RESEARCH, POLICY & IMPACT Center

Forsyth County Housing Needs Assessment

For Individuals with Intellectual and Developmental Disabilities (IDD)

RESEARCH, POLICY & IMPACT Center

Forsyth County Housing Needs Assessment for Individuals with Intellectual and Developmental Disabilities (IDD)

Report Submitted to the Piedmont Triad Regional Council

February 2023

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Introduction

According to the Institute for Exceptional Care, there are 16 million Americans with intellectual and/or developmental disabilities (IDD). IDD are a group of conditions that affect cognitive, behavioral, and motor development. IDD includes autism, cerebral palsy, Down Syndrome, intellectual disability, attention deficit hyperactivity disorder, and conditions like William Syndrome or Rhett Syndrome. These conditions are often present from childhood and can impact an individual's ability to learn, communicate, and live independently. The exact prevalence of IDD is difficult to determine due to the heterogeneity of the population, the variety of definitions used to diagnose IDD, and the lack of access to healthcare and support services.

Individuals living with intellectual and developmental disabilities often have unique needs that require specialized support and services. These needs may include:

- *Health and medical care:* Many individuals with intellectual and developmental disabilities may have health problems that require ongoing medical attention and care.
- *Communication:* Some individuals with intellectual and developmental disabilities may have difficulty communicating their needs, desires, and opinions. It's important to provide support and accommodations to help them express themselves.
- *Education:* Individuals with intellectual and developmental disabilities may require specialized education and training to develop their skills and abilities to the fullest extent possible.
- *Social and emotional support:* People with intellectual and developmental disabilities may face challenges in building and maintaining relationships with others. They may need support and guidance to help them form and maintain healthy relationships.
- *Independent living*: Some individuals with intellectual and developmental disabilities may need support to live independently and manage daily tasks, such as cooking, cleaning, and personal care.
- *Transportation*: Access to transportation can be a significant barrier for individuals with intellectual and developmental disabilities, who may require specialized vehicles or support to travel safely.

It is important to note that every individual with intellectual and developmental disabilities is unique and their needs may vary.

Forsyth County IDD Housing Needs Assessment Report

Intellectual and developmental disabilities are a significant public health issue. Estimating the number of people with IDD is critical to planning and implementing appropriate services and interventions. However, accurate estimates of the IDD population are difficult to obtain due to the complexity of the condition and the various ways it can manifest. This report compiles information from a variety of primary and secondary sources and includes data from in-depth interviews with stakeholders, a county-wide survey of individuals with intellectual and/or developmental disabilities (IDD) or their guardians and caretakers It also include a brief overview of the various efforts to address the housing and community living support needs of the IDD population in North Carolina. Finally, we conduct secondary analysis of socio-demographic and administrative data in order to estimate the overall population impacted by IDD in Forsyth County.

The research findings may be used to develop a better understanding of housing needs and social support issues that present challenges for the most vulnerable in the community. We have sought perspectives, best practices, and recommendations from disability advocates, educators, program administrators, service providers, LME/MCO representatives, as well as individuals with IDD and their family members. Through the interviews we have explored the resources available through the NC Department of Health and Human Services, the NC Innovations and TBI Waiver Programs, and many of the non-profit organizations that provide housing and community living services to individuals living with IDD. We have also provided information on the living situation of surveyed individuals, data on their sources of income, information on the available family support, and documentation of housing needs and wraparound services desired. We hope that the detailed information presented here about a very wide range of topics will help to equip the PTRC with the understanding they will need in order to address the housing needs of this population.

Background

Intellectual and developmental disabilities (IDD) can have a profound impact on an individual's ability to lead an independent life. Disabilities can range from mild to severe and can affect an individual's cognitive abilities, social skills, and daily functioning. Despite advancements in support services, individuals with IDD still face numerous barriers to independent living.

Barriers to Independent Living

Independent living refers to the ability of individuals with disabilities to live and participate in their communities without assistance or support. This includes having access to necessary resources, being able to make decisions, and having control over one's life. It also involves having the skills and resources needed to perform daily activities, such as cooking, cleaning, and personal care. For individuals with IDD, independent living requires support and accommodations that are tailored to their specific needs. There are several barriers to independent living for individuals with IDD. These barriers can impact their ability to live and participate in their communities and can result in a lower quality of life.

Affordable housing is one of the most significant barriers for individuals with IDD. Finding accessible and affordable housing options that meet an individual's needs in a highly competitive housing market with a dearth of affordable options is a daunting task. This can result in individuals with IDD being forced to live in institutions and group homes, or with family members, limiting their independence and ability to participate in their communities.

Transportation is an essential component of independent living, as it allows individuals with IDD to access community resources, attend appointments, and participate in social activities. However, many individuals with IDD face barriers to transportation, including limited access to public transportation, lack of accessible vehicles, and high cost. This can result in individuals with IDD being isolated from their communities and unable to participate in activities that are essential for their well-being.

Support services, such as personal care, respite care, assistive technology, etc. are critical for individuals with IDD to live independently. However, these services are

often limited and expensive, making it difficult for individuals with IDD to access them. In some cases, individuals with IDD may be waiting for years to receive support services, further limiting their independence and quality of life.

Education and employment opportunities play a crucial role in an individual's ability to live independently. Individuals with IDD often face barriers to education and employment, including limited access to educational programs, low-quality education, and discrimination in the workplace. These barriers can result in individuals with IDD being unable to acquire the skills and knowledge needed to live and participate in their communities.

Attitudes and stigma toward individuals with IDD can be significant barriers to independent living. Negative attitudes and beliefs about individuals with IDD can lead to discrimination, prejudice, and a lack of support from others. This can result in individuals with IDD being isolated from their communities and unable to access essential resources and support services.

The barriers to independent living for individuals with IDD can have a profound impact on their quality of life. These barriers can result in individuals with IDD being isolated from their communities, unable to access essential resources and support services, and living in institutional settings. Individuals with IDD who are isolated from their communities may experience increased stress, depression, and anxiety.

There have been numerous acts, laws, legislation, and programs established to provide for the rights and needs of individuals with intellectual and/or developmental disabilities (IDDs) in the United States. The following sections will provide a synopsis of some of the key efforts. Though not an exhaustive list, this material should provide sufficient context and background to the materials that follow in this report.

Americans with Disabilities Act (ADA)

The 1990 Americans with Disabilities Act (ADA) is a federal civil rights law that prohibits discrimination based on disability in all areas of public life, including employment, education, transportation, and access to public accommodations.[1]

[1] U.S. Department of Justice Civil Rights Division. (n.d.) Introduction to the American with Disabilities Act. ada.gov. Retrieved January 9, 2023, from https://www.ada.gov/topics/intro-to-ada/.

Under Title I of the ADA employers must provide people with disabilities an equal opportunity to be considered for recruitment, promotions, training, and pay that is available to others as well as reasonable accommodations so they can perform their duties.[2] Under Title II, state and local governments must provide people with disabilities an equal opportunity to participate in and benefit from public services such as public education, transportation, and recreation. And under Title III, all businesses and nonprofits that serve the public must provide people with disabilities an equal opportunity to access their goods and services. Religious organizations are exempt from Title III requirements.[3]

ADA Standards for Accessible Design

The ADA's Standards for Accessible Design, originally published in 1991 and updated in 2010, guide the construction and modification of accessible facilities.[4] The ADA requires that businesses and public buildings remove architectural barriers to mobility deceives such as entrance steps and narrow aisles, doorways, and bathrooms, provide accessible parking with an access aisle, and clear objects that project into walkways.[5] When barrier removal is not possible, alternatives should be provided and clearly marked.[6] Many local governments also struggle to

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Mid-Atlantic Center. (n.d.) History of the ADA. adainfo.org Retrieved January 9, 2023, from https://www.adainfo.org/ada-information/history-of-the-ada/.

2 Office of Disability Rights. (n.d.) ADA Title I. odr.dc.gov. Retrieved January 9, 2023, from https://odr.dc.gov/page/ada-title-i.

U.S. Equal Employment Opportunity Commision. (n.d.) Fact Sheet: Disability Discrimination. eeoc.gov. Retrieved January 9, 2023, from https://www.eeoc.gov/laws/guidance/fact-sheet-disability-discrimination.

Office of Disability Employment Policy. (n.d.) Accommodations. dol.gov. Retrieved January 9, 2023, from https://www.dol.gov/agencies/odep/program-areas/employers/accommodations

3 U.S. Department of Justice Civil Rights Division. (n.d.) Introduction to the American with Disabilities Act. ada.gov. Retrieved January 9, 2023, from https://www.ada.gov/topics/intro-to-ada/.

4 U.S. Department of Justice Civil Rights Division. (2011, March 16.) ADA update - A primer for small business. ada.gov. Retrieved January 9, 2023, from https://www.ada.gov/resources/title-iii-primer/.

U.S. Department of Justice Civil Rights Division. (2014, March 14.) ADA standards for accessible design Title III Regulation 28 CFR Part 36 (1991). ada.gov. Retrieved January 9, 2023, from https://www.ada.gov/law-and-regs/design-standards/1991-design-standards/.

U.S. Department of Justice Civil Rights Division. (2010, September 15.) *2010 ADA standards for accessible design*. ada.gov. Retrieved January 9, 2023, from https://www.ada.gov/law-and-regs/design-standards/2010-stds/.

5 U.S. Department of Justice Civil Rights Division. (2011, March 16.) ADA update - A primer for small business. ada.gov. Retrieved January 9, 2023, from https://www.ada.gov/resources/title-iii-primer/.

6 U.S. Department of Justice Civil Rights Division. (2011, March 16.) ADA update - A primer for small business. ada.gov. Retrieved January 9, 2023, from https://www.ada.gov/resources/title-iii-primer/.

fulfill their Title II obligations – incorrectly believing grandfathered and/or historically significant facilities are exempt from regulations or providing inadequately accessible curb ramps, communication, and programs.[7]

In 2022 the Department of Justice released guidance on web accessibility making it clear the ADA does cover the goods and services offered on websites as well as brick-and-mortar locations.[8] In 2019, about 70% of e-commerce and government websites had significant accessibility issues and many complaints have been filed since the start of the pandemic.[9]

Individuals with Disabilities Education Act (IDEA)

The Individuals with Disabilities Education Act (IDEA) is a federal law that guarantees free and appropriate public education to all children with disabilities, including those with IDDs, from birth to age 21. The Education for All Handicapped Children Act (EHA), most recently reauthorized as the Individuals with Disabilities Education Act (IDEA) in 2004, was passed by congress in 1975, opening public schools to millions of children with disabilities who had been legally denied the opportunity to develop their talents in their neighborhood schools rather than in segregated institutions.[10] While the EHA supported the rights of children with disabilities to a free, appropriate public education (FAPE) in the least restrictive environment (LRE) possible from its inception, over the years the IDEA has been amended to increase emphasis on access to general education, providing services for infants and toddlers, and making states accountable for the achievement of students with disabilities by requiring each state to develop an IDEA performance plan and annual report.[11]

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7 U.S. Department of Justice Civil Rights Division. (2020, February 24.) The ADA and city governments: Common problems. archive.ada.gov. Retrieved January 9, 2023, from https://archive.ada.gov/comprob.htm.

8 U.S. Department of Justice. (2022, March 18.) Justice Department Issues Web Accessibility Guidance Under the Americans with Disabilities Act. justice.gov. Retrieved January 9, 2023, from https://www.justice.gov/opa/pr/justice-department-issues-web-accessibility-guidance-under-americans-disabilities-act.

9 Gonzales, M. (2022, March 23.) Record number of lawsuits filed over accessibility for people with disabilities. shrm.org. Retrieved January 9, 2023, from https://www.shrm.org/resourcesandtools/hr-topics/behavioral-competencies/global-and-cultural-effectiveness/pages/record-number-of-lawsuits-filed-over-accessibility-for-people-with-disabilities.aspx.

10 https://sites.ed.gov/idea/about-idea/#IDEA-History

11 https://sites.ed.gov/idea/about-idea/#IDEA-History

The main components of the IDEA are:

- **"Children with Disabilities":** To be eligible for special education services a student must have a disability that harms educational performance that requires specially designed instruction beyond that offered in a regular classroom.[12]
- **Free Appropriate Public Education (FAPE):** A FAPE includes (1) specially designed instruction for the individual and (2) related services such as counseling and physical therapy which allow each student with a disability to make reasonable educational progress.[13]
- **Least Restrictive Environment (LRE):** The LRE is the school setting that gives a student with a disability the greatest opportunity to interact and learn with their non-disabled peers while still receiving a FAPE.[14]
- **Individualized Education Program (IEP):** A FAPE and LRE for each student with a disability are determined by that student's IEP team which includes the student's teacher(s) and parent(s) and the school's psychologist(s) and special education professional(s). A written IEP outlining the student's special education program must be developed before a student can receive special education services and be reviewed and updated annually.[15]

North Carolina Schools are making a concerted effort to maintain compliance with the Individuals with Disabilities Education Act (IDEA) by implementing a range of policies and practices:

- **Comprehensive evaluations:** North Carolina Schools conduct comprehensive evaluations to identify students who may have a disability and require special education services. The evaluation process includes assessments of the student's academic, behavioral, and emotional functioning, as well as a review of their medical and developmental history.
- **Highly qualified staff:** North Carolina Schools ensure that all special education teachers and service providers meet the state's rigorous certification and licensure standards, as well as the requirements outlined in the IDEA.

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https://sites.ed.gov/idea/spp-apr/

12 https://www.ncld.org/get-involved/learn-the-law/idea/

https://www.ecac-parentcenter.org/wp-content/uploads/Parents_guide.pdf

13 https://www.ecac-parentcenter.org/wp-content/uploads/Parents_guide.pdf

14 https://www.ecac-parentcenter.org/wp-content/uploads/Parents_guide.pdf

15 https://www.ncld.org/get-involved/learn-the-law/idea/

- **Procedural safeguards:** North Carolina Schools provide procedural safeguards to protect the rights of students with disabilities and their families. These safeguards include written notices of all decisions related to the student's education, as well as opportunities to participate in meetings and appeal decisions.
- **Response to Intervention (RTI):** North Carolina Schools use a multi-tiered RTI approach to identify and provide early intervention services to students who may be at risk for academic or behavioral difficulties. This helps to prevent unnecessary referrals for special education services.
- **Positive Behavioral Interventions and Supports (PBIS):** North Carolina Schools use PBIS to create a positive and supportive school climate that promotes positive behaviors and reduces the need for disciplinary actions.
- **Transition planning**: North Carolina Schools ensure that transition planning begins at age 14 for students with disabilities, with a focus on preparing the student for postsecondary education, employment, and independent living.

Overall, North Carolina Schools strive to provide special education services that comply with the IDEA. This involves ongoing training and professional development for staff, collaboration with families and community partners, and a commitment to meeting the unique needs of each student with a disability. Nonetheless, many North Carolina school districts face funding shortages in serving students with special needs. The state caps school funding for special needs at 13% of total enrollment rather than funding schools based on the services they provide, leaving low-wealth, minority, and rural districts struggling to make up the funding gap and unable to offer parent-requested services.[16]

Fair Housing Compliance for Disabilities

The 1968 Fair Housing Act protects people from discrimination based on race, color, national origin, religion, sex, familial status, and disability when they are renting or buying a home and covers most kinds of housing including private housing and federal, state, and local government housing.[17] Under the Fair Housing

16 https://ncpolicywatch.com/2022/10/28/many-nc-school-districts-face-funding-shortages-in-serving-students-with-special-needs/
17 https://www.ada.gov/resources/disability-rights-guide/
https://www.hud.gov/program_offices/fair_housing_equal_opp/reasonable_accommodations_and_modifications
https://www.hud.gov/program_offices/fair_housing_equal_opp/fair_housing_act_overview

Act, housing providers must make reasonable accommodations for individuals with disabilities – this could include a change to policies or procedures such as allowing a service dog to live in the residence, or physical modifications such as installing grab bars and assigning parking.[18] A request for reasonable accommodations can only be denied if it would cause an undue financial or administrative hardship for the housing provider.[19]

Multifamily housing built after 1991 and all new construction must meet the accessible design requirements of the Fair Housing Act. Requirements include accessible common spaces, doors, kitchens, and bathrooms that are wide enough for mobility deceives, accessible routes to and between units, reinforced walls for grab bars, and accessible light switches, outlets, and thermostats.[20]

Unfortunately, violations of the Fair Housing Act are not uncommon. Fair Housing Act violation complaints can be filed with the U.S. Department of Housing and Urban Development. In 2022, 31,216 Fair Housing Act complaints were filed - up by 8.7% from 2020 - and discrimination based on disability made up more than half of all complaints filed.[21] In 2021, Pendergraph Development LLC of Raleigh, NC agreed to pay $300,000 to settle claims that they violated the Fair Housing Act in the construction of 46 multifamily housing complexes in the Carolinas that were not accessible to individuals with disabilities.[22]

The Olmstead decision

The Olmstead decision, based upon arguments within Title II of the 1990 Americans with Disabilities Act (ADA), is an integration mandate that requires public entities

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https://www.hud.gov/program_offices/fair_housing_equal_opp/aboutfheo/history
18 https://www.ada.gov/resources/disability-rights-guide/
https://www.hud.gov/program_offices/fair_housing_equal_opp/reasonable_accommodations_and_modifications
https://www.hud.gov/program_offices/fair_housing_equal_opp/fair_housing_act_overview
19
https://www.hud.gov/program_offices/fair_housing_equal_opp/reasonable_accommodations_and_modifications
20 https://www.ada.gov/resources/disability-rights-guide/
https://www.hud.gov/program_offices/fair_housing_equal_opp/physical_accessibility
21 https://nationalfairhousing.org/new-report-reveals-record-number-of-housing-discrimination-complaints/
https://www.fairhousingnc.org/wp-content/uploads/2021/12/State-of-Fair-Housing-in-North-Carolina-2000-2020-FINAL-1.pdf
22 https://www.justice.gov/opa/pr/justice-department-resolves-lawsuit-alleging-disability-based-discrimination-46-multifamily

to provide individuals with disabilities services in "the most integrated setting appropriate" alongside their peers without disabilities, rather than in a segregated setting.[23] On June 22, 1999, the United State Supreme Court upheld Title II of the ADA in *Olmstead v. L.C.* stating that public entities must provide community-based services to individuals with disabilities "when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated".[24] The obligation to make reasonable modifications can only be waived if the modifications would "fundamentally alter" services.[25] Additionally, to decern if an individual does not oppose community-based treatment, the state must provide them with the opportunity to make informed decisions, taking affirmative steps to remedy a history of repeatedly telling individuals who have been institutionalized that they are not capable of community living.[26]

Although states are required to have an Olmstead plan that outlines how they will fulfill their obligation to provide individuals with disabilities community-based services, many state and local governments across the country have not yet provided appropriate integrated community alternatives to institutional settings.[27] The North Carolina Department of Health and Human Services (NC DHHS) and the US Department of Justice (DOJ) settled a lawsuit that involved the provision of community-based services to individuals with disabilities in North Carolina. The lawsuit claimed that the state violated the Americans with Disabilities Act (ADA) and the Olmstead v. L.C. decision, which established that individuals with disabilities have a right to receive services in the most integrated setting appropriate to their needs.[28] In 2012, North Carolina entered an eight-year settlement agreement with the United States Department of Justice to expand access to community-based supported housing among other integrated employment and care services after the Civil Rights Division's ADA Olmstead

23 https://archive.ada.gov/olmstead/q&a_olmstead.htm
24 https://archive.ada.gov/olmstead/olmstead_about.htm
25 https://archive.ada.gov/olmstead/q&a_olmstead.htm
26 https://archive.ada.gov/olmstead/q&a_olmstead.htm
27 https://archive.ada.gov/olmstead/q&a_olmstead.htm
28 https://www.ncdhhs.gov/providers/provider-info/mental-health-development-disabilities-and-substance-abuse-services/doj-settlement-transitions-community-living

investigation found that the State was still serving thousands of individuals with mental illness in large adult care facilities.[29]

The state failed to meet its goals within the eight-year timeframe. In 2020, the DOJ released a report indicating that North Carolina had made progress in many areas, but that more work needed to be done to fully comply with the Olmstead decision and the ADA. The courts extended the agreement to July 1, 2021, and then later to July 1, 2023.[30] North Carolina has made progress in implementing the terms of the settlement agreement. Some of the key areas of focus have included:

- **Expanding community-based services:** North Carolina has made significant investments in expanding community-based services, including housing, employment, and other supports, to help individuals with mental illness and developmental disabilities live and work in their communities.
- **Reducing reliance on institutional care:** The state has worked to reduce reliance on institutional care, such as state-run psychiatric hospitals, by expanding community-based treatment options.
- **Improving crisis response:** North Carolina has improved its behavioral health crisis response system by implementing mobile crisis teams, expanding crisis stabilization facilities, and increasing crisis intervention training for law enforcement.
- **Enhancing data collection and reporting**: The state has improved its data collection and reporting systems to better track progress in implementing the settlement agreement and to ensure accountability.

Despite these efforts, there have been ongoing challenges in fully implementing the terms of the settlement agreement, and the DOJ has continued to monitor North Carolina's progress.

Transitions to Community Living Initiative (TCLI)

The Olmstead settlement, referred to as the Transitions to Community Living Settlement,[31] requires the NC DHHS to take several steps to ensure that individuals

29 https://archive.ada.gov/olmstead/olmstead_cases_list2.htm#NC
30 https://archive.ada.gov/olmstead/olmstead_cases_list2.htm#NC
https://www.justice.gov/opa/pr/justice-department-obtains-comprehensive-agreement-regarding-north-carolina-mental-health
https://www.justice.gov/iso/opa/resources/172012823125624712136.pdf
[31] https://www.ncdhhs.gov/providers/provider-info/mental-health-development-disabilities-and-substance-abuse-services/doj-settlement-transitions-community-living

with serious mental illnesses receive the support and services they need to live in the community. The Transitions to Community Living Initiative (TCLI) is a program aimed at helping individuals transition from institutional settings such as state-run facilities to community-based living arrangements.[32] The initiative is designed to provide the support and resources necessary for individuals with disabilities to live as independently as possible within their communities.

TCLI is focused on empowering individuals with disabilities by providing them with the opportunity to live in their own homes, attend a school or work in their communities, and participate in community activities. The initiative seeks to promote community integration and improve access to health care, education, and employment opportunities for individuals with disabilities. The goal of TCLI is to ensure that individuals with disabilities have the opportunity to live fulfilling lives as active members of their communities. By providing access to the support and resources needed for community-based living, TCLI helps individuals with disabilities to lead lives of independence and dignity.[33]

The program provides funding for a variety of services and supports, including personal assistance services, home modifications, and transportation. TCLI also provides training and technical assistance to organizations to help them develop and implement successful transition programs. It also includes provisions to develop and implement a system to track and monitor the progress of individuals who are transitioning from institutional settings to the community. The program is an important step towards ensuring that individuals with disabilities in North Carolina have the opportunity to live and participate in their communities to the fullest extent possible.

Medicaid Home and Community-Based Services Wavier - NC Innovations Waiver

The NC Innovations Wavier is a Medicaid Home and Community-Based Services Wavier that supports long-term care services for individuals with disabilities that want to live in their homes rather than in an institutional setting. Each waiver recipient works with their local management entity/managed care organization

[32] https://www.ncdhhs.gov/about/department-initiatives/transitions-community-living

[33] https://disabilityrightsnc.org/resources/transitions-to-community-living/

(LME/MCO) team to develop a Person-Centered Plan of Care outlining the services they will receive such as support navigating, networking, and living in communities, employment and residential supports, and specialized consultation services.[34] Before the Innovations Waiver started in North Carolina in 2016, long-term services and supports were attached to LME/MCO-owned properties; in the Innovations Waiver's supported living model, the person with a disability has full property rights over their home and control over which services they receive.[35]

Registry of Unmet Needs (RUN)

The Registry of Unmet Needs (RUN) in North Carolina is a program that maintains a database of individuals with intellectual or developmental disabilities who are waiting for Innovations Waiver slots under the state's Medicaid waiver program. When there are no available waiver slots, individuals with disabilities may be placed on the RUN to receive services until a waiver slot becomes available. This registry allows the state to track the number of individuals who are waiting for services and prioritize the allocation of available resources. A waiver slot is essentially a funding allocation that allows an individual to receive Medicaid waiver services. When a waiver slot becomes available, the individual at the top of the RUN list who is most in need of services is offered the slot. The RUN is used to manage the waiting list for waiver slots, and individuals who are waiting for services can contact their local Department of Social Services to be added to the registry.

Unfortunately, only 22% of Medicaid recipients in North Carolina with a disability receive Innovation Wavier services and the Registry of Unmet Needs (RUN) is over a decade long with more than 15,000 people waiting for services in 2021.[36] And although wavier slots are awarded on a first-come, first-served basis, a recent study

34 https://medicaid.ncdhhs.gov/media/4839/download
https://medicaid.ncdhhs.gov/providers/programs-and-services/behavioral-health-idd/nc-innovations-waiver/waiver-services
https://medicaid.ncdhhs.gov/providers/programs-and-services/behavioral-health-idd/nc-innovations-waiver/supported-living-service
35 https://nccdd.org/supported-living-guidebook-resource-manual.html
https://nccdd.org/supported-living-guidebook-resource-manual.html
36 https://files.constantcontact.com/4119c22e001/45ecbac9-2b13-41d4-bbf9-ddfdc3938019.pdf
https://ncpolicywatch.com/2021/07/28/nc-must-end-its-cruel-and-unjust-denial-of-services-to-people-with-intellectual-and-developmental-disabilities/

found that inequities in knowledge and access meant white people, men, and urban residents were more likely to receive services.[37]

The State is making moves to increase access to community-based care for individuals with disabilities: the 2021 state budget included funding for 1,000 additional Innovations Wavier slots and the state is applying for another special Medicaid wavier program – 1915 (i) Medicaid – that will still provide some of the key services of the Innovation Wavier program.[38]

NC TBI Medicaid Waiver Program

The Traumatic Brain Injury (TBI) Medicaid Wavier is a Medicaid Home and Community-Based Services Wavier that provides community-based rehabilitation services to individuals that have suffered a traumatic brain injury with a focus on person-center planning.[39] After 20 years of advocacy from Duke's Brain Imaging and Analysis Center, the Brain Injury Association of North Carolina, and the TBI community advocates for individuals with TBI to be recognized as a unique population separate from the IDD population, in 2016 the NC general assembly approved funding for the TBI Medicaid Waiver Program.[40]

The program's three-year pilot in North Carolina from 2018 to 2021 was managed by Alliance Health (LME-MCO) and served 107 individuals in four counties: Durham, Wake, Cumberland, and Johnston.[41] Services include in-home and residential supports, cognitive rehabilitation and life skills training, and therapeutic and specialized consultation services among other services that support independent, community-based living.[42] To be eligible for the TBI Medicaid Waiver Program

37 https://journals.lww.com/jrnldbp/Fulltext/2022/09000/Inequities_in_Receipt_of_the_North_Carolina.3.aspx
38 https://www.northcarolinahealthnews.org/2021/11/18/state-budget-funds-some-mental-health-crisis-response-and-hospital-diversion-efforts/
https://www.northcarolinahealthnews.org/2022/06/16/study-finds-inequities-among-recipients-of-innovations-waiver-disability-services/
39 https://www.alliancehealthplan.org/document-library/Alliance-NC-TBI-Waiver-Individual-and-Family-Guide-3.pdf
https://disabilityrightsnc.org/resources/infomation-on-ncs-traumatic-brain-injury-waiver-pilot-program/
40 https://www.youtube.com/watch?v=gPt0msSRjio
41 https://www.bianc.net/advocacy/get-involved/tbi-medicaid-waiver-program/
42 https://www.bianc.net/advocacy/get-involved/tbi-medicaid-waiver-program/

applicants must have sustained a traumatic brain injury on or after their 18th birthday.

In 2022 the program was renewed for another five years and expanded to Mecklenburg and Orange counties, with the age of TBI lowered from 22 to 18, and eligibility increased to 300% of the federal poverty level.[43] With the TBI Medicaid Waiver Program in only 6 of the state's 100 counties, however, the state still has a long way to go to build comprehensive TBI provider networks and provide all TBI survivors with appropriate community-based care.[44]

NC Medicaid Managed Care Tailored Plan

The NC Medicaid Managed Care Behavioral Health and Intellectual/Developmental Disabilities (BHIDD) Tailored Plan is a program in North Carolina that provides managed care services for individuals with behavioral health and intellectual/developmental disabilities (IDD) who are eligible for Medicaid. North Carolina will launch the Tailored Plan on April 1, 2023.

Under this plan, individuals receive services that are tailored to their specific needs, with a focus on providing integrated care that addresses both their physical and behavioral health needs. Services provided under the BHIDD Tailored Plan include:

- Mental health and substance use disorder treatment;
- IDD services and supports;
- Primary care services;
- Pharmacy services;
- Dental services;
- Transportation services; and
- Care coordination and management

The BHIDD Tailored Plan is administered by the North Carolina Department of Health and Human Services (NCDHHS) and operates under the state's Medicaid managed care program, which launched in 2021. Tailored Plans will also serve other special populations including Innovations and Traumatic Brain Injury (TBI) waiver

43 https://www.ncdhhs.gov/divisions/mental-health-developmental-disabilities-and-substance-abuse/traumatic-brain-injury
44 https://disabilityrightsnc.org/community-living-and-equal-access/traumatic-brain-injury-tbi/shamefully-inadequate-north-carolinas-service-system-for-people-with-traumatic-brain-injuries/

enrollees and Registry of Unmet Needs (RUN) members and will be responsible for managing the state's non-Medicaid behavioral health, developmental disabilities, and TBI services for uninsured and underinsured North Carolinians.

