



NC Council on Developmental Disabilities *Overview and Update*

MFP Roundtable: Lunch and Learn

September 14, 2015

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NCCDD: Mission

NCCDD is guided by the federal Developmental Disabilities Assistance and Bill of Rights Act (DD Act) which directs us to

- Ensure that people with I/DD and their families
- participate in the design of and have access to
- individualized services and supports that promote:
 - Self-determination
 - Productivity
 - Integration, and
 - Inclusion
 - In all aspects of community life

"engage in education, advocacy, capacity building, and system change activities"



Definition of Intellectual or other Developmental Disability

- I/DD is natural – consider your family and close friends and acquaintances.
- Manifests before 22 years of age*
 - Severe, chronic
 - Cognitive or physical Impairment or combination
 - Likely to continue indefinitely
 - Substantial limitations in at least three Major life areas
 - Reflects the need for specific supports

*unlike the federal, NC definition includes head injury at any age

NCCDD 5-Year State Plan

The DD Act says Councils' five-year plan must be developed through data driven strategic planning:

- Council member engagement in the planning process
- Collaboration with the AIDD Network and other partners
- Stakeholder input on state needs and the proposed plan
- Comprehensive review and analysis of unmet needs

The DD Act says Councils' five-year plan must be reviewed annually for possible amendments.

NCCDD Framework

Outcomes Areas:

- **ASSET BUILDING**
- **EMPLOYMENT & CAREERS**
- **HEALTHY RELATIONSHIPS**
- **HOUSING AND TRANSPORTATION**
- **EDUCATION**
- **HEALTH & STABILITY**
- **FAMILIES & INDIVIDUALS ATTITUDES, BELIEFS & ABILITIES**

Cross Cutting Areas:

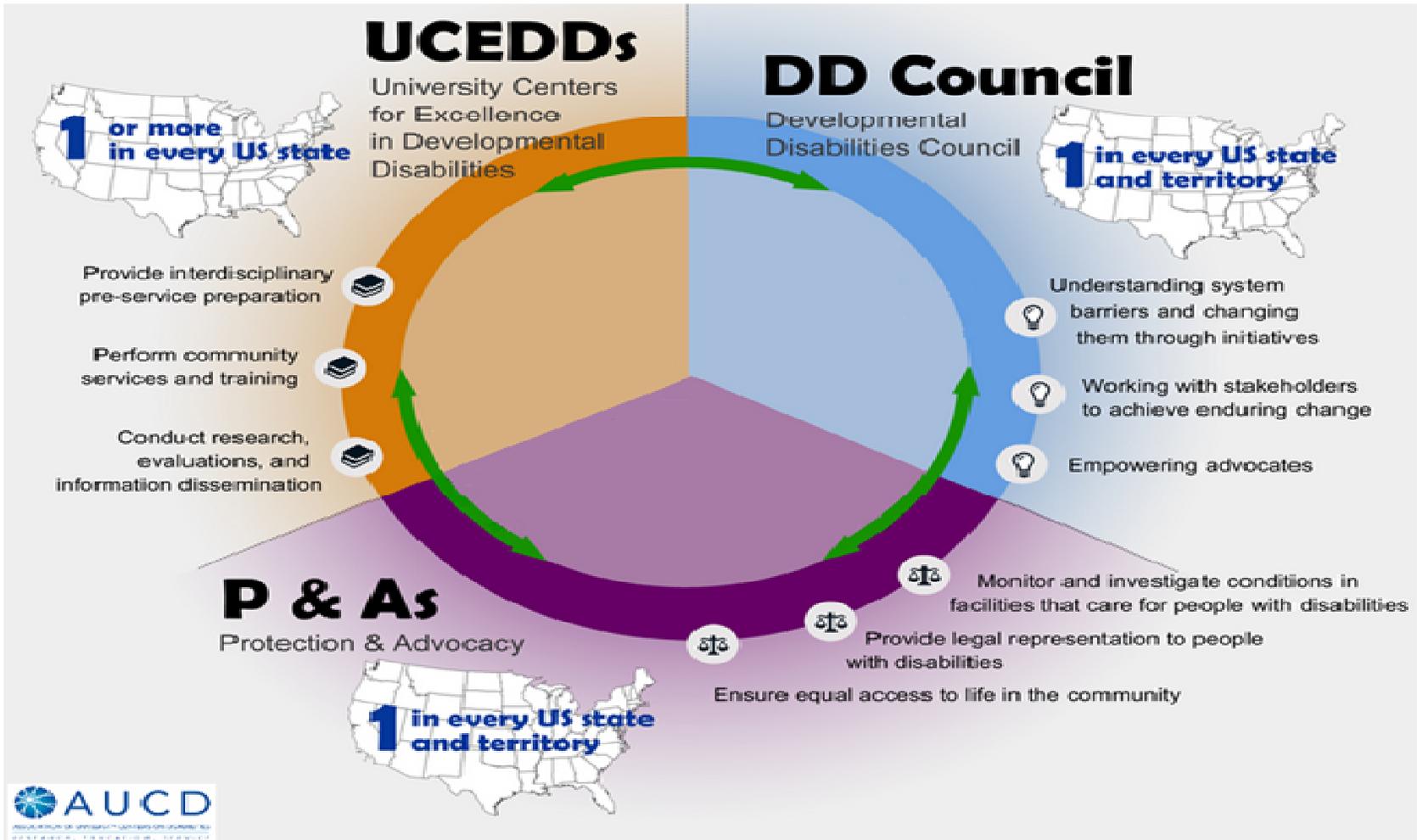
- **ADVOCACY**
- **SUPPORT SYSTEMS**
- **TECHNOLOGY**

