



NCCDD
North Carolina Council on
Developmental Disabilities

Five Year State Plan 2022 – 2026



Listen. Gather. Act.

Grant Number: 2001NCSCDD

Authorization Method: State Statute

Authorization Citation: NC State Statute 143-B, Sections 177 – 179

NCCDD FFY 2022 – 2026 Five-Year State Plan Package

NC Department of Health and Human Services

Council on Developmental Disabilities

2010 Mail Service Center

Raleigh, NC 27699--2010

Grant Number: 2001NCSCDD

IDENTIFICATION

Part A: State Plan Period: 10-01-2021 through 09-30-2026

Part B: Contact Person: Talley Wells

Contact Number: 919-527-6500

Contact Email: Talley.Wells@dhhs.nc.gov

Part C: Council Establishment

Date of Establishment: 07-01-2013

Authorization Method: State Statute

Authorization Citation: NC State Statute 143-B, Sections 177 – 179

Council Membership Section [Section 125(b)(I)-(6)]

Council Membership Rotation Plan*

The North Carolina Council on Developmental Disabilities' non-agency and public at large members are appointed by the Governor for a four (4) year term and may serve up to two (2) consecutive terms. The Senate and House of Representative members serve at the pleasure of the Governor. State entities that administer funds provided under federal law related to individuals with developmental disabilities, non-governmental, not for profit, and Department of Corrections and Division of Social Services representatives are typically the division or agency director and serve at the pleasure of the Governor while employed in that position.

Agency/Organization

Rehab Act : A1

IDEA : A2

Older Americans Act : A3

SSA, Title XIX : A4

P A : A5

University Center(s) : A6

NGO/Local : A7

SSA/Title V : A8

Other : A9

Individual with DD : B1

Parent/Guardian of child : B2

Immediate Relative/Guardian of adult with mental impairment : B3

Individual now/ever in institution : C1

Immediate relative/guardian of individual in institution : C2

Gender

- Male: M
- Female: F
- Other: O
- Geographical
- Urban : E1
- Rural : E2
- Race/Ethnicity
- White, alone : D1
- Black or African American alone : D2
- Asian alone : D3
- American Indian and Alaska Native alone : D4
- Hispanic/Latino : D5
- Native Hawaiian & Other Pacific Islander alone : D6
- Two or more races : D7
- Race unknown : D8
- Some other race : D9
- Do not wish to answer : D10

Council Members

First Name	Last Name	MI	Gender	Race/ Ethnicity	Geographical	Agency/ Organization Code/Citizen Member Representative	Agency/ Organization Name	Appt Date	Appt Expired Date	Alt/Proxy for State Agency Rep Name
Karey	Perez		F	D1	E1	A3	NC DHHS Division of Aging and AdultServices	05-08-20	06-30-24	Sarah Smith
Sandy	Terrell		F	D1	E1	A4	NC DHHS Division of Medical Assistance	03-27-15	06-30-23	Deb Goda
Kathie	Trotter		F	D2	E1	A1	NC DHHS Division of Vocational Rehabilitation	08-19-19	06-30-22	
Victor	Armstrong		M	D2	E1	A9	NC DHHS Division of MH/ DD/SAS	04-13-20	06-30-22	Mya Lewis
Kelly	Kimble		F	D1	E1	A8	NC DHHS Division of Women's and Children's Health	12-05-16	06-30-22	Danielle Matula

Carla	West		F	D1	E1	A9	NC DHHS Division of Social Services	01-27- 21	06-30-22	TeresaStrom
Nessie	Siler		F	D1	E2	B1		01-08-15	06-30-24	
William	Miller		M	D1	E1	B1		07-15-17	06-30-24	
Bryan	Dooley		M	D1	E2	B1		07-27-16	06-30-24	
Aldea	LaParr		F	D1	E1	B1		07-15-17	06-30-25	

Katherine	Boeck		F	D1	E2	B1		07-15-17	06-30-25	
Brendon	Hildreth		M	D1	E2	B1		07-15-17	06-30-25	
Cheryl	Powell		F	D1	E1	B1		01-07-15	06-30-23	
Ryan	Rotundo		M	D1	E2	B3		07-11-18	06-30-22	
Laura	Richardson		F	D4	E2	B2		09-30-20	06-30-24	
Daniel	Smith		M	D1	E1	B2		07-15-17	06-30-25	
Allison	Dodson		F	D1	E2	B3		07-11-18	06-30-23	

Charlrean	Mapson		F	D2	E2	B2		07-01-21	06-30-25	
Rebecca	NgPutnam		F	D1	E2	B2		7-01-21	06-30-25	
Dale	Stephenson		F	D1	E1	B2		07-15-17	06-30-25	
Myron	Gavin		F	D2	E2	B2		12-12-16	06-30-22	
Kerri	Eaker		F	D1	E2	C2		12-12-12	06-30-25	
Joshua	Gettinger		M	D1	E2	B2		01-08-15	06-30-22	
NaKima	Clark		F	D2	E1	B2		07-15-17	06-30-25	
Tony	Hall		M	D2	E1	B1		07-01-21	06-30-25	
Kristy	Locklear		F	D4	E2	B2		07-20-18	06-30-22	
Ronnie	Marshall		M	D1	E1	B1		09-01-20	06-30-24	
Marjorie	Serralles-Russell		F	D5	E1	B2		12-04-19	06-30-23	

Joseph	Piven		M	D1	E1	A6	Carolina Institute on Developmental Disabilities-UNC	01-01-13	06-30-22	Deb Zuver
Virginia	Knowlton Marcus		F	D1	E1	A5	Disability Rights NC	03-28-19	06-30-25	
Peggy	Terhune		F	D1	E2	A7	Monarch	10-08-13	06-30-25	
Rhonda	Cox		F	D1	E2	A9	VAYA Health-Non-Profit	01-01-20	06-30-25	Judith Kirkman
Dawn	Allen		F	D1	E1	A9	Public at Large	08-10-18	06-30-22	
Kayla	McMillan		F	D1	E1	B1		04-03-20	06-30-25	
Donna	Spears		F	D1	E1	B2		08-19-19	06-30-23	

Council Staff [Section 125(c)(8)(B)]

Disability data of Council staff will be collected. Response is voluntary, and information shared will be kept confidential and serve for data purposes only. Self-identification of disability will be captured in the following manner:

Race/Ethnicity

- White, alone : D1
- Black or African American alone : D2
- Asian alone : D3
- American Indian and Alaska Native alone : D4
- Hispanic/Latino : D5
- Native Hawaiian & Other Pacific Islander alone : D6
- Two or more races : D7
- Race unknown : D8
- Some other race : D9
- Do not wish to answer : D10

- Disability Options
- Yes : Y
- No : N
- Does not wish to answer : DWA

Gender

- Male : M
- Female : F
- Other : O

First Name of person in position	Last Name of person in position	MI	Disability	Race/Ethnicity	Gender	Position or Working Title	FT	PT
Travis	Williams		Y	D2	M	Systems Change Manager	•	<input type="radio"/>
Talley	Wells		N	D1	M	Executive Director	•	<input type="radio"/>
Cora	Gibson		N	D2	F	Administrative Assistant	•	<input type="radio"/>
Tamira	White		N	D2	F	Systems Change Manager	•	<input type="radio"/>
Philip	Woodward		Y	D1	M	Systems Change Manager	•	<input type="radio"/>
Shar'ron	Williams		N	D2	F	Business Services Coordinator	•	<input type="radio"/>
Vacant	Vacant		DWA	D10	O	Director of Operations	•	<input type="radio"/>
LaQuadia	Smith		N	D2	O	Business Officer	•	<input type="radio"/>
Letha	Young		N	D2	F	Office Assistant	•	<input type="radio"/>
Melissa	Swartz		N	D7	F	Systems Change Manager	•	<input type="radio"/>

Designated State Agency

The DSA is :other

Agency Name: Office of the Secretary, NC Department of Health and Human Services

DSA Official's name: Mandy Cohen, MD DHHS Secretary

Address*Adams Building, 101 Blair Drive, Raleigh, NC 27699

Phone*919-855-4800

FAX 919-855-4801

Email: mandy.cohen@dhhs.nc.gov

Direct Services [Section 125(d)(2)(A)-(B)]

Does it provide or pay for direct services to persons with developmental disabilities? Yes

Describe:

The Office of the Secretary is within the NC Department of Health and Human Services (DHHS). DHHS manages the provision of services for anyone receiving Medicaid for services.

DSA Roles and Responsibilities related to Council [Section125(d)(3)(A)-(G)]

Describe how the DSA supports the Council: The role of the Office of the Secretary is consistent with the description in the DD Act of the responsibilities of the DSA

Memorandum of Understanding/Agreement [Section 125(d)(3)(G)]

Does your Council have a Memorandum of Understanding/Agreement with your DSA?: Yes

Calendar Year DSA was designated [Section 125(d)(2)(B)]: 1973

State Information

Comprehensive Review and Analysis Introduction:

Include a broad overview of the Comprehensive Review and Analysis conducted by the Council. Below is information that can be included in the Introduction:

- The Council's state planning process including obtaining multi-stakeholder and **culturally diverse** input to develop the CRA; the process used to identify state plan goals and objectives.*
- Any data, research and/or information that influenced the Council's goal selections.*
- How information was gathered from focus groups including information gathered directly from a **culturally diverse group** of people with developmental disabilities and their families.*
- Information on any federally assisted State programs, plans and policies that are not included in Parts A-D*

Other, broader issues, such as social policy, culture change, funding issues, etc. that are not incorporated into Parts A-D.

In spite of the pandemic – or maybe even because of the pandemic – The North Carolina Council on Developmental Disabilities (NCCDD) engaged in robust conversations with individuals with I/DD, families of individuals with I/DD, the Hispanic/Latin-x Community, state leaders and stakeholders to develop the Council's Five-Year Plan for 2022-2026. The 18-month process of developing the Five-Year Plan began in February 2020 just as the pandemic was beginning to hit the news. The Council originally planned listening sessions in communities across North Carolina from the coast to the mountains and many communities in between. These plans had to quickly change to virtual listening sessions as the pandemic caused an end to public meetings across the state.

The Council redoubled its efforts to ensure robust attendance at its now listening sessions and to ensure survey responses from individuals with intellectual and developmental disabilities (I/DD), family members and stakeholders. Ultimately 326 individuals attended one of the Council's nine virtual listening sessions. This included thirty-three individuals who attended the young self-advocates listening session, fifty-one individuals who attended the Council's self-advocacy listening session, and fifty-two individuals who attended the Council's Hispanic/Latin-x listening session. The rest attended the six regional listening sessions. Seven Hundred and four people filled out the Council's surveys for its Five-Year Plan.

Council staff and the Council also engaged in several discussions during the Five-Year Planning process on diversity, equity and inclusion. This included a full day staff learning and discussion day on how to increase the Council's diversity, equity and inclusion in all aspects of our work. The Council joined a Diversity, Equity, and Inclusion Committee with the Department of Health and Human Services. While that work is just beginning, the Council will be including both Council members and staff in this work. The increased focus on Diversity, Equity and Inclusion informed the Five-Year Planning throughout the process. Of the surveys from individuals with I/DD the Council received, 19% were from respondents who were Black or African American, 5% from Hispanic/Latinx, 4% from Native Americans; 3% Asian; 1% Native Hawaiian or Pacific Islander; and 68% White. Family member respondents were 10% African American; 5% Hispanic; 4% Asian; 2% Native American and 80% White.

The Council had a strong Five-Year Planning Ad Hoc Committee that met monthly for most of the 18 months of the planning process. The Planning Committee was chaired by Sandra Terrell, Director of Clinical Services, Division of Medical Assistance. The Committee included five family Council members of individuals with I/DD, three Council members who were self-advocates, the Executive Director of the state's protection and advocacy organization; and an agency representative from the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services.

The following are top themes that the Council heard from the listening sessions for each region of the state and the targeted listening sessions: Mountain region -- the Registry of Unmet Needs (the waiting list) and Independent Living; Central Region -- The Registry of Unmet Needs and Employment; the Eastern Region – the Registry of Unmet Needs and

Transportation/Isolation; Self-advocates – Housing and Employment; Youth Self-Advocates – Independent Living and Employment; and Hispanic/Latin-x – Registry of Unmet Needs and Transition to Employment.

Of the 704 surveys responses the Council received, it received 204 surveys from individuals with I/DD (about half of which appeared to have been filled out by family members), 359 surveys from family members, and 141 surveys from community members. The Council collected and examined demographic and regional information related to who filled out the surveys. The most important issues identified by individuals who filled out the surveys were in order as follows (with each receiving over 20% as a top three issue): Employment; Getting the Services and Supports I Need; School/Education; Money and Finances; Planning for My Future; Having Friends and Relationships; Housing; and Transportation. The most important issues identified by family members (with each receiving over 20% as a top three issue) were: Getting the Services and Supports They Need; Employment; School/Education; Housing; Knowing What Services and Supports are Available; Planning for the Future; and Having Friends and Meaningful Relationships. Community respondents identified the following top three issues (each receiving over 20%): Getting the Supports and Services They Need; Employment; Being More a Part of the Community; Housing; and Transportation.

Based on this feedback from the community in addition to the Council's five-year planning research and work, the Council developed its draft Goals and Objectives for the 2022-2026 Five Year Plan. The process for developing the Goals and Objectives included discussion at the Council meeting of the information obtained at the listening sessions and surveys. Then, the Council held a half day facilitated virtual retreat with the Planning Committee. Finally, the Council brought the Goals and Objectives back to the Council as a final draft for discussion. The Council then released the Goals and Objectives for Public Comment during the period of March 1, 2021 through April 14, 2021. The Council received 117 responses. These responses were reviewed and discussed by the Planning Committee on April 23, 2021. The Council then further discussed the comments with the Council at its May 2021 Council meeting. After discussion and review of the Public Comments, the Council approved the draft Goals and Objectives and determined there was not a need to revise the Goals and Objectives and resubmit for Public Comment.

