop actionable NC model of care, with readiness assessment tool. 7) Pilot test and evaluate enhanced medical/health home elements.</p>	<p>1) 9/1/2013-8/31/2014 2) 9/1/2014-8/31/2015 3) 9/1/2014-8/31/2015 4) 12/1/2014-3/31/2014 5) 3/1/2014-8/31/2016 6) 3/1/2014-8/31/2016 7) 6/1/2014-8/31/2016</p>
<p>Ended 12/31/2012</p>	<p>2.6 People with I/DD will have access to the full range of needed primary and specialized health care services. <i>National Curriculum Initiative in Developmental Medicine (Mountain Area Health Education Center)</i></p>	<p>1) Identify core content for a curriculum for training in pre-medical, medical, and post-graduate medical education in adult developmental medicine. 2) Develop an advisory group. 3) Secure Family Medicine residency training sites to pilot the curriculum. 4) Identify physicians within the practices who will participate in the study. 5) Residents in training will demonstrate care to patients that is reflective of the training in adult developmental medicine.</p>	<p>1) 1/1/2011-12/31/2011 2) 1/1/2011-12/31/2011 3) 1/1/2012 - 3/31/2012 4) 4/1/2012 - 5/31/2012 5) 6/1/2012 - 5/31/2013</p>

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<p>Started 9/16/2013</p>	<p>2.7 Council will provide funding/resources that ensure accountability, advocacy, and outreach for its programs which improve the ability of service delivery systems to respond to the needs of people with I/DD and their families. <i>Medicaid Reform Stakeholder Engagement Initiative (National Association of State Directors of Developmental Disabilities Services)</i></p>	<p>6) Curriculum and outcomes are presented at professional conferences. 7) Faculty and residents to complete an evaluation and self-assessment of the program. 1) Develop a stakeholder group that is cross-disability in mental health, developmental disabilities and addictive disease and is reflective of the geographic and ethnic diversity of the state. 2) Facilitate up to six stakeholder meetings/forums. 3) Prepare and disseminate white papers based on group discussions.</p>	<p>6) 6/1/2012 - 5/31/2013 7) 12/1/2012 - 5/31/2013 1) 9/1/2013 - 10/31/2013 2) 11/1/2013 - 06/30/2014 3) 11/1/2013 - 08/31/2014</p>
<p>2.8 (Added 11/2013) Council will fund training, consultation and technical assistance to support the development of policies and practices, relative to guardianship and alternatives to guardianship, that advance integration, productivity, independence, integration, inclusion and self-determination for people with I/DD.</p>	<p>1) Develop Request for Application addressing guardianship and alternatives to guardianship for individuals with I/DD. 2) Select recipient(s) of funding and enter into contract(s). 3) Provide technical assistance to enhance the effectiveness of advocacy/systems change efforts. 4) Promulgate findings and target selected strategies for advocacy/system change interventions.</p>	<p>1) Develop Request for Application addressing guardianship and alternatives to guardianship for individuals with I/DD. 2) Select recipient(s) of funding and enter into contract(s). 3) Provide technical assistance to enhance the effectiveness of advocacy/systems change efforts. 4) Promulgate findings and target selected strategies for advocacy/system change interventions.</p>	<p>1) 1/1/2014 - 3/31/2014 2) 7/1/2014 - 7/31/2014 3) 9/1/2014 - 8/31/2016 4) 5/1/2016 - 8/31/2016</p>



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<p>Starts 10/01/2014</p> <p><b>2.9 (Added 11/2013)</b> Council will provide funding/resources to promote opportunities for people with I/DD to advance economic self-sufficiency by developing financial literacy and asset building skills. <i>Upward to Financial Stability (National Disability Institute)</i></p>	<p>1) Develop Request for Application to assist in the assessment of policy barriers and benefits related to financial literacy/asset development and perseverance for individuals with I/DD. 2) Select recipient(s) of funding and enter into contract(s). 3) Provide technical assistance to enhance the effectiveness of community capacity building efforts. 4) Promulgate findings and target selected strategies for sustainable community capacity building.</p>	<p>1) 1/1/2014 – 9/30/16 2) 1/1/2014 – 9/30/16 3) 1/1/2014 – 9/30/16 4) 1/1/2014 – 9/30/16</p>
<p>Started 9/01/2013</p> <p><b>2.10 (Added 11/2012)</b> Council will provide funding/resources to implement and maintain an emergency preparedness program that is inclusive of persons with I/DD and that builds capacity for disaster preparation, emergency response, and related procedures and systems. <i>Emergency Preparedness and Recovery (NC Department of Public Safety)</i></p>	<p>1) Convene a Technical Advisory Board to advise with regard to persons with I/DD. 2) Communication - assess current emergency preparedness communication tools and trends to assure receipt of information and methods can be readily communicated and used effectively by persons with I/DD. 3) Medical - assess the incorporation of emergency preparedness training and disaster management. 4) Functional Independence - identify emergency preparedness programs in which persons with I/DD can be educated on early disaster response. 5) Supervision - establish a statewide standard to influence policy change, enabling the creation of an emergency preparedness plan for individuals with I/DD. 6) Transportation - in collaboration with NC Department of Transportation and NC Department of Public Instruction, survey, throughout the state, methods of transportation during evacuations or disasters for persons with I/DD.</p>	<p>1) 9/1/2013- 9/30/2014 2) 9/1/2013- 9/30/2016 3) 9/1/2013- 9/30/2016 4) 9/1/2013- 9/30/2016 5) 9/1/2013- 9/30/2016 6) 9/1/2013- 9/30/2016</p>

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<p>Started 1/01/2014</p> <p>2.11 Added (11/2013)</p> <p>Council will provide funding/resources to provide people with I/DD with information to assist them in being safe from abuse, neglect, and harm and to equip direct support professionals and domestic violence support staff with the tools to meet the needs of victims with I/DD.</p> <p><i>Safety and Security: Addressing Sexual Violence and Domestic Violence Against People with I/DD</i></p>	<p>1) Release RFA on domestic violence to support the development of best practice-based, training curricula for direct support staff and domestic violence response staff to develop skills to improve prevention efforts and meet the needs of victims with I/DD</p> <p>2) Select grantee</p> <p>3) Execute first year of initiative according to grantee's approved work plan</p>	<p>1) 9/1/2013 – 12/1/2013</p> <p>2) 11/2013</p> <p>3) 1/1/2014 – 9/30/2016</p>
<p>Ongoing &amp; Started 7/01/2012</p> <p>2.12</p> <p>Council will provide funding/resources to support groups led by people with disabilities to conduct initiatives that promote voluntary compliance with the Americans with Disabilities Act (ADA) in their local communities..</p> <p><i>NC Americans with Disabilities (ADA) Network</i> <i>ADA Network Fiscal Agent (NC Alliance of Disability Advocates)</i></p>	<p>1) Consult with groups of people with disabilities to develop ADA community initiative plans.</p> <p>2) Provide follow-up, technical assistance and training to local groups to carry out their plans.</p> <p>3) Conduct leadership and ADA training for 2 new, grassroots groups.</p> <p>4) Processes reimbursement requests and in-kind match documentation from the NC ADA Network within 15 days or less of remittance.</p>	<p>1) 7/1/2012- 9/30/2016</p> <p>2) 7/1/2012- 9/30/2016</p> <p>3) 7/1/2012- 9/30/2016</p> <p>4) 7/1/2012- 9/30/2016</p>

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**GOAL 3: SUPPORTS-WORKFORCE- LEADERSHIP/PROFESSIONALS**

Advocacy, capacity building and systems change efforts of the Council will improve the knowledge and skills of the workforce that serves people with I/DD and their families.

Objectives	Implementation Activities	Timeline
<p>3.1 Council will expand, beyond the current number, the learners utilizing validated, evidence- and competency-based curricula for direct support workers who support people with I/DD. <i>College of Direct Support/Direct Course (Monarch, Inc.)</i> <i>College of Direct Support Technical Assistance (Institute for Community Integration)</i></p>	<p>1) Allocate Funding to expand implementation of the College of Direct Support (CDS)/Direct Course to at least 14 or more sites; 2) Allocate funding to conduct research in 4 sites re: curriculum and learner development to improve model coherency; 3) Allocate funding to provide targeted technical assistance and consultation to CDS sites (CDS TA); 4) Present CDS to state Practice Improvement Collaborative as an evidence-based practice to promote statewide adoption; 5) Provide necessary supports to community college system to test pilot CDS curriculum, advancing career paths for DSPs; 6) Advocate for CDS to be a state-approved training and identify funding strategies for advancing CDS statewide as an approved training; 7) Assess effectiveness of CDS initiative;</p>	<p>1) 10/01/2011 - 10/01/2016 2) 10/01/2011 - 10/01/2016 3) 10/01/2011 - 09/30/2012 4) 10/01/2011 - 12/31/2011 5) 10/01/2011 - 10/01/2016 6) 10/01/2011 - 10/01/2016 7) 07/01/2013 - 09/30/2016</p>