*PL106-402 (DD Act) Section 102 (2) Definitions/Areas of Emphasis include employment, housing, education, health, childcare and early childhood, and quality assurance.



US Administration on Intellectual and Developmental Disabilities (AIDD)

DD Act Network Partners



Historical Perspective

- Evolving Nature of Services
- Historical Timeline
 - Marginalization and separation
 - Families advised by professionals to rely on institutions
- Initial efforts toward deinstitutionalization

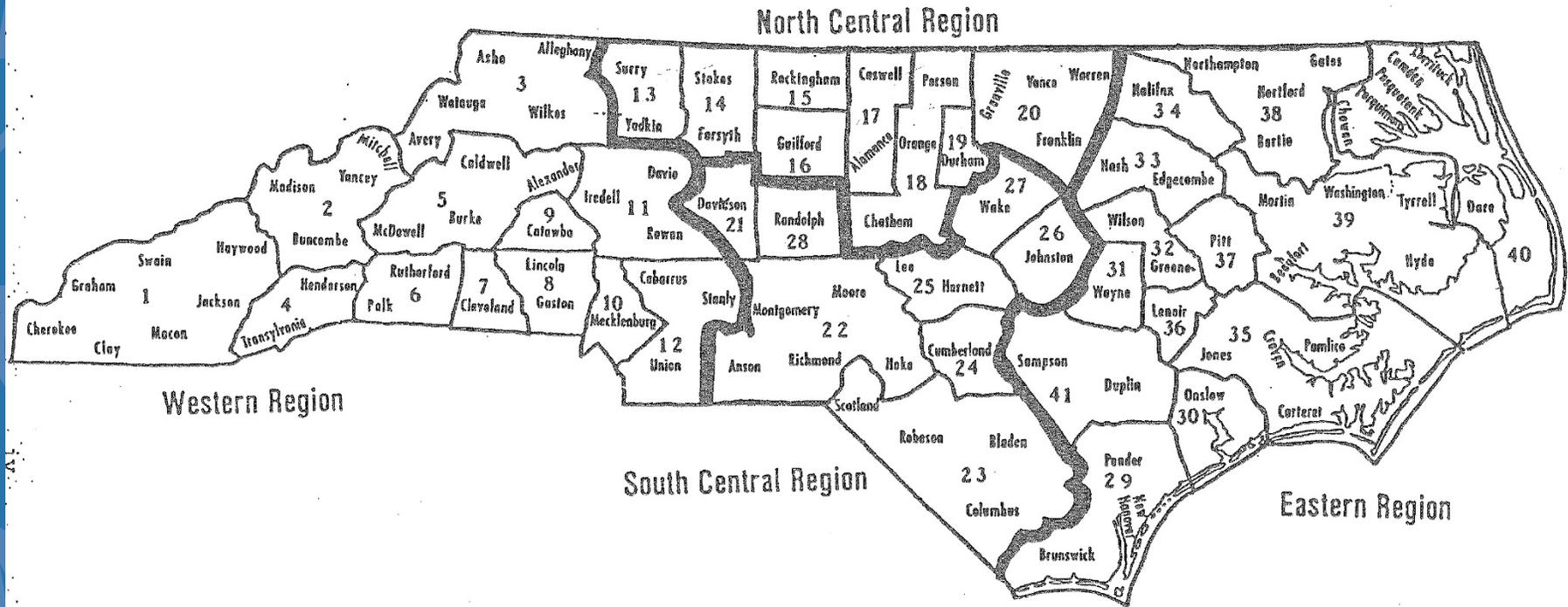
Historical Timelines

- 1960s
 - Presidents Panel
 - Calls for Deinstitutionalization
 - Medicare and Medicaid
 - Vocational Rehabilitation Amendments
 - Architectural Barriers Act
- 1970s
 - SSI created
 - Rehabilitation Act (section 504)
 - Education of All Handicapped Children Act
 - DD Act
 - Halderman V. Pennhurst

