# I/DD Data Initiative:
# An Inventory of I/DD Data and Recommendations to Improve Advocacy Efforts

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## Table of Contents

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## Executive Summary

Individuals with intellectual and other developmental disabilities (I/DD) experience worse health outcomes than the general population and need additional supports and services in order to live in and be actively included within their community. The North Carolina (NC) I/DD community is experiencing difficulty accessing necessary services and due to a long waiting list for the Innovations Waiver and an inadequate workforce to provide these services and supports. To address the lack of timely and accessible data and to advance advocacy efforts for addressing these unmet needs, our team 1) conducted an inventory of the I/DD data that is available at the state and national level and 2) facilitated convenings with a diverse group of I/DD advocates. Through this work, we have generated four overarching data recommendations to guide policy and future advocacy efforts.

| Identified Challenges | Recommendations | Strategies for Implementation |
|---|---|---|
| Access to data that is timely and comparable is a challenge due to siloed payment models. | #1: Capitalize on the shift to Whole Person Care by aligning tracking of data, and ensuring data is available and comparable across settings, programs, and regions. | 1) Identify key outcomes that are important for NCCDD advocacy efforts that also align with other agencies/organizations' efforts to maximize impact. |
| | | 2) Prioritize investments in the evaluation of Tailored Plans to improve the experience and outcomes for the I/DD community. |
| | | 3) Promote alignment of data reporting and transparency across I/DD services, education, healthcare, community services, and other supports via an I/DD Dashboard which would facilitate a fuller understanding of needs and opportunities to inform interventions. |
| Most NC residents with I/DD are not visible to advocates/ evaluators/researchers as the majority of people with I/DD are not receiving formal supports or services through state I/DD programs resulting in a significant undercount of the NC I/DD population. | #2: Increase data-driven advocacy efforts to help people with I/DD and their families know about and how to access I/DD supports and services. | 1) Create an all-payer claims database that would allow for a broad description of the NC I/DD population that is not limited to those who have Medicaid coverage, or currently receiving I/DD services, or are on I/DD waitlists. |
| | | 2) Build intentional efforts to support subpopulations at higher risk for crisis (e.g., physical or mental health crisis, housing instability) such as those in transition to adulthood period and those with aging parents. |
| There is confusion over what the following terms mean and should include: "institution" versus "ICF" versus "group home" residential settings, "I/DD services", and "I/DD budget". | #3: Align on terms, definitions, and framework for how they will be measured, tracked, and communicated. | 1) Ensure the use of clear language and definitions that are agreed upon and reinforced by other key partner organizations. |
| | | 2) Identify data elements and develop materials that show how they are defined and being tracked in a clear and ongoing manner. |
| Advocates know data is important but there is uncertainty about what data is most needed to address important unmet needs the I/DD community is experiencing. | #4: Invest in research projects that are timely and actionable from the perspective of the I/DD community. | 1) Examine prioritized research questions that I/DD community advocates identify and align with NCCDD's priorities and available resources. |
| | | 2) Develop strategies to amplify data that already exists to advance advocacy efforts. |

## Background

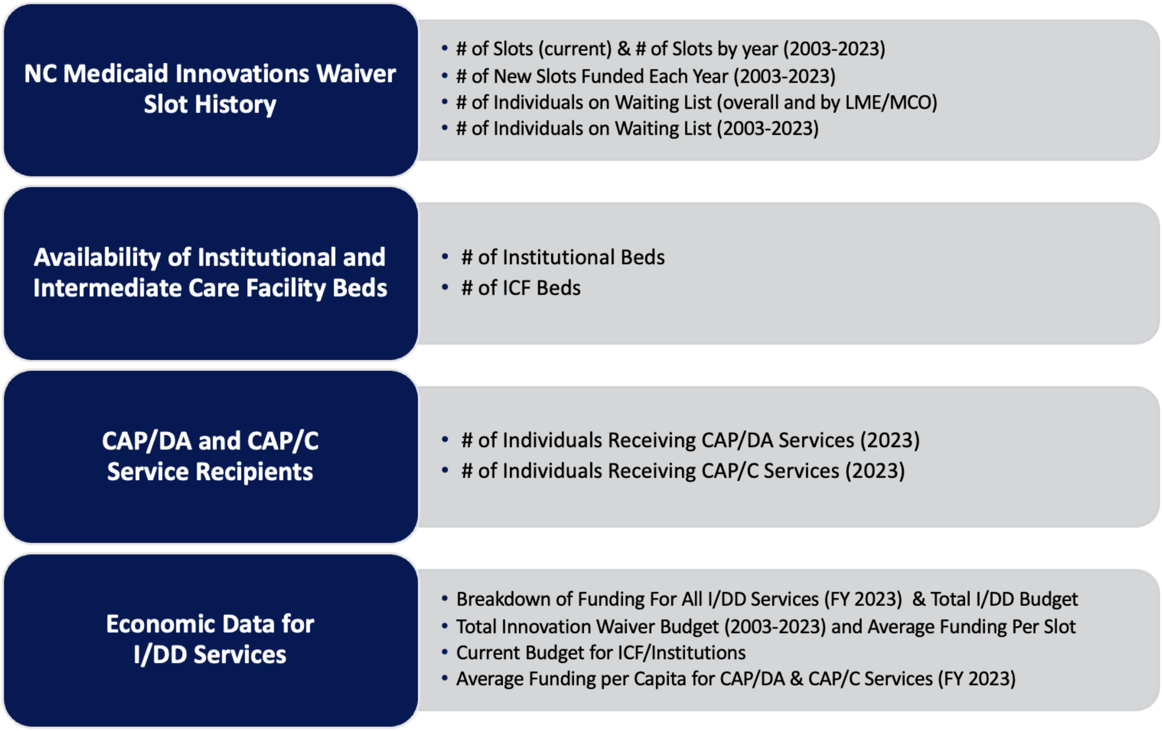
Approximately 1 in 6 (17%) children in the United States (U.S.) have an intellectual or other developmental disability (I/DD), developmental delay, or developmental disorder.[1] There are an estimated 7.4 million people with an I/DD living in the U.S. (5.3 million children and 2.1 million adults), and of these, nearly 200,000 individuals live in North Carolina (NC).[2] However, there are likely many more people with I/DD that have not been included in these estimates due to long waiting lists for diagnostic services, inequitable access to services, and differences in diagnostic labels and definitions used in research.[3,4] While children are more likely to have their I/DD conditions recognized and receive support services during childhood, when they transition to adulthood and during their adulthood, they become less visible and are often invisible to the developmental disabilities system and do not receive essential supports.[3-5] It is estimated that the majority (>59%) of adults with I/DD do not receive any services through the developmental disabilities system even though they would benefit from and are eligible for such services.[3,4,6-9]

People with I/DD experience worse health and health care outcomes than the general population. For example, compared to the non-I/DD population, people with I/DD have higher mortality rates[5] and are more likely to die of conditions that are preventable with health care interventions (e.g., pneumonia).[10] People with I/DD from racial and ethnically marginalized groups, socioeconomically disadvantaged populations, and those residing in rural settings are more likely to experience even worse health outcomes than others with I/DD who are not a part of these additional minority groups.[11-13] People with I/DD often need additional support and services to live in and be actively included within their community.[14] The NC I/DD community is experiencing unmet needs including challenges accessing necessary services and supports (e.g., the Innovations Waiver) due to long waiting lists and lack of a qualified workforce.[15-18]

The difficulty in obtaining the Innovations Waiver is one of many logistical and financial challenges that people with I/DD and their families face. The NC Innovations Waiver is the 1915(c) Home and Community-Based Services (HCBS) Medicaid Waiver approved by the Centers for Medicare and Medicaid Services (CMS) that provides individuals with important supports and services needed to live in the community instead of an institutional setting.[19] The waiver supports people with I/DD to live the life they choose and is designed to meet the needs in their home or community as well as reduce the risk of future institutionalization[19] and the use of crisis services such as the emergency department.[20] Currently, there are 14,736 people receiving the Innovations Waiver; however, an additional 17,902[21] individuals are currently on the waitlist. It is difficult to compare wait times for HCBS waivers for different states and across the different waivers available within each state, but the average wait across the US is 36 months.[18] Within NC, advocates are pleading for action as the average time to receive an Innovations Waiver slot is reportedly seven to 10 years[22,23] and some people have waited up to 17 years, while others have died while waiting.[20,24,25]

There is a ***lack of current and readily accessible data about the I/DD community that could guide the deployment of policy interventions to address these unmet needs***. Collecting data on existing I/DD population demographics, funding for current services, and care options can assist in driving forward positive change in the I/DD policy space. Our project objectives were to:

1) Create an inventory of general I/DD data that is available in public reports and state databases.
2) Collect, analyze, and report on specific data elements requested by the North Carolina Council on Developmental Disabilities (NCCDD) related to the I/DD community in NC, grouped into four key categories (as seen in Figure 1):
    a. NC Medicaid Innovations Waiver Slot History
    b. Availability of Institutional and Intermediate Care Facility Beds
    c. Community Alternatives Program for Disabled Adults (CAP/DA) and Community Alternatives Program For Children Waiver (CAP/C) Service Recipients
    d. Economic Data for I/DD Services
3) Propose recommendations on future data that could be collected, sought, advocated for or shared to better support the NC I/DD community and policy leaders in advocacy efforts.



**NC Medicaid Innovations Waiver Slot History**
- # of Slots (current) & # of Slots by year (2003-2023)
- # of New Slots Funded Each Year (2003-2023)
- # of Individuals on Waiting List (overall and by LME/MCO)
- # of Individuals on Waiting List (2003-2023)

**Availability of Institutional and Intermediate Care Facility Beds**
- # of Institutional Beds
- # of ICF Beds

**CAP/DA and CAP/C Service Recipients**
- # of Individuals Receiving CAP/DA Services (2023)
- # of Individuals Receiving CAP/C Services (2023)

**Economic Data for I/DD Services**
- Breakdown of Funding For All I/DD Services (FY 2023) & Total I/DD Budget
- Total Innovation Waiver Budget (2003-2023) and Average Funding Per Slot
- Current Budget for ICF/Institutions
- Average Funding per Capita for CAP/DA & CAP/C Services (FY 2023)

**Figure 1.** Data Elements Requested by NCCDD

## Methods

To address Objectives 1 and 2, we conducted a literature scan of published academic literature, websites, policy briefs, and other published and unpublished sources. This appraisal helped us identify what is known and what is not currently known, and also identify what is needed but not currently available or accessible. We developed an inventory of current data sources, both nationally and for NC, as well as the specific data elements outlined in Figure 1 above, from this scan. A data repository was created and provided to NCCDD to ensure this data would be readily available for future efforts. For the elements we were not able to identify through this scan, we approached leaders who may have access to this information through convening with them and other communication.

To further inform objectives 1-3, we conducted convenings with a diverse group of I/DD advocates. We did this because we wanted to center the voices, lived-experiences, and expertise of self-advocates, family caregivers, and leaders from diverse public and private organizations representing different sectors. This was instrumental in further contextualizing the data collected and informed our recommendations for what is needed to improve advocacy efforts from the perspectives of these participants in the varied areas they represent. The primary convening was held on June 24th, 2024 at the Duke-Margolis Institute for Health Policy, which included people with I/DD, family caregivers, community organization representatives, health policy consultants, researchers, leaders from the NC Council of Developmental Disabilities, leaders from the NC Department of Health & Human Services, and managed care organizations. Three smaller convenings were held, one on July 25th and two on August 19th with additional health and disability policy experts. More than 45 participants joined the convenings, virtually and in-person. The convenings began with Michelle Scotton Franklin, PhD, APRN and Talley Wells, JD, providing a background of the data initiative project, followed by a semi-structured discussion, which facilitated participants sharing their own thoughts about accessibility of current data and future data that they believe is important to collect to improve advocacy for the I/DD community and address unmet needs.

In the large June 24th convening, to further assist the discussion and allow another opportunity for participants to provide feedback, participants were invited to access *Slido*, a well-established platform developed to facilitate increased interactivity for participants of virtual and live events via features including question and answer and polling. Participants were able to access these features via a web-based *Slido* link that allowed them to input their own questions, and provide targeted feedback to the question - *What further data would be helpful to collect in the I/DD space?* This *Slido* was opened 3 days prior to the meeting and kept open for 1 day after the meeting, to ensure that all participants had ample time to input their thoughts.

The authors of this report synthesized this feedback gained through these convenings and identified six main themes of information that are not currently available but are needed for advocacy efforts to support the I/DD community in NC. These themes are: *Understanding the Needs and Service Utilization of People with I/DD*; *Needs and Experiences of Families and Other Caregivers (paid and non-paid)*; *Integrated Care: Meeting all I/DD, Behavioral, and Physical Health-related Needs*; *Planning and Long-term Support Needs*; *Costs Associated with Care*; and *State Comparisons*.

## Findings

### *Objective 1: Inventory of General I/DD Data that is Available Publicly*

Through our literature scan, we identified publicly available I/DD data sources that provide both NC-specific and national-level data. Both of these types of data are important as state-specific data sources provide essential information on what the conditions are specifically in NC. This data can provide insight into the experiences of people with I/DD and their families as well as demonstrate the impact of investments that have been made in NC when tracked over time. National-level data is essential as it gives information on what is happening across the U.S., it can be used to guide federal policy decisions. Sources that provide both NC-specific and national level data allow for comparison.

We detail data sources and repositories that provide NC-specific and national-level data on I/DD in Table 1. First, we provide NC-specific I/DD data sources. These are largely provided by the NC Department of Health and Human Services (NCDHHS) and the NC Department of Public Instruction. The NCDHHS sources include the Local Management Entity/Managed Care Organization LME/MCO Dashboard[26] and the Innovations Waiver Waitlist[21] both include information on the number of people on the Innovations Waiver waitlist. The NC Division of Health Service Regulation dashboard[27] lists licensed facilities by the type of service they provide to clients, including home care services, mental health facilities, and intermediate care facilities for individuals with intellectual disabilities. Information on financial expenditures are available through the Division of Mental Health, Developmental Disabilities, and Substance Use Services (DMH/DD/SUS) Service Utilization Dashboard[28] and the NC Medicaid Annual Report Tables Dashboard[29]. The DMH/DD/SUS Service Utilization Dashboard[28] provides information on the number of people served by LME/MCO and expenditures by category, including how many people with I/DD were supported by LME/MCOs and utilizing DMH/DD/SUS state and federal block grant funding. The NC Medicaid Annual Report Tables Dashboard[29] details financial information related to NC Medicaid expenditures, including expenditures for CAP/DA and CAP/C services and total spending on services for people with disabilities, which includes people with I/DD. Lastly, the NC Department of Public Instruction Data and State Performance Plans[30] provides the count of students being served, including the number of students with disabilities schools are serving through Individualized Education Plans. See additional details about and key findings for each of these sources in Table 1.

In terms of I/DD sources that contain NC-level and national-level data, we detail seven sources. First, the National Core Indicators (NCI)[31] is part of a national effort to measure and improve the performance of public developmental disabilities agencies. The NCI data is collected from 46 states currently, including NC, and utilizes in-person surveys of adults receiving case management and paid services from the state, surveys of families of people with I/DD, and surveys of agencies supporting people with I/DD.[31] The KFF Medicaid HCBS Waiver Dashboard[32] focuses on waiting lists for HCBS waivers, by state and populations including the I/DD and provides data from 2016 to 2023. The most recent prevalence data on developmental disabilities, including intellectual disabilities and autism, is available through the CDC. The PCORnet Data Query for I/DD[33] is the largest known, national-scale descriptive analysis of IDD populations using electronic health record (EHR; digital versions of patient's medical history) data and provides data about patients that have received health care at a PCORnet partner sites across the U.S. between 2012 to 2022.[3,33] Lastly, are the three Projects of National Significance funded by the Administration for Community Living, U.S. Department of Health and Human Services. These three projects are: 1) the Residential Information Systems Project (RISP),[9] 2) State of the States in Intellectual Disabilities,[34] and 3) ThinkWork.[35] They provide state- and national-level data. RISP[9] studies the long-term services and supports people with I/DD receive based on data provided by U.S. I/DD agencies. The State of the States in Intellectual and Developmental Disabilities details the revenue, spending, and programmatic trends in the U.S. as a whole and in each of the 50

**Table 1.** Inventory of North Carolina Specific I/DD Data Dashboards and Other Data Sources

| **Source** | **Description** | **Key Findings** |
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| I/DD Data Sources that are North Carolina Specific | | |
| Local Management Entity/Managed Care Organization LME/MCO Dashboard[26] | This dashboard from the NC Department of Health and Human Services (NCDHHS) provides updates on a variety of behavioral health indicators. Regarding I/DD, it includes the number of people on the Innovations Waiver Waitlist receiving Medicaid or state-funded behavioral health or I/DD service by LME/MCO. Updated Dashboards are posted monthly, however the "People on Innovations Waitlist Receiving Any Medicaid or State BH/IDD Service" portion is not updated as frequently. | Between October and December 2023, 45% of people on the Innovations Waiver waitlist were receiving Medicaid or state behavioral health or I/DD services while the remaining were not receiving these services. |
| Division of Mental Health, Developmental Disabilities, and Substance Use Services DMH/DD/SUS Service Utilization Dashboard[28] | This dashboard from the NCDHHS provides information on individuals served by the Division of Mental Health, Developmental Disabilities, and Substance Use Services (DMHDDSUS). The usage of state allocations and federal block grants to LME-MCOs is considered, and data is organized by demographic information. | Includes number of people served by LME/MCO and expenditures by category – including for inpatient, residential, and enhanced support services. There were 3,229 people with I/DD supported between SFY 2021 – SFY 2023 by LME/MCOs, utilizing DMH/DD/SUS state and federal block grant funding of $46.6M. |
| Innovations Waitlist Dashboard[21] | The Innovations Waitlist Dashboard displays the number of people on the waitlist for the Waiver service by LME/MCO and county in NC.<br>The notes section of the Dashboard states "data is reflective of the previous month's LME/MCO submission to NC DHHS. Publications will reflect data that is a point in time submission that is from 30 days or more in the recent past." On October 15, 2024 the data posted states "Data as of May 2024" | As of May 2024, 17,902 people were on the waitlist for Innovations Waiver services, with Wake (2,943) and Mecklenburg (1,762) counties having the highest number of people on the list.<br>As of September 2024, 18,469 people were on the waitlist for Innovations Waiver Services with Wake (2,899) and Mecklenburg (1,742) counties having the highest number of people on the list.<br>*Note: Wake and Mecklenburg are the two largest counties in North Carolina by population.* |
| NC Division of Health Service Regulation: Licensed Facilities[27] | This collection of data highlights a listing of licensed facilities by the type of service they provide to clients, including home care services, mental health facilities, and intermediate care | As of Oct 1, 2024, the total bed count of beds within intermediate care facilities for individuals with intellectual disabilities (ICF-IID) in North Carolina was 3,156, and 94% of beds |