While the NC Medicaid Managed Care Behavioral Health and Intellectual/ Developmental Disabilities (BHIDD) Tailored Plan has been designed to provide integrated and person-centered care for individuals with behavioral health and intellectual/developmental disabilities, there have been some criticisms of the program including a reduction in provider choice, lack of transparency and communication, concerns about access to care, administrative complexity, and impact on small providers. The program has limited the number of providers available to individuals, which could reduce their choice and access to care. Some advocates and providers have expressed concerns about whether the program will provide adequate access to care for individuals with complex needs. Likewise, there have been concerns about the administrative complexity of the program, particularly for smaller providers who may have limited resources to navigate the program's requirements. Finally, some of the smaller providers have expressed concerns that the program's administrative requirements and payment structure may make it difficult for them to continue to provide services. The North Carolina Department of Health and Human Services has stated that they are committed to working with stakeholders to improve the program over time.

Community Alternatives Program for Disabled Adults

The North Carolina Community Alternatives Program for Disabled Adults (CAP-DA) is a Medicaid program that provides home and community-based services for disabled adults who would otherwise require nursing home care. CAP-DA is authorized under section 1915(c) of the Social Security Act and complies with 42 CFR § 440.180, Home and Community-Based Waiver Services. The program is designed to help individuals with disabilities live in their homes and avoid institutionalization. The CAP-DA is a program that provides services and support to disabled adults so they can live in their own homes or other community settings rather than in institutions including personal care services, respite care, home modifications, and assistive technology. The program also provides care coordination and case management services to ensure that individuals receive the care they need. The

program aims to give individuals with disabilities the opportunity to lead a more independent life and participate in their communities.[45]

CAP is funded by the federal government and is administered by the states. Eligibility for the program is based on the individual's disability, income, and need for long-term care. The program is designed to serve as an alternative to institutional care for individuals who are otherwise at risk of being placed in a nursing home or other institution.

One of the key differences between CAP-DA and other community living programs is that CAP-DA is specifically designed for disabled adults who would otherwise require nursing home care. Other community living programs, such as the Medicaid waiver program, are designed to help individuals with disabilities live independently in their homes and communities, but they may not be specifically targeted to individuals who would otherwise require nursing home care. Another difference is that CAP-DA provides a broader range of services than many other community living programs. For example, the program provides home modifications and assistive technology to help individuals with disabilities live independently in their homes, in addition to personal care services and respite care.

Samantha R. et al. v. North Carolina

Samantha R., et al. v. North Carolina is a lawsuit filed in 2017 by Disability Rights North Carolina (DRNC) on behalf of individuals with intellectual and developmental disabilities (IDD) who were not receiving appropriate community-based services and support in North Carolina. The case involves a woman with IDD named Samantha Rhoney who was forced to leave her home to go live in an institutionalized care center after her at-home caretaker began cutting back services to encourage her to live independently.[46] Her parents and other families argued that North Carolina violated the Persons with Disabilities Act by failing to

[45] https://medicaid.ncdhhs.gov/providers/programs-and-services/long-term-care/community-alternatives-program-disabled-adults-capda

46 https://disabilityrightsnc.org/news/fact-sheet-faqs-samantha-r-v-north-carolina/#:~:text=The%20case%2C%20which%20was%20filed,integrated%20settings%20if%20they%20choose.

provide individuals with disabilities community care as an alternative to unnecessary institutionalization.[47]

The lawsuit alleged that the state was violating the Americans with Disabilities Act (ADA) and the Rehabilitation Act by failing to provide individuals with IDD with adequate community-based services and support and by unnecessarily institutionalizing individuals with IDD in violation of their civil rights.[48] The DRNC argued that the state had not complied with the terms of the 1999 *Olmstead v. L.C* settlement agreement, which required the state to provide appropriate community-based services and support for individuals with IDD and to ensure their health and safety during the transition from institutional to community-based settings.

In 2019, U.S. District Court Judge David L. Baddour issued a ruling in the case, finding that the state had violated the ADA and the Rehabilitation Act by failing to provide adequate community-based services and supports for individuals with IDD. Judge Baddour agreed with the families and ordered that the state develop a plan for correcting its violations of the integration mandate.

Judge Baddour's ruling required the state to develop and implement a comprehensive plan to provide community-based services and supports for individuals with IDD and to ensure their health and safety during the transition from institutional to community-based settings. The plan was required to be based on an individualized assessment of each individual's needs and to be developed in consultation with the individual and their family members. The ruling also required the state to develop and implement an effective monitoring and oversight system to ensure that the plan was being properly implemented and that individuals with IDD were receiving the services and support they needed to live safely and independently in the community.

47 https://www.wfae.org/race-equity/2022-11-02/judge-orders-north-carolina-to-provide-more-at-home-care-to-disabled-people

48 http://materials.ndrn.org/virtual20/session5/Tackling%20Medicaid%20Waiver%20Cuts/Resources/Plaintiffs%20Memo%20in%20Response%20DRNC%20final.pdf

In November 2022, after the state failed to develop a plan, Judge Baddour made a new order that set out measurable outcomes for what the state must accomplish to remedy its violation:

1. Eliminate the Innovations Wavier waiting list in 10 years,
2. Resolve the shortage of Direct Support Professionals who provide community-based support,
3. Divert or transition 3000 people who want to leave or avoid institutional settings over the next eight years and cease new admissions after 6 years except for short-term stays or stabilization, and
4. Provide quarterly reports for each measure ordered by the Court to be made public.[49]

Compliance with the court order will require a significant and sustained effort greater than all previous attempts to reform the state IDD care system. Disability rights advocates celebrated the ruling saying it called for long-overdue reforms to the state IDD system including the professionalization and competitive compensation of Direct Service Professionals, serving individuals with disabilities where they are, and a more geographically diverse workforce and a greater number of local providers.[50] NCDHHS has appealed the decision, citing concern over the aggressive timeline and end of long-term admissions that could put small group homes out of business.[51] Since then, DDHS has provided a counterproposal that would require $150 million in annual spending to eliminate the Innovations Waiver Registry of Unmet Needs (RUN) but does not specificity a timeline for other goals.[52]

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49 https://disabilityrightsnc.org/news/fact-sheet-faqs-samantha-r-v-north-carolina/#:~:text=The%20case%2C%20which%20was%20filed,integrated%20settings%20if%20they%20choose. https://www.northcarolinahealthnews.org/2022/11/07/judges-order-gives-nc-10-years-to-provide-more-at-home-disability-services/
50 https://disabilityrightsnc.org/news/fact-sheet-faqs-samantha-r-v-north-carolina/#:~:text=The%20case%2C%20which%20was%20filed,integrated%20settings%20if%20they%20choose.
51 https://www.wfae.org/race-equity/2022-11-02/judge-orders-north-carolina-to-provide-more-at-home-care-to-disabled-people
52 https://www.wfae.org/race-equity/2022-12-01/nc-health-agency-appealing-ruling-on-services-for-disabled https://www.ncdhhs.gov/media/18428/open?mc_cid=0beda75201&mc_eid=f4670fe11c https://www.ncdhhs.gov/news/press-releases/2022/11/30/ncdhhs-appeals-superior-court-ruling-samantha-r-et-al-vs-ncdhhs-and-state-north-carolina-court-case

STATE OF NORTH CAROLINA — IN THE GENERAL COURT OF JUSTICE
SUPERIOR COURT DIVISION
WAKE COUNTY — 17 CVS 6357

SAMANTHA R., by her Guardian, TIM R., MARIE K., by her guardian, EMPOWERING LIVES GUARDIANSHIP SERVICES, LLC CONNIE M., by her guardian CHARLOTTE R., JONATHAN D., by his guardian MICHAEL D., MITCHELL T., by his guardian, BETSY S., and DISABILITY RIGHTS NORTH CAROLINA,

Plaintiffs,

v.

STATE OF NORTH CAROLINA, NORTH CAROLINA DEPARTMENT OF HEALTH AND HUMAN SERVICES, and MANDY COHEN, in her official capacity as Secretary of the North Carolina Department of Health and Human Services,

Defendants.

PLAINTIFFS' MEMORANDUM IN OPPOSITION TO DEFENDANTS' MOTION FOR SUMMARY JUDGMENT

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FIGURE 1 - SAMANTHA R. ET AL. V. NORTH CAROLINA

Community Context: Forsyth County

Forsyth County, North Carolina is located in the Piedmont Triad region of the state and is part of the Winston-Salem metropolitan area. It has a total area of 413 square miles and according to the United States Census Bureau, the county had an estimated population of 382,075 as of 2021.

Forsyth County is two-thrids (65%) white, with African Americans making up approximately 27% of the population and Hispanics accounting for approximately 10% of the population. There are an estimated 11.5% of the civilian noninstitutionalized population (43,235 individuals) with one or more types of disabilities (ACS 2017-2021).

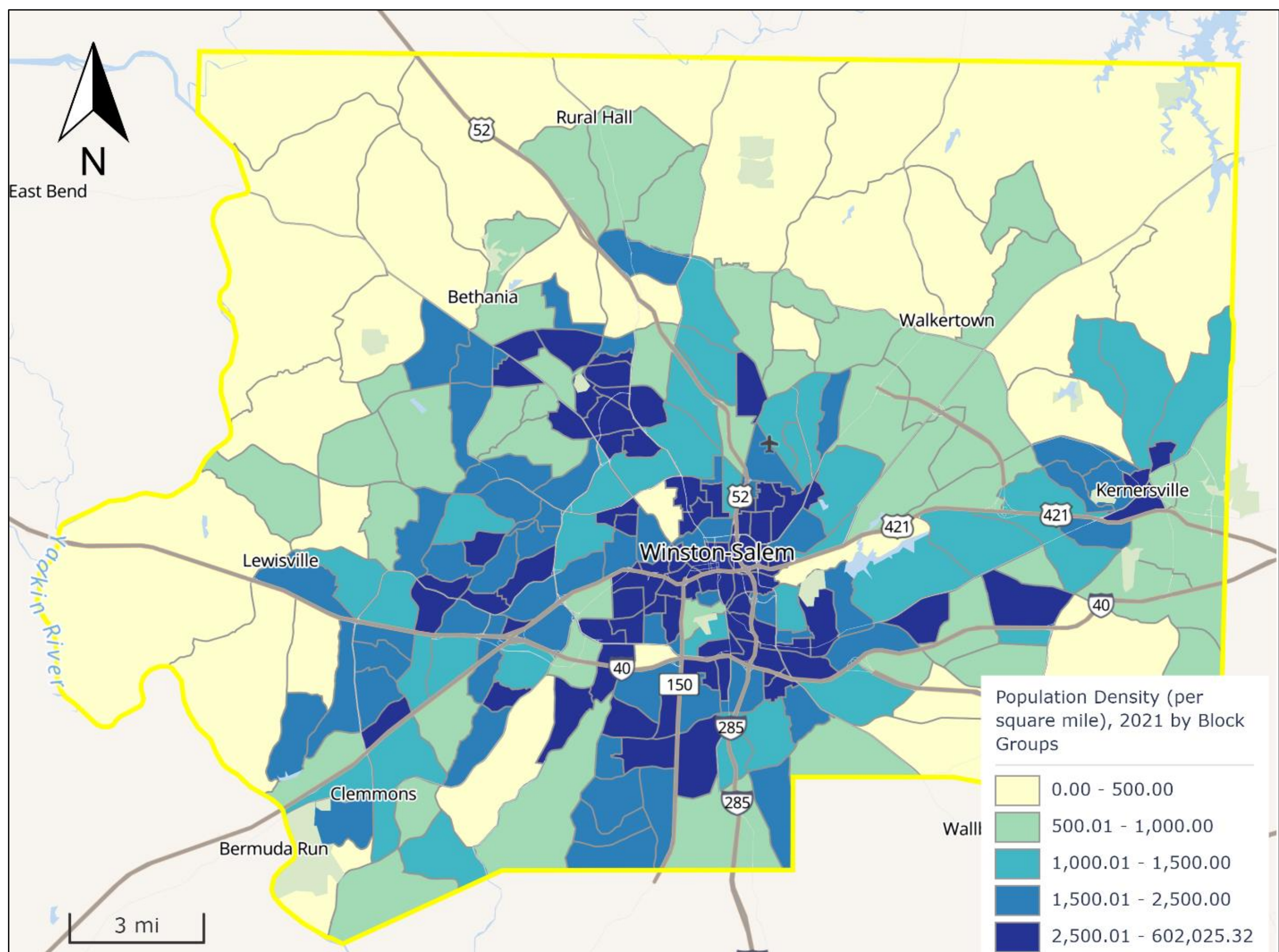


FIGURE 2 – POPULATION DENSITY FORSYTH COUNTY 2021

The median household income in Forsyth County was $62,067 in 2019, which is slightly lower than the national median household income of $68,703. According to the North Carolina Department of Commerce, the largest industries in Forsyth County are healthcare, retail trade, and manufacturing. The county is home to several major employers, including Atrium Health Wake Forest Baptist (AHWFB), Hanesbrands Inc., Truist, and Novant Health.

The unemployment rate was 3.8% in Forsyth County (Bureau of Labor Statistics, July 2022). According to the 2021 American Community Survey, the median household income in Forsyth County was $52,115. Nearly one-in-six (16.11%) were in poverty and an estimated 41,228 (10.9%) of the people in Forsyth County had no health insurance (ACS 2021).

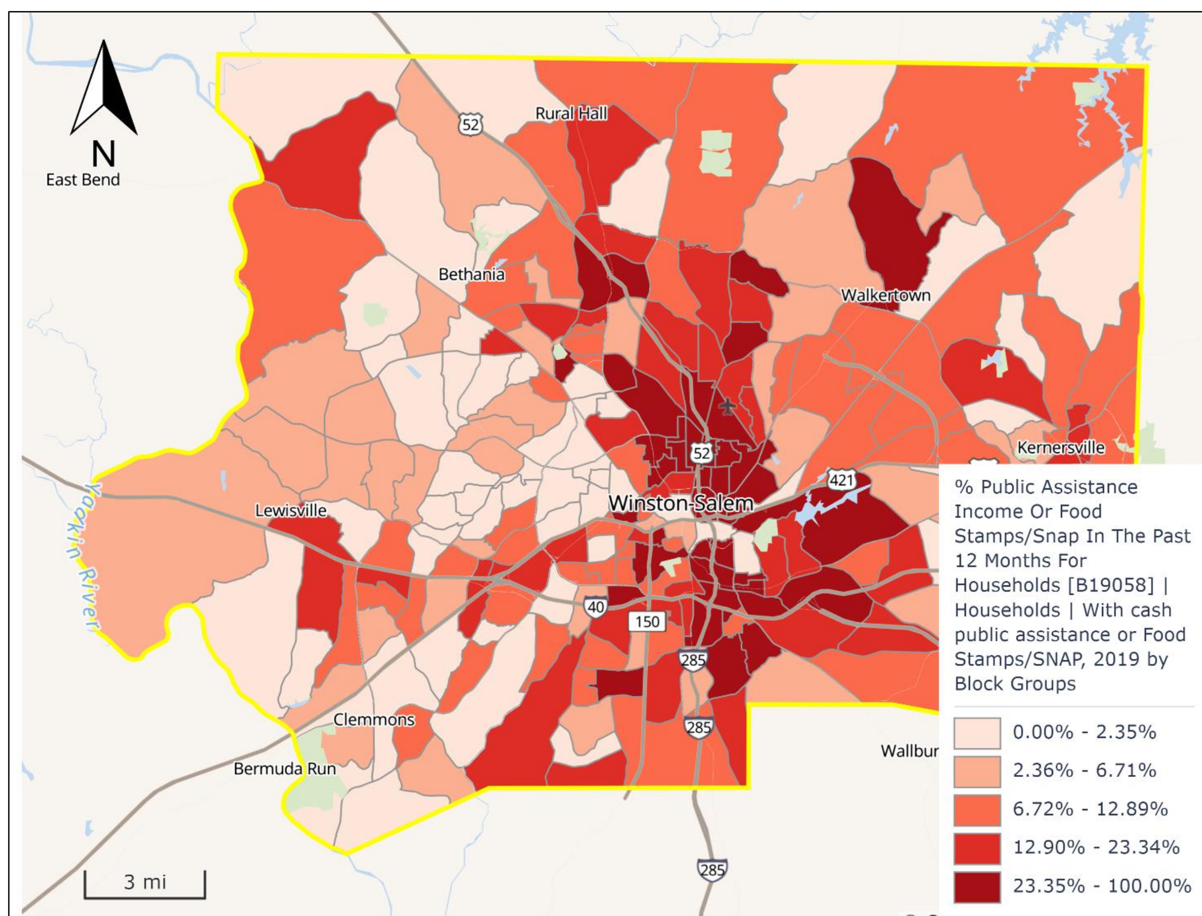


FIGURE 3 – PERCENTAGE USING PUBLIC ASSISTANCE (2019)

In terms of education, Forsyth County has a high school graduation rate of 88.3%, which is higher than the state average of 86.3%. Forsyth County is home to several institutions of higher education, including:

- *Wake Forest University:* Wake Forest is a private research university located in Winston-Salem. It was founded in 1834 and is consistently ranked among the top 30 national universities in the United States. Wake Forest offers undergraduate, graduate, and professional degree programs in a variety of fields, including business, law, medicine, and humanities.
- *Winston-Salem State University:* Winston-Salem State is a historically black public university located in Winston-Salem. It was founded in 1892 and offers undergraduate and graduate degree programs in a variety of fields, including arts and sciences, business, education, and health sciences.
- *Forsyth Technical Community College:* Forsyth Tech is a public community college located in Winston-Salem. It was founded in 1960 and offers associate degree, diploma, and certificate programs in a variety of fields, including business, health sciences, engineering, and applied technologies.
- *Salem College:* Salem is a private women's liberal arts college located in Winston-Salem. It was founded in 1772 and is the oldest women's college in the United States. Salem offers undergraduate degree programs in a variety of fields, including arts and sciences, education, and business.
- *University of North Carolina School of the Arts:* UNCSA is a public conservatory located in Winston-Salem. It was founded in 1963 and offers undergraduate and graduate degree programs in the arts, including music, dance, theater, and film.

The major hospitals in Forsyth County Atrium Health Wake Forest Baptist (AHWFB) main campus; there’s also a children’s hospital, and a cancer hospital in the complex. There are 15 mental health facilities and 19 drug and alcohol treatment facilities in this area (SAMHSA, 2019). In addition, there are five census tracts in Forsyth County (mostly around the City of Winston-Salem) have been designated as Medically Underserved Areas for having too few primary care providers, high

infant mortality, high poverty, and/or a high elderly population by the Health Resources and Services Administration (HRSA 2022).

About one-in-five (18.2%) homeowners and almost half (44.0%) of renters are cost-burdened, spending more than 30% of income on housing-related costs (ACS 2017-2021). About 12.4%. of households in Forsyth County receive public assistance income/food stamps/SNAP.

In Forsyth County, 89.77% of households have internet access. Forsyth County ranked “moderate” in terms of social vulnerability, which is a variable that considers four categories: socioeconomic (ranked as “moderate”); household composition (ranked as “low”); minority and language (ranked as “high”); and housing and transportation (ranked as “high”; CDC 2018).

Resources for Individuals with Intellectual and Developmental Disabilities

In Forsyth County, there are numerous resources available for individuals with intellectual and developmental disabilities. These resources include organizations like The Arc of Forsyth County and The Enrichment Center (TEC) which used to be the same. Families separated the two to provide advocacy through the Arc and services through TEC.

There are group homes and assisted living facilities in the county that offer specialized care for individuals with intellectual and developmental disabilities. For recreational activities, the county offers various programs through its Parks and Recreation Department, including the Therapeutic Recreation Program and the Special Olympics Program. Other resources for individuals with intellectual and developmental disabilities in Forsyth County include medical services, employment training, and educational programs.

According to the North American Industry Classification System (NAICS), the standard used by Federal statistical agencies in classifying business establishments, code 6232 is defined as "Residential Intellectual and Developmental Disability, Mental Health, and Substance Abuse Facilities." This category includes facilities that provide residential care for individuals with intellectual and developmental disabilities, mental health conditions, and/or substance abuse issues. The care provided at these facilities may include 24-hour supervision, personal care services,

and support for daily living activities. This industry also includes facilities that provide diagnostic, treatment, and rehabilitation services for individuals with intellectual and developmental disabilities, mental health conditions, and substance abuse issues. A few examples of these facilities include:

- *The Enrichment Center:* A non-profit organization that provides support and services for individuals with IDD including residential programs, day programs, employment services, and community activities.
- *Novant Health - Behavioral Health Center:* A mental health facility that offers inpatient and outpatient services for individuals with mental health and substance abuse issues. They provide individual and group therapy, medication management, and other behavioral health services.
- *Arbor Acres United Methodist Retirement Community:* A retirement community that provides independent living, assisted living, and memory care services for seniors. They offer a range of amenities and services, including dining, fitness and wellness programs, and social activities.

According to the latest data, there were a total of 44 establishments in Forsyth serving this population with nearly 600 employees total and an annual payroll of over $14 million.

TABLE 1 – IDD FACILITIES, WORKERS, AND PAYROLL

Residential Intellectual and Developmental Disability, Mental Health, and Substance Abuse Facilities [NAICS: 6232]	Forsyth
Total Mid-March Employees, 2020	592
Total First Quarter Payroll ($1,000), 2020	$3,184.00
Total Annual Payroll ($1,000), 2020	$14,373.00
Total Number of Establishments, 2020	44

Estimations of IDD Population in Forsyth County

The prevalence of intellectual and developmental disabilities varies depending on the population and definition used. Obtaining accurate estimates of the IDD population is challenging. The IDD population is estimated to be between 1% and 3% of the general population (Boyle et al., 2011).[53] However, obtaining accurate estimates of the IDD population in any specific geography or population setting is difficult due to the complex and heterogeneous nature of the condition. It is important to note that 1%-3% is a broad estimate, and the actual prevalence may vary widely based on several factors such as access to healthcare and support services, cultural attitudes, and the definition and criteria used to diagnose IDD.

As Anderson *et al.* (2019) point out in their review of studies on the prevalence of intellectual and/or developmental disability (IDD), "several different methodological approaches are used in prevalence studies, each with different foci, strengths, and weaknesses. Common approaches include population-based surveys, public health surveillance, and review of administrative data sets."[54] This section of the report will review different methods for estimating the IDD population and their strengths and limitations. It will be followed by projections for Forsyth County based on the best data available.

Method 1: Administrative Data

Administrative data are often used to estimate the IDD population. These data are collected by government agencies, healthcare providers, and other organizations for administrative purposes, such as billing and service provision. Administrative data can be used to identify individuals with IDD based on diagnostic codes (Mandell et al., 2012).[55] Medical records can provide information on the number of

[53] Boyle, C. A., Boulet, S., Schieve, L. A., Cohen, R. A., Blumberg, S. J., Yeargin-Allsopp, M., Visser, S., & Kogan, M. D. (2011). Trends in the prevalence of developmental disabilities in US children, 1997–2008. Pediatrics, 127(6), 1034-1042. https://doi.org/10.1542/peds.2010-2989

[54] Lynda Lahti Anderson, Sheryl A. Larson, Sarah MapelLentz, Jennifer Hall-Lande; A Systematic Review of U.S. Studies on the Prevalence of Intellectual or Developmental Disabilities Since 2000. Intellect Dev Disabil 1 October 2019; 57 (5): 421–438. doi: https://doi.org/10.1352/1934-9556-57.5.421

[55] Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuiseppi, C., Durkin, M. S., Giarelli, E., Morrier, M. J., Nicholas, J. S., Pinto-Martin, J. A., Shattuck, P. T., Thomas, K. C., Yeargin-Allsopp, M., & Kirby, R. S. (2012). Racial/ethnic disparities in the identification of children with autism spectrum disorders. American Journal of Public Health, 102(2), 327-333. https://doi.org/10.2105/AJPH.2011.300419

individuals with IDD who are being treated by healthcare providers, while administrative records can provide information on the number of individuals with IDD who receive government-funded support services.

This approach is also fairly common as Friedman *et al.* explain, "administrative data collections are linked with other population-based data sources appear promising as a means of estimating the size and characteristics of populations living with IDD in defined geographic locations. They offer the potential for sustainability, timeliness, accuracy, and efficiency."[56]

The strengths of administrative data include their large sample sizes and their ability to provide information on a wide range of variables, such as healthcare utilization and service delivery (Mandell et al., 2012). However, administrative data may not accurately represent the IDD population, as individuals with IDD may not receive a diagnosis or may not use services.

Partners Health Management LME/MCO – CMS Claims Data

Using the administrative data approach, the Piedmont Triad Regional Council requested aggregated and de-identified administrative procedure billing data to the NC DHHS/ Centers for Medicare & Medicaid Services (CMS) from the local management entity/managed care organization (LME/MCO) serving Forsyth county. Partners Behavioral Health Management manages and oversees publicly funded behavioral health services in fourteen counties in North Carolina. Partners Behavioral Health Management is responsible for coordinating and managing mental health, substance abuse, and intellectual/developmental disability services for individuals who are Medicaid-eligible or uninsured in its service area.

We requested Healthcare Common Procedure Coding System (HCPCS) service codes, costs per service code, unique client counts, client age and gender, and provider types. Clients were identified by Diagnosis and Procedure Codes associated with the individual within the following range of International Classification of Diseases Codes (ICD10) as shown in the table on the next page.

[56] Friedman, D.J., Gibson Parrish, R. and Fox, M.H. (2018), A Review of Global Literature on Using Administrative Data to Estimate Prevalence of Intellectual and Developmental Disabilities. Journal of Policy and Practice in Intellectual Disabilities, 15: 43-62. https://doi.org/10.1111/jppi.12220

TABLE 2 - ICD10 CODES RELATED TO IDD

Primary Dx	Description
D82.1	Di George's syndrome
F70	Mild intellectual disabilities
F71	Moderate intellectual disabilities.
F72	Severe intellectual disabilities
F73	Profound intellectual disabilities
F79	Unspecified intellectual disabilities
F80.2	Mixed receptive-expressive language disorder
F84.5	Asperger's syndrome
F88	Global developmental delay
F89	Unspecified disorder of psychological development
G12.9	Spinal muscular atrophy, unspecified
G40.301	Generalized idiopathic epilepsy and epileptic syndromes
G40.909	Epilepsy, unspecified, not intractable, without status epilepticus
G80.0	Spastic quadriplegic cerebral palsy
G80.2	Spastic hemiplegic cerebral palsy
G80.9	Cerebral palsy, unspecified
Q90.9	Down syndrome, unspecified
Q98.4	Klinefelter syndrome, unspecified
Q99.2	Fragile X chromosome
R45.6	Violent behavior
R62.0	Delayed milestone in childhood
S01.90XA	Unspecified open wound of unspecified part of the head
S06.1X5A	Traumatic cerebral edema with loss of consciousness greater than 24 hours
S06.899A	Other specified intracranial injury with loss of consciousness of unspecified duration

Medicaid Recipients for IDD Services in Forsyth County

Service billing data provided by Partners Behavioral Health Management shows that there were 823 unique clients over the 14 months covered by the data. Month-by-month counts varied from a high of 655 to a low of 597 individuals.[57] Three-fifths (59.2%) of clients were male and two-fifths (40.8%) were female. Half of the clients (53.4%) were between 21 and 40 years of age. Only 11.1% were over 60 years old.

TABLE 3 – CLIENTS BY AGE BAND

	Ages 1-10	Ages 11-20	Ages 21-30	Ages 31-40	Ages 41-50	Ages 51-60	Ages 61 and Older
Total	**35**	**102**	**218**	**219**	**118**	**118**	**91**
Percent	4.3%	12.4%	26.5%	26.6%	14.3%	14.3%	11.1%

[57] Note that CMS billing data often trails services up to 90 days after service delivery thus impacting trailing counts.

RESEARCH, POLICY & IMPACT Center

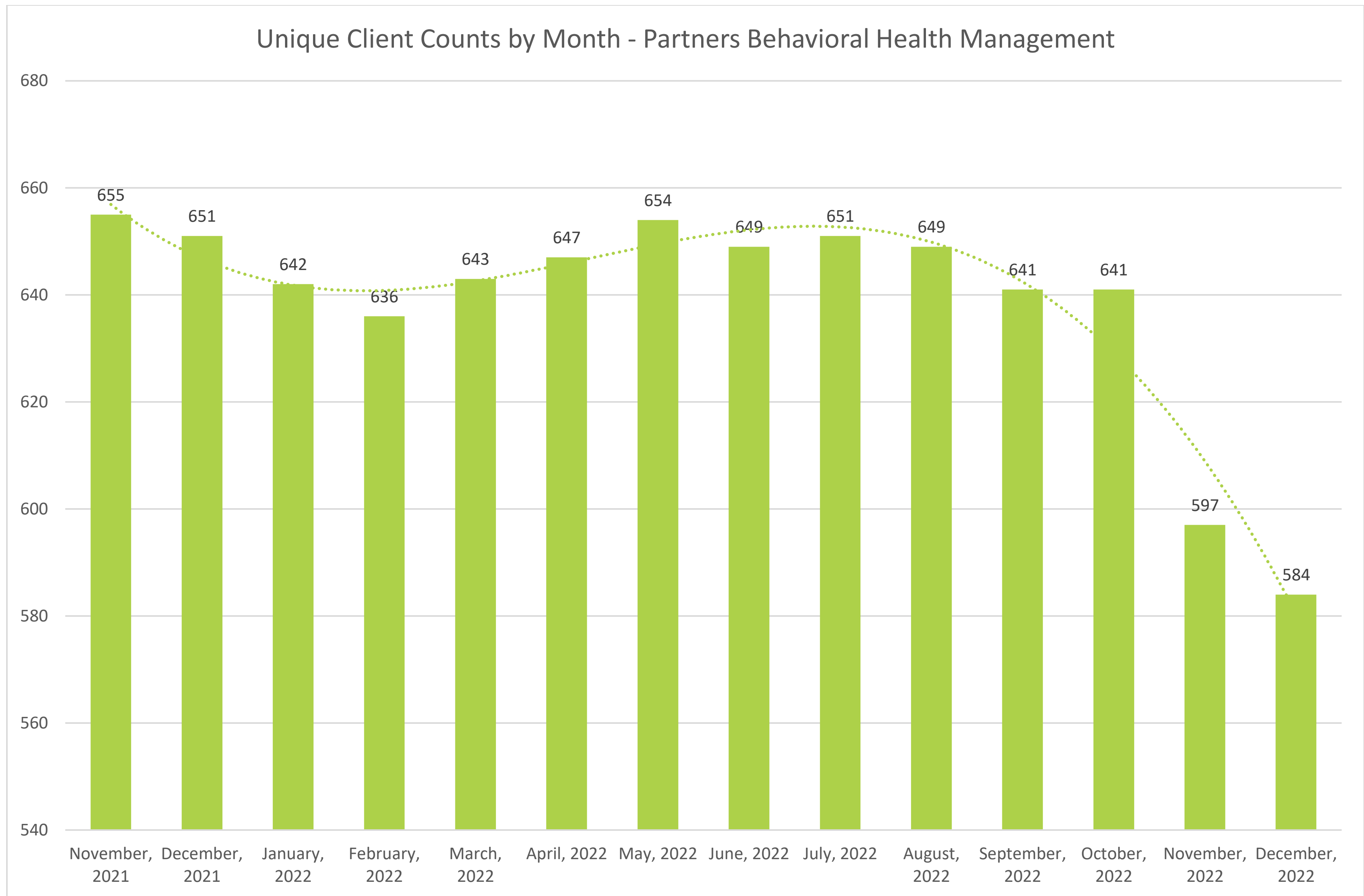


Figure 4 - Unique Client Counts Partners Behavioral Health Management Nov 2021 – Dec 2022

Service Providers in Forsyth County

Agencies provided services to 86% of all clients. Second was individual providers with 9% of all clients, physician practices (hospital) with 6%, and Innovation Modification Vendors with just under 6% of clients.