NCCDD 2011 - 2016 Five Year State Plan  
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<p>3.2 Council will fund strategies to promote competency-based training for Care Coordinators and Community Guides who support people with I/DD.</p>	<p>1) Develop Request for Application(s) for Care Coordination/Community Guides for individuals with I/DD. 2) Select recipient(s) of funding and enter into contract(s). 3) Provide technical assistance to enhance the effectiveness of advocacy/systems change efforts. 4) Promulgate findings and target selected strategies for advocacy/system change.</p>	<p>1) 1/1/2014 – 3/31/2014 2) 4/1/2014 – 4/30/2014 3) 7/1/2014 – 8/31/2016 4) 5/1/2016 – 8/31/2016</p>
<p>3.3 Council will fund leadership training for I/DD professionals. <i>Advancing Strong Leaders in the Developmental Disabilities' Field Test, Class I and II (National Leadership Consortium in Developmental Disabilities)</i></p>	<p>1) Allocate funding to the National Leadership Consortium in Developmental Disabilities to modify Advancing Strong Leaders in DD, three-year curriculum to inform and educate NC professionals in the field of I/DD. (Advancing Strong Leaders Class I); 2) Allocate funding to the National Leadership Consortium in Developmental Disabilities to modify Advancing Strong Leaders in DD curriculum to a one-year training, designed to inform and educate NC professionals in the field of I/DD. (Advancing Strong Leaders, Class II) 3) Assess effectiveness of initiative. 4) Present recommendations to Council. 5) Develop strategies for continuing to promote the development of leaders in the field of I/DD.</p>	<p>1) 10/01/2011 - 12/31/2011 2) 10/01/2012 - 09/30/2016 3) by 09/30/2015 4) by 05/31/2016 5) by 09/30/2016</p>
<p>3.4 Council will fund training of other professionals that increases their ability to provide quality services to meet the needs of people with I/DD.</p>	<p>1) Collaborate with the American Academy of Developmental Medicine and Dentistry and the Wal-Mart Foundation; the Family Medicine Education Consortium; the Assoc. of University Centers on Disability; and other strategic partners to advance the goal of embedding adult developmental medicine into the training of physicians in NC and the nation. 2) Recruit NC pilot sites for curriculum.</p>	<p>1) 10/01/2011 - 09/30/2016 2) 10/01/2011 - 09/30/2016 3) 10/01/2011 - 09/30/2016</p>

NCCDD 2011 - 2016 Five Year State Plan  
Goals, Objectives, Activities and Timelines

<p><i>Curriculum on Adult Developmental Medicine</i></p>	<p>3) Collaborate with other Councils on Developmental Disabilities that are conducting primary health care initiatives, the AADMD, and other strategic partners to expand pilot demonstration of the curriculum to other states.</p> <p>4) Host meeting with steering committee to consider next steps.</p>	<p>4) 10/01/2011 - 09/30/2016</p>
<p><b>3.5 (Added 11/2013)</b> Council will explore approaches to provide funding/resources so that employment professionals will have the support, knowledge, skills, and values that will allow them to provide improved services in the area of employment to individuals with I/DD.</p>	<p>1) Develop Request for Application for stakeholder group to assist in the assessment of policy barriers and benefits related to employment supports for individuals with I/DD.</p> <p>2) Select recipient(s) of funding and enter into contract(s).</p> <p>3) Provide technical assistance to enhance the effectiveness of employment professionals in community capacity building efforts.</p> <p>4) Promulgate Findings, and target selected strategies for sustainable community capacity building.</p>	<p>1) 1/1/2014 - 9/30/2016</p> <p>2) 1/1/2014 - 9/30/2016</p> <p>3) 1/1/2014 - 9/30/2016</p> <p>4) 1/1/2014 - 9/30/2016</p>
<p><b>3.6</b> Council will enhance the status of direct support professionals and promote the development of a highly competent human services workforce supporting individuals with I/DD. <i>NC Chapter of the National Alliance for Direct Support Professionals (Benchmark, Inc.)</i></p>	<p>1) Plan and convene no less than 4 regional forums and one state-wide conference to educate the direct support workforce and general public about the benefits of a NADSP chapter in North Carolina.</p> <p>2) Establish 501 (c)(3 ) status for a NC NADSP chapter with a board of directors, bylaws, and 100 members.</p> <p>3) Assist in transitioning the NC NADSP chapter from being grant-supported to being independently supported.</p>	<p>1) 3/1/2014 - 12/30/2014</p> <p>2) 1/1/2015 - 12/30/2015</p> <p>3) 1/1/2016 - 12/30/2016</p>

Started 01/01/2014

NCCDD 2011 - 2016 Five Year State Plan  
Goals, Objectives, Activities and Timelines

**GOAL 4: SUPPORT/STRENGTHENING SELF ADVOCACY ORGANIZATIONS**  
Council will strengthen a statewide self-advocacy program.

Objectives	Implementation Activities	Timeline
<p>4.1 Council will provide opportunities for people with I/DD to provide leadership training to others. <i>Ended 6/30/12 Infrastructure support to ASANC (Association of Self-Advocates of NC (ASANC)</i> <i>Ended 3/30/12: Making Our Voices Heard (HSRI)</i> <i>Ended 9/30/12: Building a Stronger ASANC</i></p>	<p>1) Support statewide self-advocacy efforts. 2) Allocate funding to support the development of a stronger state and local infrastructure for the Association of Self Advocates of NC (ASANC); 3) Allocate funding to support the development of a stronger state and local leadership; 4) Survey ASANC board and membership regarding satisfaction with performance of ASANC. 5) Make office space, supplies, and equipment available to support the ASANC.</p>	<p>1) 10/01/2011 - 09/30/2016 2) 10/01/2011 - 05/30/2012 3) 06/01/2012 - 09/30/2013 4) by 11/30/2011 5) 10/01/2011 - 09/30/2016</p>

NCCDD 2011 - 2016 Five Year State Plan  
Goals, Objectives, Activities and Timelines

<p>Started 09/01/2013</p>	<p>4.2 Council will provide opportunities for people with I/DD to participate in cross-disability, culturally diverse, leadership coalitions and training opportunities.</p>	<p>1) Support the development of a cross-disability coalition. 2) Assess the viability of the NC Disability Action Network as a foundation for efforts to build and strengthen a cross-disability coalition. 3) Allocate funding to build and strengthen a cross-disability coalition. 4) Select fund recipient. 5) Enter into contract. 6) Implement activities. 7) Assess effectiveness of efforts to build and strengthen a cross-disability coalition.</p>	<p>1) 06/01/2013 - 9/30/2016 2) by 06/30/2013 3) by 02/28.2013 4) by 05/30/2013 5) by 07/01/2013 6) by 07/01/2013 7) by 09/30/2016</p>
<p>Started 09/01/2013</p>	<p>4.3 (Added 11/2013) Council will assess the climate of the self-advocacy in NC to determine how best to support people with I/DD to be effective advocates at the local, regional, and state levels. <i>Advocacy Ambassador Initiative (Community Resource Alliance)</i></p>	<p>1) Release funds to support a state-wide assessment of the goals, of local self-advocacy groups and barriers and opportunities to achieving these. 2) Recruit and train 3 Advocacy Ambassadors from among the I/DD community. 3) Advocacy Ambassadors will survey self-advocacy groups across NC to determine their goals and barriers and opportunities to achieving these and submit findings to Council. 4) Develop a set of recommendations for how the NCCDD can best support statewide self-advocacy based on feedback gathered.</p>	<p>1) 9/1/2013 - 8/31/2014 2) 9/1/2013 - 10/31/2013 3) 11/1/2013 - 3/31/2014 4) 4/1/2014 - 8/31/2014</p>
<p>Starts 10/01/2014</p>	<p>4.4 (Added 11/2013) Council will provide funding/resources to assist siblings of individuals with I/DD in providing informal and natural supports for a brother or sister. <i>Sibling Support (First in Families)</i></p>	<p>1) Develop Request for Application for supporting siblings of individuals with I/DD. 2) Select recipient(s) of funding and enter into contract(s)contract(s)contract(s). 3) Provide technical assistance to enhance the effectiveness of advocacy/systems change efforts. 4) Promulgate findings and target selected strategies for advocacy/system change.</p>	<p>1) 11/2013 - 8/2014 2) 3/2014 - 8/2014 3) 9/2014 - 8/2015 4) 9/2015 - 9/2016</p>

NCCDD 2011 - 2016 Five Year State Plan  
Goals, Objectives, Activities and Timelines

GOAL 5: Council Quality Assurance/Operations

On-going	Objectives	Implementation Activities	Timeline
5.1	<p>Council will provide funding/resources that ensure accountability, advocacy, and outreach for its programs.</p> <p><i>State Plan Development, Program Management, Route to Success (Ended 6/30/2014), Impact Evaluation (Unaddressed)</i></p>	<p>1) Allocate funding for the development and monitoring of the NCCDD State Plan to ensure accountability for Goal I programs;</p> <p>2) Coordinate and conduct Program Management activities associated w/ the development and monitoring of the St. Pl. to ensure accountability for programs under this goal;</p> <p>3) Implement the "Route to Success" model as a means of monitoring &amp; ensuring accountability for programs under this goal;</p> <p>4) Conduct evaluation to assess impact of selected State Plan Programs.</p>	<p>1) 10/01/2011 - 09/30/2016</p> <p>2) 10/01/2011 - 09/30/2016</p> <p>3) 10/01/2011 - 09/30/2016</p> <p>4) 10/01/2011 - 09/30/2016</p>



NCCDD 2011 - 2016 Five Year State Plan  
Goals, Objectives, Activities and Timelines

<p>5.2 Council will provide funding/resources that promote individuals with IDD and families participating meaningfully in public policy deliberations.</p>	<p>1) Allocate funding for assistance from a policy analyst to enhance the NCCDD's advocacy for sustainable systems change</p>	<p>1) 10/01/2011 - 09/30/2016</p>
<p>5.3 Council will provide funding/resources that promotes awareness of its initiatives. <i>NCCDD Communications Initiative (Ended 12/31/2013 - The Wallace Group)</i> <i>(Started 1/01/2014 - Communications Temp Contractor)</i> <i>(10/01/2014 - Next Contract Starts)</i></p>	<p>1) Allocate funding from Communications Initiative to provide marketing and outreach for initiatives. 2) Create accessible communication materials. 3) Strengthen media relations to further the image of the Council and its programs. 4) Work with grantees to promote the objectives of the grant and assist in any marketing/recruitment efforts required for the initiative.</p>	<p>1) 10/01/2011 - 09/30/2016 2) 10/01/2011 - 09/30/2016 3) 10/01/2011 - 09/30/2016 4) 10/01/2011 - 09/30/2016</p>

