JAMES, MATTHEW G. Ed.D. Impact of Medicaid Transformation in North Carolina on People with Intellectual and Developmental Disabilities. (2023)
Directed by Dr. Carl Lashley. 242 pp.

The purpose of this study was to analyze the legislation, SL 2015-245, and the relevant North Carolina Department of Health and Human Services guidance/regulatory documents, using a critical policy analysis to determine if the legislation and proposed value-based measures to date are designed to achieve improved quality of life outcomes for people with Intellectual and Developmental Disabilities receiving LTSS. The findings show that quality of life improvement is specifically identified as a goal for this population of people within the language of the Medicaid transformation and requirements are established to person-center outcomes for the delivery of those services; yet no specific measurement strategy has been identified that aligns with best practices in monitoring quality of life or linking it with value-based payments. Therefore, this reform represents the free-market belief that more competition will improve services and decrease costs, while ignoring voices of the thousands in crisis who are not receiving adequate support or services.

IMPACT OF MEDICAID TRANSFORMATION IN NORTH CAROLINA ON PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

by

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A Dissertation
Submitted to
the Faculty of The Graduate School at
The University of North Carolina at Greensboro
in Partial Fulfillment
of the Requirements for the Degree
Doctor of Education

Greensboro

2023

Approved by

Dr. Carl Lashley
Committee Chair

DEDICATION

Thank you to everyone who went on this journey with me. I am forever humbled by the love of learning and the discovery that comes with it. To the family, friends, professors and colleagues who supported me, I will never truly be able to share how much it has meant to me, but please accept this short:

"I love you and share this accomplishment with each of you, thank you ."

APPROVAL PAGE

This dissertation written by Matthew James has been approved by the following committee of the Faculty of The Graduate School at The University of North Carolina at Greensboro.

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March 3, 2023
Date of Acceptance by Committee

March 3, 2023
Date of Final Oral Examination

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CHAPTER I: INTRODUCTION

The provision of care and services for people with Intellectual and Developmental Disabilities (IDD) has been evolving across our history in the United States. In North Carolina, we are preparing for another change as Medicaid, the system that pays for care and services, is shifting. This shift will affect people like Mark*, a person with Intellectual and Developmental Disabilities, who requires physical supports, medical interventions, continuous active treatment, and wrap-around services operationalized through a service called Long-Term Services and Supports (LTSS) and a person-driven plan. Mark is the same as you and me; he has dreams, wishes, hopes, aspirations, and expectations for his future.

Mark's person-driven goals are expected to define how his supports and services are identified and then rendered. His plan will entail essential services, like personal care to assist him with everyday physical needs from bathing, teeth brushing, dressing, toileting, and other hygiene tasks. Mark also requires assistance through transportation services to attend his Day Program, where he works on individualized goals and engages in a variety of activities he enjoys. Mark also has a part-time job, where he receives support from an Employment Coach to complete all the functions of his job. At other times, Mark needs assistance to attend both family events and other social activities that he enjoys in the community, like concerts, restaurants, and parades. Mark would not have much of an opportunity to live a full life, if he did not receive the continuous and Long-Term Services and Supports (LTSS) that are vital to his everyday success.

Today, the staffing necessary to support Mark is not sufficient to ensure a full and successful day. He has many unfilled service hours and works with new staff regularly who are not as knowledgeable about his care needs. This means that he experiences skin breakdown, misses out on some of the activities he likes best, spends more time in isolation, is under-supported to communicate with existing friends and family, and lives in a state of worry and concern about whether someone will show up to help him get out of bed each morning.

Given Mark's circumstances and those of the 200,000 North Carolina citizens with needs similar to his, the purpose of this study will be to analyze the legislation, SL 2015-245, and the relevant North Carolina Department of Health and Humana Services (NCDHHS) guidance/regulatory documents that govern services for these individuals. I have used a Quality of Life framework to determine whether and how the legislation and regulations are designed to achieve improved quality of life outcomes for people with Intellectual and Developmental Disabilities receiving LTSS.

Researcher's Interest in the Study

I have worked with people like Mark for many years and continue to witness first-hand the challenges faced by both individuals with Intellectual and Developmental Disabilities (IDD) and their families. I chose to engage in this study to help people with Intellectual and Developmental Disabilities, their families, their providers, their payers, and their system decision-makers be informed about how Medicaid program changes may impact the quality of life of people with Intellectual and Developmental Disabilities. People like Mark are in jeopardy, due to the major strains felt across North Carolina Medicaid programs, such as under-funding Home and Community Based Services (HCBS) and Community-based waivers (i.e., Innovation Waivers (Sirko, 2021), workforce crisis and quality (*The DSP Crisis: Reimbursement Rates, Retention, and Research,* 2021), continued bias for institutional services (*Lawsuit: State Programs Violate Rights of Disabled North Carolinians*, 2017), inadequate measurement systems for performance and fulfilment of services (Boyette, Cohen, & Jones, 2018), and geographic and demographic inequalities (North Carolina Institute of Medicine, 2020).

In recent years, Medicaid programs have been managed by seven local management entities--managed care organizations (LME-MCOs), each responsible for a geographic region. Under the developing Medicaid reform, there is an effort to reshape the delivery of services by changing the payers--moving away from the traditional state-sponsored management of Medicaid services through Local Management Entities towards Managed Care. This change will occur slowly for some and quickly for others, depending on the intensity of the services they receive. The North Carolina Medicaid programs for persons with more robust support needs will continue to be managed by quasi-governmental Managed Care Organizations, while others' basic services are moved to privatized insurance companies. The most fundamental change is to move the system away from paying for each service at its cost at the time it is provided (i.e., fee for service) to paying for value and achieved outcomes/savings (i.e., managed care and value-based reimbursement). To use an example, this will be a shift from a doctor/provider being compensated for seeing a client to the doctor/provider being compensated for the client's attainment of the intended outcome. This change reflects the North Carolina's legislative desire to manage costs, share risk, and increase competition to improve care.

As this change occurs, we must ensure that the North Carolina Legislature, NCDHHS, and Medicaid payers are held responsible for ensuring that this new payer system has the intended outcomes of whole-person and integrated care for people receiving Medicaid services. The public-private partnerships sought in this Medicaid reform may be able to obtain the intended outcomes if we focus on

a) the needed financial investments to revitalize the Medicaid programs (Sirko, 2021),
b) the measurement systems and outcomes which are value-based for the population (i2i Center for Integrative Health & North Carolina Community Health Center Association, 2021),
c) the quality and consistency of care management across providers (i2i Center for Integrative Health & North Carolina Community Health Center Association, 2021),
d) the quality and availability of Direct Support Professionals (The DSP Crisis: Reimbursement Rates, Retention, and Research, 2021),
e) the equity of Medicaid services across geographic regions, ethnicities, and socioeconomic statuses (North Carolina Institute of Medicine, 2020), and
f) support for the goals for IDD services that stakeholders, individuals, families, providers, and the at-large IDD have worked toward for decades (Ancor, 2019).

Best Practices in Long-Term Services and Support

Best practices in the field of care management tell us that we should be providing Mark with a robust comprehensive assessment to determine his continuous support needs and that Mark should drive his plan to ensure that the goals he works on and the services he receives are aligned (i2i Center for Integrative Health & North Carolina Community Health Center Association, 2021). Today, we rely primarily on what the clinical team and provider feel are the most appropriate services and supports and retrofit those to the individual. Persons receiving the services are not empowered to really take charge and define their needs, issues, goals, and success indicators (i2i Center for Integrative Health & North Carolina Community Health Center Association, 2021).

Person-Driven Planning

Providers of LTSS rely on person-driven planning to develop treatment plans and service goals without any “universally agreed upon standards, or competencies, for human service agency staff tasked with facilitating person-driven planning” (Tondora, Croft, Kardell, Camacho-Gonsalves, & Kwak, 2020, p. 1). There is still a need for these standards to “ensure the planning process is consistent with the values and principles of person-driven thinking, planning, and practice” (Tondora, et al., p. 1). Service delivery for these individuals is unique, and every person’s goals are designed to help the individual identify and pursue things that matter most to them. The field recognizes that person-driven approaches are the essential underpinning to a quality service delivery system. Quality is something that differs from person to person, and consumers must be empowered to exercise their rights and self-determination to maximize their quality of life (Schalock, 2004; Friedman, 2019). Self-advocates are increasingly speaking up and saying that

> making choices and decisions for ourselves is an important part of who we are. It is fundamental to having control over our own lives and important for securing all other rights: if we are not allowed to make our own decisions, how can we have a voice in anything else that is important to us? (Laurin-Bowie, 2014, p. 84)

Advocates and self-advocates are correct, and North Carolina’s Medicaid transformation to managed care will need to be carefully monitored for quality of life indicators as well as regulatory compliance. If compliance measures surrounding operational expectations and health-outcomes become the primary focus of quality and intended reform outcomes, the person-driven goals and expectations of the end user will be lost to the detriment of the end users’ satisfaction with their Medicaid services.

Quality of Services

The focus must remain on supporting the person with Intellectual and Developmental Disabilities to achieve his/her/their goals and desired outcomes. The field is currently working to implement more uniform quality outcome measures for the programs serving people with IDD. As recommended by ANCOR, a menu of outcomes for people with IDD is important because of the great variance that exists among the service goals of individuals with IDD and the programs that serve them. The outcomes measures selected to reflect value, in the Tailored Plan, will need to align with individualized goals and wishes of the recipient of service to ensure that quality of service delivery is measured by its' accomplishment of person-driven outcomes. After all, "quality is not measuring things because they are easy to measure. Measure what we value, not value what we measure" (Friedman, 2019). A lack of robust outcomes measures to reflect the diversity of the human experience, will fail to incentivize providers to accomplish person-driven outcomes in this new system. Rather, providers will be incentivized to focus on measures related to system efficiency and operations.

The National Committee for Quality Assurance has tested person-driven outcome measures as a way to bring recipients of service, their clinicians, and other vested stakeholders together in identifying and support person-driven goals. This process entails eliciting what is important, identifying and measuring person-driven outcomes, planning to achieve, reassessing, and improving or maintaining the desire outcome (Wexler, 2021).

Another option for measurement strategy would be to elicit what social determinants of health (i.e., housing, food, transportation, employment, and interpersonal safety), are impacting the attainment of desired person-driven outcomes. Many Intellectual and Developmental Disability providers have been working to impact social determinants of health through wraparound services, which have been shown to improve quality of life outcomes and create system efficiencies (Friedman, 2019). It is important to identify and address impacting social determinants of health in order to support the attainment of person-driven goals. Measuring the success of these efforts using quality-of-life measurement systems will be helpful in keeping with best services for those with Intellectual and Developmental Disabilities services best practices.

Measuring Quality of Life

The focus on processes and systems efficiencies will not ensure the satisfaction and quality of life of the person receiving Medicaid services in North Carolina. There must be a mindset shift “from a medical model to a more person-centered one, but also shift from focusing on saving to sustainability” (Friedman, 2019, p. 21). One solution being used in the field is to measure quality of life scores to monitor and report, inform quality improvement efforts, and conduct research or program evaluation.

Quality of life measurement has been used by organizations and delivery systems to provide services and supports to people with Intellectual and Developmental Disabilities. The application of the quality-of-life framework is attractive because of its philosophical foundations and the use of its domain structure to conform with best practices in measurement and implementation (Bigby, Beadle-Brown, & Bould, 2014; Mittler, 2015; Reinders & Schalock, 2014; Schalock & Keith, 2016; Schalock, Verdugo, & Gomez, 2011; van Loon, Bonham, Peterson, Schalock, Claes, & Decramer, 2013; Verdugo, Navas, Gomez, & Schalock, 2012). The collection, reporting, and analysis of quality-of-life scores at the individual, organization, and system level is helpful to connect evidence-based practices with desired quality of life outcomes (Gomez & Verdugo, 2016; Claes, van Loon, Vandevelde, & Schalock, 2015; Schalock, Gomez, Verdugo, & Claes, 2018). To follow our example, in addition to person-driven planning process, Mark's basic survival needs would be addressed through a state-funded system of services and his natural supports.

A Stable Workforce

NCDHHS, the Tailored Plans, and the providers must work together to address the critical shortfall of frontline Direct Support Professionals and Care Managers who underscore the provision of services. Having a well written and developed plan is insufficient if its intent cannot be fulfilled due to a lack of professional and qualified workforce personnel. Mark deserves the development of a person-driven plan that he drives; he deserves a framework to ensure holistic planning and measurement of fulfilment of his needed services and goals; and he deserves a stable workforce to enable his success.

Summary of Best Practices in Long-Term Services and Supports

The need to address the multi-faceted contextual factors that impact the delivery of support and services is a prerequisite to improving that system. Operationalizing the best practices of the field such as person-driven planning, high quality Home and Community-based Services, recipient of service quality of life measurement, and sufficiently available and highly trained workforce, fosters the opportunity for advancement of service delivery.

Background of NC Medicaid Transformation

North Carolina provides essential services to its residents with Behavioral and Mental Health needs (BH), Substance Use Disorders (SUD), and Intellectual and Developmental Disabilities through Medicaid, which helps to support the cost of treatment and care. Local Management Entities (LMEs) across counties and geographic regions operate and manage these programs in partnership with the Department of Health and Human Services (DHHS), which oversees the behavioral and mental health services, substances use disorder services, and disability services.

The Piloting of a Managed Care Organization in NC

In 2005, the North Carolina DHHS created a concurrent 1915(b)/(c) Medicaid waiver to serve Medicaid beneficiaries with BH, SUD, and Intellectual and Developmental Disabilities. This waiver was piloted by an LME-Managed Care Organization (MCO), Cardinal Innovations Healthcare, which also managed the Innovations waiver program for people with Intellectual and Developmental Disabilities receiving Home and Community-Based Services to prevent institutionalization. In 2009, this structure of LME-MCO was expanded using the 1915(b)/(c) Medicaid waiver across the State to create seven LME-MCOs that serves eligible residents across various geographic regions. This merged the North Carolina Medicaid and the Division of Mental Health, Developmental Disabilities and Substance Abuse Services to restructure the delivery system for Medicaid and state funded services (NCDHHS, 2021). This system was funded with a primarily fee-for-service structure using Federal and State Medicaid dollars. MCOs were intended to better regulate health and human service spending through quasi-governmental managed care systems.

Changes in Cost Management

North Carolina DHHS, prior to the implementation of the LME-MCO system, was responsible for developing services, setting rates, and conduct audits or surveys to ensure compliance with service regulations. After the implementation of the LME-MCO system, a lion’s share of those responsibilities was given to the LME-MCOs, still using a predominantly fee-for-service payment model in which the provider is paid for each service it renders, regardless of the outcome for the individual being served. Due to the diversity of care needs, service utilization, and cost of specialized services, managing the cost of care and quality is a challenge for Departments of Health and Human Services (NCDHHS, 2018), which is why this more regional approach using LME-MCOs was implemented. This trend continues toward more fully implementing Managed Care models and reducing the responsibilities of North Carolina DHHS.

New Medicaid Transformation in North Carolina

In September, 2015, North Carolina passed House Bill 372, Medicaid Transformation and Reorganization Act, which operationalized new private Managed Care Organizations (MCOs), known as Prepaid Health Plans (PHPs), to take on additional North Carolina DHHS responsibilities as well as the general Medicaid population (i.e., those under the Standard Plan) (*ACA Medicaid Expansion in North Carolina [Updated 2022 Guide]*, 2021). The Centers for Medicare and Medicaid Services (CMS) describe Medicaid managed care as “a health care delivery system organized to manage cost, utilization, and quality” (Friedman, 2019, p. 3). In this arrangement, state Medicaid agencies contract with LME-MCOs and PHPs to deliver Medicaid health benefits and pay for them using per member per month payment for delivered services. The goal is to reduce costs and share risk with prepaid health plans to help state governments manage their budgets, while exploring and implementing innovative service delivery models. NCDHHS believes that managed care can improve care coordination, access to community-based services, and outcomes for people receiving Medicaid services.

On June 15th, 2018, the North Carolina General Assembly passed House Bill 403, which amended Session Law 2015-245, “An Act to Transform and Reorganize North Carolina’s Medicaid and NC Health Choice Programs,” authorizing: 1) inclusion of behavioral health services into the Standard Benefit Plan and 2) the creation of the Behavioral Health/ Individuals with Developmental Disabilities Tailored Plans, which are specialized plans to serve members with significant behavioral health needs, intellectual/developmental disabilities, and traumatic brain injuries (NCDHHS, 2018b). The purpose was to contain costs, stabilize the budget, increase competition, and share risk, to address the multi-year financial shortfalls within the North Carolina Medicaid programs (i2i Center for Integrative Health & North Carolina Community Health Center Association, 2021). When it goes into full implementation on April 1st, 2023, this system is about to change dramatically in the way it is managed AND funded as well as the outcomes it is expected to produce.

Summary of Background of NC Medicaid Transformation

The overall trend continues to be for the North Carolina General Assembly to search for ways to operationalize health and human service delivery through less direct governmental involvement and even more importantly to control spending in these programs. The question is are their enough efficiencies to gain through corporate operations to control costs, ensure private companies make a profit, and improve the quality of care to recipients of service.

Goals and Overview of the Medicaid Transformation

By 2023, NCDHHS (DHHS) plans to transition the predominantly fee-for-service delivery system to a value-based Medicaid managed care system. Within this system, the state of North Carolina will offer four managed care products that are expected to provide integrated and whole-person care. The four options include: the Standard Plan, the Behavioral Health and Intellectual/Developmental Disability Tailored Plan, the Specialized Plan for Children in Foster Care, and Eastern Band of Cherokee Indians (EBCI) Tribal Option. These four options account for the $3.9-4.13 Billion in Medicaid expenditures in North Carolina (NCDHHS, 2019).

Standard Plans

The Standard Plans provide integrated physical health, behavioral health, pharmacy, and long-term services and supports to most Medicaid beneficiaries. This plan is also responsible for addressing other unmet health related resource needs identified through social determinants of health screenings and referrals. The Standard plans also called “NC Medicaid Managed Care” was launched in July 2021 and is operated by state contracts with insurance companies, who are paid a set rate per enrollee for all authorized services. Roughly, 1.4 to 1.8 million North Carolinians are served by the four statewide prepaid health plans (NCDHHS, 2019).

Tailored Plans

The Behavioral Health (BH) and Intellectual/Developmental Disability (I/DD) Tailored Plans provide all the services covered under the Standard Plans but also includes specialized services for people with significant behavioral health conditions, Intellectual/Developmental Disabilities, and traumatic brain injury. The BH and IDD Tailored Plans also manage the services for people receiving state-funded and waiver services. The BH and IDD Tailored plans are expected to launch April 1st, 2023. These plans will be operated by the existing Local Management Entities-Managed Care Organizations (LME-MCOs) for a period of time before the prepaid health plans (PHPs) will have a chance to compete for those member services NCDHHS, 2019).

Specialized Plan for Children in Foster Care & Eastern Band of Cherokee Indians Tribal Options

The Specialized Plan for Children in Foster Care is a plan to cover a full range of physical health, behavioral health, and pharmacy services for children in foster care. The EBCI

Tribal option will serve tribal members and their families and is managed by the Cherokee Indian Hospital Authority (CIHA) (NCDHHS, 2019).

Cost Neutral Transformation

No additional funding will come into this new payer system (cost neutral proposal). Service provision still faces a workforce crisis in both the direct service and care management positions, a focus on health-related outcomes, lacking quality measurement systems, and increased variability between LME-MCOs about the delivery of services and provider qualification operating under the BH and IDD Tailored Plan. The well-being of North Carolinians with Intellectual and Developmental Disabilities served under the Medicaid program remains at risk.

Summary Goals and Overview of Medical Transformation

The goals of the transformation seem well intentioned and begin to focus on identifying the unique needs of various populations of people, i.e., those with minor health care needs, those with intensive needs, and those with specialized needs such as children in foster care. A concerning note, however, is the cost neutral environment in which this change is occurring.

Statement of the Problem

The transition to value-based purchasing and away from fee-for-service models is complex and requires special planning and preparation to (1) ensure long-standing providers are maintained, (2) that MCOs/PHPs are prepared to serve people with Intellectual and Developmental Disabilities in a culturally competent manner, (3) and that measurement of quality is meaningful to people receiving LTSS (NCDHHS, 2018b*)*. In this new Medicaid reimbursement model, providers will need to demonstrate outcomes through approved quality measurement systems to receive the full reimbursement for their service under the theory that this will ensure better service provision by rewarding providers who submit data that demonstrates the successfulness of their approaches (NCDHHS, 2018).

Unfortunately, the providers serving people with Intellectual Disabilities in LTSS are under-prepared for this transformation and are unable to report on outcome measures for people with intellectual disabilities using their services due to a lack of resources and technical assistance (Boyette, Cohen, & Jones, 2018). There has been: 1) no uniform adoption of outcome measures by providers serving people with intellectual disabilities and 2) limited funding to support the adoption of an electronic health records system that can transmit data with the NC Health Information Exchange (HIE), the data-aggregation system adopted by the NC Department of Health and Human Services (DHHS)) (Boyette, Cohen, & Jones, 2018). While service providers for people with Intellectual and Developmental Disabilities are familiar with a variety of standards/regulations, such as Home & Community-based Supports (HCBS) and accreditation requirements such as the Council on Quality Leadership (CQL), there is no congruity across person-driven outcomes contained within the treatment/service plans. There are also no nationally accepted Person-driven Planning Standards (Tondora et al., 2020).

The concern is that a failure to provide an overarching, holistic, multi-domain framework for all person-driven service/treatment plans will result in a continuation of missed social determinants of health in the care-coordination planning, implementation, and evaluation stages of services for the 200,000 people being served by the Tailored Plans. Further, the intended outcome of the reform--to “maximize long-term services and supports populations’ quality of life and community inclusion”--won’t occur due to lack of alignment with evidence-based practices in the fields of Care Management and Quality of Life measurement.

Purpose of the Study

The purpose of this study was to analyze the legislation, SL 2015-245, and the relevant North Carolina DHHS guidance/regulatory documents using the Quality of Life framework indicators to determine if the legislation and proposed value-based measures to date, as enforced and clarified by the North Carolina DHSS, were designed to achieve improved quality of life outcomes for people with Intellectual and Developmental Disabilities receiving LTSS. A failure by the current legislation to address the holistic needs of people with Intellectual and/or Developmental Disabilities could negatively impact quality of life of service recipients and the larger system of network providers delivering services. Some of the concerns include:

a) the needed financial investments to revitalize the Medicaid programs (Sirko, 2021),
b) the measurement systems and outcomes which are value-based for the population (NCCHCA, Defining the Value of Care Management for Consumers, Families and Individuals with Lived Experiences in North Carolina: A Collaborative Approach, 2021),
c) the quality and consistency of care management across providers (i2i Center for Integrative Health & North Carolina Community Health Center Association, 2021),
d) the quality and availability of Direct Support Professionals (*The DSP Crisis: Reimbursement Rates, Retention, and Research*, 2021), the person-driven planning focus on provider identified goals versus recipient of service goals (i2i Center for Integrative Health & North Carolina Community Health Center Association, 2021), and
e) the equity of Medicaid services across geographic regions, ethnicities, and socioeconomic statuses (North Carolina Institute of Medicine, 2020).

To better understand the potential impact of the Tailored Plan the following research questions were investigated as part of this study:

1. How does NC Medicaid transformation propose to improve the services for people with intellectual and developmental disabilities in long-term supports and services?
2. How are Quality of Life principles, the professionally preferred best practices, reflected in the policies that have been enacted or proposed in North Carolina?
3. In what ways do the purposes, structures, outcomes, and implementation of NC Medicaid transformation indicate alignment with the domains of the Quality of Life framework? Also, in what ways do the purposes, structures, outcomes and implementation of Medicaid transformation indicate they are not aligned with the domains of the Quality of Life framework?

Significance of the Study

This study is important to the field for policy researchers and people participating (receiving services, supporting a family member, working as a provider of services, and/or making funding determinations) in the Intellectual and Developmental Disabilities communities. It has particular relevance for those living in North Carolina who will be directly or indirectly impacted by the changes to the Medicaid legislation through Session law 2015-245. If there are gaps in the legislation to ensuring the desired outcome, “measurement of activities related to quality of life, rebalancing, and community integration” (NCDHHS, 2018a, p. 14), then the critical policy review and QoL framework analysis will help to inform what considerations must be made to ensure the provision of a robust research-based and outcomes-based measurement system (i.e., value-based payment) for providers of people with Intellectual and Developmental Disabilities receiving Tailored Plan services in NC. These recommendations are critical as the

DHHS, through their MCO's, roll out value-based payment contracts in 2021-2023. North Carolina cannot fail its citizens with the most significant support and service needs and must be cautious of examples like that of Kansas, where Managed Care rollouts where Managed Care did not achieve the goals stated as a justification for their systems change (Nuss, 2017). Cost saving and improved care or quality of life do not always go hand in hand. This study will help to expose some of the potential shortfalls with North Carolina's Medicaid transformation through the Tailored Plans.

Description of Methods

Critical Policy Review

This critical policy review explores the proposed implementation of the BH/IDD Tailored Plans, set to launch April 2023, because the Tailored Plan will serve many people with Intellectual and Developmental Disabilities and is intended to improve the quality of life and care of the people being served. People with Intellectual and Developmental Disabilities, their families, provider agencies, funders, and other stakeholders (i.e., legislative members, community advocates, etc.) need to be aware of how these changes may impact the relationship with their service delivery system. This research explores the proposed legislative changes and expected improvements to the system, impacting 200,000 people, and critically considers them in relation to evidence-based frameworks of quality of life for persons with Intellectual and Developmental Disabilities. Through a critical policy research lens using the Schalock and Keith, 8-domain Quality of Life framework, we better understand the legislations purposes, structures, and potential outcomes through the implementation of managed care.

Analytical Frameworks

The research study employs critical policy analysis to investigate the recent legislative changes to North Carolina's Medicaid Managed Care program. Data are drawn from relevant state policy documents, legislative documents, public presentations, and evidence-based practices in the field of disability service measurement in quality of life, care management, and managed care implementation. Data have been organized from these primary documents into the Quality of Life theoretical framework tables, which are used to assess the robustness and potential gaps in the service delivery system within the regulatory and legislative documents. A further document analysis has been completed on DHHS white papers, concept papers, guidance's, reports, and presentations related to Medicaid transformation. These reports have been reviewed and information contained organized into themes.

Trustworthiness is be supported using triangulation among legislative documents, North Carolina Department of Health and Human Service policy papers, governing LTSS program regulations, presentations by public officials and evidence-based/research-based practices, all organized using a critical QoL theoretical lens. Extending the analysis, interpretations, and findings gathered during the process of conducting the critical social policy analysis are linked to larger theoretical and practical issues (Mariam, 1998). This research seeks to understand the power relationships that are impacting the LTSS for people with Intellectual and Developmental Disabilities, who are served under North Carolina's Medicaid Managed Care Programs Tailored Plan.

To deepen our understanding of the experiences of people with Intellectual and Developmental disabilities, we must also understand intersectionality of power and white supremacy within an American history of ableism rooted in racism. Disability Critical Race

Theory (DisCrit) is a theoretical framework and methodological tool to explore what has been overlooked, ignored, hidden, or intentionally not recognized within our society in order to maintain whiteness as a superior norm to that of all other people, and using ability (“Ableism”) to foster power structures in favor of whiteness (Annamma, Connor and Ferri, 2013). It is an appropriate tool to critique structures, systems, historical moments, practices in the field, and legislative reforms. DisCrit is especially helpful in connecting macro-level phenomena with real-life, micro-level experiences in understanding the impact of race and dis/ability. It is useful to broaden the analysis to explore the impact across multiple areas of life, such as education, housing, health, transportation, public services, economic opportunity, and self-determination. Race and ability intersect with dis/ability to create oppression among people identified as outside the norm by White Supremacy. DisCrit offers a lens to explore those intersections and their material impacts on people’s lived experiences (Annamma, Connor and Ferri, 2013). A deeper description of the Critical Policy Analysis methods is included in Chapter III.

Researcher’s Experience, Role, Perspective

I have worked with people with Intellectual and Developmental Disabilities who receive significant Medicaid supports since 2011. For 11 years, I have engaged in this system of supports and services as a Special Education teacher, an in-home caregiver, community advocate, Director of Operations & Director of Clinical Operations for Medicaid provider of LTSS, MCO Triad Region Provider Council President, MCO Regional Council Representative, Vice Chair of Intellectual and Developmental Disabilities Advisory, Board Director for Solutions for Independence-Center for Independent Living, and Deputy Director in educational training programs for frontline healthcare professionals. My time within this system and outside of it have shaped my attention to this transformation and how I plan to analyze it. My engagement in/with various workgroups (NC-Waiver Action Team, Intellectual and Developmental Disabilities Advisory), professional associations (North Carolina Community Health Center Association), boards (Solutions for Independence-Centers for Independent Living), and committees (LAND Advisory-NC Council on Developmental Disabilities) assists my understanding of the implications and challenges of NC Medicaid transformation and improving the quality of the services provided. Being present in these various capacities is essential to maintaining an understanding of the constant evolution of this transformation and provides the opportunity to offer insights and comments that may shape the systems and protocols being established.

Ensuring that every person, regardless of the severity of their disabilities or intensity of their services, receives supports and services that enable them to live full and meaningful lives and contribute positively to our society through activism, employment, volunteerism, social activities, as a consumer, and so forth is what is demanded by the IDD community. The QoL 8 domain framework, designed by Schalock and Keith (2016), was selected because of my commitment to utilizing research-based and cross-culturally validated frameworks that inform professional practice. Throughout my doctoral program, I have studied the Schalock & Keith (2016) QoL 8 domain framework as a tool to inform practice for professionals providing services to people with Intellectual and Developmental Disabilities.

Recent developments within the QoL framework, such as the cross-cultural validation (Schalock & Keith, 2016), use of QoL assessments to inform macro, meso, and micro-level reforms (Schalock, Baker, Claes, Gonzales, Malatest, van Loon, Verdugo, & Wesley, 2018), and budding theoretical application of the 8 QoL domains (Schalock, Verdugo, Gomez, & Reinders,

2016) have further intrigued me to explore other applications, such as informing value-based reimbursement models for people with Intellectual and Developmental Disabilities.

As a community advocate and professional serving people with Intellectual and Developmental Disabilities, I am always looking for ways to improve the quality of life through the provision of improved supports and services. Considering this evidence base, I have adopted the use of the QoL framework to analyze the BH/ IDD Tailored Plan. Alignment to this framework is essential to achieving the intended outcome of improving quality of life for people with Intellectual and Developmental Disabilities receiving Tailored Plan services in North Carolina's Medicaid programs.

Overview of Chapters

Chapter II, focuses on a detailed historical background related to Medicaid transformations towards Managed Care, the manner in which Long-Term Services and Supports have been rendered, and the outlook for current recipients of service who have Intellectual and Developmental Disabilities. We also address the historic use of the QoL framework to inform our best practices in service provision and measurement.

Chapter III, addresses the methodological approach to applying critical social policy lens of analysis to the legislative changes using the QoL framework as a framework for review. We discuss the purpose of the study, the data collection methods, data analysis strategies, trustworthiness, and how the findings were identified.

Chapter IV, reviews the findings of the comparative cross-walks, regulatory documents, policy documents, etc. with that of the QoL framework. Discussion will explore what those findings may means as far as identifying weaknesses or gaps in the legislative change to improve QoL. A deeper analysis of how neoliberalism, capitalism, white supremacy, and ableism impacts this transformation of services is also provided to understanding the realities for people with Intellectual and Developmental Disabilities living in NC.

Chapter V offers recommendations on how people like Mark and his allies can leverage opportunities within the transformation, while mitigating and advocating against the potential threats. Using a QoL life and DisCrit theoretical framework, we explicitly answer the research questions and provide insights into the contextual factors, a) the needed financial investments to revitalize the Medicaid programs (Sirko, 2021), b) the measurement systems and outcomes which are value-based for the population (i2i Center for Integrative Health & North Carolina Community Health Center Association, 2021), c) the quality and consistency of care management across providers ((i2i Center for Integrative Health & North Carolina Community Health Center Association, 2021), d) the quality and availability of Direct Support Professionals ((*The DSP Crisis: Reimbursement Rates, Retention, and Research*, 2021), e) the equity of Medicaid services across geographic regions, ethnicities, and socioeconomic (North Carolina Institute of Medicine, 2020), and f) support the goals for IDD services that stakeholders, individuals, families, providers, and the at-large IDD have worked toward for decades (Ancor, 2019), which impact the implementation of the Medicaid transformation and implementation of the Tailored Plans.

CHAPTER II: BACKGROUND AND CONTEXT

Medicaid transformation from a primarily fee-for-service model to value-based care and Managed Care is impacting over 2.3 million North Carolinians. This critical analysis study focuses on the impact of Medicaid transformation on persons with Intellectual/Developmental Disabilities served by the Tailored Plan. About 8.7% of Medicaid recipients in North Carolina are anticipated to be served by the Tailored Plan, which accounts for around 200,000 people.