Describe how the DSA (Designated State Agency) supports the Council

North Carolina's Designated State Agency is the Department of Health and Human Services. The DSA was involved throughout the development of the Five-Year Plan. The Planning Committee was chaired, as stated above, by Sandra Terrell, Director of Clinical Services at the Division of Medical Assistance. The committee also included Mya Lewis, who is with the Division of Mental Health, Developmental Disabilities and Substance Abuse Services. Representatives from the DSA attended a number of the Council's listening sessions and most, if not all, of the meetings to develop the Goals and Objectives. While the DSA was an active participant in the Five-Year Planning process, the DSA was most interested in hearing from the I/DD community as to what should be in the Five-Year Plan. The process was collaborative with self-advocates, family members, agency representatives, and staff working together to develop the Five-Year Plan based on the input and feedback of the state's I/DD community.

The Information and Technical Assistance Center for Councils and guidance from the National Association of Councils on Developmental Disabilities supported the NCCDD in developing responsive priorities for the next five years. In the subsequent sections of this document and in the attachments, the NCCDD discusses and provides documentation of its strategic planning activities to produce the Comprehensive Review and Analysis that underpins the FFY 2022 -2026 State Plan for this Council. The State Plan guides the Council's investments in systems change for this period.

Poverty Rate Percentage: 13.6 (entire population)

Racial and Ethnic Diversity of the State Population

Race/Ethnicity	Percentage Of Population
Do not wish to answer*	0
Two or more races*	2.3 (no change)
Asian alone*	3.2
Race unknown*	4.3
Hispanic or Latino (of any race)*	9.8
American Indian and Alaska Native alone*	1.6
Black or African American alone*	22.2
White, alone*	70.6 or 62.6
Native Hawaiian & Other Pacific Islander alone*	0.1 (no change)
Some other race*	3.1

State Disability Characteristics

Prevalence of Developmental Disabilities in the State: 197304

Explanation:

Using the NC Office of State Budget and Management preferred formula of 1.89 of the population and the 2019 NC Office of State Budget and Management certified population of [10.44 million] 10,439,388 people, provides an estimate of 197304 persons with developmental disabilities in NC

Residential Settings

Year	Total Served	A. Number Served in Setting of 6 or less (per 100,000)	B. Number Served in Setting of 7 or more (per 100,000)	C. Number Served in Family Setting (per 100,000)	D. Number Served in Home of Their Own (per 100,000)
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2017	17513	0.163	0.033	0.1	0.136
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Demographic Information about People with Disabilities

People in the State with a disability

People in the State with a disability	Percentage
Population 18 to 64 years*	9.4
Population 5 to 17 years*	5.7
Population 65 years and over*	34.3

Race and Ethnicity	Percentage
Do not wish to answer*	0
Some other race alone*	8.2
Asian alone*	4.4
White alone*	13.6
Two or more races*	13.1
Hispanic or Latino (of any race)*	6.3
Black or African American alone*	14
American Indian and Alaska Native alone*	20.8

Educational Attainment Population 25 and Over

Educational Attainment Population Age 25 and Over	Percentage with a disability	Percentage without a disability
Bachelor's degree or higher*	8.4	91.6
Less than high school graduate*	11.7	88.3
High school graduate, GED, or alternative*	19.5	80.5
Some college or associate degree*	14.2	85.8

Employment Status Population Age 16 and Over

Employment Status Population of *Working Age	Percentage with a disability	Percentage without a disability
Employed* 21 and over	35.3	77.4
Not in labor force*	Unknown	Unknown

Earnings in Past 12 months Population Age 16 and Over with Earnings

Civilian Non-Institutionalized Population in North Carolina (Age 16+)	Median Income
Average Income for Individuals with a Disability (Last 12 Months Age 16+)	\$23,236
Average Income for Individuals without a Disability (Last 12 Months Age 16+)	\$34,894

Poverty Status Population Age 16 and Over

Poverty Status Population Age 18+	Percentage with a Disability	Percentage without a Disability
Below 100% Poverty Level	19.6%	10.5%
100% to 149% of Poverty Level	13.1%	7.5%
150%+ of the Poverty Level	67.3%	82.0%

Portrait of State Services [Section 124(c)(3)(A)(B)]

Recreation

Recreational, leisure, and social activities are important to people with intellectual and other developmental disabilities (I/DD) because they offer important physical and psychological health benefits and opportunities to build social capital. According to the Centers for Disease Control’s (CDC) Disability and Health Data System for 2017, 40.7% of North Carolinians with a

disability were obese and 40.3% were considered inactive. The types of disabilities in North Carolina included 14% mobility impairments (serious difficulty walking or climbing stairs); 11.2% cognition (serious difficulty concentrating remembering or making decisions); 4.1% self-care (difficulty dressing or bathing).

A variety of recreational, leisure, and social activities are available across North Carolina to individuals with I/DD, and a number of resources exist to assist individuals and their families in finding these opportunities. North Carolina has a travel guide entitled ACCESS North Carolina, which is a comprehensive guide listing detailed accessibility information about tourist attractions such as state parks, zoos and museums for people with disabilities, their families and their travel companions. ACCESS North Carolina is offered in English and Spanish in print and on-line. Although the ACCESS North Carolina program no longer exists, the guide is available on-line in English and Spanish, and tourist attractions across North Carolina have showed an interest in or demonstrated a commitment to increasing accessibility for visitors with disabilities. For example, an organization named Ocean Cure in Carolina Beach sets up a beach access mat every summer to help people with mobility disabilities access the beach in their standard wheelchairs. NCCDD members got to see and experience this at the Council's May 2019 quarterly meeting in Carolina Beach.

New wheelchair-accessible playgrounds have opened during the past five years, including the Sassafras All Children's Playground in Raleigh, where NCCDD hosted its Americans with Disabilities Act (ADA) 27th anniversary celebration in July 2017; the All-Abilities Playground at the Recreation Park in Waynesville; and Harmony Playground in Clayton. The Southport. In 2020, it was announced that a small museum in the Cape Fear region called the Southport Maritime Museum has earned a big distinction: The North Carolina Maritime Museum at Southport is the state's first Certified Autism Center.

Other NC organizations that provide accessible recreation opportunities to people with I/DD across the state include Bridge II Sports, the University of North Carolina at Wilmington's Coastal Carolina Partnership for Accessible Recreation (CCPAR), Beech Mountain's Disabled Sports USA, Special Olympics North Carolina, and NC Miracle Leagues in Cary, Raleigh, Charlotte, High Point, and Wilmington. In addition to outdoor recreation, many museums such as the North Carolina Museum of Art (NCMA) and the North Carolina Museum of Natural Sciences (NCMNS) have continued to offer programming geared toward people with disabilities, including the NCMA offering tours of special exhibits in American Sign Language (ASL) and feedback sessions to gain feedback from people with disabilities on enhancing their visitor experience.

Transportation

A lack of affordable and reliable transportation is a major consideration for individuals with I/DD to fully participate in civic engagement activities, recreational and fitness opportunities, volunteer opportunities, and limits the choices where a person can live. Transportation was listed as one of the three most important issues the Council should focus on by over 20% of individuals with I/DD surveyed by the Council in 2020 and by over 20% of community stakeholders. It was also named at our Eastern Region listening session as a critical issue for the Council to focus upon. It is important to note that the Eastern region of the state tends

to be poorer and more rural and more diverse demographically than the central region of the state.

North Carolina has 98 public transportation systems, including:

- 65 community transit systems
- 15 urban single-city systems
- 1 fixed route in small cities system
- 3 consolidated small city-community systems
- 7 regional community systems
- 5 consolidated urban-community systems
- 2 regional urban systems

These systems served more than 70 million passengers in 2019.

In 2018, NCDOT launched the NC Moves 2050 Plan that, according to its website, is “a strategic transportation plan that focuses on shaping the future of transportation in North Carolina.” Fact sheets available on its website detail its overview, transportation needs, strategies for transportation success, alternative futures, drivers and opportunities, and the state of the system. NCCDD staff and members participated in the feedback process and helped to host focus groups, ensuring representation by people with disabilities and a recognition of the importance of including people with disabilities and senior citizens who may be unable to drive. The State of the System fact sheet states that the plan’s mission is: Improve quality of life for North Carolinians by:

- Building healthy communities.
- Supporting job creation and economic development.
- Providing equal opportunities so all people can thrive.

Transit plays an integral role in strengthening communities, providing access to employment and to employees and enabling people to thrive in urban and rural places across the state. The 2019 State Rehabilitation Council Annual Report covering the NC Division of Vocational Rehabilitation Services notes transportation barriers for people with disabilities. The Council’s Consumer Input and Public Outreach Committee gathered input at public forums held in Cherokee and Lumberton. In Cherokee, attendees mentioned how transportation impacts employment opportunities in the area, while participants in the Lumberton session noted that transportation was a barrier due to system capacity, time restrictions for picking up or dropping off for appointments or work. Self-advocates participating in NCCDD’s Five-Year State Plan listening sessions also shared similar concerns regarding transportation barriers, particularly in rural eastern North Carolina. Related to these barriers, NCDOT did receive a Mobility for All Pilot Program federal grant in 2020 that would fund the development of a scheduling software to allow people with disabilities in the Elizabeth City region in northeastern North Carolina to schedule rides for employment or health-related reasons. NCDOT expects this pilot to start in 2021.

Para-transit Watch lists six para-transit providers in North Carolina in Raleigh, Durham, Chapel Hill, Greensboro, Winston Salem, and Charlotte. Para-transit riders must meet eligibility requirements and complete an application for certification every two years. Costs have increased, and more of the trip must be covered by the rider. Some re-certification

requirements were waived in 2020 during the COVID-19 pandemic, and some entities such as the City of Raleigh waived fares for transportation services during the pandemic.

Transportation was made available in 2021 for all individuals ages 12 and older to obtain the vaccine for the COVID-19 shot. The North Carolina Department of Transportation, with assistance from NCCDD, applied for and received federal transportation dollars for a pilot project in five Northeastern North Carolina counties to schedule and obtain transportation for individuals with disabilities. The award was announced in 2020. Medicaid funds transportation to medical appointments for individuals with Medicaid across the state. It is arranged for and provided by the local county Department of Social Services.

Housing

In FY 2017, according to the State of the States, 2,095 individuals with I/DD lived in 16+ person settings with 205 living in nursing facilities, 1,125 in state institutions, and 765 in private ICF/IDD. An additional 265 lived in 7 to 15-person private ICF/IDD and 33 lived in other 7-15 person residential settings. 15,120 lived in less than six-person residential settings, including 1,132 in private ICF/IDD, 10,096 in Supported Living and 3,892 in other residential settings. The 2017 State of the States in Intellectual and Developmental Disabilities reports that in NC, persons with I/DD living in nursing facilities decreased from 959 in 2013 to 203 in 2017. Individuals with I/DD living in public and private ICFs-IID (intermediate care facilities for individuals with intellectual disabilities) decreased from 2,485 in 2013 to 2,162 in 2017. Those living in state institutions totaled 1,125 in 2017, down from 1,300 in 2013. The total number of individuals with I/DD identified by setting served or home size totaled 27,426 in 2015 and decreased to 17,513 by 2017. Major change was noted for individuals residing in homes with 1-6 persons: decreasing from 16,633 in 2013 to 15,120 in 2017. Those residing in homes with 7-15 persons dropped from 392 in 2013 to 130 in 2014 but went back up to 298 in 2017.

NCI 2017-2018 data for the US and NC: Individuals in NC report that 5% live in an independent home/apartment or share with a roommate as compared with 18% nationally. At least 57% live in a relative's home compared with 40% nationally, 8% were living in foster care, this is twice as high as the US average of 4%. Those living in institutions (13%)/group homes (20%) account for 33% compared to 38% nationally (6% and 32%, respectively). Data from the Olmstead Plan Stakeholder Advisory report from the Technical Assistance Center issued in May 2021 shows that, in 2019, North Carolina's Continuum of Cares had 1,673 Rapid Rehousing units and 5,798 Permanent Supportive Housing units.

The NC Institute of Medicine reported a difference in program rules for those in Adult Care Homes (ACH) and those who choose to remain at home or in their communities. That difference creates an "institutional bias" — providing greater financial coverage and health benefits for those who move into an ACH. Section 8 Housing eligibility is generally 50% of Area Median Income (AMI), but can be up to 80% in some cases; 75% of new vouchers must go to families with incomes below 30% AMI. According to the 2021 TAC Report, there are 45,220 Housing Choice Vouchers with 3,847 vouchers targeted to individuals with disabilities. Additionally, there are 21,588 public housing units, 556 Mainstream Vouchers. There are also 188 Section 811 apartments targeted for individuals with disabilities.

Data from the Olmstead Plan Stakeholder Advisory report from the Technical Assistance Center issued in May 2021 shows that, in 2019, North Carolina's Continuum of Cares had 1,673 Rapid Rehousing units and 5,798 Permanent Supportive Housing units. The report also found North Carolina has many federal and state resources that can support individuals with disabilities to live independently. Federal resources include:

- 45,220 Housing Choice Vouchers that can assist very low-income families, senior citizens, and individuals with disabilities to afford decent, safe, and sanitary housing in the private market.
- 3,847 vouchers targeted exclusively to people with disabilities
- 21,588 public housing units administered by public housing agencies (PHAs)
- 556 Department of Housing and Urban Development (HUD) Mainstream Vouchers awarded to 21 local PHAs, of which 15 are set aside for the TCLI settlement population
- \$7,000,000 awarded to the North Carolina Housing Finance Agency (NCHFA) for HUD Section 811 Project Rental Assistance units with about 188 apartments being targeted for individuals with disabilities transitioning from or at risk for institutionalization
- HUD funds — including Community Development Block Grants, the HOME Investments Partnership program, Housing Opportunities for Persons with AIDS, and Emergency Solutions Grants — targeted to reducing homelessness.

