



Building Bridges to Community

**North Carolina
Council on Developmental Disabilities
Quarterly Council Meeting
November 19-21, 2014
Hilton Garden Inn, Cary, NC**

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

leadership & advocacy
changing policy/changing practice
building inclusive community



Hilton Garden Inn
131 Columbus Avenue
Cary, NC 27518

Phone: 919-377-0440

Fax: 919-377-0445

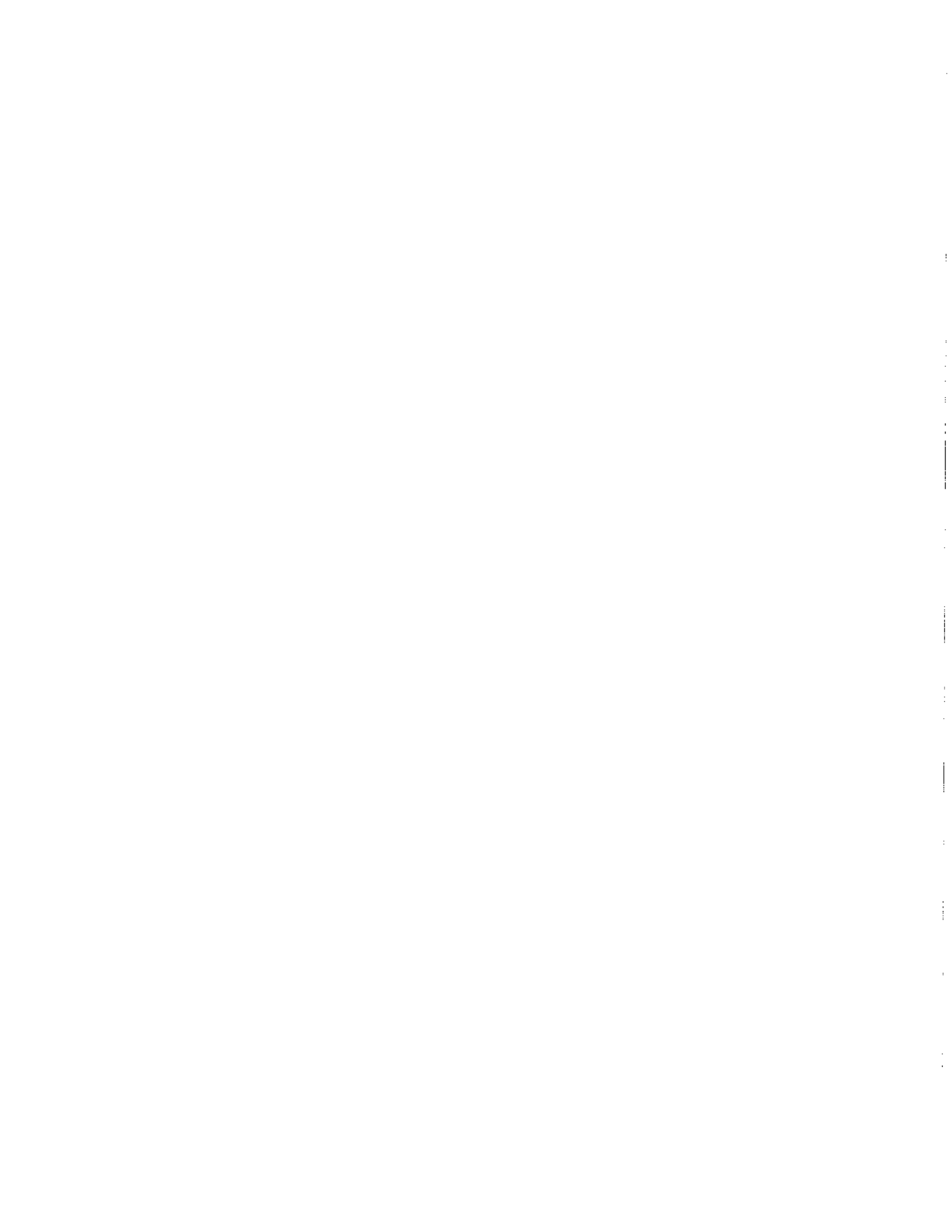


“Hello,
Council on
Developmental
Disabilities.
How may I help you?”

NCCDD STAFF ON CALL
JoAnn Toomey

(919) 337-0440
(Hotel Front Desk)

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





NCCDD Will Be Holding Officer Elections!

Three positions will be elected at the Friday Meeting:

Position: Vice-Chair (2)

Duties:

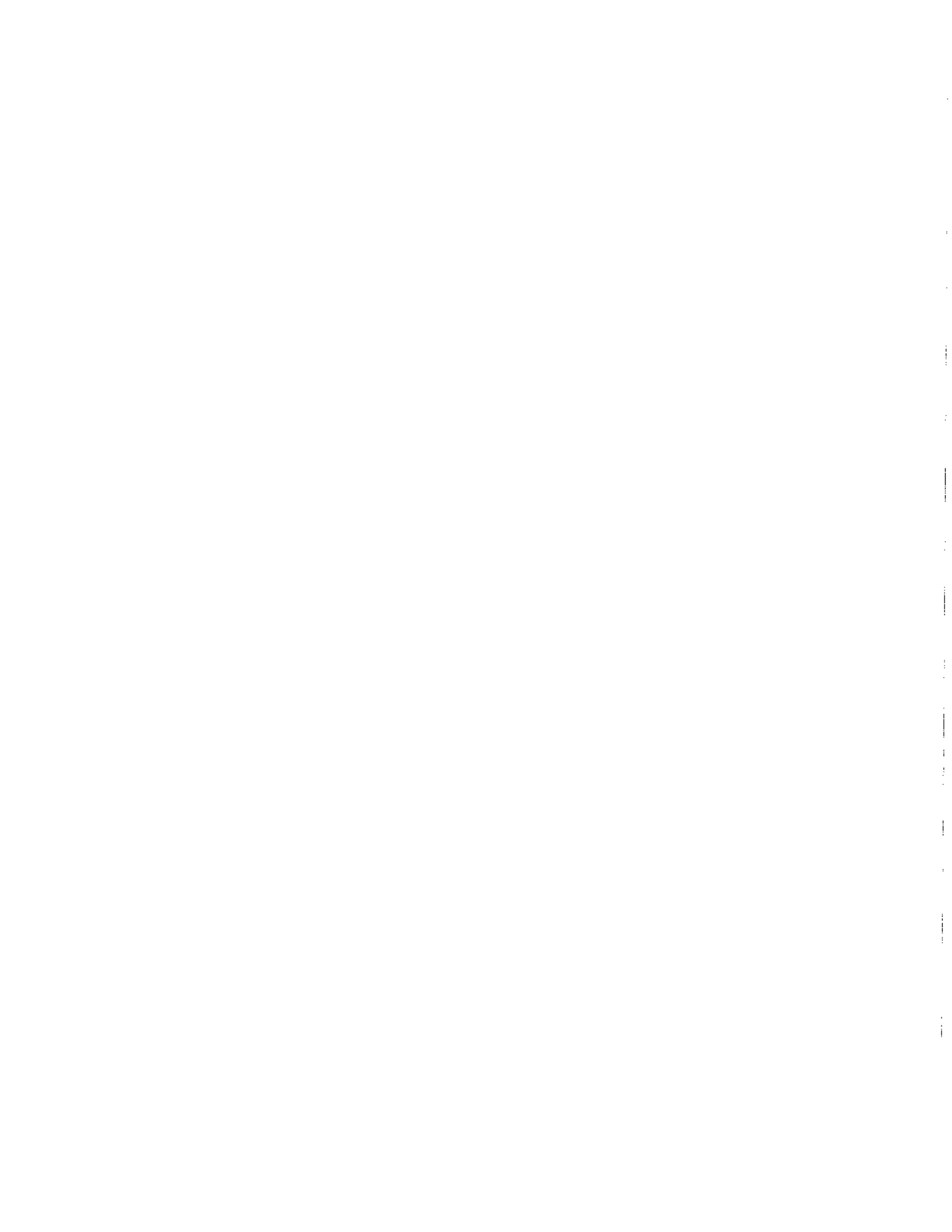
- Prepare for and participate in monthly Executive Committee meetings.
- Help the Chair in the performance of his or her duties.
- If the Chair is absent, perform his duties and assume other responsibilities as the Chair determines.
- Serve as a mentor for new NCCDD Members and provide informal orientation or delegate this role to another member.
- Whenever possible, participate in orientation sessions that occur at quarterly NCCDD meetings.
- Ensure that the NCCDD Member Handbook provides the information necessary for members to function effectively and to understand the mission, policies and practices of the NCCDD, including the roles and responsibilities of its members, officers and staff.

Position: NCCDD Secretary/Treasurer (1)

Duties:

- Call the roll at all quarterly meetings and monitor and record attendance.
- Review quarterly meeting minutes prior to their distribution.
- Ensure that the quarterly meeting minutes are presented for approval and adoption at the subsequent meeting.
- Conduct a "roll-call" vote when requested by the Chair.
- Review financial information at Council meetings.

Make a **Nomination** on Wednesday or Thursday at the
quarterly meeting



2014 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
Adonis Brown	Individual with DD
Michael Groves	Individual with DD
Wayne Black; Alternate: Rick Zechman	Agency: Div. of Social Services
Tim Smith (<i>Pending</i>)	Parent of Child with DD
Lourdes M. Fernandez	Parent of Child with DD
Crystal L. Foreman	Individual with DD
VACANT; Alternate: Danielle Matula	Agency: Women & Children's Health
VACANT; Alternate: Mary Edwards	Agency: Div. of Aging & Adult Servs.
Renate Macchirole	Public at Large
VACANT	Parent of Child with DD
Katie Holler	Individual with DD
VACANT	Individual with DD

Staff: Joshua Strasburg

COMMUNITY CAPACITY BUILDING COMMITTEE

I. Azell Reeves: Chair	Parent of Child with DD
Lisa Byrd	Individual with DD
John Carbone, M.D.; Alternate: Larry Huggins	Agency: Dept. of Public Safety
William Hussey; Alternate: Dreama McCoy (<i>both pending</i>)	Agency: Dept. of Public Instruction
Anna Cunningham	Parent of Child with DD
Wilson Finks	Individual with DD
Amanda Bergen	Parent of Child with DD
David White	Parent/Person with DD
Senator Tommy Tucker	Other: Legislative
Jim Swain; Alternate: Gina Price	Agency: Div. of Voc. Rehab.
Desiree Peterson	Individual with DD
VACANT	Parent of Person with DD

Staff: Shayna Simpson-Hall

SYSTEMS CHANGE COMMITTEE

Samuel Miller, Ph.D.: Chair
Kelly Woodall Beauchamp
Crystal Bowe, M.D.
Christina Carter; Alternate: Andrea Misenheimer
Eric Chavis
Robin Cummings, M.D.; Alternate: Deb Goda
Kerri Bennett Eaker
Representative Verla Insko
Wing Ng, M.D.
Joe Piven, M.D.; Alternate: Deb Zuver
Courtney Cantrell; Alternate: Sandy Ellsworth
Vickie Smith
Peggy Terhune, Ph.D.
Aldona Wos, M.D., Secretary;
Alternate: Dave Richard

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

Staff: Steve Strom

STAFF

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

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: Hilton Garden Inn, Cary, NC

DRAFT
AGENDA
Wednesday, November 19, 2014
Bradford A

- 1:00 – 2:15 PM **COUNCIL MEMBERSHIP**NACDD/ITACC Staff
- Topic 1: Leading by Example
 - Topic 2: FFY 17 State Plan
 - Topic 3: Representing your Community at Council Meetings
- 2:15 – 2:30 PM **BREAK**
- 2:30 – 3:45 PM **COUNCIL MEMBERSHIP QUESTIONS & ANSWERS**.....NACDD/ITACC Staff
- 3:45 – 4:45 PM **PUBLIC POLICY UPDATE AND DISCUSSION**.....Beth Stalvey, Policy Analyst, NCCDD
- 4:45 – 5:30 PM **BREAK AND HOTEL CHECK IN**
- 5:30 – 7:30 PM **HEFNER/RIDDLE AWARDS DINNER – Bradford A**.....Dave Richard/Duncan Munn Presenters

Thursday, November 20, 2014
Bradford D

- 9:00 – 9:45 AM **OVERVIEW OF COMMITTEE ACTIVITIES**.....Chris Egan & Committee Chairs
- 9:45 – 11:45 AM **COMMITTEE MEETINGS**
- a) Advocacy and Leadership – Bradford A..... Carrie Ambrose
 - b) Community Capacity Building – Bradford B..... I. Azell Reeves
 - c) Disability System Change – Bradford C.....Samuel Miller
- 11:45 – 1:15 PM **LUNCH & LEARN-NCCDD STRATEGIC COMMUNICATIONS** (buffet lunch provided).....
.....Gordon O'Neill, President, O'Neill Communications
- 1:15 – 2:00 PM **COMMITTEE UPDATES/MEMBER MOTION REVIEW** –.....Committee Chairs
- 2:00 – 3:00 PM **OPEN SESSION TBD**
- 3:00 – 3:15 PM **BREAK**
- 3:15 – 4:00 PM **DHHS UPDATE FROM THE SECRETARY**.....Secretary Aldona Wos
- 4:00 – 5:30 PM **WAIVER UPDATE/LISTENING TOUR UPDATE**.....Dave Richard/DHHS Staff
- 5:30 – 7:30 PM **NETWORKING RECEPTION FOR MEMBERS** (light dinner provided)....Ron Reeve/Chris Egan



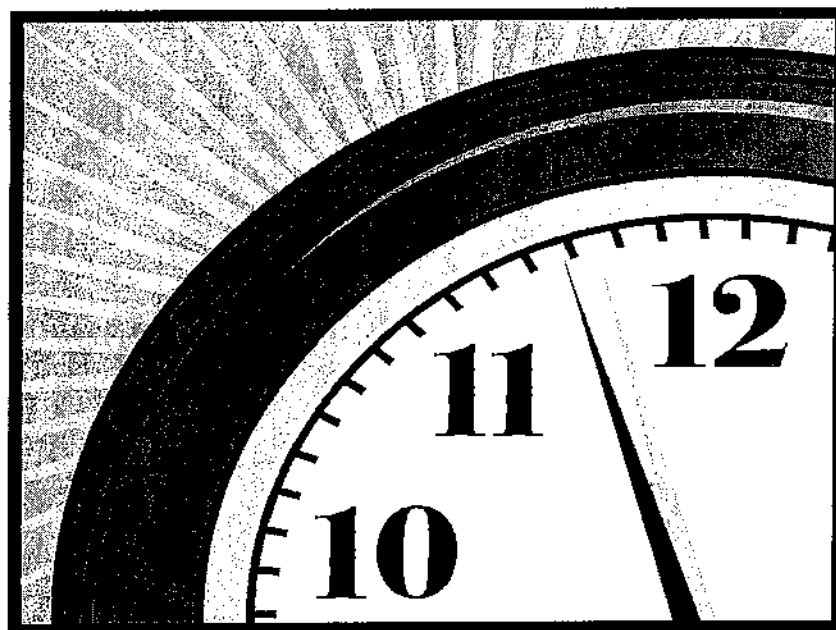
**Meeting: NC Council on Developmental Disabilities
Location: Hilton Garden Inn, Cary, NC**

**DRAFT
AGENDA
Friday, November 21, 2014
Bradford A-C**

9:00 - 9:10 AM	WELCOME/CONFLICT OF INTEREST/ SAFETY & PREPAREDNESS ..Ron Reeve
9:10 - 9:20 AM	ROLL CALLAnna Cunningham
9:20 - 9:30 AM	APPROVAL OF MINUTESRon Reeve
9:30 - 9:45 AM	DIRECTOR'S REPORTChris Egan
9:45 - 10:00 AM	FINANCE REPORTAnna Cunningham
10:00 -10:15 AM	PUBLIC COMMENT*
10:15 -11:00 AM	COMMITTEE REPORTS
	(a) Executive Committee.....Ron Reeve
	(b) Advocacy and Leadership.....Carrie Ambrose
	(c) Community Capacity Building.....I. Azell Reeves
	(d) Disability System Change.....Samuel Miller
11:00 -11:15 AM	BREAK
11:15 -11:45 AM	NEW BUSINESS Ron Reeve
	<ul style="list-style-type: none">• State Plan Amendments (Review public input)• 2015 Committee Request Forms submitted by members• Approval of NCCDD Strategic Communications Plan• Approval to draft RFA for Jean-Wolff Rossi Participant Involvement Fund
11:45 -12:30 PM	ELECTION OF OFFICERSRon Reeve
12:30 PM	ADJOURN

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

COUNCIL MINUTES



DRAFT
NC COUNCIL ON DEVELOPMENTAL DISABILITIES

Quarterly Council Meeting Minutes
North Raleigh Hilton, Raleigh, NC

August 15, 2014

MEMBERS PRESENT: Caroline Ambrose, Amanda Bergen, Eric Zechman (for Wayne Black) Crystal Bowe, Adonis Brown, Lisa Byrd, Deborah Carroll (for Robin Cummings), Larry Huggins (for John Carbone), Eric Chavis, Anna Cunningham, Wilson Finks, Crystal Foreman, Michael Groves, Katie Holler, Renate Macchirole, Danielle Matula (for Kevin Ryan), Wing Ng, Deb Zuver (for Joseph Piven), Ron Reeve, I. Azell Reeves, Gina Price (for Jim Swain), Vicki Smith, Peggy Terhune, Dave Richard (for Secretary Wos)

MEMBERS ABSENT: Christina Carter, Kerri Eaker, Lourdes Fernandez, Rep. Verla Insko, Samuel Miller, Desiree Peterson, Senator Tommy Tucker, David White, Kelly Woodall

STAFF PRESENT: Chris Egan, Cora Gibson, Shayna Simpson-Hall, Joshua Strasburg, Steve Strom, JoAnn Toomey, Yadira Vasquez, Shar'ron Williams, Letha Young

CONTRACTORS/GRANTEES PRESENT: Jennifer Bosk, John McCallum, Karen Hamilton, Beth Stalvey

GUESTS: Beverly Colwell, Renee Cummins, Mary Edwards, Sandy Ellsworth, Eric Fox, Karen Luken, David Taylor, Judy Taylor

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 North Raleigh Hilton. JoAnn Toomey then conducted the roll call.

APPROVAL OF COUNCIL MINUTES

Ron Reeve asked for approval of the May 2014 Council meeting minutes. A copy of the minutes had previously been made available to Council members. Adonis Brown made a motion to approve the minutes. Crystal Foreman seconded the motion. The motion was approved.

At this time, Mr. Reeve asked that the Council recognize JoAnn Toomey for her outstanding service and dedication during the time that the Council was without an Executive Director and presented her with a Distinguished Service Award. Mr. Reeve thanked all the staff for their efforts and also introduced new staff member, Shar'ron Williams.

DIRECTOR'S REPORT

Chris Eagan provided a brief overview of his progress since joining the Council on June 30, 2014. He spoke of the importance of the Council to continue to work with stakeholders and policymakers to make sure we have meaningful outcomes.

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

David Taylor gave an update on the upcoming SABE conference. He encouraged all Council members to attend.

Karen Luken gave an update on the Medical Health Home Initiative.

Christian Barbour sent a message via email that was read to the members: "I have been going to Vocational Rehab for almost a year now. They made me a plan and got me a job coach, I have heard from her 2 or 3 times. She says she is trying to get me a job, It's on and off and it makes me feel disappointed, depressed, and scared as if I will never be able to find a job. I plan on trying to get my license again, so I won't have to keep relying on others all the time. I hope this conference will help me and others get a job." Member discussion followed.

EXECUTIVE COMMITTEE REPORT

The Executive Committee members met June 16, 2014 and July 21, 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

In the absence of Committee chair Samuel Miller, Crystal Bowe 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: Anna Cunningham made a motion to grant NCCDD staff authority to release the Request for Application (RFA) for the "Guardianship Initiative". Crystal Foreman seconded the motion. The motion was approved.

Vicki Smith, Peggy Terhune, Deborah Zuver, Adonis Brown, Katie Holler and Wilson Finks recused themselves since they potentially would be bidding on this contract through their agencies or they are affiliated with an agency that may bid on the contract.

Motion: Wilson Finks made a motion to rescind the motion approved in May for continuation funding of Year 2 (of 3) to the National Association of State Directors of Developmental Disabilities Services (NASDDDS) for the Enhancing Disability Stakeholder Engagement in Managed Long-Term Services/Supports and Primary/Acute Care Systems Coordination Initiative. The Council now approves a no-cost extension for Year 1 (of 3) to end on October 31, 2014. Year 2 (of 3) continuation funding is approved for up to \$160,000 (Beginning November 1, 2014 to October 31, 2015). Match requirement is waived for this initiative. Anna Cunningham seconded the motion. Motion was approved.

Motion: Crystal Foreman made a motion that O’Neill Communications be approved as the contractor selected for the NCCDD Communications contract. Funding is approved for up to \$135,000 with a required minimum of 25% non-federal matching funds, for year one of up to 3 years from October 1, 2014 to September 30, 2015. Adonis Brown 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: Crystal Bowe made a motion to grant authority to staff to draft the RFA to support the implementation of the NC ADA Network Fiscal Agent initiative, 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. Adonis Brown seconded the motion. The motion was approved.

Anna Cunningham recused herself from the vote due to being affiliated with an agency that may bid on this contract.

Motion: Eric Chavis made a motion that the NCCDD will make available up to \$100,000 (January 1, 2015 to December 31, 2015), 100% federal funds of external, sole source continuation funding for year 2 of 3 years, to Cincinnati Hospital to implement the Project SEARCH Technical Assistance Initiative, with a minimum 25% non-federal match requirement. Wilson Finks seconded the motion. The motion was approved.

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. Following are the motions presented on the floor for Council consideration:

Motion: Eric Chavis made a motion that the Rape Crisis Center of Coastal Horizons, Inc. be approved for continuation funding for Year 2 (of 3) for the Safety and Security: Addressing Domestic Violence and Sexual Violence Against People with Intellectual and other Developmental Disabilities initiative. Funding is approved in the amount of \$50,000 with required minimum of 25% non-federal matching funds for the period of January 1, 2015 to December 31, 2015. Lisa Byrd seconded the motion. The motion was approved.

Adonis Brown and Crystal Foreman recused themselves from the vote due to being affiliated with an agency or organization related to this contract.

Motion: Wilson Finks made a motion that Benchmarks, Inc. be approved for continuation funding for Year 2 (of 3) for the NC Chapter of the Alliance for Direct Support Professionals initiative in the amount of \$100,000 for the period of January 1, 2015 to December 31, 2015. Match requirement is waived for this grant. Eric Chavis seconded the motion. The motion was approved.

Adonis Brown, Peggy Terhune and Renate Macchirole recused themselves from the vote due to being affiliated with an agency or organization related to this contract.

OLD BUSINESS

Chris Egan updated the members regarding the current State Plan Amendment process.

Motion: Eric Chavis made a motion to solicit public input/comment from September 15 (or earlier, if possible) to October 31, 2014 on the NCCDD state plan (Year three of five) for consideration in the development of state plan amendments effective 10/01/2014 – 09/30/2015. In November, the Council will review public input/comments and entertain approval for state plan amendment submission to the Administration on Intellectual and Developmental Disabilities (AIDD) to occur no later than December 31, 2014. Crystal Foreman seconded the motion. The motion was approved.