Historical Timelines

- 1980's
 - HCBS waiver expansion
 - Willy M. (NC)
 - Thomas S. (NC)
 - Early Person Centered Planning
- 1990's
 - American's with Disabilities Act (ADA)
 - Individuals with Disabilities Education Act (IDEA)
 - 10 Year Down-sizing Plan
 - Systematic Use of Person Centered Planning
 - Introduction of Personal Outcome Measures
 - Olmstead V. LC
 - Work Incentives Improvement Act

MAP OF AREA MENTAL HEALTH, MENTAL RETARDATION AND SUBSTANCE ABUSE AUTHORITIES



Alamance-Caswell = 17
 Albemarle = 40
 Blue Ridge = 2
 Catawba = 9
 Cleveland = 7
 Cumberland = 24
 Davidson = 21
 Duplin-Sampson = 41
 Durham = 19
 Edgecombe-Wash = 33
 Foothills = 5
 Forsyth-Stokes = 16
 Gaston-Lincoln = 8
 Guilford = 16
 Halifax = 34
 Johnston = 26
 Lee-Harnett = 25
 Lenoir = 36
 Mecklenburg = 10
 Newse = 35

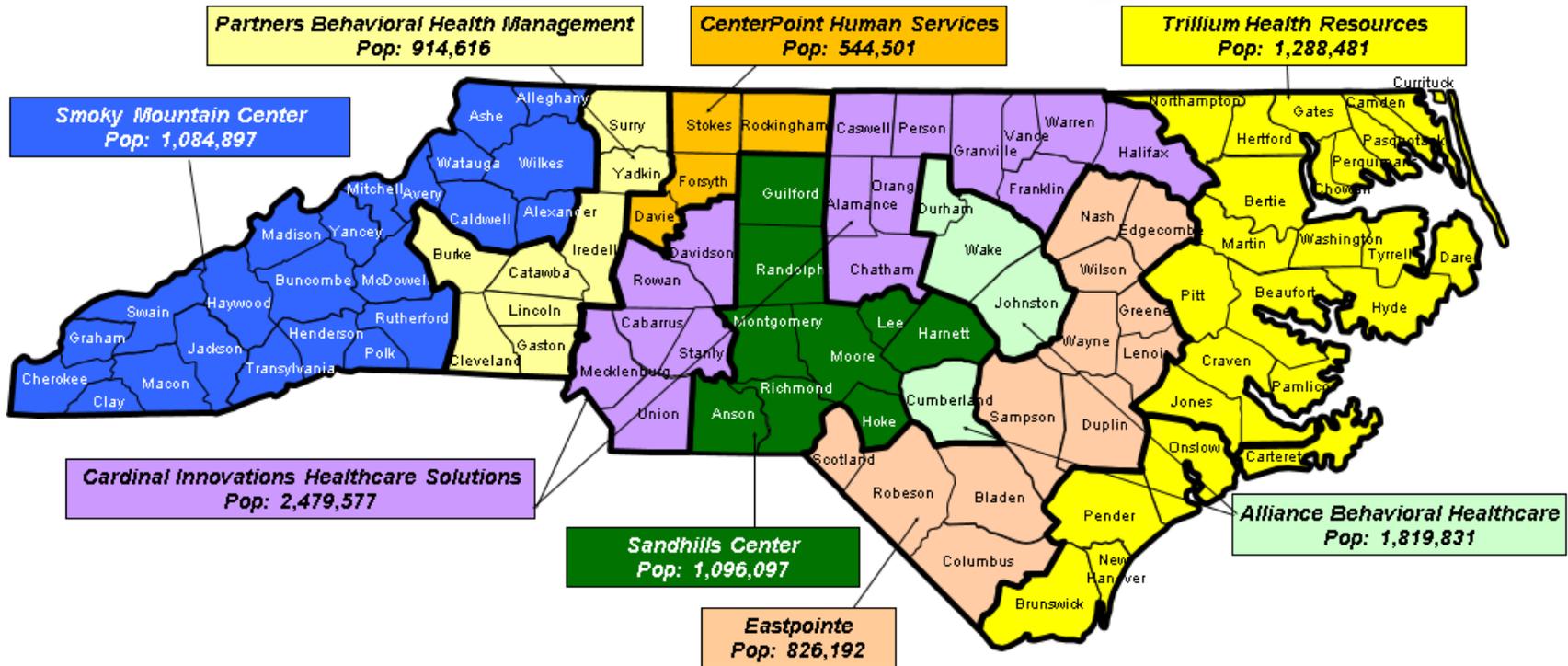
New River = 3
 Onslow = 30
 Orange-Person-Chatham = 18
 Piedmont = 12
 Pitt = 37
 Randolph = 28
 Roanoke-Chowan = 38
 Rockingham = 15
 Rutherford-Polk = 6
 Sandhills = 22
 Smoky Mountain = 1
 Southeastern Area = 29
 Southeastern Regional = 23
 Surry-Yadkin = 13
 Tideland = 39
 Tread = 4
 Tri-County = 11
 Vance-Warren-Crawville-Franklin = 20
 Wake = 27
 Wayne = 31
 Wilson-Greene = 32