At the state level, additional Housing resources and programs play an important role: The NCHFA has a strong history of implementing targeted efforts for housing development and has made targeting 10% of units for individuals with disabilities a Housing Credit Program threshold requirement and a requirement for all bond-financed development.

The Key Rental Assistance program is funded through the General Assembly to make units from the Targeting Program affordable to individuals with disabilities who have incomes as low as Supplemental Security Income (SSI).

The Transitions to Community Living Voucher program is a tenant-based voucher program operated by the LME/MCOs that provides support to tenants throughout the leasing process and a care team to support tenants after securing a unit. Tenants also have access to move-in funds, such as security deposits and utility assistance.

The Integrated Supportive Housing Program fosters a collaboration among a local housing developer, DHHS, and the LME/MCO to increase the supply of integrated, affordable rental housing. This housing consists of independent rental units where no more than 20% of the units are required to be set aside for individuals with a disability. Prospective tenants are referred by DHHS and are anticipated to come with rental assistance and connection to supportive services. The program prioritizes TCLI participants.

Supportive Housing Development Program financing is available to developments serving populations of homeless or non-homeless households with special needs who earn below 50 percent of area median income. Rent and utilities cannot exceed 30 percent of the targeted income, or 40 percent of the targeted income in developments that also provide food and transportation.

The North Carolina Housing Trust Fund can finance home ownership and rental apartments, new construction, housing rehab, and emergency repairs. It provides the state's largest source of funds to finance supportive housing and emergency repairs/accessibility modifications.

There are also state housing resources available to people with disabilities. The Key Rental Assistance program is funding from the General Assembly to make units from the Targeting Program affordable to individuals with disabilities on SSI. The North Carolina Housing Finance Authority targets 10% of units in its Housing Credit Program for individuals with disabilities.

Childcare

Eligibility for a childcare subsidy is based on income. It is possible that more children with special needs received this benefit because there is no requirement that the family provide information regarding a diagnosed developmental disability.

Interagency Initiatives

A number of state collaborative efforts address interagency needs around issues that affect individuals with intellectual and other developmental disabilities (I/DD) and their families. One of the most important collaborations is through the work of the North Carolina Council on Developmental Disabilities. Our quarterly meetings regularly include active participation, updates, and involvement of our divisions and departments of Medicaid, Vocational Rehabilitation, Mental Health and Developmental Disabilities, Public Instruction, Public Safety, Women and Children's Health and Aging.

The state is currently engaged in Olmstead Planning, which is including input from all of the divisions within our Department of Health and Human Services but is also engaging our other agencies that impact the disability community. The North Carolina Council on Developmental Disabilities is involved in most of the committee work in this effort. After the death of George Floyd, the Governor created a Taskforce for Racial Equity in Criminal Justice. The Executive Director of the North Carolina Council on Developmental Disabilities is one of the taskforce members and it includes leadership from various state and local agencies as well as legislative and judicial leaders.

North Carolina has recently created an Intellectual and Developmental Disability Workgroup, which consists of membership from various divisions within the Department of Health and Human Services and another agency, including NC Medicaid, the Division of Mental Health, Developmental Disabilities, Substance Abuse Services, the North Carolina Council on Developmental Disabilities, the Department of Vocational Rehabilitation Services, the Department of Public Instruction, the Department of Public Health, and the General Council's Office.

The Commission for MH/DD/SAS adopts rules regarding licensing, care and treatment of consumers of services, professional requirements hearings and appeals, and review of state plans. The Commission for MH/DD/SAS also advises the Secretary of the Department of

Health and Human Services (DHHS). The State Consumer and Family Advisory Committee is composed exclusively of adult consumers and family members of MH/DD/SA services who advise the NC DHHS and the General Assembly on the planning and management of the State's public MH/DD/SAS system.

The North Carolina Employment Collaborative (NCEC) is a Council funded initiative that brings together a number of different agencies, including Department of Health Human Services, the Division of Vocational Rehabilitation Services, the Department of Commerce, and the Department of Labor as well as the I/DD community and employers to increase employment for people with disabilities and meet the goals and objectives of WIOA.

NC Statewide Independent Living Council (NC SILC) is the governing council for the Centers for Independent Living which provides statewide independent living services. A majority of NC SILC members must be people with a disability; other members represent a range of agencies concerned with disabilities, including the NCCDD. The NC State Rehabilitation Council works in partnership with the NC DHHS Division of Vocational Rehabilitation Services by providing guidance in developing and expanding vocational rehabilitation services to maximize employability and independence of individuals with disabilities.

Statewide early intervention planning and service delivery for infants, toddlers and preschoolers has been based on a formal interagency agreement since 1989. The agreement was developed by the thirteen state agencies involved in providing or paying for services to young children and their families. Community Resource Connections for Aging and Disabilities is a coordinated system of information and access for all people seeking long-term support and services in North Carolina.

The North Carolina Early Intervention Branch (NCEI) within the NC Division of Public Health functions as the lead agency for the NC Infant-Toddler Program (ITP). The ITP provides supports and services for families and their children from birth to age three who have developmental disabilities, developmental delays, and other disabilities. Sixteen Children's Developmental Services Agencies (CDSAs) across North Carolina work with local service providers to support families in advancing their child's success.

North Carolina Head Start-State Collaboration (NCHSSCO) is part of North Carolina's Department of Public Instruction. The NCHSSCO is implemented and monitored by the Office of Early Learning along with other state and federally funded Pre-K programs including Title I, Even Start Family Literacy, and Preschool Exceptional Children.

The NC Assistive Technology Program (NCATP) provides assistive technology services to individuals, families, and agencies with assistive technology needs. In collaboration with the NC Rehabilitation Association, the NCATP hosts an annual conference that includes an exhibit hall of assistive technology vendors. The NC Assistive Technology Program receives grant funding under Public Law 108-364 through the Rehabilitation Services Administration, U.S. Department of Education, and is administered by the NC DHHS, Division of Vocational Rehabilitation Services.

A number of interagency collaborations in North Carolina include state government representation but were created to address specific needs and issues that affect individuals with I/DD and their families. The following collaboratives and consortia are implemented by the creating entities. The NC Developmental Disabilities Consortium (DD Consortium) includes individuals with I/DD, family members, and I/DD service agencies and advocacy organizations. Members come together to advocate for the needs of persons with I/DD. Various agencies and divisions from state government attend these meetings. The Interagency Coordinating Council (ICC) brings policy makers, service providers, and parents together to serve families of and young children with disabilities and developmental delays. ICC members work to ensure that the supports and services offered to families are aligned with their needs.

In 2014, the NCCDD Advocacy Ambassador initiative evaluated self-advocate organizing and activism in North Carolina. The findings suggested the significantly low number of self-advocate groups and low engagement of self-advocates in NC is associated with the disbanding of the Association of Self-Advocates of North Carolina (ASANC) in 2011. The Advocacy Ambassador report indicated that existing groups want, but lack resources and leadership, to continue a person-first focus, grow membership, and remain viable. Recommendations from the evaluation to build a functional self-advocacy movement included development and implementation of a 'business' model to provide education and training; technical assistance for existing and emerging groups; identification of self-advocates with leadership potential; and support to agencies to ensure access to accessible processes.

In response, the NCCDD, CIDD, and DRNC collaborated to support the development of a self-advocate collaborative. Through October 2016 and February 2021, the DD Network designated staff, in-kind resources, and nominal funding to support the emerging North Carolina Empowerment Network (NCEN) non-profit organization. In addition, the NCCDD invested in the exploration and fund release for an inclusive advocacy leadership development training initiative. Exploration led to the competitive RFA process with DRNC in collaboration with the Center for Creative Leadership (CCL) emerging as the successful applicant for proposing the Ability Leadership Program of North Carolina (ALP-NC). The ALP-NC initiative includes designing, piloting, and implementing an advocacy leadership curriculum and a train the trainer program.

Quality Assurance

In October 2016 NC DD Network organizations supported 12 self-advocates from their respective council, board, and advisories to initiate a statewide self-advocate engagement effort. The NC Empowerment Network (NCEN) non-profit organization with 13 board of directors concentrated primarily on managing day to day administration, board training, and raising funds for advisors. NCEN continues efforts to become a statewide self-advocacy organization and is the closest to a statewide self-advocacy group NC has. The NCEN maintains a collective of members from across NC. A chief struggle involves expanding membership.

The Inclusive Leadership Development Training Initiative for individuals with intellectual and other developmental disabilities (I/DD), family members and guardians, along with professionals, and other stakeholders aims to have individuals with DD in leadership roles for all aspects of the training. DD Network partner Disability Rights NC along with collaborator, the Center for Creative Leadership engaged a diverse advisory for the Ability Leadership Program of NC (ALP-NC) for curriculum development. The pilot training class included four 8-hour training sessions and was held in summer 2020. The train the trainer curriculum development and pilot class were developed and held spring/summer 2021. Four primary training classes and two train the trainer classes are planned for FFY2022.

Network Advocacy Community: The NCCDD will invest in graduates of the ALP-NC and former NC leadership development training graduates (PIP, ASL, LEND, STIR) to develop an advocacy network community. In partnership with the DD Network, the Council will support an initiative to gather, inform, and engage NC DD leadership training graduates in FFY2022. As the state's Protection and Advocacy agency, Disability Rights North Carolina (DRNC) monitors where people with disabilities receive services for health and safety issues, to ensure residents and staff are aware of the rights of the clients in the facility, and for quality of life issues.

DRNC monitors settings that serve individuals with I/DD to ensure that employees/ trainees in these facilities are providing the most appropriate, most progressively integrated services in a safe and healthy environment. DRNC's 2021 priorities include attention to self-advocacy, self-determination, and ADA concerns in various settings. For example, keeping students with disabilities in school who are suspended or excluded because of their disability, providing advocacy or legal representation where housing rights are violated, and improving criminal justice processes for people with disabilities.

The National Core Indicators (NCI) report for 2018-2019 summarizes responses from individuals and families related to self-determination and self-advocacy around personal choice. Responses from individuals living in NC include: 63% went out to religious or spiritual service in past month; 75% can see friends when they want to; 90% [no change] case manager "asks me what I want."; 95% staff "treat me with respect."; and 87% of individuals said always or usually able to choose provider agencies.

NC respondents from the 2017 Arc of the US FINDS (Family and Individual Needs for Disability Supports) survey related to self-determination and self-advocacy around personal choice vary somewhat from the NCI report: 95% said they received information about rights, compared with 93% nationally; 72% always experience services delivered respectful of family's culture; 24% usually experience services delivered respectful of family's culture; 89% said always or usually able to choose provider agencies; 38% said family member with I/DD never chooses provider; 77% said family always or usually able to choose individual support workers; and 52% said individual always or usually able to choose individual support workers, but 34% said individual could never choose.

Health/Healthcare

Information from the UNC School of Social Work indicates that despite having better potential access to health care, children with disabilities had to delay necessary medical and dental care more often. Families of children with disabilities who earned up to three times above the Federal Poverty Level still experienced similar levels of medical hardships as did poor families raising children with disabilities.

NC Office on Disability and Health and Children & Youth Branch of NC Division of Public Health (DPH) addresses access to care for individuals. Their findings indicate people with disabilities are more likely to postpone needed care, have trouble seeing specialists, and are less likely to receive coordinated care than children without special health care needs. NC Health Choice is insurance available to children in low-income families. A special needs plan includes benefits for children with special health care needs. Some services covered by NC Health Choice may be provided in settings outside a provider's office such as home and school therapies, caregiver education, case management and other I/DD services.

Services for children with special health care needs. Regarding dental Services, NC has one of the lowest dentists-to-population ratios in the country, and this problem is more pronounced in rural areas, where there are fewer dental providers. Patients with "special needs" are noted on the clinic description of patients served. According to data collected from interviews in the Medical and Health Homes initiative from children and adults with I/DD across NC, access to dental care is identified by families as one of the most challenging health issues. Families face substantial difficulty finding dentists who are competent and comfortable providing care to children and adults with I/DD with significant needs that may include communication, sensory sensitivity, and anxiety; as well as finding dentists that accept Medicaid. Traveling great distances to access dental care for a child or family member with I/DD is often another challenge. Covered dental services include:

- Preventive Services: Cleanings, Fluoride treatments, Sealants
- Diagnostic Services: Dental examinations by dentists; X-Rays; and NC does not reimburse hygienists independently but reimburses dentists for services of hygienists.
- Treatment Services: Fillings, Crowns/Tooth Caps, Root Canals, Oral Surgery

Not covered dental services include orthodontia, Emergency Room Services, and In-patient Hospital Services. On a broader health scale, NC Department of Health and Human Services (DHHS) provides financial support through its divisions and Managed Care Organizations for the following services: Specialty clinics at Eastern Carolina University and University of NC School of Dentistry for children with growth of head and facial bone anomalies. Clinics provides diagnostic, surgical, dental, orthodontic, and therapy services.

According to the NC DHHS website, Safety Net Dental Clinics are non-profit dental facilities where low income families or individuals can go for dental care. Most clinics accept insurance, N.C. Medicaid and N.C. Health Choice for Children. Many of these clinics also provide services on a sliding-fee scale to low-income patients who have no dental insurance. There are Safety Net Dental Clinics in most of North Carolina's 100 counties. However, not all of them have dental staff who are trained to treat people with disabilities.