NEW BUSINESS

Ron Reeve discussed the on-going issue regarding the difficulty for some members to up-front the costs to attend conferences and other events and then wait to be reimbursed from the Council Development Fund In-House initiative. He asked Chris Egan to further address this issue and how it also affected potential participants of the Jean Wolff-Rossi Fund for Participant Involvement. Lengthy member discussion occurred and the following motion was made:

Motion: Peggy Terhune made a motion for the Executive Committee to have the authority to explore the option of an external contract(s) for the Council Development Fund and the Jean Wolff-Rossi Fund for Participant Involvement and the possibility of including both funds in the current RFA release for the NC ADA Fiscal Agent initiative. Anna Cunningham seconded the motion. The motion was approved.

Ron Reeve asked the members for a motion to approve the 2015 Council meeting dates.

Motion: Eric Chavis made a motion to approve the Council meeting dates for 2015: **February 12 and 13, May 14 and 15, August 13 and 14 and November 18, 19 and 20.** Wilson Finks seconded the motion. The motion was approved.

Motion: Deborah Zuver made a motion to change the dates for the **August** meeting to August 6 and 7. Crystal Bowe seconded the motion. The motion was approved.

Motion: Crystal Foreman made a motion to keep the 2015 meetings in Raleigh. Lisa Byrd seconded the motion. The motion was approved.

Crystal Bowe made a motion to adjourn. Crystal Foreman seconded the motion. Meeting was adjourned.

Approved: _____

Anna Cunningham Secretary/Treasurer

Date: _____

EXECUTIVE COMMITTEE



NC Council on Developmental Disabilities (NCCDD)

FINAL

Executive Committee Minutes

July 21, 2014

10:30 A.M. – 12:30 P.M.

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

Absent: Crystal Bowe, Samuel Miller

Others present: Chris Egan, Beth Stalvey, Steve Strom, Melissa Swartz, JoAnn Toomey, Yadira Vasquez

I. Approval of Minutes:

The draft minutes of the June 2014 Executive Committee meeting were discussed.

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

II. Financial Update:

Yadira Vasquez reviewed the financial reports for the NCCDD. Ron Reeve asked the members if there were any questions and there were none.

III. Update on Communications Initiative:

Ron Reeve asked Melissa Swartz and Steve Strom to give an update on the Communications/Marketing initiative. The Selection Committee for the initiative met to review the vendor applications and presentations. A recommendation will be made to the full Council at the August meeting.

IV. 2015 Council Meeting Dates:

The members reviewed the dates that will be presented to the full Council at the August meeting for the 2015 Council meetings.

V. Review Current Conference Funding Policy:

The Executive Committee members reviewed the current Conference Funding Policy and decided to not make any changes. They did want it noted in these minutes that the Executive Committee or the full Council has the prerogative to limit speaker fees on a case by case basis and are not obligated to fund the full \$3,000 for every conference funding request.

VI. Membership Update:

The Executive Committee members reviewed the current applications on file for current vacancies. Four applicants will be recommended to the Office of the Governor, Boards and Commissions for three vacancies that exist on the Council in the non-agency membership category.

VII. Member Survey Review:

The members reviewed the standard survey template and discussed ways to encourage more members to submit them with their thoughts and ideas. There was discussion to have an outside agency handle the survey and report results; perhaps the new communications/marketing vendor.

VIII. State Plan Amendments for August Council Meeting:

Members reviewed the timeline and proposed minor changes to be made for the State Plan Amendments. The full Council will approve the draft amendments at the August Council meeting before they are released for public input. Public input will be reviewed at the November Council meeting before submission to AIDD on December 31, 2014.

IX. Legislative Update:

Beth Stalvey reviewed a tracking list for state and federal bills for July, 2014 with the members. She emphasized how fluid the information is and that she would help keep the information as current as possible. Also, she offered if any members had specific questions or areas of interest on these bills to just contact her and she will be happy to follow up.

X. Other:

Ron Reeve discussed that a NC Stakeholder Engagement Group (SEG) 2014-2015 planning session will be held on July 22nd with the NASDDDS facilitators, Nancy Thaler and Barbara Brent, the SEG co-chairs, Division leadership and the Council staff. He then called for a motion to adjourn.

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

NC Council on Developmental Disabilities (NCCDD)
FINAL

Executive Committee Minutes

September 15, 2014

10:30 A.M. – 12:30 P.M.

Present: Carrie Ambrose, Crystal Bowe, Adonis Brown, Anna Cunningham, Sam Miller, Ron Reeve

Absent: I. Azell Reeves

Others present: Chris Egan, Joshua Strasburg, JoAnn Toomey, Yadira Vasquez

I. Approval of Minutes:

The draft minutes of the July 2014 Executive Committee meeting were discussed.

MOTION: Carrie Ambrose made a motion to approve the July minutes. Sam Miller seconded the motion. The motion was approved.

II. Financial Update:

Yadira Vasquez reviewed the financial reports for the NCCDD. Ron Reeve asked the members if there were any questions and there were none.

III. Conference Funding Requests:

The following conference funding requests were reviewed for approval by the members and action was taken as follows:

- NCAPE (North Carolina Association for Persons in Supported Employment) Conference being held October 8-10, 2014 at the Blowing Rock Conference Center in Blowing Rock, NC. The request is to fund one speaker for up to \$1,000. The members voted not to fund this request based on the subject matter to be presented and the presenter residing within a close proximity to the conference.
- ECU: 7th Annual Early Intervention Conference being held October 17-18, 2014 at the Monroe Conference Center in Greenville, NC. The request is to fund three speakers for up to \$1,750.

MOTION: Anna Cunningham made a motion to approve three speakers at the 7th Annual Early Intervention Conference being held in Greenville, NC October 17-18, 2014 for an amount not to exceed \$1,500.00. Each speaker will be reimbursed at a rate of \$500.00, inclusive of speaker fee and travel expenses. Adonis Brown seconded the motion. The motion was approved.

- NC TIDE Fall Conference being held November 2-5, 2014 at the Crowne Plaza Hotel, Asheville, NC. The request is to fund one speaker for up to \$1,050.

MOTION: Anna Cunningham made a motion to approve one speaker for the NC TIDE Fall Conference in Asheville, NC November 2-5, 2014. The speaker will be reimbursed at a rate of up to \$1,050.00, inclusive of speaker fee and travel expenses. Carrie Ambrose seconded the motion. The motion was approved.

IV. Discuss motion made at August Council meeting:

A motion had been made at the August Council meeting for the Executive Committee to have the authority to explore the option of an external contract(s) for the Council Development Fund and the Jean Wolff-Rossi Fund for Participant Involvement. Executive Committee members discussed this issue and recommended that the draft RFA to be presented to the Council at the November meeting for the ADA Network Fiscal Intermediary initiative also include administering the Jean Wolff-Rossi Fund for Participant Involvement and a portion of the Council Development Fund for special circumstances regarding member travel. The Rossi fund and Development Fund are currently active in their July 1, 2014-June 30, 2015 in-house initiatives. A trial alternative for the Development Fund was approved as follows:

MOTION: Ron Reeve made a motion to approve a one-time addition of funds to the current NC ADA Network Fiscal Agent/Intermediary contractor, Alliance of Disability Advocates, in the amount of \$5,000 to administer NCCDD approved Council member travel events. Match requirement is waived for the additional \$5,000 and is added to the contract as an amendment for a total amount of \$35,000 for the time period of July 1, 2014 to June 30, 2015. Adonis Brown seconded the motion. The motion was approved.

V. Extension of Communications Liaison through December 31, 2014 with additional funds

MOTION: Adonis Brown made a motion to approve an increase to the Communications Liaison In-House Initiative by \$7,500 for a total of \$27,500. Staff paid through Temporary Solutions will continue with this increase at 15 hours/week through 12/31/14. Sam Miller seconded the motion. The motion was approved.

VI. Update on public input of State Plan Amendments

Chris Egan gave an update to the members on the status of public input of the State Plan Amendments. A full report will be made at the November Council meeting.

VII. Update on Hefner and Riddle nominations

Chris Egan updated the members that as of this date there had not been any nominations received for either award and encouraged members to get the word out. They will formally review and select from the nominations at the October meeting.

VIII. Other

Joshua Strasburg discussed, and shared with the members, a fact sheet that he helped to develop (along with the NC Coalition Against Sexual Assault, the Office on Disability and Health, and the Carolina Institute for Developmental Disabilities) through the State Violence Prevention Team.

MOTION: Anna Cunningham made a motion that the "Sexual Violence and People with Intellectual/Developmental Disabilities Fact Sheet" be housed at and supported by the NC Council on Developmental Disabilities. Carrie Ambrose seconded the motion. The motion was approved.

Ron Reeve called for a motion to adjourn.

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

NC Council on Developmental Disabilities (NCCDD)

DRAFT

Executive Committee Minutes

October 20, 2014

10:30 AM – 12:30 PM

Present: Carrie Ambrose, Crystal Bowe, Adonis Brown, Sam Miller, I. Azell Reeves, Ron Reeve

Absent: Anna Cunningham

Other present: Chris Egan, Yadira Vasquez

I. Approval of Minutes:

The draft minutes of the September 15, 2014 Executive Committee meeting were discussed.

MOTION: Carrie Ambrose made a motion to approve the September minutes. Sam Miller seconded the motion. The motion was approved.

II. Financial Update:

Yadira Vasquez reviewed the financial reports for the NCCDD. Ron Reeve asked the members if there were any questions and there were none.

III. Conference Funding Requests: None presented.

IV. Jack B. Hefner Memorial Award:

The Jack B. Hefner Memorial Award nominations received were discussed and voted upon.

MOTION: Adonis Brown made a motion to approve Kurt Timothy Reid to be the 2014 Jack B. Hefner Memorial Award recipient at the November Council meeting. Crystal Bowe seconded the motion. The motion was approved.

Sam Miller expressed a desire to include in the November meeting a written note on the distinction between the Jack B. Hefner and Helen C. "Holly" Riddle Distinguished Service Awards. A program for the event will be available at the dinner and will include this information.

I. Azell Reeves expressed concern that Council members do not have enough historical information and would like to see more individuals

nominated that meet the criteria for both awards. She would like to see a taskforce group created to go through the nominations before they are presented to the Executive Committee.

V. Helen C. "Holly" Riddle Distinguished Service Award:

The Helen C. "Holly" Riddle Distinguished Service Award nominations were discussed and voted upon.

MOTION: Ron Reeve asked that all agree to vote on the selection of three nominations by majority rule to facilitate the final decision. Adonis Brown made the motion. Sam Miller seconded the motion. Three top candidates were selected and the motion was approved.

MOTION: Adonis Brown made a motion to approve Joan S. Johnson and Maureen Morrell to be the 2014 Helen C. "Holly" Riddle Distinguished Service Award recipients at the November Council meeting. Crystal Bowe seconded the motion. The motion was approved.

Per further discussion on both awards, Chris Egan will forward information to Executive Committee members on the award history and past recipients, along with the current criteria in place for these awards. He will also arrange for letters to be sent to the recipients and nominees of both awards.

VI. November Council Meeting Agenda Discussion

The November Council Meeting Agenda was discussed and changes were made. Please refer to the attached NCCDD – Draft November Council Meeting Agenda.

At the awards dinner Wednesday evening, the Executive Committee suggested that Council member Dave Richard be the keynote speaker and Duncan Munn introduce the recipients and present the awards.

I. Azell Reeves suggested that Dave Richard's keynote might focus on what is happening at the stakeholder groups and indicate what type of representation is at those groups.

Ron Reeve requested that Chris Egan open the "Overview of Committee Activities" session on Thursday for the members to be better informed of

what will be happening in the committees. Staff will provide a power point for each Committee Chair to present during this session.

VII. Other:

Chris Egan provided an update on the Executive Committee's recommendation at the September meeting that the draft RFA for the ADA Fiscal Intermediary being presented at the November Council meeting include the Jean Wolff-Rossi Fund for Participant Involvement and a portion of the Council Development Fund. Chris indicated that the current contract for the ADA Fiscal Intermediary initiative has been amended to add member travel funds under the intention of the Council Development Fund. He advised that the Jean Wolff-Rossi Fund would be managed more effectively as a separate initiative and recommended a separate RFA for the Jean Wolff-Rossi Fund for Participant Involvement. The trial alternative for member travel under the current ADA Fiscal Intermediary initiative will continue until June 30, 2015 and future alternatives will be addressed on or before that date.

Motion: Carrie Ambrose made a motion to approve staff requesting approval at the November Council meeting to draft an RFA for the Jean Wolff-Rossi Fund for Participant Involvement. Adonis Brown seconded the motion. The motion was approved.

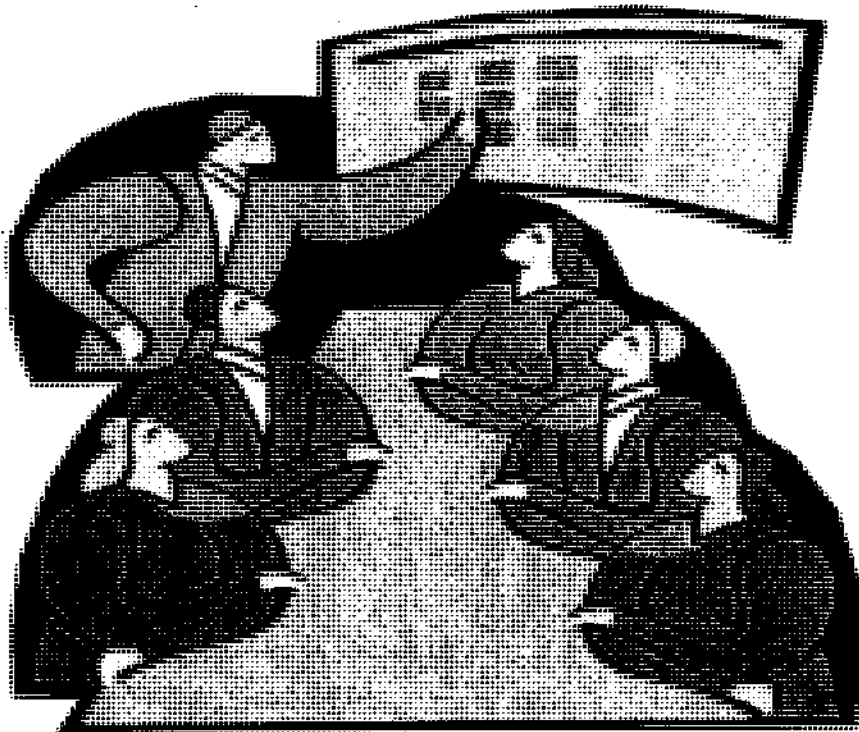
In other discussion, Sam Miller requested that the material on the O'Neill Communications NCCDD Strategic Plan be sent to Council members prior to the November Council meeting.

Ron Reeve suggested that Beth Stalvey might get a list of the types of groups out there, who is representing those groups and provide more information back to the Council, as well.

VIII. ADJOURN:

Motion: Adonis Brown made a motion to adjourn. I. Azell Reeves seconded the motion. The motion was approved.

ADVOCACY AND LEADERSHIP COMMITTEE



North Carolina Council on Developmental Disabilities

Advocacy and Leadership Committee Agenda DRAFT

November 20, 2014

9:45 a.m. – 11:45 a.m.

North Raleigh Hilton, Raleigh, NC

9:45 a.m. – 9:55 a.m.

Introduction

- Welcome
- Completion of Financial Forms and Conference Requests
- Approval of Minutes

Caroline Ambrose

9:55 a.m. – 10:25 a.m.

Initiative Review

- NC Alliance for Direct Support Professionals

Renate Macchirole

10:25 a.m. – 10:35 a.m.

Fiscal Update

Yadira Vasquez

10:35 a.m. – 10:45 a.m.

Break

10:45 a.m. – 11:45 a.m.

Initiative Update

- Advocacy Ambassadors

*Mike Mayer, CRA
Matt Potter
Monica Foster
Jonathon Ellis
Barton Cutter*

11:45 a.m.

Wrap-Up and Reminders

Caroline Ambrose

Advocacy and Leadership Committee

Caroline Ambrose, Chair

Adonis Brown

Michael Groves

Wayne Black; Alternate: Rick Zechman

Tim Smith (*pending*)

Lourdes M. Fernandez

Crystal L. Foreman

Kevin Ryan, M.D.; Alternate: Danielle Matula

VACANT; Alternate: Mary Edwards

Katie Holler

Renate Macchirole

VACANT

Staff: Joshua Strasburg

Individual with DD

Individual with DD

Individual with DD

Agency: Div. of Social Services

Parent of an individual with DD

Parent of Child with DD

Individual with DD

Agency: Women & Children's Health

Agency: Div. of Aging & Adult Services

Parent of an individual with DD

Public at Large

Parent of an individual with DD

**Advocacy and Leadership Committee
DRAFT MINUTES**

Thursday, August 14th, 2014
12:30pm – 3:00pm

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

Members Absent: Lourdes Fernandez

Visitors: Jessica Green, Meredith Staley, Debby Torres, Bryce Coleman, Emmanuel Gibson, Laura Fleming, Tara Fields, Joe MacBeth

Staff in Attendance: Joshua Strasburg, JoAnn Toomey, John McCallum

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 May 2014 Advocacy and Leadership committee meeting minutes. Adonis Brown seconded the motion. Motion was carried.

Initiative Update and Continuation Funding Request

Jessica Green and Meredith Staley gave an update on the work they have been doing so far with the Safety and Security initiative. Meredith discussed the work they did to identify and partner with Domestic Violence/Sexual Assault pilot sites as well as I/DD provider pilot sites. They identified six DV/SA pilot sites across the state, and 3 I/DD provider pilot sites. Meredith described that they are currently working to identify more I/DD provider sites. The team created a needs assessment, disseminated the assessment to the pilot sites, and have received many responses. Meredith and Jessica described their focus for the rest of the year, what their first steps will be in 2015, and answered questions about their budget for year two.

MOTION: Rick Zechman made a motion that the Rape Crisis Center of Coastal Horizons, Inc., be approved for continuation funding for year 2 (of 3) for the Safety and Security: Addressing Domestic Violence and Sexual Violence Against People with Intellectual and other Developmental Disabilities initiative. Funding is approved in the amount of \$50,000 with required minimum 25% non-federal matching funds for the period of January 1st, 2015 to December 31st, 2015. Mary Edwards seconded the motion. The motion carried.

Crystal Foreman and Adonis Brown recused themselves.

Initiative Update

Caroline Ambrose and Joshua Strasburg discussed the Partners in Policymaking (PiP) initiative information that the committee requested in May. Joshua and Caroline presented a one page report on how the PiP initiative could be strengthened through releasing it as an RFA and the timeframe for its release if the committee decided to move in that direction. John McCallum commented that it is not uncommon for Councils to occasionally release sole-sourced funds as an RFA as a quality control measure. The committee was in agreement to move down this path, and discussed next steps. The next step would be to make a motion to draft the RFA in November of 2015.

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:

Debby Torres and Bryce Coleman spoke to the committee about the issue of sibling support and their first steps with the Sibling Support initiative funded by the NCCDD. The initiative starts October 1st, 2014 and they came for a face-to-face introduction, especially to introduce their new staff member (Bryce), who replaced Krysta Gouglar. Krysta was originally named as the lead on some of the activities of the initiative. In their presentation they described the role of siblings in the family of a person with I/DD and some statistics around siblings of a person with I/DD. Bryce and Debby outlined the focus areas of the initiative including building networking opportunities, identifying the support needs, hosting SibChats, identifying leaders through both rural and urban listening tours, and partnering with the national Sibling Leadership Network to develop a state chapter of the Sibling Leadership Network. They also plan to host a statewide sibling conference.

Initiative Update and Continuation Funding Request

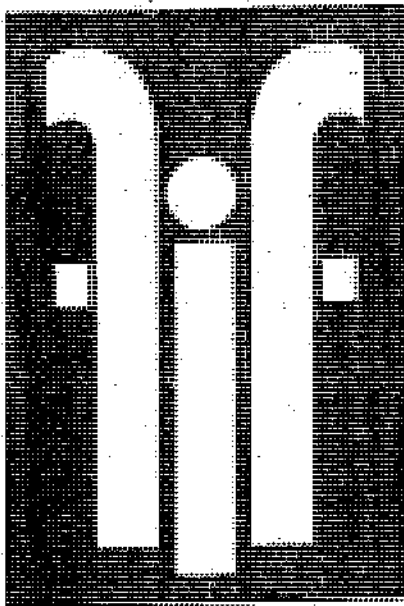
Renate Macchirole, Joe Macbeth, Laura Fleming, and Tara Fields gave an update on their work so far with the Direct Support Professional initiative. Renate gave an overview of the kickoff events, their structure, and the support that has been generated from them. Joe talked about what they've learned about the needs for DSP's in NC and that they were open to widening the scope of the state chapter from just DSP's for people with I/DD to DSP's across all service sectors. Renate shared with the committee some misconceptions that they encountered during their work and how she helped clarify what the NCADSP would actually be. Despite those misconceptions, every LME-MCO in the state has either agreed, or reached out to Benchmarks, to sponsor the NCADSP movement. Tara, Renate, and Joe outlined their next steps for year two. Laura and Tara answered questions about their proposed budget for year two.

MOTION: Crystal Foreman made a motion that Benchmarks, Inc. be approved for continuation funding for year 2 (of 3) for the NC Chapter of the Alliance for Direct Support Professionals initiative in the amount of \$100,000 for the period of January 1st, 2015 to December 31st, 2015. Match requirement is waived for this grant. Rick Zechman seconded the motion. The motion carried.

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: Mary Edwards made a motion to adjourn the August 2014 Advocacy and Leadership Committee meeting. Adonis Brown seconded the motion. The motion carried.



FAMILY SUPPORT: COMING OF AGE

FINAL REPORT AND RECOMMENDATIONS

Identifying the support needs of people with Intellectual/Developmental Disabilities or Traumatic Brain Injuries and their aging caregivers in North Carolina and the barriers involved in attaining that support.



*A First In Families of North Carolina Initiative
Funded by the North Carolina Council on
Developmental Disabilities.*

INTRODUCTION

Dear Stakeholder,

North Carolina is facing a perfect storm with the confluence of persons with Intellectual/ Developmental Disabilities (I/DD) or Traumatic Brain Injury (TBI) living at home and the aging of their primary caregivers who themselves are in need of more support. Over 71% of all adults with I/DD in North Carolina live in their family home. Of this percentage, 25% of their caregivers are over the age of 60.

This is a nationwide epidemic not unique to North Carolina. By 2030 the number of Americans over 65 is projected to grow by 30 million (a 67% increase in (Thaler, 2011), substantially increasing the need for paid caregiving services for those who are aging and/or have disabilities in the US.

As aging caregivers increasingly need caretakers of their own, they also need support in keeping their loved one at home and in the community, and access to Future Planning resources.

The issues of family support and Future Planning require intense collaboration between Aging and DD stakeholders. No longer can the two systems operate as silos. As individuals with I/DD and/or TBI age they too require extensive and unique solutions for accessing their communities.

The NC Council on Developmental Disabilities recognized that North Carolina currently does not have the capacity to meet the projected needs of its citizens who are aging and have I/DD, or their caregivers. Because of this, the Council provided funding to First In Families of NC to explore the issue and provide recommendations for meeting the needs of this population.

As part of that grant, FIFNC convened a Taskforce of dedicated professionals from I/DD and Aging service sectors, policy-informers, caregivers, and self-advocates. This group worked diligently to identify the needs of those with I/DD and their caregivers as they age. Staff from FIFNC and volunteers conducted a statewide poll to identify common concerns and shortcomings within our system. They sat one-on-one with families from Shelby to Henderson to discuss their current and future needs as well as the availability and accessibility of resources needed to meet those needs.