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|  | facilities for individuals with intellectual disabilities. | (2,959) were occupied by residents. The repository contains a breakdown of these facilities by region. |
| NC Medicaid Annual Report Tables Dashboard[29] | This dashboard houses financial information related to NC Medicaid expenditures. Included in this table are expenditures for CAP/DA and CAP/C services and total spending on services for people with disabilities. *Note: The Innovations Waiver is not explicitly included on this Dashboard. See the Innovations Waitlist Dashboard above for the Innovations Waiver specific data that is available via NC Medicaid. Innovations Waiver expenditure data is not provided publicly in the manner CAP/DA and CAP/C is here.* | In the 2023 fiscal year, the dashboard shows spending of $8,099.4M on people that are disabled which includes people with I/DD. |
| North Carolina Department of Public Instruction (NCDPI) Data and State Performance Plans[30]<br>Child Count Report – April 2024 Disaggregated[30] | NCDPI generates the Child Count Report that shows the number of students being educated within public or public charter schools throughout NC. The report is generated annually in the spring.<br>The 2024 Disaggregated Public shows the number of students with disabilities whom schools were serving in each individualized education plan (IEP) area of identification at the time of the reporting. In the next column, the 16 categories for this Disaggregated Public report are presented along with the number of students being served in 2024 within each category. | In 2024, 216,673 students had an IEP. The number of students for the respective categories were:<br>• Autism (AU): 33,453<br>• Deaf Blindness: 26<br>• Developmental Delay (DD): 18,132<br>• Deafness (DF): 170<br>• Emotional Disability (ED): 4,555<br>• Hearing Impairment (HI): 1,428<br>• Intellectual Disability (IDMI) – mild: 10,350<br>• Intellectual Disability – moderate (IDMO): 4,365<br>• Intellectual Disability – severe (IDSE): 740<br>• Learning Disability (LD): 72,975<br>• Multiple Disabilities (MU): 2,875<br>• Other Health Impaired (OH): 35,202<br>• Orthopedic Impairment (OI): 474<br>• Speech & Language Impairment (SI): 32,140<br>• Traumatic Brain Injury (TBI): 1,170<br>• Visual Impairment (VI): 618 |
| I/DD Data Sources that Contain North Carolina-level and National-Level Data |  |  |
| National Core Indicators[31] | The Core Indicators are part of a national effort to measure and improve the performance of public developmental disabilities agencies. The data is collected through in-person surveys of adults | **2022-2023 In-Person Survey National Report Findings**:<br>• *Employment* – Nationally 17% of individuals with I/DD had a job in the community (NC: 12%); 44% do not have a community job, but want one (47% in NC) |

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| | receiving case management and paid services from the state, surveys of families of people with I/DD, and surveys of agencies supporting people with I/DD.<br>Reports from each of the three survey methods outlined are published each year, and they contain information on key themes, including measures of community inclusion and belonging, employment, and satisfaction of services. Collected data is displayed for all 46 participating states which includes NC. There were 25,424 total respondents for this 2022-2023 data collection.<br>The NCI Website Chart Generator feature is publicly available. It can be used to examine how North Carolina has performed compared to other states and the national average for different measures. | • *Community Inclusion and Belonging* – 71% get to do things they like to do in the community as often as they want (NC: 79%); 81% do things in the community with the people they want (NC: 83%); 92% can be themselves when with others in groups, organizations, or communities the person takes part (NC: 94%)<br>• *Choice and decision-making* – 83% chose regular day activities (NC: 83%); 54% chose or had some input choosing where they live if not living in the family home (NC: 58%); 43% chose or had some input choosing their housemates if not living in the family home (NC: 48%) 59% chose their staff or were aware they could request to change staff (NC: 71%)<br>• *Community Participation* – 82% went out to a restaurant or coffee shop at least once in the past month (NC: 82%); 25% take part in groups, organizations or communities (in-person or virtually) (NC: 30%); 60% reported the groups, organizations, or communities they take part in include people without disabilities (NC: 67%)<br>• *Relationships* – 77% have friends who are not staff or family members (NC: 80%); 56% want help to make or keep contact with friends (NC: 67%); 68% have friends and can meet with their friends when they want (NC: 57%); 13% often feel lonely (NC: 9%)<br>• *Satisfaction* – 28% want to live somewhere else (NC: 25%); 84% have enough things they like to do at home (NC: 89%); 81% like how they usually spend their time during the day (NC: 86%); 57% have used telehealth and like using it (NC: 58%)<br>• *Self-Direction* – 19% are using a self-directed supports option (NC: 2%). No other North Carolina results are shown for any self-direction question due to low counts.<br>• *Service Coordination* – 96% were at last service planning meeting, or had the opportunity to be but chose not to (NC: 96%); 93% say their service plan includes things that are important to the person (NC: 94%); 75% say they helped make their service plan (NC: 65%); 80% know |

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| | | whom to ask if wants to change something about services (NC: 85%)<br>• *Workforce* – 93% report staff treat person with respect (NC: 93%); 86% of staff do things the way the person wants them done (NC: 85%); 40% report that staff change too often (NC: 24%); 88% report that staff have the right training to meet person's needs (NC: 95%)<br>• *Safety* – 21% felt afraid in their home, neighborhood, transport, workplace, day program/at other daily activity and/other places (NC: 21%); 93% have someone to go to for help when they feel afraid (NC: 97%)<br>• *Access* – 80% are able to get places when they want to do something fun outside the home (NC: 85%); 92% have a way to get places they need to go (like work, appointments, etc.) (NC: 98%); 84% have access to internet (NC: 89%); 91% have enough help to use technology and devices that help them in their everyday life (NC: 96%); 69% have a cell phone or smartphone (NC: 55%)<br>• *Health* – 83% had an annual physical in past year (NC: 88%); 76% had a routine dental exam in past year (NC: 75%); 53% had a vision screening in the past year (NC: 49%); 72% had a mammogram in past 2 years (NC: 70%); 49% had a pap test in past 3 years (NC: 43%)<br>• *Medication* – 49% take medications for mood, anxiety, psychotic disorders (NC: 56%); 31% take three or more medications for mood, anxiety, and/or psychotic disorders (NC: 34%)<br>• *Wellness* – 5% use nicotine or tobacco products (NC: 5%); 38% have a BMI in the obese category (NC: 38%); 82% exercise or do physical activity at least once per week for 10 minutes or more at a time (NC: 86%)<br>• *Rights and Respect* – 29% have attended a self-advocacy group, meeting, conference or event or had opportunity and chose not to (NC: 48%); 96% have a place to be |

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| | | alone in the home (NC: 97%); 80% report others ask before coming in their bedroom (NC: 79%); 44% report they can stay home if others go out (NC: 25%)<br>**Family Survey 2022-2023** [Note: Respondents in NC were not included in this Survey]<br>• Majority report that their family gets the services and supports it needs (71% Adult Family Survey; 87% Family Guardian Survey; 66% Child Family Survey)<br>• A smaller percentage felt support workers always have the right information and skills to meet their family's needs (51% Adult Family Survey; 35% Family Guardian Survey; 48% Child Family Survey)<br>• Most respondents felt that there is always a staff person available to support their family member (76% Adult Family Survey; 88% Family Guardian Survey; 68% Child Family Survey)<br>**State of the Workforce, 2022 Survey Report**<br>• Mean number of direct support professions (DSPs) per provider agency as of December 31, 2022 – 78.3 (NC: 77.3)<br>• Number of service types provided (residential supports, in-home supports, and non-residential supports) – 33.3% provided all three service types (NC: 33.8%)<br>• Percentage of agencies that turned away or stopped accepting new service referrals in 2022 due to DSP staffing issues – 49.7% (NC: 42.6%)<br>• Turnover ratios for DSPs – 40.9% (NC: 30.4%)<br>• Tenure among DSPs employed as of December 31, 2022 – 19.0% were employed less than 6 months (NC: 12.7%)<br>• Average full-time DSP vacancy rates as of December 31, 2022 – 15.3% (NC: 13.4%)<br>• Average hourly wage for DSPs – $15.79 (NC: $13.93) |
| KFF Medicaid HCBS Waiver Waiting List Dashboard[32] | This dashboard contains information on waiting list enrollment for Home and Community-Based services, by state and target population. Data is available for the years 2016-2023. Per KFF, HCBS | • People with I/DD comprise 72% of the total waiver waiting list population.<br>• People with I/DD comprise 88% of waiting lists for states without waiver eligibility screenings but only 51% for |

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| Issue Brief for 2023 linked here[18] | waiting lists are an imperfect measure of unmet needs, but there is no alternative measure. KFF explains that HCBS waiting lists reflect the populations each individual state chooses to serve, the services the state decides to provide, the resources the state uses, and the availability of workers to provide these services. [18,36] Another challenge that makes comparisons across states difficult is that states use different waiting list management approaches.[18] | states with these initial screenings. NC does screen people for eligibility.<br>- NC specific: Reports 17,008 people with I/DD are waiting and notes that NC does screen for eligibility. |
| U.S. Centers for Disease Control and Prevention Environmental Public Health Tracking[37] | The Tracking Network includes data on seven types of developmental disabilities including intellectual disabilities and autism. Additionally, it tracks important data such as the number of children receiving interventions and services. The data is available at the state level and provided for different age groups. The data sources are the U.S. Department of Education and the CDC's Autism and Developmental Disability Monitoring Network.[38] The data can be accessed via a data explorer to create maps, tables, and charts. | About 1 in 6 children have a developmental disability in the U.S.<br><br>1 in 36, 8-year-olds were identified with autism in 2020.[39] |
| PCORnet Data Query for IDD by PCORnet, the National Patient-Centered Clinical Research Network[33] | This query is the largest known, national-scale descriptive analysis of IDD populations using electronic health record (EHR; digital versions of patient's medical history) data. This query provides data about patients that have received health care at a PCORnet partner site between October 2012 to October 2022 and have one or more of the following 11 conditions: attention-deficit hyperactivity disorder, autism spectrum disorder, congenital malformation of the brain, cerebral palsy, down syndrome, fetal alcohol syndrome, fragile X syndrome, inborn metabolic disorders presenting with intellectual disability, intellectual disability as specified in ICD-9 and ICD-10, spina bifida, and other conditions presenting with intellectual disability. It includes demographic | There were 321,700 people with autism, 244,866 patients with intellectual disability, and 51,373 people with Down syndrome.<br><br>Diabetes, hypertension, anxiety, and depression were the most common co-occurring conditions recorded for this population.<br><br>There was high utilization of the emergency department (19-35%) and inpatient settings (8-31%) across IDD conditions. Telehealth services were also commonly used by individuals with IDD (33-49%), most likely in the context of the shift to telehealth as a result of the COVID-19 pandemic.<br><br>Note: a new query is in progress from PCORI with Drs. Franklin and Maslow contributing and will be made available in 2025 |

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| | characteristics (e.g., age, race, sex, socioeconomic status), other co-occurring I/DD diagnoses, and other chronic conditions and psychosocial health disorders. PCORnet represents data from more than 30 million people across the U.S. each year. | |
| Residential Information Systems Project (RISP): A Longitudinal Study of Long-Term Services and Supports for People with Intellectual and Developmental Disabilities[9]<br><br>RISP data for North Carolina[40] | RISP has been conducting research on Medicaid funded long-term supports and services (LTSS) for people with I/DD in the U.S. since 1977. RISP studies the long-term services and supports people with I/DD receive based on data provided by U.S. I/DD agencies.<br>This study answers 5 key questions:<br>1) How many people have I/DD?<br>2) How many people with I/DD get paid supports?<br>3) Where do people who get paid supports live?<br>4) How do the places people live differ by age and by state?<br>5) How have the places people with I/DD live changed? | In the U.S. in 2019:<br>• There were 67,498 people living in ICF's for people with I/DD<br>• 930,356 people getting Medicaid Home and Community Based Long-Term Services and Supports<br>• 194,983 people living with family members waiting for HCBS waiver funding<br>• To serve everyone who is waiting, states would need to expand the availability of Medicaid HCBS and Medicaid ICF/IDD by 21%.<br>In NC:<br>• In 2020 there were: 3,757 people receiving ICF/IID<br>• Average Annual Medicaid Spend Per Person for 2020 for ICF/IDD was $138,162 and for all types of waivers was $42,478. [*Note: ICF/IDDs provide more comprehensive twenty-four-hour services than waivers, to the costs cannot be directly compared with one another.*] |
| State of the States in Intellectual and Developmental Disabilities[34] | This project began in 1982 to investigate the determinants of public spending for I/DD services in the U.S. It details the revenue, spending, and programmatic trends in the U.S. as a whole and in each of the 50 states and the District of Columbia.<br><br>NC specific findings are linked here[41] and includes data on total I/DD spending for services from FY 1977 to 2021, public spending by revenue source for 2021, adjusted waiver cost per participant from 1985 to 2021, individual and family support spending from 1987 to 2021, and persons with I/DD living in facilities from 2011-2021. | NC-specific data for I/DD spending FY 1977 to 2021:<br>• In 2021 1.79 billion dollars was spent for I/DD services and 95% of this was for HCBS waiver, ICF/IID, & related Medicaid costs. The highest spend was in 2017 at 2.16 billion (adjusted to 2021 dollars).<br>• The adjusted waiver cost per participant was $69,7000 which is down from $84,100 (adjusted to 2021 dollars) in 2017.<br>• 10,822 people with I/DD live in nursing facilities, state institutions, private ICF/IID, and other residential facilities. |

|  |  |  |
|---|---|---|
| ThinkWork State Data[35] | The Think Work's State Data project makes it possible to find, sort, and analyze data related to employment for people with I/DD.<br>This project answers 5 key questions:<br>1) How many people with I/DD have competitive integrated jobs?<br>2) How do competitive integrated employment outcomes compare for people with and without disabilities? And why is it important for people with disabilities to have access to competitive integrated employment?<br>3) How has participation in state I/DD agency employment and day services changed over time?<br>4) How does participation in integrated employment services differ by state?<br>5) How many people with I/DD find jobs with help from state vocational rehabilitation agencies each year?<br>The Blue Book State Data: The National Report on Employment Services and Outcomes Through 2021[42] provides data on employment and economic self-sufficiency for people with I/DD in the U.S.<br>NC employment and economic details for people with I/DD from 2021 can be downloaded here.[43] | In 2021:[42]<br>• Nationally, 80% of people with I/DD were served in facility-based and non-work settings.<br>• Nationally, $689,741,000 was spent on integrated employment services<br>In NC in 2021:[43]<br>• 22,938 people with I/DD were served by I/DD Agencies, and of these, 15% were served in integrated employment, 50% were served in community-based non-work, 4% were served in facility-based work, and 31% were served in facility-based non-work.[44]<br>• $22,156,000 was spent on integrated employment services<br>• Based on mean annual earnings, earnings for people with no disability were $52,700, for people with any disability were $38,300, and for people with cognitive disability were $29,500. |

states and the District of Columbia. Lastly, Think Work State Data provides data related to employment for people with I/DD.

### *Objective 2: Data Elements requested by the North Carolina Council on Developmental Disabilities (NCCDD) related to the I/DD community in NC*

### Objective 2a: NC Innovations Waiver Slot History

The evaluation team went through an extensive research process that involved combining a range of data sources to develop the Innovations Waiver Slot history between 2013 and 2023 described below. In Table 2, we present information about the number of total slots, new slots funded, and the number of people on the Registry of Unmet Need (the Innovations Waiver slot waiting list) by fiscal year. See Appendix A for a visual display of the number of people with an Innovations Waiver slot and the number of people waiting on the Registry of Unmet Needs between 2013 and 2023. We have not been able to identify publicly available reports that provide these data elements prior to 2013. It is important to emphasize that the 1915(c) HCBS I/DD waiver has changed over time and has not always been called the Innovations Waiver. In addition to the name change, there were other differences, including the earlier program being a two-tiered waiver system, meaning there were two different levels of support available with two different spending limits, but with the Innovations Waiver, now there is only one waiver. The Innovations Waiver is distributed on a first-come, first-served basis, meaning this is determined by the length of time an individual has been on the waiting list,[45] unless they are receiving a waiver through reserved capacity (reserved capacity refers to additional slots for emergency needs, transition of individuals from CAP-C, Money Follows the Person, military transfers, and children with complex needs).[46] Before it was called the Innovations Waiver, the program was called the CAP-MR/DD waiver and then the CAP/IDD waiver. The CAP-MR/IDD was distributed based on acuity of need, meaning someone with higher needs would be awarded a slot first. These changes were more than semantic. The waiver changed over this period. The Innovations Waiver was originally a pilot waiver prior to becoming statewide via legislation by the North Carolina General Assembly. Through this legislation, all individuals on the CAP/IDD were transitioned to the statewide Innovations Waiver. More details about this history are available within the 2012 NC MH/IDD/SAS Health Plan Renewal.[47] Additionally, there were many more local management entities/managed care organizations (LME/MCOs) in NC that managed their own individual waiting list, and because the waiting list was not centralized it limited the tracking of data prior to 2013. There are now four MCO's administering these waiver services in NC: Alliance Health, Trillium Health Resources, Partners Health Management, and Vaya Health.