NCCDD 2011 - 2016 Five Year State Plan  
Goals, Objectives, Activities and Timelines

On-going	<p>5.4 Provide individuals with I/DD and family members/guardians of people with I/DD with opportunities to attend in-state and national events, educating participants with regard to systems change, advocacy and capacity building activities that are consistent with the NCCDD's mission. <i>Jean Wolff-Rossi Fund</i></p>	<p>1) Select five advisory committee members for the Rossi Fund from the NCCDD Council. Identify a coordinator and establish a personal service contract. 2) Process applications according to Rossi Fund guidelines, including sending letter of receipt to applicant, review of application and event brochure, approval or denial letter created/sent with reimbursement and survey form or copy of guidelines to applicant. 3) Ensure that reimbursement is submitted upon applicant's return from event. 4) Maintain Rossi Fund demographics and performance data and provide quarterly, usage, status reports to NCCDD.</p>	<p>1) 10/01/2011 - 09/30/2016 2) 10/01/2011 - 09/30/2016 3) 10/01/2011 - 09/30/2016 4) 10/01/2011 - 09/30/2016</p>
On-going	<p>5.5 Enhance NCCDD membership decision-making skills and abilities regarding board participation, and state and national practices and policies affecting people with I/DD and their families. <i>Council Development Initiative</i></p>	<p>1) Coordinate presentations for quarterly Council meetings by local, state, and national experts on topics in, or planned for inclusion in, the NCCDD State Plan. 2) Develop contract with presenters approved by Executive Committee. 3) Secure Program Report from contractor. 4) At least annually, provide board membership training to new and existing members.</p>	<p>1) 10/01/2011 - 09/30/2016 2) 10/01/2011 - 09/30/2016 3) 10/01/2011 - 09/30/2016 4) 10/01/2011 - 09/30/2016</p>
On-going	<p>5.6 Sponsors content expert speakers to present at 10 in-state or national conferences on topics in or planned for inclusion in the NCCDD State Plan. <i>Conference Funding Initiative</i></p>	<p>1) Market NCCDD Conference Funding initiative on website and in NCCDD newsletter. 2) Process conference funding application requests, then provide to Council Executive Committee for review and funding consideration 3) Following Executive Committee approval, develop and enter into contract. 4) Secure conference funding report from contractor.</p>	<p>1) 10/01/2011 - 09/30/2016 2) 10/01/2011 - 09/30/2016 3) 10/01/2011 - 09/30/2016 4) 10/01/2011 - 09/30/2016</p>

**Comprehensive List of Funded Initiatives  
2011 - 2015 Five Year State Plan**

**1 State Plan Development**

Partner with CIDD to assist NCCDD in data collection for programs under this goal.

**2 Program Management/Program Quality Management (2011)**

Supports Council Program Management Staff and their related office and travel expenses; develops, manages, and evaluates statewide program activities across approximately 20 external initiatives and multiple internal initiatives.

**3 Council Development initiative**

Provides for the education and training of the membership of the NCCDD to enhance their decision-making skills and abilities regarding practices and policies for people with intellectual and developmental disabilities (IDD) and their families.

**4 Administrative Staff and Council Expenses**

Comprises the capped 30% Administrative expense allowance for Council executive, management and administrative staff and related office and travel expenses. Also includes budgeted expenses for quarterly Council meetings and member reimbursements for Council meeting attendance.

**5 Comprehensive Communications Plan**

This initiative uses a strategic, targeted and efficient communications program to produce a measurable increase in awareness of the NCCDD and greater understanding and appreciation for Council activities.

**6 Public Policy Initiative**

Promote and enhance education activities about the capabilities, preferences, and needs of individuals with intellectual and developmental disabilities; develop and support coalitions that support the policy agenda of the Council; as well as develop and support training in self-advocacy, education of policy makers, and citizen leaderships skills.

**7 Route to Success**

An innovative logic model for assisting Councils in developing, implementing, and evaluating initiatives, such that investments are more likely to produce the systems change with which Councils are charged under the Developmental Disabilities Bill of Rights and Assistance Act (P.L. 106-402).

**8 MAHEC Mini Fellowship in Adult Developmental Disabilities**

This initiative will transform a physician training program on the care of adults with developmental disabilities from prototype to a formal incubator initiative then develop a national consensus on the curricular content of neuro development disorders for pre-medical, medical, graduate and post graduate medical education.

**9 JWR Participant Fund**

Funding for people with IDD and families to participate in diverse learning forums, garnering information necessary to make informed choices, enhance advocacy and positively impact public policy

**10 NC Partners in Policymaking**

This initiative teaches leadership skills, and the process of developing positive partnerships with elected officials and other individuals who make policy decisions about services used by North Carolinians with developmental disabilities and their families.

**11 NC ADA Network**

This initiative is designed to promote voluntary compliance with the Americans with Disabilities act (ADA) through a statewide, grassroots network of local affiliates.

**12 ADA Network Fiscal Intermediary**

This initiative is designed to distribute funds to the ADA Network affiliates, to the ADA Network Coordinator and at the request of the ADA Network Coordinator .

**Comprehensive List of Funded Initiatives  
2011 - 2015 Five Year State Plan**

**13 Advancing Strong Leaders in Developmental Disabilities**

This initiative creates a leadership program for the state's young professionals in the field of intellectual and developmental disabilities (IDD). This leadership program will create a cohesive group of emerging leaders who hold shared, core values; are equipped to advocate for and implement contemporary public policy in the IDD field and are prepared to assume the responsibilities of the state's current leaders as they retire.

**14 Supported Employment Leadership Network (SELN)**

NC Division Leaders providing technical assistance to IDD agencies to promote employment.

**15 Family Support: Coming of Age**

This initiative will identify the barriers to accessing family support; developed recommendations for removing such barriers; and recommend systems change strategies that are cost-effective and consistent with the values that both families and self-advocates espouse.

**16 Reaching the Summit of Success (Start 10/1/12)**

This initiative offers students with intellectual disabilities ongoing experiences and interactions with other students within the context of a typical college environment, integrated with access to the activities and services a college provides its students.

**17 Conference Funding**

This initiative provides funding for content expert speakers to present at conferences approved by the Council.

**18 Learning and Earning After High School: The Role of Transition Services in Raising Expectations and Attitudes for Students with Intellectual Disabilities**

With this contract, the NCCDD will create a sustainable approach to providing transition services and resources for students with intellectual disabilities, even with those with the most complex of these disabilities. The approach will begin as early as middle school and continue through high school.

**19 Bridging Practice and Policy: Transitions from Adult Care Homes**

The intent of this contract is to create a cost-effective, policy and practice blueprint or "bridge" for people with IDD who currently reside in Adult Care Homes and prefer to live in a home that they lease, share with people of their choice, or own. The initiative will clearly delineate practice innovations and policy changes with the potential to assist individuals with intellectual and developmental disabilities to transition from ACHs to homes of their own, with the appropriate services and supports. It will also address barriers and propose solutions.

**20 Medical and Health Homes for People with Intellectual and Other Developmental Disabilities: Coordination, Collaboration and Community**

To ensure people with IDD receive the right care at right time in right setting, the contractor will develop a medical and health home model with cross systems collaboration informed by individuals and families, health networks, long-term support providers and policy stakeholders. An actionable model requires data-informed input on needs, gaps, existing capacity and outcomes.

**1 Emergency Preparation**

To implement and maintain an emergency preparedness program that is inclusive of persons with IDD and that builds capacity for disaster

**2 Enhancing Disability Stakeholder Engagement in Managed Long-Term Services/Supports and Primary/Acute Care Systems Coordination**

This contract will be to support consumer and family involvement in several meetings related to the design, planning steps, waiver or state plan changes, contract and policy language, readiness review components, consumer outreach, monitoring and oversight that is important for a well-informed redesign of the state's Medicaid Waiver program.

Comprehensive List of Funded Initiatives  
2011 - 2015 Five Year State Plan

**23 Advocacy Ambassadors**

To obtain a current and accurate assessment of the state of self-advocacy in North Carolina and receive clear feedback from self-advocates about how the NCCDD can best support and advance the self-advocacy movement.

**24 Project Search**

To implement a high school transition initiative which is a business-led, one-year, school-to-work program that combines classroom instruction, career exploration, and relevant job-skills training through strategically designed internships for students with I/DD.

**25 NC Direct Support Professional Association**

Establish a local chapter of NADSP to advance the quality of the workforce that supports individuals with disabilities through increased competency, professionalism, and a voice in decision-making.

**26 Safety and Security: Addressing Sexual Violence and Domestic Violence**

To develop a meaningful, effective, and concise training for 1) providers of intellectual and/or developmental disability (I/DD) services and 2) providers of generic domestic and sexual violence prevention programs in the community.

**27 Taskforce on Inclusive Child and Afterschool Care**

This 18-month initiative is to invest in systems change efforts that promote and enhance the availability of fully inclusive, high quality child and afterschool care environments, with an emphasis on facilitating organizational or systems change that will lead to outcomes valued by families of children with intellectual and other developmental disabilities. A taskforce will assist in the development of recommendations to increase community capacity and support for addressing attitudinal, policy, procedural, training, regulatory, and funding barriers hindering the development of inclusive child and afterschool care environments for children and youth.

**28 NC Alliance for Full Participation/Employment First**

This initiative is an 18-month grant designed to enhance and promote the collaborative efforts of North Carolina's AFP Steering Committee in substantially increasing the ability of individuals with developmental disabilities to secure employment in regular, competitive, and inclusive settings. The initiative's intent will be met as a result of the provision technical assistance, including consultation and meeting facilitation, through the University of Massachusetts' Institute for Community Inclusion.