1 = Smoky Mountain
 2 = Blue Ridge
 3 = New River
 4 = Tread
 5 = Foothills
 6 = Rutherford-Polk
 7 = Cleveland
 8 = Gaston-Lincoln
 9 = Catawba
 10 = Mecklenburg
 11 = Tri-County
 12 = Piedmont
 13 = Surry-Yadkin
 14 = Forsyth-Stokes
 15 = Rockingham
 16 = Guilford
 17 = Alamance-Caswell
 18 = Orange-Person-Chatham
 19 = Durham
 20 = Vance-Warren-Crawville-Franklin

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 32 = Wilson-Greene
 33 = Edgecombe-Wash
 34 = Halifax
 35 = Newse
 36 = Lenoir
 37 = Pitt
 38 = Roanoke-Chowan
 39 = Tideland
 40 = Albemarle
 41 = Duplin-Sampson

Historical Timelines

- 2000s
 - NC System Transformation – introducing of LME
 - Expanding Private Sector toward Managed Care
 - Increased protections related to ADA
 - Broader work of Robert Perske
- 2010s
 - Affordable Care Act
 - Expansion of ADA
 - Movement toward Managed Care
 - Expanding Community Inclusive Options
 - Rosa’s Law (remove “MR” from the health and education code)



- Reflects LME-MCOs and shows the population within their catchment area as of 7/1/15.
- Total NC population is 10,054,192. Source: NC OSBM July 2015 county single-age population estimates.
- Shows the merger of ECBH and CoastalCare forming Trillium Health Resources that occurred on 7/1/15.
- Information current as of 7/1/15.



NCCDD

Innovative Initiatives (projects)

Community Capacity Building Initiatives





Upward to Financial Stability

Contractor: National Disability Institute

Purpose: Promote opportunities for people with I/DD to advance economic self-sufficiency by developing financial literacy and asset building skills.

Activity: Deliver financial education to NC students with I/DD using train the trainer model, customize financial literacy curriculum for NCCDD, facilitate statewide asset summit, and leverage public/private sector partnerships to create a resource map and tools for key stakeholders.

Outcome: Develop policies, procedures and practices that promote opportunities for people with I/DD to advance economic self-sufficiency by developing financial literacy and asset building skills.

Emergency Preparedness for People with I/DD

Contractor: NC Department of Public Safety

Purpose: Implement and maintain an emergency preparedness program that is inclusive of persons with I/DD and builds capacity for disaster preparation, emergency response, and related procedures and systems.

Activity: Convene a Technical Advisory Board to advise with regard to persons with I/DD.

- 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.
- Medical - assess the incorporation of emergency preparedness training and disaster management.
- Functional Independence - identify emergency preparedness programs in which persons with I/DD can be educated on early disaster response.
- Supervision - establish a statewide standard to influence policy change, enabling the creation of an emergency preparedness plan for individuals with I/DD.
- 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.

Outcome: Improve the capacity of the North Carolina's emergency preparedness program to meet the needs of the state's disability population in the event of a disaster.



Project SEARCH

Contractor: Cincinnati Children's Hospital Medical Center

- **Purpose:** 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.
- **Activity:** Increase the number of licensed Project SEARCH program sites in North Carolina by adding six new programs.
 - Encourage family involvement in Project SEARCH through Family Involvement
 - Curriculum implementation in existing four Project SEARCH sites.
 - Collect data on all Project SEARCH program sites on student enrollment, job placement and job retention during funding cycle.
 - 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.
- **Outcome:** Create opportunities for youth and young adults with I/DD to transition out of high school to competitive employment.

NC ADA Network

Contractor: In-House Initiative/Karen Hamilton

Purpose: Support grassroots groups, led by people with disabilities, to conduct projects that promote voluntary compliance with the Americans with Disabilities Act (ADA) in their local communities.

Activity:

- Consult with grassroots groups to develop ADA project plans.
- Provide technical assistance and training to grassroots groups to carry out their plans
- Conduct leadership and ADA training for two grassroots groups.

Outcome: Build local compliance with the accessibility policies outlined in the Americans with Disabilities Act.



NC ADA Network: Fiscal Agent

Contractor: Alliance of Disability Advocate

Purpose: Support the grassroots efforts of local ADA affiliates by providing timely, accurate reimbursement for the funding of Network Affiliate Group ADA initiatives and participant travel/training expenses.

Activity: Process reimbursement requests and in-kind match documentation from the NC ADA Network within 15 days or less of remittance.

Outcome: Build local compliance with the accessibility policies outlined in the Americans with Disabilities Act.

Reaching the Summit of Success

Contractor: University of Massachusetts

Purpose: Provide students with intellectual disabilities opportunities to interact with other students within the context of a typical college environment, integrated with access to the activities and services a college provides its students.

Activity: Develop a statewide steering committee.