National Core Indicators data for 2017-2018 for North Carolina reflects that individuals with I/DD living in the community or at home have increased their access to healthcare since the 2012-2013 data:

- Has a primary care doctor: 98%
- Overall health: Excellent: 21%, Very Good: 49%, Fairly Good: 29%, Poor: 2%
- Last physical exam: In the past year: 92%, One year ago or more: 8%
- Last dental exam: Within the past six months: 58%, Within the past year: 24%, One year ago or more: 18%
- Last eye exam or vision screening: Within the past year: 50%, Within the past two years: 26%, Within the past three years: 7%, Within the past five years: 3%, Five or more years ago: 9%, Has never had a vision screening: 5%
- Last hearing test: Within the past five years: 51%, Five years ago or more: 34%, Has never had a hearing test: 15%
- Last pap test: Within the past year: 33%, Within the past two years: 13%, Within the past three years: 6%, Within the past five years: 7%, Five or more years ago: 9%, Has never had a pap test: 31%
- Last mammogram: Within the past year: 47%, Within the past two years: 26%, Within the past three years: 1%, Within the past five years: 5%, Five or more years ago: 4%, Has never had a pap test: 16%
- Colorectal cancer screening – colonoscopy within past 10 years: Did not report colonoscopy in the past 10 years: 56%, Colonoscopy in the past 10 years: 44%
- Colorectal Cancer Screening - Flexible sigmoidoscopy within past 5 years: Did not report flexible sigmoidoscopy in the past 5 years: 98%, Flexible sigmoidoscopy within the past 5 years: 2%
- Colorectal Cancer Screening - FOBT or FIT within past year: Did not report FOBT or FIT within past year: 96%; FOBT or FIT within past year: 4%
- Colorectal Cancer Screening - Did not have screening past 10 years: Some type of screening within past 10 years: 90%, No screening in past 10 years: 10%
- Had a flu vaccine in the past year: No: 26%, Yes: 74%

Education and Early Intervention

Most people with intellectual and other developmental disabilities (I/DD) attend public schools, but many are served in segregated classrooms or schools, and too few students are completing high school with a diploma, an important prerequisite for further education or employment. Despite interest in continuing their education, very few students with I/DD move on to post-secondary education. The University of Wisconsin's Population Health Institute NC county health rankings for working-age people with disabilities 2020 report indicates that 32% had only a high school diploma, 31% had completed some college or associate degree, and 11% had a bachelor's degree or more. This data reflects a generalized perspective of low expectations for students with I/DD and other disabilities.

Research-based interventions are now required prior to determining eligibility for special education and related services in some areas of disability. In addition, a child must not be

determined to be a child with a disability if the determination is based on a lack of appropriate instruction in reading, including the essential components of reading instructions.

North Carolina uses the multi-tiered systems of support model for determining support needs of children. This can lead to Child Find being utilized to determine eligibility for Exceptional Children (Special Education) services.

North Carolina is under court order in the Leandro v. State of North Carolina to ensure children in poorer counties in North Carolina have access to basic education with competent well-trained teachers and principals and equitable access to sufficient resources. An independent educational consultant ordered to recommend ways to comply with Leandro released findings and a sequenced action plan in 2019 requiring the revision of the state funding model to provide adequate, efficient, and equitable resources.

Feedback gathered from the community listening sessions throughout the spring and summer of 2020 indicated that there is a significant number of family members and self-advocates that feel unprepared as they transition to life after secondary school. Moreover, family member feedback suggests frustrations with the limited options that are currently available to address the need to develop marketable employment related skills, as well as minimal choices for post-secondary education for students living with I/DD.

Despite these concerns, there has been progress in many areas related to education. Notably, there has been an increase in the number of Post-Secondary Education Programs now available which now totals 24. Also, thanks to the passage of WIOA, there is increased emphasis on developing alternate career pathways to employment, and work experiences for secondary students. One such alternative career pathway is registered apprenticeships, also thanks to the passage of WIOA there is an increased emphasis on Pre-Employment Transition Services. Another sign of progress related to transition is the growing body of research in employment services and supports, suggests that model fidelity to customized employment increases job placement and retention.

Former NCCDD Initiatives that have addressed system gaps in Education and Early Childhood education related to transition and education include the following:

- **North Carolina Employment First Steering Committee** A statewide workgroup formed in 2011 to strengthen collaboration and action to achieve employment goals. *Defined NC Employment First Statement of Principles
- **Project SEARCH** To increase competitive employment for persons with I/DD through the internship model
- **Reaching the Summit of Success** To develop a strategic plan of goals, timelines, and strategies to enable transition to postsecondary educational opportunities and integrated work environments
- **Learning and Earning After High School** -Designed to raise expectations, change attitudes, and provide transition services and resources for students with I/DD, even with those with the most complex disabilities.
- **Inroads to Employment**- Successfully demonstrated the feasibility of registered apprenticeships, career mentorship, and successful impact of Pre-Employment Transition Services for students living with I/DD.
- **North Carolina Employment Collaborative**-Designed to increase the percentage of

positive employment outcomes for individuals with I/DD and other disabilities by assisting lead departments under the Unified State Plan coordinate their activities to achieve their respective goals as defined in North Carolina's Workforce Innovations and Opportunities Act Unified State Plan.

- **Transition and Employment Webinar Series**-The purpose of the webinar series is to promote the value and multiple benefits to society of Employment First for individuals with developmental disabilities and their families, and to familiarize the audience with the components and infrastructure necessary to assure fidelity and performance outcomes of sustainable, competitive integrated employment as defined in WIOA. This series also covered areas that contribute to informing what constitutes a meaningful and inclusive life covering lifespan issues and transition related topics

The impact of all these former and current initiatives highlight that the complex systems navigation families and self-advocates must manage as they matriculate towards graduation is a difficult one. Unfortunately, information is siloed; for example cold hand off from local school systems to employment service and support providers. As well as limited for post-secondary education and or on the job training.

Such ongoing concerns highlight that a major area of investment for the Council over the next five years is to lead in challenging the false narrative of low expectation for students living with I/DD. As well as drive the development and adoption of alternative career pathways as highlighted in WIOA, along with assisting partners in adopting evidence-based practices for employment services provision. Lastly, efforts will also center around advocating for more coordination among LEA's, NCVR, and local businesses for securing and expanding Pre-Employment Transition Services that provide work experiences and career exploration for students living with I/DD.

Employment

As of 2020 North Carolina ranks 39th in the United States in terms of rates of working-age individuals with disabilities in the workforce (i.e., 35.3% or 241,311 of 682,617). In 2020 and in NC, 77.4% (4,342,288 of 5,603,472) of working-age individuals without disabilities were in the workforce.¹ This is an improvement from 2018 when NC ranked 42nd with a 33.5% workforce engagement rate. In 2019, Governor Cooper signed Executive Order No. 92, Employment First for North Carolinians with Disabilities, establishing North Carolina as an Employment First State.

Individuals with disabilities contribute to a diverse and innovative workforce, earn equal or higher performance ratings, and are less likely to resign than individuals without disabilities. Employment contributes to North Carolina's economic stability, improves health, improves an individual's socioeconomic status (i.e., decreases poverty), and decreases an individual's overall dependence on social welfare systems. As of 2020, 40 states have legislation, a formal policy directive, or other official state mandate addressing employment as a priority outcome.

¹ <https://disabilitycompendium.org/html-documents>

In North Carolina, there are approximately 1.3 million individuals with disabilities over the age of 5 who experience disproportionately high levels of unemployment, residential segregation, dependence, and poverty.

As of 2021, services in the United States and North Carolina continue to support non-work and segregated services that do not assist, and in some cases inhibit, individuals in accessing a productive career path or meaningful work instead of competitive, integrated employment and career exploration (e.g., Adult Developmental Vocational Program services, Day Supports services, ICF/IID services and settings). This is despite NC's ongoing implementation of the 2014 Workforce Innovation and Opportunity Act (WIOA) and the Home and Community Based Services Settings Final Rule.

According to the 2018-2019 National Core Indicators reports that in North Carolina 12% of respondents from North Carolina and 19% across NCI states were reported to have a paid job in the community, and respondents with a paid job in the community work in the following position types—in North Carolina and across NCI states, respectively:

- 59% and 41% in individually supported positions,
- 15% and 11% in competitive positions, and
- 8% and 24% in group-supported positions.
- The average number of hours that respondents with a paid job in the community—in North Carolina and across NCI states, respectively—worked in a typical two-week period:
 - 18 and 23.9 in individually supported employment,
 - NA and 26.8 in competitive positions, and
 - NA and 26.0 in group-supported employment.
- The average hourly wage among respondents with a paid job in the community, in North Carolina and across NCI states, respectively:
 - NA and \$9.54 in individually supported jobs,
 - NA and \$8.48 in competitive jobs, and
 - NA and \$8.32 in group with or without publicly funded supports.
- Respondents with a paid community job had been at their job an average of 50.5 months in North Carolina and an average of 69.6 months across NCI states.
- Among respondents with a paid community job, 15% from North Carolina and 29% across NCI states were reported to receive paid vacation or sick time.
- In North Carolina and across NCI states, respectively:
 - 28% and 28% in building or grounds maintenance.
 - 26% and 24% in food preparation or food service

- 17% and 21% in retail
- 4% and 8% in assembly, manufacturing, or packaging
- Among respondents without a paid job in the community:
 - 58% from North Carolina and 44% across NCI states reported they'd like a paid job in the community.
 - 21% of respondents from North Carolina and 29% across NCI states were reported to have integrated employment as a goal in their service plan.
 - 56% of respondents from North Carolina and 56% across NCI states reported that they attend a day program or regular activity.
 - 51% of respondents from North Carolina and 34% across NCI states reported that they do volunteer work.

NC Division of Vocational Rehabilitation Services:

The Division of Vocational Rehabilitation Services (DVRS) provides an array of direct and sponsored services to help individuals with disabilities achieve their goals for CIE and independent living. For eligible vocational rehabilitation (VR) consumers, DVRS supports the development of an individualized plan for employment (IPE), which may include counseling and assessments, education and career training, internships and other work-based learning opportunities, pre-employment transition services for students with disabilities, job placement assistance, supported employment and more. Education and outreach regarding services are provided to stakeholders through individual meetings, community events, and through strategic partnerships with other divisions of DHHS, state workforce development and educational agencies, as well as with advocacy groups and provider networks. Since the passage of the Workforce Innovation and Opportunity Act (WIOA) in 2014, DVRS provides career counseling at least annually to all individuals who are known to DVRS to be in subminimum wage employment, sharing information to assist them with making an informed choice about pursuing and achieving CIE.

Vocational services through NC DVRS is made available to NC employers at no cost as incentive to hire and retain employees with I/DD and included screening, job-matching, and training that can reduce employer's recruitment time and costs. Employers can benefit from on-site consultations by professionals such as rehabilitation engineers who help ensure that the physical workplace is a good fit for the new employee, and employers may also enjoy tax incentives for hiring a VR referral.

DVRS has a long history of providing services to transition aged youth, to include post-secondary training options that lead to an employment outcome. DVRS' efforts to provide counseling on post-secondary options increased with its federal obligation under WIOA. DVRS has also long supported post-secondary training options for individuals seeking CIE, providing funding for matriculating students with disabilities who met financial need criteria

and partnering to develop more postsecondary education opportunities for individuals with I/DD. Currently, DVRS funds college and career readiness programs for individuals who meet financial need requirements, funds work-based learning coursework for university programs and assists with employment upon completion.

From March 2020 through March 2021, 2,340 individuals with I/DD exited NC DVRS services, with 35.2% entering into competitive, integrated employment (CIE), 36% exiting without CIE, and 29% exiting without CIE prior to accessing services. Reasons for exiting includes loss of interest in work, death, deciding to pursue other things, moving out of state, etc.

In the 2019-2020 Program Year, NCDVRS provided individualized vocational rehabilitation services to over 30,000 North Carolinians with disabilities in pursuit of competitive integrated employment. Of those that received services from NCDVRS, over 95% were considered significantly or most significantly disabled and over 10,300 of those served were those with an intellectual/developmental disability. During this time-period, 4,244 of those DVRS clients reached their goal of obtaining and maintaining competitive integrated employment with wages averaging over \$10/hour. Since 2015, DVRS has developed and refined work-based learning opportunities and employment services that are community based, reducing the division's dependence on facility-based services and assuring minimum wage or greater for all clients participating in work adjustment training.

In addition, a Memorandum of Agreement (MOA) between DVRS, NC Medicaid and DMH/DD/SAS was established on February 23, 2018 for the purpose of facilitating a collaborative cross-Divisional effort to help ensure persons with disabilities have equal access to employment services, a continuum of employment services, and independent community living. This MOA formalizes and expands upon the ongoing cooperative working relationship between the Divisions.

Utilizing State Data Information in 2018:

- DVRS assisted 5,431 North Carolinians in achieving successful employment outcomes (i.e., 48% rate for all individuals starting services).
- DVRS assisted 1,483 North Carolinians with I/DD in achieving successful employment outcomes (i.e., 50% rate for all individuals with I/DD starting services).
- Upon accessing CIE, the average individual obtained:
 - \$289.18 weekly earnings (223.41 for individuals with I/DD).
 - 27 hours worked a week (24 for individuals with I/DD).
- 213,677 individuals with disabilities in NC access supplemental security income, 9,023 of which were working.

NCDVRS Services to Employers:

- Screening, job-matching, and training can reduce employer's recruitment time and costs.
- Employers can benefit from on-site consultations by professionals like our rehabilitation engineers who help ensure that the physical workplace is a good fit for the new employee.
- Employers can benefit from these services at no cost. They may also

enjoy tax incentives for hiring a VR referral.