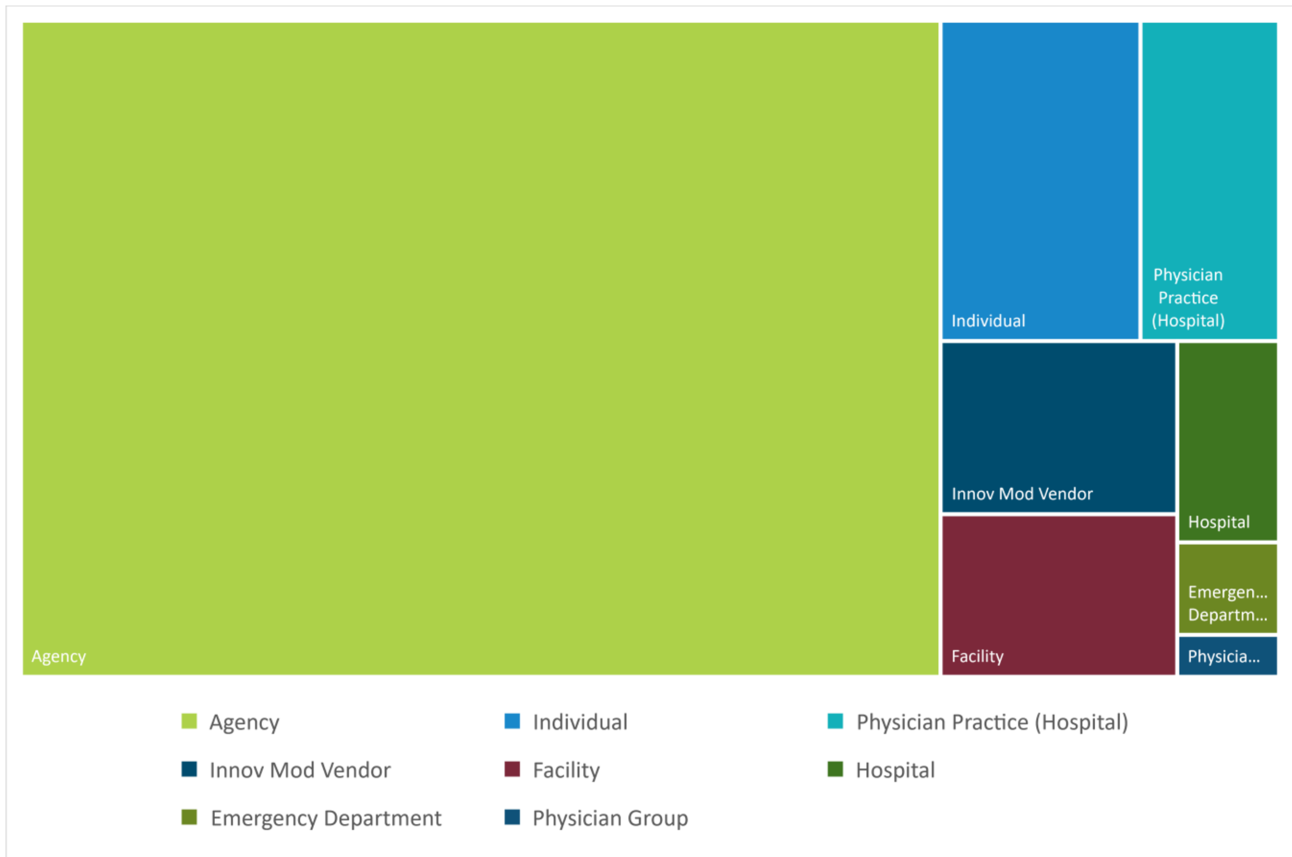


FIGURE 5 - PROVIDER TYPES BY CLIENTS SERVED

TABLE 4 – TOP 10 PROCEDURES BY NUMBER OF CLIENTS

Procedure/Revenue Code	N	%
S5150 - Respite: Individual	148	18%
T2013 TF - Community Living and Supports	146	18%
T2021 - Day Supports Individual	128	16%
0100 - ICF/IDD Hospital Admission & General Hospital	126	15%
T2041 Community Navigator Monthly	124	15%
T2012 GC - CLS Live in Caregiver Indiv	118	14%
T2021 HQ - Day Supports Group	97	12%
H2015 - Community Networking	91	11%
96130 - Psychological Evaluation and Interpretation	58	7%
90791 - Psychiatric Diagnostic Evaluation (No Medical Services)	55	7%

Billing Categories by Clients & Costs in Forsyth County

The top categories for billing according to HCPCS service codes were Respite (148 individuals, 18% of all clients); Community Living and Supports (146 individuals, 18% of all clients); Day Supports Individual (128 individuals, 16% of all clients); ICF/IDD Hospital Admission & General Hospital (126 individuals, 15% of all clients); Community Navigator Monthly (124 individuals, 15% of all clients); and Live in Caregiver (118 individuals, 14% of all clients).

CLASSIFICATIONS OF SUPPORT IN FORSYTH COUNTY

The largest classification of support by the number of clients was for Community Alternatives Program for Disabled Adults (CAP) with a third of all clients (34.5%) receiving services within this classification. This was followed closely by "other" CAP support (43.4%). Outpatient services as well as CPA residential supports were next at 19.8% of clients. CAP Respite represented 18.5% of clients.

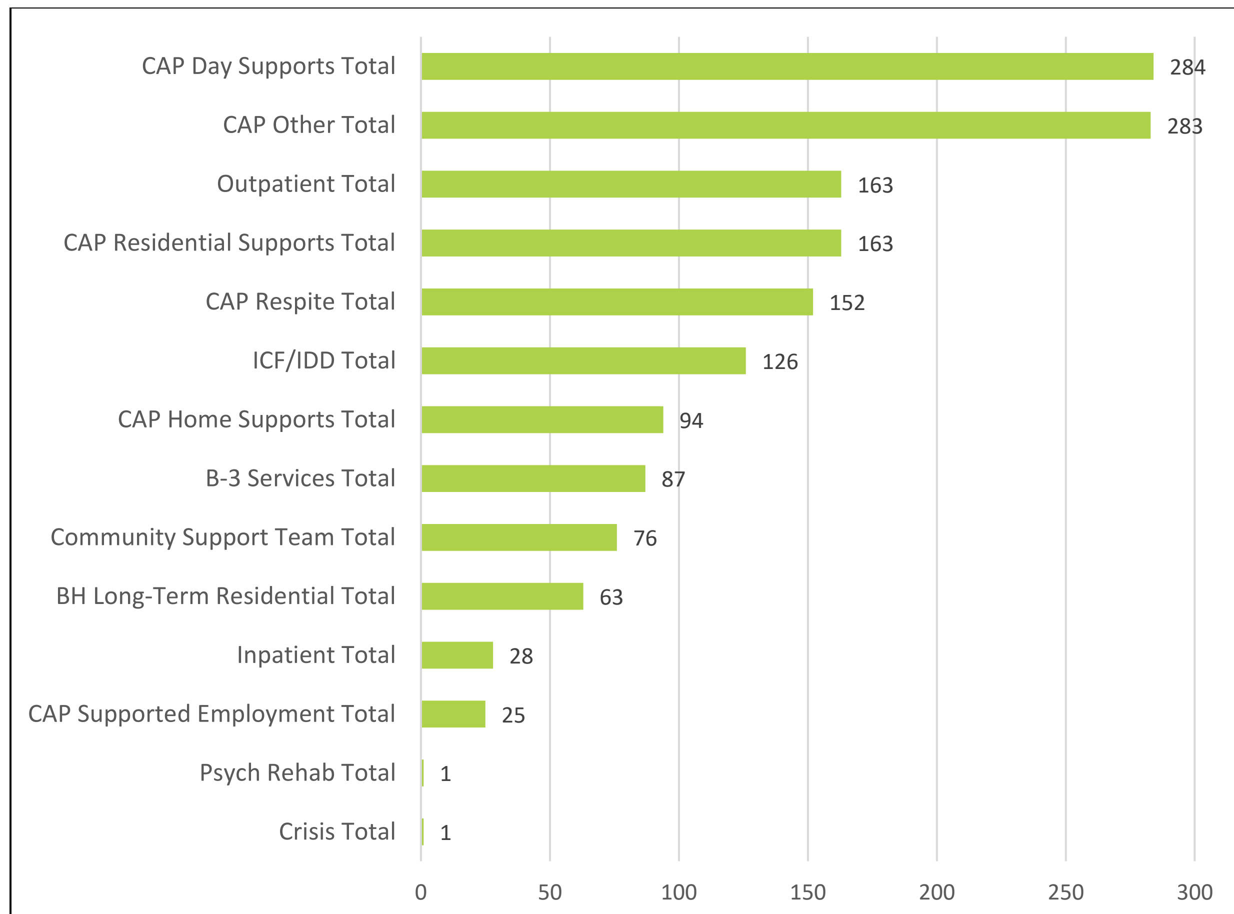


FIGURE 6 - UNIQUE CLIENT COUNT BY CLASSIFICATION OF SUPPORT

COST OF CLAIMS FOR IDD IN FORSYTH COUNTY

Total claims data was averaged over 14 months. The per month/per client average (mean) was $7,297.48. However, monthly billing expenses averaged up to $2.3 million a month for ICF/IDD Hospital Admission & General Hospital, $424,171 a month for Live-in Caregivers, and $289,066 a month for Community Living and Support.

TABLE 5 – TOP 20 AVERAGE MONTHLY COSTS BY PROCEDURE CODE

Procedure Code Description	Average Monthly Total
0100 - ICF/IDD Hospital Admission & General Hospital	$2,283,866.08
T2012 GC - CLS Live in Caregiver Indiv	$424,171.39
T2013 TF - Community Living and Supports	$289,066.56
T2021 - Day Supports Individual	$251,080.61
H2016 HI U2 - AFL Residential Supports Level IV AFL	$154,332.47
T2020 U2 - AFL Residential Supports Level III - AFL	$145,929.15
H2016 HI - Residential Supports Level IV	$117,431.64
H2015 - Community Networking	$109,600.74
T2021 HQ - Day Supports Group	$100,548.84
T2012 - CLS Community Only	$96,651.85
T2020 - Residential Supports Level III	$85,579.59
S5150 - Respite: Individual	$68,140.77
T2014 Residential Supports Level ll	$53,979.24
T2021 CR - Day Supports Individual	$42,600.68
T2033 - Supported Living 1	$33,047.15
0101 All-inclusive room and board	$25,602.50
T2014 U2 - AFL Residential Supports Level ll	$25,568.85
YP660 - DAY ACTIVITY	$25,564.29
T2016 U5 L1 - Home Living LTCS Level 1	$23,949.39
T2033 HI - Supported Living 2	$23,452.56

Method 2: Prevalence Studies & Population Estimation

Prevalence studies are the most common method for estimating the IDD population. These studies use standardized diagnostic criteria to identify individuals with IDD in a specific population (Maulik et al., 2011).[58] Prevalence studies can be conducted in various settings, including schools, healthcare facilities, and community-based organizations. The strengths of prevalence studies include their ability to provide detailed information on the prevalence of IDD in specific populations, the ability to use standardized diagnostic criteria, and the ability to identify co-occurring conditions (Maulik et al., 2011). However, prevalence studies have limitations such as the potential for underestimation or overestimation of the IDD population, depending on the criteria used for diagnosis.

Prevalence estimates of IDD are typically based on a variety of sources including population-based studies, health and medical records, and administrative databases. One of the most commonly used methods for estimating the prevalence of IDD is through population-based studies, which involve surveying a sample of individuals from a defined geographic area to determine the number of people with IDD in the general population. This method provides a more accurate estimate of the prevalence of IDD compared to relying solely on medical or administrative records.

For example, a study conducted by the Centers for Disease Control and Prevention (CDC) in the United States used population-based data to estimate the prevalence of IDD among 8-year-old children. The study found that approximately 2% of 8-year-olds in the United States have an IDD (Baio et al., 2018).[59] Another study conducted in Europe estimated the prevalence of IDD among children and adults using a combination of population-based and medical records data. The study

[58] Maulik, P. K., Mascarenhas, M. N., Mathers, C. D., Dua, T., & Saxena, S. (2011). Prevalence of intellectual disability: A meta-analysis of population-based studies. Research in Developmental Disabilities, 32(2), 419-436. https://doi.org/10.1016/j.ridd.2010.12.018

[59] Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Durkin, M., … Kirby, R. S. (2018). Prevalence of autism spectrum disorder among children aged 8 years – autism and developmental disabilities monitoring network, 11 sites, United States, 2014. MMWR Surveill Summ

found that approximately 2% of the European population has an IDD (EMDD-Europe, 2018).

In a paper by Havercamp *et al.* (2019) in the *Journal of Intellectual & Developmental Disability,* the authors note that "current national health surveillance systems in the United States offer little or no information about the prevalence and health status of adults with intellectual disability (ID) or developmental disabilities (DD).[60] The most recent meta-analysis findings show the prevalence of intellectual disability ranges from .05% to 1.55% of the population globally.[61]

Application of Prevalence Methods

The American Community Survey (ACS) is an ongoing survey conducted by the U.S. Census Bureau that collects data on various social, economic, and housing characteristics of the U.S. population. The survey asks respondents a variety of questions about their health, disabilities, and access to healthcare services, among other topics. The ACS is generally considered to be a reliable and accurate source of information on the characteristics of the U.S. population. The survey is designed to collect data from a large and representative sample of households across the country, and the sample size and methodology are regularly reviewed and adjusted to ensure that the data are statistically valid and reliable.[62]

That being said, like all surveys, the ACS is subject to some limitations and potential sources of error. Some of the potential issues that can affect the accuracy of the survey include non-response bias (i.e., when some groups are less likely to respond to the survey than others), sampling error, measurement error (i.e., when respondents provide inaccurate or incomplete information), and data processing errors. To mitigate these potential sources of error, the Census Bureau uses various

[60] Susan M. Havercamp, Gloria L. Krahn, Sheryl A. Larson, Glenn Fujiura, Tawara D. Goode, Barbara L. Kornblau, the National Health Surveillance for IDD Workgroup; Identifying People With Intellectual and Developmental Disabilities in National Population Surveys. Journal of Intellectual & Developmental Disability 1 October 2019; 57 (5): 376–389. doi: https://doi.org/10.1352/1934-9556-57.5.376

[61] McBride, O., Heslop, P., Glover, G., Taggart, L., Hanna-Trainor, L., Shevlin, M. and Murphy, J. (2021) "Prevalence estimation of intellectual disability using national administrative and household survey data: The importance of survey question specificity", International Journal of Population Data Science, 6(1). doi: 10.23889/ijpds.v6i1.1342.

[62] U.S. Census Bureau. (2022). American Community Survey (ACS). https://www.census.gov/programs-surveys/acs
U.S. Government Accountability Office. (2017). American Community Survey: Better guidance could help ensure an effective reengineered survey. https://www.gao.gov/products/GAO-18-89

statistical methods and quality control procedures to ensure that the data are as accurate and reliable as possible.

Disability Date from the ACS for Forsyth County

The ACS provides data on types of disabilities by age cohort and by census tracts. There are three types of disabilities captured in the ACS which intersect or overlap with the IDD population: cognitive difficulties, self-care difficulties, and independent living difficulties. It is noted that individuals may be counted multiple times as each disability type is non-exclusive.

We see from the table below that 1.6% of adults (or about 5,608 individuals) between 35 and 64 years old have cognitive difficulties in Forsyth County. The highest concentrations of individuals with cognitive difficulties are in South and East Winston-Salem in CT 3703, CT 3500, CT 3308, CT 1700, and CT 2701. "Cognitive difficulty" refers to a person's self-reported difficulty with concentrating, remembering, or making decisions because of a physical, mental, or emotional condition that has lasted at least six months.

Nearly 1% of the same age group have self-care difficulties. In the ACS, "self-care difficulty" refers to a person's self-reported difficulty with routine self-care activities, such as bathing or dressing, due to a physical, mental, or emotional condition. There are concentrations of individuals with self-care difficulties in South and Northeast Winston-Salem in CT 3703, CT 3500, CT3403, CT 3904, CT 3201, CT 1500, CT 2903, CT 3105, and CT 2806.

Finally, almost 2% of 35 to 64-year-olds (5,386 individuals) have independent living difficulties. The highest concentrations of individuals with independent living difficulties are in South, North, and East Winston-Salem in CT 3703, CT 1800, CT3308, CT 3108, CT 3202, CT 1500, CT 2603, CT 2703, CT 2702, and CT 2806. "Independent living difficulty" refers to a person's self-reported difficulty with performing daily activities or living independently, such as doing errands or managing money, due to a physical, mental, or emotional condition that has lasted at least six months.

TABLE 6 – DISABILITY BY TYPE FOR FORSYTH COUNTY

Forsyth County, NC	Cognitive Difficulty		Self-Care Difficulty		Independent Living Difficult	
Age	N	%	N	%	N	%
5 to 17 years	1,760	0.50%	548	0.16%	-	-
18 to 34 years	2,780	0.80%	754	0.22%	1,779	0.62%
35 to 64 years	5,608	1.61%	2,810	0.80%	5,386	1.89%
65 to 74 years	1,469	0.42%	1,055	0.30%	1,764	0.62%
75 years and over	2,532	0.72%	2,347	0.67%	4,574	1.60%
TOTAL	14,149	4.0%	7,514	2.2%	13,503	4.7%

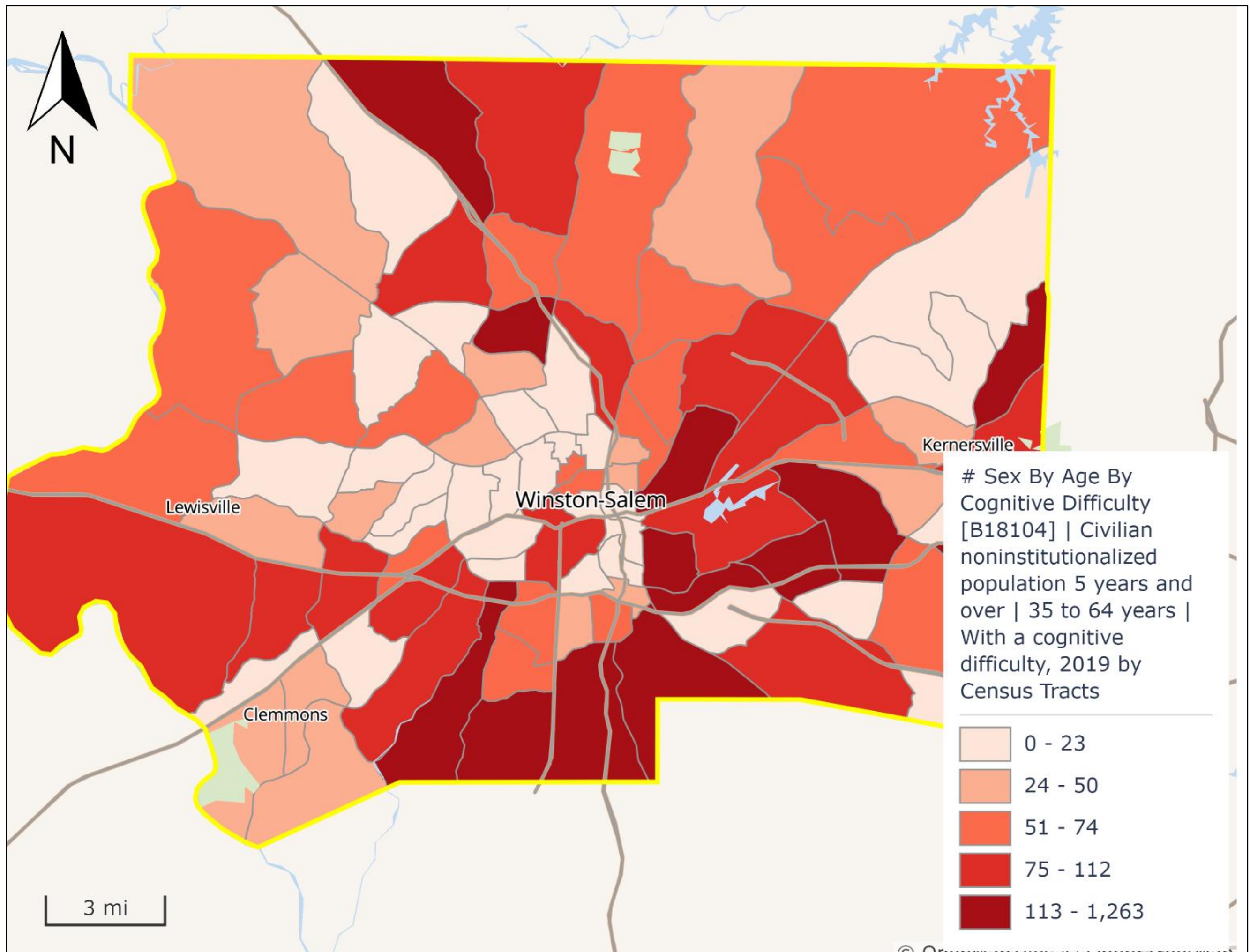


FIGURE 7 – COGNITIVE DIFFICULTIES 35-64 YEAR-OLDS FORSYTH COUNTY 2019

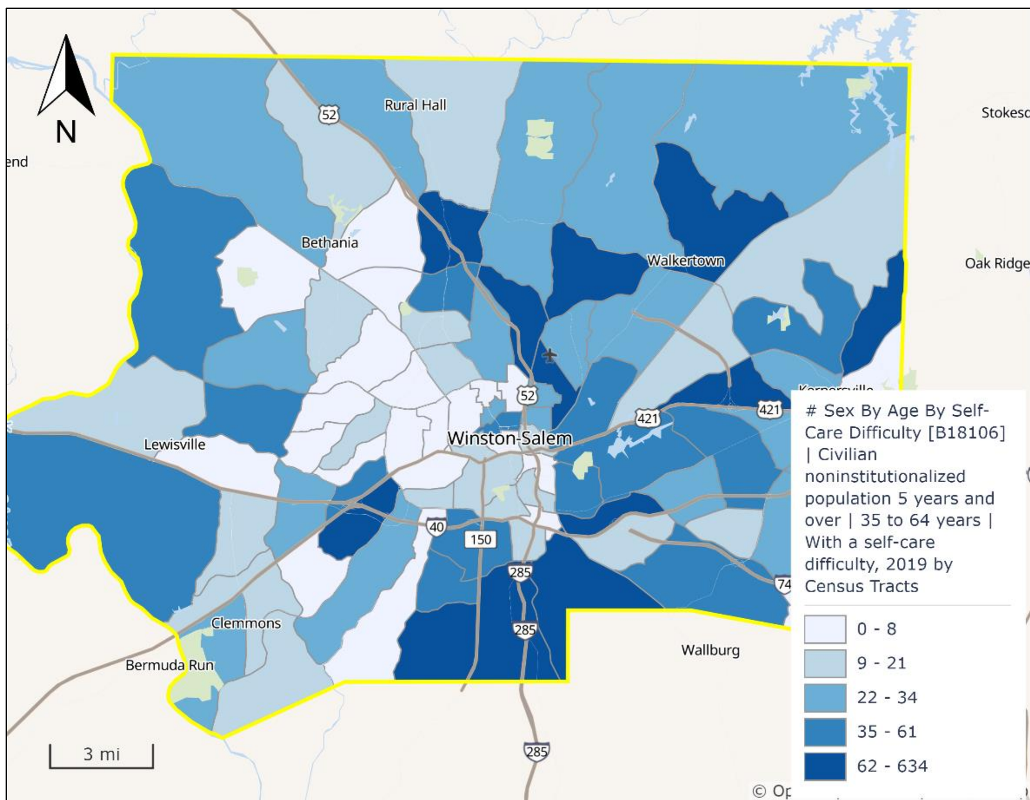


FIGURE 8 – SELF CARE DIFFICULTIES 35-64 YEAR-OLDS FORSYTH COUNTY 2019

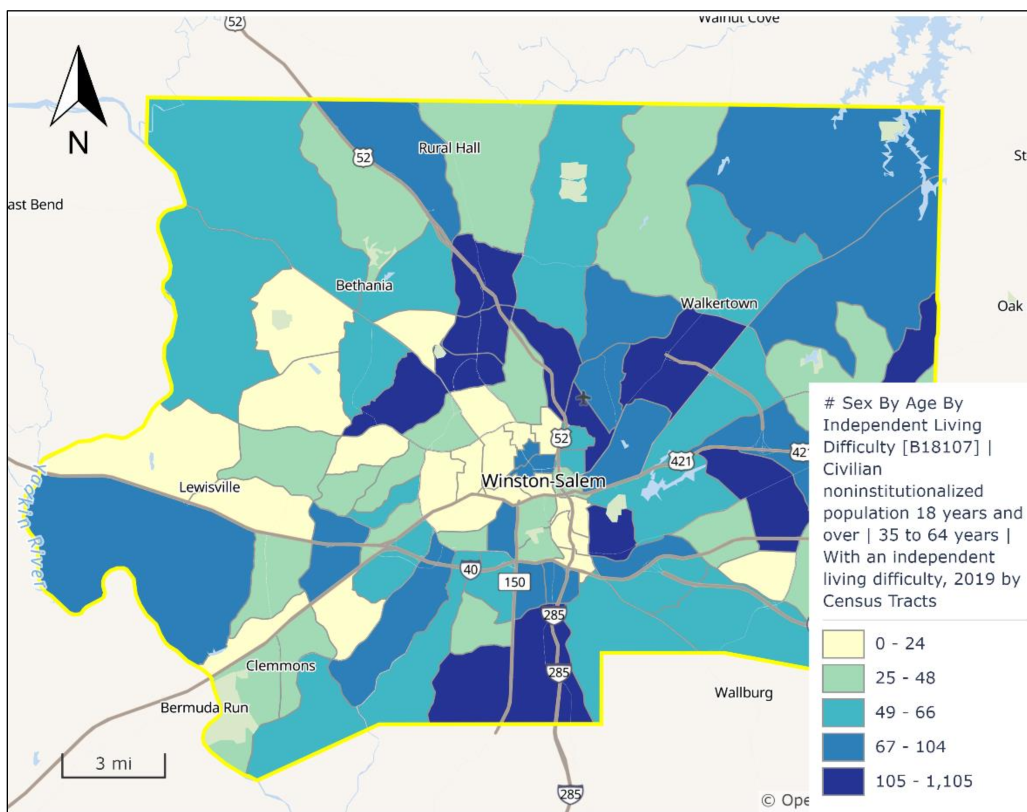


FIGURE 9 – INDEPENDENT LIVING DIFFICULTIES 35-64 YEAR-OLDS FORSYTH COUNTY 2019

HUD Disability & Public Housing Data

Data from the Affirmatively Furthering Fair Housing Data and Mapping Tool (AFFH-T), is drawn from the American Community Survey and Public Housing Authorities. It too provides some insight into the number of individuals within Forsyth County who are living with one of the following disabilities: Hearing difficulty, Vision difficulty, Cognitive difficulty, Ambulatory difficulty, Self-care difficulty, and Independent living difficulty. It adds to the above an understanding of the number of individuals with disabilities who live in housing that receives support from the Winston-Salem/Forsyth Housing Consortium which receives HOME Investment Partnership (HOME) funds from the U.S. Department of Housing and Urban Development (HUD).

HUD provides several programs to assist low-income families in obtaining affordable housing including Public Housing, Project-Based Section 8, Other Multifamily, and Housing Choice Vouchers (HCV). Public Housing refers to government-owned and managed housing for low-income families, elderly people, and people with disabilities. The Public Housing program provides units for rent to eligible families at a below-market rate. Public Housing units are owned, managed, and maintained by local public housing agencies (PHAs), which are funded by HUD. Project-Based Section 8 is a rental assistance program that provides subsidies to private landlords who reserve a portion of their rental units for low-income families. Under this program, a landlord receives a rental subsidy from HUD, and the tenant pays a reduced rent based on their income. The subsidy is tied to a specific property, so tenants can only use the subsidy at that property. Another Multifamily refers to privately owned and managed affordable housing units that are not part of the Project-Based Section 8 program. These units are typically subsidized by HUD or other federal programs and are rented to low-income families at below-market rates. The Housing Choice Voucher (HCV) Program is a rental assistance program that provides vouchers to eligible low-income families. The vouchers allow families to choose and rent a private-market apartment or house, and the family pays a reduced rent based on their income. The rental subsidy is paid directly to the landlord by the local public housing agency (PHA), which is

funded by HUD. The family is responsible for paying the difference between the subsidized rent and the total rent charged by the landlord.