The rollout of this Medicaid managed care product has been delayed due to impacts of COVID and to help ensure a successful transition (NCDHHS, 2019). Rollout is now anticipated to be implemented April 2023. This is the third delay, as North Carolina's General Assembly had already delayed the NC Medicaid transformation once for an entire year due to an inability to pass a state budget in 2018. County governments across the state considered or pursued to disengage from their Local Management Entity-Managed Care Organization (LME-MCOs) and pursue contracts with other LME-MCOs. Currently, Cardinal Innovations Healthcare has been dissolved due to county government disengagement, and Tailored Plan contracts have been awarded to Alliance Health, Eastpointe, Partners Health Management, Sandhills Center, Trillium Health Resources, and Vaya Health (NCDHHS, 2021b).

Moving between LME-MCOs means significant changes for each recipient of service and their providers of services. Within its geographic area, an LME-MCO is responsible for care management services, types and authorization for services, reimbursement rates, and several other functions. They continue to operate as new Private Health Plans (PHPs), entering the system and assuming responsibility for the Standard Plan Medicaid enrollees, many of whom were served by the existing Local Management Entities-Managed Care Organizations. It is possible that a state-wide provider may need to contract with 10+ different payers, in this new model, if they provide both Standard Plan and Tailored Plan services in NC.

The key components within the Tailored Plans to influence in favor of the recipients of service and their providers include, the value-based reimbursement models, quality of life outcomes measures, care management practices, expansion of services, standardization of process, and power structures/accountability models. will be interpreted and adapted as it they are implemented. Additionally, clarity is needed in these areas as the transformation unfolds:

- operations of care management (a key component to this transformation),
- a set of agreeable quality outcomes for value-based payments,
- equity of Medicaid services across geographic, ethnic, and socioeconomic statuses, and
- shoring up existing crises (e.g., DSP workforce, provider capacity, data sharing and reporting, and investment in HCBS)

Failure to analyze the effects of these changes will leave people with Intellectual and Developmental Disabilities who receive Long-Term Supports and Services without the intended benefits of this reform.

To understand the social equity and quality of life implications for people with Intellectual and Developmental Disabilities receiving LTSS through the Tailored Plan in North Carolina, we must understand:

- Disability Rights and Community: History, Social Responsibility, and Mandates
- Research-Based Practices in Service Provision and Measurement

- Fee-for-Service Models: Social Security Act/ Medicaid/ Local Management and Entity-Managed Care Organization
- Managed Care: Tailored Plans

Understanding these four key bodies of information through a critical lens of social policy provides the reader with a deeper knowledge of the phenomenon that is Medicaid transformation in North Carolina.

Disability Rights and Community: History, Social Responsibility and Mandates

In order to utilize the automatic table of contents, you will need to apply styles to your headings (as outlined in Chapter I). Once you have applied styles to your headings, you can then update the t The life afforded to people with Intellectual and Development Disabilities in America has greatly changed over the past two centuries. In the 1700s and early 1800s, people with disabilities were often segregated in farm-based and religious-based settings and systematically removed from their communities. For a time, the moral treatment movement seemed to focus on emotional well-being and treating people with disabilities humanely, while housing them outside of populated areas (*Disability History: Early and Shifting Attitudes of Treatment, U.S. National Park Service, 2017).* As a general bias, people with disabilities were still considered tragic, unfit, and feeble-minded during time period.

The utilitarian desire for everyone to contribute through productivity increased during in the 19th century, and schools emerged to train people with Intellectual and Developmental Disabilities. Economic conditions worsened and many people elected to send their loved ones to boarding schools, if they showed utilitarian potential, and/or institutions as states agreed to fund services for people with more significant disability supports. Between 1880 and 1900 the number of people with Intellectual and Developmental Disabilities living in institutions increased from

4,000 to 15,000 (Logsdon-Breakstone, 2012). By 1967, over 194,650 people with Intellectual and Developmental Disabilities were nationally housed in large state-operated institutions (Lakin et al., 2010). People with disabilities also ended up in jails, almshouses, poor houses, asylums for the mentally unwell, and hospitals, usually living in terrible conditions (Curan, 2005). Another 33,850 people with Intellectual and Developmental Disabilities lived in state-operated psychiatric facilities in 1967 (Lakin et al., 2010).

Eugenics

Eugenics, a belief that controlling genetics could improve the human species, has been prevalent through much of human history, from the discarding of children with birth defects in Sparta to the use of eugenics science in promoting the Trans-Atlantic slave trade. In more modern science, Darwin’s “natural selection” theory invited the discussion that protecting the societies weak would prevent advancing the human condition (Kibler, 2021). During the late 1800s and early 1900s, the moral movement diminished in favor of eugenics practices which focused on curing/correcting the disability and/or preventing procreation (i.e., sterilization, death-Nazi Germany, criminal penalties for marriage/relations, institutional confinement, etc.) (Kibler, 2021). The goal was to increase the number of so called “healthy people” and to eliminate as many “unhealthy people” from the future society through restrictions on basic freedoms. In addition, people with disabilities were organized subjected to “new” medical advances such as hydrotherapy and electroshock therapy. Other procedures like lobotomies were performed as recently as the 1950’s and are all connected to the eugenics science movement (*Disability History: Early and Shifting Attitudes of Treatment (U.S. National Park Service),* 2017).

The impact of the eugenics sciences and medical model of disability left us with the deficit-based approach to disability service in most of these providers. The deficit-based model of disability required the provider to identify the persons weaknesses and focus services on remediation and/or curing of that deficit. For people with significant life-long disabilities, curing and remediation of their disabling condition may not be possible or desirable. The public outcry to these conditions and the disability rights movement in the 60’s and 70’s facilitated the shift to community-based services rendered by community agencies who adopted positive psychology approaches (Curran, 2005).

Institutional Settings/Congregate Settings

In congregated and segregated settings, conditions and practices such as forced sterilization, beatings, lack of personal care, sickness, broken bones, physical and sexual abuse and a host of other affronts to the health and human rights of persons with disabilities occurred often. One can look as recently as Willowbrook State School of New York, which opened in 1947 and closed 1987 as a result of the national scandal regarding the treatment of people with disabilities in the institution Willowbrook State School Now on Staten Island (Frey, 2021) to see how prolific and horrific the conditions in these settings were. Due to this horrific treatment, people with disabilities have demanded the right to live in their communities.

Olmstead/ADA/ & Home and Community-Based Services

On July 26th, 1990 the Americans with Disabilities Act was passed after years of aggressive advocacy by people with disabilities for equal access. It guaranteed the rights of individuals with disabilities to receive reasonable accommodations to work and participate in all aspects of society and prohibits disability-based discrimination. This legislation built upon other critical legislative acts that improved the rights of people with disabilities, such as, the

Rehabilitation Act of 1973, the Fair Housing Amendments Act of 1988, and the Education for All Handicapped Children Act of 1975, now known as Individuals with Disabilities Education Act. President George W. Bush believed that the Americans with Disabilities Act would provide "the opportunity to blend fully and equally into the rich mosaic of the American mainstream" (Legal Aide Atlanta, n.d.). There is still work to be done to live up to this belief of people with disabilities living in the mainstream of American society.

In 1999, a landmark Supreme Court ruling, *Olmstead v. L.C.*, paved the way for community inclusion on behalf of people with disabilities. The "integration mandate" within the Americans with Disabilities Act (ADA) and the *Olmstead* ruling established that people with disabilities are expected to live full lives and that people who work or live in congregate settings have the right to the least restrictive setting within their community. Justice Ruth Bader Ginsburg stated that "unjustified segregation" of people with disabilities was a violation of ADA and is considered unlawful discrimination.

States found in violation of *Olmstead* and/or the ADA are required to develop a plan to implement changes to demonstrate actionable steps towards compliance. State Departments of Health and Human Services are responsible for providing home and community-based services to people with disabilities when: 1) the services are appropriate; 2) the person is accepting of the setting change; and 3) the services are able to be "reasonably accommodated, taking into account the resources available… and the needs of others who are receiving services…" (*Olmstead vs. L.C.,* 1999). This precedent across states enabled thousands of people with disabilities to leave institutional settings and find services in their community.

North Carolina's vision as outlined in the Olmstead Plan 2021 is for people with disabilities to exercise "their right to choose a life that is fully included in the community" (NC

Department of Health and Human Services, 2021). Our social responsibility is to ensure that people with disabilities are supported in their community in a way that promotes their individual contribution to our society. Today, our systems of support are working to evolve and shift the focus to home and community-based services and supports (HCBS). As an indicator of this progression towards community-based services and in-home services, we see trends of increasing proportions of Medicaid spending in Long-Term Supports and Services in Home and Community-Based Services (Elken, et al., 2018). Providers of HCBS are shifting to positive psychology and strength-based models of support that work to build on the person's strengths and mitigate the barriers to their attainment of individual goals. The focus is on environmental modification, education, and advocacy.

Developing Trends in Advancing Home and Community-Based Service Options

Since the expansion of funding for HCBS, passage of ADA, ruling on *Olmstead*, and other disability rights actions, there has been a significant reduction in people with Intellectual and Developmental Disabilities living in either community-based or state-operated institutions. By 2008, the number of people with Intellectual and Developmental Disabilities living in state-operated institutions dropped to 32,909 and only 765 lived in state psychiatric facilities (Lakin, et al., 2010). The population of children living in these settings has significantly dropped from 36% in 1977 to 5% in 2008 (Lakin et al., 2010). The population residing in state or community-based institutions have more complex support needs, but overall, more people with complex support needs are served in the community rather than in institutions (Lakin et al., 2010). The trend continues in a positive direction for people with Intellectual and Developmental Disabilities to be served in their community rather than state- or privately-owned institutions.

Community Integrative Service Models in North Carolina

In North Carolina, a new effort is underway to increase community living for people with serious mental illness (SMI) through the Transitions to Community Living (TLC) initiative. This model also could help inform transitions for people with more extensive disabilities. North Carolina's programs to support community integration for people with Intellectual and Developmental Disabilities include Medicaid Home and Community Based Services waivers, the Money Follows the Person program, the Children's System of Care model, and affordable housing efforts (NCDHHS, 2021). A waiver is a state specific Medicaid program which provides supports and services outside a nursing home (*Medicaid Definitions: HCBS, Waivers and Medicaid vs. Medicare*, 2021). The four primary waivers that support community integration of people with disabilities are: 1) the Innovations waiver for people with Intellectual and Developmental Disabilities, 2) the Community Alternatives Program for Children (CAP/C) waiver for children with complex medical conditions, 3) the Community Alternatives Program for Disabled Adults (CAP/DA) with complex care needs, and 4) the Traumatic Brain Injury waiver.

North Carolina has a waitlist of over 15,000 people for the Innovations waiver and 2,100 on the CAP/DA waiver waitlist. The CAP/C program is reaching is maximum count of 4,000 participants. The TBI waiver is a "pilot" with no waitlist, but only certain counties can access this service (NCDHHS, 2021). These HCBS programs intended to ensure that people with disabilities are able to maximize their potential living in their communities as the visionaries behind the ADA and the disability rights movement desired.

NCDHHS operates 14 facilities currently including, 1) developmental centers, 2) neuro-medical treatment centers, 3) psychiatric hospitals, 4) alcohol and substance use disorder treatment centers, and 5) two residential programs for children (NCDHHS, 2021). Through the LME/MCOs, the state also utilizes Intermediate Care Facilities (ICF), which serve around 2000 people with Intellectual and Developmental Disabilities. ICFs function to diagnose, treat, and rehabilitate while providing on-going evaluation, person-centered planning, 24-hour support and supervision, and management of health and service needs within a residential setting (NC Medicaid Division of Health Benefits, n.d.). ICFs are a remaining legacy of the institutional model of care within the Long-Term Supports and Services offerings for people with Intellectual and Developmental Disabilities. No moratorium exists to expand this service, but additional beds are unlikely to be created and applications for expanding ICF beds are rarely received (NCDHHS, 2021a).

The North Carolina Division of Health Service Regulations report that there are 337 Intermediate Care Facilities licensed as of 2022. To date, programs like the Money Follows the Person have helped to transition 636 individuals with Intellectual and Development Disabilities from nursing facilities, hospitals, ICFs, and psychiatric residential treatment facilities (NCDHHS, Dec. 2021). The Innovation waiver is the primary vehicle for the MFP program to transition individuals who are being served in an Intermediate Care Facilities and those who are at risk of being placed in an Intermediate Care Facility or State Institution. So, for a person like Mark who requires 24/7 care it is imperative that community-based in-home services exist, so that he does not need to live in a congregate/institutional care setting. The Innovations waiver provides the necessary Medicaid funding to pay for the in-home community-based supports and services which maintain his quality of life in his community. If Mark was living in an institutional setting or at risk of being place in one, he would benefit from the availability of the Money Follows the Person program to transition his funding from congregate/institutional care to community-based in-home care (i.e., Innovations waiver). Without these programs and services, people like Mark would be stuck living in congregate and institutional care settings, segregated from their community.

In conclusion, North Carolina's LTSS for people with Intellectual and Developmental Disabilities continues to evolve and transition toward more community integrated programs. The institutional legacy does remain across the system as a "lack of adequate community-based services and insufficient access to existing services are the primary factors contributing to the admission to, and extended stay in, institutional settings for individuals with disabilities" (NCDHHS, Dec. 2021).

An example of this institutional bias was seen in efforts to increase pay to $15 an hour for frontline Direct Support Professional (DSP) in state-operated developmental centers and state-operated facilities in 2018. Then legislation emerged for DSPs in Intermediate Care Facilities through HB665 in 2021 (NCDHHS, Dec. 2021). Finally, after incredible advocacy by families, provider associations, and disability advocates, Home and Community Based Service Providers' Direct Support Professionals were also included in the increase within NC's state budget July 2021-June 2022 (North Carolina Council on Developmental Disabilities, 2021). When the legislature allocates Medicaid rate and wages for institutional settings and fails to do the same in Home and Community-Based Services, they perpetuate institutional bias and promote services in congregate and segregated settings. The funding allocations have a huge impact on the availability of community-based services. For example, only funding State employed DSPs, who work in developmental centers, to $15 an hour while not doing so for DSPs working in the community, promotes a labor shortage in home and community-based services as staff resign and apply to work in congregate/institutional settings with higher rates of pay. It is prudent for North

Carolina to continue advancing the recommendations of the Olmstead Plan and that of disability advocates who encourage greater investment in HCBS and alternatives to institutional care settings for people with Intellectual and Developmental Disabilities.

Research-Based Practices in Service Provision and Measurement

In the previous section, we discussed the history of disability services in America and North Carolina, and we learned about the transitions and transformations in how services were delivered and what constituted best practice during that time period. We learned about the transition away from institutional level care and the shift toward community-based and integrative services for people with Intellectual and Developmental Disabilities. In this section, we are going to review the most relevant research-based and evidence-based practices in supporting the delivery of services to people with Intellectual and Developmental Disabilities. Understanding this foundation of practice will help to analyze the Medicaid transformation in North Carolina’s Tailored Plan and to see how it aligns or does not align with the research and theoretical best practices. The critical analysis will rely on a framework of disability service best practice and assess the implementation of the Tailored Plan against that framework. Understanding environmental models of disability, disability rights, supports-based paradigms, quality of life research, positive psychology, and strength-based advocacy will prepare the reader for the critical comparisons to emerge in Chapter IV.

Ecological/Social and Medical Paradigm of Disability

The history of support and services for people with disabilities has focused on predominantly biological or cultural pathology that exists within the individual. The medical model of health care, disability services, and mental health/ substance abuse supports is focused on identifying the person’s defects and curing, fixing, or eliminating those defects. The professionals providing service are seen as the sole power to correct and improve those conditions. The community of people with disabilities have argued that this model does not accomplish the goal of service users, who may strongly identify their identity with their disability.

The social model focuses on the barriers to the person's ability to participate fully in home and community life. This interaction between function and environment creates what are called *disabling environments*. The goal is to then change the environment to empower people with disabilities through education, accommodation, and universal design (Medical and Social Models of Disability, n.d.). At this time, "90% of healthcare spending in the United States is on medical care in a hospital or doctor's office" (NCDHHS, 2018, p. 1). While access to medical services is critical, the research has shown that up to 70% of a person's health is determined by "social and environmental factors, and other behavior influence by them," which lends more closely to the ecological/social model (NCDHHS, 2018, p. 1).

The shift toward an ecological/social model of disability is changing how service delivery is conceptualized as well as the desired outcomes (Schalock, 2004). Analyzing the perceptions, behaviors, and conditions of a person's interaction with their environment across Quality of Life (QoL) domains will provide introspection into the person's well-being (Schalock & Keith, 2016). The QoL concept uses an ecological/social model to approach disability, which means that it explores the person's interaction with their environment and considers in what ways the environment is deficient. Aligning the correct environmental paradigm with the disability service satisfaction measurement framework is essential to measuring the meaningful person-driven outcomes.

Rights of Persons with Disabilities

The egalitarian movement is based in human equality (i.e., social, political, and economic rights) foundations. From a legal viewpoint the egalitarian movement is seen in guaranteed education for children with disabilities, community-based service provision, and an end to overly restrictive service settings. In programming, the egalitarian movement has led to supports-based and person-centered planning, self-determination and advocacy, empowerment/rights, and quality of life related outcomes (Shogren et al, 2009). This movement led to the creation of an international convention by the United Nations to establish a new precedent in the rights of persons with disabilities, called the *United Nations Conventions on the Rights of Persons with Disabilities (CRPD)* (United Nations, 2006). The CRPD represent the first human rights treaty that has been developed by people with disabilities on behalf of people with disabilities. Building and embodying the ideology “nothing about us, without us” and based in the human rights paradigm of disability, the CRPD is a robust lens for critical scholarship. The CRPDs purpose is to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all person with disabilities, and to promote respect for their inherent dignity” (Article 1) (Series, 2019). The legal ramifications of this treaty are important, because violations result in violating international law and CRPD outlines measures to be taken when infringements on the rights of people with disabilities occur (Series, 2019). The process to critically analyze the North Carolina Tailored Plan implementation must include a framework that encompasses and reflects the values of the CRPD.

Supports Paradigm

The movement in the field toward support-based approaches has resulted in the following three significant impacts on professional practice:

1. assessing support needs,
2. determining the level of supports intensity to reduce environmental barriers to functioning, and
3. unifying multiple practices including person-centered planning, personal growth and development opportunities, community inclusion, and empowerment (Buntinx & Schalock, 2010).

Supports have been defined by Schalock et al., (2010, p. 175) as “resources and strategies that aim to promote the development, education, interests, and personal well-being of an individual and that enhance human functioning.” The goal is to determine what the present state of functioning is and what supports can be provided to maximize that person’s opportunity for the highest level of functioning. However, the goal is not to “fix” the person, because many functional limitations cannot be fixed within the current scope of medical practice, the individual’s personal viewpoint must be considered and not just the clinical label, and the “fixing” of functional limitations does not guarantee the person will have a better QoL (Buntinx & Schalock, 2010). Disability is the result of a discrepancy between a person’s functioning and opportunities to participate without support and the demands of the person’s social and physical environment. In the end, supports are designed to enhance a person’s functioning and enable participation (Schalock & Keith, 2016).

Positive Psychology

Positive psychology represents a shift in the field away from deficit-based models to strengths-based models that promote the unique characteristics that empower people to succeed. In this model, the multidimensionality of the human experience is recognized and used to identify and build on areas of strength (Schalock & Keith, 2016). The presumption of competence and the concept of a Least Dangerous Assumption (LDA) continues to support the belief in of positive psychology for people with Presumed Severe Intellectual Disabilities (PSID) and Complex Communication Disorders (CCD) (Jorgensen, 2005). Long-standing literature demonstrates that people with Intellectual Disabilities can learn to self-regulate or self-manage actions in ways that decrease their need for support (Agran, King-Sears, Wehmeyer, & Copeland, 2003; Schalock & Keith, 2016). Other studies have shown that people with Intellectual Disabilities can learn and use problem-solving and decision-making skills (Algozzine, Browder, Karvonen, Test, & Wood, 2001; Agran, Blanchard, Wehmeyer, & Hughes, 2002; Schalock & Keith, 2016). Positive psychology seeks to recognize "the valued subjective experience, positive individual traits, and civic values" (Wehmeyer, 2013).

Strength-Based Advocacy

Advocates are beginning to seek replacement structures and systems, based on a strength-based (Thompson, Wehmeyer & Shogren, 2016), social-ecological model (Stancliffe, Arnold, & Riches, 2016) that is aligned with the supports paradigm (Schalock et al., 2010) to change the conversation around Intellectual Disability. QoL instruments, assessments, and frameworks could potentially begin to be implemented within schools (Pazey, Schalock, Schaller, & Burkett, 2016) to assist in the identifying, planning, doing, and evaluating (Shogren, Schalock, & Luckasson, 2018) outcomes for students with and without disabilities.

The developments addressed in this section related to the field of Intellectual and Developmental Disabilities must be incorporated into the framework and lens used to analyze NC's Medicaid Transformation to the Tailored Plan. In the next section, we will explore the Quality of Life conceptual framework, which incorporates the ecological paradigm of disability, positive psychology, support-based paradigm, strength-based advocacy, and advancement of disability rights. Ensuring a holistic approach to critically analyzing the Tailored Plan implementation against evidence-based practices within the field of Intellectual and Developmental Disabilities supports and services.

Quality of Life Theory

QoL theory is founded on the contextual worldview of disability as an experience that "results from interacting individual and environmental factors" (Schalock, Verdugo, Gomez, & Reinders, 2016, p. 3). QoL theory is based on a clearly defined multidimensional quality of life model whose core domains are consistent with international quality of life conceptual and measurement principles (Brown, Keith, & Schalock, 2004; Schalock et al., 2002) and whose etic properties have been validated cross-culturally (Jenaro et al., 2005; Schalock et al., 2005).

There is a strong relationship between the articles of the *United Nations Convention on the Rights of Persons with Disabilities (CRPD)* (United Nations, 2006) and the 8-domains of QoL. The United Nations CRPD aligns with the QoL domains as follows-

> rights (access and privacy); participation; autonomy; independence and choice; physical well-being; material well-being (work/employment); social inclusion, accessibility, and participation; emotional well-being (freedom from exploitation, violence, and abuse); and personal development (education and habilitation). (Buntinx & Schalock, 2010, p. 284)

The QoL concept can be used to inform agencies, states, and countries about equity for people with disabilities within their systems of support and community environments. Additionally, the theory is comparable to other multidimensional quality of life theories that include core domains that operationally define the QoL concept and specify culturally sensitive domain-reference indicators that are used as the basis for measurement (Brown et al., 2013; Zuna et al., 2010).

The QoL theory and its application integrate the four significant trends currently influencing the field of Intellectual Disability: the socio-ecological model of disability, the supports paradigm, positive psychology, and the human and civil rights of persons with a disability (Schalock, Verdugo, Gomez, & Reinders, 2016).

> The importance of the quality of life concept is that it integrates these four factors [ecological model, supports paradigm, positive psychology, and rights of persons with disabilities] into a value-based, person-centered, and systematic approach to services, supports, and outcomes evaluation (Schalock, Verdugo, Gomez, & Reinders, 2016, pp. 8-9).

Measurement in QoL Theory

The QoL measurement foundations assess the degree to which well-being is attained and understood throughout the world, making them well-suited for acceptance among diverse groups of stakeholders (Verdugo, Schalock, Keith, & Stancliffe, 2005). Measuring QoL frameworks requires scientifically sound measurements based upon scrupulously researched QoL assessment scales. The eight domains most accepted by the field were developed out of a synthesis by Schalock and Verdugo (2002) from the works of Hughes, Hwand, Kim, Eisenman, and Killian (1995) and Keith, Heal, and Schalock (1996). The eight domains are:

1. personal development,
2. self-determination,
3. interpersonal relations,
4. social inclusion,
5. rights,
6. emotional well-being,

7. physical well-being, and
8. material well-being.

These domains have been “synthesized and validated through an extensive review of the international quality of life literature across the areas of IDD, special education, behavior and mental health, and aging” (Schalock & Verdugo, 2002).

A robust framework that is transferrable across populations due to its focus on both communication and cultural differences. It also focuses on the current perspectives of people with disabilities within an environmental and rights-based paradigm. Further, the QoL concept is defined by the following prominent features:

1. the degree to which the life experiences of people have meaning;
2. reflects domains that lead to a holistic and interconnected life;
3. considers important contextual factors such as, physical, social, and cultural environments in which people exist; and
4. measures experiences familiar to everyone as well as those unique to a few (Verdugo, Schalock, Keith, & Stancliffe, 2005).

With the recognition of these additional features, we can see that the Quality of Life (QoL) framework is an appropriate tool for the purpose of informing this critical analysis because it recognizes the value and worth of each person and focuses measurement on personal experiences, which helps to shift power within the system of service delivery away from provider or payer driven outcomes. The Tailored Plans must do more than simply render services; they must enhance the QoL of people receiving Long-Term Supports and Services (LTSS) within their provider networks. This requirement and goal set out by NCDHHS (DHHS) is important to people like Mark*, who has extensive and pervasive support needs, because he expects/demands his life to having meaning and purpose in a way that matters to him.

The models of QoL that are based in measurement and have been validated can be used to collect data that is used to evaluate personal outcomes and inform continuous quality improvement (Buntinx & Schalock, 2010). Schalock (2004) analyzed 16 research studies on QoL and found 125 indicators related to the 8 domains. This demonstrates the extensive potential of outcomes that could be included in an individualized care plan. The two drivers of QoL measurement systems have been the concentration of reform efforts toward assessing “the value and quality of respective programmes on the basis of consumer satisfaction and personal outcomes, and the development of new QoL-referenced models of intervention and service delivery” (Schalock, 2004, p. 206). The vehicle to changing service delivery and in improving satisfaction is improving the assessment, planning, and evaluation stages of care management.

The QoL concept offers a “framework for person-centered planning, a basic principle to guide service delivery policies and practices, and a model for exploring the impact of various individual and environmental factors on quality and life-related personal outcomes” (Schalock, Verdugo, Gomez, & Reinders, 2016, p. 1). This represents the ecological model of disability that analyzes the environmental demand and discrepancy between personal competencies to navigate those interactions.

> At its core, the concept of QoL gives us a sense of reference and guidance from the individual’s perspective, an overriding principle to enhance an individual’s well-being and collaborate for change, and a common language and systematic framework to guide our current and future endeavors. (Schalock, 2004, p. 214)

Several examples of systems adoption of the QoL framework are modeled internationally. These models usually rely on three levels of integrated data collection and analysis across the individual level, agency level, and societal/policy level. These three levels of measurement, data collection, and integrated analysis are described in the next section.

The prominent features shared above reflect pieces of this coming Tailored Plan implementation, e.g., 1) holistic and interconnected life will be directly impacted by the person-driven planning process within Care Management services, 2) contextual factors (social, physical, cultural, etc.) are intended to be improved using social determinants of health screenings and resource referrals, and 3) measuring experiences of people receiving Tailored Plan LTSS will require QoL measurement to comply with the Quality Strategy from NC DHHS. This aligns well for recipients of services because of QoL's grounding in the Intellectual and Developmental Disabilities fields most current paradigm shifts. It reflects the best practices and evidence-based practices and in the next section, a description of best practices in QoL measurement will be provided.

Three Systems: Macro, Meso, and Micro

The QoL concept has applications and impacts on various levels of the environment in which disability services are rendered. QoL measurement can occur at various levels (e.g., individual-micro, organization-meso, or societal-macro) to inform how well people receiving services are living a meaningful life. The progression of data collection begins at the individual recipient of service level through assessments, surveys and interviews. The collected QoL data are then used to inform programming, services, and supports. These data are then aggregated at the mesosystems level (i.e., organizational, provider, agency) to inform agency best practices, resource allocations, training, strategic planning, and systems changes. Finally, these agency data should be used to inform policy/funding at the macrosystems level (i.e., government, societal investment, and cultural values) (Schalock & Keith, 2016). QoL's framework integrates the application of continuous quality improvement (CQI) across all systems levels, using on-going data collection from both quantitative and qualitative methodologies. Reporting on QoL

Reporting of QoL

QoL instrumentation intends to measure the degree to which people feel fulfilled and value their life experience (Schalock & Keith, 2016) through the collection of self-reports, report of others, involvement of individual receiving supports, and assessments from interdisciplinary/clinical teams (Keith, Schalock, & Hoffman, 2016). Scales of QoL (e.g., Inico-Feaps, Gencat, San Martin, Kidslife, Personal Outcomes Scale (POS), POS Child and Adolescent (POSCA), (My Life Scale, etc.) can be used to inform continuous quality improvement efforts at all systems levels (Gomez & Verdugo, 2016). Assessing QoL serves to provide feedback to individuals across the various QoL domains (Loon, et al., 2013); some are etic (universal) and others, emic (culture-bound) (Jenaro et al., 2005; Schalock et al., 2005).

People with Intellectual and Developmental Disabilities experience some of the greatest disparities in education, employment, housing, community engagement, and health (Krahn & Fox, 2014; Larson et al., 2014; Siperstein, Parker, & Drascher, 2013). Systematic collection of qualitative data are useful for support teams, organizations, and governments, which can utilize contextual information to identify, plan, provide, and evaluate supports and services across multiple systems levels using longitudinal data (World Health Organization, 2011). Mapping longitudinal qualitative data that includes the voices of Individuals with Intellectual and Developmental Disabilities is critical to implementing supports and services that create meaningful benefits to QoL.

Researchers of Medicaid programs should consider the purpose of qualitative participatory action research as an opportunity to increase the self-advocacy of individuals with Intellectual and Developmental Disabilities through expression of “voice” and “perspective,” (Cohen, 1995) to unfreeze the status quo in policies and practices (Shogren, Schalock, & Luckasson, 2018). Creating meaningful improvements to QoL will require a framework that addresses contextual factors impacting various systems levels. The uses of within this context should be to:

1. use the QoL framework to examine issues across one or more of the 8 universal domains,
2. analyze and share data within a context-based change model to drive changes within the micro, meso, and macro systems, and
3. employ flexible data collection methods that ensure that the voices and satisfaction of individuals with Intellectual and Developmental Disabilities are captured.

Researchers in the field contend that the “all people, no matter how severe their level of disability, can and frequently do attempt to communicate” (Mirenda, Iacono, & Williams, 1990, p. 3) and the responsibility to hear those contributions lies with the listener (Razack, 1993). Using the QoL evidence-based practices will empower the voices of people with Intellectual and Developmental Disabilities and support the holistic person-driven reforms needed to unfreeze the status quo within provider networks and Medicaid payers.

Fee-For-Service Models: Social Security Act/Medicaid/Local Management Entity to Managed Care Organization

The Social Security Act of 1932 allows states to implement managed care delivery systems through managed care organizations and primary care case managers (Social Security, 2018). The authority to operate Medicaid managed care programs requires Federal approval. The most robust Medicaid managed care programs use either the State Plan Amendment (SPA), Section 1915(b) program waivers, or Section 1115 Research and Demonstration waivers. Additional programs can be offered under the Medicaid managed care program authorized by the Social Security Act, such as,

Table 1: Social Security Act Authorized Programs

Program for All Inclusive Care for the Elderly (PACE)	Section 1915(b)/1915(c) Combined Waiver
Section 1945 Health Homes	Section 1932(a)/1915(c) Combined Waiver
Section 1902(a)(70) Non-Emergency Transportation (NEMT) Program	Section 1937 Benchmark Benefits State Plan Amendment
1915(a) Waiver	1915© Waiver HCBS
Section 1915(a)/1915(c) Combined Waiver	1915(i) Waiver HCBS
1915(j) Waiver HCBS	1915(k) Waiver HCBS

Every waiver authority must comply with the Federal regulations, which require a quality managed care plan, allowance for proper appeal and grievance rights, adequate provider networks to ensure access, and opportunity to change between managed care plans. The waivers, 1932(a), 1915(a), 1915(b), 1915(c), 1915(i), 1915(j), 1915(k) and 1115 Demonstrations give States the flexibility to localize managed care delivery systems to specific areas, offer differing benefits to various people enrolled in managed care, and can require people to use managed care systems to access Medicaid services (Managed Care Authorities/Medicaid, n.d.).

In Appendix B, is a brief description of each waiver beginning with 1932(a) State Plan Basics, which allows states to provide Centers for Medicare and Medicaid Services with the type of entities that will be used to serve specific groups of enrolled persons. This plan can be operated, once approved, without the need to renew on a periodic basis. With this waiver authority, states cannot require dual eligible people, American Indians, or children with special health care needs to enroll to access their Medicaid services (Managed Care Authorities/ Medicaid, n.d.).

History of Fee-For-Service Medicaid Under Hybrid Local Management Entities and Managed Care Organizations in North Carolina

Using Waiver Authority from 1915(b1), 1915(b3), and 1915(b4) (Cardinal Innovations (NC-02), Retrieved 6-13-2021), Cardinal Innovations LME piloted a demonstration of Managed Care on April 1, 2005, which began the transformation from LME to LME-MCO in North Carolina. The financial hardship of 2011 in North Carolina's Medicaid budget resulted in the North Carolina General Assembly passing a bill to expand the pilot Managed Care Medicaid waivers statewide. The expansion meant the creation of six additional LME/MCOs to managed State, Federal, and County funds and operate as managed care organizations, overseeing and authorizing Medicaid waivers. This is a result of the state contracting with the LME-MCO to manage the Medicaid waivers. MCOs began authorizing many Medicaid services for people receiving LTSS in their geographic catchment areas (represented by individual Counties), with the exception of CAP/C and CAP/DA waivers. The LME-MCOs used the Medical Necessity framework, Service Definitions, and diagnostic information to determine type, scope, and duration of authorized services (NCDHHS, 2021). This meant that direct authorization and management of Medicaid waiver services was now conducted by independent organizations outside of the NCDHHS.