The North Carolina General Assembly determines how many new waiver slots will be added and funded through the state budget each year. From 2013 to 2023, the number of Innovations Waiver slots has slightly increased from 12,488 in 2013 to 14,736 in 2024, while the number of new slots funded each year has varied. The number of people on the waiting list has increased by 93% from 2014 to 2024. Table 3 provides information about the Innovations Waiver waitlist in May 2024 broken down by LME/MCO. Of the 17,902 individuals on the waitlist, about 38% (n = 6,790) were from Alliance Health, 24% (n = 4,636) were from Trillium Health Resources, 24% (n = 4,323) were from Partners Health Management, and 12% (n = 2,156) were from Vaya Health. In March 2024, in the News &

Observer Article “How a lack of resources in NC landed a teen with autism in a Tennessee jail,” Kelly Crosbie, MSW, LCSW the Director of the Division of Mental Health, Developmental Disabilities, and Substance Use Services shared that there were currently 14,736 Innovation Waiver slots. However, she was pleased to share that 350 additional slots had been added this year and noted that “We desperately need more slots. It’s too many years and it’s very discouraging and hard for families.”[48]

**Table 2.** NC Innovations Waiver Slots and Waiting List Data from 2013-2024

| Fiscal year (FY) | New Slots Funded in FY | Number of Slots | # of People on Waiting List |
|---|---|---|---|
| Jul 2013 – Jun 2014 (2013) | Unavailable | 12,488 | 9,278 (Sep. 2014) |
| Jul 2014 – Jun 2015 (2014) | **Directs the Department to draft a waiver to create 1,000 new slots each year over a 3-year period (1/1/16-6/30/2019)[49,50] | 12,488 | 9,613 (Sep. 2015) |
| Jul 2015 – Jun 2016 (2015) | Unavailable | 12,488 | 11,014 (Sep. 2016) |
| Jul 2016 – Jun 2017 (2016) | 250[51,52] | 12,738 | 11,609 (Sep. 2017) |
| Jul 2017 – Jun 2018 (2017) | 400[52,53] | 13,138 | 12,256 (Sep. 2018) |
| Jul 2018 – Jun 2019 (2018) | Unavailable | 13,138[54] | |
| Jul 2019 – Jun 2020 (2019) | 500[45] | 13,138[52,54] | 13,796 (Sep. 2019) |
| Jul 2020 – Jun 2021 (2020) | 500 | 13,138 | 14,966 (Sep. 2020) |
| Jul 2021 – Jun 2022 (2021) | 400[55] | 13,538 | 15,395 (Sep. 2021) |
| Jul 2022 – Jun 2023 (2022) | 600[55] | 14,138 | (Sep. 2022) |
| Jul 2023 – Jun 2024 (2023) | 350[56-61] | 14,488 | 17,530 (Dec. 2023) |
| *Additional data points not available in legislative documents but available in other sources* | | | |
| March & June 2024 | | 14,736[46,48,58,62] | |
| May 2024 | | | 17,902[21] |

Notes: Data about new slots funded per approved budget for FY 2013-2023 were obtained from sources as cited including the NC General Assembly Fiscal Research Division Legislative Budget Documents,[63] NC Council on Developmental Disabilities Annual Reports published and unpublished[52], The NCDHHS Innovations Waitlist Dashboard,[21] published news sources, as well as unpublished but verified data. When new slots were added (see New Slots Added in FY column) this number was then added to the column “Number of slots” to reflect the updated total slots for each time period. However, the July 2019-June 2021 available data show the number of slots remained constant at 13,138 based on the available data.

**Table 3.** Individuals Currently on the Innovations Waiver Waiting List by LME/MCO

| Registry of Unmet Needs by LME/MCO (as of May 2024) | | | | |
|---|---|---|---|---|
| *Alliance Health* | *Trillium Health Resources* | *Partners* | *Vaya Health* | ***Total*** |
| 6,790 | 4,636 | 4,323 | 2,156 | **17,902** |

Source: Innovations Waitlist Dashboard[21]

**Objective 2b: Availability of Institutional and Intermediate Care Facility Beds**

During our review of the literature and data sources, it was difficult to know how the sources were defining institutional and intermediate care facilities. During our meetings with community advocates, it was clear that there was confusion and uncertainty about the use of the terms institutional and intermediate care facility, and what they entailed. Therefore, in order to promote clarity and consistency, for this analysis we sought to adhere to the definitions outlined in the Samantha R. April 17th, 2024 consent order.[64] These definitions are:

- ***Institution*** or ***Institutional Setting***: A state operated or privately-operated Intermediate Care Facility, including without limitation the three DHHS state operated developmental centers, a Skilled Nursing Facility, a Psychiatric Residential Treatment Facility, an Adult Care Home, or any residential setting defined as an institution by the Centers for Medicare and Medicaid Services.
- ***Intermediate Care Facility/ICF***: A state operated developmental center or private facility meeting the federal Medicaid definition for Intermediate Care Facilities – Individuals with Intellectual Disabilities (ICF/IID)[65]
- ***Adult Care Home***: An assisted living facility licensed under N.C. Gen. Stat. Chapter 131D; see also Pashby v. Delia, 709 F.3d 307, 322 (4th Circ. 2013) (holding that residing in an Adult Care Home qualifies as institutionalization). *

Based on these definitions, an ICF is one type of institutional setting. Table 4 displays the number of ICF beds for Individuals with Intellectual Disabilities (ICF-IID) and how many were occupied or available as of October 2024. Of the 3,156 ICF-IID total beds in NC, 94% (n = 2,959) are occupied.[27] According to data from RISP in 2020, there were 3,757 people living in ICF/IID settings in NC.[9,40] From the 2021 State of the States data there were a total of 10,822 people with I/DD living in nursing facilities, state institutions, private ICF/IID, and other residential facilities.[41] This difference between ~3,000 ICF-IID beds and the ~10,000 individuals living in institutional settings requires further examination and likely is related to individuals with I/DD living in other types of institutional settings, including nursing facilities, state institutions, and other residential facilities. Part of the need for further investigation is that the other residential facilities may or may not be HCBS compliant or institutional.

**Note: While Adult Care Homes may be considered institutional in NC, it is not in terms of Medicaid as Medicaid considers a facility institutional when it provides comprehensive care including room and board. Medicaid coverage for services within an adult care home can vary by state and should be considered when comparing against institutional settings in other states.*

**Table 4.** Number of ICF Beds (as of 10/01/24)

| Total Resident Count (Beds Occupied) | Total Bed Count | Total Beds Available |
|---|---|---|
| 2959 | 3156 | 197 |

Source: NC Division of Health Service Regulation[27]

**Objective 2c: CAP/DA and CAP/C Recipient Data**

People with I/DD are also served by the CAP/C and CAP/DA waivers. The CAP/C and CAP/DA are Medicaid 1915(c) HCBS waiver programs for Medicaid beneficiaries who are medically fragile or at risk for institutionalization if the services approved in the waiver were not available. The CAP/C waiver is for people who are considered medically fragile between the zero to 20 years of age who meet a hospital or nursing facility level of care.[66,67] The CAP/C waiver provides: coordination of care (case management and care advisement), in-home care aide service, respite (institutional and in-home), financial management, individual-directed goods and services, assistive technology, attendant nurse care, community integration, community transition, coordinated caregiving, home accessibility and adaptation, non-medical transportation, nutritional services, participant goods and services, pediatric nurse aide services, pest eradication, specialized medical equipment, training/education/consultative services, and vehicle modification services.[67] The CAP/DA waiver offers services to physically disabled adults, 18 years of age or older.[62,68] The CAP/DA waiver provides: adult day health, CAP in-home aide, coordination of care (case management and care advisement), financial management services, personal assistance services, chore service (declutter/garbage disposal), community integration services, community transition, coordinated caregiving, equipment, modification and technology, individual directed goods and services, meal preparation and delivery, non-medical transportation services, nutritional services, participant goods and services, personal emergency response services, pest eradication, respite services, specialized medical supplies, and training/education and consultative services.

The waivers aim to supplement the services already available to eligible individuals and provide an alternative to institutionalization. As of November 2024, DHHS reported 11,601 individuals were enrolled in the CAP/DA waiver program in NC.[62] A total of 11,684 individuals is the maximum number of individuals that can be served at any one given time as noted on the NCDHHS CAP/DA webpage.[68] The renewal of the CAP/C waiver program in NC was approved on March 1, 2023. In year 1 (March 1, 2023 to February 29, 2024), NC DHHS requested to increase the number of CAP/C waiver individuals by 500 for a total of 4,000 individuals (see Table 5).[66] This increase in slots has been accomplished.

**Table 5.** Number of Individuals Enrolled in CAP/DA and CAP/C Waivers

| | **CAP/DA** | **CAP/C** |
|---|---|---|
| Number of individuals enrolled in the waiver | 11,172[62] – 11,648[68] | 4,000[66] |

Source: NCDHHS Report to Joint Legislative Oversight Committee on Medicaid on Enrolling Community Alternative Program for Disabled Adults (CAP/DA) Participants in BH I/DD Tailored Plans;[62] Community Alternatives Program for Disabled Adults;[68] Press Release, NC Medicaid CAP/C Waiver Renewal[66]
Notes: Waitlist for CAP/DA - As of April 2024, there were 755 individuals on the waitlist for CAP/DA; CAP/C increased in waiver slots – CMS approved the CAP/C waiver for another five years including the period from March 1, 2023 through Feb. 29, 2028 for a total of 4,000 for year 1, 4,500 for year 2, 5,000 for year 3, 5,500 for year 4, and 6,000 for year 6.

### Objective 2d: Economic Data for I/DD Services

Here we present the economic data that is available for I/DD services provided to NC when possible; however, some data is only available via the broader "disability population" category that includes the I/DD community. Based on publicly available data as well as interviews with other policy experts, it was difficult to ascertain how to fully define "I/DD services". Additional work is needed to ensure the data is complete and clearly defined to encompass the full scope of I/DD services. Here we detail the economic data we did identify as well as the available details the and details the sources provide for HCBS Waiver programs, NC Medicaid Expenditures, as well as DMH/DD/SUS State and Federal Block Grant Funds.

#### *Economic Data: HCBS Waiver Budgets*

A. Innovations Waiver HCBS Budget

The current NC Innovations Wavier application was approved by CMS this year July 1, 2024 and was approved for five years.[46] The cost limit is $184,000 per person, however, additional services can be authorized to "exceed the $184,000 waiver limit, per plan year to ensure health, safety and wellbeing, if the following criteria is met: lives independently without his or her family in a home that s/he owns, rents or leases; receives Supported Living Level III; and requires 24-hour support."[46] In Table 6, we list details on the cost neutrality demonstration for waiver Year 1 July 1, 2024 through June 30, 2029. It includes the cost breakdown projected for each of the waiver services/components. The Innovations Waiver provides community navigator, community networking, day supports, residential supports, respite, supported employment, financial support services, assistive technology, benefits counseling, community living and support, community transition, crisis services, home delivered meals, home modifications, individual goods and services, natural supports education, specialized consultation, supported living (periodic), supportive living (transition), supportive living, and vehicle modification services to individuals with intellectual disabilities or developmental disabilities ages 0 or older who meet an ICF/IID level of care. This waiver operates with a concurrent 1915(b)(1), 1915(b)(4), and 1115 authority.[67] The grand total for Innovations Waiver year 2024 to 2025 is projected to be $1,310,313,229.44. The waiver service Community Living and Support is expected to be provided to the most amount of people (n=8,705 people and has the largest cost at $554,642,905.20. Details on each waiver service including definition, limits, methods, provider specifications are provided in the approved Innovations Waiver Application.[46]

**Table 6.** Cost Breakdown Projected for the Innovation Waiver for July 1, 2024 – June 30, 2025

| Waiver Service/Component | **# of users** | **Component Costs & Grand Total** |
|---|---|---|
| Community Navigator | 400 | $376,152.00 |
| Community Networking | 5,601 | $89,675,090.55 |
| Day Supports | 5,922 | $195,817,917.96 |
| Residential Supports | 4,868 | $345,776,376.64 |
| Respite | 5,253 | $41,104,514.88 |
| Supported Employment | 1,639 | $24,840,421.76 |
| Financial Support Services | 414 | $1,035,414.00 |
| Assistive Technology | 1,102 | $1,551,241.32 |
| Benefits Counseling | 82 | $152,520.00 |
| Community Living and Support | 8,705 | $554,642,905.20 |
| Community Transition | 28 | $127,811.60 |
| Crisis Total | 130 | $334,912.50 |
| Home Delivered Meal | 1,566 | $5,375,545.56 |
| Home Modifications | 230 | $3,143,727.40 |
| Individual Goods and Services | 27 | $14244.12 |
| Natural Supports Education | 27 | $23,357.16 |
| Specialized Consultation | 27 | $8,368,791.00 |
| Supported Living – Periodic | 3 | $31,284.00 |
| Supported Living – Transition | 4 | $3,329.48 |
| Supported Living | 438 | $37,584,346.38 |
| Vehicle Modifications | 49 | $333,325.93 |
| | | **Grand Total: $1,310,313,229.44** |

**Source:** NC Innovations Waiver Application (approved 7/1/2024)[46]

The previous approved Innovations Waiver Application was approved to begin July 1, 2019 and was in effect for 5 years until June 30, 2024.[54] In Table 7, we provide the grand totals projected for the Innovation Waiver for the ten-year span from 2019 to 2029. The projections (2019 and 2024) have demonstrated an increase in dollars over time to accommodate the increase in number of participants and costs. From Year 1 of the 2019 approved application that was projected for $760,789,008.59, to 2028 (the final year of the 2024 approved application) we see an increase in participants by 1,598 and a near doubling of the dollars projected. We have not been able to access the I/DD HCBS waiver applications for years prior to 2019.

**Table 7. Innovations Waiver Budgets via Cost Neutrality Demonstration**

| Innovations Wavier Application Cost Projections | **Unduplicated Number of Participants*** | **Grand Totals** |
|---|---|---|
| 2019 Approved Application | | |
| Year 1: July 1, 2019 – June 2020 | 13,138 | $760,789,008.59 |
| Year 2: July 1, 2020 – June 2021 | 13,138 | $789,688,885.45 |
| Year 3: July 1, 2021 – June 2022 | 13,138 | $819,450,205.54 |
| Year 4: July 1, 2022 – June 2023 | 13,138 | $850,427,842.14 |
| Year 5: July 1, 2023 – June 2024 | 13,138 | $883,243,994.01 |
| 2024 Approved Application | | |
| Year 1: July 1, 2024 – June 2025 | 14752 | $1,310,313,229.44 |
| Year 2: July 1, 2025 – June 2026 | 14736 | $1,346,886,380.52 |
| Year 3: July 1, 2026 – June 2027 | 14736 | $1,384,734,758.47 |
| Year 4: July 1, 2027 – June 2028 | 14736 | $1,423,823,982.44 |
| Year 5: July 1, 2028 – June 2029 | 14736 | $1,464,162,184.93 |

Sources: NC Innovations Waiver Application (effective 7/1/2019)[54];NC Innovations Waiver Application (effective 7/1/2024)[46]

Note: The Unduplicated Number of Participants is the maximum number of participants who are served in each year that it is in effect, but the state submits a waiver amendment to CMS to modify the number of participants when any modification is needed including when new waiver slots are added by legislative appropriations.

The national State of the States[41] and the RISP[40] projects provide data on costs for the Innovations Waiver and I/DD spending. According to the most recent publicly available State of the States data from 2021, the adjusted average Innovations Waiver per participant in NC was $69,700, which is down from $84,100 (adjusted to 2021 dollars) in 2017. The total I/DD spending data for FY 1977 to 2021, showed that in 2021 1.79 billion dollars was spent for I/DD services in NC and 97% of this was HCBS waiver, ICF/IID, & Related Medicaid costs. The highest spend in NC was in 2017 at 2.16 billion (adjusted to 2021 dollars) and at that time 78%. were for HCBS waiver, ICF/IID, & Related Medicaid costs.[9,40] The RISP data shows the average annual spending by age according to setting in NC in 2020 and the most expensive care is ICF/IDD at $138,182 average annually per person while those on Medicaid waivers (note this is not limited to people on Innovations Waiver alone as it states it includes Medicaid Authorities 1115, 1915 (a)(b) or (b/c), 1915(c) as indicated) average $42,478 annually per person.[40] It is noted to be less expensive for people who are between age zero to 21 years of age ( $15,595 average annually per person) and more expensive for people 22+ years of age ($59,483 average annually per person).[40]

B. CAP/C and CAP/DA Expenditures

Table 8 provides details regarding the budgets for the CAP/DA and CAP/C waiver programs in 2023. The CAP/DA waiver program budget was $482,700,000. For the CAP/C waiver program, the budget was $105,400,000. Additional historical expenditure data is available from 2010-2023 on the NC Medicaid Annual Report Tables Dashboard.[29]

**Table 8.** Funding for CAP/DA and CAP/C Services in Year 2023

| Program | CAP/DA | CAP/C |
|---|---|---|
| Budget | $482,700,000 | $105,400,000 |

**Source:** NC Medicaid Annual Report Tables Dashboard[29]
Notes: Directions to access this data on dashboard -select NC Medicaid Expenditures by PAC and Service Type (second to last tab).