Vocational services through NC DVRS are made available to NC employers at no cost as incentive to hire and retain employees with I/DD and included screening, job-matching, and training that can reduce employer's recruitment time and costs. Employers can benefit from on-site consultations by professionals such as rehabilitation engineers who help ensure that the physical workplace is a good fit for the new employee, and employers may also enjoy tax incentives for hiring a VR referral.

As part of the NC DVRS program, the North Carolina Assistive Technology Program (NCATP) provides assistive technology solutions to North Carolinians of all ages and abilities and works with local Community Rehabilitation Programs (CRPs) to address the assistive technology needs of people with disabilities in employment settings

Other Key Information on Employment in North Carolina:

According to State Data Info, 18,577 individuals with I/DD were served through DMH/DD/SAS and NC Medicaid in 2018, with:

- 17% in Seeking Integrated Employment (\$21.556 Million)
- 12% in Facility-Based Work (\$12.386 Million)
- 35% in Facility-Based Non-Work (\$124.881 Million)
- 55% in Community-Based Non-Work (\$319.889 Million)

According to the Disability Compendium, in states where leaders, employers, and people with disabilities do the right things, people with disabilities are two times as likely to have jobs as states that don't do the right things.

Benefits Counseling:

Unfortunately for many North Carolinians living with disabilities and their families, understanding how employment impacts federal and state public benefits programs can be overwhelming and intimidating. However, work incentives research* on Work Incentives Planning and Assistance (WIPA) projects demonstrates that individuals who receive benefits counseling services are more likely to pursue employment, maintain employment, and leverage available incentives that support their goal of greater financial security and independence.²

North Carolina's current benefits counseling services are funded through Social Security, which offers these services to individuals with disabilities. The triage process is designed with prioritization requirements, focusing on individuals with paid employment. As a result of these prioritizations and the limited number of CWICs and other resources, NC is often unable to provide benefits counseling services individuals who are not already working (i.e., in a high-priority list for assistance). Individuals with I/DD who may not qualify as high-priority for Social Security are placed on a lengthy waiting list to access services from a CWIC. This

² www.ssa.gov/disabilityresearch/documents/WIPA%20brief_final010312.pdf

creates uncertainty and fear among I/DD clients about their benefits and the continuation of employment activities.

During 2018 in NC, there was very low utilization of Social Security Work Incentives for people who are employed and receiving SSI benefits. Out of all North Carolinians with Supplemental Security Income Beneficiaries (213,677 individuals), there were only 11 Plans for Achieving Self-Support (PASS), 145 Impairment Related Work Expenses (IRWE), and 46 Blind Work Expenses (BWE).

Apprenticeships:

Registered apprenticeship programs are a unique, flexible training system that combines job-related technical instruction with structured, on-the-job learning experiences.³ Unlike most internships, apprenticeships are paid and usually result in hiring. NCCDD continues to explore how to establish registered apprenticeships for individuals with I/DD, examining successful transition to employment and careers, including paid apprenticeship approaches. In addition, NCCDD's reviews engaged experts with experience establishing registered apprenticeships through the Business Apprenticeship Career Training (Business ACTS) model. The Business ACTS model utilizes public/private partnerships designed to deliver a consistent apprenticeship program that will result in better trained, more productive employees, with outcomes tracking towards positive results for individuals participating in training to become certified feeding assistants.

NCCDD's Long History of Advancing Employment and Career Opportunities:

Multiple initiatives in the past five years alone intended to advance state employment legislation (i.e., Employment First Executive Order), mechanisms for financial education and planning development, and internships for individuals with I/DD with the potential to evolve into employment and careers. Council funded initiatives, including Upward to Financial Stability, the North Carolina Benefits Counseling Services Demonstration Project, North Carolina Employment Collaborative, NCABLE Project Prosperity, Innovative Employment: Making Inroads to Long-Term Success through Apprenticeships, Pre-Transition Partnerships, and Post-Secondary Mentoring sought to advance career and financial health planning, employment, and formal legislation to advance income earning opportunities for NC citizens with I/DD.

It is also our intention that through supporting, advising, and enhancing the voice of the large untapped talent resource of individuals living with disabilities that are ready for work, the Council can influence key areas that impact the population living with I/DD, such as increasing employer recruitment of individuals living with significant disabilities, improving the employment and employment-related services and service system, and improving employer retention efforts (e.g., diversity and inclusion training) that help to retain individuals living with disabilities.

³ <https://www.dol.gov/general/topic/training/apprenticeship>

Informal and Formal Services and Supports

North Carolina has four state-operated ICF/IID facilities with 16 or more individuals: Caswell Center, J. Iverson Riddle Development Center, Murdoch Developmental Center, and O’Berry Neuro-Medical Treatment Center (OBNMTC).

Number of admissions to NC developmental centers in 2020 (or most recently reported) state fiscal year: SFY21: 85 total admissions, including Murdoch’s Adult respite (n=4) and Murdoch’s TRACK child respite (n=47). Of the 85 total admissions, 60 admissions were for people 18 years old and younger. Excluding TRACK and Respite admissions, there were 34 admissions for all 3 state developmental centers in SFY 21.

Number of the largest group of referrals and type of community residential setting: For SFY 21, the majority of individuals admitted to the center were residing in their family home prior to admission.

Regular admissions accounted for what percentage of total admissions in most recently reported SFY: Regular admissions (not respite or TRACK) accounted for 40% of all admissions for SFY 21.

Of the total admissions, how many were non-white with males? What percentage was that related to the total of admissions? Of all SFY 21 admissions (excluding TRACK and respite), there were 34 admissions. Of these 34 admissions, 17 (50%) people identified as white, 13 (38%) people identified as black, 1 (3%) person identified as latinx, and 3 (9%) people identified as other. Of all SFY 21 admissions (excluding TRACK and respite), 10 (29%) people identified as female and 24 (71%) people identified as male.

What is the age of the largest single age group of total admissions? The average age of SFY 21 admissions was 20-years of age at Murdoch, 35-years of age at Caswell, and 29-years of age at Riddle.

In FY 2017, according to the State of the States, 2,095 individuals with I/DD lived in 16+ person settings with 205 living in nursing facilities, 1,125 in state institutions, and 765 in private ICF/IDD. An additional 265 lived in 7 to 15-person private ICF/IDD and 33 lived in other 7-15 person residential settings. 15,120 lived in less than six-person residential settings, including 1,132 in private ICF/IDD, 10,096 in Supported Living and 3,892 in other residential settings. The 2017 State of the States in Intellectual and Developmental Disabilities reports that in NC, persons with I/ DD living in nursing facilities decreased from 959 in 2013 to 203 in 2017.

Individuals with I/DD living in public and private ICFs-IID (intermediate care facilities for individuals with intellectual disabilities) decreased from 2,485 in 2013 to 2,162 in 2017. Those living in state institutions totaled 1,125 in 2017, down from 1,300 in 2013. The total number of individuals with I/DD identified by setting served or home size totaled 27,426 in 2015 and decreased to 17,513 by 2017. Major change was noted for individuals residing in homes with 1-6 persons: decreasing from 16,633 in 2013 to 15,120 in 2017. Those residing in homes with 7-15 persons dropped from 392 in 2013 to 130 in 2014 but went back up to 298 in 2017.

Analysis of State Issues and Challenges [Section 124(c)(3)(C)]

Criteria for eligibility for services

Health. In NC, all newborns are eligible for newborn home visit services and early hearing screening. Kindergarten health assessment occurs within 12 months of entering school, with payment determined by income and insurance type. The WIC program is for children up to age 5, with eligibility based on income. The NC Infant-Toddler Program provides services for children up to age 3 with a certain level of developmental delay or an established condition. According to data collected from interviews in the NCCDD Medical and Health Home initiative from children and adults with I/DD across NC, families identified access to dental care as one of the most challenging health issues. Families face substantial difficulty finding competent dentists who are comfortable providing care to children and adults with I/DD with significant needs that may include communication, sensory sensitivity, and anxiety; as well as finding dentists who accept Medicaid. Information from the UNC School of Social Work indicates that, despite having better potential access to health care, children with disabilities had to delay necessary medical and dental care more often. Families of children with disabilities who earned up to three times above the Federal Poverty Level still experienced similar levels of medical hardships as poor families raising children with disabilities.

Employment. NC Division of Vocational Rehabilitation Services (DVRS) serves individuals with I/DD. Services are also provided to students eligible for an Individualized Education Plan (IEP). With the changes to the Workforce Innovation and Opportunity Act (WIOA), there is a commitment to workforce development with an emphasis on innovation and beginning earlier in high school. WIOA implementation began in 2017.

Informal and Formal Services and Supports. Eligibility for Medicaid is based on a family's monthly income and other resources. Home and Community Medicaid Waiver ("waiver") participation depends on funding availability. The individual must meet requirements for ICF-ID level of care as assessed and documented by a physician or clinical psychologist. The individual must require active treatment necessitating the ICF-ID level of care. Active treatment is aggressive, consistent implementation of a program of specialized and generic training, treatment, and health services. The individual must have a diagnosis of I/DD. In 2021, Medicaid Transformation began with individuals receiving Medicaid being moved onto Standard Plans starting on July 1st, with individuals receiving Innovations Waiver services continuing to receive services the same way until the Tailored Plans launch in 2022.

Housing. According to the April 2021 TAC Report, housing is less costly in North Carolina than the national average but is still difficult to obtain for low income individuals with disabilities. TAC cited its Priced-Out Report in stating that an individual with a disability in North Carolina would have to pay 102% of their 2021 SSI to afford a one-bedroom apartment at the federal fair market rent established by Housing and Urban Development (HUD).

A significant number of individuals with I/DD are in more segregated housing than is necessary for them. Also, a significant number of individuals with I/DD live in housing in

which federal regulations may require the provider to stop providing the housing in the setting in which the individuals live.

Transportation. Para-transit riders must meet eligibility requirements and complete an application for certification every two years. Costs have increased, and more of the trip must be covered by the rider. Some re-certification requirements were waived in 2020 during the COVID-19 pandemic, and some entities such as the City of Raleigh waived charges for transportation services during the pandemic.

Analysis of the barriers to full participation of unserved and underserved groups of individuals with developmental disabilities and their families

NCCDD activities, state plan development survey results, and key state documents identified issues involving unserved and underserved groups in NC, who include 1) individuals affected by I/DD with limited English, particularly Latin(a)(o)(x) people who comprised 9.8% of NC's population in 2019; 2) individuals living in developmental centers for which NC is 10th highest user of ICF/IDD in the nation; 3) people with I/DD living in ACHs; and 4) aging adults with I/DD living at home with aging parents. Issues in education/early intervention, housing, transportation, transition, employment, and health result in barriers and unmet needs.

Education/Early Intervention. The Individuals with Disabilities Education Act (IDEA) is a law that makes available a free appropriate public education to eligible children with disabilities throughout the nation and ensures special education and related services to those children. The IDEA governs how states and public agencies provide early intervention, special education, and related services to more than 7.5 million (as of school year 2018-19) eligible infants, toddlers, children, and youth with disabilities. Infants and toddlers, birth through age 2, with disabilities and their families receive early intervention services under IDEA Part C. Children and youth ages 3 through 21 receive special education and related services under IDEA Part B.

Housing. Most individuals with I/DD cannot afford independent housing without a housing subsidy, as most live on Supplemental Security Income (SSI). In 2021, SSI benefits were \$794 per month or \$9,528 per year for an eligible individual, not enough monthly income for individuals in most communities to purchase unsubsidized housing or support services. Hispanic and Latino people, particularly those who are undocumented immigrants without a Social Security number, have difficulty qualifying for SSI.

Health

North Carolina is one of nine states that did not expand Medicaid under the Affordable Care Act. According to the American Community Survey 2015-19, 11.3% of individuals living in North Carolina do not have health insurance. This means approximately 404,000 individuals in North Carolina do not have health insurance. According to an April 30, 2021 Technical Assistance Collaborative Report, this lack of health care coverage was a key reason why individuals with disabilities did not receive Home and Community-Based Services (HCBS) and ended up in institutions.

There are significant concerns related to barriers to services of individuals with I/DD as a result of the state's Medicaid Transformation. In June 2021, it was reported that 7,000

individuals who qualified for the Tailored Plan had affirmatively signed up for the Standard Plans, which would mean that they would lose their LME/MCO services and care coordination. After concerns were raised by the I/DD community and due to proactive work on the part of the Department of Health and Human Services, the state switched all of the 7,000 back out of the Standard Plans and is reworking how it will discuss plan options with individuals who qualify for the Tailored Plan. Additional concerns related to the Tailored Plans include provider enrollment, keeping current providers, and confusion as to the impact of the switch to Tailored Plans of individuals with I/DD.

There is also concern about the job descriptions for Care Coordinators and other roles under the Tailored Plan and whether Peer Mentors and Family Navigators can qualify to provide these services. Single stream funding to LME/MCOs was significantly reduced in fiscal year 2017. LME/MCOs were required to maintain the same level of support in non-Medicaid paid services to fiscal year 2015. This meant that in that year LME/MCOs received 190 million dollars in funding for non-Medicaid paid services but spent 265 million dollars for those services. [2021 TAC Report] This decrease in single stream funding has had lasting effects up to the present.

Obesity rates for people with I/DD are high. According to NC Division of Public Health (DPH), some steps have been taken, but some services were also cut. The NC Office on Disability and Health and Children and Youth Branch of NC DPH found that nearly 28% of adults with a disability report that they could not see a doctor within the past 12 months because of cost, compared to 13.4% of adults without a disability. Only 58% of people with I/DD had a routine dental exam in the past six months (NC Core Indicators Project, 2017-2018).