This report serves to shed light on the family support needs of aging caregivers in our state, to honor the resiliency of North Carolina citizens, to humanize the caregiver crisis, and to advise the North Carolina Council on Developmental Disabilities and its constituents on the next steps toward providing the critical supports necessary to minimize "storm damage" to individuals with I/DD and their families and prevent a profound economic crisis.

Thank you for your foresight in beginning this conversation, for entrusting FIFNC to manage this initiative, and for your commitment to the over 109,000 (Braddock, 2013) individuals with developmental disabilities and their families throughout North Carolina.

Sincerely,

Betsy MacMichael

Betsy MacMichael
Executive Director
First In Families of North Carolina

INITIATIVE SUMMARY

First In Families of North Carolina was awarded a grant from the NC Council on Developmental Disabilities to address the issues of individuals with intellectual and developmental disabilities (I/DD) as they age with their caregivers. The active grant period was July 1, 2012 – June 30, 2014.

The proposed outcomes of the initiative were:

- Aging individuals with I/DD and their caregivers will have greater knowledge about, and access to, natural supports.
- Legislators and other policymakers will be better equipped to create policies that will reduce barriers (identified by the stakeholders) to obtaining family support whether through natural or more traditional services.
- Through increased collaboration, I/DD and aging system professionals will have a greater array of resources that they can refer to those they serve, thus reaching more people.
- Families will be more knowledgeable about how to plan for the future.
- Families and individuals with I/DD will have more opportunities to give back to others as valued community members.

FAMILY SUPPORT DEFINITION

Family support is defined as the provision of information, resources, and services to families of individuals with intellectual and developmental disabilities (I/DD) to help them meet the needs of their family members and themselves. Family support is provided in a way that respects the family's culture, values, and preferences. Family support is provided in a way that is accessible, affordable, and available. Family support is provided in a way that is tailored to the needs of the family and the individual with I/DD. Family support is provided in a way that is empowering and enabling. Family support is provided in a way that is collaborative and participatory. Family support is provided in a way that is strengths-based and asset-based. Family support is provided in a way that is person-centered and individualized. Family support is provided in a way that is community-based and community-oriented. Family support is provided in a way that is evidence-based and research-informed. Family support is provided in a way that is culturally competent and culturally responsive. Family support is provided in a way that is trauma-informed and trauma-sensitive. Family support is provided in a way that is recovery-oriented and recovery-focused. Family support is provided in a way that is holistic and comprehensive. Family support is provided in a way that is integrated and coordinated. Family support is provided in a way that is continuous and ongoing. Family support is provided in a way that is flexible and adaptable. Family support is provided in a way that is innovative and creative. Family support is provided in a way that is effective and efficient. Family support is provided in a way that is sustainable and long-term. Family support is provided in a way that is transformative and life-changing. Family support is provided in a way that is empowering and enabling. Family support is provided in a way that is collaborative and participatory. Family support is provided in a way that is strengths-based and asset-based. Family support is provided in a way that is person-centered and individualized. Family support is provided in a way that is community-based and community-oriented. Family support is provided in a way that is evidence-based and research-informed. Family support is provided in a way that is culturally competent and culturally responsive. Family support is provided in a way that is trauma-informed and trauma-sensitive. Family support is provided in a way that is recovery-oriented and recovery-focused. Family support is provided in a way that is holistic and comprehensive. Family support is provided in a way that is integrated and coordinated. Family support is provided in a way that is continuous and ongoing. Family support is provided in a way that is flexible and adaptable. Family support is provided in a way that is innovative and creative. Family support is provided in a way that is effective and efficient. Family support is provided in a way that is sustainable and long-term. Family support is provided in a way that is transformative and life-changing.

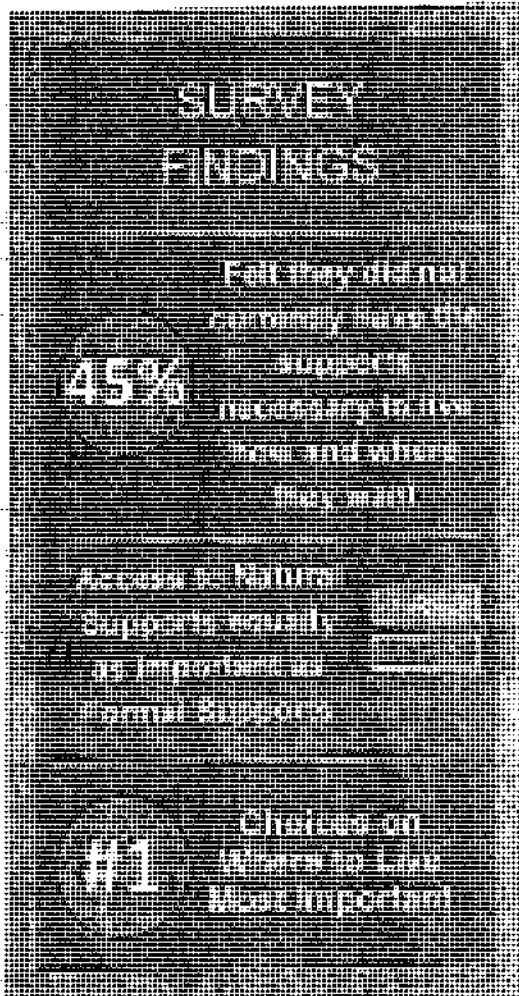


INITIATIVE IMPACT AND FINDINGS

To advise the grant work FIFNC formed a Taskforce comprised of professionals from the Aging and Intellectual/Developmental Disability (I/DD) service sectors, caregivers, and self-advocates. The Taskforce's first meeting was held in October 2012. The grant initiative and scope of work were presented, along with a history of previous national and state-lead projects to bridge Aging and I/DD sectors. Throughout the grant the Taskforce provided direction, reviewed and synthesized data received through survey and Future Chat conversations, advised staff on next steps in the work plan, and formulated policy recommendations. Three subcommittees of the Taskforce were formed to focus on the previously identified issues, from the three distinct perspectives of: policy, community/natural supports, and individual/family.

Identifying common caregiver needs

The initiative identified common needs of people with disabilities and their caregivers as they age through an online survey distributed in collaboration with Aging and Disability partner organizations statewide. The survey, distributed statewide and conducted in December of 2012, received 277 unique responses from individuals living in 55 of North Carolina's 100 counties. Respondents were asked to choose the category they most identified with. 30% responded as professionals in aging, 12% as professionals in I/DD, 17% as primary caregivers to a person with I/DD who is not over the age of 60, 9% as family members (not primary caregiver) to a person with I/DD, 7% as family members of person who is aging, 4% as caregivers to a person with I/DD over the age of 60, and 2% identified as self-advocates. 19% of respondents identified primarily as community members. (FIFNC, 2012)



TEEDY

"I don't want to live in a group home all my life. Will my brother and sister support me in my desire to not live in a group home?"

(Durham County)

INITIATIVE IMPACT AND FINDINGS

Families need a variety of formal & natural supports

Key findings from the survey include:

- Survey participants rated access to formal (government) supports and access to natural support as equally important.
- When asked "What are the most important needs for individuals with I/DD who are aging and their aging caregivers?" respondents ranked "choices on where to live", "financial security", and "respite and caregiver support" as the top three among twelve.
- 41% of respondents stated that they felt that they currently had the supports necessary to live how and where they want, 45% stated that they did not currently have the supports necessary to live how and where they want and 14% were unsure if they had the supports necessary to live how and where they want.

Personal support networks are vital to Future Planning

Twenty-five Future Chat conversations were conducted in-person by staff and volunteers throughout the state. These conversations facilitated a more personal and in-depth exploration of the challenges faced by real families and better served to illustrate the needs identified through research and survey. The conversations also allowed the interviewer to assess the future-planning readiness of each family and, when appropriate, provide information on future-planning resources available to them.

In Future Chats caregivers reported that they worried about not only the availability of care for their child, but also expressed concerns about having people in their child's life that know him/her and can provide companionship and guidance once they are no longer around. Self-advocates echoed this desire for a network of support and meaningful relationships.

RATIONALE FOR FAMILY SUPPORT

109K NC Adults with I/DD who live at home

Receive Public Support from I/DD Agencies

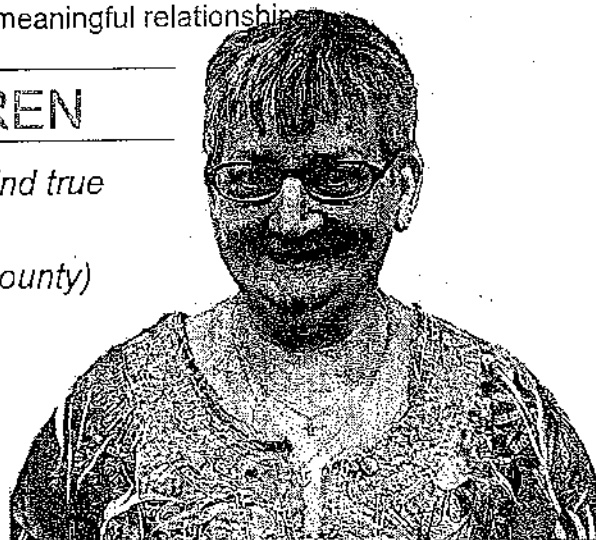
8%

25%

NC Caregivers over age 60

KAREN

*"I want to find true love."
(Durham County)*



INITIATIVE IMPACT AND FINDINGS

Natural and community (non-paid) supports can provide more organic and positive outcomes for the individual with I/DD. One family shared their son's experience living with Down Syndrome in the Siler City community. Melba D., 76 has helped her son, Todd (age 36) to develop a personal network of friends and "surrogate" family that she is confident will continue to support him throughout his life. Todd has worked at Bestfood Cafeteria in Siler City since his teenage years and has made many friends through his work. In addition to having completed legal and financial Future Planning to ensure her son's needs are met, Melba takes great solace in the peace of mind that Todd will continue to be supported after her death to remain in the community he loves.

The Council on Quality and Leadership, Personal Outcome Measures concludes "Natural support networks are groups of people whose commitment to support each other is usually lifelong. These support networks cannot be manufactured or created. They can only be nurtured as they grow and evolve over time. Families provide lifelong support and a safety net for many people. Lifelong relationships with non-family members are also part of the support (The Council on Quality and Leadership, 2000)

THE COST OF CAREGIVING

UNIVERSITY OF ILLINOIS AT CHICAGO

DEPARTMENT OF DISABILITY AND HUMAN DEVELOPMENT

Over 71% of adults with I/DD live with family members and about 25% of these family caregivers are over age 60 years. In North Carolina, over 109,000 people with I/DD live with family caregivers—and over 25,000 of these caregivers are age 60 or over. Yet, only 13% of families providing support to members with I/DD nationally and only 8% in North Carolina (9,175 families) received public support from state I/DD agencies. Unpaid family support is a large slice of the US economy, estimated at \$450 billion in 2009. More than 40 million family caregivers provide over 40 billion hours of unpaid care to family members who need assistance with activities of daily living. Most of these families provide 50-80 hours of help each week (Heller, 2014)

Supporting Individuals means Supporting Families

With the implementation of Managed Care for Long Term Support Services in North Carolina, the Council asked FIFNC to extend the scope of the grant work to include research on outcomes, opportunities and emerging best practices nationwide. Through collaboration with the Department of Disability and Human Development at the University of Illinois, a policy brief on Long Term Support Services in Medicaid Managed Care was created.

This brief provided national and state data to support the necessity and relevance of comprehensive whole-family support in a Managed Care environment.



INITIATIVE HIGHLIGHTS

The Family Support: Coming of Age Stakeholder Taskforce met four times in person over the course of the grant work. Partners from the aging service sector were especially involved in the work and eager to provide opportunities for cross-training.

Through these collaborations with regional Area Agencies on Aging (AAA), Community Resource Connections (CRCs) and the Division of Aging and Adult Services at the Department of Health and Human Services, FIFNC project staff participated in comprehensive Options Counseling training and provided cross-training on the I/DD and TBI populations in various settings, including the 2013 North Carolina Association on Aging Conference, the 2013 AAA Director's Annual meeting, and the Chatham-Orange and Wake CRC Chapter meetings.

Partnerships with colleagues in aging services also provided the opportunity for FIFNC staff to play an integral role in the formation of an entirely new CRC for Durham County residents who are aging or living with disabilities. FIFNC remains involved in the Triangle-based CRC initiatives and was the lead organization representing disability services in advocating to the Durham County Commissioners for county funding for a coordinator position for the new Durham CRC.

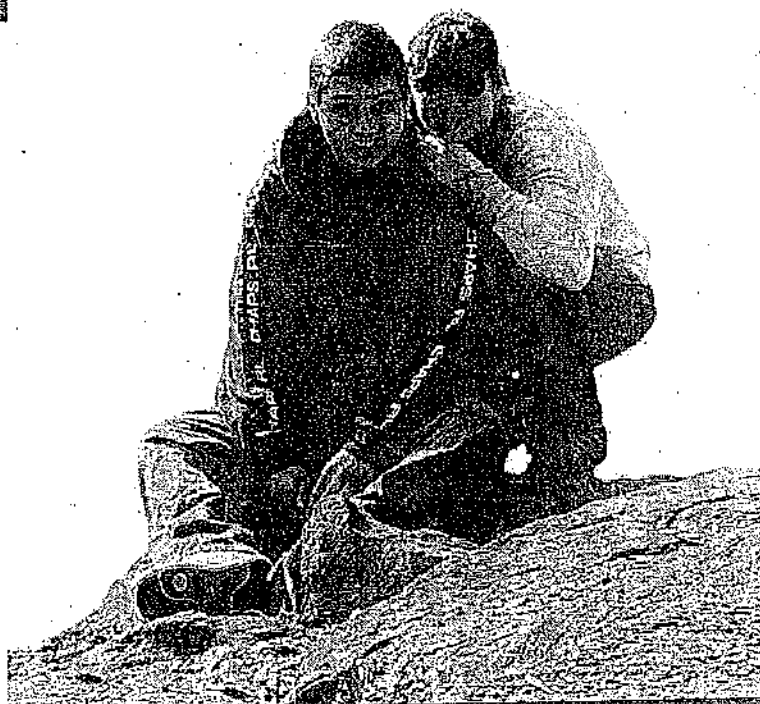
Conversations with self-advocates and caregivers who self-identified as aging, and data collected through the online survey allowed staff to:

- obtain a comprehensive view of the needs of aging caregivers throughout North Carolina,
- to identify areas in which natural supports were being utilized successfully
- further inform the work of the Taskforce.

Future Chats & Checklists

In many areas of the state, especially rural communities, natural support networks compliment and reduce reliance on public supports.

Families were eager to share their personal experiences, their hopes and their fears about what the future may hold for their loved one with I/DD or TBI. Families expressed satisfaction with the Future Planning Checklist created as part of this initiative, many sharing that it helped them move forward with putting a plan in place by presenting the information in a concise and approachable format.



INITIATIVE CHALLENGES

Council staff requested an addition to the scope of work to include national policy perspective in the wake of North Carolina's newly implemented Managed Care System. In addition, the loss of the staffing position for the Timebank required FIFNC to reconsider its original plan to use the Timebank as a platform for natural supports for aging caregivers, and to decrease social isolation through connectivity. While FIFNC still believes the Timebank is an innovative way to help meet the basic needs of families (cooked meals, home repairs, ride-sharing to doctor's appointments) and embodies the FIF tenant of reciprocity – for the purpose of this initiative it was not pursued.

Three Future Planning Workshops were scheduled throughout the state that focused on providing information to aging caregivers on Wills and Estates Planning. The first was held in Shelby in November of 2013, the second was held in Winston-Salem in April 2014 and the final was planned for New Bern in June 2014. Unfortunately, the New Bern workshop had to be cancelled due to low registration numbers. While grant staff and Taskforce members worked to promote the workshop through all known channels, low registration could be in part due to the location of the workshop and/or not having made enough relevant connections in the area. It also occurred to staff that perhaps an initial workshop on Wills and Estates Planning might be overwhelming for those individuals who have not previously been exposed to discussions on Future Planning. Especially in rural areas, it might be better to focus on a general "Future Planning" information session in a small group meeting so as not to overwhelm participants.

RECOMMENDATIONS

Recommendation One:

Identify Barriers to Future Planning for Caregivers of Individuals with I/DD

To continue and build upon the research provided through the Family Support: Coming of Age initiative the Taskforce advises the North Carolina Council on Developmental Disabilities to consider funding future initiatives that identify specific barriers which lead to reluctance in Future Planning for caregivers of individuals with I/DD. Once barriers to Future Planning are identified the Taskforce recommends implementation of a pilot incentive program for families who are actively completing Future Planning Tasks

Recommendation Two:

Require Future Planning as a Component of Every Person Centered Plan

To ensure that families are knowledgeable about the necessity of planning, to decrease the need for emergency public-funded services and to provide an easier and more self-directed transition for individuals with I/DD or TBI upon the loss of their caregiver the Taskforce recommends that the Department of Health and Human Services, Division of Mental Health, Developmental Disabilities and Substance Abuse Services require that Future Planning be included as part of



RECOMMENDATIONS

every Person Centered Plan for individuals with I/DD and TBI. LME/MCO Care Coordinators, Community Guides and service provider staff responsible for Person Centered Planning should receive adequate training to have discussions about Future Planning with the families they serve. It is recommended that there be different questions to bring up depending upon the age of the person with the disability. For younger families the requirement to plan could simply mean that they have been offered resources to start thinking about what they will be needing to do in the future, and what people need to know now, in the event of their premature death. As they age, the requirements should be much more specific.

Recommendation Three:

Provide access to information and resources on Future Planning as a Medicaid Billable Service through the LME/MCO network .

To provide access to all caregivers on resources specific to Letter of Intent, Wills and Estates Planning, Special Needs Trusts, and personal asset mapping of their community through publications (Future Planning Checklist, FIFNC, 2013), provider education and regionally sponsored workshops, the Taskforce recommends that Future Planning be considered a billable service through Medicaid and implemented in all geographic areas of North Carolina through the established LME/MCO channels.

Recommendation Four:

Identify older family caregivers to provide resources before the point of crisis.

It is speculated that there are many "unaccounted for" caregivers who are aging and have heretofore remained invisible because they are unaware of, or reticent to enter the formal system to access services and support. At the point of crisis is when their presence becomes known. Utilizing community mapping proactively will allow LME/MCOs, providers of direct family support such as First In Families of North Carolina (FIFNC) and existing collaboratives such as the Community Resource Connection (CRC) initiatives to identify caregivers who are aging. Educating these caregivers (once found) about available community resources could decrease reliance on more costly emergency supports, provide an opportunity to engage caregivers about the importance of Future Planning and help families to remain together longer.

Recommendation Five:

Continue and increase cross-training and collaboration between Aging and Disability sectors.

As formal service resources will never be adequate to meet the needs of all families, in



RECOMMENDATIONS

part due to the "perfect storm" and because the needs of individuals and families exceed the limitations of the public sector, it is imperative that partners in the Aging and Disability fields do a much better job of understanding and supporting one another. Coming of Age Taskforce Members have committed to continuing on in an advisory capacity as a resource to assist in future endeavors supporting the cross-training between Aging and Disabilities. It is recommended that additional partners be recruited for this effort in order to maximize outcomes for individuals with I/DD and their caregivers as they are aging.

CONCLUSION

The Family Support: Coming of Age initiative has been successful in identifying the needs of aging caregivers and individuals of I/DD in North Carolina. Now it is time to prepare for the storm. The recommendations and findings included in this report are anticipated to provide the North Carolina Council on Developmental Disabilities with a foundation for the next steps in preparing for the future of individuals with I/DD or TBI and their caregivers. With an anticipated growth of 67% over the next 15 years in the population over 60, FIFNC and all who have been part of this work urge the Council to use these recommendations as a starting point for future initiatives.

ARNOLD

Arnold had a promising career as an electrician when he suffered a Traumatic Brain Injury in a vehicle accident in 1997. Three years of hospitalization later and requiring around the clock care, Arnold's parents brought him to his childhood home in Shelby.

Arnold's father Jerry is a tireless advocate for his son. At age 68, he and his wife worry constantly about who will care for Arnold when they are no longer able. Like all aging parents they want to know that Arnold will continue to be cared for, supported and engaged in his community.

Arnold loves cars, his dog and everything Harley Davidson.

(Cleveland County)



WHY FUTURE PLANNING?

Future Planning is the preparation one does to ready themselves, their family and their estate for the time when they are no longer able to manage these parts of life - whether due to incapacitation, illness or death. All people could benefit from a plan for the future, but the recommendations in this report are specific to caregivers of persons living with an intellectual or developmental disability and/or Traumatic Brain Injury.

Some key components of good Future Planning in this context include preparing a Letter of Intent explaining your wishes for your child, creating a will and plan for your estate, and creating a Special Needs Trust to administer and protect money left behind to benefit your child and protect his or her public benefits. Not everyone will need all these components so every family needs quality guidance to develop their own plan. Guardianship or alternatives to guardianship should also be considered and planned.

Equally important in Future Planning is identifying or building a personalized network of support for a person with I/DD, drawing initially from current trusted relationships with friends and family and then growing the network with new people who emerge through shared interests or activities with the person with the disability. This network serves as a "safety net", to support the individual and caregiver in the present and more importantly as the caregiver ages. Individual members of the network can even be identified to provide information and advice in specific areas such as finances or health. Such "supported decision making" is a kind of guidance that encourages self-determination. Person networks are one of several alternatives to guardianship that are available options in North Carolina.

A 2012 study reported that 41% of the Baby Boomer generation (born 1946-1964) do not have a will. When polled as to why not, procrastination was cited as the biggest reason (34 percent), followed by feelings that it was unnecessary (22 percent) or too expensive (21 percent). (AARP, 2012)

Further, a 2008 survey by The Hartford Financial Services Group showed that roughly 62 percent of parents have no long-term care plan in place for their child living with a disability and that 58% have their child identified as a beneficiary to their financial assets, something which could jeopardize critical government benefits and services. (Bankrate, 2014)

More research as to the barriers preventing aging caregivers of individuals with I/DD or TBI from participating in Future Planning is needed. It is clear that reluctance towards Future Planning transcends socioeconomic barriers, therefore it is important to find out what specifically is keeping many NC families from taking critical planning steps.