Impetus for Change

The state of North Carolina is responsible for providing LTSS to eligible residents through the use of their state and federal Medicaid funding. The system has been managed in silos through separate Physical Health, Behavioral Health, and Intellectual and Developmental

Disabilities services. The Physical Services are being provided through NC Medicaid Direct and Primary Care Case Management (PCCM) (i.e., Community Care of North Carolina), so that NC DHHS could administer the various health services. Behavioral Health and Intellectual/Developmental Disabilities services are delivered through LME-MCOs (NCDHHS, 2018*;* 2021). Combining these services, is part of the whole-person integrated care being sought by the North Carolina DHHS in this transformation. Increasing competition within the free market, integrating care, and changing payment models are expected to promote improved quality of life for people receiving LTSS in NC.

In North Carolina, LTSS programs have historically been operated under a quasi-governmental LME-MCO system using a fee-for-service reimbursement model, where health care providers are paid by the state Medicaid program for the delivery of service to the beneficiary. Fee for Service is based on an authorization for service, providing that service, submitting a claim, adjudication, payment, and post-payment review. These claims are paid based upon approved rates for each delivered service by an approved provider. The state pays the Local Management Entities-Managed Care Organizations on a *capitated* basis, a per member per month payment method (MACPAC, 2018). The MCO then pays providers within their network to deliver the authorized services (Congressional Research Service, 2021). The provider reimbursement rates are controlled and managed by the LME-MCOs. Most states have used this model for Medicaid delivery, but the move toward Managed Care has increased dramatically since the 1990s. States traditionally move their beneficiaries with the least complex health care needs to managed care delivery systems, but increasingly more are electing to do the same with persons with disabilities who have more complex health and care needs (Congressional Research Service, 2021).

Managed Care: Tailored Plans

Changing the structures of payers and methodology for payment to providers from fee-for-service to value-based purchasing represents a major shift and opportunity to improve service deliver to people with Intellectual and Developmental Disabilities. The change is intended to improve Quality of Life for people receiving Long-Term Supports and Services under Medicaid waivers. North Carolina will operate two systems, the LME-MCO not-for-profit model and the Prepaid Health Plan for-profit model under its CMS approved Managed Care waivers. The Medicaid Managed Care program will operate like a health insurance plan, where Prepaid Health Plan (PHP) will assume some risk as they are responsible for covering the medically necessary services for enrollees. They are paid using a fixed amount by person and medically necessary enrolled services. In this arrangement the PHP can make a profit of up to 15%, as the Medicaid program requires that 85% of funds go toward service costs. Managed Care is designed to control the growth of the cost trajectory by helping to integrate care and connect the person with medically necessary services as soon as they require them. The overall purpose is to better use available funding to prevent acute expenditures. The strategies employed to help generate saving are:

- a focus on preventative care,
- early intervention, and
- directing to appropriate care early in treatment.

The outcome intended from these strategies is to deliver whole-person care, impact a full set of factors related to social determinants of health, localize care management, and maintain a broad network of providers by reducing administrative burden (Cohen, 2018).

Types of Services and Supports

The Behavioral Health Integration for the Standard and Tailored Plans consists of breaking down silos between physical health, behavioral health, and pharmacy providers across both populations served in their respective plans. The Standard Plan will cover those who do not have significant support needs, but those who may need:

Table 2: Standard Plans Coverage (NCDHHS, 2021b)

a) inpatient behavioral health services	b) outpatient behavioral health emergency room services
c) outpatient behavioral health service provided by direct-enrolled providers	d) peer support services
e) partial hospitalization	f) mobile crisis management
g) facility-based crisis services for children and adolescents	h) professional treatment services in facility-based crisis program
i) outpatient opioid treatment	j) ambulatory detoxification
k) research-based behavioral health treatment	l) diagnostic assessments
m) non-hospital medical detoxification	n) medically supervised or alcohol and drug abuse treatment center detoxification crisis stabilization
o) early periodic screening, diagnostic and treatment	

The Tailored Plan will be responsible to North Carolinians with the greatest need and will maintain on-going support through care management services (Cohen, *NC Medicaid Transformation Section 1115 Demonstration Waiver*, 2018). The Tailored Plans will manage the programs in the table below:

Table 3: Tailored Plans Coverage (NCDHHS, 2021)

a) Residential treatment facility services	b) Child and adolescent day treatment services
c) Intensive in-home services	d) Multi-systematic therapy services
e) Psychiatric residential treatment facilities (PRTFs)	f) Assertive community treatment (ACT)
g) Community support team (CST)	h) Psychosocial rehabilitation
i) Substance abuse intensive outpatient program (SAIOP)	j) Substance abuse comprehensive outpatient treatment program (SACOT)
k) Substance use non-medical community residential treatment	l) Substance use medically monitored residential treatment
m) Intermediate care facilities for individuals with intellectual disabilities (ICF/IID)	n) Waiver Services: Innovations Waiver Services
o) Waiver Services: TBI Waiver Services	p) Waiver Services: 1915(b)(3) services-additional support services that focus on helping beneficiaries remain in their homes and communities
q) State-Funded BH and I/DD Services	r) State-Funded TBI Services

See Appendix C for a more detailed description of the specific covered services within these programs. These programs represent the most intensive treatment/service options for North Carolinians with Traumatic Brain Injury, Intellectual and Developmental Disabilities, and Behavioral Health support needs.

Responsibilities of the Payers in NC Medicaid Transformation

The LME-MCO is required to ensure that all participants receive their medically necessary services and supports, LME-MCOs cannot deny services to save money. The five to seven remaining LME-MCOs (i.e., Cardinal Innovations Healthcare, EastPointe Healthcare, Vaya Health, Alliance Health, Partners Health Management, Sandhills Center, Trillium Health

Resources) and six additional PHPs (i.e., AmeriHealth Caritas of North Carolina, Healthy Blue, UnitedHealthcare of North Carolina, WellCare of North Carolina, Carolina Complete Health, Inc., and Eastern Band of Cherokee Indians (EBCI) Tribal Option) began operating Medicaid services under the Standard Plan, July 1st, 2021, for most Medicaid and NC Choice enrollees.

The Standard and Tailored Plans are a part of the 1115 Demonstration waiver which is also written as a Managed Care waiver. The Tailored Plan will begin operation with the existing LME-MCOs in April 2023 for enrollees with complex care needs, such as special behavioral health services, substance use conditions, and Innovations waiver for people with Intellectual and Developmental Disabilities. The LME-MCOs will operate the Tailored Plan for four years before a Request for Proposal will allow non-profit organizations to compete with the LMEs for the waivers beginning in 2026. Additionally, the Medicaid transformation will include an Opioid Strategy to increase the access to inpatient and residential substance use disorder treatment through provision of services at institutions of mental disease, and provide a more expansive array of substance use disorder treatment options for a full continuum of services.

Lastly, Healthy Opportunities Pilots provide flexible monies to pilot innovative Medicaid managed care health programs in a couple North Carolina regions. The expectation is that these pilots work collaboratively with the Managed Care plans to implement evidence-based strategies, find cost effective treatments, and consider five key social determinants of health: housing, food, transportation, employment, and interpersonal safety (NCDHHS, 2019). A value-based payment system will be used to link payments to the pilot programs as they achieve health outcome benchmarks and efficiencies improve. These pilots will be researched and evaluated to help disseminate efficiencies in care and improve outcomes, while ensuring accountability for the

Medicaid funds usage. $650 million in federal and state Medicaid funding will be provided to these pilots through October 2024, at which time they will be evaluated (Cohen, 2018).

Measurement of Fulfillment and Responsibility to Recipients of Services with Intellectual and Developmental Disabilities

The demands on providers have increased (e.g., workforce crisis, cost of living increases) (Smith, Macbeth, & Bailey, 2019), and meaningful quality measurement systems are lacking (Boyette, Cohen, & Jones, 2018). Many provider agencies who deliver LTSS in North Carolina employ quality person-centered planning processes to help people live their lives in a meaningful and successful way, achieving unique goals that are specific to their quality of life. *North Carolina's Medicaid Managed Care Quality Strategy* (2021) reiterates the requirement of the Tailored Plans to ensure measurement of the providers fulfilment of the individualized service plan as written and across settings. However, current reform activities and implementation/strategy papers for the Tailored Plan's measurement have not alluded to how fulfilment of service delivery measurement will be achieved. Also, a focus on other less individualized quality outcome reporting measures (e.g., Healthcare Effectiveness Data and Information Set) creates the concern that the systemic change in North Carolina's Medicaid programs will not result in improved quality of life for people with Intellectual and Developmental Disabilities receiving LTSS in NC. The proposed solution, SL 2015-245, which moves the NC Medicaid program further into managed care and value-based reimbursement models and away from fee for service reimbursement, requires scrutiny to determine the opportunities for improved service delivery and to identify and address gaps between the proposed reform structures and the field of Intellectual and Developmental Disabilities evidence-based practices and supports.

The LME-MCOs and private insurance companies [i.e., the Prepaid Health Plans (PHPs)] will be responsible for reporting aggregated outcomes data collected from their provider networks. These entities are learning about the data reporting requirements alongside providers and have yet to adopt an approach to obtaining, aggregating, measuring, and analyzing the data for the purpose of informing continuous quality improvement plans across the various populations served (NCDHHS, 2019). Especially challenging for these organizations is how to approach collecting data-outcomes from providers serving people with intellectual disabilities in Long-Term Supports and Services (LTSS), since the model of care and desired outcomes is different from the medical model, which is focused on improving/curing physical and mental illness and eliminating substance abuse. The ecological/environmental model is based upon individualized self-determination and preference for quality-of-life improvements.

LTSS providers will be required to report on outcomes "related to quality of life, rebalancing, and community integration activities for individuals receiving LTSS, and reflect best practices identified by the National Quality Forum" in this new Medicaid reimbursement structure (NCDHHS, 2018). The traditional outcome measures derived from the medical model alone, the Health Effectiveness Data and Information Set (HEDIS) measures, may not lead to the improved outcomes for people with Intellectual Disabilities desired by the visionaries (i.e., Deputy Secretary for NC Medicaid and Secretary of NC Department of Health and Human Services) of Medicaid reform and all the other impacted stakeholders.

Factors Impacting Transition to BH/IDD Tailored Plans and Services for People with Intellectual and Developmental Disabilities

The 1115 Demonstration Waiver authorizes the Secretary of Health and Human Services, under the Social Security Act Sec. 1115, to approval demonstrations, pilots, and investigatory projects that support and advance the Medicaid and CHIP program objectives. There is significantly more flexibility in the program to do things like provide services typically not covered by Medicaid or covering uncovered persons previously ineligible. These proposals must remain budget neutral with the expected Medicaid program costs for the state and must be renewed at 5-year intervals (About *Section 1115 Demonstrations/ Medicaid,* n.d.). In fact, the Deputy Secretary for NC Medicaid stated "The federal government, when we do an 1115 waiver and all of our waivers require that they are budget neutral. What that really means is that we do not increase spending beyond what the state and federal government projections would have been without the waiver," further he goes on to say, "…we're pleased to announce that CMS has agreed that the waiver will not increase North Carolina's Medicaid spending for these populations and services authorized under the waiver" (Cohen, 2018, p. 6). The waiver will seek to utilize Medicaid funding more efficiently to mitigate high-cost acute care. The 1115 waiver has three unique features: 1) Behavioral health integration, Tailored Plans, 2) an Opioid Strategy, and 3) Healthy Opportunities Pilots.

The transition to value-based payment is risky for providers who are unprepared to meet the requirements for reporting consumer outcome data and continue to face both funding and staffing crises (Burwell & Kasten, 2012; Smith, Macbeth, & Bailey, 2019). Providers have watched funding streams stagnate and the subsequent deterioration of on-site clinical services with each year. Providers need a clear indication of how the system rewards and penalizes using reimbursement programs tied to consumer achievement outcomes if they are to be successful in this transition.

Additionally, conflicting research exists about the impact of managed care on services for people with disabilities in the United States. Yamaki, Wing, Mitchell, Owen, & Heller (2018) found that managed care did not have the intended impact of reducing acute health expenditures and remained cost neutral to the previous system. Also, few studies have actually examined changes in quality, preferring to focus on measuring cost reductions and savings. People with Intellectual and Developmental Disabilities, however, value both access and quality and believe those are essential components of quality Medicaid managed care (Gibbons, Owen, & Heller, 2016). Further, people with Intellectual and Developmental Disabilities who receive LTSS are a most vulnerable populations within this change. They are the most at-risk and rely on these systems of services more than most other populations being affected. They also experience some of the most disruption within their services today, whether it is due to staffing shortages, poor person-centered planning, institutional bias for funding, etc. The legislative goals are lofty for this population and improving quality of life on both an individual and systems level, and they will require significant change within the structures and protocols, funding, personnel knowledge and skills, and oversight/data collection.

Current Activities within Managed Care Transformation

Currently, the NC DHHS is hosting a Tailored Care Management Technical Advisory Group to serve as the primary venue for stakeholders to engage in advisory conversations that will inform the Tailored Care Management launch. The DHHS expects that members will take issues raised among the advisory group back to their respective organizations and networks to promote dialogue among stakeholders. They began meeting on Oct. 29th, 2021 and will continue to meet monthly through September 2022. Advisory members were selected from representatives of future Tailored Plans, provider organizations that are certified or candidates to become certified as Care Management Agencies (CMAs) or Advanced Medical Home Plus (AMH+), and Tailored Plan consumer population. Topics of discussion will include areas, such as workforce, capacity building, conflict-free care management, quality measurement and incentives, Health Opportunities Pilots, member engagement, data strategy, and other ongoing program design.

The NC DHHS has conducted a series of Tailored Care Management 101 Webinars, which are designed to help develop a shared conceptual understanding of the model across the NC provider community and vested stakeholder groups. They were conducted between October and December 2021. The NC DHHS has also released the Tailored Care Management Provider Manual (June, 9th, 2020), an addendum to the manual on Community Inclusion (March 19th, 2021), as well as several bulletins during the summer of 2021 to prepare the AMH+ and CMAs and BH and IDD Tailored Plans to begin preparing for this transition. Additional information wase released in early 2022 on updates to the Tailored Care Management Provider Manual, Tailored Care Management Rates, Guidance on Care Manager Extenders, and New Frequently Asked Questions Resource from Tailored Care Management Webinar Series. Additionally, in early 2022 to June 2023, NC DHHS will also distribute $90 million across the state to help capacity building efforts of providers who will be engaging in Tailored Care Management. The investments will help to address weaknesses or deficiencies in information technology infrastructure, workforce development, and operational readiness (NC Medicaid Division of Health Benefits, n.d.-a).

While these efforts to prepare the system for transition are vital, many questions remain unanswered for a population of people with the most significant support needs in the NC Medicaid program. A significant debate is occurring around financial solvency of the care management service, which at a glance seems both under-funded and under-prepared to assume the whole-person, integrated care, at the provider level. Recipients of services that will be offered under the Tailored Plan continue to face obstacles around staffing, reimbursement rates, skilled competency-based training for professional delivering direct services, consistency across LME-MCO processes, procedures, and services, and evidence-based frameworks for person-centered planning and quality of life data measurement.

Chapter II Summary

In this study, a critical lens is applied during this transition to managed care for people with Intellectual and Developmental Disabilities receiving LTSS in NC. Although the goals seem desirable, the research is lacking in how quality is impacted for people with Intellectual and Developmental Disabilities in managed care, due to the low percentage in that model. In addition, the research that has been conducted has focused on efficiencies and cost savings rather than quality of life outcomes (Friedman, 2019). Without adequate study and research, a caution should be taken when implementing a system without an evidence-base for the population being served (Friedman, 2019). An overarching trend has been to hyper-focus on safety and standardized measures that inform the state of the system, rather than focusing on the individuals person-centered plan goals and desires. People with Intellectual and Developmental Disabilities require more than physical wellness to have a quality of care and life through a meaningful disability support service through Medicaid. They desire self-determination, equity, and equal participation.

Through a critical theory lens using the QoL 8 domain framework, the purposes, structures, and potential outcomes of the legislation and the regulatory documents that govern the implementation of LTSS for people with Intellectual and Developmental Disabilities will be highlighted. We ask does this reform address the systemic concerns (i.e., structural, financial, and quality) facing the providers and the people with Intellectual and Developmental Disabilities receiving LTSS? This critical policy study explores the current system managing LTSS within

North Carolina, the new legislation currently being implemented, and the best practices in the field of disability service provision and measurement (i.e., QoL) to reveal the purposes, structures, and potential outcomes of the legislation and regulatory structures that comprise this payer change.

In Chapter III, the methodological approach to conducting the critical policy analysis is explained and we consider the multi-faceted framework which is used to inform the analysis. The research question specific to this study is described along with the setting, data collection methods, data analysis strategies, ethical consideration, trustworthiness, and study limitations.

CHAPTER III: RESEARCH METHODS

The purpose of this study is to utilize critical policy analysis to analyze North Carolina SL 2015-245, the relevant NCDHHS and Centers for Medicaid and Medicare Services (CMS) guidance, regulatory documents, and presentations, using the Schalock & Keith Quality of Life theoretical frameworks eight-domain indicators. The goal is to determine if the legislation and value-based measures proposed to date are designed to achieve improved quality of life outcomes for people with Intellectual and Developmental Disabilities receiving Long-Term Supports and Services in North Carolina. The study identifies the opportunities in the legislation to address critical concerns in the service delivery system, including a workforce crisis, rate stagnation, and more complex medical outcome-based reporting requirements within the increasingly complex Medicaid payer system.

This research also explores the legislation's potential impact on the quality-of-life outcomes for people with Intellectual and Developmental Disabilities, who disproportionality live in poverty, are unemployed, live alone or are lonely, and have other poor social determinants of health like access to transportation, medical care, and food (Friedman, 2019). The concern is that too many payers of service 1) increase administrative burden, 2) create excessive competition and/or varying requirements, 3) cause reporting requirement discrepancies, 4) vary the authorization processes, and 5) lessen the responsibility on the part of the state legislature, which relies heavily on LME-Managed Care Organization's to manage the service delivery for people with Intellectual and Developmental Disabilities (Porter, 2021; Cohen, 2018). Ensuring that this reform mitigates those concerns and others will be paramount to a successful transformation in North Carolina.

To conduct this study, the following research questions have been crafted and aligned with critical policy analysis research methodologies. The three questions align to paint a picture of what is intended, how the intended outcomes align with the evidence-base in QoL, and what that alignment or lack of alignment tell us about the purposes, structures, and potential outcomes of the transformation.

Research Questions:

1. How does Medicaid transformation propose to improve the services for people with intellectual and developmental disabilities in long-term supports and services?
2. How are the domains of the Quality of Life framework addressed in the Legislation, Regulations, and/or guidance from NCDHHS/Centers for Medicaid and Medicare Services?
3. What does an analysis using the QoL framework reveal about the purposes, structures, and outcomes of the legislation and the regulatory documents that govern the implementation of Long Term Supports and Services?

Description of Methodology

The research methodology consists of applying a critical policy analysis and Quality of Life theoretical lens to understand and forecast how this Medicaid transformation may impact people with Intellectual and Developmental Disabilities receiving Long-Term Supports and Services (LTSS) in North Carolina. Specifically, the critical policy analysis explores the impact on people with Intellectual and Developmental Disabilities who will receive their services through the Tailored Plan from remaining Local Management Entity-Managed Care Organization's (LME-MCOs) for four years after implementation.

Critical policy analysis is useful for a deep understanding into the issues surrounding Medicaid transformation to managed care within a real-life context (Young & Diem, 2017). The concern is that this Medicaid reform may not improve quality of life for people with Intellectual and Developmental Disabilities. To better understand the potential gaps, it is helpful to use the QoL domains to organize proposed quality standards accepted by Centers for Medicaid and Medicare Services (CMS), NCDHHS, and the Local Management Entities-Managed Care Organization's (LME-MCOs), and Prepaid Health Plans (PHPs) for value-based reimbursement. The intention is to uncover the gaps, revealed through the application of the eight domain QoL theoretical framework, of the legislation and proposed implementation documents for this system of care delivery. Use of the term quality of life is often found in the legislative actions, but rarely do we see specific outcomes stated that align with the robust literature on QoL (Turnbull, Turnbull, Wehmeyer, & Park, 2003).

This study uses a similar methodology to other critical policy reviews that seek to

1. explore policy roots and processes,
2. how policies which are touted as reality are merely political rhetoric,
3. uncover the inequitable distribution of knowledge, power, and resources,
4. demonstrate the impact of policies on social stratification, and
5. how policies institutionalize inequity (Young & Diem, 2017).

In addition, critical policy analysis researchers often focus on three foundations:

1. the environment and nature of systems from which policy is implemented,
2. theoretical frameworks and theorizing as a part of methodology, and
3. a reliance on more qualitative approaches to research (Young & Diem, 2017).

Within this study, the context of NC Medicaid Transformation is understood by examining the legislative, departmental, and insurance payer/provider service model that delivers essential services to people with Intellectual and Developmental Disabilities. Using a QoL theoretical framework for critical policy analysis aligns with best practices in measurement of Intellectual and Developmental Disability Services. The paradigms that act as the foundation of the QoL theory reflect the values and perspectives of me, the researcher, as I am using my experience to apply a critical lens to generate an understanding of this policy change. The analysis is conducted through triangulation of multiple sources of data and critical approach functions as a lens that anchors one's personal vantage point from a position of moral order, ensuring justice, equality, and individual autonomy for marginalized persons (Thrupp & Timlinson, 2005). These lenses support the process of analysis by revealing the values and socio-economic politics that create certain policies for certain people and how those intended outcomes are realized through implementation.

Two examples in the research come from Turnbull, Turnbull, Wehmeyer, and Parks (2003) and Pazey, Schalock, Schaller, and Burkett (2016), who had the dual purposes of 1) addressing the lack of attention paid to students with disabilities in current educational reform policy/legislation and 2) utilizing the QoL concept as a framework to initiate policy-oriented action in both existing and proposed reform initiatives. The authors used the QoL concept as a framework to discuss and propose policy-oriented action for students with disabilities. They found that IDEA's four main tenants aligned with 5/8 QoL domains. Pazey and colleagues questioned why not apply QoL to educational reforms affecting all students? I have similarly generalized the use of the QoL theoretical 8 domain framework to disability Medicaid service legislation to identify the gaps in services impacting children and adults with Intellectual and

Developmental Disabilities receiving critical Long-Term Supports and Services. Pazey, Schalock, Schaller, and Burkett (2016) used a similar methodology as that of Turnbull, Turnbull, Wehmeyer, and Park (2003).

A critical policy analysis of NC Medicaid transformation and the implementation of the Tailored Plan calls for the unpacking of the policies that have a direct impact on the quality of life of people receiving LTSS. Research in the field has agreed with the use of qualitative methods to conduct critical policy research (Young & Diem, 2017; Ball, 1990; 1999; Gale, 2001; Halpin & Troyna, 1994). By pulling the legislation and contextually relevant documents apart through the QoL ideological and theoretical lens, we can challenge the neutrality and rationality of the legislative bodies and institutions implementing the policy changes (Troyna, 1994). Power must be considered throughout the analysis to uncover who is involved, how the process is conducted (who is included vs. who is excluded), and whose interests are primarily served (Marshall & Peters, 1999).

Critical Disability Policy Analysis

Drawing from DisCrit, critical disability theoretical foundations, which seeks to understand the power dynamics and human embodiment as it relates to identity and disability, the analysis will cover the impact of neoliberalism, capitalism, white supremacy, and ableism on this transformation. Critical disability theory involves an “in-depth analysis of the structural and as-yet incompletely understood psychic underpinnings of oppression” (Burghardt, 2011, pg. 13). One form of oppression involves devaluing an individual based upon their disability. We need to better understand the socio-political constructions of disability and how those construction impact and oppress people with disabilities. DisCrit helps us to understand the lived experiences of people with disabilities and how to transform the contextual factors/environmental factors/political and power factors that continue to oppress (Minich, 2016). Being accountable to the lives of people with disabilities, fostering emancipatory discourse, and understanding and construction of disability identity are important to positioning the researcher's and readers' worldview around various events and phenomena (Goodley, Liddiard, & Runswick Cole, 2018; Meekosha & Shuttleworth, 2009). The reader should also note that disability is unique as an identity because anyone can enter and at any time (Garland-Thomson, 2002)

The DisCrit theoretical and methodological approach provides a framework to explore to influences of race and ability as constructs of whiteness that have legitimate impacts on marginalized peoples. Annamma, Connor and Ferri (2013) find that racism and ableism work together in validating ways which reinforce one another. Much of racism is grounded in the attempt by whiteness to show itself as intellectually superior to all other peoples. People with disabilities were used as the example of being outside the desired norm. People of color were often associated with being less able and intellectual inferior and more likely to be labelled with a disability. There are serious consequences to be labelled as disabled, including isolation and rejection from cultural, ethnic, and other groups of affiliation (Goodwin, 2003). External societal labels impose identities on individuals through structures promoting racism and ableism. DisCrit helps to expose these structures, practices, and norms of whiteness embedded within our culture to support the realized power of marginalized people. DisCrit is founded in seven principles:

1. A focus on the impact of racism and ableism, which are independently upholding the notions of normalcy ("Whiteness").
2. Promotes the recognition of multidimensional identities.
3. Emphasizes the material, psychological, and social construction of race and ability and being outside those norms of whiteness.

4. Promotes the voices of marginalized people in research and decision-making.
5. Explores power within legal and historical moments, which have denied rights to some citizens.
6. Understands that improvements for people with disabilities are in the best interest of the white power structures.
7. Promotes activism and forms of resistance. (Annamma, Connor and Ferri, 2013)

The notion that “disability” is outside the reasonable scope of human variability of course is inaccurate, but nevertheless used as a foundation for racism, ableism, and practices and policies like eugenics. Both ableism and racism are so entrenched in the societal norms that they are difficult to recognize. This analysis helps to expose the normalizing process of ableism and racism within our society and its impact on people with Intellectual and Developmental Disabilities (Annamma, Connor and Ferri, 2013). The material consequences of being labelled as outside the norm have resulted in people with dis/abilities being kept quarantined (Foucault, 1977). The cognitive testing and Jim Crow era laws were employed to use ability as a justification of removing a person of colors’ rights and the prospertiy? (Bonilla-Silva, 2006). Creating a line of marginalization using ability founded in racism has been used to maintain white power structures (Annamma, Connor and Ferri, 2013). For people of color and people with disabilities, a significant outcome has been state-maintained segregation through the prison/justice system, education system, and residential disability services systems. DisCrit challenges the segregation of people based on dis/ability and promotes the voices of people experiencing this marginalization. People with disabilities have had to suffer the double-edged sword of requiring a label to receive specialized services that they need, but they must endure segregation, stigma, and questionable quality outcome metrics in receiving those service (Hart et al., 2009).

DisCrit promotes the full inclusion and belonging of people with disabilities in society and is useful in understanding how the Tailored Plan will impact full integration and self-determination. The ways in which IDD services are rendered, funded, and monitored directly impacts the ways in which people with IDD express their citizenship and see themselves as citizens. The ideal citizen is seen as contributing, healthy, strong, ready to defend the nation, and work, reproduce and expand. People not representing these attributes or representing the opposite attribute are often associated with societal drain and cost (Terry and Urla, 1995).

Applying the DisCrit framework as a component of the critical policy analysis helped to uncover the impacts of this reform for people with IDD across multiple areas of life. DisCrit is also a tool to help marginalized people resist oppression and reclaim their identities and material realities (Annamma, Connor and Ferri, 2013). This research is intended to support the advocacy and resistance of people with disabilities experiencing marginalization in service delivery, society, and within this Medicaid reform. Through this inductive process, the knowledge and findings are socially constructed and reflect my experience as a participant in this phenomenon, alongside colleagues, self-advocates, and their families (Stake & Turnbull, 1982).

Setting

The setting for this study is bound to North Carolina and specifically to the services rendered by the state to support people with Intellectual and Developmental Disabilities. Specifically, we are looking at a Macro level policy initiative led by the North Carolina State Legislature, North Carolina DHHS, and Centers for Medicare and Medicaid as it relates to Intellectual and Developmental Disabilities services. The current setting is a predominantly fee-for-service payment model through a quasi-Managed Care system (LME-MCOs), with four new Private Health Plans to administer basic health and LTSS Medicaid benefits via the Standard Plan. The existing LME-MCOs are preparing to offer the Tailored Plan in April 2023 People in North Carolina who are living with Intellectual and Developmental Disabilities are anxiously participating in this transformation, and they are watching and waiting to better understand how it will directly impact their service delivery. The recipients of LTSS services are living a challenging existence right now due to long-standing workforce availability issues, quality concerns, lack of service fulfilment, poor measurement systems to measure satisfaction, and insufficient HCBS. Many of these issues have been exacerbated by the COVID-19 pandemic, which has caused a strain on both recipients of service, their families/caregivers, the providers networks, and the health and human service systems. There is both hope and apprehension about the transformation to Managed Care and Value-based payment models for the LTSS received by people with Intellectual and Developmental Disabilities.

Data Collection Methods

To conduct this research, a review has been conducted on transformation documents on the DHHS website, public documents provided at forums, and through an in-depth literature exploration in the disciplines of Quality of Life, Intellectual and Developmental Disability Service evidence-based practices, Ecological, Supports and Rights-based Disability Paradigms, Medicaid Community Waiver Programs, Medicaid Managed Care and Payment Methodologies, and history of disability in North Carolina (Schalock, Pazey, Turnbull, Shogren, Series, Stancliffe, Logsdon-Breakstone, Elken, Curan, Lakin, Mitler and others cited in the document).

All the legislative acts, policy papers, guidance’s, reports, webinars, presentations, and transcriptions are maintained on the NCDHHS website. The transformation documents were downloaded, read, and analyzed using QoL framework annotated notes and/or graphic organizers to monitor the development and evolution of the Medicaid managed care implementation and associated themes. They serve as the historical and procedural guidance to understand the conceptual, procedural, financial, and political environment surrounding this transformation. Other sources of data included publications related to managed care for HCBS, value-based outcomes for people with Intellectual and Developmental Disabilities, LTSS transitions to Managed Care, and the use of QoL to measure satisfaction. These data sources were reviewed and content within themed and connected to the existing literature/research base.

Data Analysis Strategies

In 2004, over 20,900 articles had been published since 1985 with the term “quality of life” in the title (Schalock, 2004). The study of QoL has taken many different methodological approaches, depending on the questions being answered. To prepare this research study, the article Pazey, Schalock, Schaller, & Burkett (2016) was reviewed. In this article, the researchers shared a brief literature review of the QoL framework and disability-specific education policy in the US and then applied the QoL 8-domain framework as a tool to crosswalk the core requirements and conceptualization of the Individuals with Disabilities Education Act (IDEA). They found significant overlap between the QoL framework and the components of IDEA, promoting the idea that a QoL measurement system might be more appropriate for school reporting requirements than other federal and state requirements. Turnbull et al., (2003) also used the QoL framework to explore education reform and found that the tenants of IDEA aligned with five of the QoL domains.

In these studies, the researchers used the 8-domain QoL framework to explore regulatory and legislative documents to explore connectivity and build on the robustness of the QoL concept. The strength of this approach builds confidence in the comprehensiveness of the concept by demonstrating connections between recognized and accepted field standards and practices and the framework under exploration for application. The weakness of this approach is that it is still subjective to the researcher's perception of alignment between domains and field standards/practices. Validating the alignment process with multiple researchers and establishing a protocol will help with reliability of the data.

For this research, effort will be made to address some of the weaknesses of previous research studies using this methodological approach. The set of documents that have been reviewed for this stud, cover a span of over six years, including conceptualization and implementation guidance, white papers, and policy papers related to North Carolina Medicaid transformation. An in-depth review and analysis occurred to assist in theme identification as well as search for patterns, contradictions, or discrepancies between these documents.

Data analysis also consisted of reviewing the LTSS delivery system and current regulatory documents governing HCBS services at the macro levels through a critical QoL theoretical lens. At the macro-level we rely on the analysis of current HCBS service regulatory guidance, proposed Centers for Medicaid and Medicare Services quality standards for managed Medicaid tied to HCBS waiver services, and additional information obtained from Centers for Medicaid and Medicare Services and NCDHHS white papers, Requests for Information, presentations, and other documents (e.g., fliers, PowerPoints, etc.). Using the QoL eight domains and evidence-based practices in the field, an analysis of the holistic and integrated Managed Care model can be conducted to answer the research questions.

Finally, the collected data and themes will be triangulated with existing themes in the research to inform the various interpretations of the data. Other information sources to inform the analysis are available from disability advocacy agencies, such as ANCOR and North Carolina Provider Council. The North Carolina Provider Council also serves as a forum to present and validate analysis of documents with other agency field leaders and researchers implementing quality outcome measurement systems within their respective agencies. I participated in a sub-committee of the organization called the Data Measurement Strategies Committee, where colleagues assisted in reviewing the proposed alignments to QoL. I am using materials from those meetings, but I am not including information from human participants. Through this inductive process, generalizations, themes, and recommendations have emerged to answer the research questions (Stake, 2005).