We see in the Table below that 29% of residents in Public Housing have at least one type of disability. Nearly 20% of residents in Project-Based Section 8 and 16% of those in 'Other Multifamily' have a disability. Finally, 18% of those in the HCV Program have a disability. Thus, 1,816 individuals with disabilities, including some with IDD, live in a publicly supported housing program in the Winston-Salem Region.

TABLE 7 - DISABILITY BY TYPE WINSTON-SALEM HOME CONSORTIA & MSA (2019)

	Cnsrt-Winston-Salem, NC CONSORTIA(HOME) Jurisdiction		Winston-Salem, NC Region	
Disability Type	**#**	**%**	**#**	**%**
Hearing difficulty	8,592	2.57%	20,890	3.44%
Vision difficulty	5,994	1.79%	14,734	2.43%
Cognitive difficulty	14,944	4.46%	32,222	5.31%
Ambulatory difficulty	20,736	6.19%	45,505	7.50%
Self-care difficulty	8,040	2.40%	16,888	2.78%
Independent living difficulty	14,788	4.42%	31,444	5.18%

TABLE 8 - DISABILITY BY PUBLICLY SUPPORTED HOUSING PROGRAM WINSTON-SALEM HOME CONSORTIA & MSA

	(Cnsrt-Winston-Salem, NC CONSORTIA(HOME)) Jurisdiction		(Winston-Salem, NC) Region	
	#	**%**		
Public Housing	418	30.89%	480	29.15%
Project-Based Section 8	236	19.21%	332	19.76%
Other Multifamily	40	13.15%	62	16.05%
HCV Program	573	15.13%	942	18.32%

Computed Prevalence Projections for Forsyth County

According to the *State of the States in Intellectual and Developmental Disabilities Project* at the University of Kansas Center on Developmental Disabilities, there were an estimated 12,979 persons with IDD in NC receiving residential and other services for $1.59 billion in 2019.[63] This represents just .12% of the overall population. These figures were compiled from data from state agencies on developmental disability services and the state's Medicaid-authorized agencies. However, the NC Council on Developmental Disabilities[64] has found the prevalence of developmental disabilities to be 197,304 cases or 1.8% of the total population. This discrepancy between Medicaid enrollments and the overall prevalence of IDD in the population is a result of the administrative undercount of this system.

Given the population of Forsyth County, North Carolina in 2021 was 382,075 an approximate population-based estimate of those receiving Medicaid services should be about 459 individuals (we see from the actual LME/MCO data that this is about half of those being served). Based on the application of the NC Council on Developmental Disabilities estimate there should be about 6,877 individuals with IDD overall in the County. Additional projections have been made by RPIC utilizing estimates from McBride et al. (2021). Based on these estimates we have computed upper and lower bounds for the population of Forsyth County by age, sex, race, and ethnicity. Thus, the estimated upper bound of the total population of individuals with Intellectual and/or Developmental Disabilities is 5,922 for Forsyth County. The McBride et al. estimate is a little more conservative than the NC Council on Developmental Disabilities. Applying this estimate across demographic categories and using demographic percentages from the ACS 2021, we find that there should be approximately 2,803 males and 3,116 females in the IDD population. An estimated 3,838 IDD individuals identify as white, and 1,545 as black/African American, while an estimated 796 are Hispanic.

[63] Tanis, E.S., et al. (2022). The State of the States in Intellectual and Developmental Disabilities, Kansas University Center on Developmental Disabilities, The University of Kansas. http://www.StateoftheStates.org
[64] North Carolina Council on Developmental Disabilities. 2021. Five Year Plan FY 2022-2026. Available at https://nccdd.org/images/blog/2022/FYPBook21.pdf

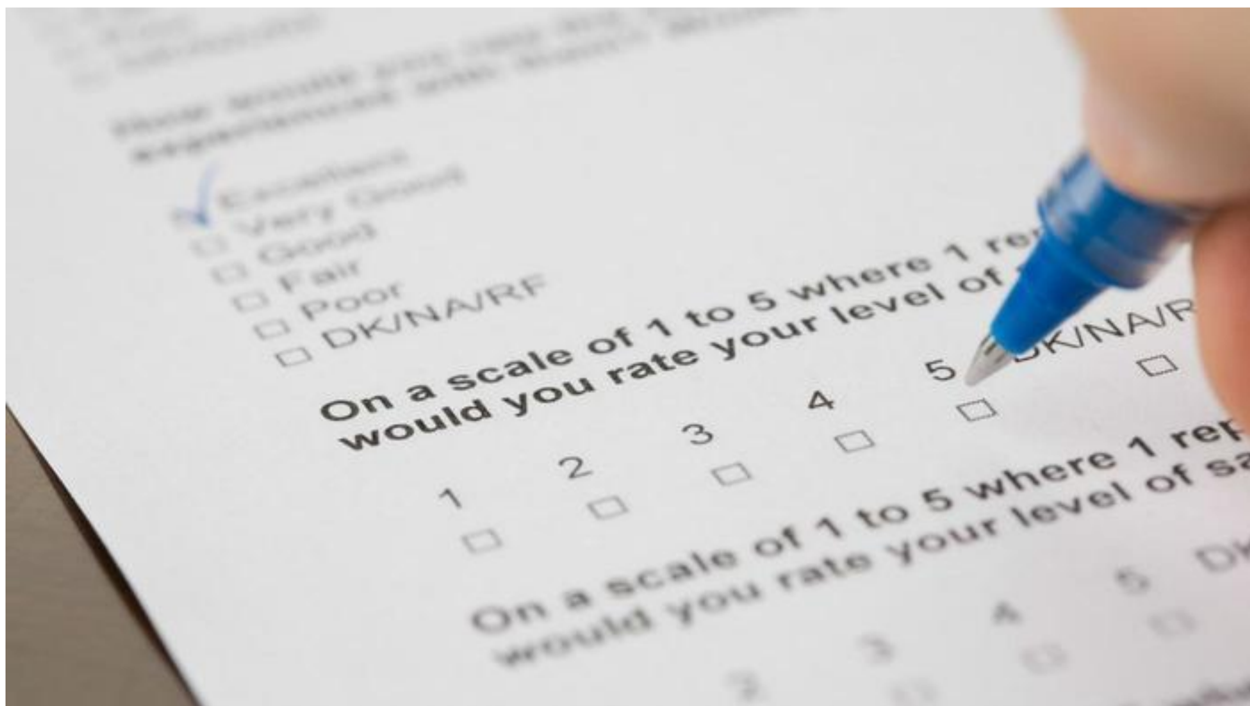
TABLE 9 – APPLICATION OF MCBRIDE *ET AL.* PROJECTIONS TO FORSYTH COUNTY DEMOGRAPHICS*

	Forsyth County, NC ACS 2021		IDD Population (Lower Bound)	IDD Population (Upper Bound)
POPULATION & SEX			0.05%	1.55%
Total Population	382,075		191	5,922
Male	180,864	47.34%	90	2,803
Female	201,003	52.61%	101	3,116
AGE				
Under 5 years	22,328	5.84%	11	346
5 to 9 years	25,581	6.70%	13	397
10 to 14 years	24,339	6.37%	12	377
15 to 17 years	15,723	4.12%	8	244
18 and 19 years	12,837	3.36%	6	199
20 to 24 years	26,216	6.86%	13	406
25 to 34 years	48,946	12.81%	24	759
35 to 44 years	43,787	11.46%	22	679
45 to 54 years	48,071	12.58%	24	745
55 to 64 years	48,860	12.79%	24	757
65 to 74 years	36,325	9.51%	18	563
75 to 84 years	17,946	4.70%	9	278
85 years and over	6,940	1.82%	3	108
RACE & ETHNICITY				
White alone	247,624	64.81%	124	3,838
Black or African American alone	99,658	26.08%	50	1,545
American Indian and Alaska Native alone	1,991	0.52%	1	31
Asian alone	10,174	2.66%	5	158
Native Hawaiian and Other Pacific Islanders alone	334	0.09%	0	5
Some other race alone	10,057	2.63%	5	156
Two or more races	11,775	3.08%	6	183
Hispanic or Latino | Not Hispanic or Latino	330,509	86.50%	165	5,123
Hispanic or Latino | Hispanic or Latino	51,373	13.45%	26	796

* DOES NOT ACCOUNT FOR DIFFERENTIAL MORTALITY RISK, RACIAL OR SEX DISPARITIES IN THE INCIDENCE OF IDD

Method 3: Self-Report

Self-report is another method used to estimate the IDD population. This method collects information directly from individuals with IDD or their caregivers about the individual's diagnosis, symptoms, and functional abilities (Smith et al., 2008).[65] Self-report surveys can be conducted in various settings, such as schools, healthcare facilities, and community-based organizations. The strengths of self-report surveys include their ability to collect information directly from individuals with IDD or their caregivers, the ability to capture a broad range of functional abilities, and the ability to identify unmet needs (Smith et al., 2008). However, self-report surveys may have limitations such as the potential for bias in responses and the potential for underestimation or overestimation of the IDD population. The remainder of this report will rely on self-report in the form of interview and survey data that details the service and housing needs of individuals with IDD in Forsyth County.



[65] Smith, M. J., Adams, H. L., & Smith, C. J. (2008). Methodological issues in survey research with individuals with developmental disabilities. Journal of Developmental and Physical Disabilities, 20(2), 153-167. https://doi.org/10.1007/s10882-007-9097-9

Key Informant Interviews

For the first phase of our primary data gathering, we conducted twelve (12) semi-structured, in-depth one-on-one interviews with community stakeholders. Interviews were conducted remotely via zoom and recorded. The interview subjects were assured that their comments would not be reported in a manner that would identify the person speaking by name or by affiliation. The comments directly quoted in this report are lightly edited for clarity or to ensure confidentiality. Interviews were between half an hour and an hour in length. Transcripts were made of each interview, reviewed by a project intern for accuracy, then reviewed for themes and quotes using a grounded approach. We interviewed people representing the following organizations and professions:

- Community-Based Care, LLC
- Disability Rights North Carolina
- First in Families of North Carolina
- Horizons Residential Care Center
- North Carolina Council on Developmental Disabilities
- North Carolina Office on Disability & Health
- Partners Behavioral Health
- The Arc of North Carolina
- The Enrichment Center
- The Piedmont Triad Regional Council
- UNCG - Beyond Academics

Medicaid & Innovation Waiver Process in North Carolina

The interview participants described Medicaid services in North Carolina, which are set up to serve individuals with disabilities and provide them with home and community-based services. However, they pointed out that State has not been successful in moving people out of institutions and into the community, despite the ruling of a judge in the Samantha R lawsuit which mandates compliance with the Olmstead Decision. An interviewer elaborates on the issues:

"Okay, so let me just start by saying we are all paying as taxpayers, lots of money for lots of bad outcomes right now. That's the way it's set up in North Carolina. We way over-rely on institutions. And our, our, goal is to get as many people as we can, who want to live in the community, given the opportunity to live in the community with the services that they need to make them as successful as they can be. So, right now, that's not that is not great in North Carolina. You may have heard of the Samantha R lawsuit. Right? So, that's five years in we got a judge's ruling that basically said yes, this is what you have to do. You have to comply with Olmstead. You have to get people out of institutions and let them live in the community and get their home and community-based services, you know, integrated with the rest of society and the state said we're going to appeal that. So that's where we are on that. And we're, you know, we're just gonna meet the appeal

The Innovation Waiver program is a Medicaid program that allows people with disabilities to live independently in the community with support, but this program has not been effective in serving the population according to several of the interviewees. One explained.

"The state has not been good about moving people into the community. There are, you know, there is an Innovation Waiver, I don't know if you know what that program is, that's a Medicaid waiver program. And in the year 2014, or 2015, they started a service called Supported Living, which was supposed to allow people, adults, right with, with disabilities, to live in the community independently of their families, with the support and services they needed. And, it could be anywhere from, they need a few hours a day to they need 24-hour support someone to sleep in whatever that, that private living arrangement is that they have. That program or that service has never really come to fruition the way you would hope that it would work. And, it's supported very few people. And, the few people that have been able to access it often rely heavily on family members to provide services that are not under the service, should be provided, but are simply not, as there are very few providers for that service."

In North Carolina, individuals with intellectual or developmental disabilities who are not receiving the services they are entitled to from agencies authorized and budgeted to provide them have limited options for recourse. First, they may file a complaint with the agency providing services or the LME/MCO that oversees and approved service delivery. A second option would be to contact the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services. This division is responsible for overseeing and regulating the services provided to individuals with intellectual and developmental disabilities in the state. Another option is to contact an advocacy organization. Several advocacy organizations in North Carolina provide support and assistance to individuals with intellectual and developmental disabilities. For example, Disability Rights North Carolina is a nonprofit organization that provides legal advocacy and representation for individuals with disabilities. The organization works to protect and advance the rights of people with disabilities in a variety of areas, including education, employment, housing, and healthcare. Finally, in some cases, individuals may need to file a lawsuit to enforce their rights and ensure that they receive the services they are entitled to.

Medicaid vs. Innovation Waiver Services

Another participant discusses the distinction between Medicaid and Innovation Waiver services. They also explain that their organization works with individuals who are diagnosed before the age of 21 with a developmental disability, which can include intellectual disabilities, traumatic brain injuries, cerebral palsy, and other conditions. The organization provides support for independent living, but the lack of appropriate housing options for this population is a major issue. The interviewee advocates for housing that is specifically designed for individuals with developmental disabilities and emphasizes the benefits of providing supportive services for this population. The speaker also notes that individuals with developmental disabilities are typically a safe and reliable population for landlords to rent to. In their own words:

> *“So it's, you don't have to qualify directly for Medicaid, you can qualify as a waiver service. And depending on Income or Social Security benefits, you the person might have a deductible. But it's*

so it is a waiver service. That's, that's a misconception because a lot of people think it's a straight Medicaid-based service, different from what's called blue, blue Medicaid, your blue card, Medicaid…. So, what innovations does is, we work with folks who are diagnosed before the age of 21, with a developmental disability, and that can be across the board, as long as you have four deficits. So, we have folks who are IDD... And then we also have folks who are traumatic brain injury, we also have folks who have cerebral palsy. So, it's, I would say 90% of our folks have intellectual disabilities, but not all. So, that's also a misconception, we, you know, we have a young lady that might be one of my folks, she's graduated from High Point University, and she's quadriplegic, cerebral palsy, so our she fits into our service definitions because of her deficits. But intellectually, she's, you know, our peer.

So that is why my heart string goes also for housing, to segue into what you're doing is because we have a handful of folks who, ***who could be independent if the housing was there****, and want to be independent and intellectually understand all the processes and steps of being independent, but would go on a typical HUD waiting list if they were looking because some of our folks are working. And if they are working, they're working part-time, because they want to keep their sense of security. And some of our folks work full-time and don't get so security, that's a very small population. So, if they're wanting to go on that sliding scale, the for like HUD housing or assistance or anything like that, that's just a huge population…. So I know it's very tricky to say that but my heart would really love for IDD folks to have some specific housing gear toward their needs. And the and the beauty of that the beauty of that for the housing community is they have supportive services. A lot of folks have representative payees. So, they have natural support, then they have Innovation Services. So, they have staff who's coming in their house and helping them do things with their own self and their skill assets and their home or their apartment. So, it's a very safe, I don't mean like, I mean, safe as far as a secure investment for our population to be the renters. And when it's a really good population, our IDD folks are*

very low with criminal charges. They're very low with drug abuse. They're very, they're very low with, like violence and loud and disorderly conduct. I mean, so they're just a prime population that needs some housing, please. So that's my soapbox."

According to participants, if someone is on the Innovations Waiver waiting list for services, the state allots a certain number of slots to each county, which are filled on a first-come, first-served basis. The determination of services starts with individualized budgets, which are based on the results of Support Intensity Scale (SIS) assessments as well as IQ and developmental testing. The SIS is a four-hour assessment that is conducted with families by local LME/MCOs and any relevant natural supports or physicians. The assessment includes a large number of questions covering various aspects of life.

After being given a slot, the individual undergoes an SIS assessment, followed by a psychological evaluation that involves IQ and developmental testing to quantitatively measure the individual's cognitive abilities and areas of deficit. Based on the results of these evaluations, the state issues a budget to the individual, which can range from $30,000 to a capped limit of $135,000. However, this limit can be exceeded if there are clinical justifications that are reviewed and approved. In the words of the interviewee:

"It actually starts at the state level with individualized budgets. So, I don't know how we do you want me to, but there's a support intensity scale, commonly called the SIS is a four-hour assessment that's done with families and it's an assessment that's created by the state, but it is given at the local level. So, we have employees who administer the SIS with the families, and any provider that they want there is invited, any natural supports, and it's just a just a huge amount of questions on all life skills in every area that you can think of. So, that's the starting point. So if someone is on a waiting list for services, and the State gives us so many slots a year, so if we get identified, okay, we have made up some numbers, you know, we have 20 slots go into Forsyth County, and we have 2000 people on the waiting list, the state looks at that waiting list just by the year you got on it. At one point, the waiting lists had an acuity issue, like you would

make an accommodation for acuity, but now it is not that way, it is just when you actually put your number in. So, if someone gets a slot, they come and get us they will get a SIS assessment. And that assessment is kind of where it starts off trying to clinically quantify where their deficits are, from their families' perspective, any natural supports or their physician can be on that call is, rare, but sometimes they are, they can be invited. So that's sort of a starting point. And then we have a psychological evaluation that is required, and that requires IQ and developmental testing so that we literally quantify an IQ, as well as areas of deficit. So, then those things combined, the state looks at those and they issue a budget to us. And so, a person's budget can vary anywhere from 30,000 to right now, it's tiered out at 135,000. The state sets that limit. There are ways to go over that limit. But, it's you know, you have to show clinical justifications and has to go through all these other tiers of review. But right now, that cap is at 135."

Number of Innovations Waiver and Medicaid Recipients in Forsyth

Participants were asked about the number of clients being served in just the Forsyth County area. One interviewee noted that there are around 800 individuals who receive services in the County. Their organization offers supported living services that allow individuals to live in their own homes with staff available on all shifts if needed. These individuals have mixed residential arrangements. Some individuals live in group homes, or assisted family living facilities, while others require more natural support and may struggle to live independently. The interviewee believes there is a "sweet spot" for individuals who, with the right assistance and environment, could graduate to live independently. The interviewee explains:

"So if we did the math on that, that puts us at around 800. But obviously, I don't have the exact statistics, but I would say 800. And of those, that's you know, that's a mixed, residential bagged. Some folks are living in group homes and are very happy in those group homes and those group homes are their homes. Some live in AFLs [alternative family living settings], which is assisted family living facility. And those are in the same genre as group

homes except for their setup primarily like, it's when it's with an individual family, who is who has set their home have like a group home. And those folks are very happy. And the reason that I say that is because I remember the big push for deinstitutionalization. Because I was in the field back in the day. And there were a lot of people who didn't want to go, that were made to go. And that hurt my heart, you know. So, I do like to put the plug in there that ***a lot of our folks are in that, are very happy in the group homes and in the AFL settings.*** *And then we have a handful of folks who will probably never say never, but it would be very challenging for them to live independently away from natural support. That will be our like our severe profound population, those folks would, you know, it'd be hard for them to live in independent housing.*

And so then we have that little sweet spot, we have that little sweet spot of folks who, with the right assistance and the right environment, could graduate as we always say, like, you know, quote, unquote, typically developing kids get to graduate out of their parent's house, they go to college dorms, or they go off apartment complexes, or whatever, and a lot of our IDD folks don't get to do that. Because, ***we don't have enough supportive housing****. So, I do think there's a sweet spot, and of those folks that could use that housing. And then, to segue into services, we have supported living definition or supported living services, which provides, it is an Innovations Waiver service, that allows for someone to live in their apartment or home and have staff on all three shifts if needed. So, it's kind of staffed in the mindset of like a group home, but it's in that person's home. So, we're typically most of our folks services are in the home during the day. We don't have third shift staffing, unless it's some type of crisis or rare situation."*

"Tiers of Need" & "Tiers of Services"

The interviewees also describe "Tiers of Need" and "Tiers of Services" within the context of supporting individuals with intellectual and developmental disabilities (IDD). A key informant explains, *"when you're talking about a more inclusive setting, you're talking about independent living or supportive living, that typically,*

this the services are structured around staff hours in the home. And, you know, really, and oftentimes, it's tiered. And, you know, the population that we serve is very, very diverse, and much more diverse than the tiers kind of suggest or would allow for. The services offered are typically structured around the availability of staff and are tiered into three levels, with the highest level requiring the most intense services. However, access to these services is limited due to financial constraints, resulting in many individuals being unable to access the support they need."

In North Carolina, Local Management Entities/Managed Care Organizations use this three-tier system to assess the level of support needed by individuals with IDD. The first tier is the lowest level of need and represents individuals who can live in the community with minimal support. These individuals may only require periodic check-ins, counseling, or other basic services. The second tier represents individuals who require more substantial support to live in the community. They may need assistance with activities of daily living (ADLs), such as meal preparation, medication management, and personal care. They may also require support with transportation, community involvement, and other aspects of daily life.

For individuals on the lowest tiers of services (Tiers 1 and 2), "minimal support" generally refers to the level of support required to help them maintain their independence and meet their basic needs. This might include assistance with activities of daily living, such as bathing, dressing, and grooming, as well as support with household tasks, transportation, and basic medical care. This assistance may come in the form of paid caregivers as well as "natural supports." Natural supports refer to the assistance and resources that individuals with intellectual and developmental disabilities can access from their families, friends, and communities to help them achieve their goals and live independently. Natural supports are seen as an important part of the NC Innovations Waiver program because they can help individuals with disabilities build relationships and connections in their communities, which can in turn help them maintain their independence and enhance their quality of life.

Also, because individuals on Tiers 1 and 2 require less intensive support than those on Tier 3, the amount and type of services they receive may be limited. This can

mean that they receive less frequent visits from service providers or have less flexibility in scheduling their services. Additionally, because the funding available for the NC Innovations Waiver program is limited, some individuals on the lowest tiers may experience waiting lists for services or delays in accessing the support they need.

The third and highest tier represents individuals with the most significant needs. These individuals may require round-the-clock support, including assistance with medical needs, behavioral support, and specialized programming to help them develop independent living skills. This includes assistance with activities of daily living (ADLs), such as bathing, dressing, grooming, and toileting. These tasks are essential for an individual's health and safety and are typically assessed by a healthcare provider. Individuals who have difficulty performing ADLs often require extensive support to live independently. Similarly, Instrumental Activities of Daily Living (iADLs) are more complex tasks that are necessary for independent living but are not directly related to personal care. These tasks may include managing finances, shopping, cooking, housekeeping, transportation, and medication management.

The types of services that are available through the NC Innovations Waiver program for individuals on Tier 3 include:

- *Personal care services:* This includes assistance with Activities of Daily Living (ADLs), such as bathing, dressing, grooming, and toileting.
- *In-Home Aide or Residential Services:* These services are typically provided by an aide who can assist with tasks such as housekeeping, laundry, grocery shopping, and meal preparation, as well as support for managing finances and accessing community resources.
- *Community Living and Support Services:* These services are provided by trained professionals who can assist with a range of iADLs, such as medication management, money management, transportation, and socialization.
- *Supported Employment Services:* These services are designed to help individuals with disabilities find and maintain employment, which can

involve iADLs such as transportation to and from work, meal planning, and time management.

- *Respite care:* This includes short-term care and support for individuals with IDD and their families, to provide temporary relief from caregiving responsibilities.
- *Specialized medical equipment and supplies:* This includes equipment and supplies needed to manage medical conditions or support individuals with disabilities, such as hearing aids, wheelchairs, or communication devices.
- *Home and vehicle modifications:* This includes adaptations to the individual's home or vehicle to make them more accessible and accommodating to an individual's needs.

By using this tiered system, LME/MCOs can allocate resources and supports to individuals based on their specific needs, ensuring that those with the most significant needs receive the highest level of support. Yet, as one advocate pointed out, not everyone has access to these three levels of support: "*Basically... it's there are three levels, one, two, and three, three is the most requires the most intense services. If you cannot afford to pay for an apartment for your adult child or buy them a house, you can't access this level of support. And so that right there that that, that means a whole bunch of people are just, you know, completely prevented from accessing that program.* ***There really is no large-scale program to move people with IDD out of institutions and into the community*** *or to prevent them from going to institutions and provide them services in the community."*

Innovations waiver services are intended to be based on an assessment of the individual's needs, and the level of support is determined by the individual's support plan, yet there has been critique that services offered are *"typically structured around the availability of staff rather than around need."* The NC Innovations Waiver program requires that service providers adhere to certain standards for staffing ratios, qualifications, and training to ensure that services are provided safely and effectively. However, the availability of staff should not limit or restrict the provision of services to participants. In cases where staffing shortages may impact service delivery, service providers are required to take steps to address

the issue and ensure that participants continue to receive the services they need. Nonetheless, stakeholders have raised concerns that the program's funding structure and reimbursement rates make it difficult for service providers to recruit and retain qualified staff. Due to staffing shortages caused by these low wages, some participants have experienced delays or gaps in services, and some have not received the level of support they need to live independently in their communities. Additionally, some providers have been forced to limit the number of participants they serve or close their programs entirely due to staffing shortages. Advocates have raised concerns that the staffing shortages have led to a lack of choice and control for participants over who provides their services, as some participants may have limited options for providers in their area.

Another interviewee mentions the difficulties faced by individuals with IDD who fall through the cracks and may end up homeless or involved in the criminal justice system. The interviewee explains, *"there's people that I know, or that I see on the streets, right, that have an IDD presentation and all those sorts of things, and they're in desperate need of help…. I just think we fail to address entirely right that in our, and how we do our criminal justice, and how we address, you know, issues of a dual diagnosis. I've worked in the criminal justice system for off and on for different parts of my career…. a large part of our jail population is that you know, it is people who are, who have a mental illness and then have self-medicated themselves, and then have gotten into behavioral trouble. And so, now they're sitting in jail, and they can't make bail. Right. And so, they're contributing to the jail overcrowding problem."*

Overall, the interviewees highlight the complexities and challenges faced by individuals with IDD in accessing the support they need, and the need for a more comprehensive approach to addressing these issues. The interviewees' previous disposition of "why don't people just fix it" has changed as a result of their involvement in this space, and they recognize the layers of complexity that add to the difficulties faced by these individuals.

Olmstead, Community-Based Settings Rule, Samantha R., & Other Efforts

The interviewees provided commentary on the various legal mandates that aim to promote community-based living for individuals with disabilities, instead of institutional living. They note though that there is still a significant amount of funding that goes into institutional living, which could be used to support individuals living in the community. They also note that while some push back against deinstitutionalization, the basic moral argument for community living centers on a dignified life with self-agency. A participant explains:

> *"So there's the Olmstead Mandate there, you know, 25 years ago, since that Supreme Court ruling, and we still, we are not really living that dream. There's something called the Home and Community Based Settings Rule, that at the federal level, it was a pretty, pretty good, good, in my opinion, pivot a few years ago, to redefining, for example, a group home a licensed group home, that would be opened next to a big developmental institution that used to be considered community. And now it's not anymore. To get federal funding. You have to, it has to be like in an, in a neighborhood, not in a, you know, just like, glued to a big giant institution. So, the Settings Rule, and Olmstead, and of course, now this Samantha R. thing that's going on, there's just a lot of a lot of push towards community. And there's really good reasons for that. And there are also a lot of parents, apparently, I think, not in the majority, but who are pushing hard to keep those institutions open. And those of us there's, I personally think it's just a difference, essentially, in values of what's important, say as a parent, you know, you look at fear, and then you can look at the dignity of experience and risk. And, you know, me, that's the as a parent, not as executive director here. I embrace the dignity of experience and risk, you know, you can be safer in a in a much more segregated licensed setting, although that's a question too, because I know a lot of people are dying in group homes and you know, but what I see is that adults who are living on their own with some supports as, as mediocre as they may be in some cases, but, you know, with this problem with the pay of workers and works, availability and you know, cruddy housing, sometimes if people can get housing, still, I feel like I've seen lots*

> *of people in my daughter for sure, that are able to grow and learn and have richer lives, because they're able to learn and make mistakes. And you know, two-year-olds make mistakes. And that's how they learn. And adults all through life, we learn if we can make mistakes, but if you're in a protected, controlled environment, where somebody tells you what time breakfast is, and what to eat, and so on, you know, it's pretty hard to evolve as a human being, intellectually, spiritually, and all the different ways that we are lucky enough to be able to grow if we can. "*

Many interview participants expressed disappointment at the recent response by the DHHS to Samantha R. ruling, stating that the notion of "choice" is used to defend the existence of large institutions is offensive and political. One interviewee explains, *"I mean, in terms of some of the lobbyists that are fighting to keep these institutions going, It's really hard. It's really hard to deal with that. And to this most recent response by DHHS, to the Samantha R. ruling, I almost wanted to cry, and I don't get emotional, really, generally listening at a press conference, but when I heard someone say, this is all about choice, because there are these families that want to keep these large institutions open. That's really, really offensive to me, because choice is great, informed choice, It's got to be informed choice. It's not. And I think what we're looking at, in some cases is for political reasons, families are, are trying to be, are, are being like polarized, pitted against each other, you know, but, um, I just, I think that I understand people that choose group homes. I really do."*

Nonetheless, there was hope about the Justice Department's push to create an Olmstead Plan in NC, even though there has been criticism of the plan. The interviewees were also hopeful about the advocacy efforts that are being led by IDD self-advocates who are engaged and skilled in the field. A key informant elaborates:

> *"Well, I think, you know, the Justice Department is it's wonderful that they're pushing us to create an Olmstead Plan. And there was a lot of criticism of the plan. I'm kind of in the weeds with it …. I think the state, I don't know, some of the advocates would really disagree, but I do think the state understands that they have to come up with a good plan. It's not about benevolence or anything, it's about responding to the Justice Department, with*

benchmarks and so forth. So I'm hopeful about that, I think it's been public enough that the advocates are gonna give them, even if the Justice Department doesn't, the advocates are going to really cause a cause of a lot of PR nightmare if, if it doesn't play out the way it's supposed to. And I, I'm, I'm hopeful about some of the advocacy efforts that are going on and the, you know, an incredible group of adult self-advocates that are engaged and skilled and passionate. And they're really leading the charge in, in a number of areas. They're not on boards, just as token, you know, presence there. They're really doing work, I've been I've lived here for so long. I don't know about other states. But there are some remarkable people here, adults with disabilities doing work, I'm hopeful that they will continue."