COMING OF AGE STAFF AND TASKFORCE

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Executive Director
First In Families of North Carolina
betsym@fifnc.org

Debby Torres
Project Director, Family Support Coming of Age
First In Families of North Carolina
dtorres@fifnc.org

FAMILY SUPPORT: COMING OF AGE TASKFORCE

Heather Burkhardt
NC Division of Aging and Adult Services
(Raleigh)

Gwen Phillips
Chatham-Orange Community Resource Connections
(Hillsborough)

Tonya Cedars
Eastern Carolina Area Agency on Aging
(New Bern)

Susan Reed
Wake County Community Resource Connections
(Raleigh)

Anna Cunningham
Parent/Caregiver
(Raleigh)

Ellen Russell
The Arc of NC
(Raleigh)

Kenneth Greenberg
Parent/Caregiver
(Charlotte)

Kathryn Sticksel
OE Enterprises
(Hillsborough)

Colleen Kilsheimer
Parent/Caregiver
(Durham)

Valerie Vizena
The Enrichment Center
(Winston-Salem)

Karen Luken
NC Office on Disability and Health
(Chapel Hill)

Jan White
NC Division of Mental Health, Developmental
Disabilities and Substance Abuse Services
(Raleigh)

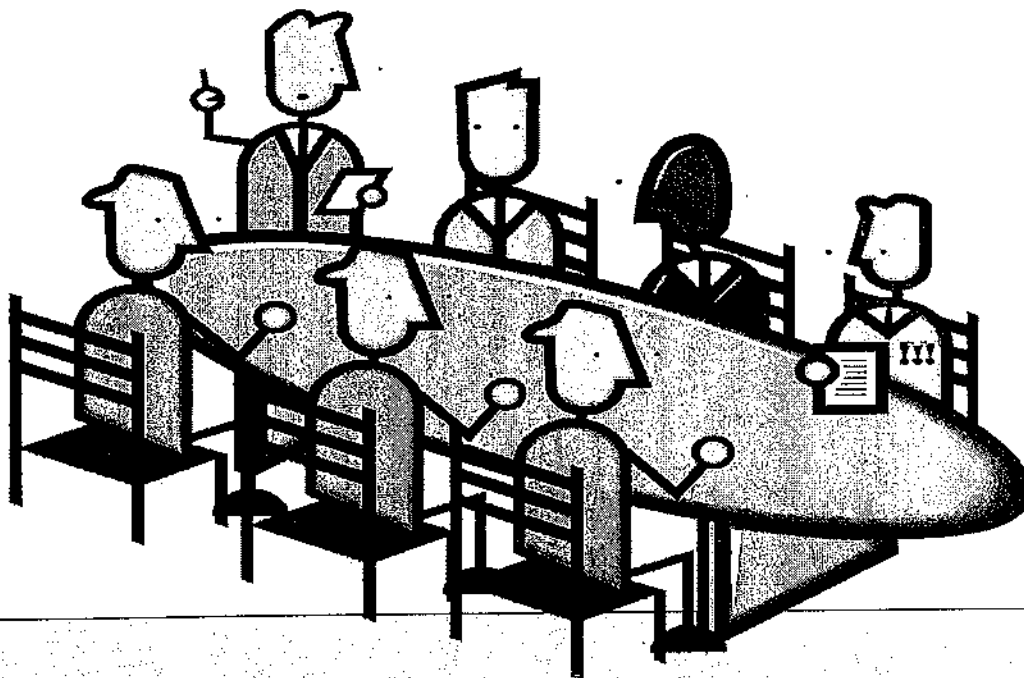
Joan Pellettier
Triangle J Area Agency on Aging
(Durham)

With special thanks to Marian Hartman

Works Cited

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COMMUNITY CAPACITY BUILDING COMMITTEE



North Carolina Council on Developmental Disabilities

Community Capacity Building Committee Agenda **DRAFT**

November 20, 2014

9:45 a.m. – 11:45 a.m.

Hilton Garden Inn, Cary, NC

9:45 a.m. – 9:55 a.m.	Introduction <ul style="list-style-type: none">WelcomeApproval of Minutes	<i>I. Azell Reeves</i>
9:55 a.m. – 10:10 a.m.	Authority to Release RFA <ul style="list-style-type: none">NC ADA Fiscal Agent	<i>Shayna Simpson and Karen Hamilton NCCDD</i>
10:10 a.m. – 10:50 a.m.	Initiative Updates <ul style="list-style-type: none">Learning and Earning After High School: The Role of Transition Services in Raising Expectations and Attitudes for Students with Intellectual DisabilitiesEmergency Preparedness	<i>Kim Corzine, Project Coordinator and Dr. Kelly Kelley, Project Director Western Carolina University</i> <i>Joanne Pierce, Grant Coordinator NC Dept. of Public Safety</i>
10:50 a.m. – 11:00 a.m.	Break	
11:00 a.m. – 11:20 a.m.	<ul style="list-style-type: none">Reaching the Summit of Success	<i>Cindy Thomas and Karen Flippo, Institute for Community Inclusion, UMass</i>
11:20 a.m. – 11:30 a.m.	Fiscal Update	<i>Yadira Vasquez, NCCDD</i>
11:30 a.m. – 11:45 a.m.	Wrap Up and Reminders <ul style="list-style-type: none">Completion of Financial Forms and Conference Request	<i>I. Azell Reeves</i>

Community Capacity Building Committee

I. Azell Reeves: Chair

Lisa Byrd

John Carbone, M.D.; Alternate: Larry Huggins

PENDING: William Hussey; Alternate: Dreama McCoy

Anna Cunningham

Wilson Finks

Amanda Bergen

Dave White

Senator Tommy Tucker

Jim Swain; Alternate: Gina Price

Desiree Peterson

Staff: Shayna Simpson-Hall

Parent of Child with DD

Individual with DD

Agency: Dept. of Public Safety

Agency: Dept. of Public Instruction

Parent of Child with DD

Individual with DD

Parent of Child with DD

Parent of Child with DD

Other: Legislative

Agency: Div. of Voc. Rehab.

Individual with DD

**Community Capacity Building
DRAFT Minutes
August 14, 2014
12:30 p.m. – 3:00 p.m.
North Raleigh Hilton– Raleigh, NC**

Members Present: I. Azell Reeves (Chairperson), Lisa Byrd, Bill Hussey; Alternate: Beverly Colwell, John Carbone, M.D.; Alternate: Larry Huggins, Anna Cunningham, Wilson Finks, Amanda Bergen, Jim Swain; Alternate Gina Price and David White

Members Absent: Desiree Peterson and Senator Tommy Tucker

Guests: Rene Cummins (NC ADA Fiscal Agent), Jaci Harris (Power of the Dream), Cassie Cunningham (Power of the Dream), Curtis Dew (Citizens Together), Linda Emery (Cincinnati Children's Hospital – Project SEARCH), Pat Keul (Project Consultant – Project SEARCH), David Taylor Jr., and Judi Taylor

Staff/Contractors/Council Chair: Shayna Simpson-Hall, Karen Hamilton (NC ADA Network), Shelsey Hall (NCCDD intern) 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 May 15, 2014 Minutes.

MOTION: Wilson Finks made a motion to accept the May 15, 2014 Community Capacity Building Committee minutes. David White seconded the motion. The motion passed.

Initiative Updates

Karen Hamilton (NC ADA Network Coordinator) reported:

This past year the NC ADA Network project worked with grassroots groups and advocates in 46 counties, to provide Americans with Disabilities Act (ADA) training and technical assistance to individuals and businesses in over 87 NC counties. These activities included:

- Conducted or hosted 32 ADA Trainings serving 1043 people
- Distributed 1625 ADA publications to 1178 people
- Provided ADA Technical Assistance to 1170 individuals or businesses
- Conducted 8 Public Awareness events including ADA exhibits, presentations and news articles

NC ADA Network representatives are serving on planning committees and task forces including:

- 10 statewide planning committees
- 18 local task forces

NC ADA Network is collaborating with 3 other Council initiatives and other groups including:

- Advocacy Ambassadors initiative
- Emergency Preparedness for People with I/DD initiative
- NCCDD Policy initiative (Beth Stalvey)
- Disability Rights NC

Jaci Harris and Cassie Cunningham (Power of the Dream Self Advocacy Group) shared about their group's local ADA Project activities. Over the next year the group plans to work on the Americans with Disabilities Act issues of accessible parking, service animals, accessibility in stores and employment rights. Ms. Harris emphasized the importance of learning about your rights and speaking up. Additionally, David Taylor – and Judi Taylor discussed issues surrounding parking control and gave an introduction to a new parking app.

Initiative Update and Authority to Draft

Rene Cummins (Director of Alliance of Disability Advocates) reported on her organization's role as the NC ADA Network Fiscal Agent. She shared how as the Fiscal Agent they enable people with disabilities and small grassroots groups to access the funds they need to conduct and participate in advocacy activities that promote the Americans with Disabilities Act as follows:

- Provide cash advances for groups and individuals with disabilities with limited financial resources.
- 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.
- Enable small grassroots groups to apply for funds and successfully conduct projects in their local communities.
- Enable individuals with disabilities to serve on boards, committees and task forces by providing funds for travel and accommodations.
- Enable people with disabilities to participate in ADA trainings and events by providing funds for travel and training costs.
- Provide quick reimbursement for groups and individuals that have limited budgets (less than 15 business days).
- Provide technical assistance, as needed, to assist individuals with disabilities to complete forms and reports.

Ms. Cummins also reported that this year, Alliance of Disability Advocates had the following outcomes as Fiscal Agent to the NC ADA Network:

- Met or exceeded all project objectives for this past project year.
- Went beyond scope of work as fiscal agent and conducted 8 ADA trainings serving more than 90 people.

Curtis Dew with Citizens Together Advocacy Group spoke on the important role the NC ADA Network Fiscal Agent plays in supporting small grassroots groups and individuals with disabilities that have limited financial resources. Mr. Dew shared examples of how the current fiscal agent, Alliance of Disability Advocates, has helped self-advocates:

- Provides cash advances for gas or food so advocates with limited resources can participate in meetings and training events;
- Processes reimbursement requests in less than one week in most cases;
- Will make arrangement with hotels if advocates do not have credit cards to check into their hotel rooms; and
- Will handle emergencies by immediately making arrangements to handle accommodation needs.

MOTION:

Authority to Draft an RFA (NC ADA FISCAL AGENT)

David White made a motion to grant authority to staff to release the RFA to support the implementation of the NC ADA Network Fiscal Agent initiative, 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. Motion was seconded by Lisa Byrd, Wilson Finks and Amanda Bergen. The motion carried. * *Anna Cunningham recused herself.*

Initiative Updates and Motion to Approve Continuation Funding

Linda Emery, Project SEARCH Project Coordinator with Cincinnati Children's Hospital and Pat Keul, Project Consultant provided the members with an update. They began with a general program description which consists of the following:

- One year program (typically aligns with school year)
- 10 - 12 young people (average)
- Individuals with a variety of disabilities
- Rotation through 3 unpaid internships with continual feedback to gain/increase job skills
- Consistent on-site staff provided by service agencies
- Outcome of employment

Purpose of the North Carolina Initiative:

1. Establish three new Project SEARCH programs in North Carolina communities - MET THIS GOAL!!
2. Provide Training and on-going support to the four existing North Carolina Project SEARCH programs - MET THIS GOAL!!

Linda informed the group that the contract negotiations were deliberate and difficult. They were able to begin work on the initiative goals in late January, 2014.

Goal 1 - Selecting the 3 new sites:

Established an Advisory Committee to assist with site selection process

- Alice Farrar, Beverly Colwell, Karen Abourjilie, David Test, and Sid Smith agreed to help distribute information and review information from interested communities.
- Distributed information to a wide variety of organizations/agencies.
- Information flyer about process to become one of the new sites.
- Webinar to clarify the information.
- Answered questions from interested communities.

"Letters of Intent" Process

- Distributed a Letter of Intent (LOI) form and asked that communities complete.
- Advisory Committee plus Project SEARCH staff scored the LOI's using a rubric. Looked for:
 - Understanding of Project SEARCH model.
 - Collaboration among education, Vocational Rehabilitation, community rehabilitation providers, potential business partners and families.
 - Commitment to participate as a team in Project SEARCH trainings.
 - All persons who scored the sites agreed upon the selected sites. All rated the top three in the same order.

Model requires technical assistance with up to 3 steps

- Overview of the model including CORE components.
- Presentations to potential host businesses and assistance with building high quality internships.
- Presentations to families/students and assistance with the intern selection process.
- Problem solving assistance with specific issues such as funding, collaboration, staffing, etc.

Three communities selected in early March 2014- the three new NC Project SEARCH sites are listed below:

- 1.) Alamance Regional Hospital Project SEARCH (partners below)
 - Alamance Burlington School District
 - North Carolina Division of Vocational Rehabilitation Services
 - Cape Fear, Inc.
 - Cardinal MCO
 - Family Advocate from Alamance Burlington School District
- 2.) Gardner-Webb University Project SEARCH – Boiling Springs (partners below)
 - Cleveland County School District.
 - Cleveland Vocational Industries, Inc.
 - North Carolina Division of Vocational Rehabilitation
 - Plan to enroll 10- 12 interns, students and young adults
- 3.) Harris Regional Hospital Project SEARCH (partners below)
 - Southwestern Community College
 - Smoky Mountain Center
 - Cherokee Nation

The goals for Year 2 are as follows:

- Increase employment outcomes to 100% for all North Carolina programs.
- Increase number of interns enrolled in each program.
- Add three additional Project SEARCH programs through selection process with support from the Advisory Committee.
- Hold at least one statewide training for all Project SEARCH programs in February – 2 days of training provided by Project SEARCH staff and augmented by shared learning among programs.
- Hold regional meetings – 2 in each area, 1 in October and 1 in April (this need was identified by the teams at June training).
- Training will include assistance in the establishment of Business Advisory Committees and implementing the Family Involvement Curriculum for each of the 7 existing Project SEARCH programs.

In closing, Linda read to the group a heartfelt letter written by one of the mother's of a Project SEARCH graduate. The letter described the remarkable changes she has witnessed in her child since she has graduated from Project SEARCH and has begun working.

MOTION:

Continuation Funding – Project SEARCH

Wilson Finks and Anna Cunningham made a motion that the NCCDD will make available up to \$100,000 (January 1, 2015 to December 31, 2015), 100% federal funds of external, sole source funding for year 2 of 3 years, to Cincinnati Hospital to implement the Project SEARCH Technical Assistance Initiative, with a minimum 25% non-federal match requirement. Lisa Byrd seconded the motion.

**Beverly Colwell recused herself.*

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 made a motion to adjourn the meeting. It was seconded by Amanda Bergen. Chairperson I. Azell Reeves adjourned the meeting at 3:01 p.m.

ANNOUNCEMENT

Save The Date of Wednesday, November 12, from 10:00am- 2:00pm (Joint Forces Headquarters at 1636 Gold Star Drive, Raleigh, NC) for the Implementation Kick-off phase of the Emergency Preparedness Initiative Grant for Persons with Intellectual and Developmental Disabilities!

We are excited to have you come to Raleigh on **November 12** to hear about the Technical Plan and our Blueprint for moving forward as we implement all the ideas, gaps and solutions we have been discussing in our CMIST Committees for the past few months.

Thanks to the Grant funds, as provided by the North Carolina Council on Developmental Disabilities, and your support, feedback and guidance, ReadyNC now meets Web Content Accessibility Guidelines (WAG 2.0) international standards for accessibility for websites!

Please make sure your friends, family, neighbors and colleagues—the whole community-- know about Ready NC – got to <http://readync.org> and check out all the new features.

Signed,

NC Department of Public Safety
Division of Emergency Management



**Reaching the Summit of Success
Policy Seminar, Part 2
September 17, 2014**

Attending: Donna Gallagher, Sandy Ellsworth, Chris Egan, Ron Reeve, David Ingram, Holly Stiles, Adonis Brown, Deb Zuber, Holly Riddle, Stephanie Haines, Beverly Colwell, Shayna Simpson-Hall, Duncan Munn, Lisa Pluff, Beth Stalvey

Staff: Cindy Thomas and Karen Flippo

The objective of this meeting is to develop specific action steps associated with the 2 recommendations drafted at the June meeting.

Recommendation #1

Joan Johnson, Duncan Munn and Kelly Kelley will write a companion document to SB 744 that requests the Joint Legislative Education Oversight Committee to study the issues related to transition from high school to post secondary education and employment for individuals with intellectual disabilities.

Status: The Joint Legislative Oversight Committee has to develop a report by December. This report must include specific policy recommendations. Duncan contacted the committee and is going to talk with committee members about steps to take, people to talk with, and inform them about high quality and effective practices in the state.

Another activity underway is to create a coordinated statewide approach to PSE. Joan Johnson is chairing this effort, and a draft vision statement is being circulated for input. (Lisa Pluff will send the statement to Karen Flippo who will forward it to the Project's Policy Team). Joan requests feedback by Sept 29th.

Several individuals commented that the current vision statement should be more explicit about the path that students can take from PSE to employment, noting that PSE is a vehicle to help individuals build their careers.

Once the vision and values statements are complete, policy development will occur.

- The PSEA policy subcommittee will be guiding the policy development work. Beverly Colwell will be asked to join the policy committee to ensure the involvement of DPI.

- Broad public awareness about PSE and its relationship to employment is needed (consider using some of the footage from PSE videos).
- Legislators should be invited to visit the PSE programs in their 'backyard'.

Recommendation #2

Interagency collaboration

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 IDD.

Status: Holly R. and Sandy are working in the area of employment and will be drafting a position statement on employment. It was suggested that DHHSA develop a position statement on post secondary education. Holly R. noted that a position statement can be circulated across multiple departments with an agency-by-agency implementation plan. In the past, this occurred in the birth -3 area. The Council can potentially serve in a coordinating role. The Department of Commerce and OSHR should be included. Holly would like suggested language in October. This product will help with other work with DMA. Stephanie and Beverly feel that the paper can be elevated to senior leaders for their approval. Once the statement(s) are complete, implementation steps can be written. A simple MOU can define the objectives, roles and responsibilities of the state agencies. This action could tie into NC's response to the Workforce Innovation and Opportunities Act, which requires an MOU between the state agencies.

Clarity is needed regarding the purpose of the waiver. It is a tool to move employment forward. It would be helpful to prepare a policy statement about employment that can be presented to the waiver committee. The policy statement could be the precursor to a Governor's Executive Order on Employment.

POSTSECONDARY EDUCATION AND INTELLECTUAL DISABILITIES A Great Match for Students, Families, Colleges, Communities

When students with intellectual disabilities (ID) attend college, it offers them the chance to have the same opportunities as students without disabilities, in an inclusive learning environment. Everyone continues to develop between high school and adulthood, and skills gained in this time period propel learners to increased self-sufficiency, career success, and a higher quality of life. Regardless of intellectual ability, college alters life prospects and opportunities. The student with ID who participates in the choices and challenges offered in a college setting acquires key skills to make goals a reality. While a standard college degree may not be the end goal, the learning that is possible in college goes well beyond that one measure. In recent years, one of the most innovative, inclusive, collaborative, and outcome-oriented movements in the field of supports for persons with intellectual and developmental disabilities has been the development of postsecondary education (PSE) opportunities.

There is a great need to increase postsecondary education (PSE) options for students with intellectual disabilities in North Carolina. Between 2010 and 2013 there were 27,810 special education graduates

In recent years, one of the most innovative, inclusive, collaborative, and outcome-oriented movements in the field of supports for persons with intellectual and developmental disabilities has been the development of postsecondary education (PSE) opportunities.

from all North Carolina high schools. While this number reflects a broad range in types and levels of disabilities, as well as varying interests and goals on the part of these students, it is clear that the need for postsecondary education options far exceeds the supply. This shortage is worsened by the fact that some state agencies with responsibility for long-term support for young adults with disabilities, such as the Division of Mental Health, Developmental Disabilities and Substance Abuse Services, are currently operating at capacity and have extensive waiting lists for services. When other realities are considered, such as the growing number of young people identified with disabilities, the demographics of aging parents and caregivers, and the increasing limitations on public funding, it is evident that PSE is a welcome addition to the range of recommended

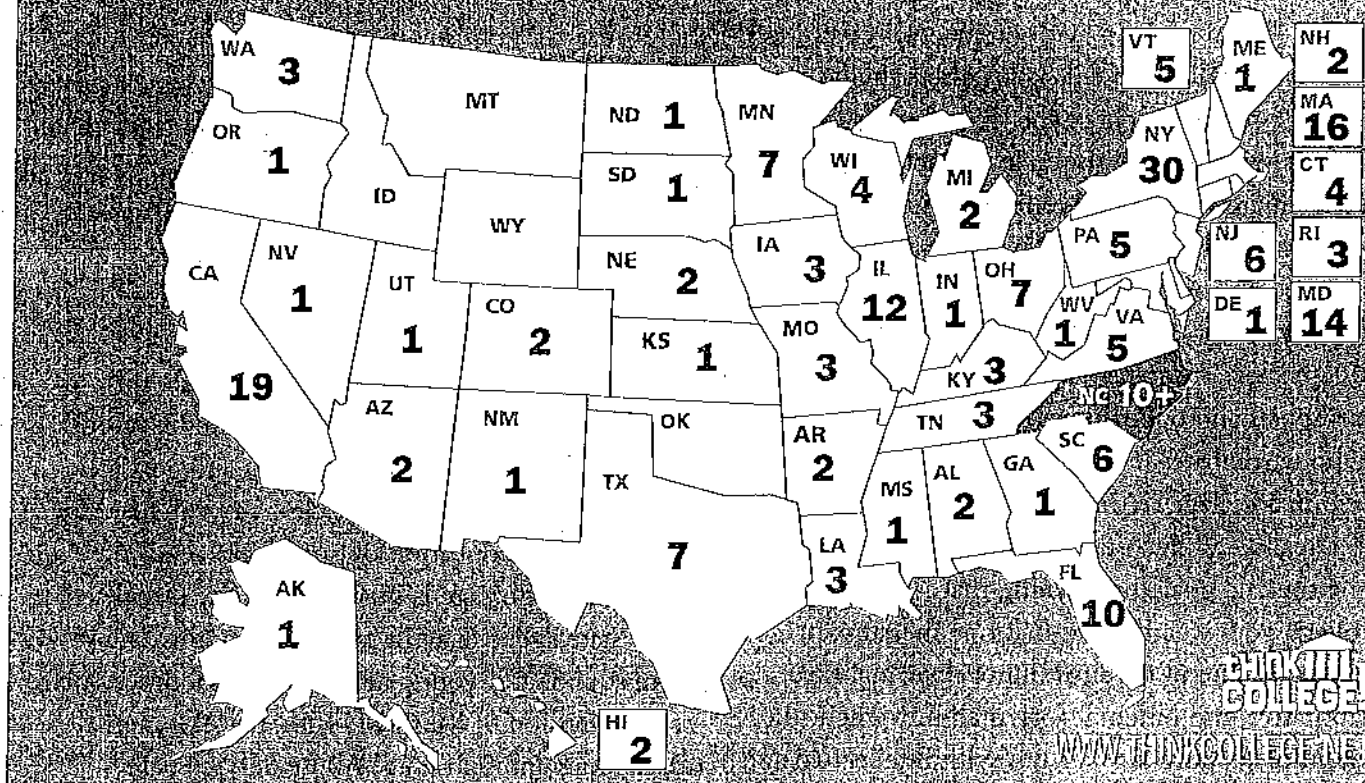


UNC

CAROLINA INSTITUTE FOR
DEVELOPMENTAL DISABILITIES



COLLEGE OPTIONS FOR PEOPLE WITH INTELLECTUAL DISABILITIES, JULY 2014 (N=219)



practices. A wide variety of education, advocacy, and planning organizations including Public Schools of North Carolina, the NC Institute of Medicine, the Division of MH/DD/SAS and the NC Council on Developmental Disabilities have recognized this need by highlighting PSE in their findings, policies, and proposed solutions.

There are several programs for students with ID in NC and others in development. They access a variety of public and private support including:

- Direct and in-kind support from the host schools
- Tuition and fee payments from families
- Start-up grants from NC General Assembly, US Dept. of Ed, and NC Council on Developmental Disabilities
- Existing state appropriations and Medicaid funds administered by state agencies such as the Division of Mental Health and Developmental Disabilities
- Natural or unpaid supports from community organizations and students without disabilities

IMPACT ON STUDENT OUTCOMES

A recent national longitudinal study on the transition of young adults with ID after high school graduation found some discouraging outcomes:

- » Low employment rates
- » Lower wages
- » Almost non-existent residential independence
- » High levels of social isolation
- » Increasing dependence on aging parents or siblings

While the movement toward PSE for persons with ID is still relatively young, and the number of graduates is relatively small, preliminary findings document that this approach has exciting potential for reversing such long-term trends. Process and outcome studies focused on students with disabilities, their peers on campus, their family members, and faculty at two NC universities illustrate several positive results from attending college.