- Conduct a literature review of evidence-based transition and competitive employment practices.
- Create a Transition/Employment First strategic plan to include goals, objectives, timelines, responsibilities and implementation strategies targeted for policymakers, funding agencies, teachers and service providers.
- Convene three strategic planning summits in three different regions of the state.
- Convene a Statewide conference

Outcome: Increase employment outcomes of youth and adults with I/DD



Learning and Earning After High School: Raising Expectations and Attitudes for Students with Intellectual Disabilities

Contractor: Western Carolina University

Purpose: Create a sustainable approach to providing transition services and resources for students with intellectual disabilities, even those with the most complex disabilities. The approach will begin as early as middle school and continue through high school.

Activity:

- Conduct an environmental scan of literature.
- Identify three to four LEAs to test pilot
- Create a tool to measure skills, interests, and abilities for Middle School Students
- Test in three to four LEAs
- Expand to up to six LEAs

Outcome: Create best practice models in post secondary education to increase employment outcomes of youth and adults with I/DD, even those with the most complex of disabilities.

Disability Systems Change Initiatives



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

Contractor: Easter Seals/UCP

Purpose: Ensure people with I/DD receive the right care at right time in the right setting.

Activity: Develop a medical and health home model with cross systems collaboration informed by individuals and families, health networks, long-term support providers and policy stakeholders. An actionable model requires data-informed input on needs, gaps, existing capacity and outcomes.

Outcome: Identify a cost-effective model to serve the medical and long-term services and support needs of individuals with I/DD.

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

Contractor: National Association of State Directors of Developmental Disabilities Services

Purpose: Support consumer and family involvement in the redesign of the State's Medicaid Waiver program.

Activity: Conduct six stakeholder engagement sessions. The first session's facilitation will begin with agreed upon processes and outcomes for the workgroup and an initial overview of key MLTSS ("managed care") principles and practices for people with disabilities. Each of the other five meetings will center on topics outlined by the National Council on Disability's Managed Care Principles and CMS Guidance to States Using 1115 Demonstrations or 1915(b) Waivers for Managed Long Term Services and Supports Programs in the context of North Carolina Medicaid Reform activities.

Outcome: Educate stakeholders to make informed decisions regarding Medicaid and managed long term services and supports (MLTSS); Provide consumer and family insight and expectations to those directing Medicaid changes; Inform and engage local constituent groups in the decision making process.





Bridging Practice and Policy: Transitions from Adult Care Homes

Contractor: Disability Rights North Carolina

Purpose: Assist individuals with intellectual and developmental disabilities to transition from Adult Care Homes to homes of their own, with the appropriate services and supports.

Activity: Identify adult care homes in North Carolina where individuals with I/DD reside. Identify any barriers that exist for individuals with I/DD who want to move from the ACH to the community and provide supports necessary to make the move.

Outcome: Create a cost-effective, policy and practice blueprint for transition of people with I/DD who currently reside in Adult Care Homes and prefer to live in the community.



Rethinking Guardianship: Building A Case For Less Restrictive Alternatives

Contractor: Division of Aging and Adult Services

Purpose: Develop models for less restrictive alternatives to guardianship with the work of multiple stakeholders such as judges, attorneys, family members, policy makers, and providers.

Activity: Identify all relevant stakeholders for a series of meetings to identify the barriers to alternatives to guardianship using the collective impact model for systems change; review the WINGS model used by other states and make recommendations for its adoption in North Carolina; explore data collection systems to be used to track reporting on public and private guardians.

Outcome: Create alternatives to guardianship that will be implemented statewide.

Advocacy and Leadership Initiatives

Sibling Support

Contractor: First in Families, NC

Purpose: Work with siblings on key issues regarding isolations, information sharing, education, alternatives to guardianship, and future planning.

Activity: Conduct a survey to identify existing supports and gaps, listening tours and sib chats to engage siblings in how best to support their roles, and to establish a North Carolina Chapter of the National Sibling Leadership Network.

Outcome: Engage siblings in communication and advocacy, greater understanding of the needs of siblings to enhance the current system, create a network of communication between sibling and providers to ensure system responds to the needs and expectations of family members now and in the future.

Advocacy Ambassadors

Contractors: Mike Mayer/Monica Foster, Barton Cutter, Jonathan Ellis, Matt Potter

Purpose: 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.

Activity: Visit all local self-advocacy groups to gather information regarding each group's:

- Organizational needs for technical assistance and support;
- Current or potential collaborative relationships;
- Membership base and active membership, level of activity, and type of activities.

Outcome: Develop a statewide network of self-advocates with I/DD and support this network in sharing their voice through education, advocacy, and participation in the policy-making process.

NC Chapter of the National Alliance for Direct Support Professionals

Contractor: Benchmarks, Inc.

Purpose: Establish a North Carolina 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.

Activity: Convene no less than 4 kick-off events in the first year in various regions of the state and one state-wide DSP conference. Establish a self-sufficient local chapter of the NADSP with 501(c)(3) status to advance direct support as a profession. Create a website and a list-serve of chapter members to disseminate information, Represent NC NADSP at the national level through at least one meeting with NADSP.