**29 MAHEC Mini Fellowship in Adult Developmental Disabilities**

This project will transform a physician training program on the care of adults with developmental disabilities from prototype to a formal incubator project then develop a national consensus on the curricular content of neuro development disorders for pre-medical, medical, graduate and post graduate medical education.

**30 NC Relationships Initiative (aka Real Relationships, Risks, and Responsibilities)**

This 18-month initiative is to promote systemic change; provide education around and information about healthy sexual and intimate relationships; offer people with I/DD opportunities for active participation in identifying barriers and solutions; and increase community capacity/willingness to address attitudinal, policy, and or regulatory barriers associated with such relationships for people with I/DD.

**31 ASANC - Infrastructure and Staff Support**

This Project is designed to provide staff support and administrative services and supports to the Executive Director, board and members of the Association of Self Advocates of North Carolina (ASANC).

**32 ASANC - Building a Stronger ASANC**

This one year initiative is designed to support the Association of Self-Advocates NC (ASANC) in their efforts to build a new stronger structure for their Association that will provide leadership and supports needed to build a strong organization where self-advocates make decisions and do the work.

Comprehensive List of Funded Initiatives  
2011 - 2015 Five Year State Plan

**33 Phase II: NCCDS Research and Expansion Initiative**

This initiative will assure access to and provide administration and coordination for all new CDS participants; develop a comprehensive public awareness and marketing plan for general and targeted groups and promote CDS and outreach to providers agencies, Community colleges, universities, and DHHS agencies

**34 Phase II: Technical Assistance NCCDS Research and Expansion Initiative**

This initiative will provide consultation, training, and technical assistance in support of the Phase II-CDS Research/Expansion initiative

**35 (Summit Implementation) Technical Assistance Collaborative (Ended 1/31/12)**

This project aims to provide technical assistance to divisions within the NC Department of Health and Human Services so that the recommendations outlined in the 2008 Summit on Developmental Disabilities can be implemented successfully. The Division of MH/DD/SAS and the Division of Medical Assistance will be the primary recipients of this technical assistance.

**36 Better Together Sibling Support Initiative**

To address the various needs and barriers that siblings of a person with an intellectual or other developmental disability face.

**37 Upward to Financial Stability**

This initiative promotes opportunities for people with I/DD to advance economic self-sufficiency by developing financial literacy and asset building skills.

**38 Rethinking Guardianship: Building A Case For Less Restrictive Alternatives**

The goal of the Rethinking Guardianship: Building A Case For Less Restrictive Alternatives Initiative is to: build a workgroup that will address changes needed to the guardianship statutes, policies, and practices on an ongoing basis; build a collection of relevant data to support innovative approaches to guardianship alternatives; build a knowledge base of best practices including states that have adopted alternatives to guardianship and the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act and; build long term support for change.

# OLD BUSINESS

~~OUTDATED~~



## MEMORANDUM

**To: North Carolina Council on Developmental Disabilities**  
**From: O'Neill Communications**  
**Re: NCCDD Creative**

O'Neill Communications presents the Council with various creative options for the rebranding of NCCDD. Enclosed are options for the NCCDD logo, the five-year plan logo, website and slogans that encompass the input received from the focus groups, the November Council meeting and conversations with partners and NCCDD staff.

**Please note that the artwork is in black and white to merely show concepts. The logos will be presented in color options at the Council meeting for input.**

### LOGOS:

#### **NCCDD Logo:**

The logos incorporate the new brand strategy of NCCDD. The logos focus on NCCDD's acronym, outreach to people and highlight its reach throughout North Carolina.

#### **Five-Year Plan Logo:**

The five-year plan outreach that will begin in March has been branded as an event by NCCDD to increase engagement. The logo will be used when communicating about this event throughout the State and for the listening sessions that will start in the spring.

### WEBSITE:

The website templates provide a clean and streamlined look; a responsive design\*; rotating banners that display most newsworthy/timely events with links to related pages; a navigation bar in order of most searched areas through web analysis; blogging for new content to increase traffic and engagement; and lots of pictures to show people, energy and activity.

\*Responsive design is optimized for mobile devices meaning that web content reorganizes to fit tablets or phones. The copy stays large enough to read and also improves search on Google or other search engine sites.

### SLOGANS:

The slogans were crafted to capture the Council's goal and mission for effective messaging and outreach.

We look forward to presenting these options to the Council at the February Council meeting.

Thank you,

Gordon O'Neill  
President/CEO

Devika Rao  
Account Manager



Logo Concepts

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**NCCDD**

North Carolina Council on  
Developmental Disabilities



**NCCDD**

North Carolina Council on  
Developmental Disabilities



**NCCDD**

North Carolina Council on  
Developmental Disabilities

# Five-Year Plan Logo Concepts

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Listen. Gather. Plan.



Listen. Gather. Plan.



Listen. Gather. Plan.



Listen. Gather. Plan.

## Slogans

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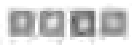
Connecting People. Changing Communities.

Connecting People. Changing Lives.

Innovation. Change. Inclusion.

Innovation. Change. Inclusive Communities.

Fostering Innovation. Creating Change.

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## PARENTING, EDUCATION & DAILY LIFE

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### PHOTO GALLERY

View our photo gallery to see the work we do in the community.

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### LEARN ABOUT THE STATE PLAN

Learn about the state plan and how we are working to improve the lives of people with disabilities.

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### INITIATIVES LIBRARY

Explore our initiatives library to find resources and information on various topics.

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### SUBMIT YOUR THOUGHTS

Share your thoughts and feedback with us. We value your input.

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AD QUIA VENT ODI PRAMUS UT EXPERIETAS SUNDAM PUS ESSIT SEQUIE MOOS RE NON SEDICITUR SIN EUDQUAN EAF AUT HOLLUP? [LEARN MORE!](#)



**OVER 175,000**  
People with disabilities in NC




**70% UNEMPLOYMENT**  
Rate for people with disabilities



**40 MEMBERS**  
of the NCCDD

### BLOG

- [EMPLOYMENT](#) >
- [EDUCATION/EARLY INTERVENTION](#) >
- [HEALTH](#) >
- [CHILD CARE AND NANNING](#) >
- [COMMUNITY](#) >
- [QUALITY ASSURANCE](#) >
- [ADVOCACY](#) >



### EDUCATION MATTERS

#### FACI QUI OCCUPATUR, VOLORECTE

Facit qui occu- tatur, volorecte. This is a placeholder text for a blog post about education matters.


### UPCOMING EVENTS



**JAN 24**  
FACI QUI OCCUPATUR  
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**FEB 4**  
FACI QUI OCCUPATUR  
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**FEB 14**  
FACI QUI OCCUPATUR  
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NORTH CAROLINA COUNCIL ON DEVELOPMENTAL DISABILITIES  
3725 POPLARWOOD COURT  
SUITE 200  
RALEIGH, NC 27604  
800-NCCDD-090



# Website #2



HOME HOW WE HELP PROJECTS PUBLIC POLICY NEWS/MEDIA HELP DESK THE COUNCIL



**PHOTO GALLERY**

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**LEARN ABOUT THE STATE PLAN**


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**INITIATIVES LIBRARY**

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**SUBMIT YOUR THOUGHTS**

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**UPCOMING EVENTS**

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**JAN 24**

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**FEB 2**

El expedit iustitiae fectus  
verit digni hii quidem  
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**FEB 12**

El expedit iustitiae fectus  
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**HOW WE HELP**

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HOME

**BLOG**

Jan 15, 2014

**GETTING THAT JOB**

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rum sicutis cinder


Jan 15, 2014

**IN THE FAMILY**

El expedit iustitiae fectus  
verit digni hii quidem  
rum sicutis cinder

**QUOTES**

*"El expedit iustitiae fectus  
verit digni hii quidem  
rum sicutis cinder Sequamus  
sandiscius. Gia nullamendunt quae. Unt  
que con perspedit earcium volendit labori  
can cum adictor epudithae vernate mpor-  
rum aut pre rem ut iuntur, que perum ad  
molum esns et, velendi iuntur"*

 Joe Jackson

**Menu**

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# Communications Initiative

November 2014: questions and answers raised during the Council meeting

1. **When is this the right time to begin the branding process?**

The short answer is this is the perfect time to start the rebranding process. Why?

- Rebranding is best done during times of change so that the new brand can better reflect the emerging situational environment.
- NCCDD has a new executive director and a new five-year planning process that will begin this year.
- Major Medicaid changes are under discussion and the public is paying close attention to the General Assembly and NC DHHS.
- This is part of the contract requirements to make recommendations about our branding.

2. **The Council has expressed a strong desire for access to information among the various committees, executive committee actions and other Council communications. What is being done about that?**

As part of the contract requirements, O'Neill Public Relations will be introducing a new website concept at the February Council meeting for member review and input. Some of the features of the website will include:

- A specific section for all Council meeting documents (agenda, minutes, etc.).
- Greater accessibility as compared to the current web site.
- An expanded information and resource section to better help people find the right resource which is expected to increase website hits by 5 times and reduce bounce rates by 50%.

3. **How will information about current initiatives, important events and wider reach be achieved through the communications initiative?**

Communication through a wider reach is a high priority of the communications effort. Some of the activities will include:

- Significantly increasing the distribution list of individuals connected to the NCCDD from 1,000 to 5,000 will be a major focus to improve the NCCDD's communications system.
- Utilizing this higher participation rate to shape the next 5-year plan.
- Organizing information about previous and current initiatives on the new website.

4. **Will we have more access and visibility of history of the organization and initiatives, past and present?**

There is value in summarizing historic perspective of the Council and the impact of its initiatives over the years.

- O'Neill Public Relations staff are building a narrative of the Council's history and the impact of the initiatives in areas such as education, employment, etc.