Increased Employment

- » Western Carolina University (WCU): all current UP students had a paid work position in 2013-14 academic year
- » UNC-Greensboro: 71% of graduates secured paid employment compared with
- » 38.8% of students with ID in the National Longitudinal Transition Study

Residential Independence

- » UNC-Greensboro: 90% Of graduates living independently compared with
- » 36.3% of students with ID in the National Longitudinal Transition Study

Decreased Social Isolation

- » UNC-Greensboro: 86% of students involved in volunteer/community service
- » National Transition Study: 18.95%
- » UNC-Greensboro: 79% of students were members of community organizations compared with
- » 36% of students with ID in the National Longitudinal Transition Study
- » WCU: students participated in 82 different courses with 107 different professors

Decreased Dependence on Family and Public Support

- » UNC-Greensboro: after four years of participation in the program, student use of public and/or parental paid support had declined by 56%
- » WCU: Following one year of participation daily average support needed by students fell by 20.9%
- » WCU: Use of independent behavior scale ratings showed average age equivalent increased by 3 years, 2 months over a one-year period

Note: WCU data based on students enrolled in 2012/13 and 2013/14 school years

UNCG data based on graduates through 2013

Recent national studies reinforce NC experiences:

An analysis of data related to Vocational Rehabilitation clients with intellectual disabilities who attended college found that these students achieved a 58% employment rate with average weekly earnings of \$338 as compared to those with no college experience who had a 32% employment rate and average weekly earnings of \$195.

Another study found that 67% of students whose education included high school special education plus postsecondary education were employed without public or private support, while those with only high school experience achieved this goal at a rate of 29%.

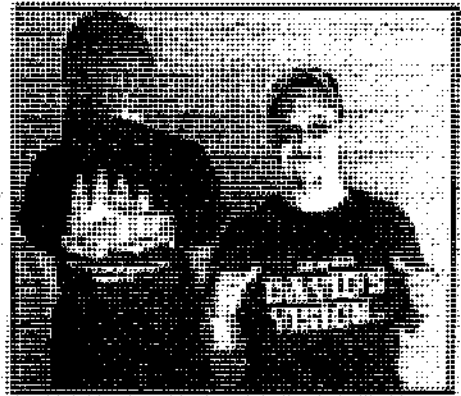
When students and their families begin to consider college, they can ask a few key questions to determine if the program is inclusive and focused on positive employment outcomes. These are both important considerations.

- Are there opportunities for academic learning with other college students?
- Is competitive employment after college a focus of the program?
- Do students participate as full members of the campus community?
- Are students allowed to make their own decisions and grow as young adults within the college structure?
- How much time do students with ID spend only with one another?

Perhaps the best way of discussing outcomes is the accomplishments of some North Carolina college students.

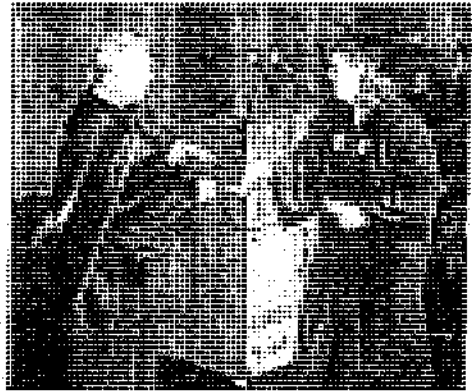
David Maennle – graduate, Western Carolina University, University Participant Program

David successfully completed internships and inclusive coursework related to emergency medical care and athletic injuries, helped in university research projects, presented at conferences and became a friend and mentor to other students with and without disabilities while attending WCU. Since graduating he has achieved two of his life goals- working at the county emergency medical services department and building his own log cabin.



Morgan Fink UNCG/Beyond Academics Student

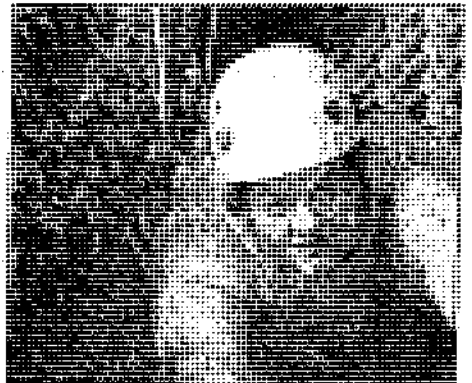
Morgan graduated in 2012 from UNCG through the Integrated Community Studies program and now lives independently in her own apartment in Greensboro. She works as a Zumba instructor and has a full life in her community outside of work, which includes volunteering as an assistant music therapist at a senior living facility, clogging with friends and being an active member of her church.



Maranda Seagle-graduate, Western Piedmont Community College, Accessible College Experience Program

Maranda successfully completed nine fully inclusive, modified curriculum courses and an internship with a concentration in Human Services while attending WPCC. Her career goal is to work as a Human Service aide. She says:

“Going to college has helped me to grow, and become a better person by learning to overcome my fears, and be more independent and self confident.”



To learn more about the options available in North Carolina, please refer to the website for the North Carolina Postsecondary Education Alliance at the Carolina Institute for Developmental Disabilities, University of North Carolina, Chapel Hill.

Visit www.cidd.unc.edu/psea/

Think College at the Institute for Community Inclusion, University of Massachusetts, Boston maintains a comprehensive website that shares a variety of resources on this subject.

Visit www.thinkcollege.net



With the passage of the Workforce Innovation and Opportunity Act (WIOA), Congress has reauthorized the Workforce Investment Act of 1998 (WIA), including the Rehabilitation Act, through 2020. Commenting on the bill's passage, President Obama stated that the bill "will help workers, including workers with disabilities, access employment, education, job-driven training, and support services that give them the chance to advance their careers and secure the good jobs of the future."

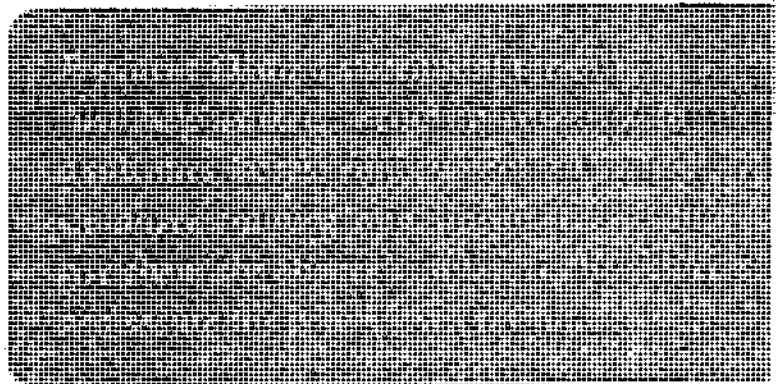
What does this 300-page legislation mean for people with disabilities? Major highlights include:

- ▶ A much larger role for public vocational rehabilitation (VR) as people with disabilities make the transition from school to adult life.
- ▶ Efforts intended to limit the use of sub-minimum wage.
- ▶ Required agreements between state VR systems and state Medicaid systems, and state intellectual and developmental disability (IDD) agencies.
- ▶ A definition of "customized employment" in federal statute, and an updated definition of "supported employment" that includes customized employment.
- ▶ A definition for "competitive integrated employment" as an optimal outcome.
- ▶ Enhanced roles and requirements for the general workforce system and One-Stop Career Centers in meeting the needs of people with disabilities.
- ▶ A number of disability agencies moving from the Department of Education (DOE) to the Department of Health and Human Services, including the Independent Living Program.
- ▶ Changes in performance measures, with potentially major implications for VR.

In general, WIOA has the potential for significant advancement in employment of people with disabilities. Here are some more details about the act's anticipated impact:

Increased VR role in transition: Each state's public VR program will now have a much larger role in the transition from school to adult life. Under WIOA, 15% of public VR funds must now be used for transition services, specifically pre-employment transition services as defined within the act.

These services include job exploration counseling, work-based learning experiences, counseling on post-secondary opportunities, workplace readiness training, and training on self-advocacy. Other services are also allowed if funds are available.



In addition, each local VR office must undertake pre-employment transition coordination activities, including working with schools and the local workforce development system to engage these entities in transition activities.

Limitations on sub-minimum wage: A new section has been added to the Rehabilitation Act, Section 511. It requires (as of 2016) a series of steps before an individual under the age of 24 can be placed in a job paying less than minimum wage (almost all of which are positions with community rehabilitation providers in sheltered workshops or enclaves). Section 511 also prohibits schools from contracting with sub-minimum wage providers.

Requirement for formal cooperative agreement between VR and state Medicaid and IDD agencies: WIOA requires that state public VR agencies have formal



cooperative agreements with the state agency responsible for administering the state Medicaid plan, and with state IDD agencies, with respect to the delivery of VR services, including extended services.

This means that VR must have in place agreements with those agencies responsible for long-term supports for people with disabilities, impacting in particular individuals with IDD, those with significant mental health issues, and those with other issues requiring long-term care funded by Medicaid.

Movement of federal programs: Under another proposed version of WIOA, the Rehabilitation Services Administration, or RSA (the parent agency of public VR), would have moved to the Office of Disability Employment Policy at the U.S. Department of Labor. While RSA will remain under the DOE, a number of other agencies will be moving from DOE to the Administration for Community Living (ACL) at the Department of Health and Human Services. This is where the Administration on Intellectual and Developmental Disabilities, and the Center for Aging and Disability, are currently based.

Agencies moving to the ACL include the National Institute on Disability and Rehabilitation Research, operating under a new name (the National Institute on Disability, Independent Living, and Rehabilitation Research), and the Independent Living Program, which will be moving from RSA to ACL.

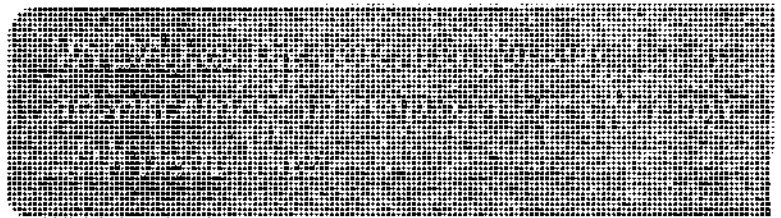
Competitive integrated employment defined: The Rehabilitation Act previously used the term *competitive employment* extensively, but never defined it (although it was defined in regulations). The WIOA now defines *competitive integrated employment* as full-time or part-time work at minimum wage or higher, with wages and benefits similar to those without disabilities performing the same work, and fully integrated with co-workers without disabilities. This is considered the optimal outcome under WIOA.

Customized employment part of Rehabilitation Act: There is now a definition of *customized employment* in federal statute, defined as “competitive integrated employment, for an individual with a significant disability, that is based on an individualized determination of the strengths, needs, and interests of the individual with a significant disability,” “designed to meet the specific abilities of the individual with a significant disability and the business needs of the employer,” and “carried out through flexible strategies.” As a result, customized employment is now among the available services from public VR nationally.

Changes in definition of supported employment: The definition for *supported employment* has been modified. The adapted definition makes it clear that supported employment is integrated competitive employment, or an individual working on a short-term basis in an integrated employment setting towards integrated competitive employment.

In addition, customized employment is now included within the definition of supported employment. Also, the standard post-employment support services under supported employment have been extended from 18 to 24 months.

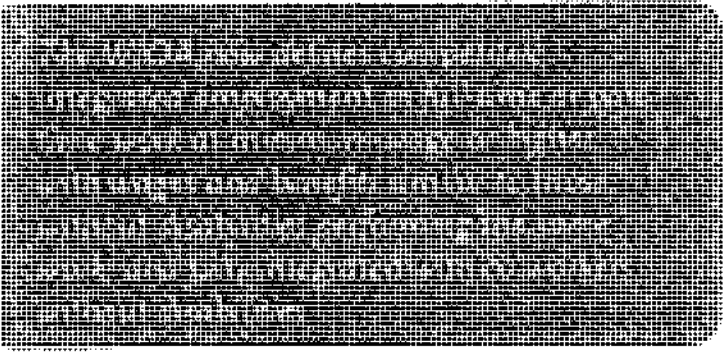
Focus of supported employment state grants on youth: While supported employment can be funded by public VR through general VR funds (\$3 billion in 2014), under the supported employment state grant program, funds are available to states to supplement supported employment services funded via the general VR funding (in 2014, the total supported employment state grant allocation was \$27 million).



Under WIOA, half of the money that states receive under the supported employment state grants will now have to be used to support youth with the most significant disabilities (up to age 24), and these youth may receive extended services (i.e., ongoing supports to maintain an individual in supported employment) for up to four years. The definition of “youth with the most significant disabilities” in the implementing regulations will be a key issue.

Technical assistance for post-secondary education: The new law allows the RSA commissioner to fund technical assistance to “better enable individuals with intellectual disabilities and other individuals with disabilities to participate in postsecondary educational experiences and to obtain and retain competitive integrated employment.”

Role of VR in One-Stop system: In 1998, WIA established a national network of One-Stop Career Centers, where assistance with employment and training is available to any individual (including people with disabilities). There are currently 1,700 One-Stops (known as American Job Centers) across the United States.



Under WIA, all One-Stop partners had representation on the state and local workforce boards. Under WIOA, this is no longer the case.

However, WIOA designates certain programs as "core programs" in the workforce development system. Public VR is among those designated as a core program, and as such will continue to be a mandatory member of state and local workforce boards. Other core programs are Adult, Dislocated Worker, and Youth workforce investment programs, the state Employment Service (Wagner-Peyser), and Adult Education and Literacy.

Changes in performance measures: Under WIOA, the core programs are subject to common indicators of performance. For adults, these include a) entering and retaining employment, b) median earnings, c) obtaining an educational credential (high school diploma, post-secondary credential), d) skill gains via post-secondary education and training, and e) effectiveness in serving employers.

These performance measures are a new requirement for state VR programs, and the changes in current VR performance indicators will be a critical implementation issue.

Funding of One-Stop infrastructure: As noted, public VR remains a mandated One-Stop partner under WIOA. One-Stops are overseen by a local workforce board, of which public VR is a member. A major issue under the WIA was payment of the cost of the One-Stop infrastructure by One-Stop partners, which WIA was unclear on. WIOA attempts to resolve this issue.

Under the new law, payment for One-Stop infrastructure and other costs will be determined at the local board level. However, if agreement cannot be reached, the governor will develop the requirements for payment of One-Stop costs by One-Stop partners. Under WIOA, public VR can be required to use a maximum of 0.75% of its funds for One-Stop infrastructure, which will gradually increase to a maximum of 1.5% after five years.

Increased emphasis on role of general workforce

development system: A number of provisions in WIOA emphasize and increase the requirements for the general workforce development system and One-Stop Career Centers to meet the needs of job seekers with disabilities.

These include:

- ▶ Local workforce development boards will have to ensure that there are sufficient service providers in the local area with expertise in assisting individuals with disabilities with their career and training needs.
- ▶ WIOA explicitly states that state and local workforce development boards, which provide oversight of the workforce development system, may include (as members) community organizations that provide or support competitive integrated employment for individuals with disabilities.
- ▶ Employment Networks (under the Social Security Administration's Ticket to Work program) are specified as optional One-Stop partners.
- ▶ Among the specified responsibilities of the state workforce development board is the development of strategies to support career pathways for individuals with disabilities to enter and retain employment.
- ▶ WIOA states that local workforce development boards may have standing committees. Among the three standing committees specified in the legislation is one on the provision of services for individuals with disabilities. This could serve as an important forum to influence the ability of the workforce system to meet the needs of job seekers with significant disabilities.
- ▶ Annual assessment of physical and programmatic access of One-Stop Career Centers for people with disabilities is now required by federal statute.
- ▶ Disability is to be a consideration in development of state performance requirements in use of workforce development funds.
- ▶ The obligation of the general workforce system to serve youth with disabilities is emphasized within WIOA in multiple places.
- ▶ Under WIOA, governors may reserve up to 15% of general workforce development funds for statewide employment and training activities (the remainder of funds go to local workforce development areas). Among the allowable activities is improving coordination of employment and training activities with programs for individuals with disabilities. Programs under state IDD agencies, State Independent Living Councils, and centers for independent living are cited as specific entities this would apply to. WIOA also states that local workforce development funds, overseen by local workforce development boards, may be used for similar activities.

WHAT'S NEXT

Implementation of WIOA will occur over the next couple of years. A major next step will be publication of proposed regulations for public comment by mid-January 2015. These regulations will provide details on the implantation of WIOA. All major provisions of WIOA, except as specifically noted in the legislation, will go into effect on July 1, 2015.

FOR FURTHER INFORMATION

For more on the WIOA, check out the U.S. Department of Labor's Training and Employment Notice:

http://wdr.doleta.gov/directives/corr_doc.cfm?DOCN=3556

Information specific to changes in the Rehabilitation Act can be found on the Department of Education website:

www2.ed.gov/about/offices/list/osers/rsa/publications/wioa-changes-to-rehab-act.pdf

FULL BILL TEXT:

<https://beta.congress.gov/bill/113th-congress/house-bill/803/text>

FOR MORE INFORMATION

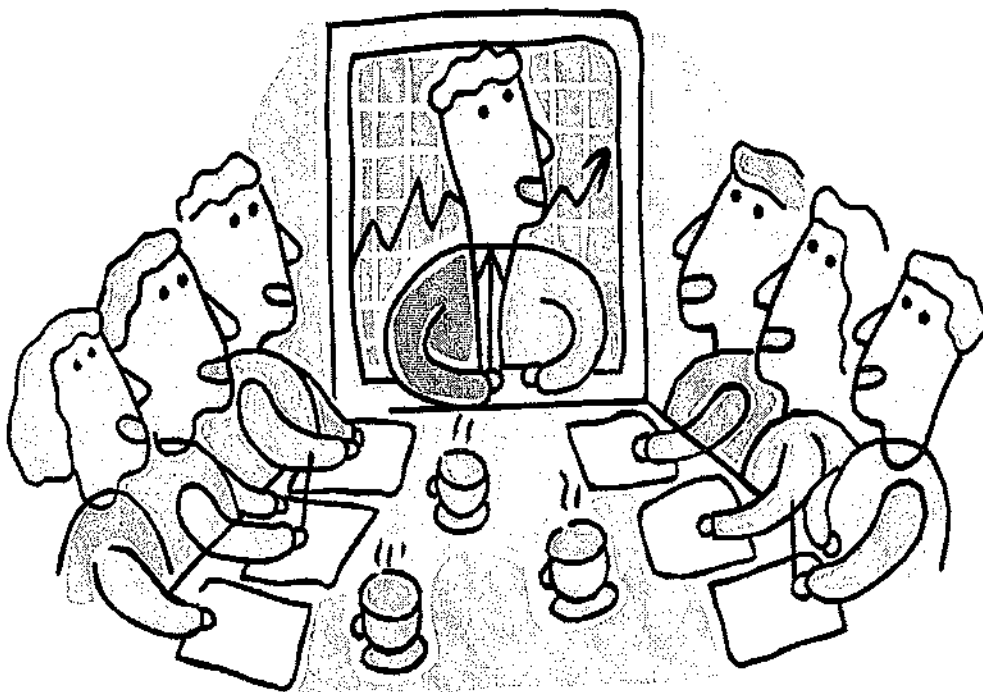
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Institute for Community Inclusion (ICI)
UMass Boston
100 Morrissey Blvd.
Boston, MA 02125
Phone: 617.287.4308
david.hoff@umb.edu

ABOUT THE AUTHOR

David Hoff is a program director at the Institute for Community Inclusion at UMass Boston. He has extensive experience in analysis of legislation and public policy from a disability perspective. He is the past president of APSE: the Association of People Supporting EmploymentFirst, and co-chairs the APSE Public Policy Committee. His background also includes three years as an administrator for a local workforce board.



DISABILITY SYSTEMS CHANGE COMMITTEE



North Carolina Council on Developmental Disabilities

Disability Systems Change Committee Agenda - DRAFT

November 20, 2014

09:45 a.m. – 11:45 a.m.

Hilton Garden Inn Cary, NC

09:45 a.m. – 09:55 a.m.	Introduction <ul style="list-style-type: none">• Welcome• Approval of August Minutes	<i>Samuel Miller</i>
09:55 a.m. – 10:05 a.m.	Fiscal Update	<i>Yadira Vasquez, NCCDD</i>
10:05 a.m. – 10:20 a.m.	Recommendations for Funding from Selection Committee <ul style="list-style-type: none">• Guardianship	<i>Crystal Bowe Steve Strom</i>
Initiative Updates		
10:20 a.m. – 10:35 a.m.	<ul style="list-style-type: none">• Stakeholder Engagement	<i>Kelly Friedlander, NASDDDS</i>
10:35 a.m. – 10:50 a.m.	<ul style="list-style-type: none">• Adult Care Homes	<i>Cas Shearin, Disability Rights NC</i>
10:50 a.m. – 11:05 a.m.	<ul style="list-style-type: none">• Medical/Health Home	<i>Karen Luken, Easter Seals UCP</i>
11:05 a.m. – 11:15 p.m.	<ul style="list-style-type: none">• Break	
11:15 a.m. – 11:40 a.m.	<ul style="list-style-type: none">• Agency of Choice Model Intro• Presentation of Agency of Choice	<i>Beth Stalvey Dakota & Kerri Eaker</i>
11:40 a.m. – 11:45 a.m.	Wrap Up and Reminders <ul style="list-style-type: none">• Completion of Financial Forms	<i>Samuel Miller</i>

Disability Systems Change Committee

Samuel Miller, Ph.D.: Chair
Kelly Woodall Beauchamp
Crystal Bowe, M.D.
Christina Carter; Alternate: Andrea Misenheimer
Eric Chavis
Robin Cummings, M.D.; Alternate: Deb Goda
Kerri Bennett Eaker
Representative Verla Insko
Renate Macchirole
Wing Ng, M.D.
Joe Piven, M.D.; Alternate: Deb Zuver
Courtney Cantrell; Alternate: Sandy Ellsworth
Vicki Smith
Peggy Terhune, Ph.D.
Aldona Was, M.D., Secretary;
Alternate: Dave Richard
Staff: Steve Strom

Parent of Child with DD
Individual with DD
Parent of Child with DD
Non-Profit Agency
Individual with DD
Agency: Deputy Sec., DHHS
Parent of Child with DD
Other: Legislative
Public at Large
Parent of Child with DD
Agency: Carolina Institute for DD
Agency: Div. of MH/DD/SAS
Agency: Disability Rights NC
Local Non-Governmental Agency
Agency: Secretary, DHHS

Disabilities Systems Change Committee

DRAFT MINUTES

Thursday, August 16, 2014

12:30 p.m. to 3:00 p.m.

Hilton North Raleigh/Midtown, Raleigh, NC

Members Present: Crystal Bowe, Deborah Carroll, Christina Carter, Eric Chavis, Sandy Ellsworth, Wing Ng, Dave Richard, Vicki Smith, Peggy Terhune, Deb Zuver

Members Absent: Samuel Miller, Kelly Woodall Beauchamp, Kerri Bennett Eaker, Verla Insko

Staff in Attendance: Steve Strom, JoAnn Toomey, John McCallum, Jennifer Bosk, Chris Egan

Guests: Beth Stalvey, Kelly Friedlander, Cas Shearin, Karen Luken, Sally Abril, John McCallum

Introduction:

Welcome: In Samuel Miller's absence, Dr. Crystal Bowe chaired the August Disability Systems Change Committee and called the meeting to order, welcomed all members, and provided an opportunity for guests to introduce themselves.