Some interviewees discussed the Community Living Initiative (CLI) initiated by the Department of Justice (DOJ) in 2012 to support people with mental health issues in transitioning from institutions to community living, to provide them with housing and employment. They note that while the program has not met its goals and still requires further development, it could serve as a model for what the state should be doing in terms of assisting individuals with IDD to move into community settings. In the words of a participant:

"The state knows how to do this because the DOJ forced them to do this for people with mental health issues. In a transition, Transition to Community Living Initiative. I think that was in 2012 that that lawsuit is still being monitored by the DOJ. It hasn't met its, its goals in providing people with mental health issues, getting them out of institutions and providing them with housing and employment. So that's still being monitored, and it's fine that we, we don't get it right, right at the first, first bite of the apple. But so, we need to go back and tinker with the programs and figure out how to make them work. And they aren't doing that with the CLI. It's taken a long time. But, you know, that's what it was. That is what it would take a parallel program like the TCLI initiative for people with IDD to figure out how to how to get them out of institutions,… and then how to provide them with permanent supportive housing. Right? You, you can't just put people in housing and say, you know, our part we have to, we

> *have to provide them the supportive services that make them succeed. And what we know from both TCLI and all kinds of studies is that support supporting people in the community is way cheaper than supporting people in institutions. And it's just bad, right? It's a better outcome for the individual and for society in general."*

Tension Between Highest Level of Services vs. Serving the Greatest Number

LME/MCOs play a significant role in authorizing services and allocating waiver slots, making them crucial to providing services to the IDD community. The LME/MCO follows the Registry of Unmet Needs (RUN) to prioritize the allocation of available resources to those who have waited for the longest.

An interviewee explained that managed care entities aim to provide quality clinical services within a budget to serve more people efficiently. However, they also emphasized that this should not come at the cost of serving people at the highest level they need. MCOs have a utilization management review department that manages budgets effectively while ensuring quality services. They explain:

> *"I do know that most managed care entities… look at clinically serving the person while staying within that IBT budget, as solidly, with the most quality we can… because if you, you know, if you can serve people in the way they need to be served, but in an efficient, cost-effective way, then you can serve more people. So that's a very tricky statement, though, for me to say, because what I don't want families to hear is, oh, you're trying to save money by not serving my member or my person at the highest that they need, because you want to serve somebody else. That is not what I'm saying… so each MCO have a utilization management review department, and that is where requests are sent to. And so, I do think that is a that is one small step that is very important is managing the budgets that we have efficiently and effectively and making sure people get quality of services, and not going you know, trying to stay within those budgets, because by doing that the state can then serve more people."*

Critiques of LME/MCOs

Yet, there was also clear criticism of the MCOs and their actual levels of service throughout many of the interviews. As one interviewee expressed, *"Here, [in North Carolina] it's only getting worse, and despite having all sorts of legal and policy weight behind people being well supported in the community."* It was explained that MCOs are responsible for providing an adequate provider network, but they have failed to do so, and many people are unable to access services as a result. The state shares responsibility for this issue as they contract with MCOs and have not required them to provide adequate services. One interviewee believed that it would require significant leadership to address this problem and provide services to the IDD community effectively. The interviewee notes:

> *"So, the, the MCO has played a huge role. I kind of want to say it's all on DHHS, because the MCOs are creatures of DHHS, right, and, and DHHS contracts with the MCO. So, they can require you know that the MCOs actually do their job and provide the services that are needed in the community. You know, one of the things that's on the MCO is to provide an adequate provider network. And they haven't done that. And the state hasn't required that they do that. And here we are. Lots of people can't get services. That's on the MCOs and the state like they share responsibility for this. And you know, at the end of the day, I think if the state knew how to do this and do it, well, they would have done it right. They, we would do it. I think we don't know how to do it. And it requires it requires significant leadership to say okay, we're gonna figure out how to do it, and we're gonna get it done. And we haven't had that. So yeah, the MCOs are super important, because they're the, they're the keepers of, they're the ones who authorized services. They're the ones who say you can have supported living level two, they're the ones who are awarded waiver, you know, have a certain number of waiver slots that they can hand out. So yeah, there's key to any, any, any program is really going to provide services for us to the IDB community, you have to have the MCOs buy-in."*

Parents and service professionals alike were very frustrated with the lack of support in navigating the systems. One parent explained:

> *"I, the parent, have had to figure out what's going to happen next what this is, and I'm completely unprepared, I don't know, who to call or what resources to seek. And so that's if there's any consistent theme. That's what it is… So, that lack of understanding, which in some ways is understandable, coupled with a system that is far from transparent, and then ultimately we do have limited options, you know, it's not like, Okay, we've got tons of different really good options out there, and all you got to do is plug into it, right. So it's, it's a really, really bad system right now. "*

Frustrations with the Registry of Unmet Needs

Many of the interviewees reflected on their experiences, or those of clients, who are on the Innovations Waiver Registry of Unmet Needs (RUN). There was concern expressed about the inclusiveness of the registry and the decades-long wait times, which can result in frustration and desperation for families. The interviewees noted that the level of quality provided in services is already diminished, and the system could potentially become overwhelmed by an increase in demand for services.

The interviewees also mention the importance of the waiver service Registry of Unmet Needs (RUN) numbers as an indicator of the state of the system. At the time of the interviews, there was an estimated 15,000 people receiving waiver services, with an additional 16,000 waiting for services. An interview participant explains,

> *"… there's concern, we don't want to dumb the system down. And I'd be the first to agree, we don't want to diminish the level of quality that we provide. At the same time, that level of quality is already diminished. Because, you know, yeah, we got 15,000, receiving some kind of service, but you got another 16 Plus, waiting for it. And with the Samantha R ruling, let's throw another 6000 people into that system that don't even show up. And the likelihood is with care management, there may be more people showing up from the woodworking effect. Who knows, we expect there will be because I run into people all the time that family members with IDD, but I've never, they've never connected into the system. So potential is it could expand. And so we just*

> *have to sit down and say no one thinks is going to solve the problem. We need to invest in it."*

The interviewees also commented on the difficulty of finding adequate staffing to cover any existing waiver slots while the Registry of Unmet Needs continues to grow. As one participant explained:

> *"And the canary in the coal mine is the waiver service numbers, those are great indicators. They are by no means the be all do all. But we know that there's about at this point, there's about 15,000 people receiving waiver services, we also know that there's an additional 16,000 and that that number was up 1000, actually 1500 from last year when these numbers were being thrown out there. And I remember saying at that time, we get to December of 2022, we will be at 30,000 total. So, waiver receiving and waiver eligible, yeah, we're actually we may be just past 30,000. So we got an addition and that's with an additional waiver 1,000 waiver slots, which means that 1,000 more people get really high-level services, we got those great marvelous we're still having a hard time finding staffing to cover those slots, but we got it and the waitlist is now which is we took 1000 people off the waitlist, and the waitlist is still 1500 1500 people more than last year when the bill passed."*

Self-Directed Waiver Supports

One possible way to assist with the backlog of individuals needing Innovations Waivers may be in the form of the "Self-Directed Waiver Supports" program. The Self-Directed Waiver Supports in North Carolina is a program that allows individuals with disabilities or elderly individuals to receive long-term support services while maintaining control over the direction of their care. This program is designed to provide individuals with ***greater choice and control*** over the services and supports they receive, as well as more flexibility in how those services are delivered. Under the program, individuals are given a budget for their long-term care services and can ***choose their own service providers***, such as personal care aides or home health agencies. This allows individuals to choose the services and supports that best meet their needs and preferences, rather than being limited to a pre-determined set of services. The program is available to individuals who meet certain eligibility criteria,

including being a Medicaid recipient, having a qualifying disability or being elderly and meeting certain income and asset requirements. As a participant explains:

> *"I think another piece that is underutilized in North Carolina is the self-directed waiver supports. There are some pockets of things and places and organizations that try to support folks to use self-directed funding. But, you know, I think it would be an amazing pair with higher ed programs. It's something that New York State has figured out, and they have a program at Syracuse University, that they uses self-directed waiver funding to basically fund their college experience. And it's fascinating, but their waiver looks different than North Carolina."*

Deciding Whether to Seek or Avoid Public Support

An interviewee also mentioned an "underground movement" among parents who are concerned about what will happen to their adult children with IDD as they transition to community living. They note that there is a lack of coordination among different groups and their ideas about how to address the issue. Some advocate for more public support, while others believe it is better to avoid public support and look for solutions on their own. The interviewee explains:

> *"And so that's, what I'm aware of, particularly in Forsyth County, is that there's just a sort of an I'll call it an underground movement, that's really not the correct term. But there's just a variety of, of folks, and pretty much all the people that I come in contact with, that have the same issue. That, gosh, what are we going to do with our adult child? And so, and that the folks that come in contact with are going to range, right, that there's going to be some folks that have very mild forms of autism are very high functioning on the spectrum. And then they have others that are very, very low functioning and need a whole level of assistance. And so really, when they, when they ask that question of will, what are we going to do? It's really a different question. Right, that some are going to be talking about the level of skilled care, perhaps, that others are not others are going to be talking about, well, gosh, how do I get this individual to handle, you*

know, transportation and balancing a job and balancing a checkbook and doing those sorts of things? Whereas others are, you know, how do I make sure that you know, they're brushing their teeth on a regular basis? Right. So it's a wide variety, but then it seems that every little group has their own sort of idea and concept of this is, this is where we are in. And I think a lot of times, each of those groups kind of feels that they're battling against the ocean all by themselves on it, right? I don't see a whole lot of coordination, right that, oh, here's the one spot to go to. Some folks have really devoted themselves to being advocates on the special needs, or unmet needs waiting list and that they, you know, that's their champion cause and they want the state to do more with that, and so forth. And, you know, I, I support those efforts. There's other folks who say, you know, what, all of that system is far too complicated and is fraught with problems, and it's an uphill battle. So what we need to do is we really need to divorce ourselves from any form of public support, because we really need to be in control as much as we can be. And so let's just look at what we can do on our own without looking at any form of public support."

Others felt that there needs to be even more caregiver advocacy to address the long Registry of Unmet Needs and the slow pace of implementation:

"I think there does need to be more of a movement of families in Forsyth County, specifically, really pushing and saying, I mean, I had a lady been with us 22 years was on the waiver waitlist 22 years and died still with state services. So, I think we all need to get more actively involved in finding out where we are, where we fall, and then keeping up with that. So, when slots come out, we are the first ones to call. Does that make sense? I don't think it'll fix everything. But knowledge is power. People need to know where we are. Maybe even the state putting out a list of the ranking for each person. So they at least know, because if you haven't called them 15 years, you're probably not even going to get a slot because nobody's even thought about you and you haven't called."

One suggestion to address this issue is to allow the Registry of Unmet Need to be maintained not by the LME/MCOs, but by Consumer and Family Advisory Councils (CFACs). CFACs are groups of individuals with disabilities and their families who work together to provide feedback and advice to organizations and agencies that provide services to people with disabilities. CFACs are designed to give people with disabilities and their families a voice in the development and implementation of policies and programs that affect their lives. Likewise, CFACs could ensure that while individuals with IDD are waiting for an Innovations Waiver slot, they would be connected to the best services possible while they are waiting.

Continuum of Housing Types & IDD Housing Needs

Housing was a key focus of the interviews. The lack of housing options ranked at the top of the needs list is equal to the Innovations Waiver Registry of Unmet Needs (RUN) and the lack of support professionals. In the words of the key informant, *"when it comes to housing, I'm involved with a lot of policy work. And, you know, I, when I'm talking to people that don't really know much at all about our world of IDD and what's going on here in North Carolina, I usually say that there is an affordable housing and the DSP or direct support professionals work crisis, these workers that come into people's homes and help them be able to live in regular settings, not licensed group homes, or ICFMRs or developmental centers. Those are the two burning issues in addition to the waitlist."*[66]

Key informants expressed the need for maintaining a continuum of housing options based on needed support and recognizing that not all individuals have the financial means or natural support to live independently. For example, one interviewee said, *"I do think the continuum is there, the whole continuum. And I think we need all of those pieces on the continuum, not just one answer, you know, and not all have money to do it on their own. And not all have help to even do it with some money provided. So, it's just I think we're always going to be coming up with new and different ways of doing things and adding to the continuum. But I don't ever see the continuum going away, or the need your current day program, it's never gonna go away completely, you got to, it's always a need for somebody to come to some type*

[66] See "Barriers to Community Support – Staffing"

*of day support****. So how can we offer many solutions, not just one, you know, because it one size does not fit all. So that's the only thing I encourage us to do not get stuck on just one.”***

HUD Group Homes & Vouchers

HUD Group Homes are residential homes, apartments, or scattered site locations that are funded by the U.S. Department of Housing and Urban Development (HUD) and are specifically designed for individuals with intellectual or developmental disabilities. These homes are typically funded through programs like Section 811 and Section 202 and provide affordable housing for individuals with disabilities. The homes may be operated by non-profit organizations or private entities, and residents typically pay a portion of their income towards rent (usually around 30%). The group homes may provide varying levels of support for residents, ranging from minimal assistance to 24-hour care. These homes aim to provide individuals with disabilities the opportunity to live independently in their communities while receiving the support they need.

The interviewees discussed their organizations’ work in providing low-income housing for people with disabilities and mental health needs through HUD funding. They operate properties such as group homes, apartment complexes, and scattered site locations, which are owned and operated by the organization. These properties are assigned vouchers that are location-specific, meaning that the ***money does not follow the person*** who uses it, but stays with the property. The organization does not provide services for the people living in the properties but works with various organizations to ensure that services and support are provided. The process of building and maintaining properties can be complicated, and there are multiple entities involved in the process, including the state, local managing entities, and HUD. The interviewees noted that there is a lack of understanding about the complexity of the housing process and the various entities involved:

> *“I think if you're a large organization that's already doing HUD, it's fine. I just came from a HUD in Florida, I ran an ALS. And there were HUD properties. There's so much, you need people just to manage the HUD properties and to oversee the paperwork annually, and the upkeep and you know,… no one in their right*

mind, and I've done HUD in North Carolina, would choose to do that probably right now in this environment, because we don't have enough money from the rates to even fund basic accreditation quality assurance training. So, adding another layer that costs more and requires more work. I don't see any provider jumping in and saying let me do that…. And there's properties, also you can't do anything else with them. When you make them HUD properties, they stay that way for I don't know, 30 years, I think it's 30, might be 20. … So, I think it's too many barriers to that. I don't work with anybody who lives in their own apartment. I did hear they had to move out of their apartment into a group home because they couldn't afford it.

So, I know me personally I can't buy my son a home. And with the inflation going up, he would be homeless. He would have to move back in with somebody If this in this environment right now, if he were living on his own, so I don't have answers to that, the rates would have to, with inflation, Medicaid rates would have to adjust, they would have to, you would hope that their Social Security, those who get Social Security Disability would go up too. But that, you know, that's not the case. So I don't know how they're surviving. And when their rent goes from nine to $1,200 a month or something like that.

Or that they would even have the wherewithal to know how to manage that. A lot of these care managers are new and young, too. I don't know that the system even knows how to help support that. Does that make sense? It's hard at 53 to figure out how to win, everything goes up, you know, so I think we're just not equipped to help manage change like that. In the provider world,

The interviewees discussed the financial aspects of balancing support needs with housing type and the HUD payer models. One talked about the negative perception of group homes, as well as the range of other options available such as supportive living, host homes, and Affordable Family Living (AFL) homes, and the financial aspects of congregate living. The key informants also pointed out how housing choices and perceptions of each of these choices have continued to evolve:

> *"It takes five people to pay the bills, minimum, to cover the overhead and a group home. So, I think it's ideal to have three bed, two bed, you know, supportive living settings, but financially a provider, you can't stay in business if you have, unless the rates are crazy, you know. So, North Carolina doesn't really give the rates to support a smaller setting. So that's a financial piece. Group homes have their own culture, you know, and very seldom are they thought of as a positive culture. You know, 50 years ago, 40 years ago, 30 years ago, parents didn't have options, because the only option was group homes, so I think older parents are always quick to say, absolutely, group homes are wonderful. No one gives birth to a child with a disability and says, 'Oh, I can't wait for them to go in a group home,' like no one, no one ever. So, I think the newer parents, the newer families that are coming along the younger generations, the 30, 40-year-old parents are saying no group homes, I mean, I think they're gonna be extinct other than those who have severe medical, severe behavioral, that can't be anywhere else. My, my thought is, because no parent wants that. So, whether it's funded or not, parents just don't want that anymore. So, I don't know how North Carolina is going to fund a three bed or a two bed, I just don't I don't know how you can do it financially unless your rates are $900 a day."*

Another individual elaborated on the changes that have occurred throughout their career:

> *And, you know, 15-20 years ago, where everybody was put in an institution, that was the alternative, that's where our homes came from a family saying we want something else for our child. As we began to transition out of institutions, a six-bed group home or a five-bed group home, those were, that was cutting edge. That was, that was not something that you know, that was new…the problem is, is now six-bed group homes are considered institutional. And it is restrictive. And to a certain degree, they are it depends on how the system was put together.*

A key informant also discussed housing programs such as Section 8, low-income housing, and 811 and 202 vouchers designated for people with disabilities and aging families. HUD 811 and 202 are specific housing programs designated for

people with disabilities and aging families. They are location-specific vouchers that are assigned to a particular property. For example, if a six-bed group home has six vouchers assigned to it, if someone moves in and meets all the criteria, they can take advantage of the voucher. If they leave, the voucher stays at the property and does not follow the person. These vouchers were established many years ago and have strict use agreements that ensure the funding remains with the property. This was initially meant to ensure stability for the funding, but it presents challenges as properties age and communities transition. While it is now possible to move the vouchers, it is a complicated process. In their words:

> *"There are tax credit approaches that are enticements to bring in outside vendors to help build and develop these types of properties. And that's, that assumes that if they're building it, there's going to be some kind of profit margin in there, which, you know, why would they do it otherwise, and so there certainly is that. All of the housing programs we operate are if you're familiar with Section Eight, low-income housing 811 is, and both 811, and 202. They are designated for people with disability and aging families, their specific programs, these, the ones that we're doing are location-specific vouchers. So, for instance, if we have a six-bed group home, we have six vouchers assigned to that group home, if somebody moves in, they take advantage of that voucher, if they meet all the criteria, if they leave the voucher stays at the property. So, the money does not follow the person that follows it stays physically attached to that location, which, you know, when most of these were put together 15, 20, 30 years ago, made a lot of sense. Because you know, we fixed it, we're not going to move these dollars around, we want them to be to be there and be developed. But as properties age, and as communities transition, where we built properties and own properties. And sometimes they were granted and gifted to us by a family that says hey, I want some place for my child to be. Other times they've been you know, we're properties that were developed apartment complexes, for instance with that intention. But as properties age, as things move, the use agreements that were originally placed on top of those, and HUD has some pretty strict use agreements, really lock in what you*

> *can and cannot do with that property. And ensures that that dollar that's assigned to that doesn't go anywhere. It is they are portable. We've, We've established that in the last couple of years that we can move those vouchers, but it's a complicated process."*

Another problem with vouchers that was pointed out, concerned the more portable Housing Choice Vouchers. The voucher program allows eligible households to find their housing, including single-family homes, townhouses, and apartments, as long as it meets the requirements of the program, including safety and quality standards. The program provides a subsidy to the landlord on behalf of the tenant, with the tenant paying 30% of their income toward rent and utilities, and the voucher covering the remaining amount, up to a determined payment standard for the area. The program aims to increase the quality of affordable housing and provide greater choice to families where they live. However, there is a lack of protections for the source of income in North Carolina. A key informant explains, "*the problem with the voucher if you have a tenant-based voucher, you know, we don't have any state and state laws against source of income. So, you don't have to take it if you don't want to … So yeah, so even if you have a voucher, that's, that's tough, and it's tough to just to find affordable housing somewhere, but then even if you can find it, the landlord's you know, the small landlords certainly don't have to take it."* Source of income protection in fair housing refers to the legal requirement that ***landlords, property managers, and other housing providers cannot discriminate*** against tenants or prospective tenants based on their source of income. This means that individuals cannot be denied housing or treated unfairly because they receive government housing assistance, such as housing choice vouchers, Social Security, or other forms of public assistance.

Concerns about Safety & Public Housing

Public housing is a form of government-subsidized housing that is made available to low-income individuals and families. Public housing is owned and managed by a government agency, typically a local housing authority, and is intended to provide affordable housing to those who cannot afford housing in the private market. Public housing units can be apartments, townhouses, or single-family homes, and

the amount of rent paid by tenants is typically based on their income. Interviewees expressed concern about placing individuals with intellectual and developmental disabilities in public housing due to the vulnerability of this population and the potential for exposure to drug use and abuse. They mention that individuals with IDD may not have the necessary skills to navigate such an environment and may be at risk of harm.

> *"This is more of a concern for the population. IDD is a vulnerable population, and you put them in public housing, you're gonna get everything, and I love the inclusivity of it, But you're gonna get the drug users, you're gonna get the abuse. I mean, you know, the population we're talking about, the socio-economic status they're in, they tend to stay in that system, and also not have the best behaviors, oftentimes, and I hate to stereotype the whole public housing, I mean, there's a lot of crime, there's a lot and I would hate to take the individuals with IDD and be alone without 24-hour supervision and put them in that type of environment. I think they're way too vulnerable…. So I would be very concerned about placing individuals with intellectual disability specifically in that type of environment. Could it work? Yes. Has it worked? Yes. Same thing with nursing homes. Like it's just not a not a good fit only because of the vulnerable nature of the disability."*

Some interviewees expressed concern about the safety of individuals with IDD living even in the general community and explained the importance of considering the property's security when choosing a living environment. They recommended installing cameras and doorbells, teaching them to use a peephole, etc. They also suggested educating landlords about the needs of people with IDD. This education was particularly needed for smaller landlords accepting vouchers. In their words:

> *"And the other one that I worry about the most is making sure that the property itself, is a safe place for the IDD client. Um, because, you know, my main concern is always safety. You know, making sure they're not moving into a place, if you know, you have a place that has dangers, that would be even someone taking advantage of them, you know, you have an environment of that nature. I would, you know, make sure that I'm not just thinking about the money you need to think about, okay, I'm*

putting the IDD person here, I want to make sure like you said, cameras do, should we maybe put cameras in in common areas, you know, do they need a different kind of doorbell that may ring that, you know, they can come accustomed to that, okay, someone's ringing my doorbell. If there's a peephole, you know, teaching them how to use the peephole, things of that nature, as what if we were rolling out something where we were trying to help landlords understand and want to participate. I've had them, let's call and say, Hey, I'd like to, how can I get the HUD because I know it's about the HUD, but how can I get the HUD and I tell them a call hook, but I also tell them, Well, you need to also learn about [the needs] of the people. Before you just call HUD and think, you know, they're gonna come with a HUD subsidy. So that's good for you. But you also need to think about them, you know, are, are the will they match with the people that are actually living in your development, you know, that specific housing unit, that type of stuff is what I worry about the most when it comes to them."

Creative Solutions to Housing Needs

Others have set out to address the problem of affordable housing in North Carolina directly. For example, one parent explained how they managed to purchase and develop 18 quadruplexes in downtown Durham with the help of a developer and a few starter families. They converted one of the quadruplexes into a big accessible apartment for people with disabilities and two market-rate rental apartments. By doing this, they received a good deal from the city and county of Durham that won't increase their property taxes much, and they have a formula in their bylaws that prevents them from making a huge profit when selling the properties. The parent explains:

"Affordable housing, of course, as you know, is like a huge problem all over North Carolina, with people with IDD, the rural areas are really a problem because there just isn't as much housing, and in the urban areas, of course, there's all this gentrification here and there and everywhere. My daughter lives in this really cool setup, but we were just the timing was just right. But a few families, five of us got a developer that would

> *purchase up these 18 quadruplexes that were all boarded up you know, with graffiti and everything that hadn't been used for a really long time. But in pretty good shape, brick, buildings in downtown Durham, and the developer said I'll develop them at cost and with an architect, if you find a few starter families to purchase a few of them, that will get us going. And that's what happened and, in our particular place, we converted the fourplex into two market rate rent apartments up top, and one big accessible apartment in the bottom level so that my daughter and her housemate who both have disabilities could rent at like subsidized rent and the upstairs two would be market rate to allow our mortgage to be a wash and but the good deal we got was the County of Durham because of the way we're doing what we're doing our have agreed not to increase our property taxes much, oh because the other thing is what we're we've we have in our bylaws that we want no flipping of course but also know when you sell you can't you can't appreciate at what the local region has appreciated. You can only there's like a formula but basically, we're not going to make a killing off these properties and so they're not going to keep raising our property tax."*

However, as one parent points out, the model of parents affording to be able to buy an apartment or home doesn't work for most: *"So, I know me personally I can't buy my son a home. And with the inflation going up, he would be homeless. He would have to move back in with somebody If this in this environment right now if he were living on his own."*

Other creative solutions were proposed. Interviewees discussed the challenges of creating inclusive housing for individuals with intellectual and developmental disabilities in an urban setting. A model for such housing is described, which involves developing a complex with IDD apartments subsidized by a nonprofit and renting the remaining units at the market rate. ***This is the approach that has been proposed by the Piedmont Triad Regional Council in its planning grant.*** A participant explains:

> *"…there's a model that nobody yet has been able to figure out how to pull it off. And probably and I can pretty well tell you why, why it is not happening. That said, if you developed, for instance,*

> *a 100-unit apartment complex, in order to be consistent with CMS, inclusive living standards, you don't group, you don't take all 100 and give them to somebody with IDD, you take 12 to 20, give or take. So, when 1/5 and you scatter them throughout, these are scattered, scattered site locations, which we have some scattered site opportunities out there that we own, but you scattered them throughout. And then you go back and you rent the entire complex at market rate. So, everybody that moves in is at market rate. And then you subsidize those 20 IDD apartments because this is now part of your inclusive living arrangement…. And the key to this is because you have to set it up as a nonprofit."*

However, the high upfront cost of construction and difficulty in finding suitable property makes it difficult to implement. An interviewee explains, *"the up-front cash to do it would be you know, you got to have just to get the construction loans, you got to have a couple of three or $4 million sitting loose, and not many nonprofits have three or $4 million, just to turn the first bucket of dirt. Once you get that going, you know, a unit facility like that's going to be $25, $30 $35 million completed. But you put the money upfront, the downpayment, in effect, and then the banks come in with the financing, and then at all, I'll just have to pencil in. But like I said, not many nonprofits have that kind of dollars, particularly in the world that we live in."*

Other models, including a land trust model with a mix of owners and renters, are discussed. The importance of diversity and customization in creating inclusive living arrangements was highlighted. The interviewees also emphasized the need for support that is more individualized and tailored to the needs of the residents, rather than a one-size-fits-all approach.

Fair Housing Protections

Participants also talked about Fair Housing protection for individuals with disabilities. In particular, there is a lack of awareness by both tenants and landlords about the Fair Housing Act and what it requires of landlords. They have encountered situations where tenants with disabilities or mental health issues have been evicted for behavior that was unable to control. As an interviewee explains:

> *"I would say there's a tremendous amount of ignorance both on the tenant's part and on the landlord's part there even is such a thing as a Fair Housing Act, and what it requires of a landlord. And I think a lot of times we'll get a call from a tenant who's being evicted, and maybe they have an IDD or maybe they have a mental health issue, or maybe both. And they're being evicted for behavior, or they're being evicted for something that they did, and maybe they've done it more than once, but maybe it was just the first time. And you got a lawyer saying 'yeah, you know, the other tenants have a right to quiet enjoyment,'… And, you know, in talking to the tenant, you find out oh, no, they were off their medication, or there was something going on with them, they didn't understand. … But it is a tremendous amount of ignorance out there about the Fair Housing Act. Like I said that it is even a thing is a shock to a lot of landlords, not the big institutional landlords because they know, but definitely the smaller ones. They have no idea and the tenants, the tenants, for the most part, just don't have any idea."*

The overall message was that there is a need for a range of options, as one size does not fit all, and the ideal solution may require multiple approaches. There was likewise agreement that ***there should be some sort of housing specifically geared towards the population of individuals with intellectual and developmental disabilities.*** The interviewees felt as if this would be a good business model for landlords or developers as individuals with IDD may have support from representative payees and innovation services, making them a secure investment as renters.