# Communications Initiative

- Information from official documents will be used to build a formative foundation of the Council's history and initiatives over the past years.
- This information will allow today's Council and all future visitors to understand the connective tissue that links the initiatives to specific systems change efforts to strengthen community.

5. How can we communicate with each other privately through email or forums as part of our committee or Council work?

Sharing and learning through initiatives, activities of members can lead to new ideas and serves to help people to be more informed.

- Council members do and can certainly communicate separately and privately. However, committee processes and Council business is conducted publicly.
- A forum is planned for the website that is intended for Council and committee use, but all traffic will be in the public view.

6. Could the 2014 proposed marketing and communications plan have been provided to the Council in advance of the November 19<sup>th</sup> meeting?

Due to the complexity of the contracting process, the RFA specified a start date of October 1, 2014, which left just six weeks until the draft communications plan was needed for the Council meeting.

- The first priority was organizing six focus groups, which the NCCDD staff worked hard to do the week of October 13 - all of which were completed by the second full week of the contract period.
- During October and the first two weeks of November, the competitive and situational analysis, the focus group assessments, strategic direction and creative development processes were being worked on at the same time.
- The draft communications plan presented to the Council had to be completed by Monday, November 17 for use in meetings scheduled with NCCDD staff on the 18th and for presentation to the Council on the 20th and 21st.
- Under the RFA requirements of completing the draft in the first 60 days of the contract, O'Neill Public Relations actually finished the draft communications plan two weeks ahead of schedule so the Council could review it at the November Council meeting.
- Ideally, two more weeks would have allowed O'Neill Public Relations to refine the draft communications plan, but would have delayed the execution of the second phase. The O'Neill Public Relations staff has been interested in and responsive to suggestions of Council members and staff and are flexible in refining the plan on an ongoing basis.

7. The 2014 proposed marketing and communications plan had a few errors in accuracy. What are the future strategies to promote accuracy of information on the web site and other publically available documentation?

- O'Neill Public Relations completed the draft report in time for the November Council meeting but review time by Council members was not possible given timelines.

# Communications Initiative

- The draft document was intended for Council members and staff and was not intended for distribution outside its current format.
- Future work will be reviewed by staff of both O'Neill Public Relations and the NCCDD for accuracy prior to distribution and monitored after publishing or distribution to maintain accuracy.

## 8. How can we clarify our sibling partner organizations?

The website will highlight sibling partner agencies (Carolina Institute on Developmental Disabilities and Disability Rights NC) and will showcase collaboration with those agencies on initiatives and activities that have an impact on the disability community in North Carolina.

## 9. The Council serves the entire state but sometimes is perceived as focusing on the Raleigh area, what will occur to increase awareness of the NCCDD as being a state-wide organization?

The NC Council on Developmental Disabilities represents all of NC.

- Events such as the ADA bus tour and five-year plan forums will occur in various areas of the state. Logo and website designs will include the possibilities of use of the state map.
- Information about the initiatives will be included on the website to demonstrate efforts to impact all of NC.
- The list of NCCDD contacts will increase and will be more representative of the state. Information about NCCDD will clearly indicate the responsibility of the NCCDD to represent individuals and families in all parts of NC.

## 10. Will NCCDD have a calendar of events and if so, what will be posted?

The new website will feature current initiatives and activities of the initiatives and other events as recommended by staff and members. The amount of information will be monitored.

## 11. What will occur to help members and staff with a short "elevator" speech?

This activity is one of the deliverables of the communications contract and will be addressed at a later time as the current priority is to get the new website ready.



# NEW BUSINESS



NEW



## NC Council on Developmental Disabilities

### 2016 – 2021 Five -Year State Plan Development

#### State Plan Goal 5: Council Quality Assurance/Operations

**Objective 1: Council will provide funding/resources that ensure accountability, advocacy, and outreach for its programs.**

NCCDD 5 Year State Plan 2011- 2016

Development Start Date	February 13, 2015
Survey Release/Public Input period	April thru July 2015
NCCDD Member Development Sessions	May & August 2015
Draft Release for Public Comment	November 2015 thru January 2016
Required Submission to AIDD	August 15, 2016
Plan Implementation Date	October 1, 2016

**What the DD Act says:** The plan shall focus on Council efforts ... by specifying five year goals, as developed through data driven strategic planning, for advocacy, capacity building, and systemic change related to the **areas of emphasis:**

- Formal and informal community supports
- Child care
- Education;
- Employment
- Health
- Housing
- Quality assurance
- Recreation
- Transportation

#### **Current NCCDD 2011 – 2016 Five-Year State Plan Goals:**

- Goal 1: Transition
- Goal 2: System response to people's needs
- Goal 3: Supports-workforce- leadership/professionals
- Goal 4: Support/strengthening self advocacy organizations
- Goal 5: Council quality assurance/operations

**Throughout the process for developing the State Plan, the Council should keep in mind four key concepts:**

- Council member engagement in the planning process
- Collaboration with the AIDD Network and other partners
- Stakeholder input on state needs and the proposed plan
- The use of data for planning purposes

NCCDD Development Schedule  
2016 – 2021 Five-Year State Plan

January 23, 2015

- Executive Committee (E.C.) reviews Five-Year State Plan development schedule and discusses process
- EC provides initial authority to pursue state plan goal 5.1: Advance Development of Five Year Plan
- Review Sole Source Policy for Carolina Institute on Developmental Disabilities (CIDD) development support with Comprehensive Review and Analysis

February 12 – 13, 2015

- 2016 - 2021 STATE PLAN DEVELOPMENT KICK OFF!
- Staff present Five-Year State Plan Development process and schedule, and
- Highlight member involvement and other development activities (e.g., survey distribution, input forum ambassadors, direct input opportunities)

March 1, 2015\*

- CIDD *potentially* starts to analyze data/results of information from various sources including surveys, listening sessions, and key state agency/organization staff interviews

April 1 – July 31, 2015

- Survey release
- Public input solicitation and listening sessions
- Key state agency/organization staff interviews
- ~~CIDD potentially starts to analyze data/results of information from various sources including surveys, listening sessions, and key state agency/organization staff interviews\*~~

May 14 – 15, 2015

- NCCDD Staff and CIDD Initiative Coordinator present “up to date” results and an update on general process activities
- COUNCIL MEMBER STATE PLAN DEVELOPMENT SESSION 1 of 2. Using preliminary state, national, and NC citizen/stakeholder data, NCCDD members discuss their interests for goal/objective areas for concentration. (Remember, public input period lasts through July 31)

June 1 – July 31, 2015

- NCCDD Staff develop *preliminary* recommendations of goals and objectives using CIDD data, listening session input and other results, and
- NCCDD Member Session 1 results

July 20, 2015

- Executive Committee reviews/gives feedback on *preliminary* recommendations goals and objectives

August 14 – 15, 2015

- Council staff with support of CIDD present results of document review and public/NCCDD member/interview data
- Staff present *preliminary* recommendations of goals and objectives
- COUNCIL MEMBER STATE PLAN DEVELOPMENT SESSION 2 of 2

November 18 – 20, 2015

- NCCDD Staff/E.C. present *tentative* Goals/Objectives
- Seek Full Council approval for PUBLIC RELEASE of DRAFT Goals and Objectives with Executive Summary of Comprehensive Review and Analysis
- Minimum 45 days per DD Act

December 1, 2015 – January 23, 2016

- DRAFT NCCDD 2017 – 2021 State Plan released for public comment

NCCDD Development Schedule  
2016 – 2021 Five-Year State Plan  
(Continued)

February 2016 Council Meeting

- Quarterly Council meeting. NCCDD Reviews and discusses public comment.
- NOTE: Significant input resulting in substantive REVISION requires second 45 day release for public comment (e.g., February 25, 2016 – April 15, 2016)

May 2016 Council Meeting

- NCCDD receives update by staff on progress of putting plan information in DD Suite OR receives results of second public comment period

August 2016 Council Meeting

- Full plan available and distributed to NCCDD; comprehensive DD Suite print out available. Council approval to submit plan to AIDD sought

August 15, 2016

- Deadline for submission to AIDD of NCCDD 2016 – 2021 Five Year State Plan

October 1, 2016

- Five Year Plan start date

\*Reflects revision from schedule provided at 1/23/2015 Executive Committee Meeting



# The State Plan Development Resource

What Does the DD  
Act Say?

## What does the DD Act Say?

The DD Act has 6 main requirements of the State Plan.

1. Establish and maintenance of the Council
2. Identification of the designated State agency
3. Comprehensive review and analysis of the services and supports available to individuals with developmental disabilities
4. Plan goals and the method to be used in evaluating progress
5. Assurances
6. Public review and comment

Additional components of the State Plan include:

- Staff list
- Budget

The DD Act requirements for the State Plan appear in Figure 1. They can also be accessed on the ADD website at: <http://www.acf.hhs.gov/programs/add/ddact/DDB.html>

## Figure 1: DD Act Requirements for the State Plan

### SEC. 124 STATE PLAN.

(a) **IN GENERAL.** -Any State desiring to receive assistance under this subtitle shall submit to the Secretary, and obtain approval of, a 5-year strategic State plan under this section.

(b) **PLANNING CYCLE.** -The plan described in subsection (a) shall be updated as appropriate during the 5-year period.

(c) **STATE PLAN REQUIREMENTS.** -In order to be approved by the Secretary under this section, a State plan shall meet each of the following requirements:

(1) **STATE COUNCIL.** -The plan shall provide for the establishment and maintenance of a Council in accordance with section 125 and describe the membership of such Council.

(2) **DESIGNATED STATE AGENCY.** -The plan shall identify the agency or office within the State designated to support the Council in accordance with this section and section 125(d) (referred to in this subtitle as a "designated State agency").