### *Funding for I/DD Services via DMHDDSUS State & Federal Block Grant Funds*

Tables 9 and 10 display the DMH/DD/SUS state and federal block grant expenditures and individuals supported by each program for the IDD population. Among the IDD population, a total of 3,229 individuals were supported by DMH/DD/SUS state and federal block grants, which totaled nearly $47 million.[28] There were $6,500,700 less spent in 2023 when compared to 2021. The residential services program served the largest number of individuals (n=1,312; 40.6%) and accounted for 18% of all expenditures ($30,221,582).[28] Facility-based day supports (i.e., vocational services and day programs) represented a third of all expenditures ($8,473,089) and supported 1,054 individuals.[28] Similarly, community-based supports, such as developmental therapies, personal care/assistance, day programs, and respite, accounted for 15% of all expenditures ($7,157,490) and supported 1,132 (35.1%) of the individuals with IDD.[28]

**Table 9.** For I/DD Disability Group, Expenditures from 2021-2023 for DMHDDSUS State & Federal Block Grant Funds

| Year | Expenditures |
|---|---|
| 2021 | $53,118,245 |
| 2022 | $50,869,891 |
| 2023 | $46,588,501 |

Source: DMHDDSUS Service Utilization Dashboard[28]

Note: from DHHS DMHDDSUS Dashboard on all Block Grant expenditures – sorted by group "I/DD"

**Table 10.** Breakdown of Funding for I/DD Disability Group, Persons Supported and Expenditures from DMH/DD/SUS State and Federal Block Grant Funds for FY 2023 – All LME/MCO Total

| Services | Persons Supported Number and Percentage of Total | Expenditures Dollars spend and Percentage of Total |
|---|---|---|
| **Residential** | | |
| Residential Services | 1312 (40.6%) | $30,221,582 (64.9%) |
| **Facility Based Day Supports** | | |
| Vocational Services | 1054 (32.6%) | $5,444,981 (11.7%) |
| Day Programs | 275 (8.5%) | $3,028,107 (6.5%) |
| **Community Based Day Supports** | | |
| Developmental Therapies | 340 (10%) | $2,469,403 (5.3%) |
| Personal Care/Assistance | 515 (15.9%) | $2,014,878 (4.3%) |
| Day Programs | 149 (4.6%) | $1,405,077 (3.0%) |
| Respite | 255 (7.9%) | $1,181,139 (2.5%) |
| Alternative/Other Community Based Support Services | 39 (1.2%) | $86,993 (0.2%) |
| **Supported Employment** | | |
| Vocational Services | 376 (11.6%) | $606,328 (1.3%) |
| **Needs Assignment** | | |
| Needs Assignment | 18 (0.6%) | $112,170 (0.2%) |
| **Outpatient** | | |
| Individual | 14 (0.6%) | $6,450 |
| Eval/Test | 13 (0.4%) | $2,113 (0.0%) |
| Group/Family | 3 (0.1%) | $222 (0.0%) |
| **24 Hour Crisis/Detox** | | |
| Facility Based | 3 (0.1%) | $6,960 (0.0%) |
| Crisis Services | 3 (0.1%) | $1,390 (0.0%) |
| **Crisis** | | |
| Crisis Services | 2 (0.1%) | $540 (0.0%) |
| **Enhanced and Support Services** | | |

|  |  |  |
|---|---|---|
| Alternative Services | 2 (0.1%) | $143 (0.0%) |
| **Other Services** |  |  |
| Alternative Services | 1 (0.0%) | $23 (0.0%) |
| **Total** | **3,229** | **$46,588,501** |

Source: DMHDDSUS Service Utilization Dashboard[28]
Note: from DHHS DMHDDSUS Dashboard on all Block Grant expenditures – sorted by group "I/DD". Directions to access this data on dashboard: At top of page select the last gray box - "Broad Category and Service Category" - then toggle on "disability group" at the bottom and choose "IDD" only.

### *Economic Data for Intermediate Care Facilities*

The NC Medicaid Annual Report Tables Dashboard[29] demonstrates total of $1.7 million were spent on intermediate care facilities (ICF) in NC in 2023 (Table 11). This is from fee-for-service data and does not include ICF/IDD costs covered by the LME/MCOs, and 0-2 population costs prior to April 1, 2023. It does not provide I/DD specific data but rather is organized by the broader "disabled" category as well as other categories. The groups shown had expenditures on ICF while the others (not shown) did not. Almost 40% (0.7M) of all ICF expenditures were for the disabled population. More than a third ($0.6 million; 33%) of ICF expenditures were spent on the AFDC Children, Other Children population. Approximately 17% of ICF expenditures were spent on the Aliens and Refugees population, and 5% were spent on the Medicaid Infants and Children population.

**Table 11.** Amount Spent for ICFs by Population for FY 2023

| Population | Amount Spent |
|---|---|
| Disabled | $0.7M |
| Medicaid Infants & Children | $0.1M |
| AFDC Children, Other Children | $0.6M |
| Aliens, Refugees | $0.3M |
| Medicaid Infants & Children | $0.1M |

Source: NC Medicaid Annual Report Tables Dashboard[29]
Notes: Directions to access this data on dashboard - select NC Medicaid Expenditures by PAC and Service Type (second to last tab). Then click on each subcategory under PAC-All (e.g., Disabled, AFDC Children, Other Children, etc.) and look at the "Intermediate Care Facility" cost on the right side for each category

### *Economic Data by Program*

Table 12 displays the expenditures for the disabled population (includes people with I/DD) by program for the fiscal year 2023. The largest expenditures were spent on LME-MCO HMO premiums ($2,562.1 million), PHP premiums ($2,056.7 million), inpatient hospital ($676.4 million), prescription drugs ($650.0 million), and nursing facility ($450.9 million). Based on conversations with NC DHHS leaders, these figures do appear to be low (e.g. intermediate care facility) and are incomplete as they only represent fee-for-service spending.

**Table 12.** Breakdown of NC Medicaid Expenditures for the Disabled Population in 2023

| Program | Amount Spent |
|---|---|
| LME-MCO HMO Premiums | $2562.1M |
| PHP Premiums | $2056.7M |
| Inpatient Hospital | $676.4M |
| Prescribed Drugs | $605.0M |
| Nursing Facility | $450.9M |
| Home Health | $286.8M |
| Outpatient Hospital | $262.0M |
| Medicare Part B Premiums | $237.6M |
| CAP/DA | $233.0M |
| Personal Care | $226.8M |
| Physician | $172.5M |
| CAP/C | $102.0M |
| Other Services | $69.6M |
| Dental | $43.7M |
| Practitioner/Non Physician | $28.9M |
| Clinics | $22.0M |
| Other Premiums | $20.7M |
| Hospice | $18.8M |
| Lab/XRay | $18.3M |
| EPSDT (Health Check) | $6.6M |
| Intermediate Care Facility | $0.7M |
| CAP/MR | $0.1M |
| Medicare, Part A Premiums | $0.0M |
| Psychiatric Hospital (<21) | $0.0M |

| | |
|---|---|
| Mental Hospitals (>65) | $0.0M |
| High Risk Interventions – Residential Care | $0.0M |

Source: Annual Report Tables Dashboard[29]
Notes: 1) This disabled population includes people with I/DD; 2) Directions to access this data on dashboard. Click the link above for the NC Medicaid Annual Report Tables Dashboard, then select NC Medicaid Expenditures by PAC and Service Type (second to last tab). Then click on Disabled to see the expenses by service type on the right (e.g., LME-MCO HMO Premiums etc.).

The NC Medicaid expenditures for the disabled population has increased steadily since 2010 (see Table 13 and Figure 2). Expenditures have increased by 87% from 2010 ($4,339,300,000) to 2023 ($8,099,400,000). The DMH/DD/SUS state and federal block grant expenditures have decreased by 12% from 2021 to 2023 (Table 11).

**Table 13.** Disabled Subgroup Expenditures for NC Medicaid Budget for each Year from 2010 – 2023

| Year | Amount Spent |
|---|---|
| 2010 | $4,339,300,000 |
| 2011 | $4,280,800,000 |
| 2012 | $4,419,900,000 |
| 2013 | $4,555,100,000 |
| 2014 | $4,875,700,000 |
| 2015 | $5,079,700,000 |
| 2016 | $5,234,700,000 |
| 2017 | $5,300,900,000 |
| 2018 | $5,606,100,000 |
| 2019 | $5,621,600,000 |
| 2020 | $6,028,000,000 |
| 2021 | $6,788,100,000 |
| 2022 | $7,832,200,000 |
| 2023 | $8,099,400,000 |

Source: NC Medicaid Annual Report Tables Dashboard[29]
Notes: 1) This disabled population includes people with I/DD; 2) Directions to access this data on dashboard. Click the link above for the NC Medicaid Annual Report Tables Dashboard, then select NC Medicaid Expenditures by PAC and Service Type (second to last tab). Then click on Disabled (under PAC-All) to select the state fiscal years on the left side to review each year's expenditures.

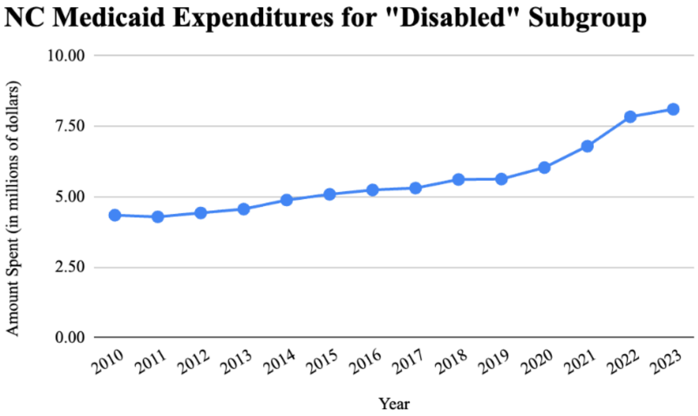


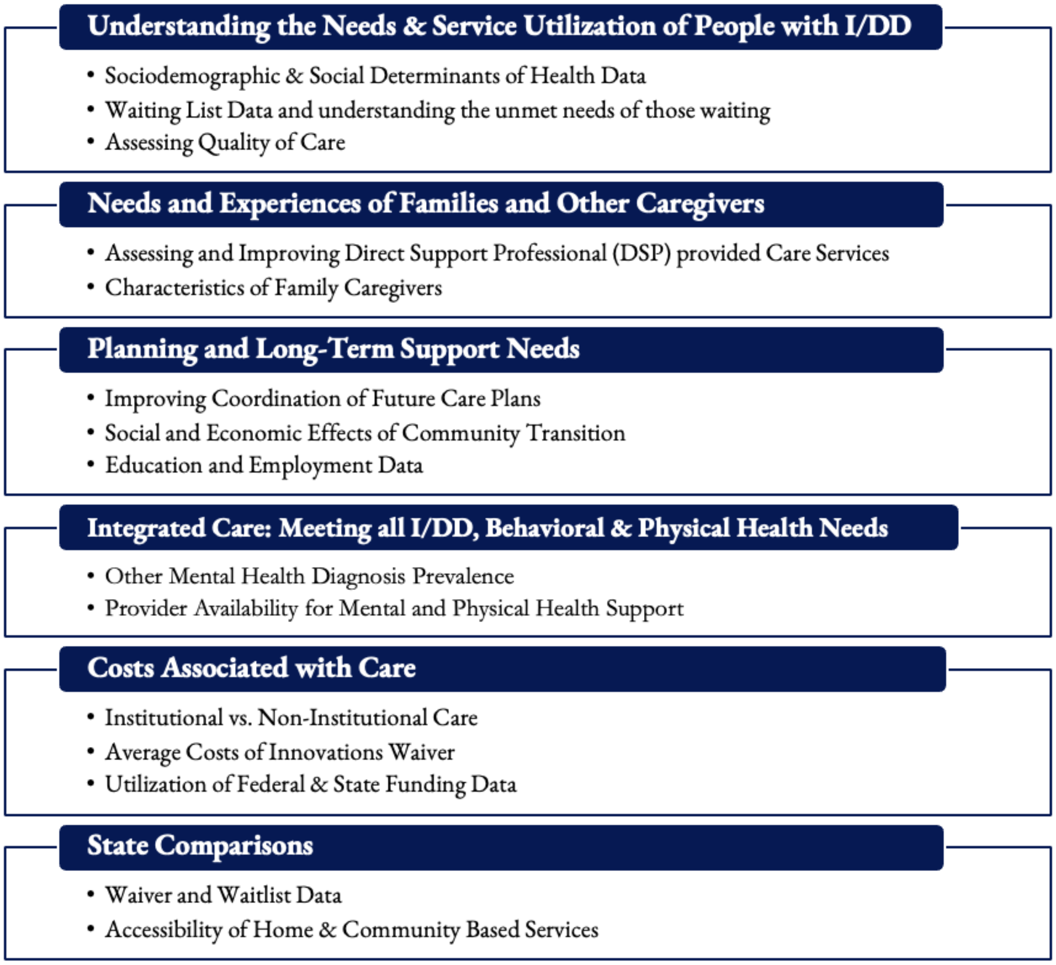
**Figure 2.** NC Medicaid Expenditures for "Disabled" Subgroup that includes People with I/DD
**Source:** NC Medicaid Annual Report Tables Dashboard[29]

## *Objectives 1 and 2 Community Context: Findings from Community Engagement Activities*

Participants shared many ideas and identified a large number of data elements and research questions that they believe need to be explored to improve the health and well-being of the I/DD community and improve I/DD services. The authors of this report synthesized this feedback and organized these findings into six main themes of information that stakeholders endorsed is needed to advocate for the I/DD community. After our convenings, we invited participants to participate in a prioritization activity. See Appendix B for additional details about how this prioritization activity was conducted and the prioritization results.

There were ***six main themes of information needed***, as outlined below and in Figure 3:

- *Understanding the Needs and Service Utilization of People with I/DD*
  - Subthemes:
    - *Sociodemographic and Social Determinants of Health Data*
    - *Innovations Waiver Waitlist: What about the People Waiting on the Registry of Unmet Needs?*
    - *Measuring Quality of Care*
- *Needs and Experiences of Families and Other Caregivers (paid and non-paid)*
- *Integrated Care: Meeting all I/DD, behavioral health, and physical health-related needs)*
- *Planning and Long-term Support Needs*
- *Costs Associated with Care*
- *State Comparisons*



**Understanding the Needs & Service Utilization of People with I/DD**

- Sociodemographic & Social Determinants of Health Data
- Waiting List Data and understanding the unmet needs of those waiting
- Assessing Quality of Care

**Needs and Experiences of Families and Other Caregivers**

- Assessing and Improving Direct Support Professional (DSP) provided Care Services
- Characteristics of Family Caregivers

**Planning and Long-Term Support Needs**

- Improving Coordination of Future Care Plans
- Social and Economic Effects of Community Transition
- Education and Employment Data

**Integrated Care: Meeting all I/DD, Behavioral & Physical Health Needs**

- Other Mental Health Diagnosis Prevalence
- Provider Availability for Mental and Physical Health Support

**Costs Associated with Care**

- Institutional vs. Non-Institutional Care
- Average Costs of Innovations Waiver
- Utilization of Federal & State Funding Data

**State Comparisons**

- Waiver and Waitlist Data
- Accessibility of Home & Community Based Services

***Figure 3.*** Themes of Information Needed to Improve Advocacy Efforts for the I/DD Community

### *Understanding the Needs and Service Utilization of People with I/DD*

This first theme focuses on gaining insight into the needs of people with I/DD, the services they need and are receiving or are waiting for. Lastly it includes elements identified to ascertain the perceived quality of care according to people with I/DD, their families, and other caregivers.

- How do we get an accurate estimate of how big the I/DD community is in NC?
- What is the current prevalence of different I/DD needs in NC? What percentage of this group are receiving the needed services?
- How many people in institutional care options, including group homes and ICFs, would like to live in a more integrated community setting?
- How many people with I/DD in NC choose to receive care in an institutional setting, including ICFs?

- What are the physical, mental, and socioemotional needs of people in ICFs? And are these needs being met?
- How can service utilization data be collected for populations with I/DD, considering the spectrum of service and resource needs?
- What are the most commonly used services by those on the Innovations Waiver?
- What types of services are currently being utilized by those who have the Innovations Waiver? How many individuals are currently authorized to receive services and of these, how many are actually receiving the services?
- Why are some services authorized but not used for people with I/DD? What are the barriers to using these services, and how can they be overcome?
- What other state-supported and privately funded services are available for people with I/DD?

### ***Sociodemographic and Social Determinants of Health Data***

- What are the demographic and social determinants of health findings for people with I/DD in NC?
    - How many people with I/DD in NC have other mental health or substance use diagnoses?
    - What are the living situations for people with I/DD in NC?
    - What is the age breakdown for people with I/DD in NC?
    - What is the racial/ethnic background breakdown for people with I/DD in NC?

### ***Innovations Waiver Waitlist: What about the People Waiting on the Registry of Unmet Needs?***

- What are the demographics and social determinants of health findings for people on the Innovations Waiver waitlist in NC?
    - What is the age breakdown for people on the waitlist?
    - What is the racial/ethnic background for people on the waitlist?
    - What are the living situations for people on the waitlist?
- How many people on the waitlist have other mental health or substance abuse diagnoses?
- How many people have died while on the waiting list?
- How does the number of people on NC's Innovations Waiver waitlist compare to other states?
- What actions have other states taken to have smaller or no waitlists for Home and Community-Based Services?
- How many people on the waitlist have Medicaid or are Medicaid eligible?
- How many people on the waitlist cannot receive services through the 1915(i) waiver because they do not have Medicaid or Medicare or are not income-eligible?
- What data do we need to advocate to end the waiting list?

### *Measuring Quality of Care*

- Do Innovations Waiver recipients that receive care from a paid family member have differences in outcomes (e.g., health, self-determination, employment, community inclusion, satisfaction, emergency department use) compared to people receiving care provided by non-family aides only?
- How satisfied are people with I/DD and their families, with the I/DD services they receive?
- Are I/DD services that are received perceived as useful by people with I/DD and their family members/caregivers?

### *Needs and Experiences of Families and Other Caregivers (paid and non-paid):*

This theme focuses on gaining insights into the experiences of families, other caregivers, and the broader community that provides support to people with I/DD. Understanding the concerns of direct support professionals (DSPs) and family caregivers (paid and non-paid) can assist researchers and policymakers in mapping out the extended I/DD community and better evaluate and compare family-based and non-family-based care models.

- What is the cost of family members exiting the workforce in order to provide support to their loved ones with I/DD?
- Is there currently a way to track who is providing DSP services including whether the DSP is a family member or non-family member?
- How many Innovations Waiver recipients receive care from a paid DSP/family caregiver/aid that is a family member?
- What are the experiences of DSPs providing care and how can this be improved to promote retention of DSP, satisfaction of DSP, and high quality of care to individuals with I/DD?
- Is emergency back-up coverage for DSPs being provided so individuals with I/DD and their families do not miss work or experience other consequence of these care needs not being provided? Are emergency back-up plans being developed, implemented, and tracked in a systematic way?
- What are the characteristics of family caregivers (parents, siblings)? For example, are they paid or unpaid, what are their caregiving hours, and what is their employment status?