Outcome: Advance best practices in providing direct support to people with disabilities; connect and empower DSPs to participate in system design and implementation at the state and national level; and promote respect and quality outcomes across the field.





Advancing Strong Leaders in Developmental Disabilities

Contractor: University of Delaware

Purpose: Support emerging leaders and provide them with the information needed to become transformational leaders in the I/DD field.

Activity: Conduct a leadership institute; quarterly workshops, monthly webinars, teleconferences, and mentoring for program participants.

Outcome: Educate and train early career leaders on I/DD to become transformational leaders in service delivery and public policy that impact the lives of individuals and their families



Partners in Policymaking

Contractor: Advocacy Institute, Inc.

Purpose: Deliver leadership and advocacy training according to the replication training model for parents and self-advocates.

Activity: Teach leadership skills, and the process of developing positive relationships with elected officials and other individuals who make policy decisions about services used by North Carolinians.

Outcome: Build a network of informed self-advocates, parents, and other family members in North Carolina who have the skills needed to education, advocate, and impact public policy in our state.





Safety and Security: Addressing Sexual Violence and Domestic Violence Against People with Intellectual and/or Developmental Disabilities

Contractor: The Rape Crisis Center of Coastal Horizons, Inc.

Purpose: Equip staff, throughout the state, with the tools to prevent domestic violence and sexual violence; to assist staff in recognizing the signs of domestic violence and sexual violence; and to intervene effectively with victims with I/DD or those with I/DD who are at risk of victimization. Training modules developed under this initiative will be based on evidence-based practice, best practice, or promising practices and have a target population of 1) frontline staff (direct support professionals in the field of I/DD) and their supervisors and 2) the staff of community programs offering domestic and sexual violence prevention programs for the general public.

Activity: 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.

Outcome: Ensure that individuals with I/DD who are victims of sexual assault and domestic violence have access to appropriate resources and a network of providers who have the unique skill set to help when needed.

Cross Cutting Initiatives



Jean Wolff-Rossi Fund

Contractor: In-House

Purpose: Enhance the likelihood that Council-funded initiatives produce lasting, systemic changes.

Activity: Provide funding for people with I/DD and families to participate in diverse learning forums, garnering information through participation in conferences and other learning events.

Outcome: Increase the number of self-advocates and family members and build their knowledge base necessary to make informed choices, enhance advocacy and impact public policy.

Council Development Fund

Contractor: In-House

Purpose: 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.

Activity: Coordinate presentations for quarterly Council meetings by local, state, and national experts on topics related to the NCCDD State Plan. At least annually, provide board membership training to new and existing members.

Outcome: Ongoing education of Council members to ensure that State Plan and subsequent initiative funding decisions are based on best practices and represent well-timed opportunities and action for systems change.

Communications Contract

Contractor: O'Neill Communications, Inc.

Purpose: Provide funding/resources to promote awareness of Council initiatives.

Activity: Provide marketing and outreach for initiatives.

- Create accessible communication materials.
- Strengthen media relations to further the image of the Council and its programs.
- Work with grantees to promote the objectives of grants and assist with marketing/recruitment efforts required for the initiative.

Outcome: Disseminate information about the Council and its grant initiatives in order to meet the Council mandate for education, advocacy, and systems change.

Council Funding Initiative

Contractor: In-House

Purpose: Ensure high quality training events and conferences through support for expert presentations on best practices and cutting edge policy I/DD issues

Activity: Provide funding for expert presentations at various conferences and training events.

Outcome: Educate professionals, self-advocates, family members, and the general public about best practices and policies that impact the ability of individuals with I/DD to achieve their life goals.

Public Policy Initiative

Contractor: In-House

Purpose: Provide public policy analysis, enabling the Council to utilize the best available data, research, and practical experiences to inform and advance its mission.

Activity: Monitor and analyze state and national legislation and regulations.

- Partner with other policy organizations.
- Provide technical assistance to self-advocates and grass roots organizations.
- Work with Council funded grantees and initiatives to identify policy implications and advocate for systems change.
- Develop multi-year research and policy development plan consistent with Council mission.
- Support the Council, staff, and communications team on public policy and best practice models.
- Prepare papers, articles, policy briefs, and other policy documents as directed.

Outcome: Ensure people with I/DD and their families have the information and supports necessary to affect public policy at the local, state, and national levels.



Transitioning Systems

- National Core Indicators
- Personal Outcomes

National Core Indicators

National Core Indicators (NCI), a joint venture between the National Association of State Directors of Developmental Disabilities Services and the Human Services Research Institute, has been in operation since 1997.

- 43% of respondents from North Carolina reported they chose or had some input in choosing their where they live.
- 3% of respondents from North Carolina are using a self-directed supports option.
- 62% of respondents from North Carolina reported they chose or were aware they could request to change their home staff.
- 14% of respondents from North Carolina were reported to be working in community-based employment.
- 75% of respondents from North Carolina reported they have a best friend (who may be staff or family).