(3) **COMPREHENSIVE REVIEW AND ANALYSIS.** -The plan shall describe the results of a comprehensive review and analysis of the extent to which services, supports, and other assistance are available to individuals with developmental disabilities and their families, and the extent of unmet needs for services, supports, and other assistance for those individuals and their families, in the State. The results of the comprehensive review and analysis shall include-

(A) a description of the services, supports, and other assistance being provided to individuals with developmental disabilities and their families under other federally assisted State programs, plans, and policies under which the State operates and in which individuals with developmental disabilities are or may be eligible to participate, including particularly programs relating to the areas of emphasis, including-

(i) medical assistance, maternal and child health care, services for children with special health care needs, children's mental health services, comprehensive health and mental health services, and institutional care options;

(ii) job training, job placement, worksite accommodation, and vocational rehabilitation, and other work assistance programs; and

(iii) social, child welfare, aging, independent living, and rehabilitation and assistive technology services, and such other services as the Secretary may specify;

(B) a description of the extent to which agencies operating such other federally assisted State programs, including activities authorized under section 101 or 102 of the Assistive Technology Act of 1998 (29 U.S.C. 3011, 3012), pursue interagency initiatives to improve and enhance community services, individualized supports, and other forms of assistance for individuals with developmental disabilities;

## Figure 1: DD Act Requirements for the State Plan

(C) an analysis of the extent to which community services and opportunities related to the areas of emphasis directly benefit individuals with developmental disabilities, especially with regard to their ability to access and use services provided in their communities, to participate in opportunities, activities, and events offered in their communities, and to contribute to community life, identifying particularly-

(i) the degree of support for individuals with developmental disabilities that are attributable to either physical impairment, mental impairment, or a combination of physical and mental impairments;

(ii) criteria for eligibility for services, including specialized services and special adaptation of generic services provided by agencies within the State, that may exclude individuals with developmental disabilities from receiving services described in this clause;

(iii) the barriers that impede full participation of members of unserved and underserved groups of individuals with developmental disabilities and their families;

(iv) the availability of assistive technology, assistive technology services, or rehabilitation technology, or information about assistive technology, assistive technology services, or rehabilitation technology to individuals with developmental disabilities;

(v) the numbers of individuals with developmental disabilities on waiting lists for services described in this subparagraph;

(vi) a description of the adequacy of current resources and projected availability of future resources to fund services described in this subparagraph;

(vii) description of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are in facilities receive (based in part on each independent review (pursuant to section 1902(a)(30)(C) of the Social Security Act (42 U.S.C. 1396a(a)(30)(C))) of an Intermediate Care Facility (Mental Retardation) within the State, which the State shall provide to the Council not later than 30 days after the availability of the review); and

(viii) to the extent that information is available, a description of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are served through home and community-based waivers (authorized under section 1915(c) of the Social Security Act (42 U.S.C. 1396n(c))) receive;

(D) a description of how entities funded under subtitles C and D, through interagency agreements or other mechanisms, collaborated with the entity funded under this subtitle in the State, each other, and other entities to contribute to the achievement of the purpose of this subtitle; and



## Figure 1: DD Act Requirements for the State Plan

(4) PLAN GOALS. -The plan shall focus on Council efforts to bring about the purpose of this subtitle, by-

(A) specifying 5-year goals, as developed through data driven strategic planning, for advocacy, capacity building, and systemic change related to the areas of emphasis, to be undertaken by the Council, that-

(i) are derived from the unmet needs of individuals with developmental disabilities and their families identified under paragraph (3); and

(ii) include a goal, for each year of the grant, to-

(I) establish or strengthen a program for the direct funding of a State self-advocacy organization led by individuals with developmental disabilities;

(II) support opportunities for individuals with developmental disabilities who are considered leaders to provide leadership training to individuals with developmental disabilities who may become leaders; and

(III) support and expand participation of individuals with developmental disabilities in cross-disability and culturally diverse leadership coalitions; and

(B) for each year of the grant, describing-

(i) the goals to be achieved through the grant, which, beginning in fiscal year 2002, shall be consistent with applicable indicators of progress described in section 104(a)(3);

(ii) the strategies to be used in achieving each goal; and

(iii) the method to be used to determine if each goal has been achieved.

(5) ASSURANCES.-

(A) IN GENERAL. -The plan shall contain or be supported by assurances and information described in subparagraphs (B) through (N) that are satisfactory to the Secretary.

(B) USE OF FUNDS. -With respect to the funds paid to the State under section 122, the plan shall provide assurances that-

(i) not less than 70 percent of such funds will be expended for activities related to the goals described in paragraph (4);

(ii) such funds will contribute to the achievement of the purpose of this subtitle in various political sub-divisions of the State;

## Figure 1: DD Act Requirements for the State Plan

(iii) such funds will be used to supplement, and not supplant, the non-Federal funds paid under section 122 are provided;

(iv) such funds will be used to complement and augment rather than duplicate or replace services for individuals with developmental disabilities and their families who are eligible for Federal assistance under other State programs;

(v) part of such funds will be made available by the State to public or private entities;

(vi) at the request of any State, a portion of such funds provided to such State under this subtitle for any fiscal year shall be available to pay up to 1/2 (or the entire amount if the Council is the designated State agency) of the expenditures found to be necessary by the Secretary for the proper and efficient exercise of the functions of the designated State agency, except that not more than 5 percent of such funds provided to such State for any fiscal year, or \$50,000, whichever is less, shall be made available for total expenditures for such purpose by the designated State agency; and (vii) not more than 20 percent of such funds will be allocated to the designated State agency for service demonstrations by such agency that-

(I) contribute to the achievement of the purpose of this subtitle; and

(II) are explicitly authorized by the Council.

(C) STATE FINANCIAL PARTICIPATION. -The plan shall provide assurances that there will be reasonable State financial participation in the cost of carrying out the plan.

(D) CONFLICT OF INTEREST. -The plan shall provide an assurance that no member of such Council will cast a vote on any matter that would provide direct financial benefit to the member or otherwise give the appearance of a conflict of interest.

(E) URBAN AND RURAL POVERTY AREAS. -The plan shall provide assurances that special financial and technical assistance will be given to organizations that provide community services, individualized supports, and other forms of assistance to individuals with developmental disabilities who live in areas designated as urban or rural poverty areas.

(F) PROGRAM ACCESSIBILITY STANDARDS. -The plan shall provide assurances that programs, projects, and activities funded under the plan, and the buildings in which such programs, projects, and activities are operated, will meet standards prescribed by the Secretary in regulations and all applicable Federal and State accessibility standards, including accessibility requirements of the Americans with Disabilities Act of 1990 (42 U.S.C. 12101 et seq.), section 508 of the Rehabilitation Act of 1973 (29 U.S.C. 794d), and the Fair Housing Act (42 U.S.C. 3601 et seq.).

## Figure 1: DD Act Requirements for the State Plan

(G) INDIVIDUALIZED SERVICES. -The plan shall provide assurances that any direct services provided to individuals with developmental disabilities and funded under the plan will be provided in an individualized manner, consistent with the unique strengths, resources, priorities, concerns, abilities, and capabilities of such individual.

(H) HUMAN RIGHTS. -The plan shall provide assurances that the human rights of the individuals with developmental disabilities (especially individuals without familial protection) who are receiving services under programs assisted under this subtitle will be protected consistent with section 109 (relating to rights of individuals with developmental disabilities).

(I) MINORITY PARTICIPATION. -The plan shall provide assurances that the State has taken affirmative steps to assure that participation in programs funded under this subtitle is geographically representative of the State, and reflects the diversity of the State with respect to race and ethnicity.

(J) EMPLOYEE PROTECTIONS. -The plan shall provide assurances that fair and equitable arrangements (as determined by the Secretary after consultation with the Secretary of Labor) will be provided to protect the interests of employees affected by actions taken under the plan to provide community living activities, including arrangements designed to preserve employee rights and benefits and provide training and retraining of such employees where necessary, and arrangements under which maximum efforts will be made to guarantee the employment of such employees.

(K) STAFF ASSIGNMENTS. -The plan shall provide assurances that the staff and other personnel of the Council, while working for the Council, will be responsible solely for assisting the Council in carrying out the duties of the Council under this subtitle and will not be assigned duties by the designated State agency, or any other agency, office, or entity of the State.

(L) NONINTERFERENCE. -The plan shall provide assurances that the designated State agency, and any other agency, office, or entity of the State, will not interfere with the advocacy, capacity building, and systemic change activities, budget, personnel, State plan development, or plan implementation of the Council, except that the designated State agency shall have the authority necessary to carry out the responsibilities described in section 125(d)(3).

(M) STATE QUALITY ASSURANCE. -The plan shall provide assurances that the Council will participate in the planning, design or redesign, and monitoring of State quality assurance systems that affect individuals with developmental disabilities.

(N) OTHER ASSURANCES. -The plan shall contain such additional information and assurances as the Secretary may find necessary to carry out the provisions (including the purpose) of this subtitle.

## Figure 1: DD Act Requirements for the State Plan

(d) PUBLIC INPUT AND REVIEW, SUBMISSION, AND APPROVAL.-

(1) PUBLIC INPUT AND REVIEW. -The plan shall be based on public input. The Council shall make the plan available for public review and comment, after providing appropriate and sufficient notice in accessible formats of the opportunity for such review and comment. The Council shall revise the plan to take into account and respond to significant comments.

(2) CONSULTATION WITH THE DESIGNATED STATE AGENCY.- Before the plan is submitted to the Secretary, the Council shall consult with the designated State agency to ensure that the State plan is consistent with State law and to obtain appropriate State plan assurances.

(3) PLAN APPROVAL.-The Secretary shall approve any State plan and, as appropriate, amendments of such plan that comply with the provisions of subsections (a), (b), and (c) and this subsection. The Secretary may take final action to disapprove a State plan after providing reasonable notice and an opportunity for a hearing to the State.