Housing Amenities for IDD Residents

Universal design is the design of products, environments, and systems that are usable by all people, to the greatest extent possible, without the need for adaptation or specialized design. It is an approach to design that considers the needs of people with diverse abilities and disabilities and aims to create inclusive and accessible environments that can be used by everyone, regardless of their age, size, ability, or disability. Examples of universal design include curb cuts, automatic doors, adjustable height work surfaces, and text-to-speech software. At a

minimum, the interviewees discussed the need for inclusive housing which is physically accessible to individuals with disabilities:

> *"Well, minimally, you know, handicap accessible for a huge chunk of our population. And even though that sounds simple, it's not, you know, it's you know, sometimes doors have to be widened, there's most a lot of times ramps, we need a lot of people think ramps, and that is wonderful. That ramp gets you in a house that often needs doors to be wide or bathrooms are not accessible. So, I do I have toured apartments and condominiums and stuff with some of our members, previously, not as a supervisor, and the ramp takes us in, but then we're inside and we're like, oh, you know, this person can't get their wheelchair through the bathroom door. Or it's a high-standing tub or you know, so handicap accessibility is the is the first."*

The interviewees also suggest that technology can be utilized to create a situation where individuals can receive help when needed without someone being present all the time. They explain how Simply Homes, an assistive technology provider, offers technology such as sensors, timers, voice-activated locks, camera systems, medication reminders, bed shakers, and heated bathroom floors to assist individuals with disabilities. The interviewee explains:

> *"Innovations has assistive technology and equipment and supplies. So it is within our program, it is a very important role…. [Simply Homes] are probably the biggest provider of assistive technology in the way that you're describing it for our catchment area. So, for instance … is quadriplegic, and has cerebral palsy, and his mother passed away, he wants to remain in the home. So, she was his natural support. And so, we just had Simply Homes go out about a month ago and they did an assessment and so his stove will have a certain sensor and timer on it. He has a voice-activated lock so he can come in and out of his front door. He has, you know, the Ring bell alarms, that camera system in his, in his bedroom so he can see who's coming and going. He has trying to think of all the bells and whistles, he has reminders for his medications."*

The interviewees also explored the possibility of creating a scattered site model where staff is not present all the time, but a central unit would be equipped with technology that can alert them when someone needs help. The key informants believe that reducing personnel hours and using the savings to provide housing subsidies could create stability for individuals and families in need of support. The speaker thinks that this idea could be feasible, especially for scattered-site models with multiple units. Says one participant:

> *"And, but, you know, how do you create kind of like a scattered site model where, let's say, you've got an apartment complex, and there are 10 units scattered throughout the apartment complex? And then there's a central unit, where it's like a staff person is, not cameras, but like, has some technology that helps to alert them or the person can alert them if they need something, to where they can be there right away. But they're not like I said, they're not kind of in that person's, in that person's space all the time. Because that's the, like, you know, second to the housing, the staffing is the majority cost, like that's the other big driver of expense, you know, really is this is the personnel hours and you know, understandably, but that's the other big driver. So, you know, if we were able to reduce kind of the costs on the personnel side, and maybe free up some of that for housing subsidy, that might open up some other options."*

Barriers to Community Support – Staffing

One of the major issues facing the Innovations Waiver program in North Carolina is the lack of staffing. The program requires a significant number of trained and experienced professionals, such as nurses, therapists, and direct support professionals, to deliver services to individuals with disabilities. However, participants' interviews spoke about the lack of qualified staff members to meet the growing demand for services. One participant explained:

> *"So staffing is very challenging, because now, then I think, you know, the jobs, in general, are getting very competitive in jobs, not to, you know, not to say that any job is easier than another. But if you are looking at caring for somebody, or providing*

habilitative services to somebody that's going to require a lot of physicality. Or you could go be a manager at Abercrombie. You know, so it's not to minimize what that manager is going through, but or not even a manager just as a clerk, you know, they're both getting paid 15 $16 an hour. I think it goes back to all the health professions, teachers, etc. I mean, I think that's something that's, that needs to look at. But yes, that is an issue that, that, unfortunately, provider agencies sometimes get, you know, a bad rap, so to speak, because they people will say, why don't you pay your staff more, I've worked, I've moved up the food chain through a provider agency, and it's very tight, when you look at, you're also trying to just pay through your, you know, provide insurance and benefits and sick time and vacation time. And, you know, you've got to bring that whole package to get the employee, and the funding is just not high enough."

The shortage of staff has resulted in several problems. First, as we have discussed, there are long waiting times for services, which means that individuals with disabilities may not receive the support they need promptly. Second, even when individuals can access services, they may not receive the level of support they require, as staff members are often stretched thin and unable to provide comprehensive care. For example, one participant said, *"there are plenty of people out there that have the innovations waiver now that there's approved for services in the home or the community, but they can't get it because there's no staff, or there's no provider."* Finally, the lack of staffing can lead to staff burnout and turnover, which further exacerbates the staffing shortage.

The Innovations Waiver program has taken steps to address the staffing shortage, such as increasing funding for staff salaries and benefits and investing in staff training and development. However, these efforts have yet to fully address the problem, and more needs to be done to ensure that individuals with disabilities in North Carolina have access to the support and services they need.

Staffing is the biggest challenge across all services and has resulted in the delay or inability to start services for many who receive Medicaid-funded support. The main issue is that funding and staffing are linked, as the waiver services provided by these agencies are based on rate scales set by the state. This trickles down to the

agencies' ability to pay their employees and still offer benefits, which is compounded by the overhead costs of maintaining brick and mortar buildings. As a result, staffing is challenging and competitive, especially for positions requiring physicality and care for others.

The key informants acknowledge that this is a crisis resulting from the State itself, as the pay for these services has not been made adequate to attract reliable staff. The author highlights that the lack of staff is the biggest barrier to providing residential and independent services and the crisis has been exacerbated by COVID-19, with people not showing up and new generations being less responsible. As one said, *"unfortunately, funding and staffing are linked, you know, because the, the waiver services are based on rate scales that are set by the state. And so that trickles down to even though it's not partners, but what our provider agencies who are employing these staff can pay, and then still offer things like benefits, you know, and then most of those companies still have brick and mortar buildings, you know, so they're not all virtual, and so they have a lot of overhead."*

The interviewees noted that they have tried everything to attract and retain staff, including increasing pay rates, and hiring a team of recruiters, but the rates still do not match the cost of hiring and maintaining staff, especially in North Carolina where the minimum rate is $15 an hour but it costs $23 just to hire a staff member. Others suggest that there may be ways to expand the labor pool by recruiting high school students:

> *"One way is to ease the rules on who we can employ and who we can employ, for instance, and they're actually already working on it. We get somebody out of high school, technically, we can hire you with a high school diploma, or a GED. And you got to have that. And currently, the rule says you have to be 18 years old, what happens to that kid that comes out of high school, he's 17 years old, and he or she wants to come to work in this business. I can't employ you till you turn 18 I'm sorry. There are some apprenticeship programs, we're engaged in one of them right now that we're trying to kick off. That takes not just kids out of high school, but it takes kids who are in high school and maybe even as early as junior high and engages them in exposing them*

> *not just to long-term services and supports that I would be hiring, but health care if you're talking healthcare workers in hospitals and clinics, people that work the IDD world and mental health world, direct support staff, adult care home, and childcare."*

Another suggestion has been to make Direct Support Professionals (DSPs) full-time, salaried positions as low hourly wages and limited or no benefits are contributing problems. Despite the important role that DSPs play in the lives of people with disabilities, they are often paid very low hourly wages and may not receive benefits such as health insurance or paid time off. Contributing to the issue is the limited funding available for disability services in general, but also the fragmented and decentralized nature of the disability services system, which can make it difficult to coordinate and standardize compensation and benefits across different providers. For DSPs, low wages and limited benefits can make it difficult to attract and retain qualified workers, leading to high turnover rates and staffing shortages. This, in turn, can lead to reduced quality of care and support for individuals with disabilities, as well as increased stress and burnout for the DSPs who remain on the job.

Another suggestion related to DSPs is for LME/MCOs to compensate agencies for non-service delivery tasks such as attracting, interviewing, conducting background checks, and training DSPs with first aid, all of which currently come out of the agencies' margins. If DHHS and the LME/MCOs could absorb part of the DSP marketing expense (especially during high turnover periods) it would also reduce agency expenses. Job openings and job fairs could be at the state's expense. Background checks could be universal and paid for by the state. Training could be in a statewide Learning Management System (LMS) and portable with the DSP to work across agencies. The structure of the system needs to change.

Falling Through The Cracks

Many of the key informants talked about the individuals they knew who were 'falling through the cracks' in the systems of care for those with IDD. They talked about how the social safety net failed people, including those who are not Medicaid eligible, non-citizens, and those who are not receiving the support they need due to a lack of resources or responsiveness by agencies. Participants shared many

anecdotes about people who needed but didn't receive services. One particular story was that of a person on the autism spectrum who also was schizophrenic, and had been living in a shed due to his estrangement from his family. The interviewee shared:

> *I met an adult who the church that we were members of at that time, was helping, and really what it came about is that they said, gosh, we need to get some things for [the individual] this year. And as I was kind of overhearing eavesdropping on this conversation to church, I said, who is Robe[the individual]? And they said, Oh, [the individual] is a fella who grew up in the church, and now he lives in a shed out behind [a church member's] house, right? And so, again, me being me, I thought, well, that doesn't sound good. What we need to do is we need to call DSS. DSS needs to get involved. I know people at DSS, I can make a phone call, right? ….His grandparents died when he was 40, maybe 30 And he lived in the family home. The power got cut off. Electricity is cut off. And he basically lives in the family home, you know, getting water in a jug from the neighbor, raising chickens, and living off the plot of land that is like a half-acre…I mean, basically living a 19th-century lifestyle …. family comes back into his life, and realizes he has this asset. It's not much, but he has this home. And so they swindled him out of the home, and then he becomes homeless. And the story for [the individual] that's positive is he's not addicted to any alcohol or drugs. He's really not had a serious interaction, or negative interaction with the criminal justice system. But obviously, that's [the individual] is exceptional in that, right, that we've got a whole host of people who are in society, they're there."*

Community Survey Findings

The in-depth interviews with the dozen community stakeholders provide a good picture of the breadth of community concerns and issues but do not tell us how broad and pervasive these issues may be. To supplement the rich qualitative data and secondary sources, we also designed an online survey. The survey was sent to individuals with IDD, families/caretakers of individuals with IDD, as well as staff of organizations serving individuals with IDD. Survey solicitations were published on social media, in email listservs, and through social service agencies in the community. The survey opened on January 9th, 2023, and closed on February 14th, 2023. A total of 42 surveys were fully completed.

Demographics of Individuals living With Intellectual Or Developmental Disabilities

Of the 42 respondents to the survey, nearly two-thirds (65.9%) indicated that they are a caretaker or guardian of an individual living with an intellectual or developmental disability. Another 14.6% were professional that provides services related to individuals living with an intellectual or developmental disability. And 9.8% identified as an individual living with an intellectual or developmental disability. Over half (56%) of respondents said that they, or the individual living with IDD, were male. The median age was between 25-34 years old. A majority (76.0%) of respondents indicated that they (or the individual living with an intellectual or developmental disability) are white, while 8.0% were black or African American.

TABLE 10 – RESPONDENT'S ROLE

Role	Responses		Percent of Cases
	N	%	
I am an individual living with an intellectual or developmental disability	4	9.5%	9.8%
I am a caretaker or guardian of an individual living with an intellectual or developmental disability	27	64.3%	65.9%
I am a professional that provides services related to individuals living with an intellectual or developmental disability	6	14.3%	14.6%
I am an advocate for rights for individuals living with IDD (eg I serve on an IDD Consumer & Family Advisory Council, etc.)	3	7.1%	7.3%
other (please explain)	2	4.8%	4.9%
Total	42	100.0%	102.4%

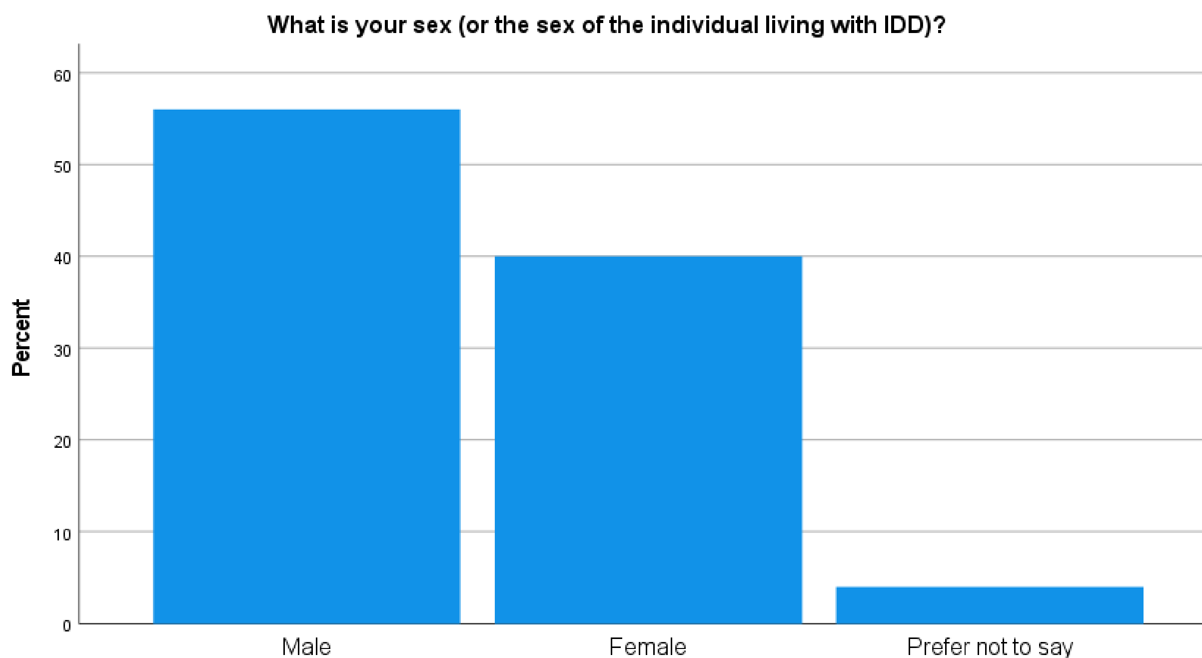


FIGURE 10 – SEX OF INDIVIDUAL WITH IDD

TABLE 11– AGE OF INDIVIDUALS WITH IDD

	Frequency	Percent	Valid Percent	Cumulative Percent
Under 18	3	7.3	12.0	12.0
18 - 24	5	12.2	20.0	32.0
25 - 34	6	14.6	24.0	56.0
35 - 44	6	14.6	24.0	80.0
45 - 54	3	7.3	12.0	92.0
55 - 64	2	4.9	8.0	100.0
Total	25	61.0	100.0	
Missing System	16	39.0		
Total	41	100.0		

Disability Status

Nearly all of the respondents indicated that they, or the person they cared for, had multiple categories of disability. Most frequent was ‘independent living difficulty’ which included 83.3% of cases, closely followed by the cognitive difficulty which included 79.2% of cases. A third of cases indicated ambulatory and self-care difficulties while a quarter had vision difficulties and 16.7% had hearing difficulties.

Disability	Responses		Percent of Cases
	N	Percent	
Hearing difficulty: deaf or having serious difficulty hearing	4	5.2%	16.7%
Vision difficulty: blind or having serious difficulty seeing, even when wearing glasses	6	7.8%	25.0%
Cognitive difficulty: Because of a physical, mental, or emotional problem, having difficulty remembering, concentrating, or making decisions	19	24.7%	79.2%
Ambulatory difficulty: Having serious difficulty walking or climbing stairs	8	10.4%	33.3%
Self-care difficulty: Having difficulty bathing, bath rooming, or dressing	8	10.4%	33.3%
Independent living difficulty: Because of a physical, mental, or emotional problem, having difficulty doing errands alone such as visiting a doctor's office or shopping	20	26.0%	83.3%
Employment Disability: Because of a physical, mental, or emotional condition having difficulty working at a job or business	12	15.6%	50.0%
Total	77	100.0%	320.8%

FIGURE 11 – DISABILITY STATUS OF INDIVIDUALS WITH IDD

Living Situation

Most (60%) were living in a home with family or guardians, while 11.4% lived alone in a house or apartment, and 8.6% were living in an adult care home or group home setting. About half (54.3%) of the respondents lived in a home with 2-3 individuals. About 7.3% received some form of a voucher or rental assistance and 4.9% lived in public housing.

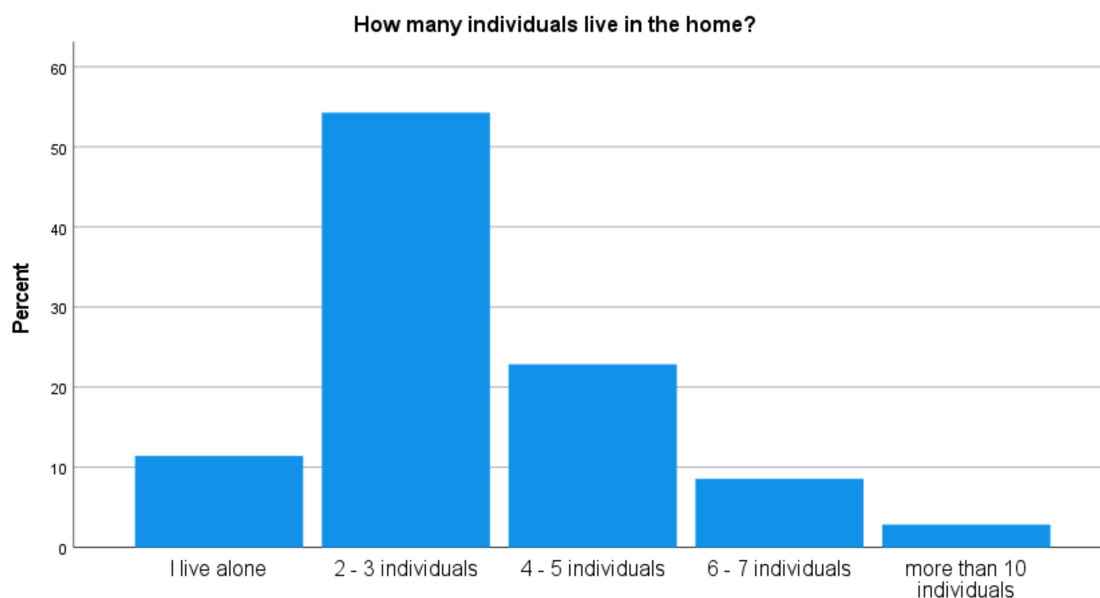


FIGURE 12 – NUMBER OF RESIDENTS IN THE HOME

Income Sources & Earnings

Nearly a third of respondents (30.4%) indicated that the combined gross (before tax) income of all members of the household was under $30,000 annually. Two-fifths (44.7%) earned between $40,000 and $80,000 annually, while 17.3% earned between $80,000 and $150,000. Finally, 17.4% earned over $150,000 annually. About three-fifths (60.0%) of the individuals living with IDD received supplemental social security income. Likewise, 40.0% of the respondents said that the individual living with IDD earned income from working. Only 2 individuals (4.9% of respondents) received support from the wills and trusts of parents or other family assets.

TABLE 12 – GROSS HOUSEHOLD INCOME

Annual Income	Frequency	Percent	Valid Percent	Cumulative Percent
Less than $10,000	1	2.0	4.3	4.3
$10,000 - $19,999	4	7.8	17.4	21.7
$20,000 - $29,999	2	3.9	8.7	30.4
$40,000 - $49,999	3	5.9	13.0	43.5
$60,000 - $69,999	1	2.0	4.3	47.8
$70,000 - $79,999	4	7.8	17.4	65.2
$80,000 - $89,999	1	2.0	4.3	69.6
$100,000 - $149,999	3	5.9	13.0	82.6
More than $150,000	4	7.8	17.4	100.0
Total	23	45.1	100.0	
System Missing	28	54.9		
Total	51	100.0		

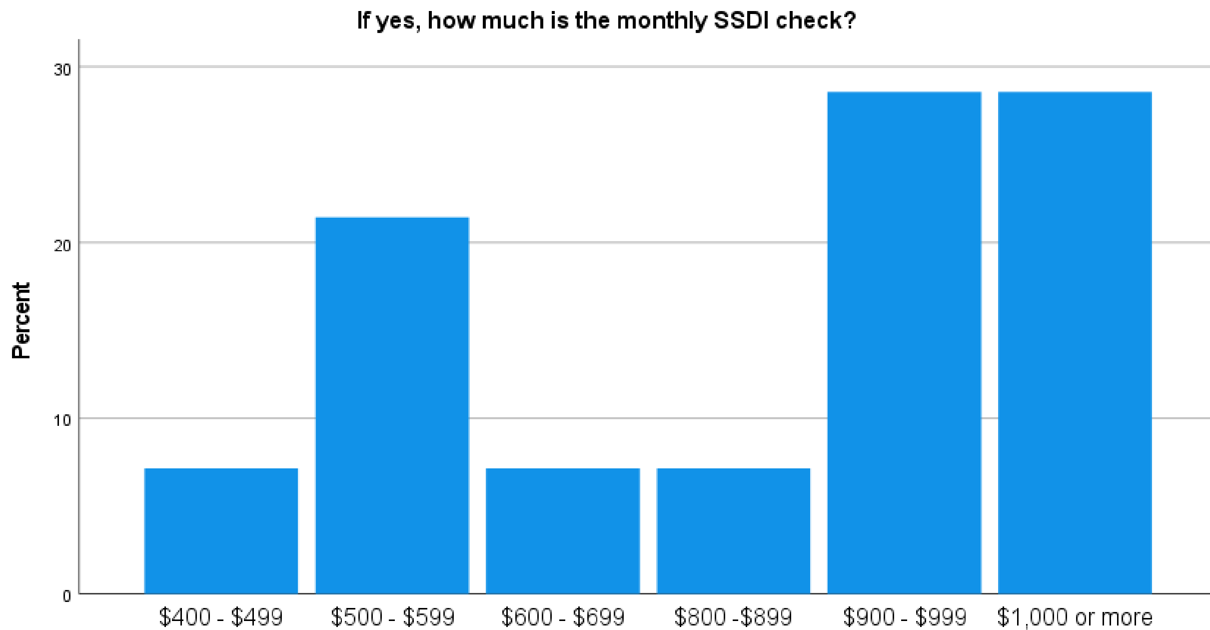


FIGURE 13 – SSDI MONTHLY INCOME

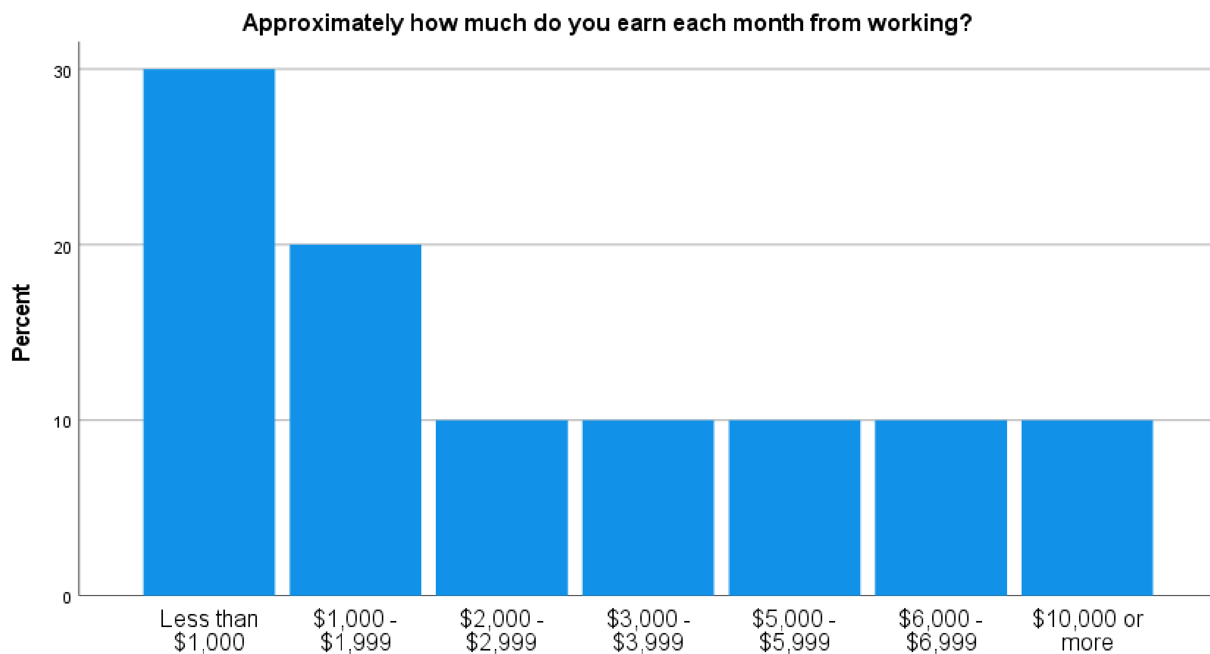


FIGURE 14 – MONTHLY INCOME FROM WORKING

Health Insurance & Waiver Status

Most respondents (61.5%) were covered by NC Medicaid while equal proportions had Medicare (26.9%) and 26.9% had employer-based health insurance. Very few had military/VA health insurance or non-group private health insurance. Nearly two-fifths (37.0%) said they are on the waiting list for N.C. Innovations Waiver Services

TABLE 13 – HEALTH INSURANCE COVERAGE

Insurance	Responses		Percent of Cases
	N	Percent	
NC Medicaid	16	43.20%	61.50%
Medicare	7	18.90%	26.90%
Employer-based health insurance	7	18.90%	26.90%
Military health insurance	1	2.70%	3.80%
Non-group private health insurance	1	2.70%	3.80%
Other	5	13.50%	19.20%
Total	37	100.00%	142.30%

Home & Community-based services

The largest categories of services currently being received were case management (42.9% receive this service); followed by Community integration (38.1%); and Home Medical Equipment (33.3%). More than half, 55.6% indicated there are services they need but currently don't receive. The greatest unmet needs were for case management (35.7% need this service); then Community integration and Respite services (28.6% need these); and finally Personal assistance, Assistive technologies, Training/ educational programs, and Vocational day program all with 21.40% each.

About one-fifth of respondents said that the individual with IDD received up to 40 hours of assistance from Personal Care Assistants (PCAs). PCAs are individuals who provide direct support and assistance with activities of daily living (ADLs) and instrumental activities of daily living (iADLs) to individuals with disabilities. The support they provide can include assistance with tasks such as bathing, dressing, grooming, toileting, and medication management, as well as assistance with household tasks such as cooking, cleaning, and shopping. Nearly two-thirds of respondents (67.7%) said they received no visits from PCAs and 3.2% received 40-80 hours and 9.7% received 80-120 hours of assistance.

TABLE 14 -SERVICES RECEIVED VS. NEEDED

Services	Receive			Need		
	Responses		Percent of Cases	Responses		Percent of Cases
	N	Percent		N	Percent	
Adult day health care	3	2.70%	14.30%	1	2.30%	7.10%
Assistive technologies	5	4.40%	23.80%	3	7.00%	21.40%
Case management	9	8.00%	42.90%	5	11.60%	35.70%
Cleaning or chore services	3	2.70%	14.30%	1	2.30%	7.10%
Community integration	8	7.10%	38.10%	4	9.30%	28.60%
Community Transition	1	0.90%	4.80%	0	0.00%	0.00%
Consumer-directed services	4	3.50%	19.00%	2	4.70%	14.30%
Coordinated caregiving	6	5.30%	28.60%	0	0.00%	0.00%
Financial management	3	2.70%	14.30%	1	2.30%	7.10%
Home Medical Equipment	7	6.20%	33.30%	1	2.30%	7.10%
Home modifications	5	4.40%	23.80%	0	0.00%	0.00%
In-home aide	3	2.70%	14.30%	2	4.70%	14.30%
Meal preparation and delivery	3	2.70%	14.30%	1	2.30%	7.10%
Medical Transportation	3	2.70%	14.30%	1	2.30%	7.10%
Non-medical transportation	6	5.30%	28.60%	1	2.30%	7.10%
Nutritional services	3	2.70%	14.30%	0	0.00%	0.00%
Personal assistance	6	5.30%	28.60%	3	7.00%	21.40%
Personal Care	6	5.30%	28.60%	1	2.30%	7.10%
Personal Emergency Response Services	2	1.80%	9.50%	0	0.00%	0.00%
Pest Eradication	1	0.90%	4.80%	0	0.00%	0.00%
Respite services	4	3.50%	19.00%	4	9.30%	28.60%
Specialized medical supplies	3	2.70%	14.30%	0	0.00%	0.00%
Training/ educational programs	4	3.50%	19.00%	3	7.00%	21.40%
Vocational day program	2	1.80%	9.50%	3	7.00%	21.40%
Wrap-around services	2	1.80%	9.50%	1	2.30%	7.10%
Other (please specify)	11	9.70%	52.40%	5	11.60%	35.70%
	113	100.00%	538.10%	43	100.00%	307.10%

Housing Issues

Only a few individuals (5.0%) indicated that they had any severe housing issues currently. Severe housing issues include:

- 2.4% Crowded - there is not enough space for everyone living in my home;
- 4.9% Inaccessible - the home is not designed or modified to suit my disabilities;
- 4.9% Unaffordable - the cost of housing is too high; and
- 2.4% Unhealthy - the conditions of the home are impacting the health or well-being of residents

Preferred Housing Amenities

Participants were also asked what sort of comforts, amenities, or features they would like to see in their future housing. Top of the list was Wi-Fi Included (72%), security systems and cameras (68%), emergency call buttons (56%), and washers and dryers in units (56%).

TABLE 15 – PREFERRED HOUSING AMENITIES

	Responses		Percent of Cases
	N	Percent	Percent
Wi-Fi Included	18	6.50%	72.00%
Security Systems & Cameras	17	6.10%	68.00%
Emergency Call Button	14	5.00%	56.00%
Washer And Dryers In All Units	14	5.00%	56.00%
On-Site Cafeteria Or Restaurant	12	4.30%	48.00%
Utilities Included	12	4.30%	48.00%
Community Clubhouse Or Community Lounge	11	4.00%	44.00%
Multi-Purpose Game Room	11	4.00%	44.00%
Shower Grab Bars, Bench	11	4.00%	44.00%
Accessible Fitness Center	10	3.60%	40.00%
One-Level Stepless Entry	10	3.60%	40.00%
Security Access	10	3.60%	40.00%
USB Outlets	10	3.60%	40.00%
Easy-Access Drawers, Cabinets, And Storage Areas	9	3.20%	36.00%
Multigenerational Community	9	3.20%	36.00%
Accessible Pool	8	2.90%	32.00%
Indoor Mailboxes	8	2.90%	32.00%
Accessible Trails	7	2.50%	28.00%
Community Garden	7	2.50%	28.00%
Storage	7	2.50%	28.00%
Lever-Style Handles On Doors And Faucets	6	2.20%	24.00%
Shared-Use Kitchen	6	2.20%	24.00%
Co-Working Spaces	5	1.80%	20.00%
Movie Theater	5	1.80%	20.00%
Sensory Room	5	1.80%	20.00%
Wheelchair Accessibility	5	1.80%	20.00%
"Smart" Lighting (Voice Or App Controls)	4	1.40%	16.00%
Accessible Playground	4	1.40%	16.00%
Height-Adjustable Counters	4	1.40%	16.00%
Physical Therapy	4	1.40%	16.00%
Wide Doorways	4	1.40%	16.00%
Nest Thermostat	3	1.10%	12.00%
Assistive Dev	2	0.70%	8.00%
Classrooms	2	0.70%	8.00%
Dog Park	2	0.70%	8.00%
White Noise Machines	2	0.70%	8.00%
	278	100.00%	1112.00%

Housing Desires & Plans

The community survey on housing plans reveals that there is a wide range of preferences and concerns among respondents. Some respondents prefer their children to live with them, while others advocate for high-quality group homes. Others want their children to live independently with support and services, while some are unsure or don't have finalized plans. Respondents emphasized the importance of accessibility, safety, security, support, transportation, and community living arrangements that offer private rooms, medication administration, and adequate space. There were also concerns about the lack of semi-independent housing options, the rising cost of renting, and the need for racially diverse resident populations. Participants were asked to write-in responses to the community survey regarding their housing desires. Among the responses were:

- Safe and affordable housing, without rent assistance;
- Positive experiences at a group home facility that provides quality care, transportation, hot meals, and meaningful activities for TBI survivors;
- Improvements such as better insulation, no rodents or water problems, and updated accessible bathrooms;
- The desire for 62+ apartments and more housing options, including semi-independent situations and independent living with necessary support;
- Need for paid support to show up on schedule, and pay raises for staff who do a tremendous job;
- Smaller homes for residents with complex medical needs to provide social and medical support on one campus; and
- The desire for loved ones to live independently but close to family or in a tiny home on their property.