Dr. Bowe called for a motion to approve the May 2014 Disability Systems Change Committee minutes. Eric Chavis made a motion to approve the minutes. Dave Richard seconded the motion. Motion carried.

Fiscal Updates:

- 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*".

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

Policy Report and Updates from the NC General Assembly Short Session

Dr. Beth Stalvey, policy analyst contractor, presented an overview of the NC

General Assembly policy that was enacted during the short session. The work of the Disability Systems Change initiatives coincided with the major policy updates that were debated during the short session. Committee members had many questions on how to continue advocating for changes that would serve the citizens of North Carolina. Dr. Stalvey suggested that members join a monthly policy call on Medicaid reform so that the members can be better informed prior to the General Assembly reconvening in January 2015. Dr. Bowe and the members thanked Dr. Stalvey for her presentation.

Initiative Updates and motions for continuation funding:

- Kelly Friedlander, contractor for NASDDDS, provided an update on the current initiative, "Medicaid Reform Stakeholder Engagement". The work of the contractor had been slowed due to the General Assembly debating Medicaid reform. Ms. Friedlander presented the plan for the remainder of Year 1 with a suggestion to the committee to do a no cost extension for 30 days. Following the update and a review of the revised work plan for the remainder of year 1, Dr. Bowe asked for a motion on a no cost extension and a revision of the year 2 contract period. Vicki Smith made a motion to rescind the motion approved in May for continuation funding of Year 2 (of 3) to the National Association of State Directors of Developmental Disabilities Services (NASDDDS) for the Enhancing Disability Stakeholder Engagement in Managed Long-Term Services/Supports and Primary/Acute Care Systems Coordination Initiative. The Council now approves a no-cost extension for Year 1 (of 3) to end on October 31, 2014. Year 2 (of 3) continuation funding is approved for up to \$160,000 (Beginning November 1, 2014 to October 31, 2015). Match requirement is waived for this initiative. Eric Chavis seconded the motion. Motion was carried.
- Cas Shearin, Disability Rights NC, provided an update on the "Adult Care Home Transition" initiative. Members were pleased with the number of residents identified by Disability Rights in the Adult Care Homes who were candidates to move into the community. Following a question and answer session, Dr. Bowe 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 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.
- Following the review of the initiatives, Dr. Bowe asked Council staff member, Steve Strom, to present an update on the Guardianship RFA. Before Mr. Strom presented an overview of the Guardianship RFA, Dr. Bowe asked that

anyone on the Disability Systems Change committee who had a potential conflict of interest or may have interest in applying for the grant to sign the appropriate form and leave the room during the discussion. Dr. Bowe also asked that all visitors to exit the room during the presentation. Committee members Dr. Peggy Terhune, Deb Zuber, and Vicki Smith recused themselves from the presentation and left the room during the discussion. Each of those members worked for an agency that had an interest in applying for the grant. Mr. Strom presented the research behind the RFA and the work that had already been done by DHHS at the direction of the General Assembly. Following a question and comment period by the committee, Dr. Bowe asked for a motion. Eric Chavis made a motion to grant NCCDD staff authority to release the Request for Application (RFA) for the "Guardianship Initiative". Dr. Wing Ng seconded the motion. The motion was carried.

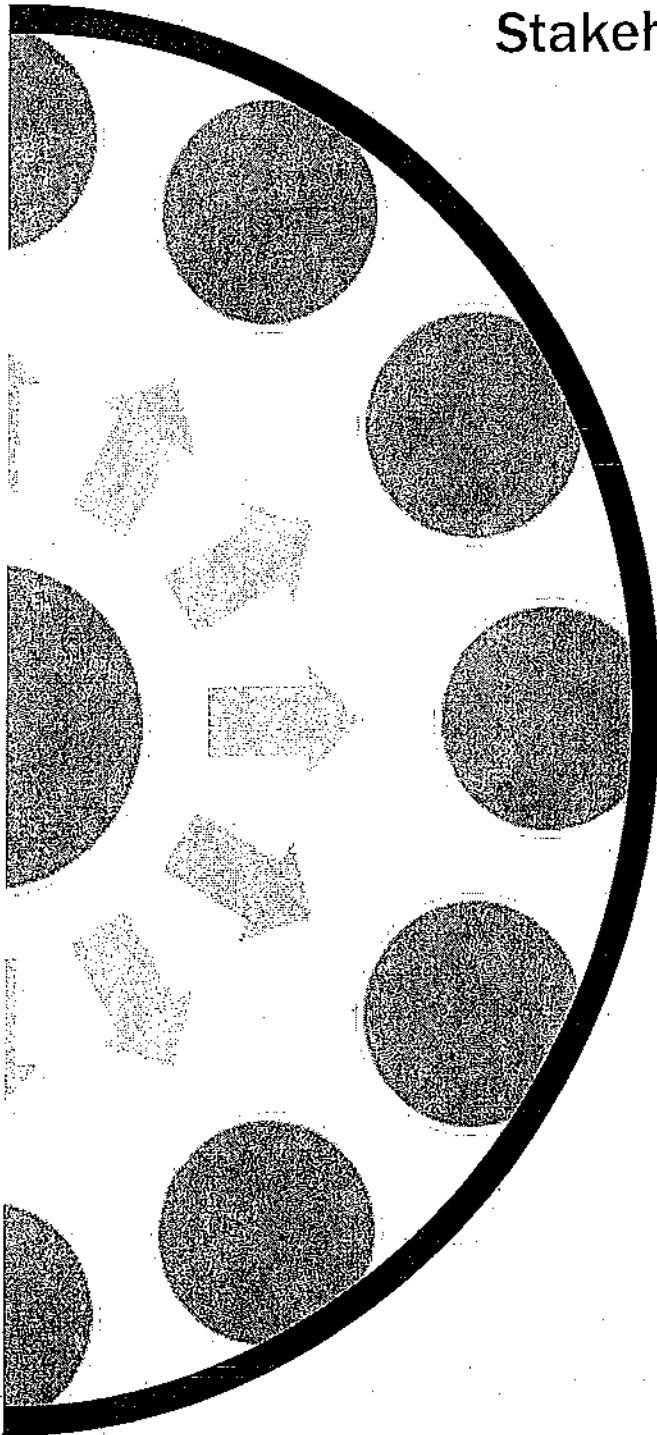
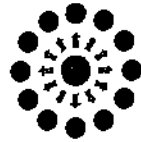
- Dr. Bowe asked Council staff, Steve Strom, to provide an update on the work of the selection committee and their work on recommending a vendor for the Council's communications needs. Mr. Strom informed the committee that two vendors had responded to the scope of work released by the Council, The Wallace Group and O'Neill Communications. Based on the review of each vendor's responses to the scope of work, the committee recommended O'Neill Communications is the selected vendor. Dr. Bowe called for a motion. Eric Chavis made a motion that the O'Neill Communications, Inc. be approved as the contractor selected for the NCCDD Communications contract. Funding is approved for up to \$135,000 with a required minimum of 25% non-federal matching funds, for year one of up to 3 years from October 1, 2014 to September 30, 2015. Dave Richard seconded the motion. Motion was carried.

Wrap Up and Reminders:

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

The SEG Way to a Healthy North Carolina

North Carolina Stakeholder Engagement Group Initiative



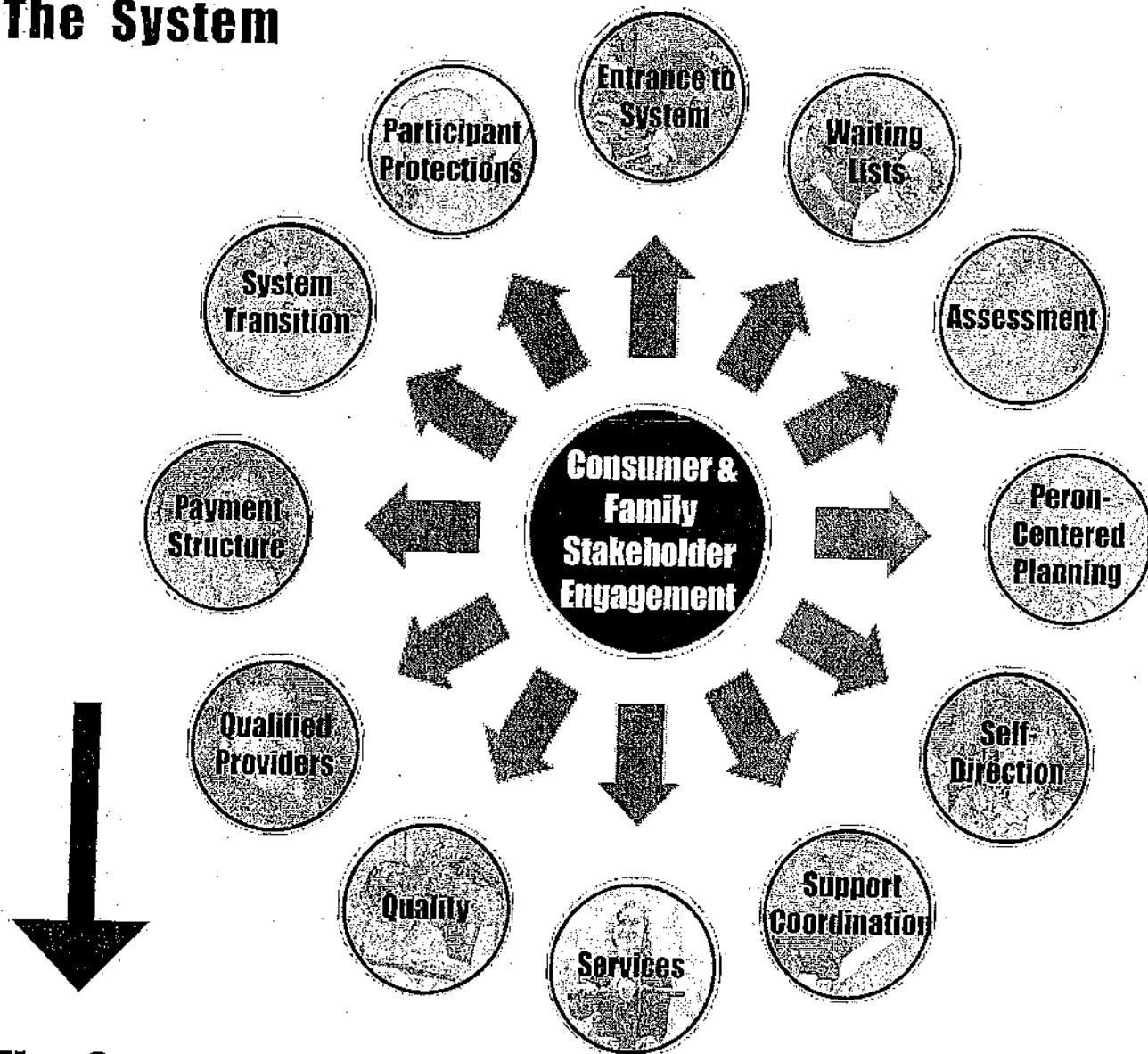
Outcomes and
Expectations for
Managed Long Term
Services and Supports

3125 Poplarwood Court Suite 200 • Raleigh, NC 27604 • 919.850.2901

Co-Chairs: Michael Mayer, Ph.D., President of National Alliance of Mental Illness (NAMI-NC)
and Ron Reeve, Chairman, North Carolina Council on Developmental Disabilities (NCCDD)

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@cra.cc or Ron Reeve, Chairman of the North Carolina Council on Developmental Disabilities (NCCDD) at rr77777@carolina.rr.com

The SEG Way to a Healthy North Carolina North Carolina Stakeholder Engagement

Talking Points

Who is the "Stakeholder Engagement Group"?

We are currently the only group in North Carolina who is made up of only individuals receiving services and their family members and *no provider organizations with a potential for a conflict of interest*. We are called "Stakeholders" because we are affected by the decisions the state makes about long term care. We are called "cross-disability" because we represent developmental disabilities, mental health, addictive diseases, individuals with physical disabilities, and family caregivers. Our members came from all areas of the state.

What do we Want to do With This Information?

We want the leaders at DHHS, at Medicaid, and our state legislators to know what is important to us! As they develop plans for consolidating LME/MCOs, as they make plans for medical care, as they make plans for how we get services, we hope they will seriously consider what we have said, that they will carefully look at these outcomes and expectations, and discuss real ways to make improvements today and in the future that make these outcomes and expectations reality.

What Did we Discuss?

Our group very quickly defined five outcomes that were important to individuals and families from all disability groups. We want a system that helps us be more independent—a system that: 1) has no waiting lists; 2) where individuals have jobs in integrated employment settings; 3) that individuals live inclusively in their communities; 4) that people with disabilities have the ability to develop assets, and; 5) that the system is accountable for meaningful outcomes. We spent a lot of time

discussing our important expectations of the system such as: getting services for the first time, assessment, support coordination, assuring the availability of qualified providers, and protecting our rights.

Why Did We Get Together?

North Carolina wants to make changes to the way Medicaid services are delivered. We met to develop a consensus about what we want from a long term care system—the values, principles, needs, and outcomes important to us – and then to communicate that consensus to key decision makers. Because the results of the system re-design was our focus we did not focus on "how" the state should get there - such as who is in charge and how the money flows. We met for six days over the past six months and learned from state and national experts about how Medicaid works and the expectations of the Federal Government, options for what the future system might look like, and how we could best get our consensus message to the right people – or, put another way, "get our voices heard".

How do we Talk About the Handout?

Here we are – the "Consumer and Family Stakeholder" – in the middle and at the heart of the entire system! We talked about 13 specific areas of the system that were important to our ability to get the supports and services we need. Of course all of these things help us get to our outcomes – no waiting lists, integrated employment, inclusive living, asset development, and an accountable system. We hope you will use these materials too to talk about your experiences and expectations. Nothing about us without us!



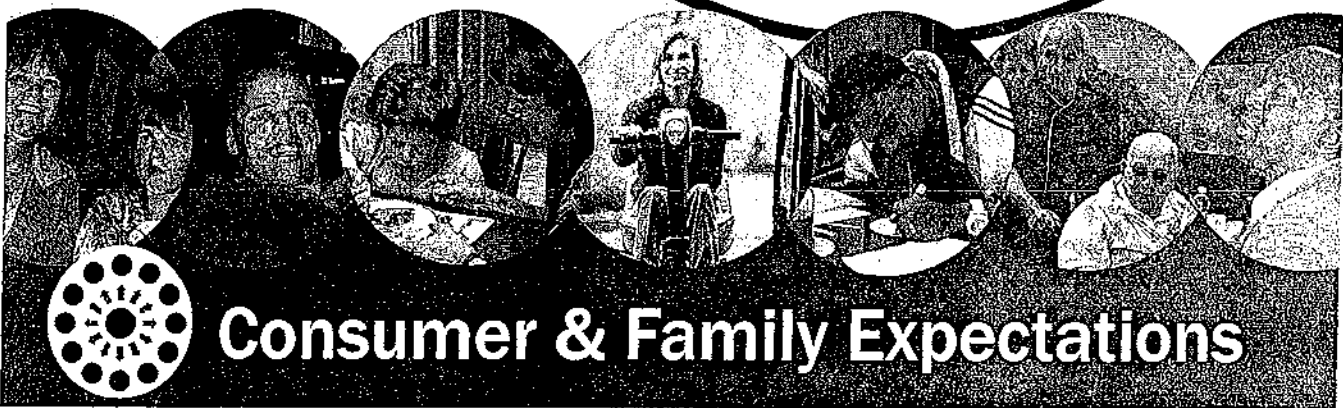
Stakeholder Engagement Group (SEG): Meaningful Outcomes for Managed Long Term Services and Supports

We are a unique group comprised entirely of individuals receiving services and family members. We are the only cross-disability stakeholder group representing developmental disabilities, mental health, addictive diseases, individuals with physical disabilities, and family caregivers.

The Stakeholder Engagement Group worked for six months to reach consensus on outcomes - "WHAT" is needed in the long-term support system, rather than "HOW" to get there in terms of administration.

The outcomes important in a person's life are: **inclusive living, integrated employment, asset development, no waiting lists, and an accountable system.**

Stakeholders identified 13 common areas of the long term services and support system and their expectations for each



Entrance into the System

- Utilize only one application to get all public services.
- Employ a person who helps with enrollment and has nothing to gain from the choice of services.
- Maintain a similar array of services across the state.
- Allow individuals to move from one part of the state to another and keep services.

Waiting Lists

- Provide everyone with the service they need, at the right amount, at the right time and in the right place.
- Serve everyone - no individual waits for services.
- Move people from the waiting list based on urgency and severity of need.

Assessment

- Guide but do not predict what services are received.
- Build on what is important to person and is working in their life.
- Utilize a whole person approach that addresses individual life needs.
- Implement process for ongoing review and development as person will change and grow.
- Require consistent process and tools across the state and MCOs.

Self-Direction

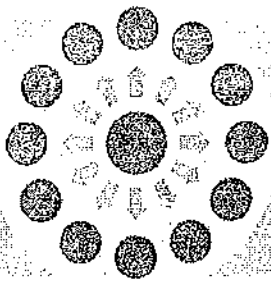
- Individual control and flexibility of funds to meet needs with services within an allowable budget.
- Educate person and providers about self-direction and support them to use it.
- Provide financial and business management supports.

Person-centered Planning

- Drive plan by the personal goals and desired outcomes as indicated by the individual
- Create an on-going living document that changes as person changes - not just paper
- Involve team that is valued and is selected by the person to include family, support professionals planners, and any others.
- Allow the plan to drive the authorization of services - the authorizers do not drive the plan.

Support Coordination

- Develop a personal and consistent relationship between the person and the support coordinator.
- Require coordinators to have a working (best practice) knowledge of local resources and how to connect people to communities.
- Advocate for individual rights, responsibilities, and choices in an independent appeals process.



Our Partners: The Stakeholder Engagement Group is supported by the North Carolina Department of Health and Human Services, (DHHS), the North Carolina Council on Developmental Disabilities (NCCDD), the National Association of State Directors of Developmental Disabilities Services (NASDDDS) – the professional association for the State’s I/DD state authority, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMH/DD/SAS).

Services

- Promote independence and community inclusion through all services.
- Make employment and careers the preferred outcome of all education and services (“Employment First”).
- Pay for the desired outcomes, not just units of service.
- Allow flexibility to meet the unique needs of each person and family.
- Make outcome expectations and service access consistent across the state.

Quality

- Focus the Comprehensive Quality Strategy on the valued outcomes versus the quality of the process.
- Involve participants and their families in independent oversight.
- Communicate the results of the oversight process in a timely, accurate, and is easily accessible and understood formats.
- Evaluate success in all areas of a person’s life through meaningful outcome measures.
- Enforce requirements and maintain standards statewide.

Qualified Providers

- Provide participant choice by having multiple providers in each specialty area of service.
- Require provider to be qualified, trained and monitored to achieve outcomes for people they support.
- Recruit and retain providers by paying for the actual costs and rewarding good performance.
- Encourage certification and recognition of direct support workers.

Payment Structure

- Move from fee-for-service to incentive payments for outcomes; assist providers to change business models.
- Allow flexibility to better match services with individual needs.
- Share costs of services and the outcomes providers report with consumers.
- Provide timely payments for approved services and outcomes to all providers.

System Transition

- Involve cross disability consumers and families in all levels of strategy development and implementation through recognized advisory boards; provide sufficient time for review of concepts and proposals.
- Determine readiness of the state; managed care entities; providers, consumers, families for new management structures. Readiness includes enough staff, the right skills competencies, the right values.
- Implement and standardize operational and IT systems across the state to assure continuity of service.
- Communicate information to enrolled participants and families – and to those not yet enrolled – about the new program, their rights and responsibilities.
- Develop a process for transferring participants to new system to prevent gaps in service; plan for rapid identification and resolution of problems.

Participant Protections

- Educate individuals, families and support providers about participants rights and responsibilities.
- Assure safety and support for individuals and families when reporting concerns or making claims.
- Investigate, track, and provide prompt follow up on critical incidents (including abuse, neglect and exploitation) and make results clear to all.
- Continue services during disputes and appeals.



Stakeholder Involvement “Nothing About Us Without Us”

- Sustain cross-disability, culturally diverse, and geographically representative consumer and family involvement in state and LME/MCO governance structures
- Provide funds directly to independent peer and family networks and consumer/family advisory committees to involve members, educate and disseminate information.

Spreading the Word

Possible Activities



- Present this information to the local groups and organizations in which you are a member. Share the information you learned about Medicaid and this consensus agreement in these meetings.



- Write a letter to your local LME/MCO telling them about the Stakeholder Engagement Group and your agreement with the consensus statements of the Stakeholder Engagement Group. This letter could be from you, from an advocacy group you belong to, from friends, from family members, or all of these. *If you would like a sample letter, please contact the DD Council Office.*



- Write a letter to your State Representative or Senator, LME/MCO provider, agency provider and/or local organizations, telling them about your agreement with the Stakeholder Engagement Group statements. Again, this letter could be from you, from an advocacy group you belong to, from friends, from family members, or all of these. *If you would like a sample letter, please contact the DD Council Office.*



- Set up a meeting with your State Representative or Senator, LME/MCO provider, agency provider and/or local organizations telling them about your agreement with the Stakeholder Engagement Group, and the outcomes and expectations from the group. You could meet alone, with friends or family members, or with several members of an advocacy group you participate in. You can give them this information so they have it in their hands.



- Take this information to your local CFAC group and share it with them and encourage them to become active in supporting the work of the Stakeholder Engagement Group.