### *Integrated Care: Meeting all I/DD, Behavioral, and Physical Health-related Needs*

This theme focuses on gaining insights into the I/DD, mental health, and other physical health needs of people with I/DD and the availability of services to address these needs in an integrated manner. This data can inform strategies to improve access to whole-person care as well as illuminate and address system-level issues such as workforce shortages that are limiting services to people with I/DD and other health-related needs.

- How many people with I/DD also have other mental health diagnoses?

- How many providers in NC are trained to support people with I/DD that may also have mental health conditions?
- How accessible are specialized physical health providers for people with I/DD, for services such as dentistry and orthodontics?
- How does the number of providers of I/DD services vary in rural and urban settings?
- For people that may have multiple diagnoses, how many care managers are serving those with mental health needs versus I/DD needs?

### *Planning and Long-term Support Needs*

This theme focuses on the need for future support for people living with I/DD. Stakeholders can better understand the challenges and opportunities facing the I/DD community in areas crucial for personal development, independence, and social integration. The data on employment rates, types of jobs, and earnings can inform targeted vocational programs and policies to enhance job opportunities and financial independence. At the same time, educational attainment statistics can guide efforts to improve inclusive education practices. Data on aging can help inform strategies for assisting people with I/DD to age in place and prevent crises that can trigger higher levels of care that are avoidable.

- How can we determine the level of support needs for those seeking competitive integrated employment in order to help individuals and their families determine the right course of education and employment selection? How could this strategy be used to help individuals with I/DD and employers find and provide successful compensative integrated employment?
- How many individuals with I/DD are living in NC without a plan for their future support needs? For example, how many individuals’ only source of care is an aging caregiver, which underscores the urgency of the need for DSPs and future planning?
- How can we understand and improve the coordination of care plans that are instituted for individuals with I/DD once their family members pass away?
- How many employment positions are open that a person with I/DD could fill?
- What are the costs of mental health services for people with I/DD who express feelings of loneliness and isolation, and would no longer be needed if they participated more actively in their communities?
- What are the social and economic effects of moving people with I/DD out of congregate/institutional settings and into community settings?
- How can we connect school data, in order to understand how many eligible children in special education are not currently on the Innovations Waiver or waiting list?

### *Costs Associated with Care*

This theme provides insights into the financial, social, and systemic aspects of care for individuals with I/DD. Collecting this data would allow researchers and policymakers to better evaluate cost effectiveness of support models and quantify community inclusion benefits.

- What are the costs of institutional-based care (institution and ICF) and the costs of the care provided by the Innovations Waiver? How do these costs compare?
- What is the average annual cost per person receiving ICF services?
- What is the average annual cost per person receiving the Innovations Waiver?
- How effective has federal and state funding been historically? Can that be extrapolated into a cost/benefit analysis looking forward?
- What is the cost of boarding (longer stay in emergency department or inpatient) because of lack of appropriate care outside of the hospital?
- What is the cost of skilled nursing facility-based care for older adults with I/DD?
- How much of the service cost is truly going to the providers versus the direct support professionals (DSPs)?
- How can we show the cost of people not being included in their communities?

***State Comparisons***

The elements for this theme are focused on understanding how NC compares to other states and gaining understanding of strategies other states have utilized to reduce or eliminate their waiting list for I/DD services.

- How does the number of people on NC's waitlist for the Innovations Waiver compare to other states Home and Community-Based Services Waiver waiting list? What actions have other states taken to reduce or eliminate their waiting list for Home and Community-Based Services?
- What do other states provide/pay for that helps people live in the community so that fewer people with I/DD are left with institutional care as a sole option?
- How does the average cost per person spent on Innovations Waiver services in NC compare to other states?

## Objective 3: Recommendations

This data initiative, including the engagement we have had with I/DD community members and other advocates, has revealed valuable insights on data needs to advance the health and well-being of the I/DD community in NC. From our review of publicly available information, we have identified numerous sources of data related to the I/DD population in NC. There are several data dashboards specific to NC that are managed by state agencies that provided information including the number of individuals on the Innovations Waiver waitlist and whether they are receiving services,[26] economic data on state and federal funding allocated to LME/MCOs to support individuals with I/DD,[28] data on NC Medicaid expenditures for the CAP/DA and CAP/C waiver programs,[29] number of ICF beds occupied,[27] and school data for children with I/DD and an IEP.[30] However, many of these dashboards do not provide access to historical data and are not updated in real-time, and there is a several-month lag with the update. Several other organizations (e.g., PCORnet, RISP, State of The States in Intellectual and Developmental Disabilities) have published quantitative and qualitative data on the I/DD population related to quality of life, employment, service utilization, placement, and expenditures. Many of these national projects include data specific to NC, but the time periods and cadence of published reports vary depending on data source. When reviewing the data requested by the NCCDD, which included NC Medicaid Innovation Waiver slot history, availability of institutional and ICF beds, CAP/DA and CAP/C waiver quantities, and economic data for I/DD services (all I/DD services; funding Innovations Waiver, CAP/DA and CAP/C; and budget for ICFs/institutions), a number of challenges were identified, such as inconsistent use of terms and definitions, lack of specificity, and lack of access to current and historical data. During our community engagement activities, stakeholders highlighted the importance of collecting and maintaining an inventory of data regarding the I/DD community and the current services and supports that are provided and still needed.

Through this work we have generated four overarching data recommendations to guide policy and future advocacy efforts. In table 14, we summarize challenges we identified through this project, our recommendations to address each of these challenges, and strategies NCCDD could implement, advocate for, or share to better support the NC I/DD community and policy leaders in advocacy efforts.

**Table 14:** Identified Challenges, Recommendations, and Strategies for Implementation to address Current Data Needs and Improve Advocacy Efforts

| Identified Challenges | Recommendations | Strategies for Implementation |
|---|---|---|
| Access to data that is timely and comparable is a challenge due to siloed payment models. | #1: Capitalize on the shift to Whole Person Care by aligning tracking of data, and ensuring data is available and comparable across settings, programs, and regions. | 1) Identify key outcomes that are important for NCCDD advocacy efforts that also align with other agencies/organizations' efforts to maximize impact. |
| | | 2) Prioritize investments in the evaluation of Tailored Plans to improve the experience and outcomes for the I/DD community. |
| | | 3) Promote alignment of data reporting and transparency across I/DD services, education, healthcare, community services, and other supports via an I/DD Dashboard which would facilitate a fuller understanding of needs and opportunities to inform interventions. |
| Most NC residents with I/DD are not visible to advocates/ evaluators/researchers as the majority of people with I/DD are not receiving formal supports or services through state I/DD programs resulting in a significant undercount of the NC I/DD population. | #2: Increase data-driven advocacy efforts to help people with I/DD and their families know about and how to access I/DD supports and services. | 1) Create an all-payer claims database that would allow for a broad description of the NC I/DD population that is not limited to those who have Medicaid coverage, or currently receiving I/DD services, or are on I/DD waitlists. |
| | | 2) Build intentional efforts to support subpopulations at higher risk for crisis (e.g., physical or mental health crisis, housing instability) such as those in transition to adulthood period and those with aging parents. |
| There is confusion over what the following terms | #3: Align on terms, definitions, and framework for how they | 1) Ensure the use of clear language and definitions that are agreed upon and reinforced by other key partner organizations. |

| | | |
|---|---|---|
| mean and should include: “institution” versus “ICF” versus “group home” residential settings, “I/DD services”, and “I/DD budget”. | will be measured, tracked, and communicated. | 2) Identify data elements and develop materials that show how they are defined and being tracked in a clear and ongoing manner. |
| Advocates know data is important but there is uncertainty about what data is most needed to address important unmet needs the I/DD community is experiencing. | #4: Invest in research projects that are timely and actionable from the perspective of the I/DD community. | 1) Examine prioritized research questions that I/DD community advocates identify and align with NCCDD’s priorities and available resources. |
| | | 2) Develop strategies to amplify data that already exists to advance advocacy efforts. |

**Recommendation #1: Capitalize on the Shift to Whole Person Care by Aligning Tracking of Data, and Ensuring Data is Available and Comparable Across Settings, Programs, and Regions.**

Per our review, we have identified various data sources that include economic data on the costs associated with I/DD services in NC. These data sources include the DMH/DD/SUS Service Utilization Dashboard,[28] NC Medicaid Annual Report Tables Dashboard,[29] RISP,[9,40] States of the States in Intellectual and Developmental Disabilities,[34] and the budgets outlined in the NC Innovation Waiver Applications. However, the economic data on costs of I/DD services, including those in institutional versus community-based care settings have been difficult to access, assess, and compare. The only publicly available I/DD-specific service data expenditures we were able to locate are the DMH/DD/SUS block grant expenditures by service group for those with I/DD,[28] and these expenditures are not delineated by where the individuals reside and receive services and exclude non- I/DD-specific services such as physical health care and prescriptions. Additionally, NC Medicaid expenditures by service program are available for the disabled population,[29] but this includes individuals with I/DD as well as those with other physical and mental disabilities, who did not engage in any substantial gainful activity.[69] Differences in payment models and what services are included as well as how siloed payment models are makes it difficult to access data that is timely and comparable. With the Tailored Plans launch on July 1, 2024 and the shift to whole-person managed care,[70] there will be greater visibility and integration of I/DD services with all of Medicaid funded services which may improve transparency. This means physical health care, behavioral health care, and pharmacy expenditures regardless of setting can now be tracked for individuals with I/DD enrolled in Tailored Plans, though there are many individuals outside of these systems, including those that do not have Medicaid and are on the waitlist for the Innovations Waiver.

***Implementation Strategy 1: Identify key outcomes that are important for NCCDD advocacy efforts that also align with other agencies/organizations’ efforts to maximize impact.*** There are recent and ongoing key investments being made to help improve data visibly and measurement of important outcomes in NC. We provide two examples that are I/DD-specific which are the 2024-2025 NC

Olmstead Plan[61] and the NCDHHS DMH/DD/SUS DSP Workforce Plan.[17] Both of these plans help address the requirements of the Consent Order associated with Samantha R., et al. v North Carolina and the NC Department of Health and Human Services to help people with I/DD have the supports and services they need to live in the community.[17,61,64] Both of these projects are tracking outcomes that are important for improving the health of the I/DD community. The 2024-2025 NC Olmstead Plan is a roadmap for addressing the health and wellbeing of children and families, youth, adults, and elders with disabilities and it details six priority areas [Priority Area 1: Increase Opportunities for Individuals and Families to Choose Community Inclusion through Access to Medicaid Waiver HCBS; Priority Area 2: Strengthen Opportunities to Divert and Transition Individuals from Unnecessary Institutionalization; Priority Area 3: Address Gaps in Community-Based Services; Priority Area 4: Increase Opportunities for Pre-Employment Transition Services and Competitive Integrated Employment; Priority Area 5: Strengthen Opportunities to Divert and Transition Individuals from the Criminal Justice System and Promote Successful Reentry to Inclusive Communities; Priority Area 6: Promote Workforce Development, Recruitment, and Retention].[61] For each priority area, the NC Olmstead Plan details NC's efforts to date, proposed strategies to improve each area, and detailed the measures chosen to track baseline data and progress over time.[61] Through this I/DD Initiative project, we had the opportunity to learn about the data-driven plan NCDHHS is working on with Mathematica. We learned that there is much overlap with the topics that we examined for this initiative and the outcomes they are measuring. The Olmstead strategy is focusing on their target measures (e.g., Innovations waiver waitlist, number of people using HCBS programs, number people residing in institutional settings, people receiving supported employment, direct support workforce) in a robust and ongoing manner.[61]

The NCDHHS DMH/DD/SUS Direct Support Professional (DSP) Workforce Plan, released June 2024, is a multi-year plan to address the critical DSP workforce crisis and build a DSP workforce to improve key outcomes for the I/DD community including increasing the utilization of community living support, decreasing wait time for services due to DSP availability, and decrease DSP turnover.[17] The NC Olmstead Plan,[61] this DSP Workforce Plan,[17] along with NC DMH/DD/SUS Strategic Plan for 2024-2029[71] are seeking to increase access to quality I/DD services and track this improvement over time. The DMH/DD/SUS Strategic Plan for 2024-2029 details how it will implement outcome measurement system to track outcomes and impact via 31 measures (see Table 1) that includes data we sought through this initiative.[71] By identifying key outcomes that are important for NCCDD advocacy efforts that also align with other NCDHHS Departments and outside organizations, advocacy efforts can be amplified to maximize impact. NCCDD has clearly prioritized funding initiatives to address the Innovations Waiver waiting list (e.g., Meet the Need NC,[72] "Unmet' the Film Project[73]) the DSP workforce shortage, (A Preliminary Report on the Economic Impact of the I/DD Community[74]) and efforts to support advocacy for systems change in NC driven by self-advocates, family members, professionals, and other stakeholders (e.g. Ability Leadership Project of NC[75]).[73] We affirm the importance of these efforts to date and the importance of remaining focused on these key outcomes as they are integral for the I/DD community and require sustained efforts to achieve resolution. In Recommendation 3, we provide additional strategies to improve communication, track outcomes, and amplify efforts.[73]

***Implementation Strategy 2: Prioritize investments in the evaluation of Tailored Plans to improve the experience and outcomes for the IDD community***. Prior to July 1, 2024, people with I/DD receiving ICF-level care already had expenses bundled but those living in the community and receiving Innovations Waiver services only had behavioral health expenditures visible to MCOs. This policy change will facilitate the ability to compare costs between settings more accurately. This is also an opportune time to prioritize investments in evaluating Tailored Plans[70] and the impact this whole person approach has on the health and wellbeing outcomes of people with I/DD. Tracking data through whole-person functioning via Tailored Plans can help provide a fuller picture of the drivers that facilitate improved outcomes (e.g., when someone has stable housing that pushes them to independence).[76] NCDHHS has identified quality measures for Tailored Plans to ensure quality through managed care and to enable assessment of Tailored Plans performance on these quality measures. For these reasons, prioritizing investments in the evaluation of Tailored Plans to improve the experiences and outcomes for the I/DD community will be important.

***Implementation Strategy 3: Promote alignment of data reporting and transparency across I/DD services, education, healthcare, community services, and other supports via an I/DD Dashboard, which would facilitate a fuller understanding of needs and opportunities to inform interventions.*** The Innovations Waiver waiting list is continuing to grow and outpacing the new slots being added. With I/DD Tailored Plan care management efforts, the waiting list will likely grow faster as individuals with I/DD are determined to be eligible for the Innovations Waiver in a timelier manner. Currently, it is challenging to ascertain how may Innovations Waiver slots are available each year based on publicly available data. Furthermore, as part of our historical review, we found that the Innovations Waiver slot information, especially new slots added, was available in different source documents or not available at all. It is unclear if the time period for the number of slots that were available and the number on the waiting list for a given fiscal year align as the source documents do not provide details about when and how this data were calculated. Due to these factors, determining what specifically is needed regarding the Innovations Waiver slots is difficult. Alignment of advocacy efforts targeted on gaining waiver slots and access to 1915(i) services while they are waiting is key to addressing important unmet needs across systems.

Additionally, alignment of data reporting and transparency across I/DD services, education, healthcare, community services, and other supports via an I/DD Dashboard would facilitate fuller understanding of needs and opportunities to inform interventions. Having a robust I/DD Dashboard could provide the opportunity to track impact outcomes within and across these systems over time. For example, it could inform an economic evaluation to see how much is needed to resolve the Innovations Waiver waiting list and evaluate the 1915 (i) services and how they are assisting people while they wait. Having centralized data sources could allow policymakers, researchers, and service providers to make evidence-based decisions regarding meeting the needs of individuals with I/DD and allocating resources more effectively. Furthermore, these data sources could facilitate trend analysis, allowing stakeholders to forecast future needs and evaluate the impact of interventions and policy changes.

## Recommendation #2: Increase data-driven advocacy efforts to help people with I/DD and their families know about and access I/DD supports and services.

There is a significant undercount of people with I/DD, meaning there is a gap between the number of people with I/DD who are documented in public systems and the actual size of the population living with an I/DD condition. In the background section and the summary of data above, we have presented evidence to support this undercount. To further emphasize the importance of this we will further describe the challenges related to the "invisibility" of many individuals with I/DD. This is important because the majority of people with I/DD are not receiving formal supports or services through state I/DD agencies and this also means the majority of people with I/DD are not visible to any of the data sources described in this report. We provide a Venn diagram (see Figure 4), to visually show the overlap of those who are known to the NC I/DD agencies in relation to the overall I/DD population in NC. The estimated overall I/DD population in NC is 200,000,[2] but only 14,736[46,48,58,62] people have an Innovations Waiver slot, while 17,902 people are on the Innovations Waiver waiting list,[21] and the NCDHHS LME/MCO Data Dashboard indicated that from October to December 2023, only 45% of the individuals on the Innovations Waiver waitlist received any Medicaid or state behavioral health/IDD service.[26] It is important to note that even if people are on the waitlist, they cannot receive services through the 1915(i) waiver while they wait if they do not have Medicaid or Medicare, are not income-eligible, or have not yet been connected to services that would make their need for I/DD services evident. Individuals with I/DD and their families are limited by what they can receive through private payers and/or provide for themselves out of pocket. This can mean doing entirely without I/DD services and supports.