Summary

Community Living Efforts

In this report, we discussed the barriers that individuals with intellectual and developmental disabilities (IDD) face in leading an independent life, including a lack of affordable housing, limited access to support services, and limited public financial resources. These barriers can impact their ability to live and participate in their communities, resulting in a lower quality of life.

We also highlight several important pieces of legislation in the United States that provide for the rights and needs of people with IDD: the Americans with Disabilities Act (ADA), the Individuals with Disabilities Education Act (IDEA), and the Fair Housing Act. The 1968 Fair Housing Act protects people with disabilities from discrimination in housing and requires housing providers to make reasonable accommodations and modifications. The Fair Housing Act requires multifamily housing built after 1991 to meet accessible design requirements. Unfortunately, violations of the Fair Housing Act are still common, with disability-based discrimination making up more than half of all complaints filed in 2022. The 1990 Americans with Disabilities Act (ADA) prohibits discrimination based on disability, requiring employers, state and local governments, and businesses to provide equal opportunities to people with disabilities. The ADA's Standards for Accessible Design guide the construction of accessible facilities. The Individuals with Disabilities Education Act (IDEA), passed by Congress in 1975 and reauthorized in 2004, provides access to public education for children with disabilities. The act mandates that states ensure students with disabilities receive a Free Appropriate Public Education (FAPE) in the least restrictive environment (LRE). An Individualized Education Program (IEP) is developed for each student with a disability, outlining the student's special education program.

We also reviewed several of the cases that have dictated compliance with ADA and other laws and regulations and helped to shape efforts to provide housing and services in more inclusive settings. First, The North Carolina Department of Health and Human Services (NC DHHS) and the US Department of Justice (DOJ) settled a lawsuit that claimed that the state violated the Americans with Disabilities Act

(ADA) and the *Olmstead v. L.C. decision*. The settlement requires the state to provide community-based services to individuals with disabilities following the ADA and the Olmstead decision. The settlement requires the state to transition individuals with disabilities from institutional settings to community-based living arrangements.

Most relevant to our study is the case of *Samantha R., et al. v. North Carolina* a lawsuit filed in 2017 by Disability Rights North Carolina (DRNC) on behalf of individuals with intellectual and developmental disabilities (IDD) who were not receiving appropriate community-based services and supports in North Carolina. The lawsuit alleged that the state was violating the Americans with Disabilities Act (ADA) and the Rehabilitation Act by failing to provide adequate community-based services and support for individuals with IDD and by unnecessarily institutionalizing them. In 2019, U.S. District Court Judge David L. Baddour found that North Carolina had violated the ADA and Rehabilitation Act and ordered the state to develop a comprehensive plan to provide community-based services and support for individuals with IDD. However, in November 2022, after the state failed to develop a plan, Judge Baddour issued a new order that set out measurable outcomes for the state to remedy its violation. The North Carolina Department of Health and Human Services (NCDHHS) has appealed the decision and provided a counterproposal that would require $150 million in annual spending to eliminate the Innovations Waiver Registry of Unmet Needs, but does not specify a timeline for other goals.

We also reviewed several different Medicaid programs in North Carolina that attempt to provide resources for community living for individuals with disabilities. The Traumatic Brain Injury (TBI) Medicaid Waiver program provides community-based rehabilitation services to individuals who have suffered a TBI, while the NC Medicaid Managed Care Behavioral Health and Intellectual/Developmental Disabilities Tailored Plan provides managed care services for individuals with behavioral health and intellectual/developmental disabilities. The Community Alternatives Program for Disabled Adults (CAP-DA) is a Medicaid program that provides home and community-based services for disabled adults who would otherwise require nursing home care. Each program has its specific target group,

eligibility criteria, and services, but some programs have received criticism for the reduction in provider choice, lack of transparency and communication, and concerns about access to care, administrative complexity, and impact on small providers.

Forsyth County Community Context

Forsyth County has a population of around 382,075 people as of 2021. The county has a median household income of $52,115 and major industries include healthcare, retail trade, and manufacturing. The county has a high school graduation rate of 88.3% and is home to several colleges and universities. The area has several resources available for individuals with intellectual and developmental disabilities, including group homes, assisted living facilities, and specialized programs through the Parks and Recreation department. There were 44 establishments in Forsyth serving this population with nearly 600 employees total and an annual payroll of over 14 million dollars.

Estimating IDD Population in Forsyth County

Earlier in this report, we discussed the challenges of accurately estimating the population of people with intellectual and developmental disabilities (IDD) in a specific geographic location and reviewed different methods for estimating this population, with a special focus on administrative data. The strengths of administrative data include large sample sizes and the ability to provide information on a wide range of variables. However, administrative data may not accurately represent the IDD population as individuals may not receive a diagnosis or use services.

We presented data obtained through the administrative data approach in Forsyth County from Partners Behavioral Health Management, including the number of unique clients, their age and gender, the types of service providers and billing categories, and the cost of claims for IDD services in the county. Service billing data shows that there were 823 unique clients over the 14 months covered by the data. Month-by-month counts varied from a high of 655 to a low of 597 individuals. Three-fifths (59.2%) of clients were male and two-fifths (40.8%) were female. Half of the clients (53.4%) were between 21 and 40 years of age. Only 11.1% were over

60 years old. The largest classifications of support were for the Community Alternatives Program for Disabled Adults (CAP) and "other" CAP support. Monthly billing expenses averaged up to $2.3 million for ICF/IDD Hospital Admission & General Hospital, $424,171 for Live-in Caregivers, and $289,066 for Community Living and Support. Total claims data was averaged over 14 months and came to $7,297.48 per month/per client.

We continued to explore other methods for estimating the population of IDD individuals within Forsyth County. The most common estimation method is prevalence studies, which use standardized diagnostic criteria to identify individuals with IDD in a specific population. Prevalence estimates of IDD are typically based on a variety of sources, including population-based studies. We cited examples of studies that used population-based data to estimate the prevalence of IDD among children and adults in the US and Europe. We also discussed the limitations of prevalence studies, including the potential for underestimation or overestimation of the IDD population.

We used three data sources for our prevalence estimates: the American Community Survey (ACS), Affirmatively Furthering Fair Housing Data and Mapping Tool (AFFH-T), and computed prevalence by application of demographic data. We find in all three approaches a significant discrepancy between the number of individuals receiving Medicaid services for IDD and the overall prevalence of IDD in the population.

The ACS is an ongoing survey conducted by the US Census Bureau that collects data on various social, economic, and housing characteristics of the US population, including data on types of disabilities. From this information, we found that 1.6% of adults in Forsyth County between 35 and 64 years old have cognitive difficulties, with the highest concentrations in South and East Winston-Salem. Additionally, nearly 1% of the same age group have self-care difficulties, with concentrations in South and Northeast Winston-Salem, and almost 2% have independent living difficulties, with concentrations in South, North, and East Winston-Salem. These difficulties refer to a person's self-reported difficulty with routine self-care activities, concentrating, remembering, making decisions, performing daily

activities, or living independently due to a physical, mental, or emotional condition that has lasted at least six months.

Data from AFFH-T uses information from the American Community Survey and Public Housing Authorities to provide insight into the number of individuals in Forsyth County with disabilities in categories such as hearing, vision, cognitive, ambulatory, self-care, and independent living difficulties. It also reveals that 1,816 individuals with disabilities, including some with IDD, live in publicly supported housing programs in the Winston-Salem region, with 29% of those in Public Housing, 20% in Project-Based Section 8, 16% in Other Multifamily, and 18% in the Housing Choice Voucher Program having a disability.

Using demographic data for Forsyth County, we found the estimated upper bound of the total population of individuals with IDD is 5,922, based on projections using McBride et al. (2021). Using the slightly higher figure from the NC Council on Developmental Disabilities we estimate approximately 6,877 individuals with IDD overall in the County. Both numbers are significantly higher than the number receiving Medicaid services.

Key Informant Input

Between Nov 22, 2022, and Jan 6, 2023, interviews were completed with 12 experts in the area of IDD and housing. Interviews were conducted remotely via zoom and recorded, and the participants were given assurances of anonymity. The interviewees discussed the Medicaid and Innovation Waiver programs in North Carolina, which are meant to provide home and community-based services for individuals with disabilities but have not been successful in moving people out of institutions and into the community. The key informants discussed the process for determining services and setting individual budgets for care. Many interview participants expressed disappointment at the recent response by the DHHS to *Samantha R.'s* ruling. Additionally, the Innovations Waiver waiting list was a source of frustration for many, with concerns over inclusiveness and wait times leading to diminished quality of services and potentially overwhelming the system.

There was a clear tension also between parents and advocates and those who work for LME/MCOs. These institutions, which represent the state in the local

management of care, are responsible for authorizing services and allocating waiver slots to provide services to the IDD community. While they aim to provide quality clinical services efficiently, criticisms of inadequate provider networks and lack of transparency in navigating the system were noted.

Some parents of adults with intellectual and developmental disabilities were concerned about their children's transition to community living and the lack of coordination among different groups in addressing the issue. Some advocated for more public support, while others believe it is better to avoid public support and look for solutions on their own. Some felt there needs to be more caregiver advocacy to address the long waiting time and slow pace of implementation. One possible solution discussed was the "Self-Directed Waiver Supports" program which allows individuals with disabilities or elderly individuals to receive long-term support services while maintaining control over the direction of their care. Participants receive a budget for their long-term care services and can choose their service providers, allowing them to choose services that meet their needs and preferences.

Interviewees discussed housing as a key concern in supporting individuals with intellectual and developmental disabilities. Maintaining a continuum of housing options was seen as important, with the recognition that not everyone has the financial means or natural support to live independently. HUD Group Homes were mentioned as a viable option, but their complexity and expense to operate and maintain made it challenging for providers to build and maintain them. Interviewees also noted that providing low-income housing for people with IDD is complicated and requires collaboration with various organizations to ensure support and services are provided. The financial aspect of balancing support needs with housing was also discussed, with rising costs of living and low Medicaid rates impacting the ability of individuals to live independently.

Interviewees further highlighted the challenges people with IDD face when seeking affordable housing in North Carolina. One issue is the lack of affordable housing, and while housing choice vouchers are available, there is no state protection for the source of income. This means that landlords can refuse tenants who receive government assistance. Another issue is public housing's safety for vulnerable IDD

individuals, who may be exposed to drug use and abuse. Interviewees suggest installing security cameras and educating landlords about the needs of people with IDD.

Creative solutions were discussed to address the problem of affordable and inclusive housing in North Carolina for individuals with IDD. One parent describes how they purchased and developed quadruplexes in downtown Durham with the help of a developer and a few starter families, while another interviewee proposed a model for developing a complex with IDD apartments subsidized by a nonprofit and renting the remaining units at market rate. However, high upfront costs and difficulty in finding suitable properties make these solutions challenging to implement.

In talking about amenities needed for individuals with IDD, the interviewees discussed the need for universal design in housing with a focus on physical accessibility. They also suggested the use of assistive technology, such as sensors, timers, and camera systems, to assist individuals when needed, without requiring someone to be present all the time. The possibility of a scattered site model, where a central unit equipped with technology could alert staff when help is needed, was also explored as a way to reduce personnel hours and provide housing subsidies to those in need.

The Innovations Waiver program in North Carolina, which delivers services to individuals with disabilities, is facing a major issue of lack of staffing. The program requires a significant number of trained and experienced professionals to deliver services to individuals with disabilities, but the shortage of staff has resulted in long waiting times for services, burnout, and turnover of staff members. The Innovations Waiver program has taken steps to address the staffing shortage, such as increasing funding for staff salaries and benefits and investing in staff training and development. However, these efforts have yet to fully address the problem, and more needs to be done to ensure that individuals with disabilities have access to the support and services they need. Staffing is the biggest challenge across all services, and funding and staffing are linked, as the waiver services provided by these agencies are based on rate scales set by the state.

The argument has been made for the professionalization and standardization of Personal Care Assistants (PCAs) and Direct Support Professionals (DSPs) for individuals with IDD based on the recognition that these workers play a critical role in supporting individuals with IDD to live independently in their homes and communities. Better workplace incentives, more training, career ladders and opportunities for advancement, and standardization of job requirements will help in improving the quality of care. Furthermore, by providing higher wages (including salaried full-time positions) and benefits, it can help to attract and retain qualified and committed staff, which is particularly important given the high turnover rates in the field. Standardization and professionalization of the PCA and DSP workforce can help to ensure that these workers receive the respect and recognition they deserve for the important work they do.

Community Survey Results

An online survey was conducted to supplement the qualitative data gathered from interviews and secondary sources on concerns and issues related to intellectual or developmental disability in the community. The survey received 41 completed responses from individuals with IDD, families/caretakers, and staff of organizations serving individuals with IDD. Most respondents were caretakers or guardians (65.9%) and white (76.0%). Nearly all respondents indicated multiple categories of disability, with the most frequent being independent living difficulty (83.3%) and cognitive difficulty (79.2%). About 30.4% of households had a combined gross income under $30,000 annually, with 60% of individuals with IDD receiving supplemental security income. Most respondents had NC Medicaid for health insurance, with a smaller portion covered by Medicare or employer-based insurance. Additionally, nearly 37% were on the waiting list for N.C. Innovations Waiver Services.

The majority of the individuals with IDD surveyed were living in a home with family or guardians, while a smaller percentage lived alone or in a group home setting. Over half were living in a home with just 2-3 individuals. The most common services were case management, community integration, and home medical equipment, but over half of the respondents indicated they need additional services that they currently do not receive.

Preferred housing amenities included Wi-Fi, security systems, and emergency call buttons. There was a range of preferences and concerns regarding housing plans, with some respondents preferring group homes, others advocating for independent living, and concerns regarding accessibility, safety, and support. Respondents had desires for safe and affordable housing, improvements in existing housing, and more housing options with the necessary support.

Solutions to Housing Needs for Individuals with IDD

As we have heard, Individuals with intellectual or developmental disabilities face numerous challenges in finding affordable and safe housing options that allow them to live independently in communities. While group homes and other institutional settings have been common solutions in the past, many advocates believe that these options are not always the best choice for everyone. There is a clear and pressing need for more affordable, neuro-inclusive housing options with built-in support for individuals with IDD and their families. These options must remove the barriers of accessibility and affordability while also providing for individualized long-term services and support continued education and vocational programming, and intentional spaces and opportunities to foster neurodiverse friendships and community connections for increased community inclusion and support.

The solution to the housing issue calls for an 'all of the above' approach with multiple simultaneous opportunities being developed including mixed-income tax credit developments with non-profit management; shared equity owner-occupied homes; reclaimed, rehabbed, and modified existing single-family homes; shared housing with built-in natural supports; Accessory Dwelling Units (ADUs); and leveraging of assistive technology to reduce overall costs of supportive care while increasing independence and autonomy of individuals with IDD. Some of the proposed solutions include the following possibilities.

Accessible Home Modifications

Modifying existing homes to be more accessible is one way to provide affordable and safe housing for individuals with IDD. This could include installing grab bars,

wheelchair ramps, sensors, cameras, and other features that make the home more user-friendly.

Reclaiming Vacant Homes

Reclaiming and rehabbing vacant homes for use by individuals with intellectual or developmental disabilities is a strategy for creating more affordable and accessible housing options. The concept involves identifying vacant or abandoned properties, renovating them to make them habitable, and converting them into homes that can be used by individuals with disabilities. This approach has several benefits. It can help to revitalize blighted neighborhoods by addressing the issue of abandoned or derelict properties. Also, it can create a sense of community by bringing people together in neighborhoods that may have been previously abandoned or underutilized.

Accessory Dwelling Units

Accessory Dwelling Units (ADUs) are additional housing units built on the same property as an existing home, often in a separate building or as an addition to the primary residence. ADUs can provide an opportunity to create affordable and accessible housing options for individuals with intellectual or developmental disabilities. Family caregivers can build an ADU on their property to provide a safe and accessible living space for their family members with disabilities. This can provide a level of independence and privacy while also allowing for proximity to caregivers who can provide support as needed. Similarly, nonprofit organizations or developers can build ADUs specifically designed for individuals with intellectual or developmental disabilities with built-in “smart” home technologies.

Community Land Trusts

Community land trusts are non-profit organizations that hold land and make it available for affordable housing. Individuals with IDD, and other low-income individuals, can purchase homes on the land trust, ***paying only for the cost of the home and not the land.*** In this way, equity is shared between the homeowner and the non-profit. Creating permanently affordable housing may require the implementation of deed restrictions or other devices. CLTs can make housing more affordable and secure for those with limited incomes. ***Non-profit organizations or***

government agencies could assist with the creation of land trusts and the development of affordable housing.

Shared Housing & Housing Cooperatives

Shared housing models where individuals with IDD can live with roommates or housemates can provide a supportive and affordable housing option. Roommates can share the cost of rent and other household expenses, while also providing each other with companionship and support. ***Non-profit organizations or government agencies could assist in matching potential housemates and offering support services.***

Similarly, housing cooperatives are owned and operated by their members, allowing individuals with IDD to have a say in how the housing is managed and operated. Cooperatives can provide affordable and safe housing while also promoting a sense of community and ownership. Non-profit organizations or government agencies could help with start-up costs and ongoing management.

Mixed-Income Housing Developments

Mixed-income housing developments are residential communities that offer a mix of affordable housing units and market-rate units, providing a variety of housing options to individuals with different income levels. This approach to housing development aims to promote economic diversity, reduce segregation, and provide affordable housing options for individuals who may not otherwise be able to afford to live in a particular area.

Mixed-income housing developments typically involve ***partnerships*** between private developers, non-profit organizations that manage the complexes or provide services and support, and government agencies that provide funding. Affordable units are often subsidized by the government through tax credits or vouchers, Community Development Financial Institutions, or by private organizations. They are made available to individuals or families who meet certain income or disability requirements. Market-rate units are typically available to those who can afford to pay the market rate for housing which helps to offset the costs of the supported units.

This concept can also be combined with ***rehabbing and reusing underutilized properties including the repurposing of existing buildings, such as schools or hospitals,*** for use as housing for individuals with intellectual or developmental disabilities. This can help to preserve historic or culturally significant buildings while also addressing the need for affordable and accessible housing for individuals with IDD.

Operationalizing Solutions to Affordable Housing for IDD Individuals

All of these solutions and more may need to be implemented simultaneously to make a significant impact. It requires a comprehensive and coordinated effort that involves different stakeholders, including government agencies, housing developers, service providers, and community organizations. A clear plan should be developed that outlines the vision, goals, and objectives of the housing development. The plan should also outline the number and types of units that will be set aside for individuals with intellectual and developmental disabilities and the criteria for eligibility.

Affordable housing development for individuals with IDD ***should also provide a clear plan for supportive services*** that meet the needs of individuals with intellectual and developmental disabilities. This may include services such as case management, job training, and habilitative care. It is important to work with local service providers and non-profit organizations to ensure that these services are available.

Community engagement is also crucial in ensuring that an affordable housing development is successful. This involves engaging with residents and stakeholders in the supportive service community to understand their needs, concerns, and ideas. It is also important to involve individuals with intellectual and developmental disabilities and their families to ensure that their needs are fully addressed.

Of course, it is important to identify potential sources of funding and develop a financing plan that ensures the long-term sustainability of the development. The plan should include a clear and sustainable manner for keeping subsidized units in good repair and at an affordable rate. This may include proposals for renting or selling units at market rate, promoting title restrictions that limit who might qualify,

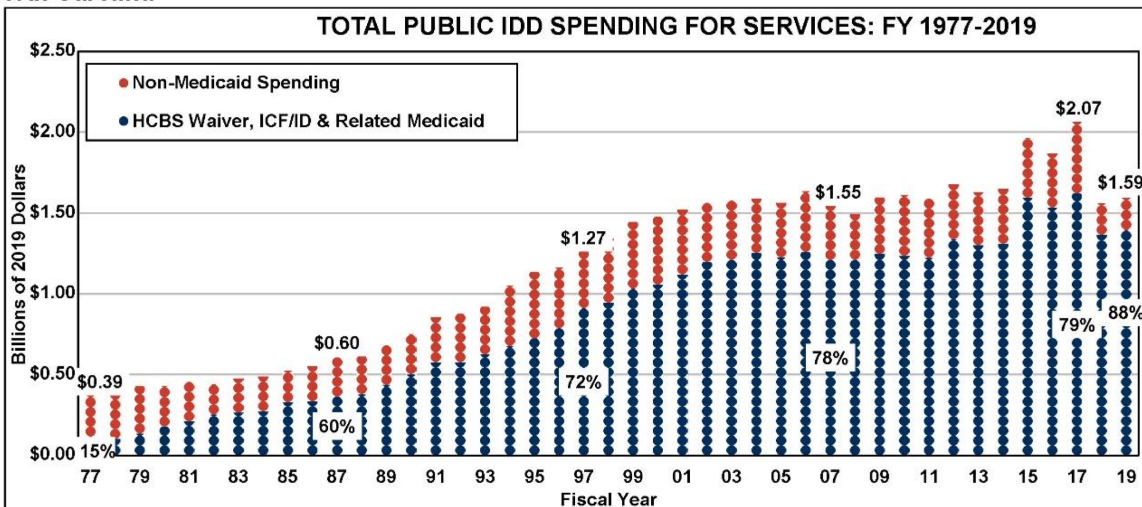
or leveraging funding from Medicaid or HUD to provide vouchers. The up-front costs of developing affordable housing are steep. A few ways to finance these costs include:

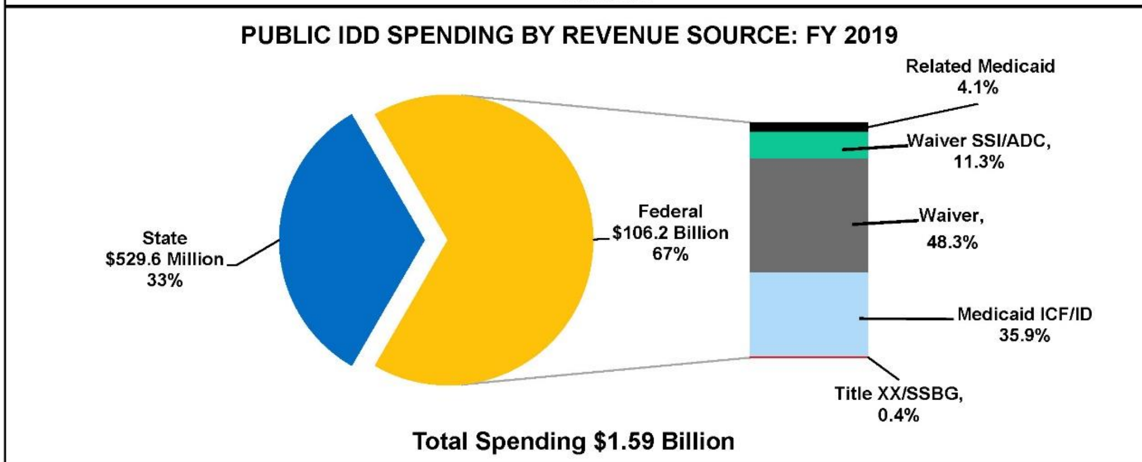
1. **Tax-Exempt Bonds:** Tax-exempt bonds are issued by state and local governments to finance affordable housing development. The interest earned on these bonds is exempt from federal income tax.
2. **Community Development Block Grants (CDBG):** CDBGs are a federal program that provides grants to state and local governments for community development, including affordable housing.
3. **Federal Home Loan Bank (FHLB) Affordable Housing Program:** This program provides grants and subsidized loans to financial institutions to finance the development of affordable housing.
4. **Section 8 Housing Choice Voucher Program:** This program provides rental assistance to low-income households, which can help to make affordable housing more accessible.
5. **Low-Income Housing Tax Credits (LIHTC):** This is a federal program that provides tax credits to private investors who finance the development of affordable rental housing.
6. **Private Financing:** Private financing, including loans from banks or other financial institutions, can also be used to finance affordable housing development.
7. **State and Local Funding:** State and local governments may also provide funding for affordable housing development through grants, loans, or tax incentives.

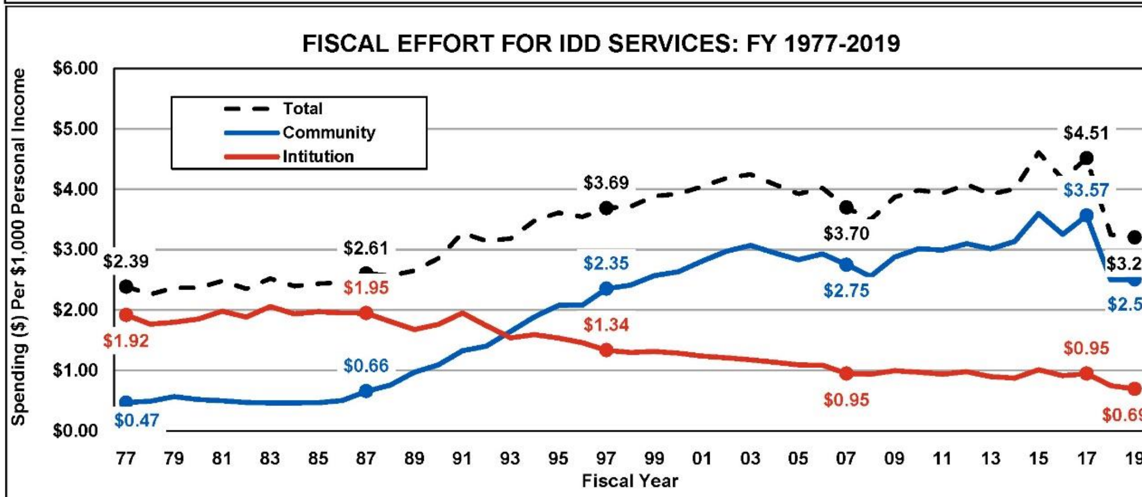
These are just a few of the many possible solutions for providing affordable and safe housing for individuals with IDD that are not group homes or other institutional settings. The key to success is a collaboration between government agencies, non-profit organizations, and individuals with IDD and their families to design and implement housing solutions that meet the unique needs of each person while also being cost-effective and of high quality.