Employment. While state leaders and agencies have declared an intent to hire more individuals with disabilities and to make Employment First a priority of agencies, unemployment remains stubbornly high for people with disabilities. According to a September 2020 Current Population Study, 13.4% of individuals with disabilities were unemployed compared to 7.5% for those who did not have a disability. Vocational Rehabilitation Services were impacted by the COVID-19 pandemic. The number of job placements for March through September 2020 was half that of the same period in 2019 with 1,754 job placements in 2020 compared to 3,515 in 2019.

Concerns have been raised throughout the state related to Transitions from school to employment and meaningful days for students with disabilities transitioning from school. An indication of the significant interest in employment and transition for people with disabilities was the fact that the Council held Employment and Transition Webinars in the spring and summer of 2021 with average attendance at the first four sessions of over 200 individuals from across the state for the three-hour webinars. Self-advocates and family members have repeatedly raised concerns about being requested to serve on advisory committees, provide input, and provide services without compensation. There is an insufficient number of self-advocates paid for doing self-advocacy or peer mentor work.

Transition. The North Carolina Medical Journal (2009; Volume 70, Number 6) found that the availability and quality of transition services and supports vary across the state. People with I/DD need coordinated services/supports, but those services are often fragmented across

state agencies, and the complexity of the current system makes it difficult for many people with I/DD and their families to identify and obtain needed services and supports. Interagency planning and coordination is particularly important during transitions.

Targeted Disparity. There are currently just over one million Hispanic/Latin-x individuals living in North Carolina (1,026,000 in 2019). The population grew by 28.3%, which was much faster than the national growth rate of 19.6%. The state's largest Hispanic Latin-x populations were in Mecklenburg, Wake, Forsyth, Guilford and Durham counties, with a quarter of the state's population living in Wake and Mecklenburg.

The total poverty rate as of 2018 for the Hispanic population was 27% in North Carolina and 37% for children. This was almost double the state's poverty rate for all individuals, which was 14% for all individuals and 19% for all children in the state. 77% of Hispanic individuals living in North Carolina speak a language other than English at home, 34% speak English less than very well, and 41% are immigrants (as of 2018). In 2018, 17% of Hispanic individuals in North Carolina did not have a computer and broadband in their home. Only 54% of individuals who were Hispanic in North Carolina had health insurance. The Hispanic/Latin-x community continues to be a community in North Carolina with less access to I/DD services. During its listening sessions, particularly a listening session with the Hispanic/Latin-x community, and through recent webinars conducted with Spanish speaking North Carolinians, the Council has identified the Hispanic/Latin-x community as the Targeted Disparity community in which the Council will focus in the 2022-2027 Five Year Plan.

NCCDD will increase engagement and involvement of Hispanic/Latin-x individuals and families. It will do this through direct engagement with individuals in the Hispanic/Latin-x community to increase access and engagement in I/DD services, advocacy activities, and education opportunities. This will include ensuring Council initiatives include active outreach and engagement with the Hispanic/Latin-x community, listening, education, and engagement sessions with individuals in the Hispanic/Latin-x community, and a continuous discernment and activity process to determine best ways to engage and include the Hispanic/Latin-x community in all aspects of Council work.

Also, after the death of George Floyd, the Council's DSA engaged the Council and all of the divisions at the Department of Health and Human Services (DHHS) in discussions and activities related to equity in all aspects of its work. Council staff also became actively involved in a Diversity Equity and Inclusion Council associated with DHHS. The Council and Council staff will continue to make equity and diversity key aspects of its work in its 2022-2027 Five-Year State Plan.

The availability of assistive technology

The North Carolina Assistive Technology Program (NCATP) serves people of all ages and abilities. Nine centers across the state serve children, adults, and older adults with disabilities and their families. Free services include device demonstration, device loan, device reutilization, training/technical assistance and public awareness. Fee-based services are provided to agencies and schools and other organizations that include assistive technology assessment, community-based assessment, feature matching and device trial, and training

on specific devices/software consultation, workshops and training. NC Division of Services for the Deaf and the Hard of Hearing, which administers an Equipment Distribution Program that distributes technology and equipment that allows Deaf and Hard of Hearing people and people with speech disabilities to communicate over the telephone. NCATP also has a Grant Advisory Council with a member who represents the Hispanic/Latino population and a member who represents NCCDD tasked with advising NCATP on how to spend the federal funds they receive.

The NCATP website offers information and resources, including funding information. In federal fiscal year 2019, NCATP provided 1,366 device demos and 1,605 device loans. In federal fiscal year 2020, which was affected by the COVID-19 pandemic causing NCATP offices to close for in-person services, NCATP provided 669 device demos to 1,308 individuals, ranking 6th in the country. Meanwhile, NCATP provided 769 device loans, ranking 9th in the country. NCATP also ranks 8th in the nation for savings due to re-utilization. The 2019 numbers more closely represent a typical year for NCATP. NCATP is also making industry-to-provider connections (e.g., Smart Homes, Inc.), has a highly regarded blog on Assistive Technology, and produced a video in 2014 called “An Accessible Life” that NCCDD screened for its members in 2016. NCATP is funded by the Administration for Community Living (ACL) in the U.S. Department of Health and Human Services and is administered by the NC Department of Health and Human Services’ Division of Vocational Rehabilitation Services.

Waitlist Data/Information

Year	State Pop (100,000)	Total Served	Number Served per 100,000 state pop	National Average served per 100,000	Total persons waiting for residential services needed in the next year as reported by the State, per 100,000	Total persons waiting for other services as reported by the State, per 100,000
2019	188124	35884	0.189	202	0.0517	0.0517

a. Entity who maintains wait-list data in the state for the chart above:

NCDHHS Division of Medicaid

b. There is a statewide standardized data collection system in place for the chart above:

Yes, but the collection system has many faults including the fact that it is based on reporting by different LME/MCOs which may not use standardized procedures between them. The state, therefore, has requested to use increased HCBS funds from the American Rescue Plan to develop a uniform data collection and reporting system related to the waiting list. NCCDD is involved in an advisory group that is receiving regular updates on this process and providing feedback.

c. Individuals on the wait-list are receiving (select all that apply) for the chart above

No Services: true

Only case management services: true

Inadequate services: true

Comprehensive services but are waiting for preferred options: true

Other:

d. To the extent possible, provide information about how the state places or prioritizes individuals to be on the wait- list (Narrative Below in “Use space below to provide any information or data available...)

Provide any information or data available related to the response above

Individuals seeking services will do so through their assigned LME/MCO, of which there are currently seven, serving specific NC catchment areas. Waivers are provided to individuals based on when the individuals joined the waiting list. In other words, the first to come on to the waiting list will be the first to come off when a slot becomes available in an LME/MCO. That said, waiting lists are managed by LME/MCOs using their own policies and procedures. There are approximately 50 Innovations Waivers made available across the state to individuals who have an emergency. These emergency Waivers generally run out before the end of the fiscal year. The CAP-C Waiver is provided based on assessed level of severity. NC’s managed care program has established a capitated funding process by which LME/MCOs receive a per-member, per-month total. LME/MCOs must serve all individuals within the capitated amount and assume the associated responsibility and risk. If the MCO achieves Medicaid savings (these savings are then identified as (b)(3) services), the savings can be invested in serving others on the registry of unmet needs through (b)(3) services.

e. Description of the state's wait-list definition, including the definitions for other wait lists.

In June 2021, the number of people on the waiting list for the Innovations Waiver, which is called the Registry of Unmet Needs, was 15,585, according to a presentation to the Developmental Disabilities Consortium by the Division of Medicaid. Wake County had the highest number of individuals waiting in a geographic area with 2,497 waiting. As of December 2019, there were 14,474 individuals on the Registry of Unmet Needs. [LME/MCO Report December 2019 <https://www.ncdhhs.gov/media/9021/download>]. This means that the waiting list grew by over 1,000 individuals in a year and a half.

There are currently 13,138 Innovations slots. Therefore, the number of individuals waiting for a Medicaid waiver exceeds the number of active slots.

The number of people waiting for the Innovations Waiver is difficult to pinpoint at any one time because the numbers are tracked by regional Local Management Entities/Managed Care Organizations (LME/MCOs). The state is developing a unified database, which should enable a more accurate count of the number of people waiting as well as additional demographic and support need information.

According to an April 30, 2021 Technical Assistance Collaborative (TAC) Report, the wait for an Innovations Waiver is likely higher than the 9.5 years that it was in 2017. The factors contributing to the growing waiting list, include:

- The Medicaid State Plan does not include home and community-based services for individuals with I/DD and approximately 2/3 of individuals on the Registry of Unmet Needs do not receive services through their LME/MCO.
- Children and young adults under 21 are on the waiting list with only 46% of children age 17 and under receiving services. All children are required to receive services if they receive Medicaid under Early and Periodic Screening Diagnosis and Treatment (EPSDT).

The following was the breakdown by regional LME/MCO of those waiting in North Carolina, according to the December 2019 report:

- Alliance: 3,886 waiting, 0% waiting for Residential Services; 21% receiving state funded services; 79% not receiving any LME/MCO services; 3070 not receiving any LME/MCO services;
- Cardinal :3989 on waiting list; 5% waiting for residential services; 35% receiving state funded services; 65% not receiving any LME/MCO services; 2,593 not receiving any LME/MCO services;
- Eastpointe: 548 on waiting list; 1% waiting for residential services; 34% receiving state funded services; 66% not receiving any LME/MCO services; 362 not receiving LME/MCO services;
- Partners: 1,614 on waiting list; 6% waiting for residential services; 34% receiving state funded services; 66% not receiving any LME/MCO services; 1,065 not receiving any LME/MCO services;
- Sandhills: 1,941 on waiting list; 2% waiting for residential services; 52 receiving state funded services; 48% not receiving LME/MCO services; 932 not receiving LME/MCO services;
- Trillium 1,148 on waiting list; 0% waiting for residential services; 64% receiving state funded services; 36% not receiving any LME/MCO services; 413 not receiving LME/MCO services;
- Vaya: 1,348 on waiting list; 4% waiting for residential services; 27% receiving state funded services; 73% not receiving LME/MCO services; 984 not receiving LME/MCO services
- Vaya: 1,348 on waiting list; 4% waiting for residential services; 27% receiving state funded services; 73% not receiving any LME/MCO services; 984 not receiving any LME/MCO services
- TOTAL: 14,474 on waiting list; 3% waiting for residential services; 35% Receiving state funded services; 65% not receiving any LME/MCO services 9,408 not receiving any LME/MCO services

f. Individuals on the wait-list have gone through an eligibility and needs assessment.

Yes

Provide any information or data available related to the response above.

All individuals with I/DD must apply and then be screened by an LME/MCO prior to joining waiting list. The LME/MCOs administer a level of care assessment considering risk and needs for those requesting services. For those receiving HCBS Waiver services, the state historically employed the use of NC Support Needs Assessment Profile (NC SNAP) to assess risk and need, However North Carolina has transitioned to the use of the Supports Intensity Scale (SIS) assessment for all individuals receiving Innovations Waiver services. NC chose to implement the SIS due to the comprehensive nature of the assessment and the “strengths based” assumption of the assessment in considering the supports needed for success in community. In addition, NC will base the use of a resource allocation method pursuant to the scores received through the SIS. In addition, administration of the SIS requires demonstrated and ongoing inter-rater reliability of assessors as compared to a “master” assessor

There are structured activities for individuals or families waiting for services to help them understand their options or assistance in planning their use of supports when they become available (e.g., person-centered planning services)?

Yes

g. Specify any other data or information related to wait-lists.

LME/MCOs conduct needs assessments by a Care Navigator. The assessment captures potential risks and safety considerations that include health and behavioral areas of concern. Care Navigators explain potential support options, if any, if the Innovations Waiver is unavailable. LME/MCOs also have information available on their websites related to the processes available for obtaining the Innovations Waiver, joining the Registry of Unmet Needs, and other services. The state is transitioning to a “Tailored Plan” for individuals with I/DD who are on the Registry of Unmet Needs and receiving state services or the Innovations Waiver. Care coordinators will support individuals on obtaining available services. Tailored Plans begin July 1, 2022.

i. Summary of Waiting List Issues and Challenges

The unmet needs of individuals with I/DD, particularly those on the Registry of Unmet Needs, was named as one of the most critical issues the I/DD community faces at our listening sessions and from the surveys we received. This is not surprising given the fact that the waiting list grew by 1,000 individuals in the last year and a half. Many of the individuals on the Registry of Unmet Needs will need a Medicaid waiver due to an aging caregiver, transitions from school, needs for independent living, and otherwise before they will get through the waiting list. This is a critical issue for the I/DD community in North Carolina.

There are significant equity concerns with how individuals and families learn about the Registry of Unmet Needs and other I/DD services. Since the state operates the waiver and other services on a first come first serve basis, those who obtain the information and sign up for services will receive them much sooner. This means that lower income and non-white individuals and families are more likely to receive fewer I/DD services. The difficulties of individuals with unmet needs were greatly exacerbated during the pandemic.

Due to concerns about the waiting list, the Council hired a contractor to do a small pilot project over the last year to interview each of the LME/MCOs about their waiting lists, the

needs of individuals on the waiting lists, and how they operate their waiting lists. The contractor also worked with Duke University to interview leaders in seven other states to understand how other states handle their waiting lists. The contractor also worked with the Council to engage in frequent conversations with the Department of Health and Human Services, individuals and families with I/DD, and stakeholders across the state. There was growing interest from the state agency and stakeholders for the Council to do a multi-year initiative to impact the Registry of Unmet Needs.