Personal Outcome Measures Data

The Council On Quality and Leadership established the Personal Outcome Measures database in 1993. 43% of respondents from North Carolina reported they chose or had some input in choosing their where they live.

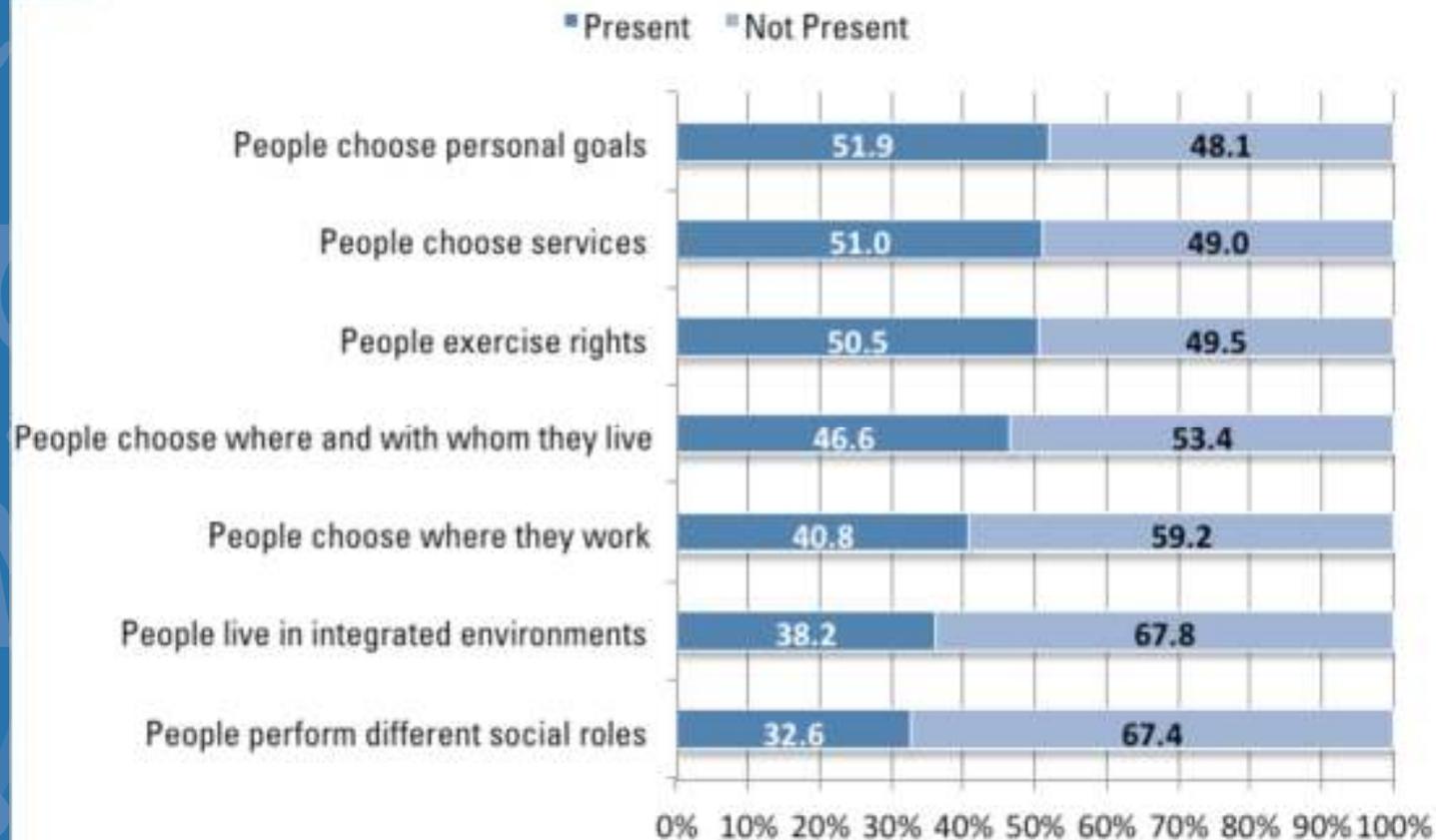
Based on over 8,200 people interviews conducted during CQL Accreditation visits for 20 years, findings reveal:

- *Safety, security, and health are well supported in these organizations*
- *Exercising meaningful choice in important life decisions remains a challenge for most people*
- *Community integration and enhanced social roles are the least likely to be present in people's lives*

Setting the Bar for Quality: The Personal Outcome Measures® National Database 20th Anniversary Report