Ethical Considerations

Within social policy, there is an ethical obligation to reveal and share the potential effects of policies, to question and speak up against policies that may cause human suffering or harm, and stand beside marginalized people with Intellectual and Developmental Disabilities who require LTSS to manage their lives and hopefully enjoy a quality of life (Apple, 2019). Ethically, I must also disclose my bias and personal perspective that people with Intellectual and Developmental Disabilities are being severely under-funded, represented, and respected within our health and human services system. They are marginalized and disempowered through a complex bureaucracy that has limited services, and left over 15,000+ people waiting for support, through a complex system of Medicaid waivers. Even people receiving Medicaid waiver services are often unable to enjoy the benefits of that waiver service, due to insufficient staffing and other issues related to workforce quality and capacity.

I also must consider my personal background as a person who is white, Canadian, from a middle-class family, who experienced a learning disability in reading but who is currently living without a disability causing any limitation in life functioning. I must acknowledge my closeness to the problem and personal desire for a system that will provide needed financial relief to providers serving individuals with disabilities. I must also consider my belief in full inclusion and how that may impact my assessment of legislation's overall quality, and how my personal beliefs, while research-based, may not reflect those of everyone in the community who will be personally impacted.

Additional ethical concerns to be aware of, in relation to this type of research, are the attempts to serve various political objectives. Medicaid and its transformation are highly political, and it serves a very critical population who rely on this lifesaving and supporting services. Changes to this delicate system can have great impact on individual's lives.

Trustworthiness

To provide a reasonable degree of trustworthiness with these findings, the research utilizes the following recommended qualitative case study practices:

1. research questions are clearly written,
2. triangulation is used to support theme analysis and answers to the research questions,
3. sampling was purposeful,
4. data was systematically organized and collected as it became available, and
5. data was analyzed using the appropriate critical policy lens, aka the QoL theoretical framework (Russel, Gregory, Ploeg, DiCenso, & Guyatt, 2005).

Triangulation analysis techniques were used to inform the findings (Knafl & Breitmayer, 1989), largely focusing on triangulating macro-level policy documents from Centers for Medicaid and Medicare Services and DHHS with evidence-based and QoL theoretical foundations. Implementation requirements and guiding documents were compared to overarching politically influenced reform language and communication of desired outcomes.

My personal experience offers me a unique perspective of this transformation. I have attended webinars, trainings, presentations, read an array of advocacy-based policy white papers (NADSP, CQL, ANCOR), and closely followed every announcement and policy-oriented paper from Centers for Medicaid and Medicare Services & NCDHHS. I actively participated on the call with Centers for Medicaid and Medicare Services discussing the RFI for HCBS quality outcomes measurement with fellow colleagues from NCPC sub-committee.

In relation to QoL, I have been studying and applying that concept to both practice and research for over six years across my doctoral program. I have taken a personal interest and completed several independent studies, taking a deep dive into QoL history, research, measurement in monitoring and reporting, theoretical applications, and foundations. Working closely through email, phone calls, and webinars with Dr. Robert Schalock has been another strategy to ensure that my approach to research is in line with the field's expectations (Krefting, 1991). Finally, the analysis of macro level documents with the QoL framework was initially performed by during my role as a Director of Clinical Operations for an IDD provider. Part of this professional role included interacting with professional peers in the field who participated in investigating how the QoL framework was being implemented in NC. This reviewed analysis helps to ensure that the findings are agreeable across experts in the field. This overall should support dependability (Krefting, 1991).

Limitations

Some NCDHHS policy documents, if not uploaded to the public domain website, may not have been considered in this study. There is a possibility that not every policy document provided by NCDHHS, was read if it was not uploaded to the public domain website. It is important to understand that these findings are also specific to a population of people with Intellectual and Developmental Disabilities being served through Long-Term Supports and Services through North Carolina’s Medicaid Tailored. These constitute the significant limitations to the research, and it should be acknowledged that there is a personal connection to the phenomena and that personal perceptions, gained through inductive exposure to the phenomena, are a part of the findings. These perceptions may reflect bias on my part, the researcher, despite efforts to mitigate such interferences.

Chapter III Summary

In Chapter III, the methodology was described and the process of conducting the critical policy research. Through the application of QoL and DisCrit frameworks an analysis of the outcome measures and key documents connected to the implementation of the Tailored Plans is provided in Chapter IV. The Chapter IV analysis provides an insight into the opportunities and threats associated with the transformation to the Tailored Plans.

CHAPTER IV: ANALYSIS

In this study, the QoL and DisCrit frameworks will provide lenses that will inform people with Intellectual and Developmental Disabilities and their allies about the nature of the Medicaid transformation. The goal is to showcase opportunities and threats to the lives of people with Intellectual and Developmental Disabilities, while also resisting forces and power structures that marginalize people with disabilities by promoting ableism and racism.

This chapter begins with a description of the key documents that were analyzed using the QoL framework is provided. This includes the degree to which the measures/requirements/standards/best practices included in these documents aligned with the eight domains of the QoL framework. Next, an overview of the goals of NCDHHS and North Carolina General Assembly in implementing the Tailored Plan for people with Intellectual and Developmental Disabilities. Lastly, we explore the current transformation under the lens of critical policy analysis and discuss the realities and motivations behind the transformation by looking at power structures, ableist and racist underpinnings, breadth of representation among the community of people with Intellectual and Developmental Disabilities, and opportunities to resist marginalizing factors/practices/goals/structures/and spaces. This prepares us for Chapter V's recommendations and opportunities for change to combat threats while promoting the quality of life opportunities in the language of the Tailored Plan.

If sufficient alignment with the QoL framework exists within the reform at the policy level one recommendation would be to use of the QoL evidence-based measurement system as a reporting and monitoring mechanism to inform the North Carolina General Assembly, Department of Health and Human Services, their subcontractors, the Managed Care Organizations and Prepaid Health Plans, and people with Intellectual and Developmental

Disabilities and their allies of the successfulness of the Tailored Plans. Further, the critical lens of DisCrit is empowering to the community of people who demand “nothing about us, without us” and provides a tool to support self-determination and resistance of oppression through knowledge, critique, and deeper understanding.

People with Intellectual and Developmental Disabilities and their allies demand that improved quality of life outcomes materialize, and they continue to resist the realities of their service delivery (i.e., understaffed, undertrained, lost service hours, lack of community-based services, housing crisis, lingering impacts of COVID, waitlists for critical services, etc.). I hope this critical policy analysis helps to further those advocacy efforts in the face of much confusion and complication as capitalistic politics reshape the way health care and disability services are paid for and provided in North Carolina.

Analysis of Quality Measure Sets

NCDHHS is utilizing quality measures for the initial roll out of the Standard and Tailored Plans that come from the following sources:

- Healthcare Effectiveness Data and Information Set (HEDIS) measures;
- National Committee for Quality Assurance (NCQA) health plan accreditation requirements;
- Centers for Medicare & Medicaid Services (CMS) Adult and Child Core measure sets (NCDHHS, 2022);
- National Quality Forum;
- The Institute for Healthcare Improvement;
- The Agency for Healthcare Research and Quality (AHRQ); and

- Substance Abuse and Mental Health Services Administration (SAMHSA) (NCDHHS, 2021).

These initial identified measure sets and potential future expansion sets, were reviewed against the QoL framework, domains, and definitions to determine the alignment between value-based measure outcomes and the evidence-based QoL framework. In addition, North Carolina DHHS has selected the National Quality Forum domains to organize measures. This domain framework was also compared to the QoL framework for analysis of structural oversight of service delivery and identified outcome measure sets within.

To begin the analysis, we review the current value-based Behavioral Health I/DD Tailored Plan Medicaid measure set, from which initial accountability plans will prioritize and focus on. As the implementation continues, it is expected that additional measures will be added and refined. We will also review many of the existing requirements within I/DD programs, as well as those outcome measures that are pending or potentially next to be added as outcome measures.

Behavioral Health I/DD Tailored Plans Medicaid Measure Set

In the policy paper, *North Carolina's Medicaid Quality Measurement Technical Specifications Manual for Standard Plans and Behavioral Health Intellectual/Developmental Disability Tailored Plans* (2022) NCDHHS, provides initial outcome measures, the responsible agency for administering/collecting the measure, and an alignment to QoL domains. Appendix E provides the coding analysis and measure information for the Behavioral Health I/DD Tailored Plan Medicaid Measure Set, which is going to serve as the initial set of measures during implementation.

This initial set of measures is completely focused on the individual’s health, health services, and health needs, sleep, activities of daily living, access to support aids and food/nutrition—all aspects of the physical well-being domain of the QoL framework. We do not see the other seven domains represented in this measurement set. This omission of the other domains is troubling in that beginning frameworks of value-based payment systems will solely focus on health-related outcomes, which do not reflect the broad language of the reform to improve recipients of LTSS quality of life. Initial reporting structures and payment models should reflect a diversity of outcomes across domains for the population using LTSS, so that providers are incentivized for supporting person-centered plan outcomes across the non-health related domains.

Behavioral Health I/DD Tailored Plans State-Funded Measure Set

This set of measures is used to infer quality provided to Tailored Plan enrollees who are supported in their services using North Carolina state-funds as opposed to Federal Medicaid funds. The table in Appendix F provides an overview of measures, responsible agencies, and QoL aligned domain for analysis.

In this set of measures, for which the key monitoring body is NCDHHS, there continues to be a primary focus on physical well-being. Three of the twelve measures are aligned with the material well-being domain which focuses on employment, housing, wages belonging, and assets. Hence, material well-being and physical well-being are the only two domains represented by the measures for Tailored Plan services using state-funds. The other six domains remain unaccounted for and in the next section, we review the final adopted measures set that will apply to both Standard Plans and Tailored Plans.

Standard Plans and Behavioral Health I/DD Tailored Plans Measures Set

The measures reviewed in this section apply to both Standard Plans and Tailored Plans with the initial launch of Managed Care. See the table in Appendix G to review the alignment between measure and QoL domains.

The measures set for both Standard and Tailored Plans relies on a 30 identified metrics to focus initial quality and performance improvement plans managed by Prepaid Health Plans (PHPs). These 30 metrics are once again primarily related to the physical well-being domain, with two measures having a secondary alignment with material well-being (i.e., CAHPS survey and measure of institutional residential placements- housing impact). One measure, the CAHPS Home and Community-Based Services Survey, represents all eight QoL domains, although each domain is only touched on and not extensively covered. The CAHPS measure covers the primary topics of:

- Receiving necessary services;
- Access and outreach from providers;
- Quality of case manager;
- Choice making within services;
- Transportation for medical needs;
- Safety; and
- Empowerment and community inclusion. (CAHPS, 2017)

The CAHPS survey questions align with the QoL domains in the following ways. **Emotional well-being** is covered through questions about safety and situations that may have jeopardized personal safety. Some examples include questions about threats, verbal abuse, poor treatment, exploitation, and physical abuse. **Interpersonal relations** are seen in the questions regarding access to friends and family and positive interactions with homemaker/staff. **Self-determination** is present in questions related to making decisions about use of time, activities of daily living, and leisure/recreation. It is also present in the questions about services and the recipient of services ability to make changes to focus on things that are important to them. **Personal development** is marginally highlighted in questions about understanding staff explanations easily, being provided opportunities to learn when working with staff and being encouraged to do things for oneself. **Rights** is accounted for in questions about equal treatment from staff and homemakers, for example respect, privacy, dignity, and being listened to carefully. It is also represented in questions that address identification of needed services and provision of staff to fulfil the service plan. Some questions ask about the consequences of the unavailability of staff on health and well-being. **Social inclusion** is seen in questions about needed supports to access community activities, recreation, and leisure. This includes questions about access to transportation for non-medical needs. **Material well-being** is addressed in questions related to in-home conditions (laundry, cleanliness, etc.), the provision of supports to live in that environment, and if the person receives/needs support for employment related tasks. Material well-being is also present in a question about having needed support to obtain or repair adaptive equipment such as, wheelchairs and walkers. **Physical well-being** is the most dominant representation of QoL category within the survey. It represents questions related to personal care (e.g., showering, toileting, dressing), nutrition (e.g., support to eat), medication management, medical transportation, and overall satisfaction with physical health and mental health.

Summary of Measure Sets Analysis

We can draw from these measures set analysis that almost all measures focus on the physical well-being domain of the QoL framework. Fortunately, the CAHPS Home and Community-Based Services Survey includes questions to address all eight domains of the QoL framework, though not robustly. Concerns exist that Long-Term Supports and Services (LTSS) measurement will focus on outcomes that are skewed so much in favor of physical well-being and only a couple of measures will cover the material well-being domain. Having only one measure to represent the other six QoL domains means that LTSS providers have limited options to showcase their value and impact outside of physical well-being domain. We have also made an assumption that the CAHPS survey tool that will be implemented by NCDHHS for LTSS recipients will be the Home and Community-Based Services Survey and not one of other healthcare surveys for physical health services.

In the first three measure sets, we see an overwhelming focus on adopting outcomes measures that focus on physical well-being. A handful focus on the secondary category of material well-being. Only one measure accounted for any other domains of the QoL framework. In the next section, we review additional proposed measures, existing measures/standards within current LTSS programs, and alignment between QoL and National Quality Forum (NQF) domains.

Proposed Measure for Future Implementation

NCDHHS (DHHS) has indicated that in subsequent years of the reform to Managed Care additional quality outcome measures and metrics will be implemented. Some metrics are connected to a growing focus on social determinants of health that are becoming increasingly prevalent. Other measures will come from accreditation. The North Carolina DHHS has indicated that it will require Prepaid Health Plans (PHPs) to obtain National Committee for Quality Assurance (NCQA) accreditation. Some accreditations are specific to services/programs. LTSS is an additional accreditation for each PHP to render LTSS services in North Carolina. NCQA, in addition to Health Plan accreditation, provides a health measure set called Healthcare Effectiveness Data and Information Set (HEDIS), a widely used healthcare improvement tool with 90 measures across 6 domains:

- Effectiveness of care
- Access/Availability of Care
- Experience of Care
- Utilization and Risk Adjusted Utilization
- Health Plan Descriptive Information
- Measures Reported Using Electronic Clinical Data Systems (NCQA, 2022)

HEDIS measures are currently included within the outcome sets identified and implemented by the North Carolina DHHS for the initial roll out. An expansion of these measures is likely.

In addition, certain Medicaid LTSS programs/services, such as Home and Community-Based Services (HCBS), have standards that are specific to those services that enable people with disabilities to live in the community of their choosing. In addition, outcome measures specific to HCBS are being released for additional input by Centers for Medicare and Medicaid Services (CMS). We can surmise that these measures from the Centers for Medicare and Medicaid Services (CMS), which fund a significant portions of North Carolina’s HCBS services, will later be used to further measure quality among providers of HCBS.

Lastly, NCDHHS (DHHS) has developed a Social Determinants of Health Screening Tool, which addresses factors outside of healthcare which impact a person's health and wellness. In this section, we will review the following documents 1) 2023 HEDIS Measures, 2) the Recommended Measure Set for Medicaid-Funded Home and Community-Based Services, 3) Social Determinants of Health Screening, 4) HCBS Final Rule, 5) NC HCBS Final Rule Transition Plan, and 6) HCBS Setting Optional Tool.

2023 HEDIS Measures

The National Committee for Quality Assurance (NCQA) provides a health measure set called Healthcare Effectiveness Data and Information Set (HEDIS). These measures are widely adopted across healthcare settings as a tool to help improve the effectiveness of healthcare services provided physicians, Preferred Provider Organizations (e.g., Prepaid Health Plan), and other organizations. NCQA reports that over 200 million people are enrolled in healthcare plans that use HEDIS measures to report results (NCQA, 2022). See Appendix H for review of the 2023 HEDIS measures against the QoL framework.

The analysis of the HEDIS 2023 measures confirms that they are all aligned with the physical well-being domain of the QoL framework. Only one measure (i.e., Social Need Screening and Intervention) had a secondary QoL domain alignment with material well-being. Material well-being is linked because the measure covers housing and transportation needs.

We know that NCQA will play a critical role in Prepaid Health Plan oversight, primarily as the accreditation organization for them to deliver Standard Plan and Tailored Plan services. This critical role in PHP oversight and current adoption of select HEDIS measures for the implementation phase of Standard and Tailored Plans gives a strong indication that additional measures from this HEDIS 2023 may be included in future monitoring efforts. These measures are highly focused on physical health and do not provide opportunities for providers to be monitored and recognized for services and supports that align with the other seven domains of the QoL framework.

Final Measure Set for Medicaid-Funded Home and Community-Based Services

Home and Community-Based Services (HCBS) are a type of Long-Term Services and Supports (LTSS) that are provided in the beneficiaries' home or communities rather than an institutional setting. Trends over time indicate increased spending on LTSS on HCBS programs and a decreased spending on institutional settings. States have utilized HCBS programs to comply with Federal and State rules and decisions, for example the Americans with Disabilities Act (ADA) and the *Olmstead* decision, where it is unlawful to isolate people with disabilities in institutional settings. In North Carolina, *Samantha R. et al. vs. NCDHHS* was filed by Disability Rights NC (DRNC) in 2017 on behalf of people with disabilities who were institutionalized or at risk of institutionalization due to the states failure to provide adequate community-based services (Disability Rights North Carolina, 2022). The judge has ruled in favor of *Samantha R et al*., but NCDHHS has appealed the ruling. As the ruling stands, the state of North Carolina is required to expand access to home and community-based services. A few other requirements include:

- Provide services to the 16,314 people currently on the waiting list of Innovational Waiver slot, which is the HCBS waiver in NC, within 10 years.
- Address and resolve the immense shortage of Direct Support Professional workers.
- Assist 3,000 people in their request to leave or avoid institutional settings and cease new admissions to institutions within 6 years, except for short-term stays (e.g., respite and short-term stabilization).

- State must collect data and submit quarterly reports on each measure to the judge, DRNC and it will be posted publicly. (Disability Rights North Carolina, 2022)

With all of the emphasis shifting to Home and Community-Based Services in North Carolina, it is prudent to examine the measure set now prescribed to HCBS by CMS, as it will serve as the reporting structure for states and their contracted PHPs. Below, we examine the measure set which has been in development for the last seven years, through a Rehabilitation Research and training Center grant funded by the Health and Human Service's Administration for Community Living's National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) to develop, test, and obtain National Quality Forum (NQF) approval for HCBS quality measures. Their development was initiated by an NQF report in 2016 that emphasized the need for a core set of HCBS measures and a menu of supplemental measures for specific populations, settings, and programs. Initially, this researcher examined the Recommended Measure Set for Medicaid-Funded HCBS that was sent out as a Request For Information, which included a base set, extended set, and potential set for future implementation. The HCBS Quality Measure Set was also organized into 11 domains that are intended to ensure an extensive breadth and depth of monitoring. However, in the final version the measures are organized by 1915(c), the Medicaid authority described in Appendix B, waiver assurances and sub-assurances. The measures do not exhaustively cover all assurances and sub-assurances required by states operating HCBS programs (Centers for Medicare and Medicaid, 2022).

This final measure set was released in a letter to the State Medicaid Director in July 2022. It provides additional information about which measures can be used to assess assurances and requirements as set forth by the HCBS Setting final rule, another document that is analyzed later on in this chapter. An example of how the HCBS Quality Measure Set will address assurances within HCBS programs implemented by states can be seen in the measures that ensure:

- All participant needs and goals are addressed in the service plan, using waiver services and other means;
- Annual revisions occur to the service plan or when warranted by changes in need;
- Delivery of services occurs in conjunction with the service plan, which outlines the type, scope, amount, duration, and frequency; and
- Choice is provided to recipients within waiver services and providers.

This is a key component to examine, as right now using these measures is voluntary, but state actions to operationalize the appropriate service delivery as outlined in the service plan will be both reported and monitored. This shift moves the monitoring responsibility away from the recipient and their family to the providers, the PHPs, and the state.

Initially, the use of this measure set is voluntary, but within a short time it will be used to collect data on specific programs and authorities (e.g., Money Follow the Person) and additional reporting guidance will be released soon to help state prepare for reporting requirements on many HCBS assurances using this measure set (Centers for Medicare and Medicaid, 2022). See Appendix I for review of the Final Measure Set for Medicaid-Funded HCBS against the QoL domains.

The Final Quality Measure Set for HCBS is much more inclusive of the eight QoL domains that any other measure set reviewed so far. It encompasses all eight domains of QoL framework, the same as the Recommended Measure Set, with the exception of a few measure changes for example within the Personal Development domain. These two measures (i.e., NCI 32 and NCI-AD-14) were not included in the final set. These measures had to do with people expressing their desire to increase independence in functional skills and case manager recommendations for services to help meet unmet needs and goals. Overall, this set of measures aligns much more closely with the specific population of people with disabilities and what the field promotes as core values (independence, support, equality, growth, and inclusion).

Criticisms on the HCBS Quality Measure Set

Criticisms/recommendations for changes to these measures have emerged however from disability advocates and organizations (e.g., ANCOR and North Carolina Providers Council) who feel they still need to change or be thoughtful of some key considerations. These concerns include:

a) A need to enhance person-centeredness, the use of person first language, and measurement of recipient’s satisfaction and overall quality of life;
b) A need to reflect the preferences of people with I/DD and develop more population specific measures;
c) Oversee that base payments remain sufficient as measures become incorporated into value-based payment models;
d) Be considerate of different provider maturities and abilities to report, ensuring not to create an abundance of reporting burdens;
e) Pilot project certain measures that are more specific to life-satisfaction and personal outcome measures;
f) Be cautious of having too many required measures, but offer a wide array of extended measures (ANCOR, 2020)

Additionally, the Consortium for Citizens with Disabilities (CCD) has issued recommendations that focused on transparency, community input, context within providers and meaningful measurement, enhancing community integration measures, promoting health equity, filling measure gaps, and alignment with the HCBS Settings Rule to provide required assurance reporting (ANCOR, 2020). These comments and recommendations can be seen in the Final Quality Measure Set for HCBS. For example, CMS has decided to align the quality measures with the various assurances required by the HCBS Setting Rule, and although the measures do not fully cover the HCBS Setting Rule assurances and subassurances at this time, it is noted as an area of expansion by CMS. Other measures like Personal Outcome Measures are also seen in the Final Quality Measure Set for HCBS, which attempts to incorporate personal satisfaction measures. CMS is agreeing to use a specific set of measures on certain programs, gradually rolling out more over time, as a way to not shock the system of services and supports.

In conclusion, the future implementation of the Final Quality Measure Set for HCBS and its direct linkage to providing documentation of certain HCBS Final Setting Rule assurances and sub assurances, guarantees that it will become more impactful across the service delivery landscape in time. For now, we can celebrate the fact that it does incorporate all eight domains of the QoL framework and we can seize the opportunity to enhance the measure set and the provider/service delivery context by taking into consideration the recommendations shared above.

Social Determinants of Health Screening

Within North Carolina’s shift to Managed Care, a central component has been to focus on what are called social determinants of health or those other non-health related factors that impact a person’s wellness. The North Carolina DHHS conducted a literature review of best practices related to screening and identifying social determinants of health. In doing so, North Carolina DHHS was able to identify screening questions that had been nationally validated for a variety of factors outside of healthcare that impact overall health (i.e., food, housing, transportation, and interpersonal safety). The research strength is that the findings (i.e., screening questions) reflect a broad review of the available research and synthesizes the best practices and themes.

Social and environmental factors can determine as much as 70% overall health (NCDHHS, 2018). For example, typically a person with asthma will be treated for their condition when being seen at a physical health facility, but with social determinants of health service providers also inquire into that person’s environment and living situation to determine if some other social service intervention may help with their asthma. For example, the asthma may be exacerbated by a very old and soiled carpet, and after connecting the individual to a local church who could help with the renovation the persons’ asthma improved and they no longer needed to be seen by a physician. This results in a better use of health care spending, while also addressing more holistically the needs of people being seen by health care facilities. See Appendix H for an overview of the alignment between the Social Determinants of Health Screening tool and the QoL eight domains.

We are still unsure how this Social Determinants of Health focus will be incorporated into specific services and programs for people receiving LTSS and who have Intellectual/Developmental Disabilities. The scope and breadth of the questions does at least partially address factors within every QoL domain. The questions do help to investigate areas of interest that impact well-being outside the singular perspective of health care and offer a broader understanding of what it means to be healthy and how systems of support and service can be redesigned to connect people to what they need rather than what is available.

However, the weakness of the NCDHHS literature review is that is failed to include a robust QoL concept, which is evidenced in the current screening tool questions. For example, in transportation the question asks: “Within the past 12 months, has a lack of transportation kept you from medical appointment, getting your medicines, non-medical meetings or appointments, work, or from getting things that you need?” (NCDHHS, 2018, p.7). This question does not include leisure and social activities, which reduce social isolation and improve the emotional well-being of people with IDD. NCDHHS recognizes the importance of addressing social isolation for this population, as they state, “older adults and individuals with disabilities who live in their community and do not have access to transportation report higher rates of social isolation,” yet this important consideration is missed in the screening question (NCDHHS, 2018, p. 8). The recommendation is to ensure the screening questions for the chosen domains of food, housing, transportation, and interpersonal safety are reflective of the evidence-base on QoL for people with IDD. See Appendix J for an overview of the Social Determinants of Health Screening Tool.

Home and Community-Based Services Final Setting Rule

The Home and Community-Based Services (HCBS) Final Setting Rule offers providers the requirements to deliver HCBS Medicaid-funded services. These rules/requirements are fairly straight-forward and are listed below for view.

a) Setting is integrated in and supports full access to the community;
b) Personal choice by the individual among setting options;
c) Requires individual privacy, dignity and respect, and freedom from restraint and coercion;
d) Maximizes opportunity for autonomy and independence in life choice-making;
e) Offers choice in service providers and services;

f) Personal privacy is provided including a lockable door, choice in roommate and ability to personally furnish or decorate;
g) Control of individual schedule and access to food at all times;
h) Ability to have visitors at any time; and
i) Physical accessibility (Centers for Medicare and Medicaid, 2014).

As, LTSS funding moves increasingly toward HCBS and away from institutional settings, more and more programs serving people with Intellectual and Developmental Disabilities will be required to comply with these rules. Therefore, it is important to understand their impact on those receiving HCBS today and those who may transition to HCBS through programs like the Money Follows the Person. See Appendix K for a review of the HCBS Settings Final Rule aligned with the QoL domains.

Of the eight QoL domains, we see six accounted for by CMS HCBS Settings Final Rule. The personal development and emotional well-being domains are the only two we do not see represented by the HCBS Settings Final Rule. No alignment was founded with concepts related to personal competence, education or personal performance, nor to contentment, self-concept, or a lack of stress. For these reasons, personal development and emotional well-being were not aligned with any key provisions/rules. The other six domains were accounted for in at least some minor fashion. The largest representation of key provisions was aligned with the self-determination domain. Followed by physical well-being and rights. Social inclusion, material well-being, and interpersonal relations were accounted for by one requirement or rule.

North Carolina DHHS HCBS Final Rule Transition Plan

North Carolina has developed a plan to comply with the HCBS Final Setting Rule and implemented it by providing a tool for providers to assist in compliance (North Carolina DHHS, 2015). For this research, the tool was analyzed against the QoL framework. As anticipated, it aligned in the same manner as the HCBS Final Setting Rule from CMS, since it has only minor variances. Personal development and emotional well-being remain omitted. Self-determination, social inclusion, and rights were all heavily represented, followed by a secondary group who had two alignments (i.e., interpersonal relations and material well-being), and finally physical well-being aligned with one measure. This also aligns with the trend we noted in the CMS version. See Appendix L for overview of alignment with the QoL domains.

Summary of Analysis of Proposed Measures

This concludes our section analysis of additional proposed measures for future implementation. In these measure sets, we see a much more expansive array of alignments across QoL domains, which is promising. It is likely that many of these measures will be implemented in the future, due to their specific association with either CMS Medicaid rules, accreditation requirements as a Prepaid Health Plan (PHP) by NCQA, or NCDHHS initiatives, such as social determinants of health). While these measures much more adequately address the QoL framework, we still see some gaps and critiques from the disability advocacy community, related primarily to individual goal setting, self-determination, and quality of life satisfaction measurement. What is apparent is that both the Social Determinants of Health Screening Assessment and the Quality Measure Set for HCBS both represent all eight domains of the QoL framework. The HCBS measures will slowly be implemented over time, and we do not yet know in which ways measures will be implemented across various programs or even which programs. Additionally, not every LTSS recipient of service with I/DD receives HCBS, so that must be kept in mind as we think about people with I/DD living in institutional settings. We also do not yet know how a Standardized Social Determinants of Health Screening might be used within the population of people with I/DD using LTSS. The HCBS Settings Final Rule is also only applicable to recipients of HCBS but does account for six of the eight QoL domains. Finally, the HEDIS measures are almost entirely physical well-being related and follow the trend of what was seen in the measures implemented during the transition. It is positive to see the accounting of all eight domains of the QoL framework within these additional measures we anticipate seeing included in the near future.

I do hesitate that much of this reform only applies to recipients of LTSS through HCBS programs and recommend seeing what changes are made within institutional settings, especially in light of the recent *Samantha R vs. North Carolina* DHHS lawsuit. In the next section, we will look at some existing documents that govern LTSS programs in North Carolina to see how well current requirements align with the QoL framework.

Existing Standards within CMS LTSS Institutional Care Programs

In North Carolina, the Centers for Medicare and Medicaid State Operations Manual, in Appendix J, addresses specifically requirements for services rendered in Intermediate Care Facilities for people with Intellectual and Developmental Disabilities (ICF/IID). This analysis in Appendix M helps to see what alignment currently exists for LTSS recipients with Intellectual and Developmental Disabilities in North Carolina who receive their services in an institutional setting.

The ICF/IID program requirements as set forth by the State Operations Manual align with all eight domains of the QoL framework. The weakest alignment is with the emotional well-being domains, which only has one aligning measure/requirement. Physical well-being has the most accounted for measures followed by personal development, self-determination and rights. The other domains that are less accounted for, including material well-being, interpersonal relations, and social inclusion. With these requirements/expectations in place for existing institutional-based LTSS programs and alignment with all eight of the QoL domains, it is reasonable to recommend QoL measurement best practices within monitoring practices conducted by providers, PHPs, and NCDHHS.

National Quality Forum (NQF) and Quality of Life (QoL) Domain Alignment

In this last section, of the QoL analysis of the Medicaid Transformation documents discussed in Chapter IV, the National Quality Forum domains and the QoL domains are compared and discussed. The NQF measure approval was also sought by CMS as part of the development of their Quality Measure Set HCBS. The NQF is a non-profit, membership-based organization developed to improve healthcare. NQF prides its organization on being the gold-standard in healthcare quality and being the endorser of evidence-based and valid measures (Centers for Disease Control. 2022). NQF aligns well with North Carolina’s vision for the future, as it has a heavy focus on using social determinants of health to address gaps in our society by saving on healthcare spending (Health Payer Intelligence, 2022). The NQF domains serve to inform North Carolina Medicaid Transformation, both in the background as approver of healthcare quality measures and in the front as a framework to organize communities to address social determinants of health. See the comparison in Appendix N.

To begin, the first domain of QoL, personal development, was aligned with the NQF service delivery and effectiveness domain. The self-determination domain was aligned to the person-centered planning and coordination NQF domain. This was chosen because the NQF measure specifically aligns the person-centered planning process at the persons direction. Self-determination is also linked with the choice and control NQF domain. This domain expressly describes the individual making choices about their life, services, supports, and implementation.

Social inclusion is linked with the community inclusion NQF domain, as it discusses linkages within the community and being socially connected to the individual's preference. Interpersonal relations are connected with caregiver support, since they both reflect the factors of family member involvement and support. Emotional well-being was somewhat loosely aligned with the workforce NQF domain, since a major component of stress for people receiving LTSS and their families is the availability and stability of the Direct Support Professional workforce to provide vital support. The rights QoL domain is linked with the human rights and legal rights NQF domain, as both represent the legal and human rights of people with disabilities (although NQF is specific to those receiving HCBS). Material well-being is linked with the equity NQF domain due to the alignment between availability of resources to long-term services and supports, which impacts the opportunity for housing, employment, and overall financial status. Physical well-being was linked with the holistic health and functioning NQF domain, as it pertains specifically to health interventions. The other two NQF domains (i.e., System Performance and Accountability & Consumer Leadership in System Development) did not have an alignment with the QoL domains. The two NQF domains focused on systems measurements and were not able to be linked to individual outcomes.