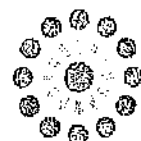


- Tell your local paper about your participation in this group and why it is so important to people who have disabilities and their families. If you are interested in getting the information into your local paper, *let NCCDD know and we can help you with a sample.*

The SEG Way to a Healthy North Carolina North Carolina Stakeholder Engagement

Group Members

- — Jean Anderson, *Stanfield, NC*
Governor's Advisory Council on Brain Injury member;
Partners in Policymaking graduate; BIANC member
- — Crystal Bowe, *Belmont, NC*
NCCDD member; Family Physician; Family
member with I/DD
- — Chris Campu, *Raleigh, NC*
NC State Student; Governors Institute on Substance Abuse
and Mental Health member; Founder of the Collegiate
Recovery Community at NC State; Peer Support for
Substance Abuse
- — Eric Chavis, *Greensboro, NC*
NCCDD member; Arc of Greensboro member
- — Ben Coggins, *Gastonia, NC*
Partners Behavioral Health CFAC member, State CFAC
member, Partner's BHM board member; Peer Support
Specialist
- — Anna Cunningham, *Raleigh, NC*
NCCDD member; NC State CFAC member; Alliance
CFAC member; NC Commission on MHDDSA member;
The Power of the Dream, Inc / HANDmeUPs president;
First in Families Lifetime Connections charter member;
FIFNC member; Parent of 2 daughters with I/DD
- — Jonathan Ellis, *Murfreesboro, NC*
NCCDD member; FIFNC member; UCEDD Keller
Institute on DD member; Advocacy Ambassador NCCDD
- — Monica Foster, *Landis, NC*
The Life Beyond Limits Coach® & Inclusionista, founder;
Professional Blogger/Writer for the Riot; Advocacy
Ambassador NCCDD, Arc of NC and US, member; Spina
Bifida Association of the Carolina's member
- — Sue Guy, *Goldsboro, NC*
State CFAC Chair; Local Consumer Family Advisory
Committee member
- — Merlie Jackson, *North Wilkesboro, NC*
Smokey Mountain CFAC member; FIFNC member; High
Country First-In-Families member; Parent of a daughter
with I/DD
- — Valerie King, *Yadainville, NC*
Mended Little Hearts National Advocacy chair, Congenital
Heart Public Health Consortium member; National Birth
Defects Prevention Network, member; Pediatric Congenital
Heart Association, member; Parent of daughter with I/DD
- — Susie Lenfestey, *Lenior, NC*
The Arc NC board member; The Breakfast Club Org
Co-founder and President
- — Mike Mayer, *Mebane, NC*
NAMI-NC President; Arc NC member; Cardinal
Innovations Best Practices Workgroup; Seeing Is Believing
Initiative Director; Self Advocacy Ambassador Initiative
Advisor; Family member of a person with a disability
- — Pat McGinnis, *Marion, NC*
PAIMI Vice Chair; DRNC member; Smoky CFAC Chair;
NCCANSO member; NCMHCO member
- — Sam Miller, *Greensboro, NC*
NCCDD member; Arc of Greensboro member; UNCG
Associate Dean of the School of Education; Father of a
son with I/DD
- — Matt Potter, *Pfafftown, NC*
Centerpoint Humans Services board of directors member;
Wake Forest Athletic Department consultant; CRA
Ambassador
- — Ron Reeve, *Charlotte, NC*
NCCDD Chair; Father of a son with I/DD
- — Tony Sowards, *Raleigh, NC*
DWAC member; Sunrise Recovery Center, board member;
Oxford House Outreach Worker; A person in long-term
recovery
- — Nessie Siler, *Manteo, NC*
Partners in Policymaking graduate; Pathways to an
Accessible College Experience at College of the Albemarle
in Dare Co., Mentor; Monarch Voices of Power, Facilitator
- — Teresa Staley, *Greensboro, NC*
NC Independent Living Centers, board member; Joy
A. Shabazz Center for Independent Living, board
member



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





**NC Council on Developmental Disabilities
Five Year State Plan Amendments
Year 4 of 5: 10/1/14 - 9/30/15**

Public Input Period: August 16, 2014 - October 31, 2014

**NCCDD Approves Draft Amendments Process
Public Input Release
Public Input Ends
NCCDD Review Public Input
Amendments Submission to AIDD**

**August 16, 2014
September 15, 2014
October 31, 2014
November 21, 2014
December 31, 2014**

State Plan Input Results

Along with solicitations distributed to the NCCDD mailing list through Constant Contact, large print and Braille copies of the NCCDD Five Year State Plan and request for input was mailed for display at multiple NCCDD libraries and state agencies.

The NCCDD received feedback from three people each of them in relation to costs of services for family members with developmental disabilities. One respondent specifically praised the NCCDD and indicated the need for more programs like the Jean Wolff-Rossi Fund.

Technical edits of the NCCDD Five - Year State Plan includes Membership and staff updates, Designated State Agency update, Public Input and Review, and Projected Budget, (Refer September 5 communication from Sara Newell, AIDD Program Specialist)

North Carolina Council
on Developmental Disabilities



Council News

creating awareness and understanding



State Plan Is Open for Public Comment

The NC Council on Developmental Disabilities' (NCCDD) 2011 - 2016 Five -Year State Plan tells the public how services and programs for individuals with I/DD and their families should look by 2016. The plan provides guidance to the Council on how it spends its resources. Each year, Councils are required by the Administration on Intellectual and Developmental Disabilities (AIDD) to review and update their plan if necessary.

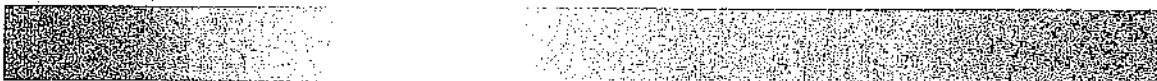
The NCCDD invites the public to review the current state plan, including the goals and objectives section on pages 25 - 50, and provide feedback and suggestions on how the NCCDD proposes to spend its resources. Upon request, the state plan is also available in Braille format, large print, and on compact disc (CD) by calling (919) 850-7901 or 1-800-357-6916/TTY.

[Click Here for More Details](#)

[Review the State Plan in PDF format](#)

[Review the State Plan in Microsoft Word format](#)

You can click [here](#) to make a public comment by e-mail at info@nccdd.org by October 31st.



Committee or Venue	State Plan ID	Activity Description
Member Development Session		
	5.5	National Association for Councils on Developmental Disabilities/Information and Technical Assistance Center for Councils on Developmental Disabilities(NACDD/ITACC)
ADVOCACY AND LEADERSHIP		
	3.6	NC Chapter of the National Alliance for Direct Support Professionals
	4.3	Advocacy Ambassador Initiative
COMMUNITY CAPACITY BUILDING		
	2.12	Authority to Release RFA: ADA Network Fiscal Agent/ Intermediary
	1.5	Learning and Earning After High School: The Role of Transition Services in Raising Expectations and Attitudes for Students with Intellectual Disabilities
	2.1	Emergency Preparedness
	1.8	Reaching the Summit of Success
DISABILITY SYSTEMS CHANGE		
	2.8	Review Committee Recommendations: Guardianship Policy Report/Updates from NC General Assembly Short Session
	5.2	Enhancing Disability Stakeholder Engagement in Managed Long-Term Services/Supports and Primary/Acute Care Systems Coordination
	2.7	Bridging Practice and Policy: Transitions from Adult Care Homes
	2.3	Medical and Health Homes for People with Intellectual and Other Developmental Disabilities: Coordination, Collaboration and Community
	2.5	Agency of Choice Model Discussion
	??	
Overview of Committee Activities		
	5.4	Request to draft Request for Application: Participant Involvement Fund Administrative and Fiscal Agent
Member Development Session		
	5.3	NCCDD Communications and Marketing Initiative

5.5 Waiver Update/DHHS Listening Tour Update

5.5 Network Resource-Building Reception

**INFORMAL PUBLIC POLICY
FORUM**

5.2 Catalyst for Change – Be the Change Public Policy Initiative

AWARDS PRESENTATION

??

Deputy Secretary Dave Richard
Duncan Munn

FULL COUNCIL MEETING (Standard Meeting Items only November 2014)

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.</p> <p><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.</p> <p>2) Select grantee(s) and negotiate grants.</p> <p>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 05/51/2012</p> <p>2) By 06/30/2012</p> <p>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.</p> <p><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.</p> <p>2) Select recipient(s) of funding and enter into contracts(s).</p> <p>3) Provide technical assistance to enhance the effectiveness of advocacy/systems change efforts.</p> <p>4) Promulgate findings and target selected strategies for advocacy/system change.</p>	<p>1) 07/01/2012-12/31/2013</p> <p>2) 07/01/2012-12/31/2013</p> <p>3) 07/01/2012-12/31/2013</p> <p>4) By 12/31/2013</p>

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

Ended 12/31/11	Started 7/1/2012
<p>1.3 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>1.4 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>
<ol style="list-style-type: none"> 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. 	<ol style="list-style-type: none"> 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.
<ol style="list-style-type: none"> 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 	<ol style="list-style-type: none"> 1) 01/01/2011 - 09/30/2016

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

<p><i>Started 9/01/2013</i></p> <p>1.5 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"</i> <i>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>	<ol style="list-style-type: none"> 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). 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. 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. 4) Present the results of the initiative to date to one or more state conferences for LEA Exceptional Children's directors. 5) Create a management environment for the system that will allow it to be used within LEAs on a fee-for-service basis. 6) Use outreach from DPI to incorporate outcome data from pilots and to promote the system within LEAs. 	<ol style="list-style-type: none"> 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><i>Started 10/01/2011</i></p> <p>1.6 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>	<ol style="list-style-type: none"> 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). 2) Assist DMH/DD/SAS to analyze employment policies and practices and potential options for change. 3) Implement policies and practices across DMH/DD/SAS that advance competitive employment of people with disabilities in integrated, community workplaces. 	<ol style="list-style-type: none"> 1) 10/1/12-9/30/16 2) 10/1/12-9/30/16 3) 10/1/12-9/30/16

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

<i>Started 9/30/2013</i>	<i>Started 10/01/2012</i>
<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 VDD. <i>Project SEARCH (Cincinnati Hospital)</i></p>	<p>1.8 Council will provide funding/resources to assist families and students with VDD 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>
<ol style="list-style-type: none"> 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. 	<ol style="list-style-type: none"> 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 VDD. 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.
<ol style="list-style-type: none"> 1) 9/30/13-9/30/16 2) 9/30/13-9/30/16 3) 9/30/13-9/30/16 4) 9/30/13-9/30/15 5) 9/30/13-9/30/16 	<ol style="list-style-type: none"> 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

NCCDD 2011 - 2016 Five Year State Plan
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 IDD 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 IDD 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"> 1) Allocate funding to identify barriers to the development of healthy, safe relationships for people with IDD; 2) Convene stakeholder group to make recommendations re: the development of policies and practices that advance healthy, safe relationships for people with IDD; 3) Target selected strategies for advocacy/capacity building/systems change; 4) Assess effectiveness of advocacy/capacity building/systems change efforts; 5) Allocate funding to identify barriers to the inclusion of children and youth with IDD in typical child and afterschool care settings or programs; 6) Convene stakeholder group to make recommendations re: the inclusion of children and youth with IDD in typical child and afterschool care settings or programs; 7) Target selected strategies for advocacy/capacity building/systems change; 8) Assess effectiveness of advocacy/capacity building/systems change efforts. 	<ol style="list-style-type: none"> 1) 10/01/2011 - 12/31/2011 2) 10/01/2011 - 09/30/2012 3) 10/01/2011 - 09/30/2012 4) 10/01/2011 - 09/30/2012 5) 10/01/2011 - 06/30/2012 6) 10/01/2011 - 06/30/2012 7) 10/01/2011 - 06/30/2012 8) 10/01/2011 - 06/30/2012

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

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

<p>On-going</p> <p>2.2 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 VDD 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 Council will provide resources to support the development of policies and practices for people with VDD 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 VDD (Disability Rights NC)</i></p>	<p>1) Locate individuals with VDD 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 (j) option.</p> <p>2) Provide advocacy, support to individuals with VDD 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 VDD 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 VDD.</p> <p>5) Develop a "blueprint" to close the front door of adult care homes to people with VDD and ensure the successful transition for people with VDD 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 People with VDD have transportation options that are affordable, accessible, reliable, flexible and safe.</p>	<p>1) Promote the participation of people with VDD on local transportation boards to ensure local, state, and federal policy implementation.</p>	<p>1) by 09/30/2016</p>

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

<p><i>Started 9/01/2013</i></p> <p>2.5 People with V/DD will have access to the full range of needed primary and specialized health care services. <i>Medical Health Home for People with VDD (Easter Seals UCP of NC and VA)</i></p>	<ol style="list-style-type: none"> 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 VDD 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. 	<ol style="list-style-type: none"> 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><i>Ended 12/31/2012</i></p> <p>2.6 People with V/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>	<ol style="list-style-type: none"> 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. 	<ol style="list-style-type: none"> 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

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

	<p>Started 9/16/2013</p>	
<p>2.7</p> <p>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.</p> <p><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.</p> <p>7) Faculty and residents to complete an evaluation and self-assessment of the program.</p> <p>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.</p> <p>2) Facilitate up to six stakeholder meetings/forums.</p> <p>3) Prepare and disseminate white papers based on group discussions.</p>	<p>6) 6/1/2012 - 5/31/2013</p> <p>7) 12/1/2012 - 5/31/2013</p> <p>1) 9/1/2013 - 10/31/2013</p> <p>2) 11/1/2013 - 06/30/2014</p> <p>3) 11/1/2013 - 08/31/2014</p>
<p>2.8 (Added 11/2013)</p> <p>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.</p> <p>2) Select recipient(s) of funding and enter into contract(s).</p> <p>3) Provide technical assistance to enhance the effectiveness of advocacy/systems change efforts.</p> <p>4) Promulgate findings and target selected strategies for advocacy/system change interventions.</p>	<p>1) 1/1/2014 - 3/31/2014</p> <p>2) 7/1/2014 - 7/31/2014</p> <p>3) 9/1/2014 - 8/31/2016</p> <p>4) 5/1/2016 - 8/31/2016</p>

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

<p><i>Starts 10/01/2014</i></p> <p>2.9 (Added 11/2013) 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.</p> <p><i>Upward to Financial Stability (National Disability Institute)</i></p>	<ol style="list-style-type: none"> 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. 	<ol style="list-style-type: none"> 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><i>Started 9/01/2013</i></p> <p>2.10 (Added 11/2012) 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.</p> <p><i>Emergency Preparedness and Recovery (NC Department of Public Safety)</i></p>	<ol style="list-style-type: none"> 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. 	<ol style="list-style-type: none"> 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

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

Started 1/01/2014	Ongoing & Started 7/01/2012
<p>2.11 Added (11/2013)</p> <p>Council will provide funding/resources to provide people with VDD 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 VDD.</p> <p><i>Safety and Security: Addressing Sexual Violence and Domestic Violence Against People with VDD</i></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 ADA Network Fiscal Agent (NC Alliance of Disability Advocates)</i></p>
<ol style="list-style-type: none"> 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 VDD 2) Select grantee 3) Execute first year of initiative according to grantee's approved work plan 	<ol style="list-style-type: none"> 1) Consult with groups of people with disabilities to develop ADA community initiative plans. 2) Provide follow-up, technical assistance and training to local groups to carry out their plans. 3) Conduct leadership and ADA training for 2 new, grassroots groups. 4) Processes reimbursement requests and in-kind match documentation from the NC ADA Network within 15 days or less of remittance.
<ol style="list-style-type: none"> 1) 9/1/2013 – 12/1/2013 2) 11/2013 3) 1/1/2014 – 9/30/2016 	<ol style="list-style-type: none"> 1) 7/1/2012- 9/30/ 2016 2) 7/1/2012- 9/30/2016 3) 7/1/2012- 9/30/ 2016 4) 7/1/2012- 9/30/ 2016

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

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><i>Ended 9/30/2012</i></p> <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.</p> <p><i>College of Direct Support/Direct Course (Monarch, Inc.)</i></p> <p><i>College of Direct Support Technical Assistance (Institute for Community Integration)</i></p>	<ol style="list-style-type: none"> 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; 	<ol style="list-style-type: none"> 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

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

<p>3.2 Council will fund strategies to promote competency-based training for Care Coordinators and Community Guides who support people with VDD.</p>	<ol style="list-style-type: none"> 1) Develop Request for Application(s) for Care Coordination/Community Guides for individuals with VDD. 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. 	<ol style="list-style-type: none"> 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><i>On-going</i> 3.3 Council will fund leadership training for VDD professionals. <i>Advancing Strong Leaders in the Developmental Disabilities' Field Test, Class I and II (National Leadership Consortium in Developmental Disabilities)</i></p>	<ol style="list-style-type: none"> 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 VDD. (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 VDD. (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 VDD. 	<ol style="list-style-type: none"> 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><i>Refer 2.6</i> 3.4 Council will fund training of other professionals that increases their ability to provide quality services to meet the needs of people with VDD.</p>	<ol style="list-style-type: none"> 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. 	<ol style="list-style-type: none"> 1) 10/01/2011 - 09/30/2016 2) 10/01/2011 - 09/30/2016 3) 10/01/2011 - 09/30/2016

NCCDD 2011 - 2016 Five Year State Plan
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<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. 4) Host meeting with steering committee to consider next steps.</p>	<p>4) 10/01/2011 - 09/30/2016</p>
<p>3.5 (Added 11/2013) 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. 2) Select recipient(s) of funding and enter into contract(s). 3) Provide technical assistance to enhance the effectiveness of employment professionals in community capacity building efforts. 4) Promulgate Findings and target selected strategies for sustainable community capacity building.</p>	<p>1) 1/1/2014 - 9/30/2016 2) 1/1/2014 - 9/30/2016 3) 1/1/2014 - 9/30/2016 4) 1/1/2014 - 9/30/2016</p>
<p><i>Started 01/01/2014</i> 3.6 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 (Benchmarks, 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. 2) Establish 501 (c)(3) status for a NC NADSP chapter with a board of directors, bylaws, and 100 members. 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 2) 1/1/2015 - 12/30/2015 3) 1/1/2016 - 12/30/2016</p>

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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.</p> <p><i>Ended 6/30/12 Infrastructure support to ASANNC (Association of Self-Advocates of NC (ASANNC))</i></p> <p><i>Ended 3/30/12: Making Our Voices Heard (HSRJ)</i></p> <p><i>Ended 9/30/12: Building a Stronger ASANNC</i></p>	<ol style="list-style-type: none"> 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 (ASANNC); 3) Allocate funding to support the development of a stronger state and local leadership; 4) Survey ASANNC board and membership regarding satisfaction with performance of ASANNC. 5) Make office space, supplies, and equipment available to support the ASANNC. 	<ol style="list-style-type: none"> 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

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<p>4.2</p> <p>Council will provide opportunities for people with VDD to participate in cross-disability, culturally diverse, leadership coalitions and training opportunities.</p>	<ol style="list-style-type: none"> 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. 	<ol style="list-style-type: none"> 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>Started 09/01/2013</p> <p>4.3 (Added 11/2013)</p> <p>Council will assess the climate of the self-advocacy in NC to determine how best to support people with VDD to be effective advocates at the local, regional, and state levels.</p> <p><i>Advocacy Ambassador Initiative (Community Resource Alliance)</i></p>	<ol style="list-style-type: none"> 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 VDD 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. 	<ol style="list-style-type: none"> 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>Starts 10/01/2014</p> <p>4.4 (Added 11/2013)</p> <p>Council will provide funding/resources to assist siblings of individuals with VDD in providing informal and natural supports for a brother or sister.</p> <p><i>Sibling Support (First in Families)</i></p>	<ol style="list-style-type: none"> 1) Develop Request for Application for supporting siblings of individuals with VDD. 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. 	<ol style="list-style-type: none"> 1) 11/2013 - 8/2014 2) 3/2014 - 8/2014 3) 9/2014 - 8/2015 4) 9/2015 - 9/2016

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

GOAL 5: Council Quality Assurance/Operations

Objectives	Implementation Activities	Timeline
<p>On-going</p> <p>5.1 Council will provide funding/resources that ensure accountability, advocacy, and outreach for its programs. <i>State Plan Development, Program Management, Route to Success (Ended 6/30/2014), Impact Evaluation (Unaddressed)</i></p>	<ol style="list-style-type: none"> 1) Allocate funding for the development and monitoring of the NCCDD State Plan to ensure accountability for Goal I programs; 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; 3) Implement the "Route to Success" model as a means of monitoring & ensuring accountability for programs under this goal; 4) Conduct evaluation to assess impact of selected State Plan Programs. 	<ol style="list-style-type: none"> 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

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

On-going			
5.2	<p>Council will provide funding/resources that promote individuals with V/DD 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>
On-Going	<p><i>NCCDD Public Policy Initiative</i></p> <p>5.3</p> <p>Council will provide funding/resources that promotes awareness of its initiatives.</p> <p><i>NCCDD Communications Initiative (Ended 12/31/2013 - The Wallace Group)</i></p> <p><i>(Started 1/01/2014 - Communications Temp Contractor)</i></p> <p><i>(10/01/2014 - Next Contract Starts)</i></p>	<p>1) Allocate funding from Communications Initiative to provide marketing and outreach for initiatives.</p> <p>2) Create accessible communication materials.</p> <p>3) Strengthen media relations to further the image of the Council and its programs.</p> <p>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</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>

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<p><i>On-going</i></p> <p>5.4</p> <p>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.</p> <p><i>Jean Wolff-Rossi Fund</i></p>	<ol style="list-style-type: none"> 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. 	<ol style="list-style-type: none"> 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><i>On-going</i></p> <p>5.5</p> <p>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.</p> <p><i>Council Development Initiative</i></p>	<ol style="list-style-type: none"> 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. 	<ol style="list-style-type: none"> 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><i>On-going</i></p> <p>5.6</p> <p>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.</p> <p><i>Conference Funding Initiative</i></p>	<ol style="list-style-type: none"> 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. 	<ol style="list-style-type: none"> 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

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.

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.

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

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-

21 Emergency Preparation

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

22 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.

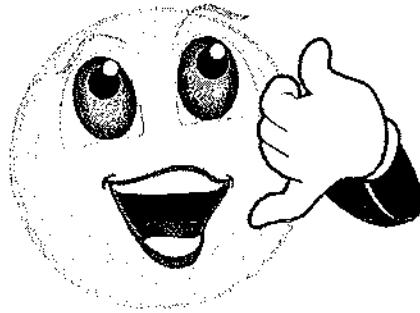
36 Better Together Sibling Support Initiative

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

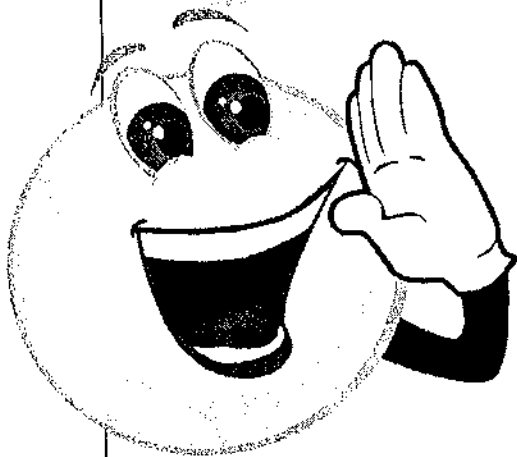
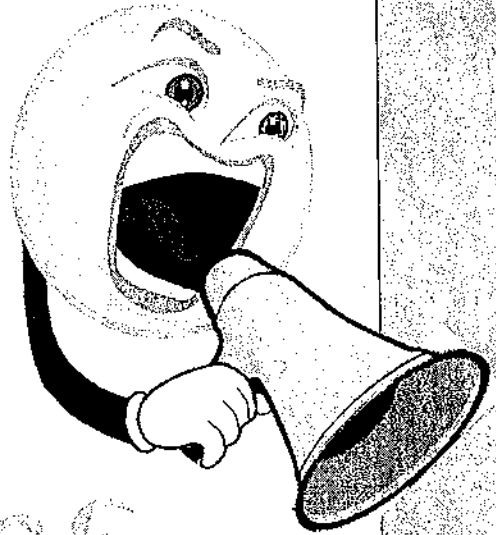
37 Upward to Financial Stability

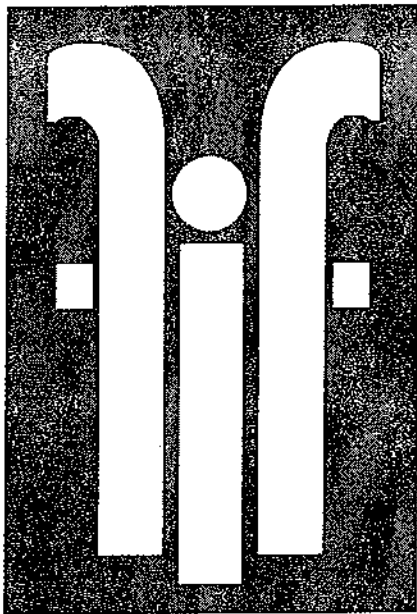
This initiative promotes opportunities for people with I/DD to advance economic self-sufficiency by developing financial literacy and asset building skills.