This is due to a confluence of factors that have focused on the waiting list, including: (1) the state is currently engaged in Olmstead Planning and developing and implementing a long-term plan to meet the needs of individuals on the Registry is a key issue involved in Olmstead Planning; (2) the state is undergoing Medicaid Transformation and developing a Tailored Plan which will provide care coordination and greatly impact the ways in which individuals with I/DD receive services for both those on the waiting list and those receiving services; (3) the state is under an order from a court in Orange County that has specifically held that the state is out of compliance with Olmstead for individuals with I/DD; (4) the General Assembly is likely to pass a law or resolution this year to require the state to come up with a ten year plan to meet the needs of individuals on the Registry; (5) the state is likely to include up to 1,000 new Innovations Waivers in the 2021 budget that it passes. And (6) the state is moving from waiting lists at each LME/MCO to a unified waiting list.

Analysis of the adequacy of current resources and projected availability of future resources to fund services.

There are not sufficient resources to meet the need for individuals with I/DD based on the current budgets of the state. That is the reason the state currently has a waiting list that exceeds 15,000. There is the potential for these resources to meet much more of the need in the future, however. This is for two reasons. First, the state allocates a disproportionate amount of funding to institutions and to individuals in institutions rather than to individuals in the community. The state has engaged the Technical Assistance Collaborative, which issued an April 2021 report recommending that the state reallocate more funds to the community and lessen the amount of funds in institutions and move people with I/DD out of institutions. This is a key topic in the current Olmstead Planning engaged at the state. Second, North Carolina has seen a dramatic increase in tax revenue. With this additional revenue and additional short-term funding from the American Rescue Plan, the state will have additional resources to put into I/DD services. Finally, the state is strongly considering adding services into its Medicaid State Plan, which would provide additional services to individuals who receive Medicaid who are on the waiting list.

Analysis of the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are in facilities receive.

NC Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF-IID) rules requires active treatment for all needs. All ICF/IID facilities must be re-certified on an annual basis with the NC Division of Health Services Regulation (DHSR) having a window of 15 months and must conduct surveys within an average of 12.9 months. For individuals residing

in state-operated developmental centers, medical supports are closely monitored with routine medical care occurring through the institutional setting or secured through a local or specialized provider. While community ICF also requires active treatment, it becomes the responsibility of the provider operating the ICF to assess and support the provision of routine and specialized medical care services.

The latest count reviewed by the Council showed that the state had 334 private ICF/IDD programs with some ICF programs having more than one licensed facility. There were 2,786 beds in three Developmental Centers (Murdoch, J. Iverson Riddle, and Caswell) and 1 Neuro with 1,362 beds (O-Berry).

Direct support professionals are paid higher in state institutions in most instances than they are in the community. There were additional payments made to DSPs in institutions during the pandemic in order to ensure adequate care during the crisis. Such additional payments, however, increased the disproportion in pay for DSPs inside institutions compared to the community.

The state has too many individuals with I/DD in institutions and pays for a disproportionate amount of services in institutions rather than the community. The state is currently engaged in Olmstead planning. The state is under a Court order from a state judge in Orange County, North Carolina stating that the state is out of compliance with the Olmstead decision for individuals with I/DD. As part of the state's Olmstead process, state leaders and community advocates have worked together to develop the following recommendations to enable more individuals with I/DD to transition into the community:

1. Ensure transitions to community include connection and linkage to peer, natural, and social networks to support individuals social-emotional needs and continue to work towards establishing communities of support dependent from families.
2. Ensure thorough exploration and consideration of least restrictive community alternatives and diversion efforts prior to referral for admission to institutional settings.
3. Ensure education of available options is provided prior to or at point of referral to an ICF-IID, state run developmental disability center, nursing facility, adult care homes, Psychiatric Residential Treatment Facility, or other state funded institutional setting and person is linked with an in-reach contact. Ensure that people referred to a State Psychiatric Hospital have needs that cannot be met by a community option such as a community psychiatric unit.
4. Ensure individual's plan addresses goals to transition to more integrated setting.
5. Implement individualized rates based on needs of the individual.
6. Implement rate reduction over time.
7. Determine performance-based outcome measures for ICF-IID providers, PRTFs, and other institutional care settings.
8. Develop process to enable review of ICF-IID, PRTFs, and other institutional care settings provider denials of referrals.
9. Ensure that ICF-IID providers provide sufficient notice of discharge and remain involved in planning efforts when an individual is in the ED or admitted to a crisis or other inpatient setting.

10. Identify position in Department to provide oversight and policy direction to community ICF-IIDs.
11. Establish Diversion Sites to provide observation, stabilization and treatment for individuals with Intellectual Disabilities / and Traumatic Brain Injury to reduce admissions of these populations to State Psychiatric Hospitals and Institutional Care Settings, consistent with 122C-263(d)(2).
12. Increase the number of Innovations Waivers by 16,000 over the next five years.

The state is working to expand its pilot TBI waiver that is limited to a small geographic part of the state to a TBI waiver statewide. There will be a need to monitor this process and provide feedback to ensure success.

To the extent that information is available, the adequacy of home and community-based waivers services (authorized under section 1915(c) of the Social Security Act (42 U.S.C. 1396n(c))

In 2021, the greatest challenge to individuals with I/DD who receive the Innovations Waiver is the lack of competent direct support professionals to serve individuals in the community. This challenge is due in large part to the low pay of direct support professionals. There were additional factors during the pandemic, including concerns about the virus, increased responsibilities, competing jobs with higher pay, and expanded unemployment benefits.

To respond to some of these challenges, North Carolina expanded flexibilities under Appendix K.

However, the state did not increase wages for pay for direct support professionals like it did for DSPs serving individuals in institutional settings. The General Assembly is considering in 2021 increases to DSP pay but if such increases take effect, the pay will still be low and there likely will continue to be a DSP shortage.

Rationale for Goal Selection [Section 124(c)(3)(E)]

Based on an analysis of the FFY 2017 – 2021 state plan and mandates of the DD Act, a NCCDD Five Year State Plan Development Ad Hoc Committee (est. 9/2019) initiated the process of state plan development. The ad hoc committee highlighted active priorities of the 2017-2021 plan and potential priorities driven by areas of emphasis in the DD Act. These priorities were used to design and advance the marketing effort and materials used in soliciting public input for the development of the FFY 2022 -2026 state plan.

Despite the pandemic – or maybe even because of the pandemic – The North Carolina Council on Developmental Disabilities (NCCDD) engaged in robust conversations with individuals with I/DD, families of individuals with I/DD, the Hispanic/Latin-x Community, state leaders and stakeholders to develop the Council's Five-Year Plan for 2022-2026. The 18-month process of developing the Five-Year Plan began in February 2020 just as the pandemic was beginning to hit the news. The Council originally planned listening sessions in communities across North Carolina from the coast to the mountains and many communities

in between. These plans had to quickly change to virtual listening sessions as the pandemic caused an end to public meetings across the state.

The Council redoubled its efforts to ensure robust attendance at its now listening sessions and to ensure survey responses from individuals with intellectual and developmental disabilities (I/DD), family members and stakeholders. Ultimately 326 individuals attended one of the Council's nine virtual listening sessions. This included thirty-three individuals who attended the young self-advocates listening session, fifty-one individuals who attended the Council's self-advocacy listening session, and fifty-two individuals who attended the Council's Hispanic/Latin-x listening session. The rest attended the six regional listening sessions. Seven Hundred and four people filled out the Council's surveys for its Five-Year Plan.

The Council had a strong Five-Year Planning Ad Hoc Committee that met monthly for most of the 18 months of the planning process. The Planning Committee was chaired by Sandra Terrell, Director of Clinical Services, Division of Medical Assistance. The Committee included five family Council members of individuals with I/DD, three Council members who were self-advocates, the Executive Director of the state's protection and advocacy organization; and an agency representative from the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services.

The following are top themes that the Council heard from the listening sessions for each region of the state and the targeted listening sessions: Mountain region -- the Registry of Unmet Needs (the waiting list) and Independent Living; Central Region -- The Registry of Unmet Needs and Employment; the Eastern Region -- the Registry of Unmet Needs and Transportation/Isolation; Self-advocates -- Housing and Employment; Youth Self-Advocates -- Independent Living and Employment; and Hispanic/Latin-x -- Registry of Unmet Needs and Transition to Employment.

Of the 704 surveys responses the Council received, it received 204 surveys from individuals with I/DD (about half of which appeared to have been filled out by family members), 359 surveys from family members, and 141 surveys from community members. The Council collected and examined demographic and regional information related to who filled out the surveys. The most important issues identified by individuals who filled out the surveys were in order as follows (with each receiving over 20% as a top three issue): Employment; Getting the Services and Supports I Need; School/Education; Money and Finances; Planning for My Future; Having Friends and Relationships; Housing; and Transportation.

The most important issues identified by family members (with each receiving over 20% as a top three issue) were: Getting the Services and Supports They Need; Employment; School/Education; Housing; Knowing What Services and Supports are Available; Planning for the Future; and Having Friends and Meaningful Relationships. Community respondents identified the following top three issues (each receiving over 20%): Getting the Supports and Services They Need; Employment; Being More a Part of the Community; Housing; and Transportation.

Based on this feedback from the community in addition to the Council's five-year planning research and work, the Council developed its draft Goals and Objectives for the 2022-2026

Five Year Plan. The process for developing the Goals and Objectives included discussion at the Council meeting of the information obtained at the listening sessions and surveys. Then, the Council held a half day facilitated virtual retreat with the Planning Committee. Finally, the Council brought the Goals and Objectives back to the Council as a final draft for discussion.

The Council then released the Goals and Objectives for Public Comment during the period of March 1, 2021 through April 14, 2021. The Council received 117 responses. These responses were reviewed and discussed by the Planning Committee on April 23, 2021. The Council then further discussed the comments with the Council at its May 2021 Council meeting. After discussion and review of the Public Comments, the Council approved the draft Goals and Objectives and determined there was not a need to revise the Goals and Objectives and resubmit for Public Comment.

Collaboration [Section 124(c)(3)(D)]

NCCDD is actively engaged with its NC DD network partners, Disability Rights North Carolina (P&A) and the Carolina Institute for Developmental Disabilities (UCEDD) to support, establish and promote common priorities for systems change. Collaboration efforts range from serving in leadership positions on network partner governing boards – DRNC and CIDD are voting members of the NCCDD and the NCCDD is represented as a non-voting ex officio member of the DRNC Board of Directors and the Advisory Council for CIDD. This level of engagement leads to active common knowledge and support of the goals and/or targets of each partner, including a significant role in support of the goals and objectives of the NCCDD Five Year Plan.

The three partners have most recently created a partnership to promote the vaccine for Covid-19 to individuals with I/DD and other disabilities across the state. At the first event, Governor Roy Cooper attended the vaccine event. All of the events are sponsored by all three organizations.

DRNC is currently the recipient of a NCCDD initiative to foster advocacy leadership for people with I/DD (Goal 3.3). The ALP-NC initiative prepares people with I/DD to participate in each aspect of the delivery of leadership development training as well become Self-advocate leaders of the NC advocacy movement. The ALP-NC inclusive leadership development training also focuses on family members, professionals, and other stakeholders in both the public and private sector.

The final component of the leadership training initiative is coordination and maintenance of the graduates of NC advocacy leadership programs (ALP—NC, NCPPI, NCASL, LEND, and STIR). Network collaboration is currently underway with a specific focus on a self-advocacy network in NC with the aim of helping to strengthen this network in accordance with DD Act mandates.

In addition, the NCCDD is actively engaged in a number of policy-level governance groups with examples including:

Financial Asset Development

- NCCDD promotes high expectations for individuals starting at birth through adulthood with a focus on strong transitions and meaningful choices so that individuals with I/DD and their families will be more informed and will have a path from school to post-secondary education and/or employment, and development of assets. The NCCDD engages in leadership within various policy-level task force workgroups including the governance efforts of the NC federally funded Office of Disability Employment Policy (ODEP) grant and statewide employment first leadership workgroup supporting Employment First in NC, the direction of Workforce Innovation and Opportunity Act (WIOA), and involvement with the NC Business Leadership Network (NCBLN).

Community Living

- DRNC: COVID 19 vaccine access and high interest in RUN work by NCCDD
- The NCCDD is emphasizing more choice and opportunity for integrated and inclusive community living, responsive health care, and healthy relationships. The NCCDD is actively involved with the NC Practice Improvement Collaborative, most recently focused on expanding awareness of the importance of integrated and coordinated management of healthcare for individuals with I/DD. The NCCDD also participated with the NC Institute of Medicine to focus on aging and disability. The NCCDD is represented on the Raleigh Mayors Committee for Persons with Disabilities, supports the NC Youth Leadership Forum, and is also represented on the recently established NC General Assembly's Advisory Committee for Education and Employment Opportunities for Students with Disabilities.

The NCCDD, with staff and members, engages with the Home and Community Based Services Waiver Committee and Transition Planning (new community elements) Committee, NC Respite Coalition, NC Money Follows the Person Rebalancing Fund Committee, and NC Victims Task Force and the No Wrong Door Governance Team. NC Money Follows the Person and the NCCDD will issue a joint Request for Applications, supporting Community Living. In addition, the NCCDD serves as a governor appointed as a member of the Board of Directors for the NC Brain Injury Advisory Council (BIAC) which also serves as a network collaboration as DRNC serves with this Board providing opportunity to help shape direction of future outcomes related to TBI supports in NC.

Leadership Development

- The NCCDD is focused on increased understanding, systems change and leadership. As such, the NCCDD serves on the NC SILC Board of Directors (ex officio, non-voting), NC DD Consortium, Guardianship Stakeholders Group (as part of a formerly funded initiative), CIDD Advisory Board, DRNC Board of Directors (ex officio, non-voting), and Olmstead Governance Team.

Two members of the NC General Assembly (NCGA) actively serve with the NCCDD. The NCGA maintains a bi-partisan DD Caucus that was established in 2017. The Council attends each

meeting for the caucus to serve as an ongoing resource. The NCCDD also meets regularly with NC DHHS leadership.