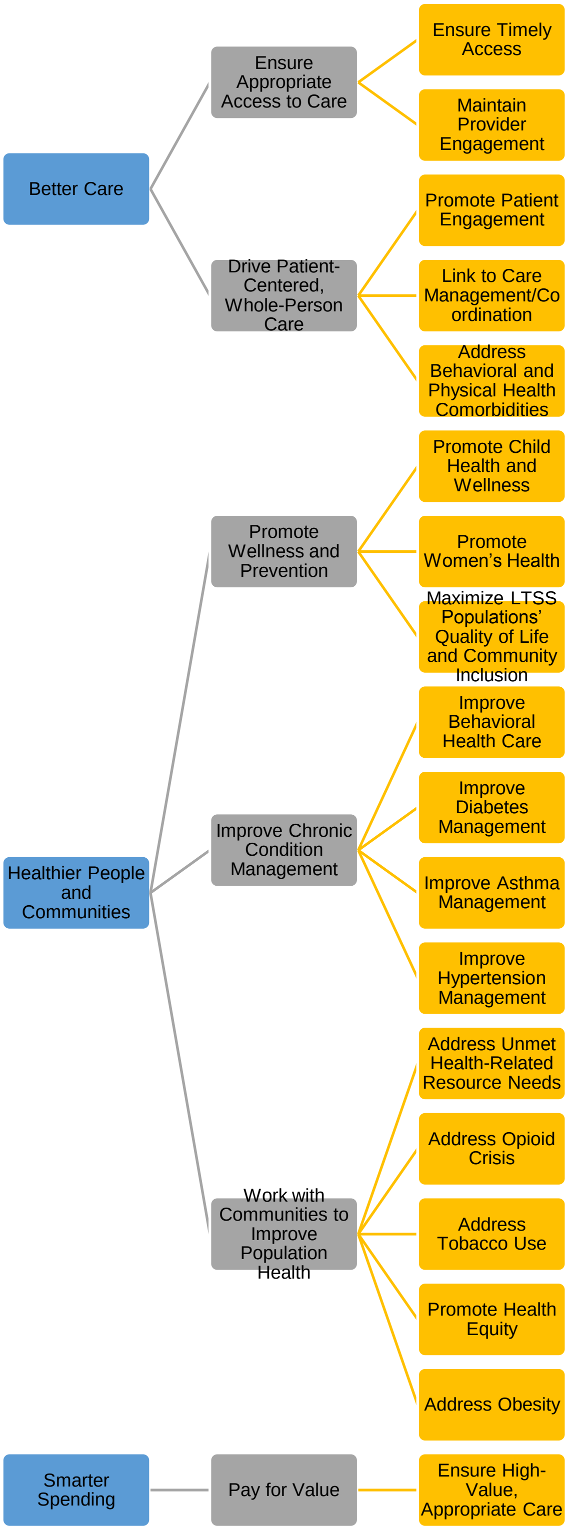
Overall, the NQF domains are aligned with the eight QoL domains, although admittedly some may not be the closest of alignments, such as the QoL emotional well-being and material well-being domains. An important distinction to also note is that the NQF domains pertain specifically to HCBS programs, whereas the QoL domains can be applied across all programs and services supporting people. The NQF domains also focused more on the health and process of the system of service. QoL domains have a greater focus on individual outcomes.

In the next section, we will remind ourselves about the goals set forth by the NC Legislature and the NC DHHS, to prepare for the Critical Policy Analysis using DisCrit framework as a way to identify issues of power, race, and ableism.

Goals of the Transformation

The North Carolina General Assembly and Department of Health and Human Services laid out the following goals of the transformation for all people and some specific to people with Intellectual and Developmental Disabilities. The Big Three Goals of the Standard and Tailored Plans

Figure 1: The Big Three Goals of the Standard and Tailored Plans Implementation



(NCDHHS, 2021)

As Secretary Cohen said, the goal is “to improve the health of North Carolinians through an innovative, whole-person centered, and well-coordinated system of care that addresses both medical and non-medical drivers of health” (NCDHHS, 2018). To accomplish this, they propose to

1. provide whole-person care utilizing coordinated physical health, behavior health, intellectual/developmental disability services, pharmacy services, and care models,
2. address social determinants of health by uniting community resources with health care systems,
3. provide care management services that are localized and available in the home or community and
4. maintain a robust provider network by minimizing administrative burdens. (NCDHHS, 2022)

Specifically, for people with Intellectual and Developmental Disabilities this means the creation of an integrated health plan, the Tailored Plan. For people receiving Long-Term Supports and Services (LTSS), the goal set forth by NCDHHS (DHHS) is to provide quality-driven, person-centered, and community-based LTSS by focusing on whole-person care and improved health outcomes through comprehensive needs management, using a designated care manager and multidisciplinary team. These services will be paid for by transitioning Medicaid and NC Health Choice programs from fee-for-service models to managed care, beginning with the new community-based and provider-based care management model (NCDHHS, 2018).

Based upon the goal language set forth by NCDHHS, i.e., to “maximize LTSS populations’ Quality of Life and Community Inclusion”, their commitment that quality of care will be measured so that it is meaningful to people who receive LTSS (NCDHHS, 2021; 2018).

We can confidently apply both QoL and DisCrit analytical frameworks to explore the realities of these commitments/goals within the reform.

Accountability Structures and Key Document Analysis using QoL

The NCDHHS has established a reporting and accountability structure to monitor the operations of PHPs/MCOs and their network providers. In the subsequent sections, this reporting structure is described along with the key documents that contain the outcome measures associated with the implementation of the Tailored Plans and services for LTSS recipients with IDD. These outcome measures represent the identified value within the system, as they will be used to operationalize value-based reimbursement agreements.

Flow of Reporting

Federal Medicaid regulations require NCDHHS to develop and oversee a managed care quality strategy that assists PHPs in improving the quality of services. For example, the North Carolina DHHS has selected quality measures specific to certain populations, like people receiving LTSS, where they will monitor PHPs improvements of the population's health, functioning, and health prevention. PHPs will also be expected to self-monitor and implement quality assessment and performance improvement programs (NCDHHS, 2018). PHPs will need to come up with data collection and monitoring practices with their provider networks to capture and report "measurement of activities related to quality of life, rebalancing, and community integration" (NCDHHS, 2018a, p. 14). Specific quality strategy goals for PHPs delivering the Tailored Plan include:

- Ensure appropriate access to care
- Drive person-centered, whole-person care
- Promote wellness, prevention, and improved quality of life

- Improve chronic condition management
- Actively engage communities to improve population health, and
- Pay for value (NCDHHS, 2018).

NCDHHS quality and accountability strategy within managed care will entail

- implementation of outcome measures connected to specific goals of the transformation
- reduction of health disparities, and
- incentivizing providers for the attainment of quality goals and outcomes. (NCDHHS, 2021)

Since these goals/activities are operationalized through the individual's person-centered plan, it is critical that PHPs ensure plan enrollees receive what is outlined in the plan to obtain their individualized goals and outcomes. People identified as having Special Health Care Needs or in need of LTSS are required to receive a comprehensive assessment to identify any ongoing special treatment or care monitoring. Their treatment/support plans are documented in a federally required person-centered plan and serve as the monitoring tool to document and report the persons scheduled and received services.

PHPs are responsible for creating "mechanisms to assess the quality and appropriateness of care provided to beneficiaries needing LTSS, including assessment of care between settings and a comparison of services and supports received with those set forth in the beneficiary's treatment/service plan" (NCDHHS, 2021, p. 20). A well-written plan is of little use if it lacks the personnel, community-based providers, or funding to support it. Additionally, moving into more integrated community settings is unlikely, if supports and services are not available in the community to operationalize the individualized treatment/service plan.

A substantial component of this reform relies on measuring certain outcomes and financially rewarding those providers obtaining them. In the next section, we begin the analysis by reviewing existing and proposed quality measures against the QoL eight domain framework. This analysis will help to inform to what degree providers can be rewarded for improving recipients' quality of life, while obtaining outcomes that result in financial reward.

In this last section, the Discrit lens will be used to understand the implementation and shift of this system of care and explore how these findings fit within the context of North Carolina. As the finding are discussed, using the Discrit lens later in the chapter, a deeper critique of the capitalistic underpinnings and free market principles will be examined along with how certain people/organizations/enterprises gain and lose power.

Critical Policy Lens Using DisCrit Framework

Using the DisCrit framework discussed in Chapter II, an analysis of the context of Medicaid transformation is provided. Earlier a framework was provided which utilized seven principles to understand critical disability. Below I have utilized the seven principles to discuss the environment in which this reform is occurring and the implications for people with disabilities who continue to be marginalized and discriminated against.

1. A focus on the impact of racism and ableism, which are independently upholding the notions of normalcy (Annamma, Connor and Ferri, 2013).

The LTSS programs for people with Intellectual and Developmental Disabilities, historically have been developed under ableist and racist influences. The preponderance of people of color with disabilities incarcerated, the sub-minimum wage, violence (i.e., lobotomies, beatings, shock-therapy), institutional disability segregation, over-medication, etc. were all to done instill compliance and minimize/separate variations to the societal "norm." Through a vast effort by self-advocates and their allies, people with disabilities have been successful in reclaiming many of their human rights, but still people with intellectual/developmental disabilities live in institutional settings across North Carolina. Around 2000+ Intermediate Care Facility residents are being provided housing in congregate settings. Another 16,000+ people are waiting on the Registry of Unmet Needs for HCBS and others receiving HCBS go without staffing coverage and consistency of support.

2. Emphasizes the material, psychological, and social construction of race and ability and being outside those norms of whiteness (Annamma, Connor and Ferri, 2013).

The goal has been to control spending and allow competition among PHPs who receive fixed allocations, (i.e., budget control) to administer healthcare services. It seems that with a net neutral transformation, the goal is to find savings to improve care. Value-based and risk-sharing payment systems increase the ability of PHPs to manage the terms of resource allocation to provider agencies who are struggling to develop the technological and personnel infrastructures to provide more advanced reporting. The current gap in pay between what is needed and what is available for Direct Support Professionals, as one example, seems so great that without a significant infusion of resources, it is outside the scope of simple resource reallocation.

Shifting the power balance back in favor of large insurance companies, who are receiving fixed per member per month rates and expected to reduce overall health expenditures through innovation, competition and choice. Doubling down on capitalistic, free-market practices, within a public service sector that has been underfunded and finds itself in a state of crisis (e.g., 16,000+ people on waitlists, those with authorized services going unfulfilled due to short staffing, lack of community-based services, and institutional care bias) using a neutral budget, appears to favor the status quo rather than make any significant changes to service provision. Value-based performance must also not be used as a tool to force additional compliance onto providers to obtain the core service provision rate. A greater focus must be made to individual measures of autonomy, belonging, self-determination, personal satisfaction and overall quality of life (ANCOR, 2020).

Most accountability and monitoring structures serve to monitor quality outcomes that result in reduced costs and/or health related savings. For example, the Recommended Measure Set for Medicaid-Funded Home and Community-Based Services are largely reflective of the health of the system rather than being reflective of the needs and preferences of people with Intellectual and Developmental Disabilities (ANCOR, 2020). The HEDIS measures are healthcare measures, which are implemented to improve and maximize healthcare spending. The initial set of Tailored Plan and Standard Plan measures are focused on mostly physical well-being related domains. Much of the value, within value-based care at this time, is therefore in health-related outcomes. This has a significant impact on the disability community, who recalls the medical model of care that finds the person with a disability deficient and in need of curing.

Many people with disabilities receiving LTSS live in perpetual fear that they will not have the availability or properly qualified staff to remain living in a community-based setting. Burnout among family members can directly impact interpersonal relations and well-being domains. Every day I heard my friend, who lived with a significant physical disability and received the Innovations Waiver, that he was paralyzed by fear. Too often his staff did not come, too often he had to rehire and restart training on his support needs, too often his mom and dad had to provide for his essential care in the home, and too often did he think about life in an institutional setting when they were gone. He condemned the lack of funding to pay his staff a live-able or desirable wage and worked to develop systems to educate and employ more Direct Support Professionals.

3. Explores power within legal and historical moments, which have denied rights to some citizens (Annamma, Connor and Ferri, 2013).

Inadequacy of network of community-based providers and funding for those providers has left people isolated and without essential services. Denying citizens, the right to live and participate as full citizens in their communities of choice has a negative impact on the entire community. Historically, access to care has been measured by the number of contracted of available providers. This has not always provided a clear sense of whether or not members where actually being served by this network and obtaining the goals and outcomes they sought. In this new reform, North Carolina DHHS expects that PHPs use a multifaceted technique to ensure provider availability, accessibility, flexibility/adaptability, and measure recipients realized access (NCDHHS, 2018).

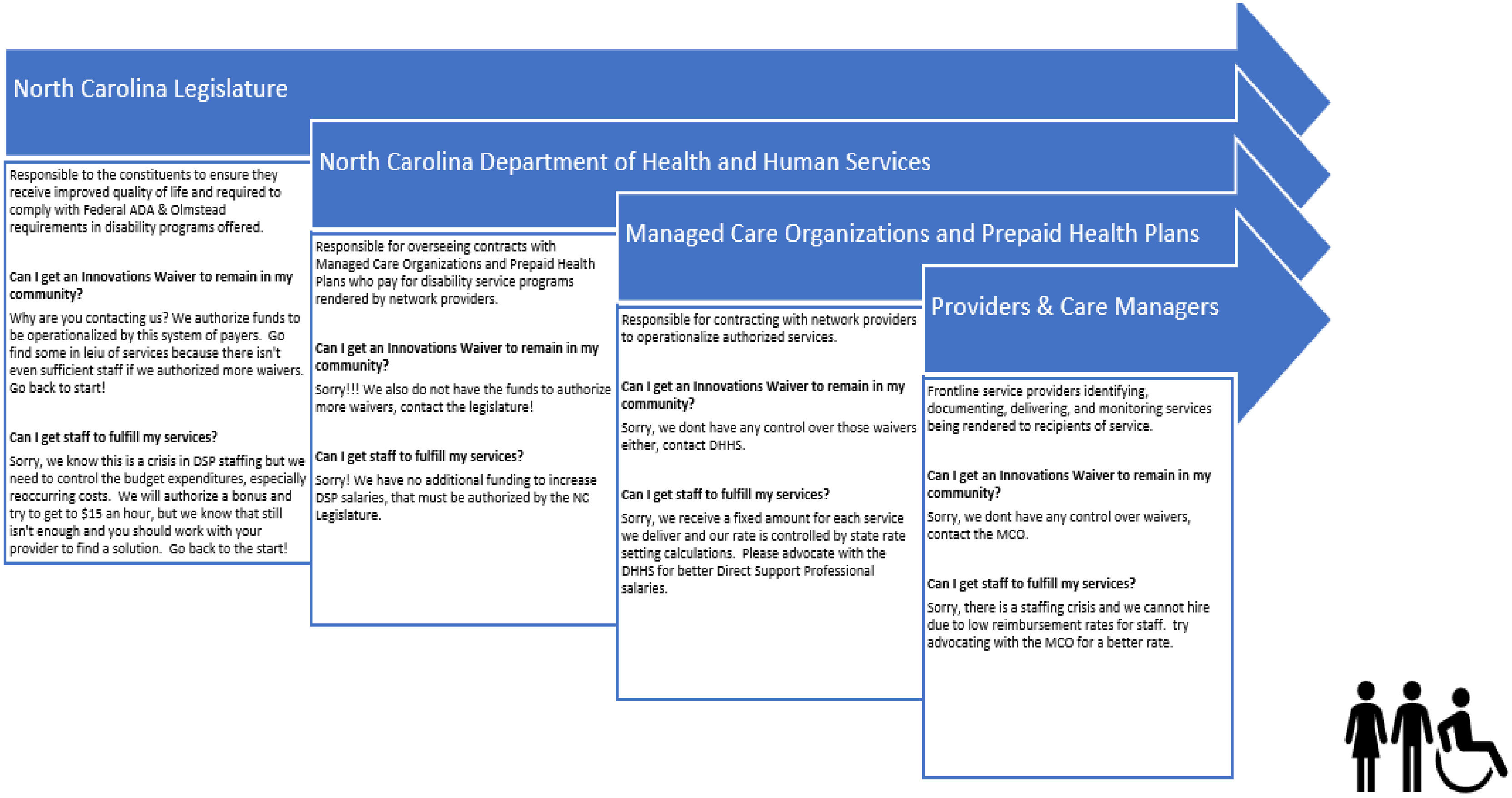
In the recent light of the Lawsuit *Samantha R. v. NCDHHS*, a legal requirement has been issued to expand HCBS options to the 16,000+ on the Registry of Unmet Needs, reduce the reliance on institutional care, and addressing the Direct Support Professional Crisis. Having appropriate funding, workforce, and HCBS services enables people with disabilities to maximize their agency and human rights. A new technique, cannot resolve the inadequacy of providers and staff available today. Just changing the way existing funds are allocated lacks an understanding of how resource deprived the existing social service net is for people receiving LTSS with Intellectual and Developmental Disabilities in North Carolina.

4. Understands that improvements for people with disabilities are in the best interest of the white power structures; and

5. Promotes the recognition of multidimensional identities (Annamma, Connor and Ferri, 2013).

Currently, we have the language of the reform that promotes quality of life and satisfaction as well as more options and better services. However, in the review of the QoL representation among initial measure sets for Tailored and Standard Plans, there is a complete focus on physical health outcomes. NCDHHS has not demonstrated how it plans to report on the attainment of personalized outcomes within individualized service plans. The reality is a reform with language that represents what is desired, but a lack of commitment to expanding resource allocations and improving the existing challenges for frontline providers. The reform supports the capitalistic desire to cap spending and manage costs within an already struggling system. Moving to this budget approach benefits the white power structure in the legislature who can use the PHPs and North Carolina DHHS as buffers between them and the accountability for ensuring North Carolinian's needs are appropriately funded. This makes little sense however as HCBS programs are more cost effective than institutional care. The difference is that at this moment the burden for the support and care of 16,000+ people is resting on the shoulders of their family members and natural supports. While this may seem like the most cost-effective option, this burden impacts the productivity of North Carolinians and limits the creation of more jobs as HCBS Direct Support Professionals.

Figure 2: Can I Get my Services?



North Carolina Legislature

Responsible to the constituents to ensure they receive improved quality of life and required to comply with Federal ADA & Olmstead requirements in disability programs offered.

Can I get an Innovations Waiver to remain in my community?

Why are you contacting us? We authorize funds to be operationalized by this system of payers. Go find some in leiu of services because there isn't even sufficient staff if we authorized more waivers. Go back to start!

Can I get staff to fulfill my services?

Sorry, we know this is a crisis in DSP staffing but we need to control the budget expenditures, especially reoccurring costs. We will authorize a bonus and try to get to $15 an hour, but we know that still isn't enough and you should work with your provider to find a solution. Go back to the start!

North Carolina Department of Health and Human Services

Responsible for overseeing contracts with Managed Care Organizations and Prepaid Health Plans who pay for disability service programs rendered by network providers.

Can I get an Innovations Waiver to remain in my community?

Sorry!!! We also do not have the funds to authorize more waivers, contact the legislature!

Can I get staff to fulfill my services?

Sorry! We have no additional funding to increase DSP salaries, that must be authorized by the NC Legislature.

Managed Care Organizations and Prepaid Health Plans

Responsible for contracting with network providers to operationalize authorized services.

Can I get an Innovations Waiver to remain in my community?

Sorry, we dont have any control over those waivers either, contact DHHS.

Can I get staff to fulfill my services?

Sorry, we receive a fixed amount for each service we deliver and our rate is controlled by state rate setting calculations. Please advocate with the DHHS for better Direct Support Professional salaries.

Providers & Care Managers

Frontline service providers identifying, documenting, delivering, and monitoring services being rendered to recipients of service.

Can I get an Innovations Waiver to remain in my community?

Sorry, we dont have any control over waivers, contact the MCO.

Can I get staff to fulfill my services?

Sorry, there is a staffing crisis and we cannot hire due to low reimbursement rates for staff. try advocating with the MCO for a better rate.

Can I get staff to fulfill my services?

Can I get an Innovations Waiver to remain in my community?

6. Promotes the voices of marginalized people in research and decision-making (Annamma, Connor and Ferri, 2013).

This analysis is a tool to support the agency of people with disabilities and their allies, who would seek to ensure that this reform support the belief, nothing about us without us. That this critique can provide additional resources to the voices of resistance, who do not wish for another payer system, but rather a fully-funded system that provides equity in citizenry to North Carolinians.

NCDHHS (DHHS) states that it values the input of people receiving LTSS and their families. In an effort to include these stakeholder inputs, the North Carolina DHHS requires PHPs to maintain an LTSS advisory committee made up of enrollees accessing LTSS, representatives of enrollees of LTSS, providers, and PHP staff participating in authorizations or care management functions (NCDHHS, 2018). Having membership within the advisory council is one thing, but having true agency to enforce changes within the shaping of service implementation is not being provided.

North Carolina DHHS will also require a number of Patient-Reported Outcome Measures**.** NCDHHS will use the following tools to assess and report on patients' healthcare experience:

- Consumer Assessment of Healthcare Providers and Systems (CAHPS);
- Adult and Child Survey;
- Mental Health Statistics Improvement Program (MHSIP) Consumer Satisfaction Survey;
- North Carolina Treatment Outcomes & Program Performance System (NC-TOPPS);

- National Core Indicators (NCI); and
- Others to be identified (NCDHHS, 2022).

A heavy focus remains on the medical model of measurement and limited description of how the individual attainment of goals and fulfillment of service plan documented services will be attained and monitored. This remains a concerning reality as quality of life measurement is not included here, only in the language of the reform goals.

7. Promotes activism and forms of resistance (Annamma, Connor and Ferri, 2013).

There are opportunities within North Carolina to advocate for improvements in quality of service delivery and recipients of service quality of life, while also resisting forces that marginalize the community of people with Intellectual and Developmental Disabilities. Three examples below, shed some light on recent activism and resistance within the transformation to the Tailored Plans.

Personnel Preparation Advocacy

In the Tailored Plan, PHPs will need to demonstrate that Care Management provider personnel have received the appropriate training to integrate care and provide comprehensive needs management for people with intensive support needs. The training topics are expansive to the diverse needs of the people being serves and include topics like sensitivity and awareness, communication device use, ADA compliance, independent living, addressing barriers and inequalities in health care, and the impact of social determinants of health (NCDHHS, 2018). However, this time, PHPs are being allowed to develop and design their own training programs and implement them gradually for staff over a period of time after being assigned a case load.

Organizations like the Arc of NC are advocating for a college/career pathway and standardized training program to serve all Care Managers, Care Extenders, and Direct Support

Professionals. In my collaboration with Arc of NC leadership their commitment was evidenced in their efforts to connect disability instructors with the NC Community College system leadership. Additionally, Arc of NC affiliated providers sent DSPs to attend training programs which provided National certification.

Legislative Advocacy

The reality is that in the last budget Direct Support Professional pay was a significant issue that received attention from both political parties. In the end, some funding was allocated to increase pay, but it was not enough to reach $15 across as minimum and it was going to come in both the form of a bonus and gradual pay increase. The North Carolina Provider Association, the North Carolina Coalition on Aging, PHI National, and parent-led DSP workforce groups organized in early 2020, requested that the North Carolina General Assembly addressed these requests by passing legislation that increases rates for ICFs and HCBS providers to increase DSP wages. The NC General Assembly also allocated funding for Group Home Stabilization, additional 1,000 Innovation Waiver slots, increases in private duty nursing rates, funding for adult and pediatric TBI waiver pilot, $25 million one-time fund to establish the Children with Disabilities Reserve, and requirement for DHHS to create a plan to ensure an adequate provider network to provide Innovation Waiver services (Arc of NC, 2021). Even with this extensive advocacy the increases still did not bridge the gap to ensure all DSPs would make a minimum of $15 an hour, which is no longer competitive with Target and other entry-level employers paying $20 an hour.

Legal Advocacy

Many within the disability community are cheering the recent *Samantha R. v. NCDHHS,* in which the judge has ruled that North Carolina's Department of Health and Human Services take action to address the Direct Support Professional workforce crisis, expand HCBS to all 16K+ people waiting on the North Carolina Registry of Unmet Needs (these are people who qualify for HCBS), and reduce institutionalization. NCDHHS is appealing this ruling. Continued advocacy is needed to ensure accountability is provided to individuals and families who are not receiving services due to a lack of funding, providers, and staff.

Summary

Intensive advocacy has created opportunities to resist the capitalistic forces and lack of accountability from the North Carolina General Assembly and the Department of Health and Human Services to address the service crisis faced by people with IDD. On-going advocacy efforts are needed to promote equity within the LTSS provided to North Carolinians with disabilities. Some gains were made in the recent budget approval, but with a multi-billion-dollar surplus it seen unconscionable that the NC General Assembly was unable to allocate the funds needed to shore up DSP wages, HCBS provider rates, and 16,000+ additional HCBS Waivers slots.

Summary and Material Implications

In this chapter, an analysis was conducted of selected and potential outcome measures were provides using the QoL framework as well as the existing requirements for HCBS and ICF/IID setting LTSS. The finding of those analyses left us with the conclusion that current measures for implementation will rely primarily on the physical well-being domain. Material well-being domain is also addressed in some measures. The potential future measures are much more reflective of the QoL eight domains, although some like the HEDIS measures remain completely oriented toward the physical well-being domain. The current requirement for HCBS and ICF/IID are quite reflective of the eight QoL domains.

Using the DisCrit framework exposes contextual issues and factors that continue to marginalize people with disabilities, their families, and their allies, while allowing a failing systems of social support to stumble by. From this analysis, it should be clear that the QoL framework is aligned with the goals of the North Carolina Medicaid reform and with existing program requirements for people with Intellectual and Developmental Disabilities. It should also be clear that current measures to be implemented are very healthcare focused and provide limited opportunities for value-based rewards for actions that impact other areas of living. The measures that will be implemented in the future are more inclusive of the eight QoL domains but still lack a true person-centeredness. And a series of contextual factors create a less than ideal reality for recipients of LTSS and their providers as this Medicaid transformation occurs within a net neutral budget and an end to many COVID resource provisions. In Chapter V, the discussion will begin and be described as opportunities and threats to best support advocacy efforts and the voices of people with disabilities living in North Carolina.

CHAPTER V: SUMMARY OF FINDINGS

It is now 2023 and the Tailored Plan continues to be delayed until April, as the North Carolina Department of Health and Human Services, the North Carolina General Assembly, Managed Care Organizations, and Prepaid Health Plans seek to prepare for this substantial shift toward value-based purchasing and Managed Care. For Mark however things look more or less the same with the exception of added confusion and disruption. Mark and some of his fellow service recipients all lost their case managers when one of the Managed Care Organizations was disbanded and its regions were merged into other existing Managed Care Organizations. Mark is getting used to his new case manager and some changes in services from his old MCO to new MCO. Mark is disappointed to hear that some of his day program services, which had been paid for using state-funds, were no longer included in his plan, since this MCO has less of those resources and the North Carolina General Assembly did not expand direct state-funding for disability services. Mark and his mother also sat on the old MCOs advisory board, but under this new configuration of MCO regions, the boards have been condensed. Now only Mark's mother is represented on the broader regional advisory board. Mark, his, mother, and his friends believe meaningful agency is harder when less representation is held at the local level. Another mother who is also a field expert/professional has commented that the Transformation Advisory Group hosted by NCDHHS has felt more like a show and tell than a true dialogue and request for stakeholder input.

Mark and his fellow advocates are concerned that this system change has more to do with system efficiency and cost control than improved services and quality of life. Some of Mark's providers voiced concerns about rates going back down after the COVID increases and even a loss of revenue when they re-signed contracts with new MCOs according to region reconfigurations. Mark has heard about the new Care Management services. While it sounds good, he worries about changing staff who assist in his plan development. He also hears that his provider of choice did not apply to be a Care Management service provider, because of the low reimbursement rates and they wanted to avoid a conflict of interest for their clients, which is required by Medicaid rules. Mark feels that a lot is happening; he is trying to keep up with the changes, delays, reconfigurations, etc., but his day-to-day struggles have not changed.

He still has not had reliable staffing and just trained his sixth staff for 2022. He calculates that between 20-35% of his covered hours are missed due to no back-up staffing. He loses at least 50% of his total authorized hours. The staff he has been able to hire seem to be looking for short term employment and do not see the support they provide as that of a long-term carer. His mother is able to provide a good bit of his care, but she is aging. Mark knows that he needs more consistent, reliable, and professional staff to avoid negative health consequences for himself and his mother. Mark is struggling to remain employed, to enjoy the company of his friends, and participating in social clubs due to his lack of staffing support.

Transportation is especially difficult on his mother, and Mark cannot drive independently. Public transportation does not service the area where Mark lives; so, he continues to look for alternatives. Mark feels that with the situation as poor as it is today, any reform should focus on closing these critical service gaps. In addition, Mark advocates for an expansion of Home and Community-Based Services (HCBS) to support the 16,000+ people who have been identified as eligible for the Innovations Waiver, which provides the essential services to live in the community, find and keep employment, participate in social and leisure activities, obtain medical treatment, and other activities of daily living. Mark knows some of his friends have waited over 20 years for services on the Registry of Unmet Needs Waitlist.

To assist Mark and the other advocates who are fighting for a better quality of life that is reliant on the system of disability services, these research questions were investigated to provide clarity about the complex North Carolina healthcare transformation to Managed Care:

1. How does NC Medicaid transformation propose to improve the services for people with intellectual and developmental disabilities in long-term supports and services?
2. How are Quality of Life principles, the professionally preferred best practices, reflected in the policies that have been enacted or proposed in North Carolina?
3. In what ways do the purposes, structures, outcomes, and implementation of NC Medicaid transformation indicate alignment with the domains of the Quality of Life framework? Also, in what ways do the purposes, structures, outcomes and implementation of Medicaid transformation indicate they are not aligned with the domains of the Quality of Life framework?

The discussion below provides explicit and direct responses to these research questions using the analysis and histories outlined in previous chapters. In addition, this chapter provides a framework for advocates to see opportunities, threats, and those elements of the transformation that represent both an opportunity and a threat, to challenge unjust realities, and to take advantage of reform language to improve agency. To conclude this chapter, some recommendations are proposed that critique the system's current realities and those of the proposed solution, Managed Care. Mark's reality will be contrasted with that of an ideal scenario of service provision and community inclusion, so that the gap between where we are and where we should be can be best understood. This critical contrast is essential in a time when some feel that the disability revolution is over and that integration has been accomplished, since a majority of people with high incidence disabilities are living in the community. Those who are often not as apparent are people with more extensive support needs who have continued to reside in institutional settings or are at risk of living in one of those settings without the necessary supports in the community and home. A light must be shone on the plight of these people with disabilities who continue to be segregated, who are left without necessary services, and who disenfranchised by systems built on powerful mechanisms of oppression.

Research Question #1: The Transformation as Planned

The first research question asked how the North Carolina Medicaid transformation proposes to improve long-term services and supports for people with Intellectual and Developmental Disabilities. The best person to summarize this is former Secretary of Health and Human Services, Mandy Cohen, who stated

> I hope at this point you are familiar with our vision for Medicaid transformation, and how it will improve the health of North Carolinians through an innovative, whole-person centered, and well-coordinated system of care that addresses both the medical and non-medical drivers of health. (DHHS, 2018, p. 1).

Specifically, for people receiving LTSS, NCDHHS has outlined the goal 2(A)(iii), which brings explicit attention to the LTSS population’s Quality of Life and Community Inclusion. This goal in itself provides a clear answer to our research question and verifies the use of the QoL eight domains and theoretical framework to analyze the legislative reform to see how well it aligns with the evidence base on QoL.

One of the key services enacted in this reform is localized care management services provided by community-based providers. Historically, these services have been provided by the Managed Care Organizations (MCOs). As the system moves towards more fully implemented Managed Care, it requires the MCOs to distribute their care management services gradually within their provider network, until they provide only a very limited care management service. NCDHHS has prioritized care management services for a core set of initial populations being served by the Tailored Plan, including enrollees with eligible LTSS needs; children and adults with “special health care needs;” people with significant unmet needs related to social determinants of health; and those groups prioritized by the PHPs. NCDHHS believes a community-based care management service will ensure appropriate services for people with Intellectual and Developmental Disabilities (NCDHHS, 2018).

In this design, one care manager will organize a multi-disciplinary team to carry out a more complex responsibility to identify needs, plan, implement strategies, and evaluate outcomes across the domains of physical health, behavioral health, I/DD, TBI waiver, Innovations waiver, pharmacy, and social services (NCDHHS, 2019). Care managers would benefit from a QoL framework for planning, implementing strategies, and evaluating outcomes to align their care management services with the reform’s goals of an improved QoL and increased community integration.

NCDHHS in its Medicaid care management strategy also outlines key principles to guide implementation and quality monitoring. These key guiding principles expose additional goals of the Medicaid reform for LTSS recipients receiving care management services through community-based providers. These key guiding principles are as follows:

1. Ensure access to appropriate care management and coordination services, within the various environments of functioning, with integrated primary care, specialty care, and community-based resources;

2. Persons being services with complex medical, behavioral, or social support needs should involve a multi-disciplinary team with whole-person care plan developed and written;
3. Care management is provided in the local area, with requirements for face-to-face visits;
4. Seamless access to enrollee-level information for care managers through technology interfaces;
5. Connecting individuals with unmet health-related needs with appropriate resources to support those unmet social determinants of health; and
6. Care management practices will fit within statewide priorities “for achieving quality outcomes and value” (NCDHHS, 2018, pg. 4).

We can clearly see in the principles above that additional goals include the focus on identifying and connecting an individual who is receiving care management services with resources to address social determinants of health and unmet health-related needs. We also see the focus on social determinants of health in the screening questions developed by the North Carolina DHHS to standardize the screening process for recipients of service. The four main areas to be screened and assessed by MCOs and PHPs include food, housing, transportation, and interpersonal safety/toxic stress (NCDHHS, 2018). These domains are considered areas in which early intervention can prevent or alleviate healthcare spending by better using community-based resources. Linking individuals with resources and services within the community is a practice that care managers are familiar with. They are responsible for enacting and completing a comprehensive assessment and person-centered care plan for each enrollee with LTSS needs to ensure that their unique and individualized care needs are met. It is now anticipated that these additional domains related to social determinants of health will also be included in the comprehensive planning, resource alignment, and outcome evaluation.