FOR YOUR INFORMATION



F.Y.I.





FAMILY SUPPORT: COMING OF AGE

FINAL REPORT AND RECOMMENDATIONS

Identifying the support needs of people with Intellectual/Developmental Disabilities or Traumatic Brain Injuries and their aging caregivers in North Carolina and the barriers involved in attaining that support.

North Carolina Council
on Developmental Disabilities



*A First In Families of North Carolina Initiative
Funded by the North Carolina Council on
Developmental Disabilities.*

INTRODUCTION

Dear Stakeholder;

North Carolina is facing a perfect storm with the confluence of persons with Intellectual/Developmental Disabilities (I/DD) or Traumatic Brain Injury (TBI) living at home and the aging of their primary caregivers who themselves are in need of more support. Over 71% of all adults with I/DD in North Carolina live in their family home. Of this percentage, 25% of their caregivers are over the age of 60.

This is a nationwide epidemic not unique to North Carolina. By 2030 the number of Americans over 65 is projected to grow by 30 million (a 67% increase in (Thaler, 2011), substantially increasing the need for paid caregiving services for those who are aging and/or have disabilities in the US.

As aging caregivers increasingly need caretakers of their own, they also need support in keeping their loved one at home and in the community, and access to Future Planning resources.

The issues of family support and Future Planning require intense collaboration between Aging and DD stakeholders. No longer can the two systems operate as silos. As individuals with I/DD and/or TBI age they too require extensive and unique solutions for accessing their communities.

The NC Council on Developmental Disabilities recognized that North Carolina currently does not have the capacity to meet the projected needs of its citizens who are aging and have I/DD, or their caregivers. Because of this, the Council provided funding to First in Families of NC to explore the issue and provide recommendations for meeting the needs of this population.

As part of that grant, FIFNC convened a Taskforce of dedicated professionals from I/DD and Aging service sectors, policy-informers, caregivers, and self-advocates. This group worked diligently to identify the needs of those with I/DD and their caregivers as they age. Staff from FIFNC and volunteers conducted a statewide poll to identify common concerns and shortcomings within our system. They sat one-on-one with families from Shelby to Henderson to discuss their current and future needs as well as the availability and accessibility of resources needed to meet those needs.

This report serves to shed light on the family support needs of aging caregivers in our state, to honor the resiliency of North Carolina citizens, to humanize the caregiver crisis, and to advise the North Carolina Council on Developmental Disabilities and its constituents on the next steps toward providing the critical supports necessary to minimize "storm damage" to individuals with I/DD and their families and prevent a profound economic crisis.

Thank you for your foresight in beginning this conversation, for entrusting FIFNC to manage this initiative, and for your commitment to the over 109,000 (Braddock, 2013) individuals with developmental disabilities and their families throughout North Carolina.

Sincerely,

Betsy MacMichael

Betsy MacMichael
Executive Director
First In Families of North Carolina

INITIATIVE SUMMARY

First In Families of North Carolina was awarded a grant from the NC Council on Developmental Disabilities to address the issues of individuals with intellectual and developmental disabilities (I/DD) as they age with their caregivers. The active grant period was July 1, 2012 – June 30, 2014.

The proposed outcomes of the initiative were:

- Aging individuals with I/DD and their caregivers will have greater knowledge about, and access to, natural supports.
- Legislators and other policymakers will be better equipped to create policies that will reduce barriers (identified by the stakeholders) to obtaining family support whether through natural or more traditional services.
- Through increased collaboration, I/DD and aging system professionals will have a greater array of resources that they can refer to those they serve, thus reaching more people.
- Families will be more knowledgeable about how to plan for the future.
- Families and individuals with I/DD will have more opportunities to give back to others as valued community members.

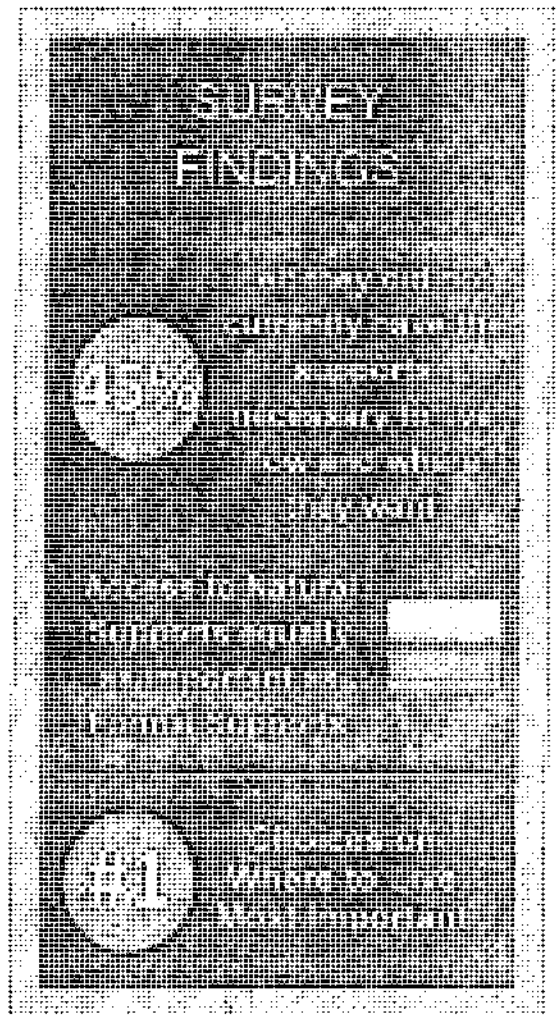


INITIATIVE IMPACT AND FINDINGS

To advise the grant work FIFNC formed a Taskforce comprised of professionals from the Aging and Intellectual/Developmental Disability (I/DD) service sectors, caregivers, and self-advocates. The Taskforce's first meeting was held in October 2012. The grant initiative and scope of work were presented, along with a history of previous national and state-lead projects to bridge Aging and I/DD sectors. Throughout the grant the Taskforce provided direction, reviewed and synthesized data received through survey and Future Chat conversations, advised staff on next steps in the work plan, and formulated policy recommendations. Three subcommittees of the Taskforce were formed to focus on the previously identified issues, from the three distinct perspectives of: policy, community/natural supports, and individual/family.

Identifying common caregiver needs

The initiative identified common needs of people with disabilities and their caregivers as they age through an online survey distributed in collaboration with Aging and Disability partner organizations statewide. The survey, distributed statewide and conducted in December of 2012, received 277 unique responses from individuals living in 55 of North Carolina's 100 counties. Respondents were asked to choose the category they most identified with. 30% responded as professionals in aging, 12% as professionals in I/DD, 17% as primary caregivers to a person with I/DD who is not over the age of 60, 9% as family members (not primary caregiver) to a person with I/DD, 7% as family members of person who is aging, 4% as caregivers to a person with I/DD over the age of 60, and 2% identified as self-advocates. 19% of respondents identified primarily as community members. (FIFNC, 2012)



TEEDY

"I don't want to live in a group home all my life. Will my brother and sister support me in my desire to not live in a group home?"

(Durham County)

INITIATIVE IMPACT AND FINDINGS

Families need a variety of formal & natural supports

Key findings from the survey include:

- Survey participants rated access to formal (government) supports and access to natural support as equally important.
- When asked "What are the most important needs for individuals with I/DD who are aging and their aging caregivers?" respondents ranked "choices on where to live", "financial security", and "respite and caregiver support" as the top three among twelve.
- 41% of respondents stated that they felt that they currently had the supports necessary to live how and where they want, 45% stated that they did not currently have the supports necessary to live how and where they want and 14% were unsure if they had the supports necessary to live how and where they want.

Personal support networks are vital to Future Planning

Twenty-five Future Chat conversations were conducted in-person by staff and volunteers throughout the state. These conversations facilitated a more personal and in-depth exploration of the challenges faced by real families and better served to illustrate the needs identified through research and survey. The conversations also allowed the interviewer to assess the future-planning readiness of

each family and, when appropriate, provide information on future-planning resources available to them.

In Future Chats caregivers reported that they worried about not only the availability of care for their child, but also expressed concerns about having people in their child's life that know him/her and can provide companionship and guidance once they are no longer around. Self-advocates echoed this desire for a network of support and meaningful relationships.

RATIONALE FOR FAMILY SUPPORT

109K NC Adults with I/DD who live at home

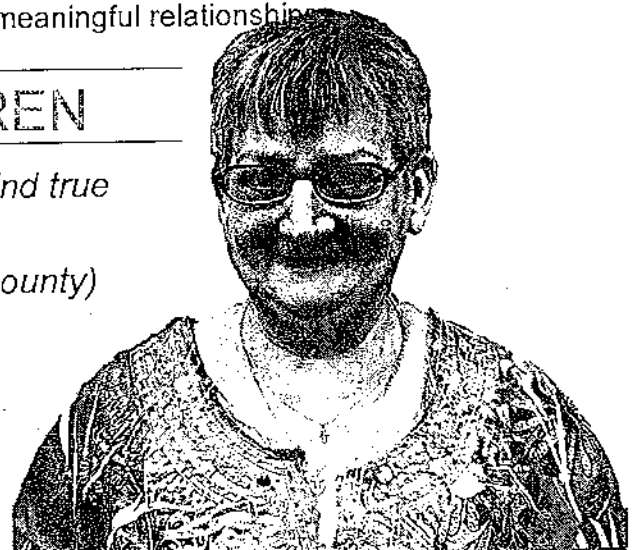
Receive Public Support from I/DD Agencies

8%

25% NC Caregivers over age 60

KAREN

*"I want to find true love."
(Durham County)*



INITIATIVE IMPACT AND FINDINGS

Natural and community (non-paid) supports can provide more organic and positive outcomes for the individual with I/DD. One family shared their son's experience living with Down Syndrome in the Siler City community. Melba D., 76 has helped her son, Todd (age 36) to develop a personal network of friends and "surrogate" family that she is confident will continue to support him throughout his life. Todd has worked at Bestfood Cafeteria in Siler City since his teenage years and has made many friends through his work. In addition to having completed legal and financial Future Planning to ensure her son's needs are met, Melba takes great solace in the peace of mind that Todd will continue to be supported after her death to remain in the community he loves.

The Council on Quality and Leadership, Personal Outcome Measures concludes "Natural support networks are groups of people whose commitment to support each other is usually lifelong. These support networks cannot be manufactured or created. They can only be nurtured as they grow and evolve over time. Families provide lifelong support and a safety net for many people. Lifelong relationships with non-family members are also part of the support (The Council on Quality and Leadership, 2000)

THE COST OF CAREGIVING

Over 70% of adults with I/DD live with family members and about 25% of these family caregivers are over age 60 years. In North Carolina over 100,000 people will help live with family caregivers and over 25,000 of these caregivers are age 60 or over. Yet, only 15% of families providing support to members with I/DD nationally and only 3% in North Carolina (9,175 families) received quality support from state I/DD agencies. In total family supports a large slice of the US economy, estimated at \$450 billion in 2009. More than 40 million family caregivers provide over 40 billion hours of unpaid care to family members who need assistance with activities of daily living. In fact, these families provide 50-60 hours of help each week (Heller, 2011)

Supporting Individuals means Supporting Families

With the implementation of Managed Care for Long Term Support Services in North Carolina, the Council asked FIFNC to extend the scope of the grant work to include research on outcomes, opportunities and emerging best practices nationwide. Through collaboration with the Department of Disability and Human Development at the University of Illinois, a policy brief on Long Term Support Services in Medicaid Managed Care was created.

This brief provided national and state data to support the necessity and relevance of comprehensive whole-family support in a Managed Care environment.



The Family Support: Coming of Age Stakeholder Taskforce met four times in person over the course of the grant work. Partners from the aging service sector were especially involved in the work and eager to provide opportunities for cross-training.

Through these collaborations with regional Area Agencies on Aging (AAA), Community Resource Connections (CRCs) and the Division of Aging and Adult Services at the Department of Health and Human Services, FIFNC project staff participated in comprehensive Options Counseling training and provided cross-training on the I/DD and TBI populations in various settings, including the 2013 North Carolina Association on Aging Conference, the 2013 AAA Director's Annual meeting, and the Chatham-Orange and Wake CRC Chapter meetings.

Partnerships with colleagues in aging services also provided the opportunity for FIFNC staff to play an integral role in the formation of an entirely new CRC for Durham County residents who are aging or living with disabilities. FIFNC remains involved in the Triangle-based CRC initiatives and was the lead organization representing disability services in advocating to the Durham County Commissioners for county funding for a coordinator position for the new Durham CRC.

Conversations with self-advocates and caregivers who self-identified as aging, and data collected through the online survey allowed staff to:

- obtain a comprehensive view of the needs of aging caregivers throughout North Carolina,
- to identify areas in which natural supports were being utilized successfully
- further inform the work of the Taskforce.

Future Chats & Checklists

In many areas of the state, especially rural communities, natural support networks compliment and reduce reliance on public supports.

Families were eager to share their personal experiences, their hopes and their fears about what the future may hold for their loved one with I/DD or TBI. Families expressed satisfaction with the Future Planning Checklist created as part of this initiative, many sharing that it helped them move forward with putting a plan in place by presenting the information in a concise and approachable format.



INITIATIVE CHALLENGES

Council staff requested an addition to the scope of work to include national policy perspective in the wake of North Carolina's newly implemented Managed Care System. In addition, the loss of the staffing position for the Timebank required FIFNC to reconsider its original plan to use the Timebank as a platform for natural supports for aging caregivers, and to decrease social isolation through connectivity. While FIFNC still believes the Timebank is an innovative way to help meet the basic needs of families (cooked meals, home repairs, ride-sharing to doctor's appointments) and embodies the FIF tenant of reciprocity – for the purpose of this initiative it was not pursued.

Three Future Planning Workshops were scheduled throughout the state that focused on providing information to aging caregivers on Wills and Estates Planning. The first was held in Shelby in November of 2013, the second was held in Winston-Salem in April 2014 and the final was planned for New Bern in June 2014. Unfortunately, the New Bern workshop had to be cancelled due to low registration numbers. While grant staff and Taskforce members worked to promote the workshop through all known channels, low registration could be in part due to the location of the workshop and/or not having made enough relevant connections in the area. It also occurred to staff that perhaps an initial workshop on Wills and Estates Planning might be overwhelming for those individuals who have not previously been exposed to discussions on Future Planning. Especially in rural areas, it might be better to focus on a general "Future Planning" information session in a small group meeting so as not to overwhelm participants.

RECOMMENDATIONS

Recommendation One:

Identify Barriers to Future Planning for Caregivers of Individuals with I/DD

To continue and build upon the research provided through the Family Support: Coming of Age initiative the Taskforce advises the North Carolina Council on Developmental Disabilities to consider funding future initiatives that identify specific barriers which lead to reluctance in Future Planning for caregivers of individuals with I/DD. Once barriers to Future Planning are identified the Taskforce recommends implementation of a pilot incentive program for families who are actively completing Future Planning Tasks



Recommendation Two:

Require Future Planning as a Component of Every Person Centered Plan

To ensure that families are knowledgeable about the necessity of planning, to decrease the need for emergency public-funded services and to provide an easier and more self-directed transition for individuals with I/DD or TBI upon the loss of their caregiver the Taskforce recommends that the Department of Health and Human Services, Division of Mental Health, Developmental Disabilities and Substance Abuse Services require that Future Planning be included as part of

every Person Centered Plan for individuals with I/DD and TBI. LME/MCO Care Coordinators, Community Guides and service provider staff responsible for Person Centered Planning should receive adequate training to have discussions about Future Planning with the families they serve. It is recommended that there be different questions to bring up depending upon the age of the person with the disability. For younger families the requirement to plan could simply mean that they have been offered resources to start thinking about what they will be needing to do in the future, and what people need to know now, in the event of their premature death. As they age, the requirements should be much more specific.

Recommendation Three:

Provide access to information and resources on Future Planning as a Medicaid Billable Service through the LME/MCO network

To provide access to all caregivers on resources specific to Letter of Intent, Wills and Estates Planning, Special Needs Trusts, and personal asset mapping of their community through publications (Future Planning Checklist, FIFNC, 2013), provider education and regionally sponsored workshops, the Taskforce recommends that Future Planning be considered a billable service through Medicaid and implemented in all geographic areas of North Carolina through the established LME/MCO channels.

Recommendation Four:

Identify older family caregivers to provide resources before the point of crisis.

It is speculated that there are many "unaccounted for" caregivers who are aging and have heretofore remained invisible because they are unaware of, or reticent to enter the formal system to access services and support. At the point of crisis is when their presence becomes known. Utilizing community mapping proactively will allow LME/MCOs, providers of direct family support such as First In Families of North Carolina (FIFNC) and existing collaboratives such as the Community Resource Connection (CRC) initiatives to identify caregivers who are aging. Educating these caregivers (once found) about available community resources could decrease reliance on more costly emergency supports, provide an opportunity to engage caregivers about the importance of Future Planning and help families to remain together longer.

Recommendation Five:

Continue and increase cross-training and collaboration between Aging and Disability sectors.

As formal service resources will never be adequate to meet the needs of all families, in



RECOMMENDATIONS

part due to the “perfect storm” and because the needs of individuals and families exceed the limitations of the public sector, it is imperative that partners in the Aging and Disability fields do a much better job of understanding and supporting one another. Coming of Age Taskforce Members have committed to continuing on in an advisory capacity as a resource to assist in future endeavors supporting the cross-training between Aging and Disabilities. It is recommended that additional partners be recruited for this effort in order to maximize outcomes for individuals with I/DD and their caregivers as they are aging.

CONCLUSION

The Family Support: Coming of Age initiative has been successful in identifying the needs of aging caregivers and individuals of I/DD in North Carolina. Now it is time to prepare for the storm. The recommendations and findings included in this report are anticipated to provide the North Carolina Council on Developmental Disabilities with a foundation for the next steps in preparing for the future of individuals with I/DD or TBI and their caregivers. With an anticipated growth of 67% over the next 15 years in the population over 60, FIFNC and all who have been part of this work urge the Council to use these recommendations as a starting point for future initiatives.

ARNOLD

Arnold had a promising career as an electrician when he suffered a Traumatic Brain Injury in a vehicle accident in 1997. Three years of hospitalization later and requiring around the clock care, Arnold’s parents brought him to his childhood home in Shelby.

Arnold’s father Jerry is a tireless advocate for his son. At age 68, he and his wife worry constantly about who will care for Arnold when they are no longer able. Like all aging parents they want to know that Arnold will continue to be cared for, supported and engaged in his community.

Arnold loves cars, his dog and everything Harley Davidson.

(Cleveland County)



WHY FUTURE PLANNING?

Future Planning is the preparation one does to ready themselves, their family and their estate for the time when they are no longer able to manage these parts of life - whether due to incapacitation, illness or death. All people could benefit from a plan for the future, but the recommendations in this report are specific to caregivers of persons living with an intellectual or developmental disability and/or Traumatic Brain Injury.

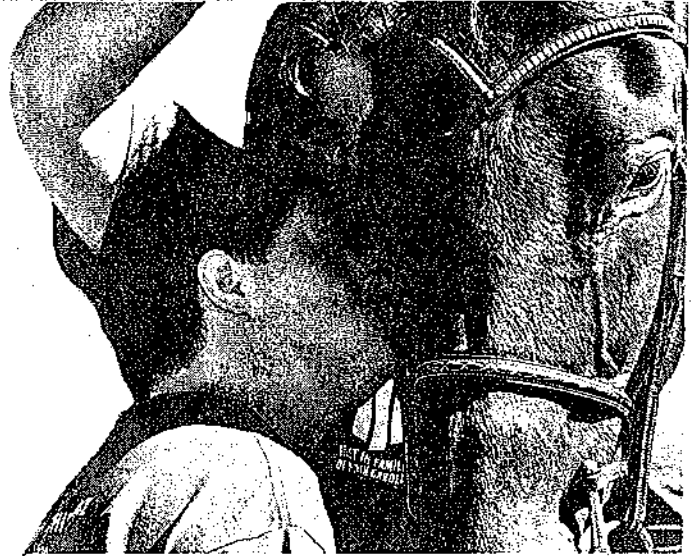
Some key components of good Future Planning in this context include preparing a Letter of Intent explaining your wishes for your child, creating a will and plan for your estate, and creating a Special Needs Trust to administer and protect money left behind to benefit your child and protect his or her public benefits. Not everyone will need all these components so every family needs quality guidance to develop their own plan. Guardianship or alternatives to guardianship should also be considered and planned.

Equally important in Future Planning is identifying or building a personalized network of support for a person with I/DD, drawing initially from current trusted relationships with friends and family and then growing the network with new people who emerge through shared interests or activities with the person with the disability. This network serves as a "safety net", to support the individual and caregiver in the present and more importantly as the caregiver ages. Individual members of the network can even be identified to provide information and advice in specific areas such as finances or health. Such "supported decision making" is a kind of guidance that encourages self-determination. Person networks are one of several alternatives to guardianship that are available options in North Carolina.

A 2012 study reported that 41% of the Baby Boomer generation (born 1946-1964) do not have a will. When polled as to why not, procrastination was cited as the biggest reason (34 percent), followed by feelings that it was unnecessary (22 percent) or too expensive (21 percent). (AARP, 2012)

Further, a 2008 survey by The Hartford Financial Services Group showed that roughly 62 percent of parents have no long-term care plan in place for their child living with a disability and that 58% have their child identified as a beneficiary to their financial assets, something which could jeopardize critical government benefits and services. (Bankrate, 2014)

More research as to the barriers preventing aging caregivers of individuals with I/DD or TBI from participating in Future Planning is needed. It is clear that reluctance towards Future Planning transcends socioeconomic barriers, therefore it is important to find out what specifically is keeping many NC families from taking critical planning steps.



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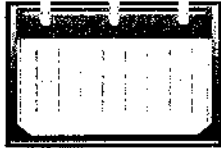
With special thanks to Marian Hartman

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Council Meeting Dates

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

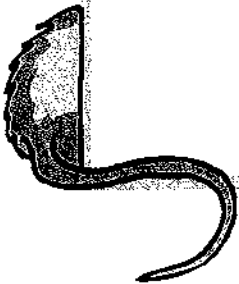
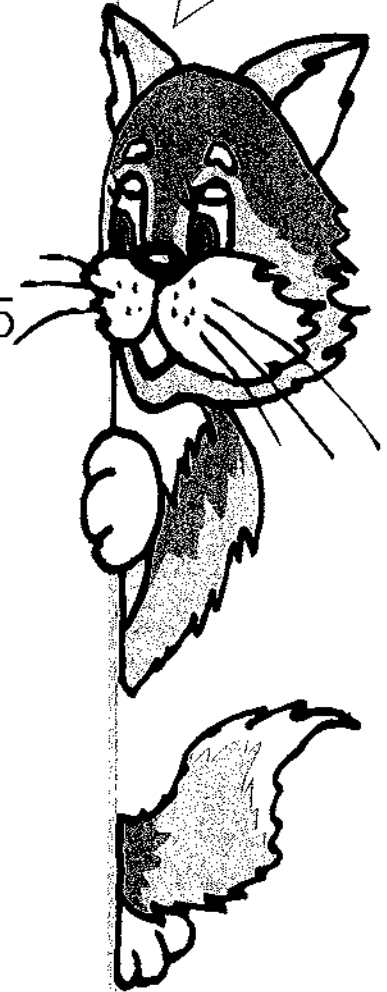


February 12 & 13, 2015

May 14 & 15, 2015

August 6 & 7, 2015

November 18-20, 2015



Location: North Raleigh Hilton

3415 Wake Forest Road

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