Personal Outcome Measures Findings

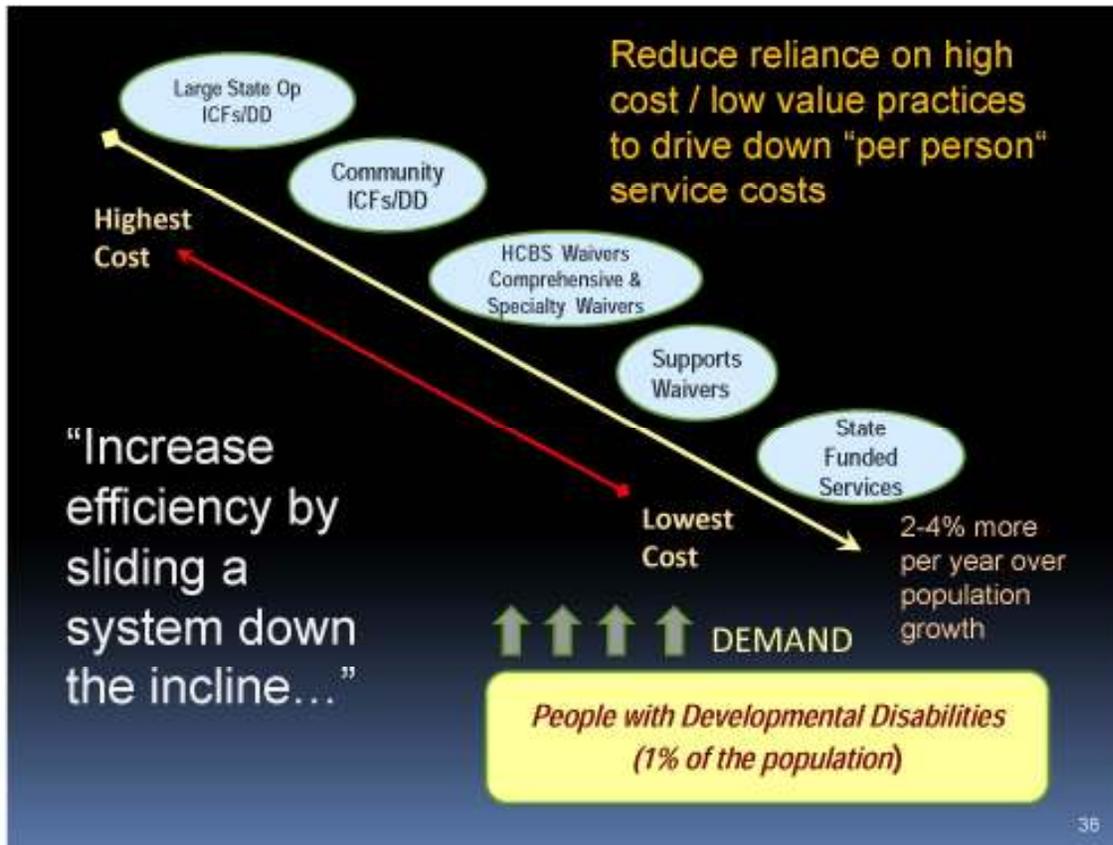


The regression analysis revealed these outcomes to have the greatest degree of predicting many more outcomes for the person:

- Exercising rights
- Choosing where to live
- Choosing where to work
- Performing different social roles

Setting the Bar for Quality: The Personal Outcome Measures® National Database **20th Anniversary Report**
(The Council on Quality and Leadership www.thecouncil.org)

Goals for System Transition



In comparison to many other states, North Carolina remains heavily vested in institutional models of support for people with intellectual and developmental disabilities. Yet, greater personal outcomes and cost savings are achieved when moving toward integrated approaches.

Evolving Federal Perspective

- Measures of Quality
- Person and Family Centered and HCBS
- National Core Indicators
- WIOA
- ABLE Act
- Medicaid Buy-in

Resources & References

- NC Council on Developmental Disabilities website
- National Association of Councils on Developmental Disabilities
- Human Service Research Institute: Strategic Analysis for Change, August 2011
- Setting the Bar for Quality: The Personal Outcome Measures® National Database **20th Anniversary Report, 2013**
- NCI Adult Consumer Survey Outcomes - North Carolina Report 2011-2012 Data
- Susan L. Parish, S., Roderick A. Rose, R., Michal Grinstein-Weiss, M., Erica L. Richman, R., & Megan E. Andrews, M. (2008). Material hardship in U.S. families raising children with disabilities. 75(1), 71-92.
- Phil Smith and John O'Brien (2007) Have We Made Any Progress? Including Students With Intellectual Disabilities in Regular Education Classrooms. Intellectual and Developmental Disabilities: October 2007, Vol. 45, No. 5, pp. 297-309.
- North Carolina DD Consortium Public Policy Statement on DD System Design, 2012
- The SEG Way to a Healthy North Carolina: Report of the NCCDD Funded NC Stakeholder Engagement Group Initiative, March 2014
- US Department of Labor Office of Disability Employment Policy
- US Department of Labor, Employee Assistance Referral Network (EARN) Accessed 2014
www.earnworks.com