## NCCDD Planning Framework

Cross Cutting Initiatives

### Outcomes

### Advocacy

### Support Systems

### Technology

#### ASSET BUILDING

- Upward to Financial Stability.....\$75k

#### EMPLOYMENT & CAREERS

- Project SEARCH.....\$100k
- Supported Employment Leadership Network...\$35k
- Reaching the Summit of Success.....\$50k

#### HEALTHY RELATIONSHIPS

- Safety and Security: Domestic Violence....\$50k

#### HOUSING AND TRANSPORTATION

- Adult Care Home Transition to Community....\$75k

#### EDUCATION

- Learning and Earning after High School....\$180k

#### HEALTH AND STABILITY

- Medical & Health Homes.....\$75k
- Emergency Preparedness....\$125k

#### FAMILIES and INDIVIDUALS ATTITUDES, BELIEFS and ABILITIES

- Guardianship.....\$75k
- Sibling Support.....\$50k

- Communications.....\$135k
- SEG.....\$160k

- Advocacy  
Ambassadors...\$180k

- Partners in Policy  
Making...\$205k
- Public Policy ....\$60k

- Advancing Strong  
Leaders..\$200k
- ADA Network...\$60k

- Wolff-Rossi Fund....\$30k
- ADA Fiscal Intermed..\$35k

- Council Development  
Fund...\$50k
- NC ADSP ....\$100k

- Conference Funding....\$24k

2017-2020 Strategic Planning Budget

# PROPOSAL

## NCCDD Five-Year Plan Development

### Abstract

The Carolina Institute for Developmental Disabilities (CIDD) proposes to work cooperatively with the NC Council on Developmental Disabilities (NCCDD) to gather information per the format provided by the NACDD/Information and Technical Assistance Center for Councils on Developmental Disabilities (ITACC). This information will become the basis for long-range planning for supports and services for people with developmental disabilities in North Carolina. The Five-Year Plan Development project will result in compiled information in the required format to form the basis of the NCCDD Five-Year Plan. This plan will guide funding priorities affecting the 2017-2021 fiscal years.

### Scope of Work

In this project, the CIDD will

1. Collaborate on design and implementation of major elements toward development of the NCCDD Five-Year Plan:
  - Compile data from a range of national and state sources as specified in the NACDD/ITACC State Plan Development Resource.
  - Provide input to identify community leaders to reach specific groups through focus meetings, e.g., the Hispanic community, American Indian community, and other groups to be identified;
  - Review compiled information from Disability Rights NC listening sessions and similar sessions held by other agencies;
  - Review compiled information from NCCDD meetings with representatives from NCCDD member agencies and other key agencies to be identified;
  - Develop Qualtrics survey to gather input from individuals with IDD, families, professionals, and community members; analyze compiled results;
  - Draw information from the range of pertinent documents including strategic plans, needs assessments, and policy recommendations to create the Comprehensive Review and Analysis.
2. Provide regular updates to Council staff and membership.
3. Review specific activities per action plan, subject to revision through ongoing collaboration.
4. Conduct evaluation of Plan development process; present results to NCCDD.

### Deliverables

As a result of this project, the following items will be produced.

1. Electronic and paper forms of Qualtrics survey for individuals, families, and community members.
2. Recommendations developed through project activities for Comprehensive Review and Analysis for use by Council staff in writing final five-year plan.
3. PowerPoint presentations and handouts on Five-Year Plan process related to the Comprehensive Review and Analysis development.
4. Evaluation questionnaire, compiled results, and final document summarizing process with recommendations to be used for future planning activities.

The initiative will be for up to an amount of \$83,000 (level-funded) beginning with the period of March 1, 2015 – December 31, 2015, with a required minimum of 25% non-federal matching funds.

PROPOSAL

North Carolina Council on Developmental Disabilities (NCCDD)

PROPOSED ACTION PLAN FOR NCCDD Five-Year Plan Development - March 2015 through November 2015

(1) Expected Outcome of Project Activities Listed Below: Pertinent information and data are culled from key documents from state and national agencies/organizations that address the needs of individuals with developmental disabilities across the lifespan and their families. Such information includes needs assessments including service gaps, policy statements, planning goals, and other state/national data per the NACDD/ITACC State Plan Development Resource (SPDR).

Contact Person: Deborah Zuver (Project Director) Phone Number: 919.962.3603

Project Activities Leading to Outcome Above	Responsible Person	Timeline
1. Review agency/organization list from previous Five-Year Planning Project to identify key documents beyond NACDD/ITACC SPDR	Deb Zuver; Melissa Swartz	3/15/15 - 4/1/15
2. Revise agency/org. list from previous Five-Year Plan Project for tool to track key documents prior, capturing information, ensuring an accurate and objective process.	Deb Zuver; Morgan Parlier; Greg Olley [support from Melissa Swartz]	3/15/15 - 4/1/15
3. Including information from updated agency/organization list, obtain data through state and national sources as stipulated in NACDD/ITACC SPDR resource for comp. review and analysis.	Deb Zuver; Morgan Parlier; Greg Olley	4/1/15 - 6/30/15
4. Create summary table highlighting key points from state and national sources (1) needs assessments, (2) policy statements, (3) planning goals as identified in docs; list key data. Analyze summary table with attention to key areas/issues, data that demonstrate need/ services provided; duplication of response or lack thereof. Review geographic, ethnicity/cultural, life span considerations.	Deb Zuver; Morgan Parlier; Greg Olley	5/1/15 - 7/30/15
5. Ensure required data, per NACDD/ITACC SPDR) are available to be inserted into DD Suite State Plan format.	Deb Zuver; Morgan Parlier; Greg Olley	4/15/15 - 8/1/15

## Development Planning for Five-Year Plan 2017 - 2022

## NC Council on Developmental Disabilities

Budget Justification  
April 1, 2015 - December 31, 2015Personnel

	<u>Title</u>	<u>FTE%</u>	<u>Salary</u>	<u>Benefits</u>	<u>Total</u>
Greg Olley	Principal Investigator	8%*	\$7,240	\$1,968	\$9,208
Deborah Zuver	Project Coordinator	45%	\$20,793	\$8,558	\$27,351
Morgan Parlier	Project Analyst	35%	\$16,638	\$5,206	\$21,844
Brian Wrighten	IT	8%	\$4,254	\$1,292	\$5,546
Teresa Buckner	Project Assistant	15%	\$4,238	\$1,576	\$5,814
	Totals:		\$53,163	\$16,600	\$69,763

\*In addition to the 8% FTE that will be paid by the Council on Developmental Disabilities, an additional 1.264% FTE (for the months April through June only) will be contributed to meet the total 25% match. This match includes \$498 in salary and associated benefits of \$135, totaling \$633. This contribution will come from funds from the Carolina Institute for Developmental Disabilities, using non-federal sources.

Salaries for professional staff are based on qualifications of the employee, existing salaries for others of the same profession and standing in this University, and salary data for relevant disciplines nationwide (where applicable). Salary increases are included at 3% for FY 15-16, as well as a 3% increase for health insurance.

Fringe benefits are based on a 22.634% composite for Social Security and retirement plus \$5,378 for health insurance.

**Principal Investigator:** Greg Olley will be responsible for overall planning and management. He will meet regularly with the team and participate in reporting to NCCDD, including a final report and any interim reporting. Dr. Olley will oversee review of key policy and planning documents of identified organizations for data collection, the Comprehensive Review and Analysis, and other targeted project activities. He will participate a review of the process to evaluate steps involved to assist planning for the next state plan project.

**Project Coordinator:** Deb Zuver will be responsible for daily administration of project activities and will oversee the timely completion of tasks. She will be responsible for reviewing several key policy and planning documents of identified organizations, and other targeted disability advocacy groups. She will initiate planning activities and review processes related to gathering information with NCCDD staff and the O'Neill Communications group. Ms. Zuver will ensure that data collection activities and the comprehensive review and analysis are completed per ITACC guidelines. Ms. Zuver will review responses, resulting from meetings led by NCCDD staff and members. Activities include reviewing responses to surveys and interviews, analyzing themes and providing summary information/recommendations to be



submitted to NCCDD for staff to develop into five-year planning drafts. Ms. Zuver will present process and results at quarterly NCCDD meetings. She will also provide a review of the process to evaluate steps involved to assist planning for the next state plan project.

**Project Analyst:** Morgan Parlier will be responsible for compiling and analyzing survey results and tracking review results from key policy/planning documents of identified organizations and other targeted disability advocacy groups. She will translate information from documents into functional and comprehensive data as summary tables as required by the Comprehensive Review and Analysis section of the ITACC. She will review DD suites and required data to ensure that this information has been identified and included in material to be further analyzed. Ms. Parlier will analyze these combined data, in collaboration with Ms. Zuver to create summary documents for Comprehensive Review and Analysis section of the ITACC, identifying recommendations to be provided to the NCCDD for staff to create five-year planning drafts. Ms. Parlier will attend NCCDD presentations, as needed.

**Information Technology Specialist:** Brian Wrihten will maintain the local area network and provide computer and related technology services for the project. He will provide support to utilize Qualtrics or other survey tools and provide assistance for presentations whether through webinar activities or other project opportunities. Mr. Wrihten will assure the availability of presentation equipment through Information Technology Support at the CIDD.

**Project Assistant:** Teresa Buckner will be responsible for copying and compiling materials for meeting presentations and interviews. She will assist the team with a range of tasks needed to complete action plan items, e.g., typing summaries, data entry, and compiling meeting and presentation materials.

**Supplies:** \$1,900

Project supplies include office supplies such as file folders, printing cartridges, paper, pens, etc. (\$1,500). Duplication costs (\$400) are requested to provide review materials and other documents related to this project, including reports and presentations. Project supplies will be directly related to conducting the proposed project and are necessary to carry out the project.