Keeping in mind key guiding principle number one, we are reminded that a core provision of measurement related to LTSS recipients is the execution of their person-centered plans services across settings of functioning. The same measurement goals apply to the care management and coordination of services. Each person-centered plan serves as the individualized agreement between MCO/PHP and the recipient of service for what goals will be worked on, services rendered to accomplish those goals, and measurement strategies to evaluate the completion of their identified goals.

The goals of the reform for recipients of LTSS are expansive and robust, focused on achieving improved quality of life and community integration through the development and implementation of a person-centered plan that is developed through localized care management services. These services will include a new focus on social determinants of health and using enhanced technology integrations to monitor enrollees received services and connect them with needed community-based resources. People receiving LTSS have diverse support needs, service utilization, and expenses. NCDHHS, believes that Managed Care offers a significant opportunity to improve care coordination, access to community-based services and outcomes for the most vulnerable population. It is key that this shift disrupts services as little as possible and that PHPs/MCOs are culturally competent to serve people with LTSS needs and further that quality of care is measured in a way that is meaningful to people who utilize LTSS (NCDHHS, 2018).

A less discussed, but just as important goal, for the entire Medicaid population is to manage health care spending. NCDHHS, has explained that this reform is budget neutral, which means that the anticipated Medicaid costs will not increase. Savings are anticipated in other areas by reducing spending, spending more efficiently, and obtaining quality outcomes that are value-based. As much as the reform represents a positive direction towards more community-based, integrated, and whole-person care, it also relies on anticipated savings to pay for expanded services like Care Management that is being made available to all of those on the Registry of Unmet Needs or other waiver waitlists as well. An estimated 16,000+ additional people will be served.

There represents a significant risk to the realizations of the reforms goals language if resources are not allocated to ensure the proper implementation. Already concerns were being voiced by community-based providers who were challenging the reimbursement rates for care management services and the technology requirements to integrate enrollee services across their various providers. Other providers simply refused to apply at this time, since so much was uncertain. It could mean a conflict of interest for enrollees who utilize other services at their provider agency. The goals outlined in this reform align well with best practices in the field related to improved quality of life and community integration, but realities of implementation create both threats and opportunities we will discuss later in this chapter.

Specifically, outside of care management, we also continue to note a focus on health-care outcomes as identified measures to value-base. The notion of value-basing outcome measures that are important to the population is valid, but within LTSS each service recipient is responsible with their team to identify what those individualized goals/outcomes are for the individual. This requires individualized goals and measures, which is different from utilizing standardized healthcare measures and practices. The focus for LTSS recipients is also more broadly defined to include quality of life and community integration. This is specific to those with significant needs because of a history of separation, exclusion, and denial of rights. These initial outcomes do not represent the final requirements of PHPs by NCDHHS, as they anticipate increasingly holding PHPs more accountable for quality outcomes specific to certain populations like LTSS recipients (NCDHHS, 2018).

Through a value-based Managed Care system, NCDHHS anticipates improving the quality of life and community integration of LTSS recipients. The goal is to provide community-based, whole-person, integrated care through localized care management services and service coordination to enhance quality of life. The additional focus on social determinants of health and addressing unmet health-needs facilitated through enhanced technologies is also an anticipated outcome of this reform that will benefit LTSS recipients. These expanded Care Management services and value-based reimbursements will be supported through health-care savings and reductions in spending. These goals are robust and align with the North Carolina General Assembly’s goals of controlling spending and improving care for North Carolinians.

Research Question #2: The Transformation and Quality of Life

The second research question asked, how Quality of Life principles, the professionally preferred best practices, are reflected in the policies that have been enacted or proposed in North Carolina. In Chapter 4, the currently selected measures, proposed future measures, and some existing LTSS program requirements/rules were analyzed against the eight Quality of Life domains to reveal the alignment between the QoL principles and Medicaid transformation in North Carolina. The analysis relied on the selected measures, rules, and requirements that are connected with the LTSS programs, the Tailored Plan, and the overall Medicaid reform in North Carolina. These measures, rules and requirements represent the value as recognized by NCDHHS and will be the first measures to be aligned to reimbursement models. In a reform based on the premise of a neutral budget, it is important to understand what is being reimbursed, because it shows us the focus of financial resources.

In the measures currently used, we see a predominant focus on measures related to health and healthcare. Three measures connected with the Tailored Plan for state-funded services are related to the material well-being domain. Otherwise, all other measures are solely aligned to the physical well-being domain in Tailored Plans initial measure sets. The last measure set related to the transformation represents both the Standard and Tailored Plans. This measure set focuses again primarily on the physical well-being domain with the exception of one measure, the CAHPS survey, which represents all eight domains. Therefore, within the initial measure sets for the implementation of Managed Care, we see all measures related to the physical well-being domain with the exception of three material well-being measures and one survey measure representing all eight domains of the QoL framework. In the existing program measures and standards, the ICF/IID program requirements within the State Operations Manual were reviewed, as they represent an LTSS program outside of HCBS. These standards aligned with all eight QoL domains as well.

In the proposed measures for future implementation, we explored HEDIS 2023 measures, the Final Measure Set for Medicaid-Funded Home and Community-Based Services, Social Determinants of Health Screening Tool, and HCBS Final Setting Rule. Overall, these measures provided a much more well-rounded representation of the QoL domains, as several of these measures are tailored specifically to the population of LTSS recipients and people with Intellectual and Developmental Disabilities. For example, both the HCBS Final Setting Rule and the HCBS Final Measure Set was designed to reflect the needs of the LTSS population who have Intellectual and Developmental Disabilities and live in their communities of choice. The HCBS

Final Measure Set represents all eight QoL domains, while the Final Setting Rule represents six of the eight domains. The HEDIS measure set is 100% health related, as expected, with one measure overlapping with the material well-being domain. In the Social Determinants of Health Screening tool questions, every domain of the QoL framework is addressed to some degree. This is promising that the new direction of healthcare in North Carolina is looking more holistically at the whole-person's needs and aligning well with the QoL framework within the research. Overall, the additional measures for future implementation much more holistically address the QoL domains. The reform in its proposed version aligns quite well with the QoL framework.

In conclusion, a strong focus exists on health-related measures. Promisingly, the existing and future proposed measures/standards are better aligned with a wider array of QoL domains. This ensures a more equitable opportunity for providers to be valued for providing services that result in outcomes outside the physical well-being domain. Initial value-based agreements may be more challenging for LTSS providers who are focused on more than health outcomes, but hopefully this trend toward greater QoL representation in future measures will provide new opportunities. Providers should advocate for the valuing of existing measures/standards that they work hard to regularly meet and that result in improved quality of life for the service recipient. The system should be seeking ways to pilot value-based purchasing agreements with providers across both health-related and other QoL domain related measures.

Research Question #3: Alignment Between Medicaid Transformation Implementation and QoL Framework

The third research question asked, in what ways the purposes, structures, outcomes, and implementation of NC Medicaid transformation indicate alignment and misalignment with the domains of the Quality of Life framework, the four components of this question are separated out below.

Purposes

The purpose of Medicaid Transformation is written in a way that it aligns with the QoL framework and supports the community integration of people receiving LTSS. The initial Quality Strategy Aims, Goals and Objectives Framework outlines three key goals to have Better Care, Healthier People and Communities, and Smarter Spending. Within this framework goal of Healthier People and Communities, a specific goal is outlined for the LTSS population, which is to “Maximize LTSS Populations’ Quality of Life and Community Inclusion” (NCDHHS, 2019, p. 2). NCDHHS believes that the BH IDD Tailored Plans through their provision of integrated managed care products, covering physical health, behavioral health, I/DD, TBI, LTSS, and pharmacy services is essential to delivering whole-person care for populations with intensive support and service needs (NCDHHS, 2018). The integration provides an opportunity to break down silos of services and care, while addressing unmet health-related resource needs. This system of care is intended to address both the medical and non-medical drivers of health. This holistic focus on the entire person and their quality of life, not just medical care, aligns well with the QoL research as it relates to people with Intellectual and Developmental Disabilities.

Structures

In the *Behavioral Health I/DD Tailored Plan RFA Pre-Release*, NCDHHS shares an intention to “advancing integrated and high-value care, improving population health, engaging and supporting providers and beneficiaries, and establishing a sustainable program with more predictable costs (NCDHHS, 2020, p. 1).” To attain this, NCDHHS is implementing the BH I/DD Tailored Plans and including a key structure, care management, to operationalize individualized service and treatment plans as well as provide care coordination services. NCDHHS believes that placing care management as close to the beneficiary as possible will improve health outcomes. Additionally, the realization of fully integrated managed care can only be achieved through provider and community-based care management products and structures.

By in large, the payer structure is the significant change of this reform along with the implementation of localized care management for BH I/DD Tailored Plan recipients. The addition of Prepaid Health Plans (PHPs) is less impactful at this time for Tailored Plan recipients as the Tailored Plans will continue to be rendered by the existing MCO system. In several years, these contracts will become available for the new PHPs to compete for. The types of services and allocations for funding remain largely the same, unless impacted by separate legislation outside of the implementation of managed care.

The person-centered planning processes and structures within the Care Management service represent the core alignment with QoL practices and principles, since they reflect the individualized wishes and needs of the person receiving services. The structures of person-centered planning do align with the QoL framework and best practices in the field of services for people with Intellectual and Developmental Disabilities.

Outcomes

Each MCO/PHP is required to develop a series of quality measurement plans that will be used to monitor improvements to care within both the Standard and Tailored Plans. The MCOs/PHPs will be rewarded through financial incentives for meeting certain quality standards and outcomes. Additionally, they will be required in their BH IDD Tailored Plan contracts with NCDHHS to create “incentive arrangements for providing integrated care and for achieving measurable outcomes, and strategies to minimize cost-shifting between the LME/MCO and the partnering entity (NCDHHS, 2018, p. 1).” NCDHHS has customized a set of quality objectives for BH IDD Tailored Plans that reflect both the primary focus of integrated care for individuals with significant support and service needs, while also addressing “quality of life, community integration, and social determinants of health” (NCDHHS, 2018, p. 4). While the language of the reform speaks to quality of life, community integration, and social determinants of health, the reality is that current selected measures only represent two of the eight QoL domains. As additional measures are added, it is anticipated that more of the QoL domains will be represented, especially within the Medicaid-funded Home and Community-Based Services of LTSS. Many programs already had existing measures/rules/requirements that also align much more closely with the eight domains of the QoL framework. At this time, the majority of the alignment is to the physical well-being domain and a partial alignment with the material well-being domain.

Implementation

Since the initiation of the transformation to Managed Care, the major stakeholders (i.e., NCDHHS and the MCOs/PHPs) have been conducting activities to prepare for initial implementation. Due to factors such as budget, COVID, county disengagement, NCDHHS staffing, PHP/MCO readiness, provider readiness, and legal challenges, the implementation of the Behavioral Health IDD Tailored Plan has been delayed three times. Concerns about implementation have also surfaced within various advocacy groups who continue to see this more as a reform related to payer processes than any actual improvement to the services being rendered or failing to be rendered. During this tumultuous transition, one of the major MCOs was also disbanded and its regions absorbed into the remaining MCOs. This caused thousands of people to transition to a new MCO prior to the change to the Tailored Plan. The implementation has at best been choppy, and we have yet to see actual launching of the BH IDD Tailored Plans.

The DisCrit analysis draws upon some key concerns worth noting during the initial phases of implementation. These are highlighted here below:

HCBS Waiver Waitlists

The reform will not address the funding needs that prevent 16,000+ people with disabilities from attaining an appropriate HCBS waiver. Changing the manner in which services are paid, did not result in added funding to address the waitlists. Currently, the NC General Assembly authorized funding for 1,000 additional slots. Some people have waited up to 20 years to receive services. This reality has cost the independent agency and potential contribution of tens of thousands of North Carolinians, who could obtain jobs, volunteer, engage in social activities, and share their inherent worth and thoughts with the world at large.

A new legal precedent, *Samantha R. v. NCDHHS,* states that North Carolina must expand HCBS options to the 16,000+ people on the Registry of Unmet Needs, reduce the reliance on institutional care, and address the workforce crisis. The NC DHHS has decided to appeal this ruling to the disappointment of thousands of North Carolinians, including Disability Rights NC, who filed the case on behalf of Samantha and thousands of other North Carolinians. This decision to appeal by NC DHHS reflects the lack of representation among leadership of people with disabilities who are eligible to receive the services overseen by the DHHS. Standing against this legal decision and instead proposing another plan which fails to address institutional bias or the DSP workforce shortage in an active way (not just collect data), aligns well with a capitalistic desire to save money and manage spending. It does not align well with the principles of enhancing quality of life for recipients of LTSS and we should remember that the 16,000+

people on the HCBS Waitlists will be receiving Tailored Plan Care Management services, while they wait for a state appropriated waiver. The failure to provide the necessary services to identified eligible citizens is a denial of rights and results in the continued marginalization of the voices of people with disabilities. The DisCrit principles recognize how this denial of rights and marginalization impacts the material, psychological, and social construction of disability in North Carolina and devalues the lives of people with disabilities.

Neutral Medicaid Budget

The reform relies on a net neutral Medicaid budget and does not expand services but rather changes the way they are paid (i.e., value-based purchasing) and in some cases rendered (i.e., community-based care management). In this neutral Medicaid budget reform, it is clear that any improvements for people with disabilities must also result in the best interest of the white power structures, which desires to reduce and limit Medicaid spending. The decision of the NC General Assembly to distance the State government and state operated departments from decision-making related to rate setting, service authorizations, and management of service delivery funding, in favor of privately operated organizations and insurance agencies, represents a distancing of responsibility. This distancing is enacted to mitigate the accountability of the NC General Assembly to increase allocations for disability services and general healthcare spending in NC. The promotion of managed care and its rhetoric of integrated, whole-person care, without addressing the rate insufficiency of HCBS providers, serves the interests of financial conservatists and capitalists who serve as NC General Assembly members.

Institutional Settings

The reform will not move away from institutionally based services that continue to exist for people with I/DD nor will it seek to reduce the reliance on Intermediate Care Facilities for people with I/DD. The NC DHHS states in its response to the *Samantha R v. NC DHHS* ruling, that it will work to reduce the size of three large ICFs, but makes no commitment to reducing and permanently eliminating institutional settings for people with IDD in NC. The judge has ruled a much more permanent reduction in institutional care and settings in NC, as setting has a significant impact on the quality of life opportunities. Institutional setting bias and funding bias, harms HCBS growth in NC and impacts the freedoms of people who needs more extensive support needs to live in their communities of choice. Further, it is not a choice if the level of care available in an institutional setting is not available within the community. Keeping ICFs in operation benefits the for-profit companies that have invested interests in sustainable and reliable Medicaid reimbursements. These for-profit companies have investors with expectations for profits and returns, within a system that is struggling to hire and retain staff because of poverty wages. It is unlikely that individuals are having real choice, when available resources are in such limited supply.

Value-Based Purchasing and Absence of Person-Driven Outcomes

The exact nature of value-based purchasing agreements will be left up to each individual PHP/MCO and current outcome measures largely reflect the physical well-being domain. Each person who will receive care management services under the Tailored Plan will have a person-centered plan developed which outlines individual goals and objectives that align with the dreams and wishes of the recipient of service. The attainment of these goals is to-date not a value-based reimbursement measures that PHPs/MCOs can incentivize providers of HCBS or other LTSS with. The measures need to reflect a menu that is expansive enough to capture the multidimensional identities of people with disabilities. Further, the individualized service plan goals represent the voices of individuals with IDD and to fail to value-base those goal attainments is to marginalize the voice of the recipient of service within the service delivery measurement structures. DisCrit principles promote these recommendations. When measures focus on system well-being, efficiency, and savings, the realities of the transformations goals become clearer. The measurement foci direct us to the allocation of resources, which we know are as limited as they were under the fee for service system, and this direction points in favor of attaining healthcare savings through reductions in service authorization.

Evidence-Based QoL Measurement

The measurement activities are not aligned with QoL research-based practices and do not use a QoL framework to organize and monitor improvements to service delivery. In Alberta Canada, they have implemented the *My Life*: *Personal Outcomes Index*, to measure the quality of life of adults with developmental disabilities since 2011 (Alberta Government, 2023). This measurement system is using an evidence-based QoL instrument to collect the self-reports of individuals with IDD and their guardians. It organizes the data into the eight QoL domains and is able to produce reports that demonstrate how best to allocate resources and services to improve quality of life across multiple domains simultaneously. The North Carolina model, so far has been for providers to select an instrument in conjunction with the PHP/MCO, but no aggregate standardized collection is occurring nor is it occurring across a holistic set of evidence-based domains. Without an evidence-based QoL measurement system, the voices of the recipients of service are further marginalized under a blanket of measurement related to the health of the system rather than the holistic well-being of the individual. The measures reflect a strong focus on healthcare and physical well-being, which represents the medical model of disability in which the person is in need of treatment to be cured. The goal is to reduce or term services after being provided the right treatment. This model sees the person as deficient and in need or remediation. Outcomes must shift to reflect the whole-person and the diversity of their human experience to align with the evidence-based practices of the QoL framework.

Personnel Shortages

The Care Managers, Direct Support Professionals, and interdisciplinary team members are becoming more and more difficult to recruit, train, and retain. A lack of investment and focus on this workforce has led to a crisis. The existing authorized shifts go unfulfilled and group home and institutional settings have had to rely on emergency state personnel during COVID to cover staffing needs. It is without a doubt that the system is nearing collapse without an answer to the workforce shortage. Wages continue to remain low despite years of advocacy for a meaningful wage that gets workers out of poverty. Other efforts have focused on a career pathway and recruiting new people into the field. The NC DHHS and the General Assembly must do more to shore up this workforce as it is the bloodline to helping people live meaningful lives of their choice within the community.

Standardization

With 6 MCOs and additional PHPs being added, the complexity of contracting with payers for providers is increasing. Each organization may have varying policies, services, protocols for practices that result in authorizing services or being paid for providing services, etc. etc. A lack of standardization exists across the existing MCOs in services rendered, reimbursement rates, staff training, and internal processes/requirements for reporting on outcomes. In the new Tailored Plans, additional requirements for reporting on outcomes and goals must also occur and each organization operating the Tailored Plan may also approach that differently. The more differentiation that exists between the Tailored Plans the more challenging it will be for providers serving people across multiple regions to keep up.

Representation

A lack of meaningful stakeholder input has resulted, since the advocacy and advisory councils have been reorganized. In the instance of the transformation advisory group, member sentiment was that it was a report-out by NCDHHS of what was happening rather than an honest conversation about whether that would be the best option. DisCrit challenges the decision-making authorities that maintain the health of the system at the expense of the individual being marginalized. To create engagement opportunities is one way to thwart agency, as the advocates feel they are being considered, but in reality, they are being told what is happening without any authority to impact those decisions. Failure by NC DHHS and their PHPs/MCOs to create representation engagement space with real agency on behalf of people with lived experience is a truly missed opportunity.

Summary on Implementation

These concerns represent many of the foundational elements of DisCrit, which impose racism, ableism, and whiteness within the structures and environments that all people live. The continued marginalization of the voices of people with disabilities within their service provision and service leadership leads to the denial of rights and impacts the material, psychological, and social identities of able bodied and non-able bodied, white and non-white, male and non-male, affluent and non-affluent, etc. Understanding these realities and contextual factors bolsters the opportunities for advocates to resist pitfalls and promote best practices within the implementation of managed care in North Carolina.

Overall, Behavioral Health I/DD Tailored Plans will be required to obtain NCQA Health Plan Accreditation with LTSS distinction for Health Plans by the end of the 3rd contract year. Many more implementation activities are occurring and will occur once the launch occurs in

2023. Some providers received start-up funding to help prepare for the launch of Care Management services, and several healthy pilot projects are underway addressing identified social determinants of health. The reporting practices are designed using a medical model and have yet to determine how best to value the accomplishment of individualized goals that are determined by the recipient of LTSS. Reporting and measurement practices should align with the evidence-based practices and framework of the QoL research, so that the stated goal of improving quality of life and community integration can be appropriately monitored.

In conclusion, the purposes and structures of Medicaid Transformation are potentially aligned with the QoL framework in a way that offers opportunities for the legislative reform to improve recipients of service quality of life. The current outcomes and implementation do not provide as much encouragement that this reform will result in improved quality of life, since they seem to remain focused on a medical model of disability. The outcomes remain at this time focused on physical well-being measures and the implementation of the Tailored Plans continues to experience delay after delay. Currently, the environment also overwhelms this reform, since the needs and demands of the disability community are reaching a boiling point of frustration. The answers to resolve many of these concerns are not incorporated into the BH I/DD Tailored Plan with its net neutral Medicaid budget.

Discussion of Threats and Opportunities/Recommendations for Future Practice

The implementation of Managed Care requires both a hopeful and skeptical outlook. Critically examining the Tailored Plans and the environment that they exist provides introspection potential outcomes of implementation. Existing power structures (i.e., Conservative Republican dominated NC General Assembly, capitalistic pro-market forces, and white-male able-bodied socio-cultural norms) along with environmental realities (i.e., HCBS Waitlists in the tens of thousands, workforce crisis, institutional bias, etc.) challenge the rhetoric within the language of improved quality of life for recipients of LTSS written in the transformation to managed care.

In this section, a series of critical factors related to the Medicaid Transformation are discussed in relation to opportunities, threats, or both to people with Intellectual and Developmental Disabilities, who are experiencing the transformation to Managed Care in North Carolina. These factors will be written as threat and/or opportunity statements that can be used to drive discourse by those advocating for meaningful quality of life enhancements for people with Intellectual and Developmental Disabilities, in North Carolina, who receive Long-Term Services and Supports (LTSS). Each of the threats correspond to critical critiques of the system as proposed and align with one or more of the DisCrit framework components. The main goal with these statements is to offer advocates and allies a tool that promotes positive dialogue of resistance against marginalizing forces. This being a key tenant of DisCrit.

Value-based Reimbursements

Opportunity

Value-based reimbursements offers flexibility within the system to reinforce certain practices and strategies that result in attainment of meaningful outcomes that lead to improved lives and better utilize available resources. It shifts the accountability to outcomes rather than simply measuring if services were received and gives the payer an opportunity to value the goals and wishes of the recipient of service.

Threat

Value-based reimbursements could be used to further penalize an under-funded system of service delivery if certain variables are not carefully considered. The first variable is whether proper value is assigned to outcomes that are meaningful to the recipient of service. The second variable is whether measurement and reporting requirements (including technology infrastructures) quickly overburdens the providers of services. The third variable is the reliance on attainment of value-based metrics to cover the basic cost of service delivery. And the fourth variable and important consideration is ensuring that standardization exists between PHPs/MCOs in how they contract and design value-based reimbursement strategies with network providers. These critical considerations play a large role in determining the financial threat to providers within this transformation.

Standardized Outcome Measures

Opportunity

Standardized Outcome Measures to monitor and advance improvements to service delivery provide an opportunity to compare programs, regions, and other factors which relate to improved service delivery. Specifically in Home and Community-Based Services, these standards can also be used to help demonstrate compliance with rules and requirements. Integrating outcomes related to “beneficiary choice, independent living, employment and community participation” offers value to a set of more holistic, whole-person measures (NCDHHS, 2019, p. 18). There is an opportunity to ensure outcome measures focus on person-centeredness and assessment of individual satisfaction and quality of life (ANCOR, 2020).

Threat

Standardized Outcomes Measures that are included within the measurement requirements for the Standard and Tailored Plans and the HCBS Quality Measure Set do not reflect the individualized goals and outcomes desired by each recipient of service who creates a person-centered plan to design and direct their services. The system must find a way to incentivize the attainment of individualized goals and outcomes, which represent the true improvements within the system. This is a system of human services and the recipients of services are humans with unique needs, goals, and wishes. When they grow, improve, and accomplish goals, the system is succeeding in improving their quality of life. Measures of system well-being will not provide this level of scrutiny or awareness of impact.

Home and Community-Based Provider Network

Opportunity

Expanding the HCBS provider network will ensure that recipients of HCBS have a choice in their provider and access to an adequate provider network providing services within their community of choice. This expansion would also provide essential support to already identified persons on the Registry of Unmet Needs. Expanding HCBS further reduces the need to rely on institutional care and prevents institutional admission.

Threat

In recent years, the North Carolina legislature has voted to increase pay for state employees of institutional settings and then for community-based institutional settings, while HCBS providers and people self-directing had to fight to be included in any financial increases. The most recent increase looks unlikely to get the HCBS direct support professional staff to a minimum of $15 an hour, which is already guaranteed in the institutional settings. This variance in funding creates a bias towards institutional services and care which threaten the availability and success of HCBS providers.

Workforce

Opportunity

Direct Support Professionals (DSPs) are the critical gear in the service delivery system that ensure it moves at all. Without the frontline professionals working with people with disabilities almost no actual services would be provided. Finally, in the midst of the COVID crisis, a much-needed light has been shown on the importance of DSPs and national organizations like the National Alliance for Direct Support Professionals are advancing efforts to certify, retain, and improve living conditions for this critical workforce. There is an opportunity to recognize, provide training and certification pathways, improve recruiting and retention programs, and financially incentivize this profession for long-term sustainability and growth.

Threat

The current massive shortage of DSPs means that existing authorized services are often not provided or provided poorly. The needed expansion of services for at least 16,000+ people on the Registry of Unmet Needs and persons who would exit an institutional setting with appropriate staffing support, means that an already overburdened workforce is horribly unprepared to take on the additional demand. Without improvements to living conditions, recognition, training and certification, and working conditions, the DSP workforce will continue to be insufficient and lacking in skills to serve people with more extensive support needs.

Care Management

Opportunity 1

Robust care management services for LTSS recipients provides an opportunity for additional efforts to be made which “ensure enrollees receive and maintain care in the setting most appropriate to their needs” and are supported through a transitional care management program to utilize community-based LTSS when exiting nursing homes/institutional settings (NCDHHS, 2018, p. 7). This advances the directives of community inclusion and integration, which are known to enhance quality of life.

Opportunity 2

Care Extenders, a member of the multi-disciplinary team, who support care managers in delivering Tailored Care Management. They will be able to complete functions like coordinating services, appointment scheduling, care assessment, and health promotion. The eligibility includes people with lived experience and their family members. This is an exciting "opportunity to advance paid, professional family navigation and peer support in the I/DD service system (Community Bridges, 2022, p.3)."

Threat

Similar to the DSP crisis, Care Managers, who can develop a person-centered plan in partnership with the recipient of service, have been in limited supply and relationships are really important within these professions. With the end of Cardinal Innovations Healthcare, one of the MCOs, the other MCOs were each hiring the available care managers, but it still meant changes to care managers for many families. In the new Tailored Plan, people on the Registry of Unmet Needs will be eligible for care management, which means a large expansion of professionals to serve this population.

Training

Opportunity

There exists an opportunity to develop a comprehensive statewide care manager and extender training program and operationalize it through the North Carolina Community College system to prepare the current and future workforce engaged in care management services. This also would assist in recruitment of future professionals through early introduction programs.

Threat

No formal care manager training program existed to certify these professionals through conventional professional education pathways. Currently, the PHPs/MCOs are required to develop a training program to educate their care managers, with some modules being prerequisites but many on-going as they as they act as care managers. The role is much more expansive and robust for the Tailored Plan population, which means that knowledgeable staff will be essential to aligning service coordination. It is required that every person-centered care plan for beneficiaries with special health care needs or LTSS eligibility be developed by a person with expertise in LTSS service coordination in addition to the person-centered planning process training (NCDHHS, 2021).

Rates/Reimbursement

Opportunity

If Medicaid payers connected value-based payments to providers who are showcasing innovation in the field of disability service practices and assisting individuals in achieving their personal goals and wishes, then improvements in the system of service delivery could be realized.

Threat

If reimbursement rates for care management services within the Tailored Plan, providers will not apply and engage in the effort required to prepare to deliver this service with quality. Large statewide providers are also preferred because the provider capacity will need to be more robust to keep up with billing, reporting, and program requirements. This could result in a marginalization of small community-based providers.

Electronic Health Record/Care Management Platform

Opportunity

This new integration of health information across service providers and ready access by treatment team members, who are a part of the individuals person-centered plan/treatment plan, means that individuals will receive better care. Providers will be better aligned in their treatments and coordination.

Threat

The integrated platform for care management requires more than a basic electronic health record, which some smaller providers still exist without today. The requirements for provider integrations, communications, and data collection means that advanced electronic health record and care management platforms will be needed. These platforms are another cost, in an environment which many providers are financially challenged. The larger state-wide and multi-state providers will be the most likely to have the needed funding and internal capacity to operate the needed care management platform.

Managed Care/Free Market Forces

Opportunity

Managed care offers a better use of financial resources to provide more and higher quality services, while reducing costs (Williamson et al., 2017). If managed care for I/DD services can successfully utilize market forces of competition, operate a more efficient payer system under private/corporate ownership, and value-base the right outcomes to maximize quality, then it offers an exceptional opportunity to advance I/DD LTSS services and supports (Friedman, 2019).

Threat

Managed care for people with Intellectual and Developmental Disabilities is lacking and evidence-base. Most of the research has looked into cost effectiveness and savings, rather than an improvement to services, supports, and outcomes that are important to people with Intellectual and Developmental Disabilities (Williamson et al., 2017). Further, quality outcome measures to value-base within managed care for the I/DD population receiving LTSS are emerging, and some contention exists about the lack of person-centeredness, self-determination, and personal autonomy represented in those new outcome measures (Friedman, 2019). Services for people with Intellectual and Developmental Disabilities are lifelong and whole-person oriented, which is much different than acute health care needs. Costs will always exist, and more volume does not result in automatic savings, especially in programs that have been historically underfunded (Friedman, 2019). To produce savings, the system should focus on aligning persons with the correct services and increased value should be focused on achieving additional quality.

Technology

Opportunity

North Carolina has invested in promoting existing technology tools and also new tools to enhance capabilities that assist clinicians and care managers in accessing patient-data, hospital admissions and discharge alerts, assessment results, risk stratification, care plans, and social determinants of health information (NCDHHS, 2021).

> The Department believes that effective, integrated, and well-coordinated care management depends on care team members having the ability to efficiently exchange

> timely and actionable member health information and use that information to monitor and respond to medical and nonmedical events that could impact a member’s well-being (NCDHHS, 2020, p. 11)

State law requires that Medicaid providers, who utilize an Electronic Health Record (EHR) be connected to the Health Information Exchange that collects patient data to produce Electronic Clinical Quality Measures and provide clinical reports to providers (NCDHHS, 2021). NCDHHS believes that the

> success of Tailored Care Management will depend on BH I/DD Tailored Plans, AMH+ practices, CMAs, CINs and other Partners, and pharmacies, as well as physical health, behavioral health, I/DD, TBI, LTSS, and social service providers collecting, using, and sharing data in support of an integrated and coordinated approach to care. (NCDHHS, 2020, p. 11)

NCDHHS is committed to reducing costs and complexity through consistent approach to collecting and reporting data and using the Health Information Exchange to aggregate data from multiple sources (NCDHHS, 2021). In addition, NCDHHS has operationalized a system called NCCARE360, which is the first statewide coordinated care network that assists with connecting people with identified needs to available community resources. The platform includes medical and non-medical community resources, which supports a coordinated, community-oriented, and person-centered approach to delivering care to North Carolinians (NCCARE360, 2022).

Threat

Smaller providers with limited financial resources to afford an Electronic Health Record will find themselves ineligible to connect with the Health Information Exchange and will not benefit from the clinical reports being produced.

QoL Language

Opportunity

> The QoL concept offers a
>
> framework for person-centered planning, a basic principle to guide service delivery policies and practices, and a model for exploring the impact of various individual and environmental factors on quality and life-related personal outcomes. (Schalock, Verdugo, Gomez, & Reinders, 2016, p.1)

The QoL concept aligns well with NCDHHS focus on social determinants of health, advancing quality of life through integrated and robust Tailored care management, and person-centered planning. Further, an intended goal is the development of value-based outcome practices and policies to enhance service quality for LTSS recipients. The improved quality of life and a research-based QoL concept being at the forefront of this reform for LTSS recipients, provides an opportunity to integrate the "[ecological model, supports paradigm, positive psychology, and rights of persons with disabilities] into value-based, person-centered, and systematic approach to services, supports, and outcomes evaluation" (Schalock, Verdugo, Gomez, & Reinders, 2016, p. 8, 9).

Threat

There is the threat that this language has been used to sell the changes being made towards more privatization and corporate control within the Medicaid programs. Promising improvements in quality of life, but really offering more or less the same dysfunctional and underfunded system of disability support services as before. However, in this design the responsibility continues to migrate away from the NC legislature and the NC DHHS as they contract out these responsibilities to private insurance companies and managed care organizations.

Social Determinants of Health

Opportunity

The key provisions of integrated care managers include addressing unmet health-related resource needs, such as, housing, food, transportation, interpersonal safety, and employment. These unmet health-related resource needs represent the core domains of NCDHHS identified Social Determinants of Health (SDOH). There is an opportunity to expand into additional areas, such as, housing quality & safety, childcare, education, employment, and health literacy (NCDHHS, 2018).