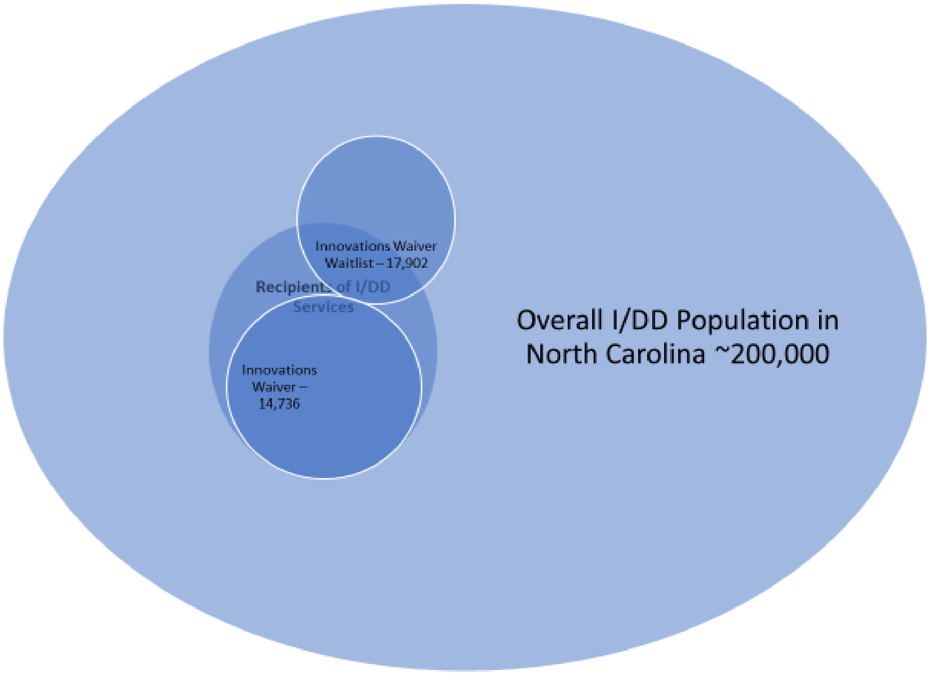


**Figure 4.** Visual to Show the Undercount of I/DD and How Many of the I/DD Community are not Receiving I/DD services.

Based on this NC data that demonstrates the undercount of I/DD, combined with the RISP findings demonstrating that nationally only 22% of people with I/DD were known to or were served by state I/DD agencies,[9,77] we know the majority of the I/DD community is not currently receiving formal public supports and services. The reasons for this undercounting of people with I/DD are varied. These reasons can range from they do not know that they have an I/DD condition (e.g., lack of access to diagnostic testing), individuals with milder forms of I/DD or dual diagnoses might not be formally recognized within the systems (e.g., healthcare, education), stigma associated with I/DD and cultural barriers resulting in families avoiding seeking diagnosis or services, and limited data collection systems that rely on public service-based systems (Medicaid, education) that miss people who are not receiving services, are uninsured, or are in the private healthcare system. However, it should be noted that not everyone with I/DD with need services. We propose two implementation strategies to increase data-driven advocacy efforts to help people with I/DD and their families know about and access I/DD supports and services.

***Implementation Strategy #1: Create an all-payer claims database that would allow for a broad description of the NC I/DD population that is not limited to those who have Medicaid coverage, or currently receiving I/DD services, or are on I/DD waitlists.***

It is important to prioritize collecting data on the entire I/DD population in NC which would include those already receiving I/DD services as well as those currently outside of the system. This investment could provide improved estimates of the full population as well as track other important factors. An all-payer claims database could facilitate the tracking and monitoring of sociodemographic factors and social determinants of health data to facilitate an understanding of how subpopulations of people with I/DD can be effectively supported, especially those that are on the waiting list for services and those underrepresented on the waiting list and among I/DD supports and services. For example, the DMH/DD/SUS Service Utilization Dashboard provides a breakdown by race and ethnicity, but only for those individuals receiving I/DD services.

Through this all-payer approach, it could also be possible to identify who is currently receiving I/DD supports, which supports, and who needs supports. There is clear evidence that agencies in NC are experiencing a DSP crisis and the impact of this is underscored by the State of the Workforce Survey data that demonstrated two-fifths of agencies in NC turned away or stopped accepting new service referrals in 2022 due to DSP staffing issues.[31] This mean more people with I/DD are not receiving the essential I/DD services and supports they need regardless of their payers. The I/DD service system is currently unable to address the demand for services and our lack of data on the full I/DD community in NC and their needs (met and unmet) makes it difficult to fully elucidate what is needed and enact meaningful policy to improve services and supports for those that need them. As of 2023, there were 23 states that have an all-payer claims database that is either mandatory or voluntary.[78] For example, in 2021, Texas established the mandatory Texas All-Payor Claims Database to "improve population health by providing the most comprehensive disease prevalence and incidence surveillance data available to decision-makers accountable for improving state population health."[79] The Office of the Assistant Secretary for Planning and Evaluation (ASPE) at the U.S. Department of Health & Human Services has provided important guidance on all payer claims databases, how they can be used to study prevalence of I/DD and other factors as we are suggesting, and for using them to conduct patient-centered outcomes research.[78] In addition to providing a broad description of the NC I/DD population, this data could be used to illuminate how people may be systematically excluded from services, explain delays to their accessing services, and inform efforts to address these barriers.

***Implementation Strategy #2: Build intentional efforts to support subpopulations at higher risk for crisis (e.g., physical or mental health crisis, housing instability) such as those in transition to adulthood period and those with aging parents.***

We know from our findings from this initiative as well as other literature that people with I/DD are at greater risk for crisis (e.g., physical or mental health crisis,[80] housing instability or homelessness[81]) if they do not have adequate supports. For example, the PCORnet I/DD query[33] demonstrated there was high utilization of the emergency department (19-35%) and inpatient settings (8-31%) across I/DD conditions. The transition from adolescence into adulthood as well as the period when the individuals with I/DD are aging and have aging caregivers places them at even greater risk for crisis.[82] These crises can limit their self-determination and increase the potential that they may need higher level of care. Our convening participants shared concerns about lack of support systems, increased medical needs (of the individual with I/DD and/or their caregiver), and caregiver strain, and we know these factor puts people with I/DD at further risk for crisis. Based on this, we believe it is imperative to build intentional efforts to support subpopulations at higher risk for crisis.

We need data to guide the development of interventions to support adolescents and young adults with I/DD as well as those with aging parents we identify as over the age of 65. For example, understanding how many individuals only source of care is an aging caregiver underscores the urgency of the need for DSPs and future planning. Such crises (e.g., physical or mental health crisis, aging parent unable to provide adequate care for themselves or their family member with I/DD) can result in increased suffering, avoidable hospitalizations, higher levels of care, increased financial costs for the family, and risk for institutionalization). Additionally, these crises are also difficult for the systems (e.g., healthcare, education, community) to address, and they could be prevented with thoughtful monitoring and tailored interventions. At this time, the only publicly available data are on crisis services utilized by individuals with I/DD we found is via the PCORnet I/DD query we referenced above and the DMH/DD/SUS Data Dashboard which displays the total amount of block grant funds spent on crisis services for the I/DD population. Neither data source identifies how many of these individuals have an aging caregiver. Therefore, it is important to identify the best process for tracking these data and building intentional outreach efforts for these subpopulations at higher risk for crisis such as those in transition to adulthood and those with aging parents (>65 years old).

One such intervention that NCDHHS funds and the Co-authors are involved with running is NC-PAL (Dr. Maslow, MD, MPH leads NC-PAL, Dr. French and Dr. Franklin lead components of NC-PAL).[83] It is one of the focused interventions the NCDHHS DMH/DD/SUS Strategic Plan 2024-2029[71] has funded to support integrated behavioral health and primary care models in the delivery system. We have a workstream dedicated to the I/DD community. The NC-PAL I/DD team (Dr. Franklin co-leads) works with providers (pediatrics providers and family medicine providers who provide care to all ages) in primary care settings providing education and other support other to assist practices in providing high-quality care for patients with I/DD and their families. NC-PAL involves Family Partners (parents with lived experience in providing support and system navigation to an individual with I/DD) available to work with and provide training for practice personnel to support patients and their families with system navigation and resource connection. Another NC-PAL workstream, the Child Welfare Collaborative (Dr. French co-leads) provides support to social services including education and consultation to DSS agencies that also includes children with I/DD. Continued investments in interventions that support the I/DD community at these critical developmental periods across systems are crucial for preventing crises and promoting health and wellbeing.

### **Recommendation #3: Align on terms, definitions, and framework for how they will be measured, tracked, and communicated.**

Another challenge to effective advocacy is that leaders and members within the advocacy community are using different terms and different definitions. There is confusion over what the following terms mean and should include: institution versus ICF versus group home residential settings, I/DD services, and I/DD budget. Upon review of the publicly available data, we found variability in how the I/DD population was referred to and defined, depending on the data source. For instance, the NC Medicaid Annual Tables Dashboard uses a disabled category term while the DMH/DD/SUS Data Dashboard uses I/DD term. As noted above, the disabled term is more expansive and includes individuals with other physical or mental health impairment in addition to I/DD. Those individuals included in the LME/MCO Dashboard and Innovations Waiver Waiting List are limited to those who meet eligibility criteria for the waiver. Many of the sources do not explicitly describe how the cohort included in their data analysis was defined. In addition, the advocacy community is interested in similar outcomes (e.g., health, employment), but there are differences in how they refer to and measure these outcomes as well. This is something we realized early on in this project as we saw example of how leaders in the field have different interpretations and/or hesitations about how others use and understand the terms. This can be a limiting factor to the goals of collaboration and effective system advocacy. This was particularly the case about what composes an I/DD budget, I/DD services, and differences in residential settings (institution versus ICF versus group home).

***Implementation Strategy #1: Ensure the use of clear language and definitions that are agreed upon and reinforced by other key partner organizations.*** There is need for alignment over language. What is an institution vs ICF vs group home? What is included in I/DD services and what is considered part of the I/DD budget? In order to promote clarity and consistency, for this analysis we sought to adhere to the definitions outlined in the Samantha R. April 17th, 2024 consent order.[64] This is one example of how we recommend aligning language, such as in the case with the Samantha R. consent order, and creating materials that use plain language definitions.

In the other example of what constitutes the "I/DD services," it is important to define the component services that are included in the definition of I/DD services. How may this include the full scope of services including those paid for by private payers? This clear definition is important to then effectively track utilization of these services.

Ensuring clear language and definitions will allow for important more nuanced questions to be examined in the future:

- How many people with I/DD live in group homes in NC?
- How many people with I/DD live in groups homes within ICFs?
- How many people with I/DD live in group homes who have the Innovations Waiver?
- How many people total with I/DD live in group homes?

Challenges with terms and inconsistent use can be resolved by improving messaging around this in plain language materials and referencing shared definitions consistently. These efforts to ensure use of clear language and definitions that are agreed upon and reinforced by other key partner organizations will promote clarity as well as inform how they are being measured and tracked.

***Implementation Strategy #2: Identify data elements and develop materials that show how they are defined and being tracked in a clear and ongoing manner.*** Throughout the project, we learned about other initiatives that are seeking to improve data availability, tracking, and communication of results to different stakeholders. We have woven examples of this in the other recommendations and emphasize the importance for alignment on how outcomes are defined, tracked, and communicated. These examples have included the Olmstead Plan and the data-driven plan NCDHHS is working on with Mathematica. Also, as a part of the Samantha R. consent order there are LME/MCO accountability measures as well as evaluations DHHS will do such as support the DSP Workforce and increase reporting. These improvements in data collection and access to data can be used to improve advocacy efforts broadly. Having current data about unmet needs (e.g., services, housing) and communicating it clearly, consistently, and broadly is important for system change.

There are four additional projects we provide as examples that demonstrate effective defining, tracking, and communicating in a clear and ongoing manner. We recommend NCCDD and partner organizations consider the strategies these projects demonstrate as they could be utilized to promote consistent collecting, tracking, and communicating of data that can lead to systems change. The first project is how the advocacy organization Vision for Equality,[84] in Pennsylvania, established the PA Waiting List Campaign[85] to end the waiting lists for Medicaid services for people with intellectual disability and autism.

Vision for Equality[84] established the PA Waiting List Campaign (PA refers to Pennsylvania), in 1997, and they have a detailed strategy for how they communicate the unmet needs to legislators and other stakeholders.[85] They track and communicate their findings the same way every year and provide these details through different materials including on their "fact sheet." They develop a document for visits with legislators with suggestions and talking points that advocates can use to guide setting up their visit, informing the discussion as well as including materials they can leave with the legislators to help them "understand the waiting lists impact on families who are waiting and convince them to support the Governor's long-term plan to end the emergency category on the waiting list," along with the Governors proposed budget for that year. Additionally, on their website they make relevant historical data easily accessible (the total people waiting (n=13,200) Pennsylvania budget, number of people served, and the total people waiting (n=13,200)). The PA Waiting List Campaign has developed a clear pathway for securing, organizing, and communicating this data to the community, legislators, payers, and other audiences so that they can understand and act. Though there are differences between NC and PA that should be considered, there are elements from this organization's approach that could be helpful for refining advocacy efforts in NC.

The three other projects we provide as examples that demonstrate effective defining, tracking, and communicating in a clear and ongoing matter are the three Projects of National Significance. Findings from this initiative included data from these projects (see Table 1). These three projects, Residential Information Systems Project (RISP),[9] State of the States in Intellectual Disabilities,[34] and ThinkWork[35] each answer five key questions using long-term information. They remain focused on the same questions and include the same data each time and then communicate their results in the same way. This improves quality of their work, consistency of their findings, and clarity as they communicate their results. Similarly, NCCDD could identify what outcomes it prioritizes tracking, develop a plan with other stakeholders who are critical for accessing this data (if NCCDD is not generating it themselves), in order to ensure it is available in a timely and consistent manner.

### **Recommendation 4: Invest in Research Projects that Are Timely and Actionable According to the I/DD Community.**

Throughout this I/DD Initiative effort, we heard many examples of how advocates know data is important but there is uncertainty about what data is most needed to address important unmet needs the I/DD community is experiencing. It is important to acknowledge it is easy to identify research questions that would be "interesting" to answer. However, it is critical to ask research questions that will result in action, when possible, that can be answered with available data, and that are conducted in a timely manner to drive necessary improvements. Data that is actionable is key.

The emphasis placed by various stakeholders on the importance of future research for addressing the needs and service utilization of people with I/DD were reflected in the critical discussions held during the Duke-Margolis convenings in July and August. These convenings highlighted the urgency of understanding and quantifying the prevalence of I/DD within NC, as well as assessing the scope and effectiveness of existing services available to this population. As we described through

Recommendation #2, collecting accurate data on the size of the I/DD community is a foundational step that not only informs the magnitude of the issue but also serves as a baseline for evaluating service gaps and unmet needs.

In addition to prevalence, it is essential to evaluate how individuals with I/DD interact with available services—both those specifically designed for the I/DD population and those addressing broader social needs. By understanding patterns of service utilization, policymakers can identify which services are most accessed and which areas may be underutilized and by whom. This information can also reveal disparities in access, especially for marginalized communities within the I/DD population, and alleviate barriers they may be experiencing.

***Implementation Strategy #1: Examine prioritized research questions that I/DD community advocates identify and align with NCCDD's priorities and available resources.*** We recommend intentionally focusing on the data needs and research questions the community identified through the convenings we conducted. This is not a comprehensive list of actionable research. Some of these are area already captured in the recommendations above and others represent other important areas of inquiry. Here we highlight some of the themes we identified and additional rationales for why they should be prioritized.

- ***Understanding the Needs and Service Utilization of People with I/DD -*** As identified previously, the true prevalence of I/DD in NC unknown, which makes it challenging to identify the current needs of those with I/DD. Participants suggested determining the current prevalence of different I/DD needs in NC as well as what percentage of the group is receiving the needed services more broadly and then limited to those with the Innovations Waiver. As part of this research aim, it would be helpful to determine and compare what types of services the I/DD population with and without the waiver are utilizing. It will be critical to identify the best method for collecting service utilization data among those with I/DD to ensure it is comprehensive and all-inclusive. In an attempt to better understand the needs of this group of individuals, participants suggested finding out how many individuals who are in institutional care options, including group homes and ICFs, would like to live in a more integrated community setting.
- ***Needs and Experiences of Families and Other Caregivers (paid and non-paid) -*** Often family members are responsible for taking care of loved ones with I/DD, which can result in them having to leave their jobs. To fully understand the financial implications, participants have suggested calculating the cost per family member that exits the workforce to provide support for individuals with I/DD. In addition to understand the opportunity costs, it is important to understand the experience of those DSPs (family and non-family) who provide care to support efforts regarding retention, satisfaction, and high quality of care. As noted in the National Core Indicators, there is a high rate of turnover of DSPs (30.4%), and 42.6% of agencies had to turn away service referrals in 2022 due to DSP staffing issues. Understanding what factors promote DSP retention and satisfaction is essential to ensuring there are enough qualified DSPs to meet the needs of the I/DD population. Participants also expressed that identifying how many individuals with the Innovations Waiver receive care from a paid DSP/family caregiver/aid that

is a family member was a top research priority. These data will help researchers, policymakers, and advocates better understand the needs of DSPs and the role that family members play in providing care to individuals with I/DD

- ***Planning and Long-term Support Needs -*** Participants expressed concerns about the lack of long-term planning for those with I/DD. This is particularly concerning when an individual with I/DD has an aging caregiver. Although this is known as an area of concern, no data is available in NC regarding how many individuals with I/DD do not have a plan for their future support needs. By understanding the number of individuals without a long-term plan, this will allow policymakers to make decisions and inform interventions that will ensure that all individuals with I/DD are adequately supported throughout their lifespan. Participants explained that the biggest advocates for institutional care are families with parents older than 65. They explained that they are more likely to have their children placed in ICF and that they believe this is based on the fears related to the system failing to provide community supports. Given this, it would be beneficial to understand both the social and economic effects of moving people with I/DD out of congregate/institutional settings and into community settings. It is also important to understand what parents older than 65 need and how to provide this support systematically to prevent families experiencing crisis. It is important to characterize the size of this population and engage in targeted advocacy and interventions to understand and address their needs. Participants described how aging caregivers have expressed their comfort with the "one-stop shop" of ICF. Additionally, it is important to examine how many families are not clamoring for institutional care and how are their situations differ. How can effective wraparound services be provided and insured in community settings? This inquiry is critical to accomplish the goals of the Olmstead Plan. In addition to addressing concerns related to long-term planning and moving people with I/DD into community settings, participants also reported that determining the level of support needs for those seeking competitive integrated employment was important. According to the National Core Indicators,[31] only 12% of individuals with I/DD in NC had a job in the community while 47% did not have one but wanted one. With this additional information, caregivers would be able to ensure that individuals with I/DD are able to secure employment that would be a good fit based on their skills and education. This would also allow caregivers to provide accurate guidance to individuals with I/DD regarding education and training that is needed to pursue certain employment opportunities.