5 Year Goals [Section 124(4); Section 125(c)(5)]

Goal #1: Financial Asset Development

By 2026, INCREASE FINANCIAL SECURITY THROUGH ASSET DEVELOPMENT FOR INDIVIDUALS WITH INTELLECTUAL AND OTHER DEVELOPMENTAL DISABILITIES (I/DD).

Increase financial asset development for individuals with intellectual and developmental disabilities (I/DD) so that they and their families have greater opportunities for choice, self-determination, independence and community engagement.

OBJECTIVE A: Increase Employment First within educational institutions, governmental entities, and society at large.

Measurement: More educational institutions, governmental entities, and the larger community will prioritize employment in the general workforce (Employment First) for citizens with disabilities in North Carolina.

OBJECTIVE B: Increase integrated competitive employment and long-term careers for people with I/DD through best and promising practices.

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

OBJECTIVE C: Increase financial asset development and security by increasing knowledge (financial education/benefits planning), developing financial plans and implementing the plan's goals.

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

Goal #2 Community Living

By 2026, INCREASE COMMUNITY LIVING FOR INDIVIDUALS WITH INTELLECTUAL AND OTHER DEVELOPMENTAL DISABILITIES (I/DD)

Throughout their lifespan transition and lifespan planning, more individuals with intellectual and developmental disabilities (I/DD) will access housing, transportation, healthcare, health and wellness; participate in employment and community life; and be respected, valued and supported in their communities.

OBJECTIVE A: Increase access to affordable, accessible, safe, and fully integrated housing that provides choice and flexibility regarding where and with whom they live.

Measurement: More individuals with I/DD will choose where and with whom to live in their community.

OBJECTIVE B: Increase individuals with I/DD's access to transportation by identifying and implementing strategies to eliminate barriers through collaboration with transportation agencies, state and local agencies, organizations, and advocacy groups.

Measurement: More individuals with I/DD will have transportation options to support community living and employment.

OBJECTIVE C: Increase equitable access to home and community-based healthcare, preventative healthcare, wellness opportunities, and address unmet health-related resource needs through individual, family, and stakeholder education and provider capacity building.

Measurement: More individuals with I/DD will have timely and equitable access to, and continuity of healthcare, preventative health, and wellness opportunities through system improvement and individual, family, and stakeholder education.

OBJECTIVE D: Increase person and family-centered transition education and lifespan planning.

Measurement: More individuals with I/DD will take part in transition and lifespan planning to address areas of employment, education, community living, and community relationships.

OBJECTIVE E: Increase the knowledge, training, and support for professionals that provide services to people with I/DD.

Measurement: More professionals in the field of I/DD will receive professional supports and training development to support and to advance rights, options, and opportunities, of individuals with I/DD.

Goal #3 Advocacy/Self-Advocacy Development

By 2026, INCREASE ADVOCACY FOR INDIVIDUALS WITH INTELLECTUAL AND OTHER DEVELOPMENTAL DISABILITIES (I/DD)

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

OBJECTIVE A: Increase support to a statewide self-advocacy organization(s) through leadership development and coalition participation by:

- (I) establishing or strengthening a program for the direct funding of a state self-advocacy organization(s) led by individuals with I/DD,
- (II) supporting opportunities for individuals with I/DD who are considered leaders to provide leadership training to individuals with I/DD who may become leaders and,

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

Measurement: More individuals with I/DD will knowledgeably advocate and take part in decisions that affect their lives, the lives of others and systems that affect those lives.^[P]_[SEP]

OBJECTIVE B: Increase individual, family, public and systems educational opportunities and engagement to improve the lives of individuals with I/DD and the system; with additional specific **targeted disparity** emphasis to increase the knowledge and engagement of members of the Hispanic/Latinx communities.

Measurement: More individuals with I/DD and family members will receive training and advocacy opportunities to better advocate on decisions that impact their lives, the lives of others and the system.

OBJECTIVE C: Increase understanding and awareness of policymakers, state leaders, and the larger community of the unmet needs of individuals with I/DD in North Carolina; with additional specific emphasis on **DD Council collaboration** with the University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDDS) and the Protection and Advocacy of Individual Rights System (P&A).

Measurement: The DD Network (DD Council, UCEDD, and P&A) will collaborate to develop and widely disseminate materials that explain critical aspects of the service system in a way that is easily understood and usable by people with developmental disabilities and their families.

Evaluation Plan [Section 125(c)(3) and (7)]

During the previous Five Year Plan, the North Carolina Council on Developmental Disabilities (NCCDD) adopted the Collective Impact model because it closely aligns with the mission - to ensure that people with intellectual and developmental disabilities (I/DD) and their families participate in the design of and have access to culturally competent services and supports, as well as other assistance and opportunities, which promote inclusive communities - as supported by the DD Act, continues to guide the Council's efforts. These efforts move the state toward building supports, policies and practices that engage people with I/DD and their families in the planning and living of their own lives.

The Council will continue using the Collective impact model to evaluate its programs and practices. By employing a measurement tool, the Council is able to measure its decisions against a reliable systems change strategy and realize a greater force for positive change within the State. The Council is uniquely positioned in State government to work in collaboration to effect change. To be successful, the Council must work together with many organizations in government, nonprofit, faith communities, and the business sectors to address change. And the Council must use a proven tool that can help members develop

standard performance requirement and standards and evaluate the effectiveness of their investments in each initiative.

There are five essential elements to a Collective Impact Project, which include:

1. **Common Agenda:** All participants share a vision for change that includes a common understanding of the problem and a joint approach to solving the problem through agreed-upon actions.
2. **Shared Measurement:** All participating organizations agree on the ways success will be measured and reported, with a short list of common indicators identified and used for learning and improvement.
3. **Mutually Reinforcing Activities:** A diverse set of stakeholders, typically across sectors, coordinate a set of differentiated activities through a mutually reinforcing plan of action.
4. **Continuous Communication:** All players engage in frequent and structured open communication to build trust, assure mutual objectives, and create common motivation.
5. **Backbone Support:** An independent, funded staff dedicated to the initiative provides ongoing support by guiding the initiative's vision and strategy, supporting aligned activities, establishing shared measurement practices, building public will, advancing policy, and mobilizing resources.

Communities Are Ready or Near-Ready for Collective Impact When:

1. There is a "champion" for this cause who has the ability to engage and encourage multiple sectors in the community and is willing to use that ability to help the community solve this problem;
2. There is some local funding available to begin this effort or in-kind resources (protected time for selected staff members) to begin working to obtain funding;
3. There is a history of other kinds of successful collaboration in the community among at least some of the relevant stakeholders;
4. The general public is aware of this problem and cares about it, or can be readily made aware and will care if they are aware.

Methodology to determine needs being met and Council results being achieved:

Formative strategies are used throughout the Council's work. These are complemented by rigorous data gathering, as well as independent evaluation of funded initiatives. Principal among these is the regular meeting between contractors and Council staff, for review of activity plans, successes and barriers, and adjustments that might be required for the project to move forward as planned.

The NCCDD inputs are the resources used to support achieving goals; these resources are countable. They may be Council resources (funding, staff or NCCDD member time, technical assistance); or activities conducted outside NCCDD that are consistent with Council goals

and objectives, but which the NCCDD does not sponsor. For example, if the NCCDD were conducting a needs assessment it would count as an input the funding staff time needed, and the number of survey responses. If at the same time, a professional association in the state decided to develop an online survey in the topical area for the needs assessment, the Council could count that effort as an input toward its goal. Outputs are also counted. Some outputs will be immediate. Others will be longer term and reflect the complex process of achieving Council goals.

An outcome or systems change is hard to measure. In fact, it continues to be necessary to look at many outputs over several years to see if attitude change, knowledge level, research results, the work of diverse stakeholders and champions, and the many unforeseen happenings along the way have actually achieved Council goals. Contractors report activities throughout the contract cycle, and the staff reports contractor efforts, consistent with the Five-Year Plan.

The DD Suite tool enables the Council to track efforts to assure alignment with this plan. In addition to formal reporting to AIDD, contractors update Council members at quarterly meetings in addition to the written reports which are reviewed regularly by the Council committees and associated staff, so that members are fully informed about the activities, outputs, and outcomes of the initiative. The contractors serve as content experts and resources and provide their knowledge outside the initiative in other systems change efforts.

The NCCDD meets quarterly along with its committees; its executive committee meets on a monthly basis, and the ad-hoc committees meet regularly outside the Council meetings. Of particular importance are those areas where implementation may be going less well. For initiatives that find barriers to implementation and for other efforts that experience less success than expected, reports made to the Council engage the expertise of both its members and staff in collaboration with Contractors to identify solutions. When substantive changes are required, these are reported in the annual update and amendment to the Plan. In this area, program staff familiar with the Collective Impact model provide technical assistance to the contractors and assist members in understanding that barriers are inevitable but not “deal breakers”.

Contractors are encouraged to focus their efforts on targeted system change activities. There is clarity from the beginning of an initiative about the nature of its work, its intended inputs, outputs, outcomes, and a clear sense of how the initiative contributes the Council’s State Plan resulting in system change. Committee and Council members know what to expect from each initiative and are prepared for the potential obstacles that may arise.

This breadth of activity serves the NCCDD in another way. Because of the broad scope and background of Council members, each is able to make linkages between NCCDD’s work and work outside Council resources. A Council member that, e.g., sits on an advisory board for a state organization can facilitate connections between the Council initiative and the relevant organization’s efforts, fostering collaboration and maximizing Council resources. Some systems are complex; it may be beyond the power of the Council alone to bring about needed system change. By ensuring that all NCCDD members and staff have good knowledge about the broad array of the Council’s work, the NCCDD can connect members to serve as

resources to initiatives, as well as encourage work on activities outside the NCCDD related to its goals and objectives.

How the annual review identifies trends and needs and for updating the Comprehensive Review and Analysis section:

Council members are ideally positioned to develop perspectives that range from the very broad, national level to the very detailed - what is happening in one of the North Carolina counties or local communities. The NCCDD staff regularly informs Council members about national initiatives, national issues, and provides information about any state policy and practice. There are regular Member Forums at each Council meeting where new information is shared; additionally, interested Council members are encouraged to participate in national and state venues and bring their perspective back to the Council.

North Carolina Council, with support from the NCCDD's Council Development Fund, the Information and Technical Assistance Center for Councils (ITACC), and OIDD itself, periodically hosts and attends national meetings, as well as meetings of neighbor Councils, to discuss issues at the regional and national level.

Members and staff take what they learn back to their committees and the Council as a whole as well as their local communities. Connections are made at these conferences and events so that an informal network develops and is able to share information. Participation on the Council of state and regional agency representatives, along with legislators, further enables NCCDD to access policy and practice decisions that are being made at the agency level. Dialogue with agency staff broadens the forum for discussion. This broader perspective contributes to realizing the Council's mission - to enable inclusive communities, not just for people with I/DD but for all people in North Carolina. By reflecting the issues that face people with I/DD, in the context of their communities, the Council is able to influence the viewpoint of the agencies responsible for the delivery of services and supports.

Added to these broad points of view is the data that emerges from Council initiatives and the personal experiences of Council members. This combination of quantitative and qualitative material provides a powerful and comprehensive "state of the state" in North Carolina and a backdrop against which to review new findings from Council initiatives. The opportunity to compare and contrast the "big picture" with personal experience, or what's happening in two different parts of the state, or what an initiative planned and what the initiative is finding during implementation, enables NCCDD to explore the reasons for differences, the power of the data, and to share what it learns with policy makers. With the constants of the DD Act and the Council mission, members and staff identify what works, what should work, and what does not work in North Carolina, and discuss these issues with the national experience as the point of reference.

Logic Model

(See Attachment #1)

Projected Council Budget [Section 124(c)(5) (B) and 123 (c) (8)]

	Subtitle B \$	Other(s) \$	Total
Financial Asset Development	\$492602	\$104216	\$596818
Community Living	\$503742	\$111134	614876
Advocacy Development	\$501221	\$112453	613674
General management (Personnel, Budget, Finance, Reporting)	\$555186	\$50278	\$605464
Functions of the DSA	\$40586	\$40586	\$81172
Total	\$2093337	\$418667	\$2512004

Assurances [Section 124 (c) (5) (A) – (N)]

See Attachment #2

Written and signed assurances have been submitted to the Administration on Intellectual and Developmental Disabilities, Administration for Community Living , United States Department of Health and Human Services, regarding compliance with all requirements specified in Section 124 (C)(5)(A) -- (N) in the Developmental Disabilities Assurance and Bill of Rights Act. :

true

Approving Officials for Assurances

For the Council (Chairperson): true

Designated State Agency

A copy of the State Plan has been provided to the DSA: true

Public Input and Review [Section 124 (d) (I)]

Describe how the Council made the plan available for public review and comment. Include how the Council provided appropriate and sufficient notice in accessible formats of the opportunity for review and comment.

Using its Communications Initiative, the NCCDD engaged in a 16-month “LISTEN. GATHER. ACT.” marketing effort to gather public input for the development of the Five-Year State Plan. To inform the goals and objectives, the effort included fourteen listening sessions held statewide, and electronic and hard copy distribution of three stakeholder-specific surveys that targeted people with intellectual and other developmental disabilities (I/DD), families, and service and community stakeholders.

A 45-day, public release of the draft goals and objectives resulted in favorable feedback. Both the input and comment activities included contact with diverse stakeholders in a variety of venues with regard to both the surveys and the draft goals and objectives. The effort was inclusive of the diverse populations and geography of North Carolina. All materials generated were offered and available in multiple accessible formats including Braille, upon request, and large print. In addition, surveys and most announcements soliciting public input and comment were provided in Spanish.

Describe the revisions made to the Plan to take into account and respond to significant comments.

Public comment on the NCCDD draft goals and objectives were favorable and did not require revisions.