The Department feels that the “integration of SDOH and addressing unmet resource needs in treatment, planning, and provision of services will result in overall improved health outcomes (NCDHHS, 2021).” PHPs/MCOs will be required to screen enrollees in LTSS unmet health-related resource needs/social determinants of health and address those through several strategies that capitalize on local community-based resources (NCDHHS, 2019). The research related to I/DD and LTSS also proports the use of SDOH to look more holistically at the persons needs outside of health and physical well-being. It is best summarized by researcher Friedman below:

> It is important to measure beyond traditional health metrics not only because it can help produce cost savings (e.g., social determinants of health) and be utilized to formulate value-based payment programs, but also because integrated services are the law as mandated by the HCBS Settings Rule, *Olmstead v. L.C.*, and the Americans with Disabilities Act. (Friedman, 2019, p. 20)

The concept benefits from the interdependence of community resources and referrals, which address root causes of health disparities and help to mitigate expensive health care expenditures, but more importantly mitigate the unnecessary suffering of people in need of support across various domains of their lives.

Threat

The operationalization of health care screening tools to capture social determinants of health risk and connect them with resources, will depend upon the availability of resources to connect individual with, as well as, the robustness of those screening tools to capture the multi-faceted ways in which the environment impacts people of various populations health and well-being. The biggest concern that these tools will not reflect the populations of people most marginalized in the healthcare and disability service field, i.e., people of color and people with disabilities.

Threats and Opportunities Summary

Both opportunities to enhance the Medicaid system and threats that further jeopardize an at-risk system of disability supports and services depend on how Medicaid Transformation is implemented and operationalized. The opportunities represent the recommendations for future practice, as North Carolina continues to advance towards implementing the Tailored Plans in 2023.

The opportunities within this reform are significant, they represent a chance to recognize the voices of each recipient of service through their person-drive outcomes, and to value then by incentivizing providers who help them achieve those dreams/wishes/goals. Localized care management that is connect with a robust community network, enhanced with integrated technology, provides a steppingstone forward and enhances the ability to connect people with the resources they need. Focusing on more than just health care and looking at the social determinants of health expands the scope of service delivery and support a holistic intervention to support the whole person. It could be the start of a system which really supports community integration and improvements in quality of life. However, the realities of implementation and the current environment threaten that opportunity. The verbiage of quality of life is present, but seeing that become a reality will require commitment and alignment between recipients of service, providers, payers, NCDHHS, and the North Carolina General Assembly. Further, they will need to be aligned with the evidence-based practices on QoL planning, practice, and measurement for people with Intellectual and Developmental Disabilities to experience a true change in service quality.

Limitations

The findings of this research have limitations that should be taken into consideration. One of the primary limitations is that the legislative transformation is still in progress and subject to change at the direction of the Secretary of Health and Human Services, Governor, Legislature, and any legal rulings by the Judicial branch. The documents that were examined against the QoL domains are also subject to alteration by NCDHHS. Further, the PHPs/MCOs will have individual flexibilities to implement their own programs at which time a better understanding of how the new system will operate can be determined. This research is limited to the Session Law 2015-245 and all related bills to North Carolina’s move to integrated managed care. Other legislative and judicial actions may have been discussed to bring context to the environment. The research also focuses primarily on recipients of Long-Term Supports and Services who have Intellectual and Developmental Disabilities. The QoL evidence base to analyze this reform was selected, because it comes from practice and implementation among this population of people with Intellectual and Developmental Disabilities receiving LTSS.

Recommendations for Future Research

This initial critical policy research sets the foundation for a deep understanding of the move towards managed care in North Carolina. This research explores initial alignment between QoL and the guiding goals, policies, and practices that represent this shift towards managed care. Future research should look into the initial years of implementation and update this research with how MCOs/PHPs advanced value-based programs and quality outcome measurement. In addition, research should be conducted with recipients of service, their families/advocates, and providers to assess their valuation of using the QoL framework as a tool to inform person-centered plan development, implementation and measurement, as well as meso and macro level decision-making and data collection. Another vein of research should explore the degree to which quality of life improvement are realized or not realized for recipients of service, within the existing system and then within managed care. These represent some of the key areas for future research that will continue to inform people with Intellectual and Developmental Disabilities and their allies, who are fighting for equity within an environment and society that marginalizes them in favor of capitalistic gains.

Final Thoughts

As North Carolina moves into managed care for people with Intellectual and Developmental Disabilities receiving LTSS services, advocates and allies must be prepared to challenge fiscal policies and budgets that focus on cost reductions and savings at the expense of quality of services. Any savings should be reinvested into programs for people with Intellectual and Developmental Disabilities, some of whom have been identified and not served for over 20 years. Think about loved ones who might be identified as in need of institutional level care and left to wait up to two decades before receiving those needed services to remain in their community of choice. The marginalization and denial of rights that continues to occur under fiscal responsibility is a moral failure by the NC legislature and must be resisted.

North Carolina requires that there be available institutional settings available to meet the need of its citizens but does not guarantee adequate HCBS waivers for that same population. If more sustainable HCBS programs were operating in North Carolina many people with more intensive support needs living in institutional settings would be able to live in their communities of choice. A failure to bolster HCBS represents an institutional bias and further causes calculated harm to people with Intellectual and Developmental Disabilities and their families. Once again, this marginalization goes against the community integration mandates of DisCrit and the need to promote equity in material (housing/ finances/ transportation) well-being. For too long, the use of personal choice has been used to excuse institutional settings, while HCBS resources were stifled and left without the needed expansion and improvement to serve people with more extensive support needs.

The move to managed care alone will not resolve the significant threats that exist today and may exist in the future to LTSS for people with Intellectual and Developmental Disabilities. The North Carolina General Assembly cannot hope to achieve equity within this service delivery system by simply maintaining a fixed budget and operationalizing private insurance companies with a goal to make profits for shareholders. The reality is that savings can be achieved within this system because it relies heavily on institutional care, and in most cases community-based services are less expensive to render. To produce savings, the system should focus on aligning persons with the correct services and increased value should be focused on achieving additional quality (Friedman, 2019).

Another embarrassment and cost for North Carolina is the placement of children and adults with medically complex conditions with out-of-state providers (NCDHHS, 2020). This causes the recipient of service to be separated from their communities and families, while costing North Carolina a considerable financial resource. North Carolina must shift how it delivers services and must realize that these savings from better service alignment will not make up for the service delivery gap that has failed 16,000+ people in North Carolina, on the Registry of Unmet Needs awaiting a HCBS waiver, who have been in desperate need of help--the type of help that none of us would take for granted (i.e., bathing, eating, toileting, social activities, work/employment, doctors' visits, voting, etc.). The North Carolina General Assembly must take responsibility for its inaction and failure to allocate the needed resources to protect its most vulnerable citizens.

> Long-term services and lifelong supports are the underpinning of managed LTSS for people with IDD – you can manage and coordinate that but always will be responsible for some level of services and payment. Stability leads to better outcomes and results for everyone. (Friedman, 2019, p. 20)

Recent judicial action is requiring that North Carolina leaders take significant action to address the shortage of HCBS, the workforce crisis among DSPs, and the needed services for the thousands on the Registry of Unmet Needs. NCDHHS is challenging this ruling and I cannot think of a more egregious action than to dispute this ruling, when we know these citizens with disabilities, who require institutional level care, have gone so long without those critical services. Advocates and allies must continue to resist the actions of institutions that maintain the status quo of the system at the expense of the individual with lived experience. The North Carolina General Assembly, the Governor, the Secretary of Health and Human Services, and NCDHHS must align with the needs of their most vulnerable and at-risk citizens with disabilities who cannot wait any longer for meaningful service quality improvements.

The shift to managed care brings to bear the beneficial concept of paying for value and attaining measurable outcomes that demonstrate improvements to health and other social determinants of health. This concept already exists in disability services for recipients of LTSS, who are guaranteed person-centered care plans which outline individualized goals and the services/strategies to achieve those goals. These goals represent the outcomes that the provider and therefore payer are hoping to achieve on behalf of that individual. Separating the systems goals from that of the recipient's goals, therefore makes little sense. The goals of the service system should therefore be the attainment of the goals of the collective individuals they serve. A key provision in the shift to managed care under the Tailored Plan is that PHPs/MCOs will be required in their Quality Assessment and Improvement Programs to create "mechanisms to assess the quality and appropriateness of care provided to beneficiaries needing LTSS, including assessment of care between settings and a comparison of services and supports received with those set forth in the beneficiary's treatment/service plan (NCDHHS, 2021, p. 20)." As of yet, I have not seen the PHPs/MCOs answer how they plan to report and monitor this key requirement "a comparison of services and supports received with those set forth in the beneficiary's treatment/service plan", nor has NCDHHS focused measurement activities and technologies in a way to capture this essential data. Those receiving services today and those who will under the Tailored plans, or who will under the expansion of HCBS as ruled by judicial verdict, will not receive the needed benefits if those services are of poor quality and alignment with their goals and wishes. Addressing the contextual environmental threats that exist outside the scope of this legislative reform is critical if the anticipated goals of improved quality of life and community integration for people with Intellectual and Developmental Disabilities receiving Long-Term Supports and Services is to be achieved.

As for Mark . . .

Mark is waiting for his staff this morning. He missed his trip to the farmers market with his best friend because he couldn't get out of bed without help and was too embarrassed to ask his friend to provide personal care supports. He has been in a soiled attend for 3 hours and his skin is burning. His agency reported that the new staff has not returned calls and no back-up staff were scheduled due to staffing shortages. The staffing scheduler is on her way, but she already had to stop by two other clients this morning to make up for call outs. Mark's mother is on the way back from her vacation early because she fears Mark's staff has quit without notice. She knows he is being left with limited support by the agency and that it will take time to hire a new staff and train them. She is tired and worries how much longer her body will hold up. Stress and concern seeps into every day, as institutional care looms the longer this situation continues.

Mark is supposed to be at work on Monday, but he requires staff support to be on-site, he has worked with his employer to come up with workarounds to contribute from home, but he is less impactful than when on-site. The employer is thinking about hiring another employee to help make up for the loss of Mark's contribution and he wants to do more.

Mark has switched care managers and is trying to see the benefit in this transition to managed care. It seems that despite changes at the macro and meso-level policy and practice, little changes for Mark in his day-to-day service delivery. Mark is joining the LTSS Advisory committee hosted by his PHP/MCO and hopes to learn more about how to improve quality in his service delivery and others like him receiving or waiting to receive LTSS. Mark knows that he has worth and value. He knows that with quality supports he could contribute more. Mark is going to use this research to advocate for himself and his allies to ensure that the leadership in North Carolina delivers on their promise to improve their quality of life and community integration.

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APPENDIX A: GLOSSARY OF TERMS

Abbreviation	Explanation
ADL	Activities of Daily Living
ANCOR	American Network of Community Options and Resources
BH I/DD	Behavioral Health and Intellectual/Developmental Disabilities
CARF	Commission on Accreditation of Rehabilitation Facilities
CCD	Complex Communication Disorders
CMS	Centers for Medicare and Medicaid Services
CQI	Continuous Quality Improvement
EHR	Electronic Health Record
HCBS	Home & Community-based Supports
HEDIS	Health Effectiveness Data and Information Set
HIE	NC Health Information Exchange
HRCC	Horizons Residential Care Center
IDEA	Individuals with Disabilities Education Act
LDA	Least Dangerous Assumption
LTSS	Long-Term Services and Supports
LME-MCOs	Local Management Entity- Managed Care Organizations
NCPC	North Carolina’s Providers Council
(NC) DHHS	NC Department of Health and Human Services
NQF	*National Quality Forum*
PHPs	Prepaid Health Plans
PIP	Performance Improvement Programs
SP	Standard Plan
TP	Tailored Plan
QoL	Quality of Life
RFI	Request for Information
UN CRPD	United Nations Convention on the Rights of Persons with Disabilities

APPENDIX B: MEDICAID WAIVERS

Waiver	Description	Process	Conditions/Restrictions
1915(a)	Allows for States to implement a voluntary managed care system through a third party	Procured using a bidding procurement process	Final payment decision requires CMS approval.
1915(b)	Is a Medicaid Managed Care Waiver that covers behavioral health services identified in the State Medicaid Plan, inpatient psychiatric and substance use hospitalization, and Intermediate Care Facilities for Individuals with Intellectual Disabilities. Four subsections: (b)(1) Freedoms of Choice- restricts services to within the network of providers for the managed care entity, (b)(2) Enrollment Broker- uses a third party central broker, (b)(3) Non-Medicaid Services Waiver- applies savings to authorize additional services, and (b)(4) Selective Contracting Waiver- restricts choice of provider to provide treatment/care.	The most common and streamlined application for States is to individually contract with providers using a fee-for-service delivery system. This delivery system streamlines the process of documenting the economic effectiveness of the waiver program. States are required to demonstrate that enrolled members maintain access. Some additional considerations are that dual eligible persons, American Indians, and children with special health care needs can be required to enroll in the managed care system. Further, States must demonstrate cost-neutrality or cost-effectiveness to that of other Medicaid Waiver programs and approval is limited to 2 year renewals	1915(b) waiver Continuity of Care for Individuals with Intellectual Disabilities and requires that any individual admitted with an intellectual disability for residential services (other than short term care) and who are supported all or partially by State-appropriated funds, hold the right to residential services an alternate facility if the current placement for treatment is no longer able to meet the level of care needs. There is a federal entitlement to institutional services for anyone that meets the service eligibility criteria and makes a request for Intermediate Care Facility-for Individuals with Intellectual and Developmental Disabilities. This entitlement is written into State law through 122C-63. Waiver States can create HCBS waivers to support people with long-term care needs in their community and home, to prevent institutionalization. These services cannot be more costly than institutional care, must ensure safety and well-being, meet quality program standards for the population served, and follow an individualized person-centered care plan

1915I	Innovations Waiver for people with Intellectual and Developmental Disabilities, a Home and Community Based Waiver	The budget maximum for recipient on the Innovations Waiver is $135,000 per year and has remained at that rate for over 10 years. There is an eligibility criterion for the Innovations Waiver that must be met requiring that you (the applicant) be supported within the existing budget amount	Eligibility does not guarantee enrollment in an Innovations Waiver slot. LME-MCOs are paid using a capitated rate structure in which they take the average Innovations Waiver budget (i.e., $60,000) and distribute per enrollee per month payments to LME-MCOs to deliver person-centered treatment plans to individuals with an Innovations Waiver slot.
1915(i)	The State plan for HCBS, which provides flexibility to the State on which services are made available	Criteria is set by the State for eligibility, using a needs assessment, typically resulting in receipt of acute-medical services (e.g., skilled nursing) and long-term services (e.g., supported employment, case management, and respite) in the home and community	These programs must allow for self-direction on the part of the recipient. Compliance from the State require an independent and unbiased evaluation process, ensure access to the benefit to all eligible persons, ensure provider standards of quality, development of person-centered service plans, and monitoring through a continuous quality assurance program
1915(j)	Self-directed person assistance services (PAS), that provides personal care and other services under the State Medicaid Plan or 1915I waiver in place	Services are voluntary and participation requires self-direction. Training and expense for the support is established by the recipient of services	An assessment is required to determine eligibility followed by the development of a service plan and budget using a person-centered approach
1915(k)	Community First Choice (CFC) and it permits States to provide Direct Support Professional attendants within the home and community to eligible Medicaid enrollees under the State Plan.	To incentivize this waiver the Federal Share is increased by six percentage points for services related to this program	This option was included in the passage of the Affordable Care Act of 2010.

APPENDIX C: STATE PLAN AND MEDICAL WAIVER SERVICES

Medicaid State Plan Services	• Substance Abuse Non-Medical Community Residential Treatment • Substance Abuse Medically Monitored Community Residential Treatment • Substance Abuse Intensive Outpatient Program • Substance Abuse Comprehensive Outpatient Treatment Program	• Residential Level 1 • Residential Level 2 – Group Home or Family Setting • Residential Level 3 and Level 4	• Assertive Community Treatment • Child/Adolescent Day Treatment • Community Support Team • Psychosocial Rehabilitation • Intensive In-Home Services • Multi-Systemic Therapy • Intermediate Care Facilities/Individuals with Intellectual Disabilities • Psychiatric Treatment Residential Facilities
1915(b)(3) Services Transitional Living Intensive Recovery Supports In-Home Skill Building Personal Care/ Individual Support Respite One Time Transitional Cost	**Innovations Waiver Services** Day Supports-Developmental Day Day Support-Individual/Group Community Navigator; Community Navigator Training for Employer of Record Community Networking-Individual/Group; Community Networking-Classes/Conferences Crisis Behavioral Consultation; Specialized Consultative Services; Financial Support Supplies	**TBI Waiver Service** Adult Day Health Crisis Intervention and Stabilization Community Networking-Individual and Group; Classes and Conferences Residential Supports 1-3 Supported Employment-Individual and Group Natural Supports Education; Natural Supports Education Conference Personal Care Respite Care- Community Individual/Group/Institutional Home Modifications	**In-Lieu-Of Services** Behavioral Health Urgent Care Outpatient Plus Rapid Care Services Behavioral Health Crisis Assessment and Intervention Child First Outpatient (*North Carolina Medicaid Managed Care: Behavioral Health and Intellectual/Developmental Disability Tailored Plan Eligibility and Enrollment*, 2021). ○

Supported Employment Supported Employment Maintenance	In-Home Intensive Community Living and Supports; In-Home Skill Building- Individual/Group Personal Care Crisis Intervention & Stabilization Supports Respite Care-Community Individual/Community; Group/Community Facility Respite Care Nursing- LPN/RN Supported Employment- Individual/Group; Supported Employment- Long Term Follow-Up Individual/Long Term Follow-up Group Out of Home Crisis Residential Supports 1-4 Supported Living- Levels 1-3 Assistive Technology- Equipment and Supplies Community Transition Supports Home Modifications Individual Goods and Services Natural Supports Education Natural Supports Education-Conference Vehicle Adaptations	Respite Care Nursing- RN and LPN In-Home Intensive Individual Goods and Services Life Skills Training- Individual Group Specialized Consultative Services; Financial Supports; Crisis Behavioral Consultation Assistive Technology- Equipment and Supplies Out of Home Crisis Community Transition Supports Vehicle Adaptations Resource Facilitation Cognitive Rehabilitation	

APPENDIX D: LIST OF REVIEWED REGULATORY/GUIDANCE'S FOR HCBS, LTSS DELIVERY, TAILORED PLANS IMPLEMENTATION/VALUE-BASED PURCHASING

	List of Reviewed Regulatory/Guidance's for HCBS Delivery
1	Final Quality Measure Set for Medicaid Funded- Home and Community-Based Services
2	State Operations Manual
3	HCBS Settings Optional Tool
4	NC HCBS Transition Plan
5	HCBS Final Rule
6	Request for Information: Recommended Measure Set of Medicaid-Funded Home and Community-Based Services
7	Social Determinants of Health Screening Questions
8	NADSP: Dear Congressional Leaders, 2021
9	NCPC: Letter to RFI: Recommended Measure Set of Medicaid-Funded Home and Community-Based Services, 2020
10	IAP: Medicaid Innovations Accelerator Program: Value-Based Payment for Home and Community-Based Services: Intellectual and Developmental Disability Systems, 2018

	List of Reviewed Regulatory/Guidance's for LTSS Delivery
1	Coordinating Care from Out-of-State Providers for Medicaid-eligible Children with Medically Complex Conditions, 2020
2	DHB Welcomes KEPRO: Comprehensive Independent Assessment Entity Kick-Off Webinar, 2020
3	Connecting to HIE and the 1115 Waiver: What Providers Need to Know 2018
4	North Carolina's Vision for Long-Term Services and Supports under Managed Care, 2018
5	June 22, 2021 Division of Health Benefits Stakeholder Webinar: Centers for Medicaid and Medicare Services 10% FMAP Increase for HCBS Services Under the American Rescue Plan
6	NC Medicaid Transformation Section 1115 Demonstration Waiver Webcast, 2018
7	The Move to Managed Care for Intellectual and Developmental Disability Services: Guidance for State Medicaid and DD Directors, and Payers, 2019

	List of Reviewed Regulatory/Guidance's Medicaid Managed Care- Tailored Plan Implementation/ Value-Based Purchasing
1	Behavioral Health I/DD Tailored Plan RFA Pre-Release, 2020
2	Overview of the Beneficiary Enrollment Experience in NC Medicaid Managed Care for Medicaid Providers, 2019
3	North Carolina's Medicaid Accountable Care Organizations (ACOs) for Standard Plans and Providers: Building on the Advanced Medical Home Program to Drive Value-based Payment, 2020
4	Maximizing the NCCARE360 Network to Advance the Public's Health: A Guide for NC Local Health Departments, 2019
5	Draft Transition of Care Policy, 2020 & Transition of Care Policy, 2021
6	Behavioral Health and Intellectual/Developmental Disability Tailored Plan: Tailored Care Management Certification *AMH+* and *CMA* Application Instructions, 2020-2021
7	North Carolina's Medicaid Managed Care Quality Strategy, 2021
8	North Carolina Medicaid Managed Care: Behavioral Health and Intellectual/Developmental Disability Tailored Plan Eligibility and Enrollment, 2019 & 2021
9	Behavioral Health I/DD Tailored Plan Memo on State-Funded Services Design Updates, 2020
10	North Carolina's Value-Based Payment Strategy for Standard Plans and Providers in Medicaid Managed Care, 2020
11	Centers for Medicaid and Medicare Services 2018 Updates to the Child and Adult Core Health Care Quality Measurement Sets, 2017
12	National Core Indicators: Indicator List (2020-2021)
13	Behavioral Health and I/DD Tailored Plan: Tailored Care Management Provider Manual, 2020
14	North Carolina's Care Management Strategy for Behavioral Health and Intellectual/Developmental Disability Tailored Plans, 2019
15	North Carolina Medicaid Transformation Seven-Year Forecast Legislative Report 2019
16	Plan for Implementation of Hospital Quality Outcomes Program and PHP Quality Outcomes Program, 2018
17	NC Health Information Exchange Connectivity Feasibility Study, 2018
18	Plan for Implementation of Behavioral Health and Intellectual/Developmental Disability Tailored Plans. 2018
19	Using Standardized Social Determinants of Health Screening Questions to Identify and Assist Patients with Unmet Health-related Resource Needs in North Carolina, 2018
20	North Carolina's Care Management Strategy Under Managed Care, 2018
21	Operational Overview of the Medicaid and NC Health Choice Programs for SFY 2018
22	Behavioral Health and Intellectual/Developmental Disability Tailored Plan, 2017
23	OptimaHealth: 2019 HEDIS Measures Healthcare Effectiveness Data and Information Set & 2023

APPENDIX E: BEHAVIORAL HEALTH I/DD TAILORED MEDICAID MEASURE SET

National Quality Forum #	Measure Name	Standard Origination	Quality of Life Domain Alignment
Pediatric Measures			
1516	Child and Adolescent Well-Care Visits	NCQA	Physical Well-being
0038	Childhood Immunization Status	NCQA	Physical Well-being
0108	Follow-up Care for Children Prescribed Attention-Deficit/Hyperactivity Disorder (ADHD) Medication (ADD)	NCQA	Physical Well-being
1407	Immunization for Adolescents (IMA)	NCQA	Physical Well-being
2800	Metabolic Monitoring for Children and Adolescents on Antipsychotics (APM)	NCQA	Physical Well-being
NA	Total Eligible Receiving at least one Initial or Periodic Screening	DHHS	Physical Well-being
2801	Use of First Line Psychosocial Care for Children and Adolescents on Antipsychotics (APP)	NCQA	Physical Well-being
1392	Well-child Visits in the First 30 Months of Life (W30)	NCQA	Physical Well-being
Adult Measures			
0105	Antidepressant Medication Management (AMM)α	NCQA	Physical Well-being
0032	Cervical Cancer Screening (CCS)	NCQA	Physical Well-being
0033	Chlamydia Screening in Women (CHL)	NCQA	Physical Well-being
0059	Comprehensive Diabetes Care: Hemoglobin A1c (HbA1c) Poor Control (>9.0%) (HPC)23	NCQA	Physical Well-being
3389	Concurrent Use of Prescription Opioids and Benzodiazepines (COB)	PQA	Physical Well-being
3175	Continuation of Pharmacotherapy for Opioid Use Disorder (OUD)α	University of Southern California	Physical Well-being
0018	Controlling High Blood Pressure (CBP)	NCQA	Physical Well-being
1932	Diabetes Screening for People with Schizophrenia or Bipolar Disorder Who Are Using Antipsychotic Medications	NCQA	Physical Well-being
0039	Flu Vaccinations for Adults (FVA, FVO)*	NCQA	Physical Well-being

0576	Follow-up After Hospitalization for Mental Illness (FUH)α	NCQA	Physical Well-being
0027	Medical Assistance with Smoking and Tobacco Use Cessation (MSC)*24	NCQA	Physical Well-being
1768	Plan All-cause Readmissions (PCR) [Observed versus expected ratio]	NCQA	Physical Well-being
NA	Rate of Screening for Unmet Resource Needsα	DHHS	Physical Well-being
0418 / 0418e	Screening for Depression and Follow-Up Plan (CDF)25	CMS	Physical Well-being
NA	Total Cost of Care*	To Be Determined	Physical Well-being
2940	Use of Opioids at High Dosage in Persons Without Cancer (OHD)α	PQA	Physical Well-being
2950	Use of Opioids from Multiple Providers in Persons Without Cancer (OMP)α	PQA	Physical Well-being
Maternal Measures			
NA	Low Birthweight26	DHHS	Physical Well-being
1517	Prenatal and Postpartum Care: Timeliness of Prenatal Care (PPC)	NCQA	Physical Well-being
NA	Rate of Screening for Pregnancy Risk	DHHS	Physical Well-being

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APPENDIX F: BEHAVIORAL HEALTH I/DD TAILORED PLAN STATE-FUNDED

MEASURE SET

Measure	**Standard Origination**	**QoL Domain Alignment**
Alcohol and Drug Abuse Treatment Center (ADATC) Readmissions within 30 Days and 180 Days	DHHS	Physical Well-being
Average Length of Stay in Community Hospitals (mental health treatment & substance use disorder treatment)	DHHS	Physical Well-being
Community Mental Health Inpatient Readmissions within 30 Days	DHHS	Physical Well-being
Community Substance Use Disorder Inpatient Readmission within 30 Days	DHHS	Physical Well-being
Initiation of Services (alcohol or other drug abuse or dependence treatment, and one for persons receiving MH treatment)	DHHS	Physical Well-being
Engagement in Services (alcohol or other drug abuse or dependence treatment, and one for persons receiving MH treatment)	DHHS	Physical Well-being
Housing Retention: Maintains TCL Supportive Housing Target	DHHS	Material Well-being
Housing Retention: Percent of Individuals Who Retained TCL Supportive Housing	DHHS	Material Well-being
State Psychiatric Hospital Readmissions within 30 Days and 180 Days	DHHS	Physical Well-being
TCL Population Employment	DHHS	Material Well-being
Follow-up After Discharge from Community Hospitals, State Psychiatric Hospitals, and Facility-based Crisis Services for Mental Health Treatment (7 days and 30 days)*	DHHS	Physical Well-being
Follow-up After Discharge from Community Hospitals, State Psychiatric Hospitals, State ADATCs, and Detox/Facility Based Crisis Services for substance use disorder (SUD) Treatment (7 days and 30 days)*	DHHS	Physical Well-being

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APPENDIX G: STANDARD PLANS AND BEHAVIORAL HEALTH I/DD TAILORED PLANS MEASURE SET

National Quality Forum #	**Measure Name**	**Standard Origination**	**QoL Domain Alignment**
Pediatric Measures			
N/A	Avoidable Pediatric Utilization PDI 14: Asthma Admission Rate PDI 15: Diabetes Short-term Complications Admission Rate PDI 16: Gastroenteritis Admission Rate PDI 18: Urinary Tract Infection Admission Rate	Agency for Healthcare Research and Quality (AHRQ)	Physical Well-being
N/A	Percentage of Eligibles Who Received Preventive Dental Services	CMS	Physical Well-being
0024	Weight Assessment and Counseling for Nutrition and Physical Activity for Children/Adolescents (WCC) (the total of all ages for each of the three rates)	NCQA	Physical Well-being
Adult Measures			
1879	Adherence to Antipsychotic Medications for Individuals with Schizophrenia (SAA)	NCQA	Physical Well-being
N/A	Admission to an Institution from the Community (AIF)	NCQA	Physical Well-being; Material Well-being
0023	Adult BMI Assessment (ABA)	City of New York Department of Health and Mental Hygiene	Physical Well-being
N/A	Ambulatory Care: Emergency Department (ED) Visits (AMB)	NCQA	Physical Well-being
1800	Asthma Medication Ration (AMR)	NCQA	Physical Well-being

N/A	Avoidable Adult Utilization: PQI 01: Diabetes Short-term Complication Admission Rate PQI 15: Asthma in Younger Adults Admission Rate PQI 05: COPD or Asthma in Older Adults Admission Rate PQI 08: Heart Failure Admission Rate PQI 15: Asthma in Younger Adults Admission Rate	AHRQ	Physical Well-being
2372	Breast Cancer Screening (BCS)	NCQA	Physical Well-being
0061	Comprehensive Diabetes Care (CDC): Blood Pressure Control (<140/90 mm Hg)	NCQA	Physical Well-being
0575	Comprehensive Diabetes Care (CDC): Hemoglobin A1c (HbA1c) Control (<8.9%)	NCQA	Physical Well-being
0547	Diabetes and Medication Possession Ration for Statin Therapy	NCQA	Physical Well-being
2607	Diabetes Care for People with Serious Mental Illness: Hemoglobin A1c (HbA1c) Poor Control (<9.0%) (HPCMI)	NCQA	Physical Well-being
3489	Follow-up After Emergency Department Visit for Mental Illness	NCQA	Physical Well-being
3488	Follow-up After Emergency Department Visit for Substance Use (FUA)	NCQA	Physical Well-being
2082/3210e	HIV Viral Load Suppression (HVL)	HRSA	Physical Well-being
N/A	Inpatient Utilization (IU)	CMS	Physical Well-being
2856	Pharmacotherapy Management of COPD Exacerbation (PCE)	NCQA	Physical Well-being
N/A	Prevention Quality Indicator (PQI) 92: Chronic Conditions Composite (PQI 92)	AHRQ	Physical Well-being
N/A	Statin Therapy for Patients with Cardiovascular Disease (SPC)	NCQA	Physical Well-being
2597	Substance Use Screening and Intervention Composite	American Society of Addiction Medicine	Physical Well-being
3400	Use of Pharmacotherapy for Opioid Use Disorder (OUD)	CMS	Physical Well-being

Maternal Measures			
2903/2904	Contraceptive Care: All Women (CCW)	US Office of Population Affairs	Physical Well-being
2902	Contraceptive Care: Postpartum (CCP)	US Office of Population Affairs	Physical Well-being
1382	Live Births Weighing Less Than 2,500 Grams	CDC	Physical Well-being
N/A	Prenatal Depression Screening and Follow-Up (PND)	NCQA	Physical Well-being
Select Public Health Measures			
NA	Diet/Exercise o Increase fruit and vegetable consumption among adults o Increase percentage of adults who get recommended amount of physical activity Opioid Use o Reduce the unintentional poisoning mortality rate Tobacco Use o Decrease the percentage of adults who are current smokers o Decrease the percentage of high school students using tobacco o Decrease the percentage of women who smoke during pregnancy o Decrease exposure to secondhand smoke in the workplace	NA	Physical Well-being
Patient Satisfaction			
0006	CAHPS Survey	AHRQ	Personal Development Interpersonal Relations Social Inclusion; Self-Determination; Physical Well-being; Material Well-being; Emotional Well-being; Rights
Provider Satisfaction			
NA	Provider Survey	DHHS	NA

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APPENDIX H: HEDIS MEASURES 2023