**Travel:** \$443

Travel expenses include eleven (11) round trips at 70 miles each at .575 per mile to Raleigh between Carrboro and for meetings between project staff and NCCDD project officer, planning meetings, quarterly NCCDD meetings and; contacts with O'Neill Communications Group as needed (\$443).

**Communication:** A modest amount of \$50 is included for the occasional need to ship materials.

	Direct Costs:	\$72,156
	Indirect Costs @ 15%:	\$10,823
	Total Costs Supported by Agency:	\$82,979
Contribution from Carolina Institute for Developmental Disabilities:		\$633
Contribution from The University of North Carolina at Chapel Hill:		\$27,020
	Total Project Costs:	\$110,639
	Required Match of 25% of Total Project Costs:	\$27,660

Matching Requirement:

The Carolina Institute will contribute \$633 in salary and associated fringe benefits from April 2015 through June 30, 2015 to meet the required 25% match required by the agency.

The University of North Carolina at Chapel Hill will provide indirect costs in the amount of \$27,027 as unrecoverable indirect costs to meet the required 25% match of the agency. The direct cost of \$72,156 times 52% equals \$37,521, less the allowed 15% indirect of \$10,823 equals \$26,698. Also, UNC-CH will provide the unrecoverable indirect costs on the salary and benefits for Dr. Olley (\$633 times 52% equals \$329).

DRAFT



## NC Council on Developmental Disabilities Catalyst for Change: Be the Change Public Policy Initiative

**Quality Assurance Goal:** QA.0 People with developmental disabilities and families will have access to the information and supports necessary to affect public policy at the local, state, and national levels.

**QA.0.8:** Engage NCCDD Membership in advancement of state and federal level policy.  
NCCDD 5 Year State Plan 2011-2016

Anticipated Grant Start Date  
Anticipated End Date

July 1, 2015  
June 30, 2016

### *Public Policy Initiative*

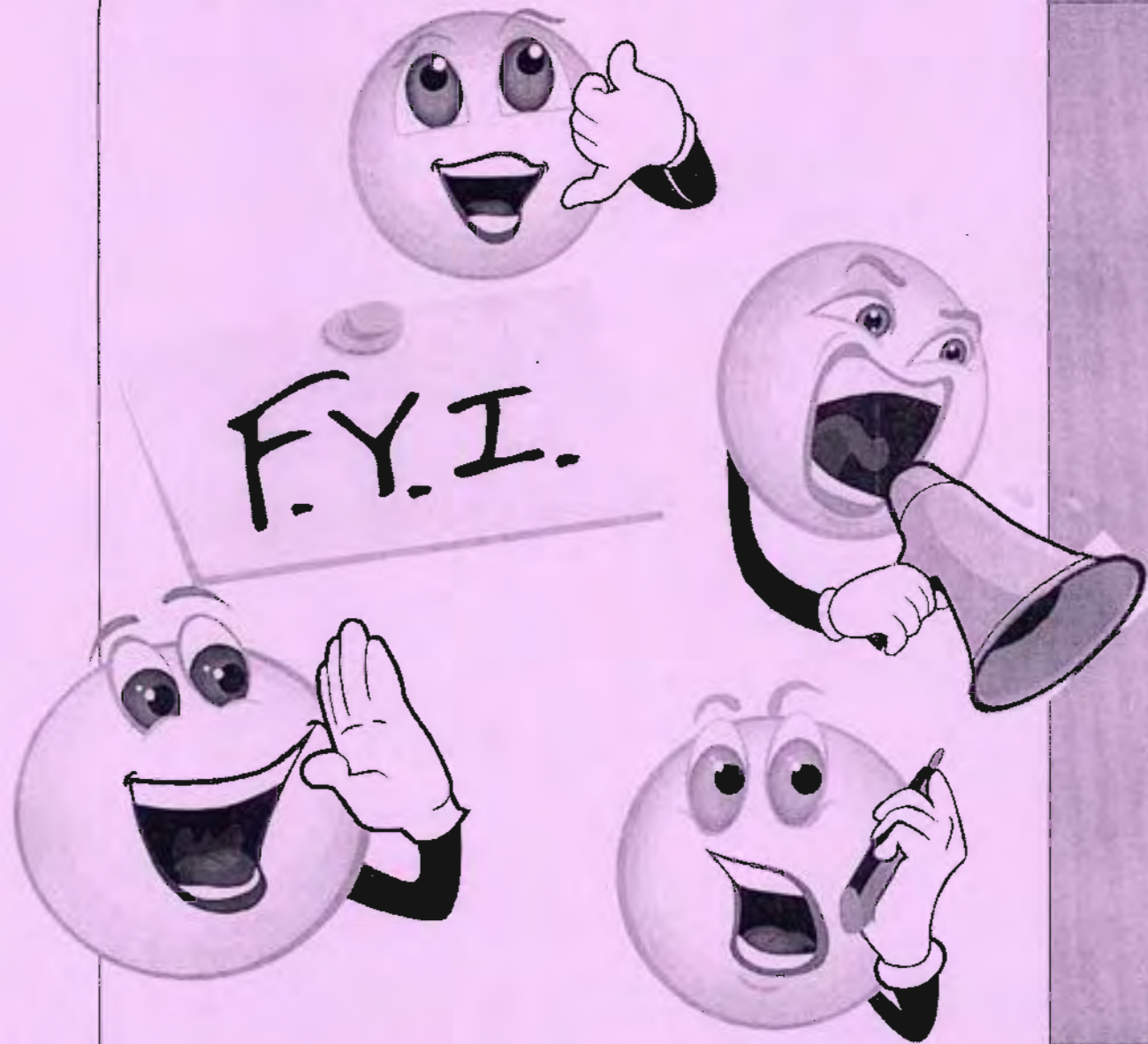
This initiative compiles research, policy analysis, and best practices review to develop a strategic program to advance the Council's mission. The work of the public policy initiative will engage the Council and its network to inform national and state programmatic, fiscal, and policy discussions and contribute to positive decisions that improve the lives of individuals with developmental disabilities and their families.

Building on the foundations established from 2010-2012, the North Carolina Council on Developmental Disabilities will be positioned to increase the level of interaction with state and national leaders in order to more purposefully promote its systems change agenda. Strategies to increase the voice of the Council in policy arena include:

- 1) Engage Council members through policy resource and training opportunities;
- 2) Assist Council membership in the development of position statements and other tools to communicate core policy principles;
- 3) Serve as resource to self-advocates and encourage involvement in public policy activities by fostering linkages between grass roots and national/state system networks;
- 4) Shape policy directions and needed action from current Council funded initiatives and grantees.
- 5) Work closely with the communications initiative to inform self-advocates, families, and stakeholders of key policy discussions and opportunities for action;
- 6) Collect input from individuals with developmental disabilities and families on programmatic and policy issues;
- 7) Build a policy collaborative comprised of current and former Council members, current and past grantees, and Partners in Policymaking® graduates to perform targeted public policy activities;
- 8) Track and provide ongoing technical assistance to state leaders, partners, and stakeholders on policies that affect persons with developmental disabilities;
- 9) Compile data and impact statements to better inform current policy debates and decisions, and
- 10) Advance the goals and objectives outlined in the new five-year state plan.

To carry out the intent of this objective, the NCCDD will make available up to \$60,000, for a twelve (12) month period to fund the project coordinator and in-house expenditures.

# FOR YOUR INFORMATION



## Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act (UAGAPPJA)

**Adult guardianship** is a legal relationship under which a person is appointed by a court to act on behalf of an adult deemed 'incapacitated' due to medical conditions, mental health, or I/DD. The guardian then has the authority to make decisions about the person's personal affairs (e.g., living situation), medical decisions, and/or financial affairs.

**UAGAPPJA** (*pronounced "YOU-AH-GAP-JAH"*) is a national law that addresses issues related to *jurisdiction* of an adult guardianship case. This law is narrow in scope and does not apply to broader guardianship laws. A second act, the **Uniform Guardianship and Protective Proceedings Act** is a more expansive and comprehensive act that addresses all areas of the guardianship process.

UAGAPPJA focuses on three main areas:

- 1) determination of the most appropriate state for initial guardianship filing,
- 2) transfer of a guardianship action from state to state, and
- 3) recognition and registration of guardianship orders in states other than the primary state of jurisdiction or filing

North Carolina is one of a handful of states that have not yet enacted UAGAPPJA.

**Example:** Sarah's mother lives in North Carolina but is no longer able to live alone or make financial or health decisions on her own. Sarah lives in Georgia and decided to move her mother to Georgia with her. Sarah filed for guardianship in Georgia so she could manage her finances and medical care. Sarah's mother owns a home in NC but Sarah cannot sell the house or manage assets until she has guardianship status in NC (which can take months and can be expensive). UAGAPPJA would set provisions for NC to recognize the guardianship status from Georgia and Sarah would have the legal authority to more quickly manage her mother's assets here in NC.

In North Carolina, Clerks or assistant clerks of court serve as the judge for matters relating to guardianship. The guardian can serve as a surrogate decision maker in all areas of a person's life (full guardianship) or only in certain areas (limited guardianship) where the Court deemed the individual competent to make decisions (e.g., medical decisions, financial assistance). Guardians can serve temporarily or indefinitely depending on the nature of the incapacity.

At the national level, the Olmstead decision (1999) and Department of Justice settlements call for individuals with disabilities to be placed in 'less restrictive living and work environments to give an individual as much control over their life as possible'. However, in practice Courts make decisions without a consistent interpretation of guardianship, or an understanding of less restrictive alternatives to guardianship. Similarly, loved ones petitioning for guardianship of a family member may not be informed of the full range of less restrictive alternatives which would allow them to help their family member without removing all individual rights and personal autonomy.