Appendix A – State Profile for IDD Spending Fiscal Years 1977-2019[67]

North Carolina

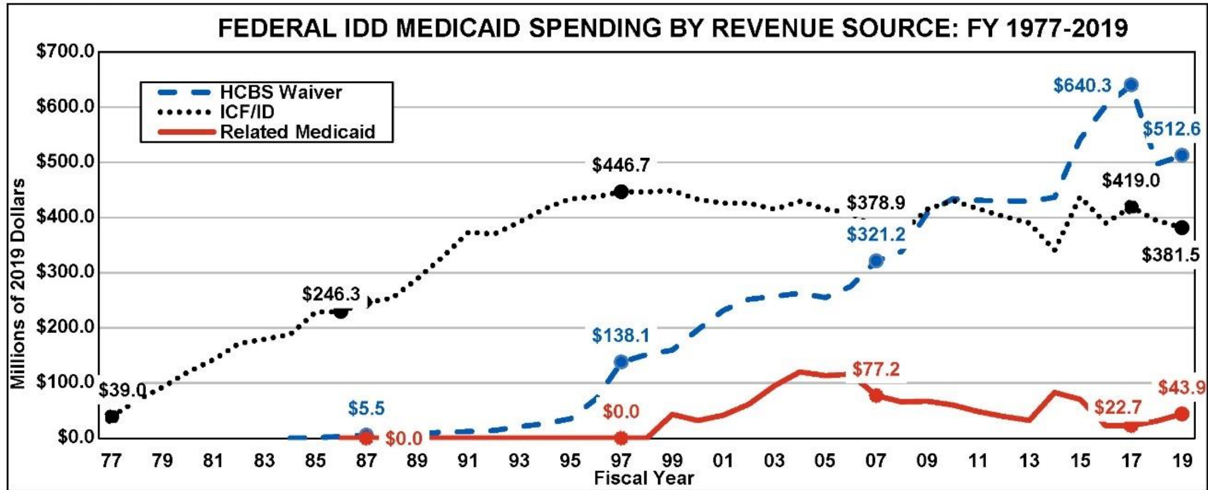


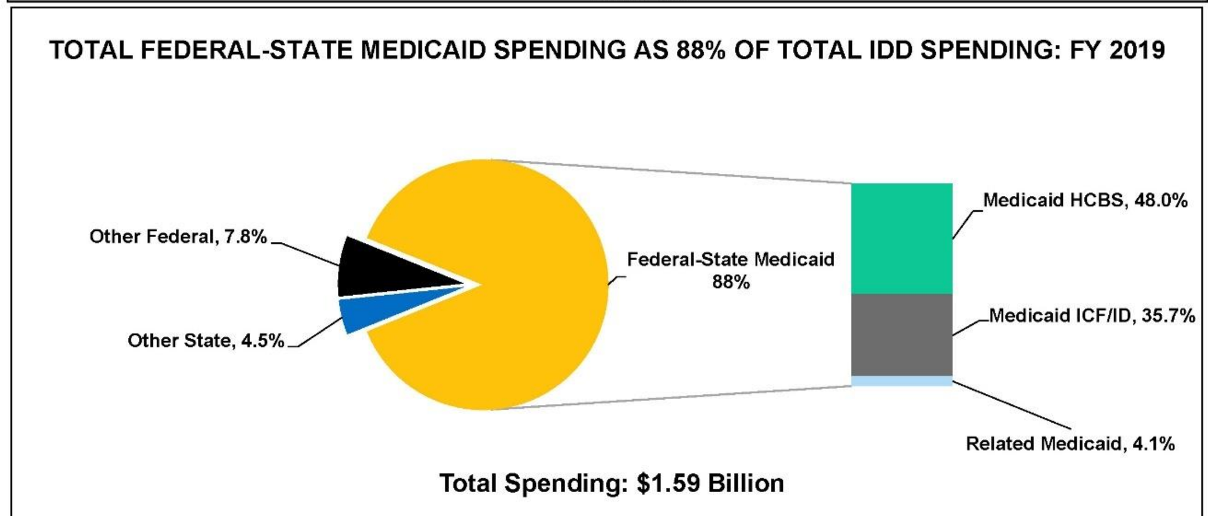


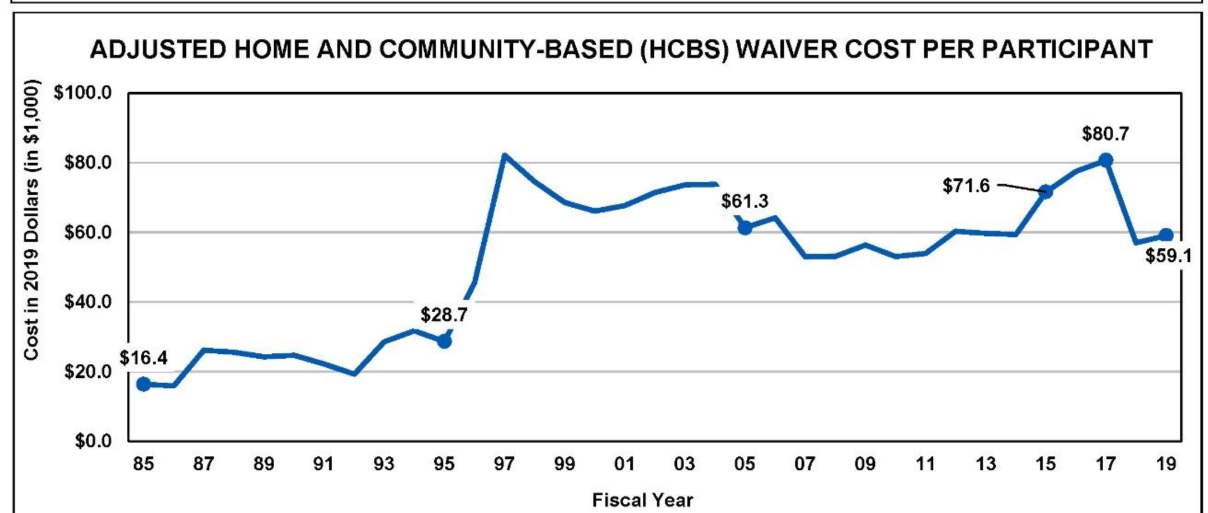


Source: Tanis, E.S., et al. (2022). The State of the States in Intellectual and Developmental Disabilities, Kansas University Center on Developmental Disabilities, The University of Kansas. http://www.StateoftheStates.org

North Carolina







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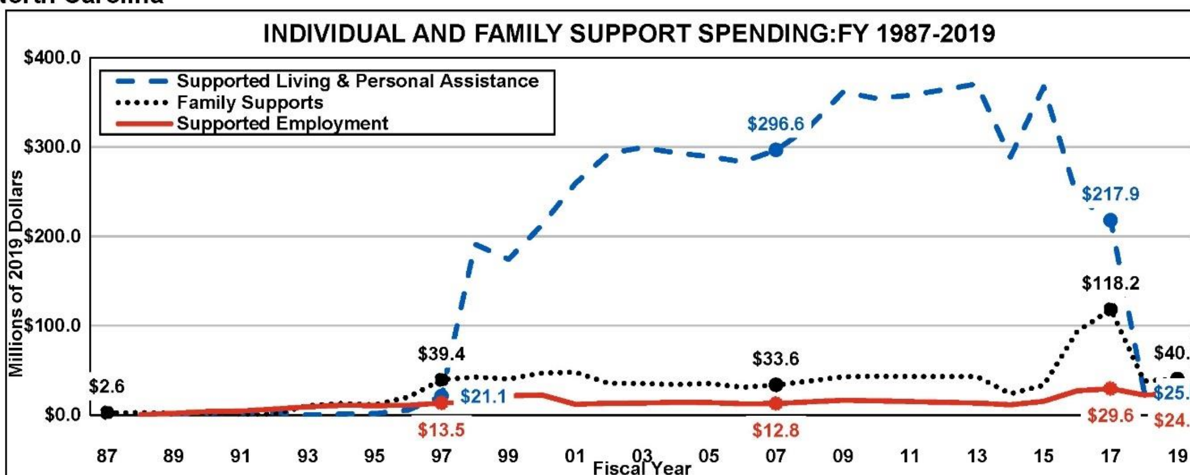
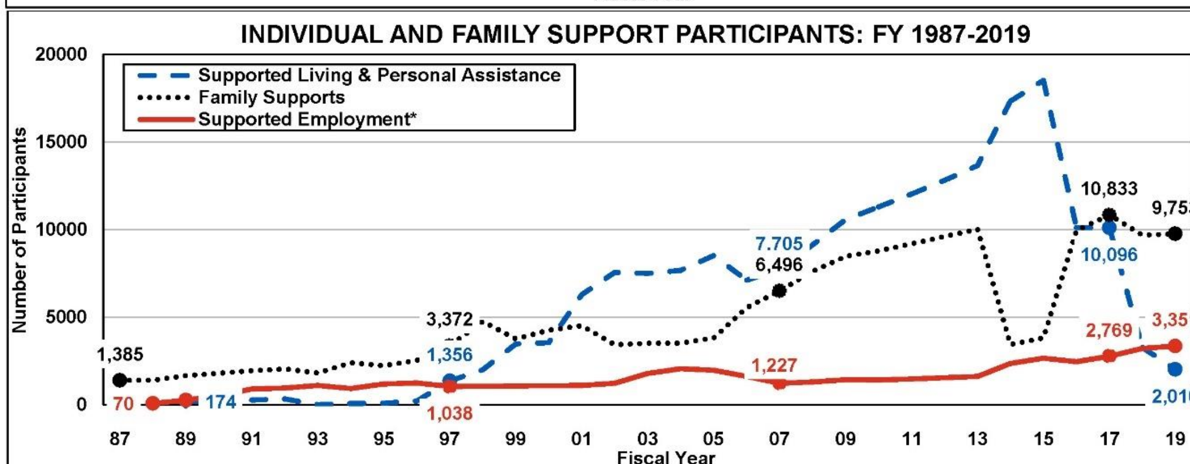
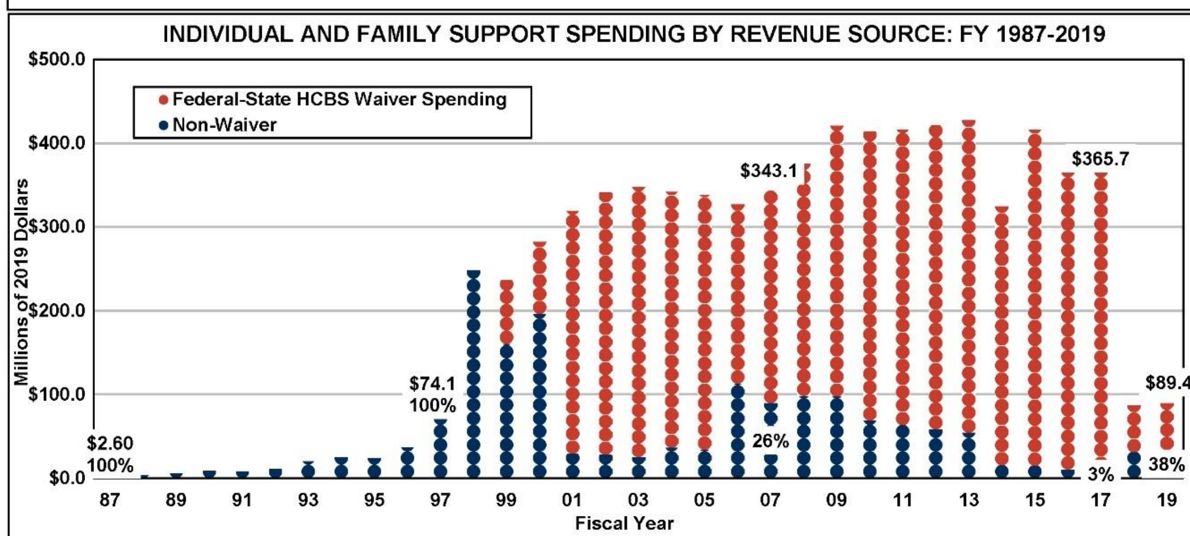
North Carolina





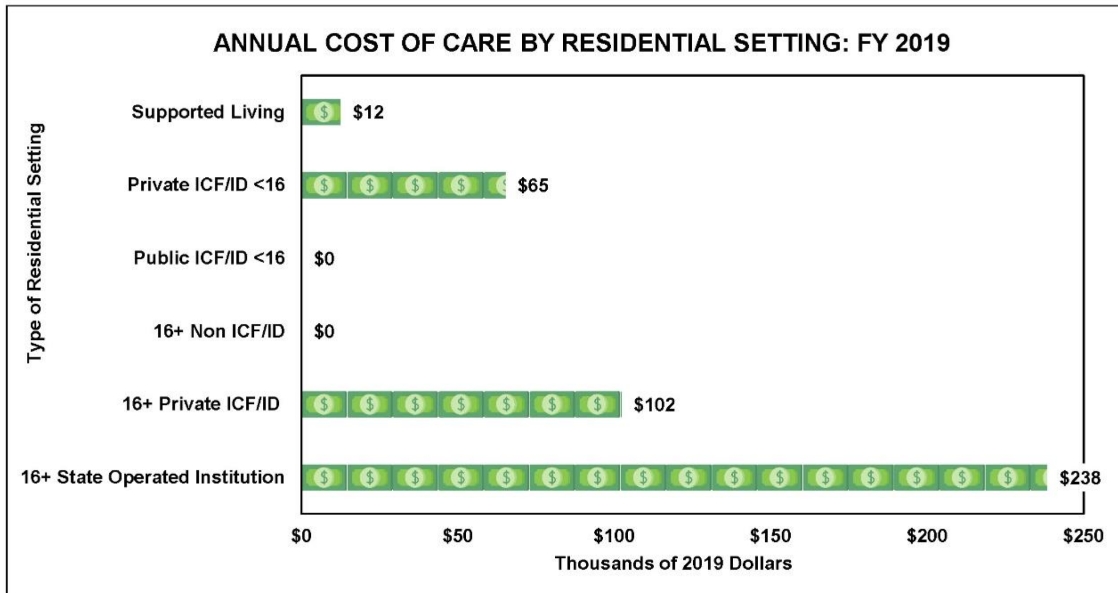


Source: Tanis, E.S., et al. (2022). The State of the States in Intellectual and Developmental Disabilities, Kansas University Center on Developmental Disabilities, The University of Kansas. http://www.StateoftheStates.org

North Carolina

PERSONS WITH IDD BY SIZE OF SETTING: FY 2009-2019

	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
TOTAL	**18,369**	**18,031**	**18,795**	**18,890**	**19,657**	**25,280**	**26,768**	**15,589**	**15,541**	**14,202**	**12,979**
16+ PERSONS	**3,297**	**3,270**	**3,250**	**3,005**	**2,932**	**2,198**	**2,205**	**2,034**	**2,122**	**2,857**	**2,585**
Nursing Facilities	949	963	962	960	959	190	201	208	205	936	685
State Institutions	1,638	1,603	1,572	1,351	1,300	1,241	1,194	1,120	1,125	1,196	1,154
Private ICF/ID	630	624	636	614	593	765	808	684	765	681	685
Other Residential	80	80	80	80	80	2	2	22	27	44	61
7-15 PERSONS	**1,283**	**338**	**384**	**392**	**392**	**130**	**150**	**310**	**298**	**465**	**521**
Public ICF/ID	0	0	0	0	0	0	0	0	0	0	0
Private ICF/ID	443	338	384	392	392	130	150	279	265	465	521
Other Residential	840	0	0	0	0	0	0	31	33	0	0
≤6 PERSONS	**13,789**	**14,423**	**15,161**	**15,493**	**16,333**	**22,952**	**24,413**	**13,245**	**13,121**	**10,880**	**9,873**
Public ICF/ID	0	0	0	0	0	0	0	0	0	0	0
Private ICF/ID	1,599	1,608	1,613	1,500	1,500	1,755	2,011	1,054	1,132	1,740	1,775
Supported Living	10,570	11,289	12,026	12,813	13,653	17,330	18,518	8,621	8,097	3,266	2,016
Other Residential	1,620	1,526	1,522	1,180	1,180	3,867	3,884	3,570	3,892	5,874	6,082



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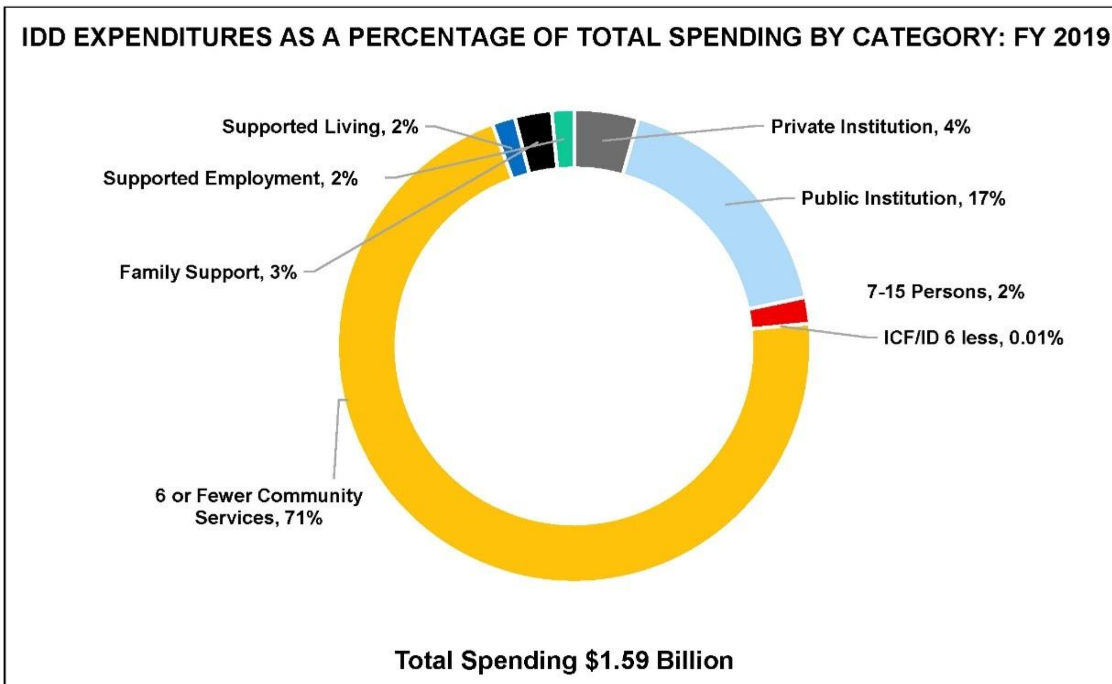

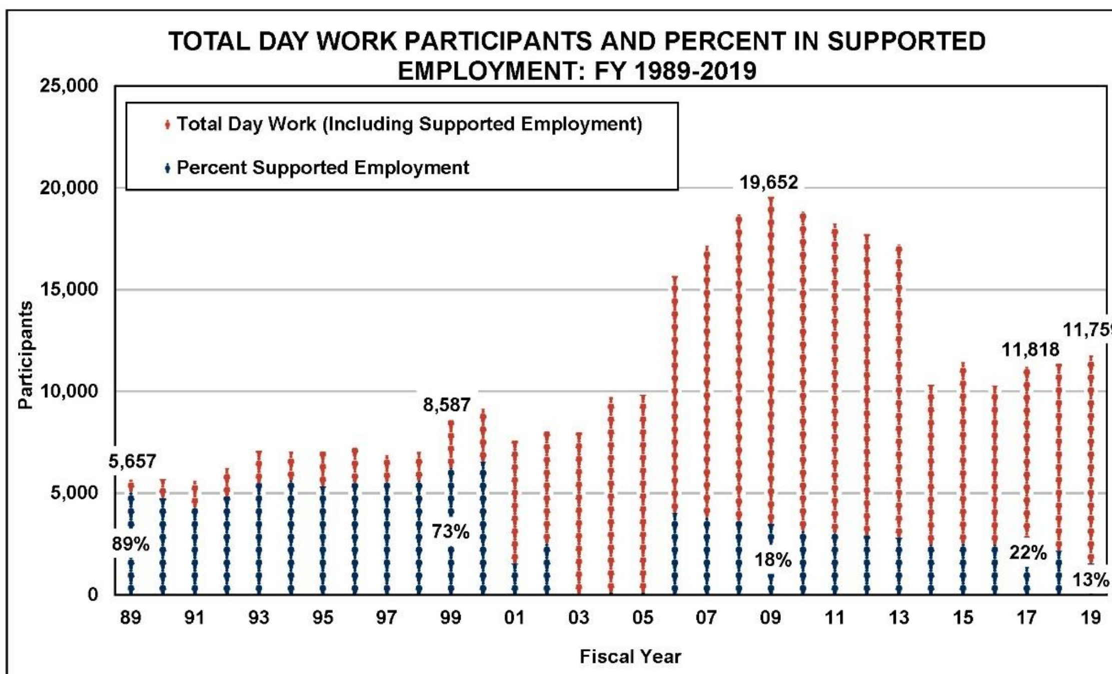

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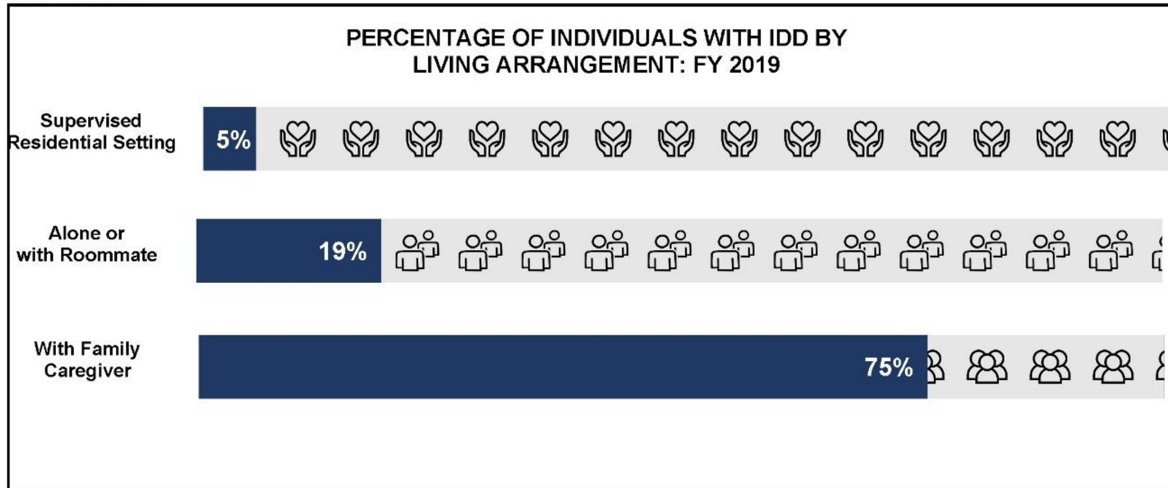
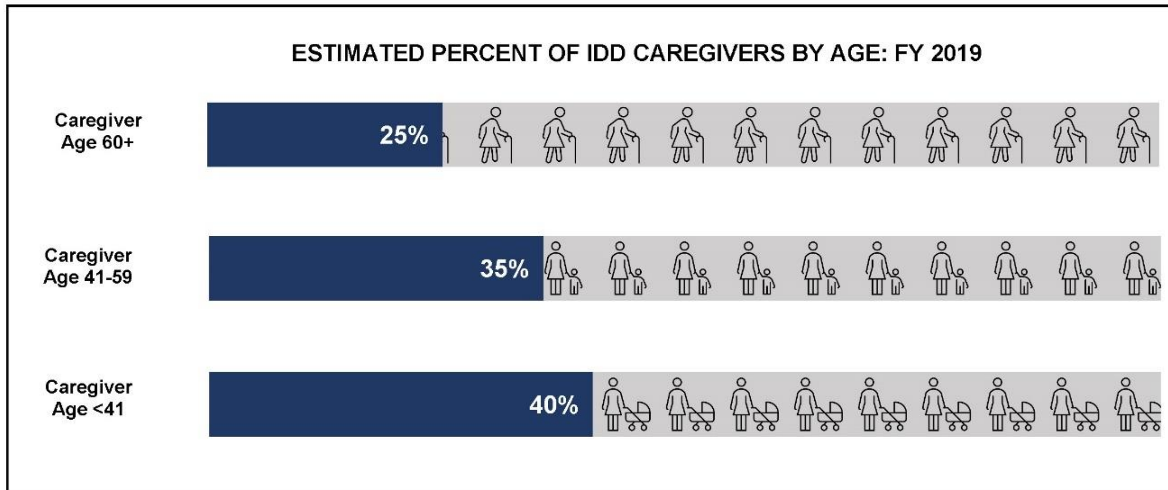
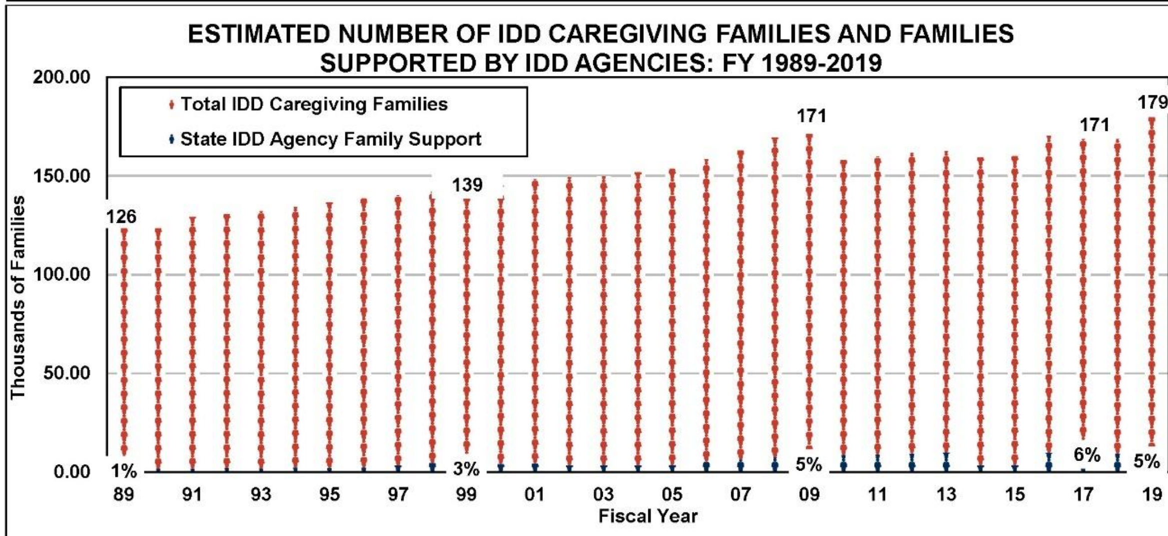
North Carolina







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Appendix B – Statewide IDD Resources

The Arc of North Carolina

This statewide advocacy organization provides information, resources, and support to individuals with intellectual and developmental disabilities and their families. Website: https://arcnc.org/

Special Olympics North Carolina

This organization provides sports and fitness programs for individuals with intellectual disabilities. Website: https://www.specialolympicsnc.com/

Community Partnerships for Children

This organization provides support to families with children with developmental disabilities, including respite care and support groups. Website: https://www.cpfcinc.org/

North Carolina Division of Aging and Adult Services

This state agency provides a range of services and support to older adults and individuals with disabilities, including case management, home care, and in-home services. Website: https://www.ncdhhs.gov/divisions/aging-adult-services

North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services:

This state agency provides a range of services and support to individuals with mental health, developmental, and substance use disorders. Website: https://www.ncdhhs.gov/divisions/mental-health-developmental-disabilities-and-substance-abuse-services

North Carolina Department of Health and Human Services, Developmental Disabilities Services:

This state agency provides a range of services and support to individuals with developmental disabilities, including case management, day programs, and in-home services. Website: https://www.ncdhhs.gov/services/developmental-disabilities

North Carolina Division of Services for the Blind

This state agency provides a range of services and support to individuals who are blind or have low vision, including rehabilitation, training, and employment services. Website: https://www.ncdhhs.gov/divisions/services-blind

North Carolina Council on Developmental Disabilities

This state council provides information, advocacy, and support to individuals with developmental disabilities and their families. Website: https://www.nccdd.org/

Supplemental Security Income

Supplemental Security Income (SSI) is a program in the United States that provides financial assistance to people with low income who are aged, blind, or disabled. SSI is funded by the federal government and administered by the Social Security Administration (SSA).
https://www.ssa.gov/benefits/ssi/
Supplemental Security Income
https://www.ssa.gov/pubs/EN-05-11000.pdf
What you Need to Know When You Get Supplemental Security Income
https://www.ssa.gov/pubs/EN-05-11011.pdf
SSI Child Disability Starter Kit (for children under age 18) Starter Kit
https://www.ssa.gov/disability/Documents/SSA-1171-KIT.pdf
What You Should Know Before You Apply for SSI Disability Benefits for a Child
https://www.ssa.gov/disability/Documents/Factsheet-CHLD.pdf
Checklist - Child Disability Interview
https://www.ssa.gov/disability/Documents/Checklist%20-%20Child.pdf
What You Need To Know About Your Supplemental Security Income (SSI) When You Turn 18
https://www.ssa.gov/pubs/EN-05-11005.pdf

Social Security Disability

Social Security Disability (SSD) is a program in the United States that provides income support to individuals who are unable to work due to a disability. The program is administered by the Social Security Administration (SSA) and funded by payroll taxes.
https://www.ssa.gov/benefits/disability/
Disability Benefits
https://www.ssa.gov/pubs/EN-05-10029.pdf
Helping Someone Apply Online
https://www.ssa.gov/benefits/retirement/planner/thirdparty.html
Checklist for Online Adult Disability Application
https://www.ssa.gov/hlp/radr/10/ovw001-checklist.pdf
Working While Disabled: How We Can Help
https://www.ssa.gov/pubs/EN-05-10095.pdf

Appendix C – 2023 Social Security Cost-of-Living Adjustment (COLA):

Based on the increase in the Consumer Price Index (CPI-W) from the third quarter of 2021 through the third quarter of 2022, Social Security and Supplemental Security Income (SSI) beneficiaries will receive an 8.7 percent COLA for 2023. Other important 2023 Social Security information is as follows:

Tax Rate	2022	2023
Employee	7.65%	7.65%
Self-Employed	15.30%	15.30%

NOTE: The 7.65% tax rate is the combined rate for Social Security and Medicare. The Social Security portion (OASDI) is 6.20% on earnings up to the applicable taxable maximum amount (see below). The Medicare portion (HI) is 1.45% on all earnings. Also, as of January 2013, individuals with earned income of more than $200,000 ($250,000 for married couples filing jointly) pay an additional 0.9 percent in Medicare taxes. The tax rates shown above do not include the 0.9 percent.

	2022	2023
Maximum Taxable Earnings		
Social Security (OASDI only)	$147,000	$160,200
Medicare (HI only)	No Limit	
Quarter of Coverage		
	$1,510	$1,640
Retirement Earnings Test Exempt Amounts		
Under full retirement age	$19,560/yr. ($1,630/mo.)	$21,240/yr. ($1,770/mo.)
NOTE: One dollar in benefits will be withheld for every $2 in earnings above the limit.		
The year an individual reaches full retirement age	$51,960/yr. ($4,330/mo.)	$56,520/yr. ($4,710/mo.)
NOTE: Applies only to earnings for months prior to attaining full retirement age. One dollar in benefits will be withheld for every $3 in earnings above the limit.		
Beginning the month an individual attains full retirement age	None	

	2022	2023
Social Security Disability Thresholds		
Substantial Gainful Activity (SGA)		
Non-Blind	$1,350/mo.	$1,470/mo.
Blind	$2,260/mo.	$2,460/mo.
Trial Work Period (TWP)	$ 970/mo.	$1,050/mo.
Maximum Social Security Benefit: Worker Retiring at Full Retirement Age		
	$3,345/mo.	$3,627/mo.
SSI Federal Payment Standard		
Individual	$ 841/mo.	$ 914/mo.
Couple	$1,261/mo.	$1,371/mo.
SSI Resource Limits		
Individual	$2,000	$2,000
Couple	$3,000	$3,000
SSI Student Exclusion		
Monthly limit	$2,040	$2,220
Annual limit	$8,230	$8,950
Estimated Average Monthly Social Security Benefits Payable in January 2023		
	Before 8.7% COLA	After 8.7% COLA
All Retired Workers	$1,681	$1,827
Aged Couple, Both Receiving Benefits	$2,734	$2,972
Widowed Mother and Two Children	$3,238	$3,520
Aged Widow(er) Alone	$1,567	$1,704
Disabled Worker, Spouse and One or More Children	$2,407	$2,616
All Disabled Workers	$1,364	$1,483