***Implementation Strategy #2: Develop strategies to amplify data that already exists to advance advocacy efforts.*** Some of these questions participants asked in our convenings can be answered or at least partially answered with existing data***.*** We have provided an extensive Table 1 to help capture these key findings and help demonstrate where additional information can be obtained. This existing data is already readily available and, in some databases/projects is collected repeatedly so it can be compared over time.

There is a wealth of data available in the data sources we identified in this report, and it is important to leverage this data to advance advocacy efforts. For example, in our convenings, participants expressed the importance about *Understanding the Needs and Service Utilization of People with I/DD (Theme 1),* including the characteristics of caregivers and their concern about the risk for families having greater risk for crisis as parents age. According to the State of the States data for NC in 2021, the majority of caregivers (60%) were over the age of 41 years (35% ages 41-59 and 25% age 60+).[41] In 2019 in NC, 17% of people with I/DD were living with aging caregivers that are 60+ years of age.

Additionally, we know how many are using crisis services and potentially, if it is not already being collected, a variable could be added to include the age of their caregiver and this would allow for determining if these two variables are significantly associated and what other variables may impact these outcomes (i.e., crisis services) and other important outcomes.

## Conclusion

In summary we recommend: 1) Capitalize on the shift to Whole Person Care by aligning tracking of data, and ensuring data is available and comparable across settings, programs, and regions; 2) Increase data-driven advocacy efforts to help people with I/DD and their families know about and how to access I/DD supports and services; 3) Align on terms, definitions, and framework for how they will be measured, tracked, and communicated; and 4) Invest in research projects that are timely and actionable from the perspective of the I/DD community. Informed by these research findings and recommendations, implementation efforts could improve allocation of resources, prioritize funding for critical services, and tailor interventions that address unmet needs within the I/DD community. This data-driven approach can be utilized to improve the health and wellbeing of individuals with I/DD and their families as well as support advocacy efforts by self-advocates, caregivers, healthcare providers, and policy advocates who are working toward sustainable change. With comprehensive data, stakeholders will be positioned to confidently and effectively engage in evidence-based advocacy.

In closing, we want to acknowledge the incredible advocacy efforts that have facilitated the opportunities we now have and the improvements that have been made to strengthen services for the I/DD community. What is known and what is currently being shown through data and people with lived-experience are instrumental in building stronger systems of supports and services and data that help ensure that goals are being accomplished and are being done equitably for I/DD community.

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**Appendix A: Innovations Waiver Data from 2013-2024**

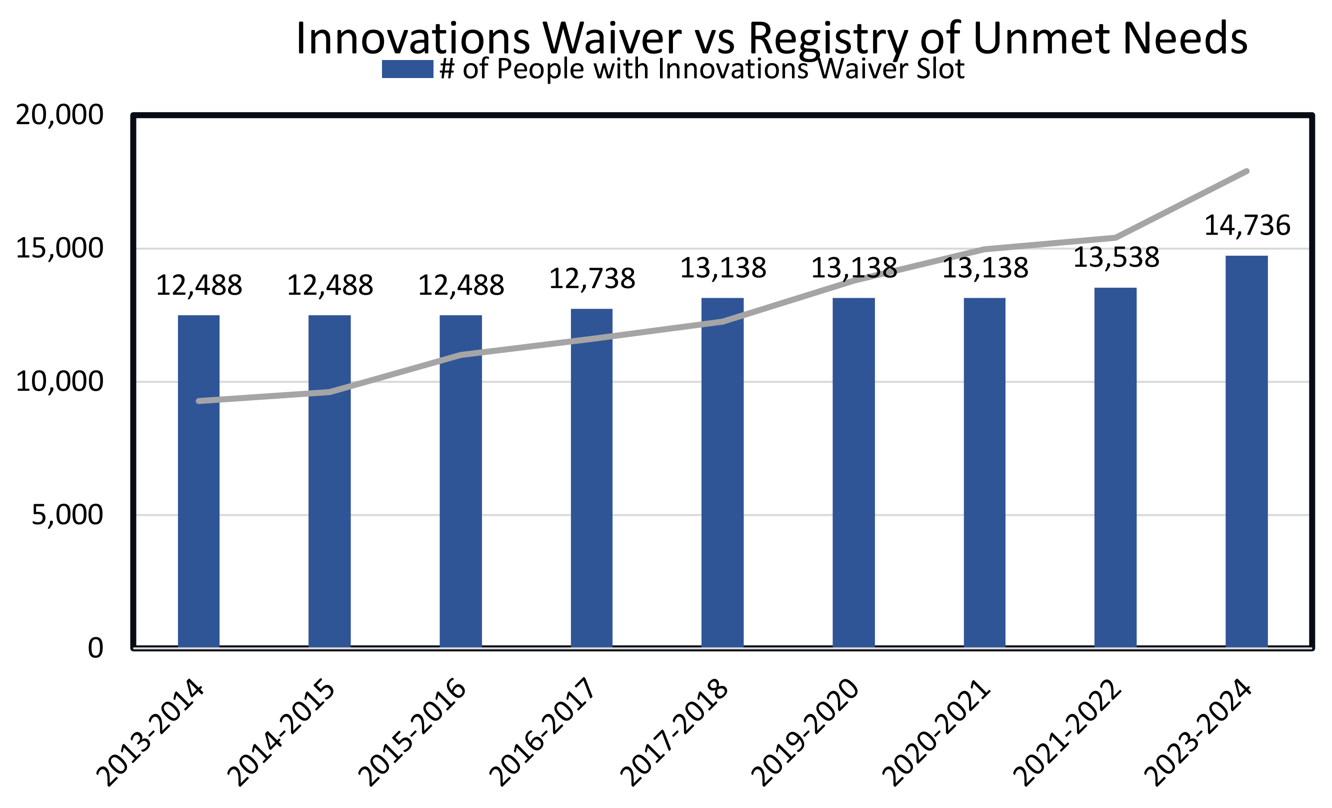


**Figure 1.** Innovations Waiver Data from 2013-2024 depicting the number of people receiving an Innovations Waiver slot and the number of people waiting on the Registry of Unmet Needs each year

## Appendix B: Research Questions Prioritization Activity Results

Through the convenings we hosted, we identified these six main themes of information that is needed to improve advocacy effort for the I/DD community:

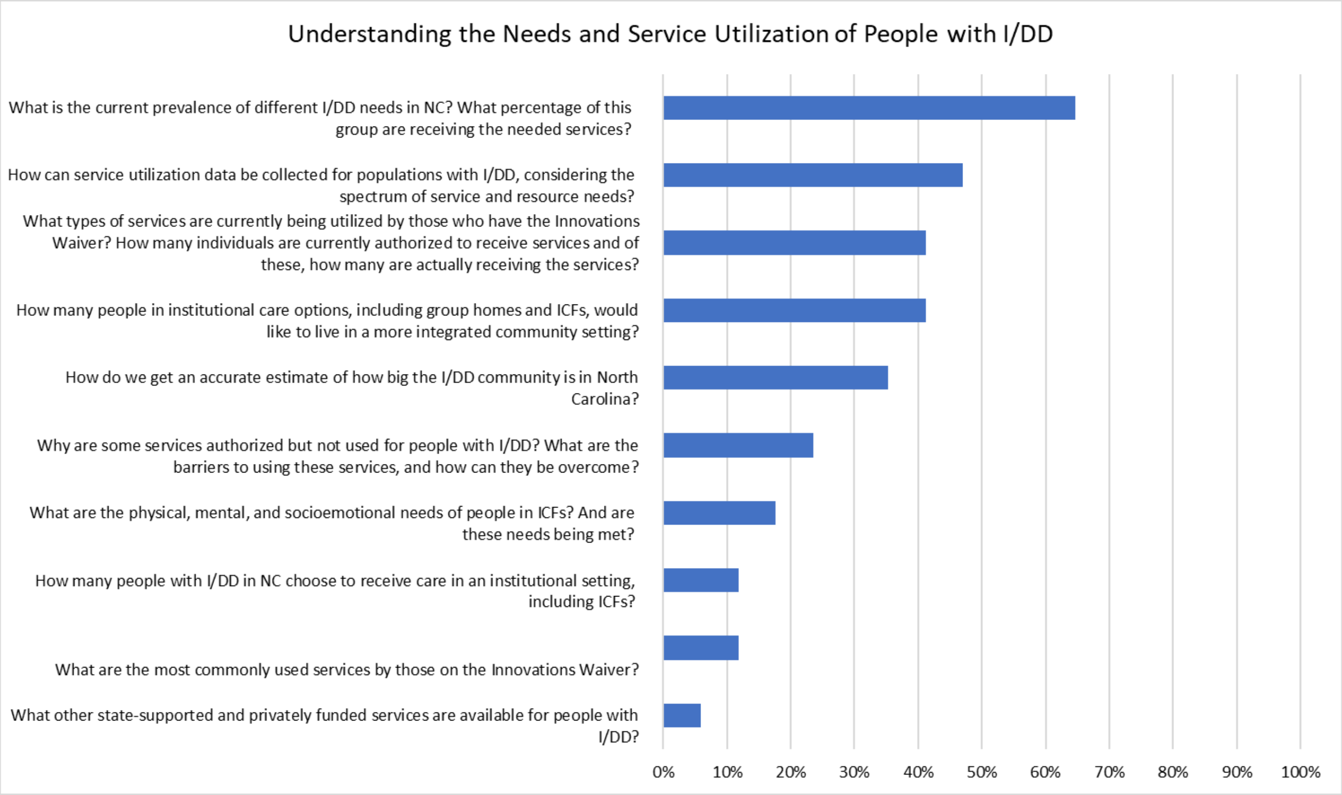
1. *Understanding the Needs and Service Utilization of People with I/DD*
    a. Subthemes:
        i. *Sociodemographic and Social Determinants of Health Data*
        ii. *Innovations Waiver Waitlist: What about the People Waiting on the Registry of Unmet Needs?*
        iii. *Measuring Quality of Care*
2. *Needs and Experiences of Families and Other Caregivers (paid and non-paid)*
3. *Integrated Care: Meeting all I/DD, Mental health, and Physical health-related needs*
4. *Planning and Long-term Support Needs*
5. *Costs Associated with Care*
6. *State Comparisons*

Each of these themes was identified based on the research questions participants had shared during the convenings and are shared in the findings section of this report. In September 2024, our team sent participants a 7-question Qualtrics survey. Six of the questions, one per theme, aimed to assess and identify the research questions that participants thought to be high priority from each theme. They were prompted to pick their top questions for each theme. For example, for the Theme *Understanding the Needs and Service Utilization of People with I/DD* which has 10 questions, they were asked to select their top three. Then, the seventh question asked stakeholders to rank the themes themselves in terms of priority from 1-6.

17 participants completed at least a portion of the prioritization activity, and 15 participants completed the survey in full. The questions that were selected as most important for each theme are provided below.

### *Understanding the Needs and Service Utilization of People with I/DD*

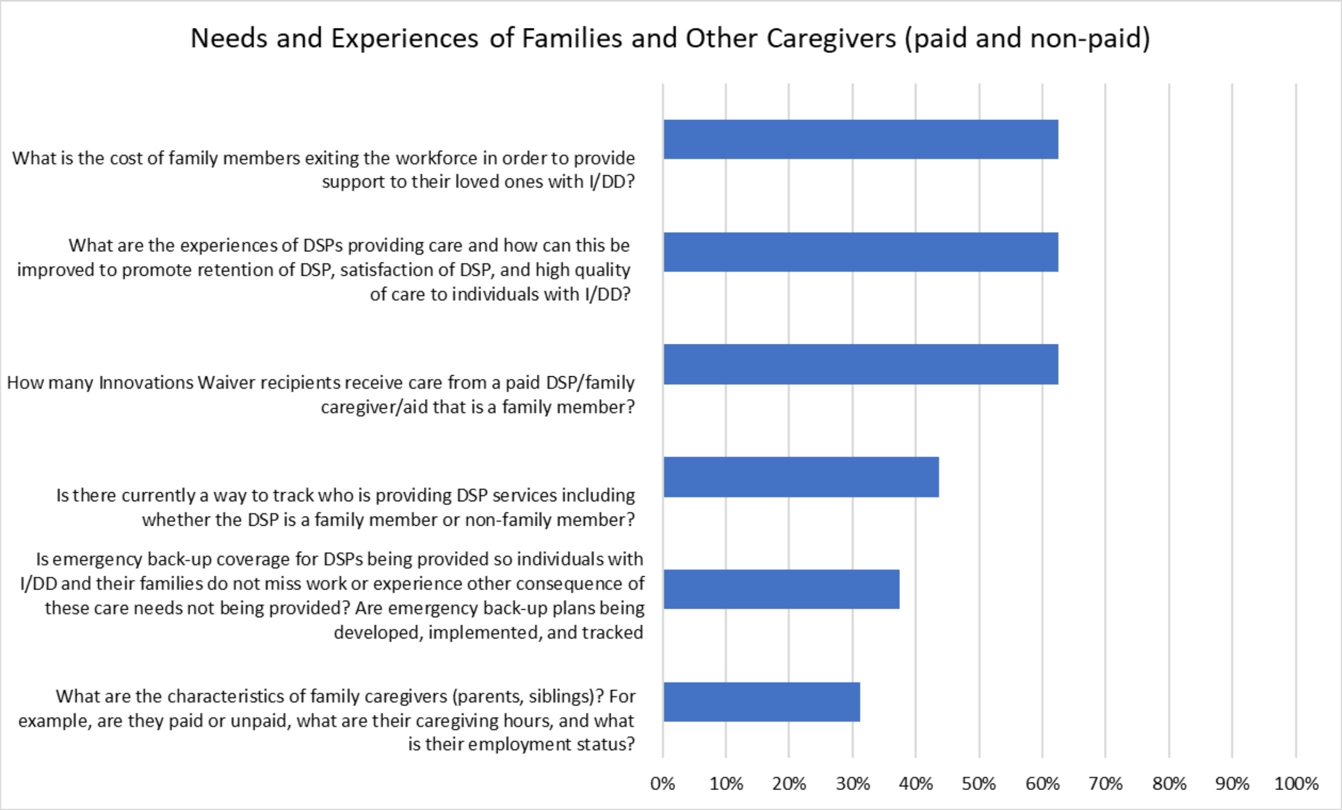
Of the 17 participants who completed this question, more than half (n = 11; 65%) indicated that identifying the current prevalence of different I/DD needs in NC as well as the percentage of individuals with I/DD that are receiving the needed services was one of the three most important research questions. The second highest ranked research question was related to identifying how service utilization data could be collected for populations with I/DD (n = 8, 47%). Seven participants (41%) each ranked the following questions as the top three most important research questions: 1) What types of services are currently being utilized by those who have the Innovations Waiver? and 2) How many people in institutional care options, including group homes and ICFs, would like to live in a more integrated community setting? About a third of respondents (n = 6; 35%) ranked identifying how to get an estimate of how big the I/DD community is in NC as one of the top three most important research questions. The remaining research questions were ranked as most important by less than a quarter of respondents.



Notes: Participants were asked to rank the *top three most important* research questions. 17 participants answered this question.

### ***Needs and Experiences of Families and Other Caregivers (paid and non-paid)***

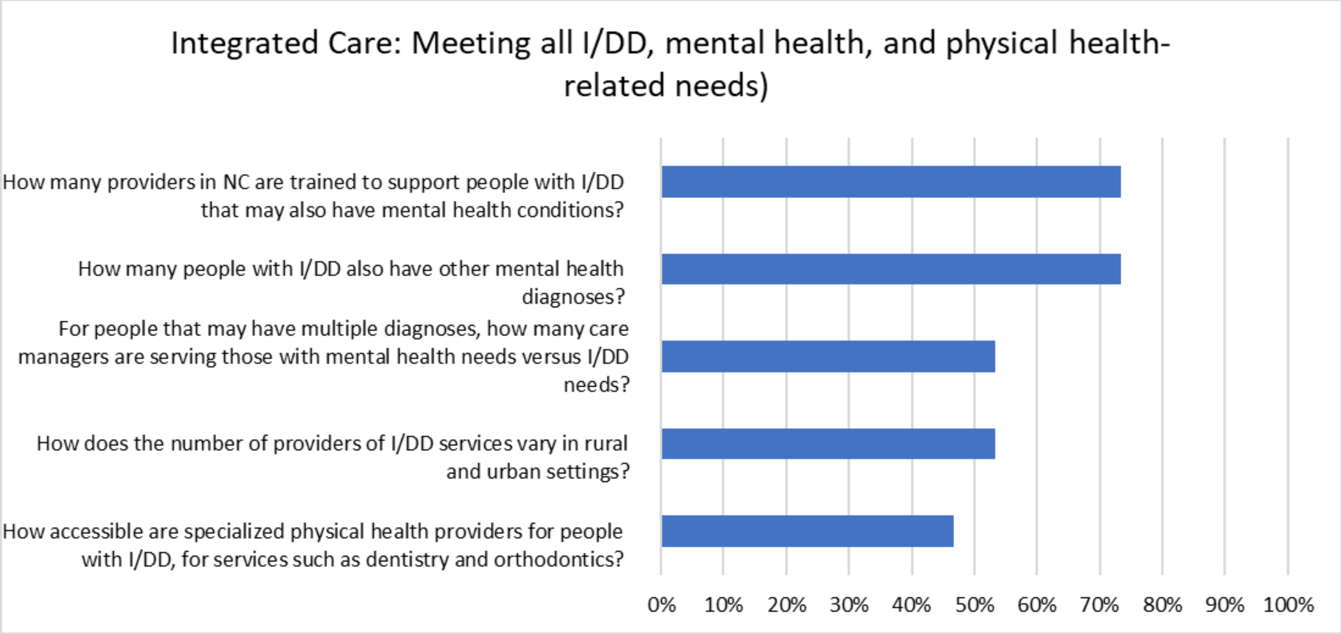
When participants were asked to choose the three most important research questions, more than three-fifths of participants (n = 10; 63%) ranked the following questions as high priority: 1) What is the cost of family members exiting the workforce in order to provide support to their loved ones with I/DD?, 2) What are the experiences of DSPs providing care and how can this be improved to promote retention of DSP, satisfaction of DSP, and high quality of care to individuals with I/DD?, and 3) How many Innovation Waiver recipients receive care from a paid DSP/family caregiver/aid that is a family member? Forty-four percent (n = 7) of respondents indicated that finding out whether there is a way to track who is providing DSP services was one of the top three most important research questions. Approximately a third of participants (n = 6; 38%) ranked the question about whether there is emergency back-up coverage for DSPs being provided so individuals with I/DD and their families do not miss work or experience other consequence of these care needs not being provided as most important. Five participants (31%) ranked the need to find out the characteristics of family caregivers as one of the top three most important research questions.



Notes: Participants were asked to rank the *top three most important* research questions. 16 participants answered this question.

### *Integrated Care: Meeting all I/DD, Mental health, and Physical Health-related Needs*

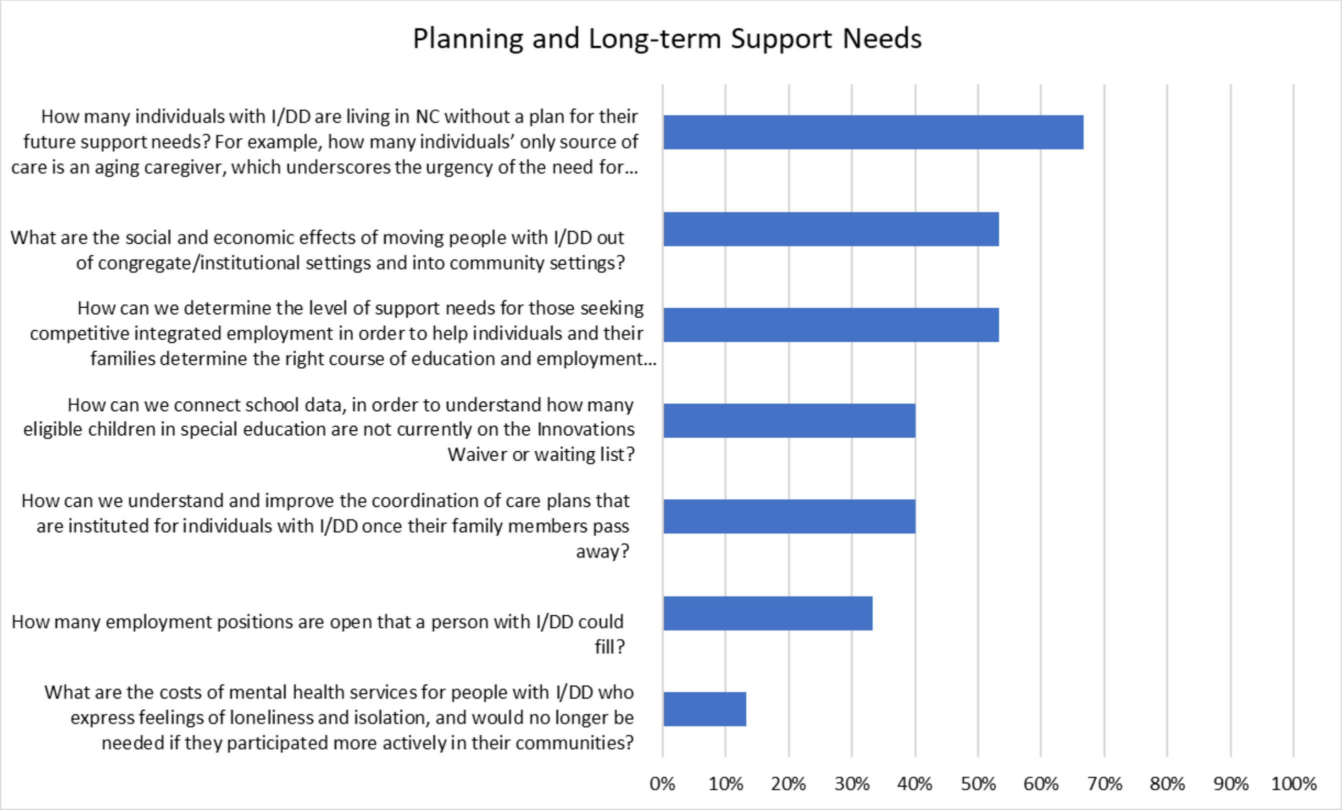
Among this theme, the research questions ranked as the most important were about identifying how many providers in NC are trained to support people with I/DD that may also have mental health conditions (n = 11; 73%) and the number of people with I/DD who also have other mental health diagnoses (n = 11; 73%). About half of respondents (n = 8; 53%) ranked the following questions as one of the top three most important: 1) For people that have multiple diagnoses, how many care managers are serving those with mental health needs versus I/DD needs?, and 2) How does the number of providers of I/DD services vary in rural and urban settings. Forty-seven percent of participants (n = 7) ranked how accessible specialized physical health providers for people with I/DD, for services such as dentistry and orthodontics, as one of the top three most important questions.



Notes: Participants were asked to rank the *top three most important* research questions. 15 participants answered this question.

### *Planning and Long-term Support Needs*

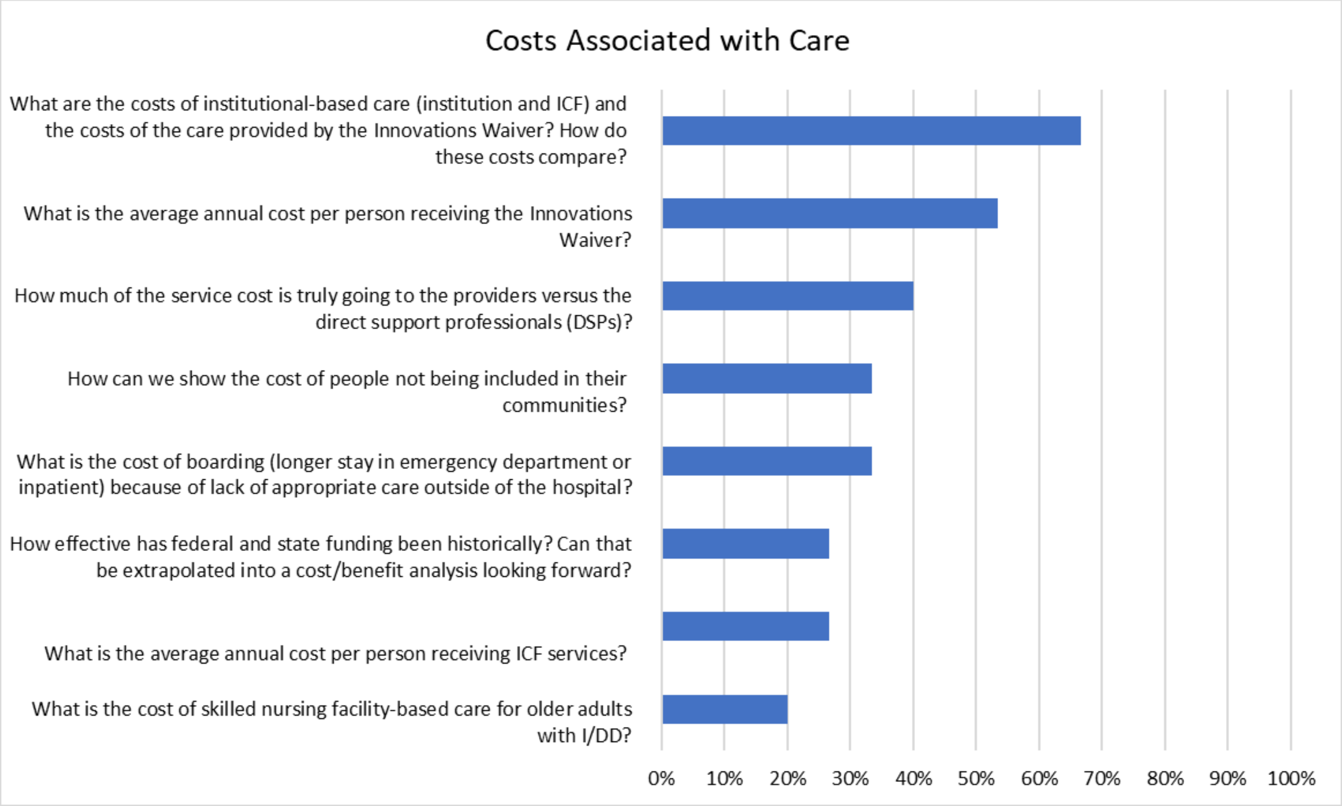
Two-thirds of participants (n = 10; 67%) ranked the question about how many individuals with I/DD are living in NC without a plan for their future support needs as one of the top three most important questions. About half of participants (n = 8; 53%), ranked the research questions about 1) identifying the social and economic effects of moving people with I/DD out of congregate/institutional settings into community settings, and 2) determining the level of support needs for those seeking competitive integrated employment in order to help individuals and their families determine the right course of education and employment selection as most important. Six participants (40%) ranked the following questions as the top three most important: 1) How can we connect school data, in order to understand how many eligible children in special education are not currently on the Innovations Waiver or waiting list?, and 2) How can we understand and improve the coordination of care plans that are instituted for individuals with I/DD once their family members pass away? Five participants (33%) ranked the question about how many employment positions are open that a person with I/DD could fill as top research question. Two participants (13%) indicated that the question about determining the costs of mental health services for people with I/DD who express feelings of loneliness and isolation, and would no longer be needed if they participated more actively in their communities as most important.



Notes: Participants were asked to rank the *top three most important* research questions. 15 participants answered this question.

### ***Costs Associated with Care***

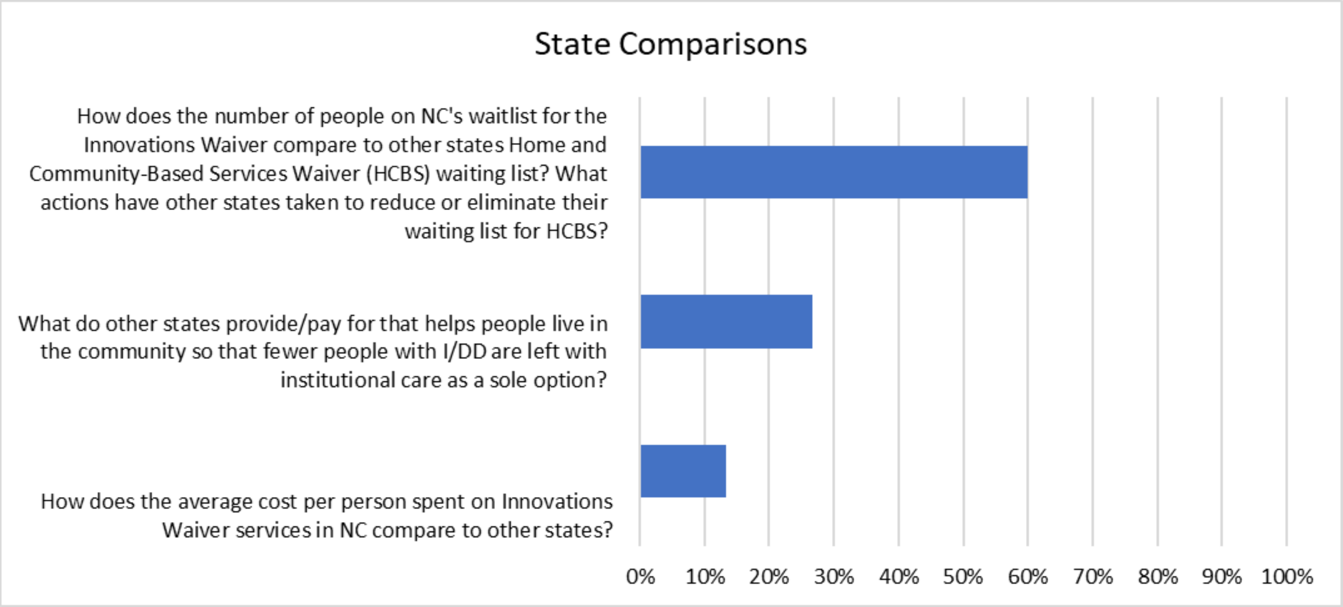
Approximately two-thirds of respondents (n = 10, 67%) ranked 1) identifying the costs of institutional-based care (institution and ICF) and 2) the costs of care provided by the Innovations Waiver as one of the top research questions. The second highest ranked question of importance was identifying the average annual cost per person receiving the Innovations Waiver (n = 8; 53%). Two-fifths of participants (n = 6; 40%) indicated that the research question about how much of the service cost is truly going to providers versus direct support professionals (DSPs) was one of the most important research questions. A third of participants (n = 5) ranked the following two questions as one of the top three most important: 1) What is the cost of boarding (longer stay in emergency department or inpatient) because of the lack of appropriate care outside the hospital?, and 2) How can we show the cost of people not being included in their communities? Less than a third of respondents (n = 4; 27%) ranked the questions about how effective federal and state funding have been historically and the average annual cost per person receiving ICF services. Three participants (20%) ranked the question about the cost of skilled nursing facility-based care for older adults with I/DD as one of the most important research questions.



Notes: Participants were asked to rank the *top three most important* research questions. 15 participants answered this question.

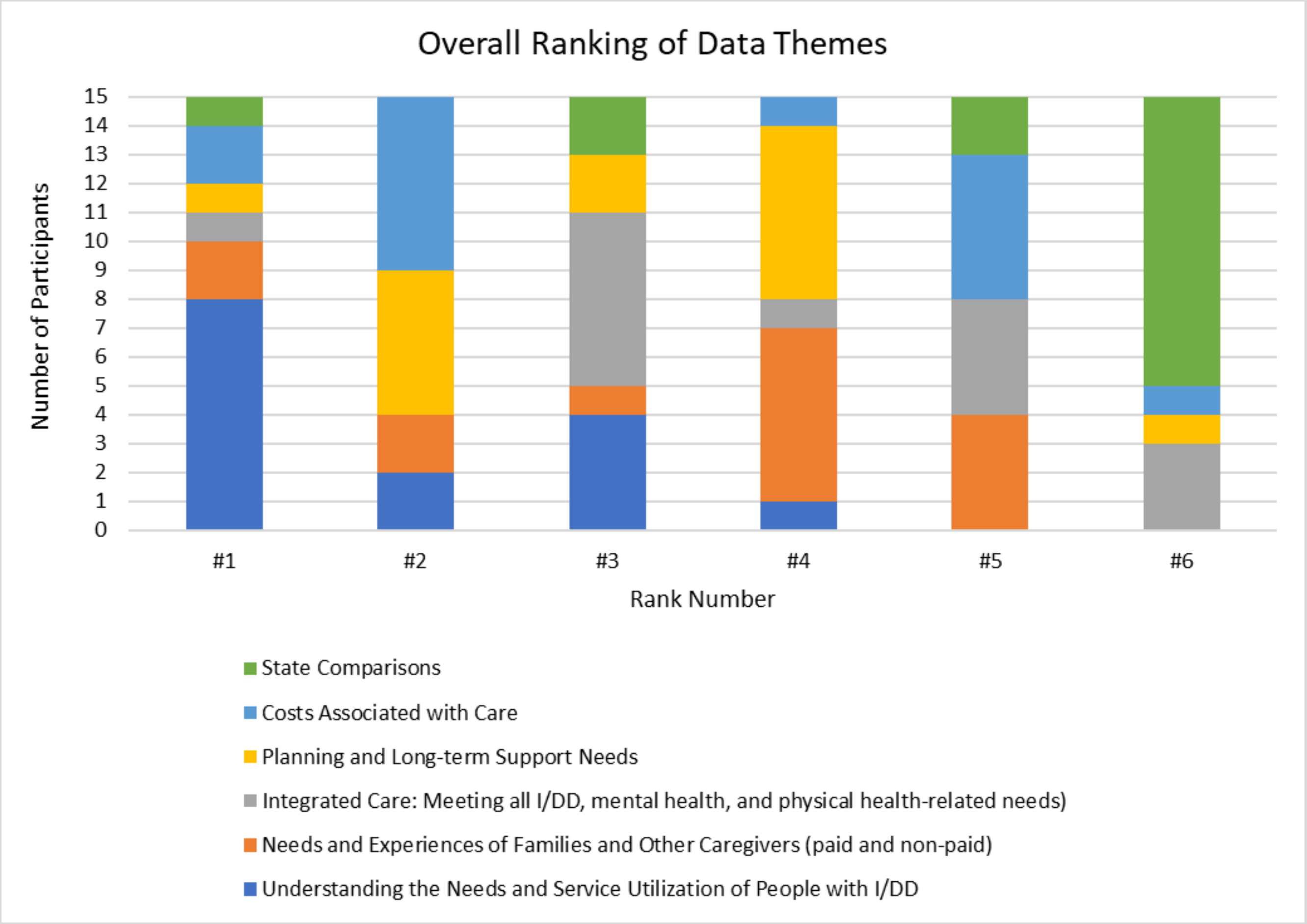
### ***State Comparisons***

For this theme, and because there were only three research questions as options, participants were asked to rank the single most important research question. More than half of participants (n = 9; 60%) indicated that understanding how the number of people on NC's waitlist for the Innovations Waiver compares to other states Home and Community Based Services Waiver (HCBS) Waiver Waiting List as the most important research question. Less than a third of participants (n = 4; 27%) ranked the question about understanding what other states provide/pay for that helps people live in the community so that fewer people with I/DD are left with institutional care as a sole option as most important. Only two participants (13%) indicated that identifying how the average cost per person spent on the Innovations Waiver services in NC compare to other states was most important.



Notes: Participants were asked to rank the *most important* research question. 15 participants answered this question.

In the last question, stakeholders (n = 15) ranked each of the six themes of data in order of most important to least important. The figure below shows the results of the prioritization activity. While responses were varied, stakeholders tended to rank the theme, *Understanding the Needs and Service Utilization of People with I/DD* as one of their highest priority categories while the theme, *State Comparisons* was consistently ranked as one of the lowest priority categories. In summary, it is important that readers do not take these results to mean that any of these questions are not import but rather, these are the research questions that these participants identified as high priority.



Of the 6 data themes, participants were asked to rank order these in terms of priority. 15 participants answered this question.