HEDIS Domain	Measure Name	Measure Description	QoL Domain Alignment
Effectiveness of Care	Weight Assessment and Counseling for Nutrition and Physical Activity for Children/ Adolescents WCC	The percentage of members 3–17 years of age who had an outpatient visit with a PCP or OB/GYN and who had evidence of the following during the measurement year. • BMI percentile documentation*. • Counseling for nutrition. • Counseling for physical activity. * Because BMI norms for youth vary with age and gender, this measure evaluates whether BMI percentile is assessed rather than an absolute BMI value.	Physical Well-being
Effectiveness of Care	Childhood Immunization Status CIS	The percentage of children 2 years of age who had four diphtheria, tetanus and acellular pertussis (DTaP); three polio (IPV); one measles, mumps and rubella (MMR); three haemophilus influenza type B (HiB); three hepatitis B (HepB), one chicken pox (VZV); four pneumococcal conjugate (PCV); one hepatitis A (HepA); two or three rotavirus (RV); and two influenza (flu) vaccines by their second birthday. The measure calculates a rate for each vaccine and three combination rates.	Physical Well-being
Effectiveness of Care	Immunizations for Adolescents IMA	The percentage of adolescents 13 years of age who had one dose of meningococcal vaccine, one tetanus, diphtheria toxoids and acellular pertussis (Tdap) vaccine, and have completed the human papillomavirus (HPV) vaccine series by their 13th birthday. The measure calculates a rate for each vaccine and two combination rates.	Physical Well-being
Effectiveness of Care	Lead Screening in Children LSC	The percentage of children 2 years of age who had one or more capillary or venous lead blood test for lead poisoning by their second birthday.	Physical Well-being
Effectiveness of Care	Cervical Cancer Screening CCS	The percentage of women 21–64 years of age who were screened for cervical cancer using any of the following criteria: • Women 21–64 years of age who had cervical cytology performed within the last 3 years. • Women 30–64 years of age who had cervical high-risk human papillomavirus (hrHPV) testing performed within the last 5 years. • Women 30–64 years of age who had cervical cytology/high-risk human papillomavirus (hrHPV) cotesting within the last 5 years.	Physical Well-being
Effectiveness of Care	Colorectal Cancer Screening COL	The percentage of members 45–75 years of age who had appropriate screening for colorectal cancer.	Physical Well-being
Effectiveness of Care	Chlamydia Screening in Women CHL	The percentage of women 16–24 years of age who were identified as sexually active and who had at least one test for chlamydia during the measurement year.	Physical Well-being
Effectiveness of Care	Care for Older Adults COA	The percentage of adults 66 years and older who had each of the following during the measurement year: • Medication review. • Functional status assessment. • Pain assessment.	Physical Well-being
Effectiveness of Care	Oral Evaluation, Dental Services OED	The percentage of members under 21 years of age who received a comprehensive or periodic oral evaluation with a dental provider during the measurement year.	Physical Well-being

Effectiveness of Care	Topical Fluoride for Children TFC	The percentage of members 1–4 years of age who received at least two fluoride varnish applications during the measurement year.	Physical Well-being
Effectiveness of Care	Appropriate Testing for Pharyngitis CWP	The percentage of episodes for members 3 years and older where the member was diagnosed with pharyngitis, dispensed an antibiotic and received a group A streptococcus (strep) test for the episode.	Physical Well-being
Effectiveness of Care	Use of Spirometry Testing in the Assessment and Diagnosis of COPD SPR	The percentage of members 40 years of age and older with a new diagnosis of COPD or newly active COPD, who received appropriate spirometry testing to confirm the diagnosis.	Physical Well-being
Effectiveness of Care	Pharmacotherapy Management of COPD Exacerbation PCE	The percentage of COPD exacerbations for members 40 years of age and older who had an acute inpatient discharge or ED visit on or between January 1–November 30 of the measurement year and who were dispensed appropriate medications. Two rates are reported: 1. Dispensed a Systemic Corticosteroid (or there was evidence of an active prescription) within 14 days of the event. 2. Dispensed a Bronchodilator (or there was evidence of an active prescription) within 30 days of the event. Note: The eligible population for this measure is based on acute inpatient discharges and ED visits, not on members. It is possible for the denominator to include multiple events for the same individual.	Physical Well-being
Effectiveness of Care	Asthma Medication Ratio AMR	The percentage of members 5–64 years of age who were identified as having persistent asthma and had a ratio of controller medications to total asthma medications of 0.50 or greater during the measurement year.	Physical Well-being
Effectiveness of Care	Controlling High Blood Pressure CBP	The percentage of members 18–85 years of age who had a diagnosis of hypertension (HTN) and whose blood pressure (BP) was adequately controlled (<140/90 mm Hg) during the measurement year.	Physical Well-being
Effectiveness of Care	Persistence of Beta-Blocker Treatment After a Heart Attack PBH	The percentage of members 18 years of age and older during the measurement year who were hospitalized and discharged from July 1 of the year prior to the measurement year to June 30 of the measurement year with a diagnosis of AMI and who received persistent beta-blocker treatment for six months after discharge.	Physical Well-being
Effectiveness of Care	Statin Therapy for Patients With Cardiovascular Disease SPC	The percentage of males 21–75 years of age and females 40–75 years of age during the measurement year, who were identified as having clinical atherosclerotic cardiovascular disease (ASCVD) and met the following criteria. The following rates are reported: 1. Received Statin Therapy. Members who were dispensed at least one high-intensity or moderate-intensity statin medication during the measurement year. 2. Statin Adherence 80%. Members who remained on a high-intensity or moderate-intensity statin medication for at least 80% of the treatment period.	Physical Well-being

Effectiveness of Care	Cardiac Rehabilitation CRE	The percentage of members 18 years and older who attended cardiac rehabilitation following a qualifying cardiac event, including myocardial infarction, percutaneous coronary intervention, coronary artery bypass grafting, heart and heart/lung transplantation or heart valve repair/replacement. Four rates are reported: • Initiation. The percentage of members who attended 2 or more sessions of cardiac rehabilitation within 30 days after a qualifying event. • Engagement 1. The percentage of members who attended 12 or more sessions of cardiac rehabilitation within 90 days after a qualifying event. Engagement 2. The percentage of members who attended 24 or more sessions of cardiac rehabilitation within 180 days after a qualifying event. • Achievement. The percentage of members who attended 36 or more sessions of cardiac rehabilitation within 180 days after a qualifying event.	Physical Well-being
Effectiveness of Care	Hemoglobin A1c Control for Patients With Diabetes HBD	The percentage of members 18–75 years of age with diabetes (types 1 and 2) whose hemoglobin A1c (HbA1c) was at the following levels during the measurement year: • HbA1c control (9.0%). Note: Organizations must use the same data collection method (Administrative or Hybrid) to report these indicators.	Physical Well-being
Effectiveness of Care	Blood Pressure Control for Patients With Diabetes BPD	The percentage of members 18–75 years of age with diabetes (types 1 and 2) whose blood pressure (BP) was adequately controlled (<140/90 mm Hg) during the measurement year.	Physical Well-being
Effectiveness of Care	Eye Exam for Patients With Diabetes EED	The percentage of members 18–75 years of age with diabetes (types 1 and 2) who had a retinal eye exam.	Physical Well-being
Effectiveness of Care	Kidney Health Evaluation for Patients With Diabetes KED	The percentage of members 18–85 years of age with diabetes (type 1 and type 2) who received a kidney health evaluation, defined by an estimated glomerular filtration rate (eGFR) and a urine albumin-creatinine ratio (uACR), during the measurement year.	Physical Well-being
Effectiveness of Care	Statin Therapy for Patients With Diabetes SPD	The percentage of members 40–75 years of age during the measurement year with diabetes who do not have clinical atherosclerotic cardiovascular disease (ASCVD) who met the following criteria. Two rates are reported: 1. Received Statin Therapy. Members who were dispensed at least one statin medication of any intensity during the measurement year. 2. Statin Adherence 80%. Members who remained on a statin medication of any intensity for at least 80% of the treatment period.	Physical Well-being
Effectiveness of Care	Osteoporosis Management in Women Who Had a Fracture OMW	The percentage of women 67–85 years of age who suffered a fracture and who had either a bone mineral density (BMD) test or prescription for a drug to treat osteoporosis in the six months after the fracture.	Physical Well-being
Effectiveness of Care	Osteoporosis Screening in Older Women OSW	The percentage of women 65–75 years of age who received osteoporosis screening.	Physical Well-being

Effectiveness of Care	Diagnosed Mental Health Disorders DMH	The percentage of members 1 year of age and older who were diagnosed with a mental health disorder during the measurement year. Note: The measure provides information on the diagnosed prevalence of mental health disorders. Neither a higher nor lower rate indicates better performance.	Physical Well-being
Effectiveness of Care	Antidepressant Medication Management AMM	The percentage of members 18 years of age and older who were treated with antidepressant medication, had a diagnosis of major depression and who remained on an antidepressant medication treatment. Two rates are reported. 1. Effective Acute Phase Treatment. The percentage of members who remained on an antidepressant medication for at least 84 days (12 weeks). 2. Effective Continuation Phase Treatment. The percentage of members who remained on an antidepressant medication for at least 180 days (6 months).	Physical Well-being
Effectiveness of Care	Follow-Up Care for Children Prescribed ADHD Medication ADD	The percentage of children newly prescribed attention-deficit/hyperactivity disorder (ADHD) medication who had at least three follow-up care visits within a 10-month period, one of which was within 30 days of when the first ADHD medication was dispensed. Two rates are reported. 1. Initiation Phase. The percentage of members 6–12 years of age with a prescription dispensed for ADHD medication, who had one follow-up visit with a practitioner with prescribing authority during the 30-day Initiation Phase. 2. Continuation and Maintenance (C&M) Phase. The percentage of members 6–12 years of age with a prescription dispensed for ADHD medication, who remained on the medication for at least 210 days and who, in addition to the visit in the Initiation Phase, had at least two follow-up visits with a practitioner within 270 days (9 months) after the Initiation Phase ended.	Physical Well-being
Effectiveness of Care	Follow-Up After Hospitalization for Mental Illness FUH	The percentage of discharges for members 6 years of age and older who were hospitalized for treatment of selected mental illness or intentional self-harm diagnoses and who had a follow-up visit with a mental health provider. Two rates are reported: 1. The percentage of discharges for which the member received follow-up within 30 days after discharge. 2. The percentage of discharges for which the member received follow-up within 7 days after discharge.	Physical Well-being
Effectiveness of Care	Follow-Up After Emergency Department Visit for Mental Illness FUM	The percentage of emergency department (ED) visits for members 6 years of age and older with a principal diagnosis of mental illness or intentional self-harm, who had a follow-up visit for mental illness. Two rates are reported: 1. The percentage of ED visits for which the member received follow-up within 30 days of the ED visit (31 total days). 2. The percentage of ED visits for which the member received follow-up within 7 days of the ED visit (8 total days).	Physical Well-being

Effectiveness of Care	Diagnosed Substance Use Disorders DSU	The percentage of members 13 years of age and older who were diagnosed with a substance use disorder during the measurement year. Four rates are reported: 1. The percentage of members diagnosed with an alcohol disorder. 2. The percentage of members diagnosed with an opioid disorder. 3. The percentage of members diagnosed with a disorder for other or unspecified drugs. 4. The percentage of members diagnosed with any substance use disorder. Note: The measure provides information on the diagnosed prevalence of substance use disorders. Neither a higher nor lower rate indicates better performance.	Physical Well-being
Effectiveness of Care	Follow-Up After High-Intensity Care for Substance Use Disorder FUI	The percentage of acute inpatient hospitalizations, residential treatment or withdrawal management visits for a diagnosis of substance use disorder among members 13 years of age and older that result in a follow-up visit or service for substance use disorder. Two rates are reported: 1. The percentage of visits or discharges for which the member received follow-up for substance use disorder within the 30 days after the visit or discharge. 2. The percentage of visits or discharges for which the member received follow-up for substance use disorder within the 7 days after the visit or discharge.	Physical Well-being
Effectiveness of Care	Follow-Up After Emergency Department Visit for Substance Use FUA	The percentage of emergency department (ED) visits among members age 13 years and older with a principal diagnosis of substance use disorder (SUD), or any diagnosis of drug overdose, for which there was follow-up. Two rates are reported: 1. The percentage of ED visits for which the member received follow-up within 30 days of the ED visit (31 total days). 2. The percentage of ED visits for which the member received follow-up within 7 days of the ED visit (8 total days).	Physical Well-being
Effectiveness of Care	Pharmacotherapy for Opioid Use Disorder POD	The percentage of opioid use disorder (OUD) pharmacotherapy events that lasted at least 180 days among members 16 years of age and older with a diagnosis of OUD and a new OUD pharmacotherapy event.	Physical Well-being
Effectiveness of Care	Diabetes Screening for People With Schizophrenia or Bipolar Disorder Who Are Using Antipsychotic Medications SSD	The percentage of members 18–64 years of age with schizophrenia, schizoaffective disorder or bipolar disorder, who were dispensed an antipsychotic medication and had a diabetes screening test during the measurement year.	Physical Well-being
Effectiveness of Care	Diabetes Monitoring for People With Diabetes and Schizophrenia SMD	The percentage of members 18–64 years of age with schizophrenia or schizoaffective disorder and diabetes who had both an LDL-C test and an HbA1c test during the measurement year.	Physical Well-being

Effectiveness of Care	Cardiovascular Monitoring for People With Cardiovascular Disease and Schizophrenia SMC	The percentage of members 18–64 years of age with schizophrenia or schizoaffective disorder and cardiovascular disease, who had an LDL-C test during the measurement year.	Physical Well-being
Effectiveness of Care	Adherence to Antipsychotic Medications for Individuals With Schizophrenia SAA	The percentage of members 18 years of age and older during the measurement year with schizophrenia or schizoaffective disorder who were dispensed and remained on an antipsychotic medication for at least 80% of their treatment period.	Physical Well-being
Effectiveness of Care	Metabolic Monitoring for Children and Adolescents on Antipsychotics APM	The percentage of children and adolescents 1–17 years of age who had two or more antipsychotic prescriptions and had metabolic testing. Three rates are reported: 1. The percentage of children and adolescents on antipsychotics who received blood glucose testing. 2. The percentage of children and adolescents on antipsychotics who received cholesterol testing. 3. The percentage of children and adolescents on antipsychotics who received blood glucose and cholesterol testing.	Physical Well-being
Effectiveness of Care	Advance Care Planning ACP	The percentage of adults 66–80 years of age with advanced illness, an indication of frailty or who are receiving palliative care, and adults 81 years of age and older who had advance care planning during the measurement year.	Physical Well-being
Effectiveness of Care	Transitions of Care TRC	The percentage of discharges for members 18 years of age and older who had each of the following. Four rates are reported: • Notification of Inpatient Admission. Documentation of receipt of notification of inpatient admission on the day of admission through 2 days after the admission (3 total days). • Receipt of Discharge Information. Documentation of receipt of discharge information on the day of discharge through 2 days after the discharge (3 total days). Patient Engagement After Inpatient Discharge. Documentation of patient engagement (e.g., office visits, visits to the home, telehealth) provided within 30 days after discharge. • Medication Reconciliation Post-Discharge. Documentation of medication reconciliation on the date of discharge through 30 days after discharge (31 total days).	Physical Well-being
Effectiveness of Care	Follow-Up After Emergency Department Visit for People With Multiple High-Risk Chronic Conditions FMC	The percentage of emergency department (ED) visits for members 18 years of age and older who have multiple high-risk chronic conditions who had a follow-up service within 7 days of the ED visit.	Physical Well-being

Effectiveness of Care	Non-Recommended Cervical Cancer Screening in Adolescent Females NCS	The percentage of adolescent females 16–20 years of age who were screened unnecessarily for cervical cancer. Note: A lower rate indicates better performance.	Physical Well-being
Effectiveness of Care	Non-Recommended PSA-Based Screening in Older Men PSA	The percentage of men 70 years and older who were screened unnecessarily for prostate cancer using prostate-specific antigen (PSA)-based screening. Note: A lower rate indicates better performance.	Physical Well-being
Effectiveness of Care	Appropriate Treatment for Upper Respiratory Infection URI	The percentage of episodes for members 3 months of age and older with a diagnosis of upper respiratory infection (URI) that did not result in an antibiotic dispensing event.	Physical Well-being
Effectiveness of Care	Avoidance of Antibiotic Treatment for Acute Bronchitis/Bronchiolitis. AAB	The percentage of episodes for members ages 3 months and older with a diagnosis of acute bronchitis/ bronchiolitis that did not result in an antibiotic dispensing event.	Physical Well-being
Effectiveness of Care	Use of Imaging Studies for Low Back Pain LBP	The percentage of members 18–75 years of age with a principal diagnosis of low back pain who did not have an imaging study (plain X-ray, MRI, CT scan) within 28 days of the diagnosis.	Physical Well-being
Effectiveness of Care	Potentially Harmful Drug-Disease Interactions in Older Adults DDE	The percentage of Medicare members 65 years of age and older who have evidence of an underlying disease, condition or health concern and who were dispensed an ambulatory prescription for a potentially harmful medication, concurrent with or after the diagnosis. Report each of the three rates separately and as a total rate. • A history of falls and a prescription for antiepileptics, antipsychotics, benzodiazepines, nonbenzodiazepine hypnotics or antidepressants (SSRIs, tricyclic antidepressants and SNRIs). • Dementia and a prescription for antipsychotics, benzodiazepines, nonbenzodiazepine hypnotics, tricyclic antidepressants, or anticholinergic agents. • Chronic kidney disease and prescription for Cox-2 selective NSAIDs or nonaspirin NSAIDs. • Total rate (the sum of the three numerators divided by the sum of the three denominators). Members with more than one disease or condition may appear in the measure multiple times (i.e., in each indicator for which they qualify). Note: A lower rate indicates better performance for all rates.	Physical Well-being

Effectiveness of Care	Use of High-Risk Medications in Older Adults DAE	The percentage of Medicare members 67 years of age and older who had at least two dispensing events for the same high-risk medication. Three rates are reported: 1. The percentage of Medicare members 67 years of age and older who had at least two dispensing events for high-risk medications to avoid from the same drug class. 2. The percentage of Medicare members 67 years of age and older who had at least two dispensing events for high-risk medications to avoid from the same drug class, except for appropriate diagnoses. 3. Total rate (the sum of the two numerators divided by the denominator, deduplicating for members in both numerators). The measure reflects potentially inappropriate medication use in older adults, both for medications where any use is inappropriate (Rate 1) and for medications where use under all but specific indications is potentially inappropriate (Rate 2). Note: A lower rate represents better performance.	Physical Well-being
Effectiveness of Care	Deprescribing of Benzodiazepines in Older Adults DBO	The percentage of members 67 years of age and older who were dispensed benzodiazepines and achieved a 20% decrease or greater in benzodiazepine dose (diazepam milligram equivalent [DME] dose) during the measurement year.	Physical Well-being
Effectiveness of Care	Use of Opioids at High Dosage HDO	The percentage of members 18 years of age and older who received prescription opioids at a high dosage (average morphine milligram equivalent dose [MME] ≥90) for ≥15 days during the measurement year. Note: A lower rate indicates better performance.	Physical Well-being
Effectiveness of Care	Use of Opioids From Multiple Providers UOP	The proportion of members 18 years and older, receiving prescription opioids for ≥15 days during the measurement year, who received opioids from multiple providers. Three rates are reported. 1. Multiple Prescribers. The proportion of members receiving prescriptions for opioids from four or more different prescribers during the measurement year. 2. Multiple Pharmacies. The proportion of members receiving prescriptions for opioids from four or more different pharmacies during the measurement year. 3. Multiple Prescribers and Multiple Pharmacies. The proportion of members receiving prescriptions for opioids from four or more different prescribers and four or more different pharmacies during the measurement year (i.e., the proportion of members who are numerator compliant for both the Multiple Prescribers and Multiple Pharmacies rates). Note: A lower rate indicates better performance for all three rates.	Physical Well-being
Effectiveness of Care	Risk of Continued Opioid Use COU	The percentage of members 18 years of age and older who have a new episode of opioid use that puts them at risk for continued opioid use. Two rates are reported: 1. The percentage of members with at least 15 days of prescription opioids in a 30-day period. 2. The percentage of members with at least 31 days of prescription opioids in a 62-day period. Note: A lower rate indicates better performance.	Physical Well-being

Measures Collected Through the Medicare Health Outcomes Survey	Medicare Health Outcomes Survey HOS	This measure provides a general indication of how well a Medicare organization manages the physical and mental health of its members. The survey measures each member's physical and mental health status at the beginning and the end of a two-year period. A two-year change score is calculated and each member's physical and mental health status is categorized as better, the same or worse than expected, considering risk adjustment factors. Organization-specific results are assigned as percentages of members whose health status was better, the same or worse than expected.	Physical Well-being
Measures Collected Through the Medicare Health Outcomes Survey	Fall Risk Management FRM	The two components of this measure assess different facets of fall risk management. • Discussing Fall Risk. The percentage of Medicare members 65 years of age and older who were seen by a practitioner in the past 12 months and who discussed falls or problems with balance or walking with their current practitioner. • Managing Fall Risk. The percentage of Medicare members 65 years of age and older who had a fall or had problems with balance or walking in the past 12 months, who were seen by a practitioner in the past 12 months and who received a recommendation for how to prevent falls or treat problems with balance or walking from their current practitioner.	Physical Well-being
Measures Collected Through the Medicare Health Outcomes Survey	Management of Urinary Incontinence in Older Adults MUI	The following components of this measure assess the management of urinary incontinence in older adults. • Discussing Urinary Incontinence. The percentage of Medicare members 65 years of age and older who reported having urine leakage in the past 6 months and who discussed their urinary leakage problem with a health care provider. • Discussing Treatment of Urinary Incontinence. The percentage of Medicare members 65 years of age and older who reported having urine leakage in the past 6 months and who discussed treatment options for their current urine leakage problem. • Impact of Urinary Incontinence. The percentage of Medicare members 65 years of age and older who reported having urine leakage in the past 6 months and who reported that urine leakage made them change their daily activities or interfered with their sleep a lot. Note: A lower rate indicates better performance for this indicator.	Physical Well-being
Measures Collected Through the Medicare Health Outcomes Survey	Physical Activity in Older Adults PAO	The two components of this measure assess different facets of promoting physical activity in older adults. • Discussing Physical Activity. The percentage of Medicare members 65 years of age and older who had a doctor's visit in the past 12 months and who spoke with a doctor or other health provider about their level of exercise or physical activity. • Advising Physical Activity. The percentage of Medicare members 65 years of age and older who had a doctor's visit in the past 12 months and who received advice to start, increase or maintain their level exercise or physical activity.	Physical Well-being

Measures Collected Through The CAHPS Survey	Medical Assistance With Smoking and Tobacco Use Cessation MSC	The following components of this measure assess different facets of providing medical assistance with smoking and tobacco use cessation: • Advising Smokers and Tobacco Users to Quit: A rolling average represents the percentage of members 18 years of age and older who were current smokers or tobacco users and who received advice to quit during the measurement year. Discussing Cessation Medications: A rolling average represents the percentage of members 18 years of age and older who were current smokers or tobacco users and who discussed or were recommended cessation medications during the measurement year. • Discussing Cessation Strategies: A rolling average represents the percentage of members 18 years of age and older who were current smokers or tobacco users and who discussed or were provided cessation methods or strategies during the measurement year.	Physical Well-being
Access/ Availability of Care	Adults' Access to Preventive/Ambulatory Health Services AAP	The percentage of members 20 years of age and older who had an ambulatory or preventive care visit. The organization reports three separate percentages for each product line. • Medicaid and Medicare members who had an ambulatory or preventive care visit during the measurement year. • Commercial members who had an ambulatory or preventive care visit during the measurement year or the two years prior to the measurement year.	Physical Well-being
Access/ Availability of Care	Initiation and Engagement of Substance Use Disorder Treatment IET	The percentage of new substance use disorder (SUD) episodes that result in treatment initiation and engagement. Two rates are reported: • Initiation of SUD Treatment. The percentage of new SUD episodes that result in treatment initiation through an inpatient SUD admission, outpatient visit, intensive outpatient encounter, partial hospitalization, telehealth visit or medication treatment within 14 days. • Engagement of SUD Treatment. The percentage of new SUD episodes that have evidence of treatment engagement within 34 days of initiation.	Physical Well-being
Access/ Availability of Care	Prenatal and Postpartum Care PPC	The percentage of deliveries of live births on or between October 8 of the year prior to the measurement year and October 7 of the measurement year. For these members, the measure assesses the following facets of prenatal and postpartum care. • Timeliness of Prenatal Care. The percentage of deliveries that received a prenatal care visit in the first trimester, on or before the enrollment start date or within 42 days of enrollment in the organization. • Postpartum Care. The percentage of deliveries that had a postpartum visit on or between 7 and 84 days after delivery.	Physical Well-being
Access/ Availability of Care	Use of First-Line Psychosocial Care for Children and Adolescents on Antipsychotics APP	The percentage of children and adolescents 1–17 years of age who had a new prescription for an antipsychotic medication and had documentation of psychosocial care as first-line treatment.	Physical Well-being

Experience of Care	CAHPS Health Plan Survey 5.1H, Adult Version CPA	This measure provides information on the experiences of commercial and Medicaid members with the organization and gives a general indication of how well the organization meets members' expectations. Results summarize member experiences through ratings, composites and question summary rates. Four global rating questions reflect overall satisfaction: 1. Rating of All Health Care. 2. Rating of Health Plan. 3. Rating of Personal Doctor. 4. Rating of Specialist Seen Most Often. Five composite scores summarize responses in key areas: 1. Claims Processing (commercial only). 2. Customer Service. 3. Getting Care Quickly. 4. Getting Needed Care. 5. How Well Doctors Communicate. Item-specific question summary rates are reported for the rating questions and each composite question. Question Summary Rates are also reported individually for one item summarizing the following concept: 1. Coordination of Care. Note: Medicare member experience with the organization is assessed through the Medicare CAHPS survey. Medicare CAHPS is not a HEDIS measure, Medicare CAHPS is maintained and administered by the Centers for Medicare & Medicaid Services (CMS) on behalf of Medicare Advantage (MA) plans.	Physical Well-being
Experience of Care	CAHPS Health Plan Survey 5.1H, Child Version CPC	This measure provides information on parents' experience with their child's Medicaid organization. Results summarize member experiences through ratings, composites and individual question summary rates. Four global rating questions reflect overall satisfaction: 1. Rating of All Health Care. 2. Rating of Health Plan. 3. Rating of Personal Doctor. 4. Rating of Specialist Seen Most Often. Four composite scores summarize responses in key areas: 1. Customer Service. 2. Getting Care Quickly. 3. Getting Needed Care. 4. How Well Doctors Communicate. Item-specific question summary rates are reported for the rating questions and each composite question. Question Summary Rates are also reported individually for one item summarizing the following concept: 1. Coordination of Care.	Physical Well-being
Experience of Care	Children With Chronic Conditions CCC	This measure provides information on parents' experience with their child's Medicaid organization for the population of children with chronic conditions. Three composites summarize satisfaction with basic components of care essential for successful treatment, management and support of children with chronic conditions: 1. Access to Specialized Services. 2. Family Centered Care: Personal Doctor Who Knows Child. 3. Coordination of Care for Children With Chronic Conditions. Item-specific question summary rates are reported for each composite question. Question summary rates are also reported individually for two items summarizing the following concepts: 1. Access to Prescription Medicines. 2. Family Centered Care: Getting Needed Information.	Physical Well-being

Utilization and Risk Adjusted Utilization	Well-Child Visits in the First 30 Months of Life W30	The percentage of members who had the following number of well-child visits with a PCP during the last 15 months. The following rates are reported: 1. Well-Child Visits in the First 15 Months. Children who turned 15 months old during the measurement year: Six or more well-child visits. 2. Well-Child Visits for Age 15 Months–30 Months. Children who turned 30 months old during the measurement year: Two or more well-child visits. Note: This measure has the same structure as measures in the Effectiveness of Care domain. The organization must follow the Guidelines for Effectiveness of Care Measures when calculating this measure.	Physical Well-being
Utilization and Risk Adjusted Utilization	Child and Adolescent Well-Care Visits WCV	The percentage of members 3–21 years of age who had at least one comprehensive well-care visit with a PCP or an OB/GYN practitioner during the measurement year. Note: This measure has the same structure as measures in the Effectiveness of Care domain. The organization must follow the Guidelines for Effectiveness of Care Measures when calculating this measure.	Physical Well-being
Utilization and Risk Adjusted Utilization	Ambulatory Care AMB	This measure summarizes utilization of ambulatory care in the following categories: • Outpatient Visits, Including Telehealth. • ED Visits	Physical Well-being
Utilization and Risk Adjusted Utilization	Inpatient Utilization—General Hospital/Acute Care IPU	This measure summarizes utilization of acute inpatient care and services in the following categories: • Maternity. • Surgery. • Medicine. • Total inpatient (the sum of Maternity, Surgery and Medicine).	Physical Well-being
Utilization and Risk Adjusted Utilization	Antibiotic Utilization for Respiratory Conditions AXR	The percentage of episodes for members 3 months of age and older with a diagnosis of a respiratory condition that resulted in an antibiotic dispensing event.	Physical Well-being
Utilization and Risk Adjusted Utilization	Plan All-Cause Readmissions PCR	For members 18 years of age and older, the number of acute inpatient and observation stays during the measurement year that were followed by an unplanned acute readmission for any diagnosis within 30 days and the predicted probability of an acute readmission. Note: For commercial and Medicaid, report only members 18–64 years of age.	Physical Well-being
Utilization and Risk Adjusted Utilization	Hospitalization Following Discharge From a Skilled Nursing Facility HFS	For members 65 years of age and older, the percentage of skilled nursing facility discharges to the community that were followed by an unplanned acute hospitalization for any diagnosis within 30 and 60 days.	Physical Well-being
Utilization and Risk Adjusted Utilization	Acute Hospital Utilization AHU	For members 18 years of age and older, the risk-adjusted ratio of observed-to-expected acute inpatient and observation stay discharges during the measurement year.	Physical Well-being

Utilization and Risk Adjusted Utilization	Emergency Department Utilization EDU	For members 18 years of age and older, the risk-adjusted ratio of observed-to-expected emergency department (ED) visits during the measurement year.	Physical Well-being
Utilization and Risk Adjusted Utilization	Hospitalization for Potentially Preventable Complications HPC	For members 67 years of age and older, the rate of discharges for ambulatory care sensitive conditions (ACSC) per 1,000 members and the risk-adjusted ratio of observed to expected discharges for ACSC by chronic and acute conditions.	Physical Well-being
Utilization and Risk Adjusted Utilization	Emergency Department Visits for Hypoglycemia in Older Adults With Diabetes EDH	For members 67 years of age and older with diabetes (types 1 and 2), the risk-adjusted ratio of observed to expected (O/E) emergency department (ED) visits for hypoglycemia during the measurement year. Two rates are reported: • For all members 67 years of age and older with diabetes (types 1 and 2) the risk-adjusted ratio of O/E ED visits for hypoglycemia during the measurement year, stratified by dual eligibility. • For a subset of members 67 years of age and older with diabetes (types 1 and 2) who had at least one dispensing event of insulin within each 6-month treatment period from July 1 of the year prior to the measurement year through December 31 of the measurement year, the risk-adjusted ratio of O/E ED visits for hypoglycemia, stratified by dual eligibility.	Physical Well-being
Health Plan Descriptive Information	Enrollment by Product Line ENP	The total number of members enrolled in the product line, stratified by age.	NA
Health Plan Descriptive Information	Language Diversity of Membership LDM	An unduplicated count and percentage of members enrolled at any time during the measurement year by spoken language preferred for health care and preferred language for written materials.	NA
Health Plan Descriptive Information	Race/Ethnicity Diversity of Membership RDM	An unduplicated count and percentage of members enrolled any time during the measurement year, by race and ethnicity.	NA
Measures Reported Using Electronic Clinical Data Systems	Childhood Immunization Status CIS-E	The percentage of children 2 years of age who had four diphtheria, tetanus and acellular pertussis (DTaP); three polio (IPV); one measles, mumps and rubella (MMR); three haemophilus influenza type B (HiB); three hepatitis B (HepB), one chicken pox (VZV); four pneumococcal conjugate (PCV); one hepatitis A (HepA); two or three rotavirus (RV); and two influenza (flu) vaccines by their second birthday. The measure calculates a rate for each vaccine and three combination rates.	Physical Well-being
Measures Reported Using Electronic Clinical Data Systems	Immunizations for Adolescents IMA-E	The percentage of adolescents 13 years of age who had one dose of meningococcal vaccine, one tetanus, diphtheria toxoids and acellular pertussis (Tdap) vaccine, and have completed the human papillomavirus (HPV) vaccine series by their 13th birthday. The measure calculates a rate for each vaccine and two combination rates.	Physical Well-being

Measures Reported Using Electronic Clinical Data Systems	Breast Cancer Screening BCS-E	The percentage of women 50–74 years of age who had a mammogram to screen for breast cancer. *The Breast Cancer Screening (BCS) measure was retired for MY 2023, only the ECDS version of this measure will now be reported.	Physical Well-being
Measures Reported Using Electronic Clinical Data Systems	Cervical Cancer Screening CCS-E	The percentage of women 21–64 years of age who were screened for cervical cancer using any of the following criteria: • Women 21–64 years of age who had cervical cytology performed within the last 3 years. • Women 30–64 years of age who had cervical high-risk human papillomavirus (hrHPV) testing performed within the last 5 years. • Women 30–64 years of age who had cervical cytology/high-risk human papillomavirus (hrHPV) cotesting within the last 5 years	Physical Well-being
Measures Reported Using Electronic Clinical Data Systems	Colorectal Cancer Screening COL-E	The percentage of members 45–75 years of age who had appropriate screening for colorectal cancer.	Physical Well-being
Measures Reported Using Electronic Clinical Data Systems	Follow-Up Care for Children Prescribed ADHD Medication ADD-E	The percentage of children newly prescribed attention-deficit/hyperactivity disorder (ADHD) medication who had at least three follow-up care visits within a 10-month period, one of which was within 30 days of when the first ADHD medication was dispensed. Two rates are reported. • Initiation Phase. The percentage of members 6–12 years of age with a prescription dispensed for ADHD medication, who had one follow-up visit with a practitioner with prescribing authority during the 30-day initiation phase. • Continuation and Maintenance (C&M) Phase. The percentage of members 6–12 years of age with a prescription dispensed for ADHD medication, who remained on the medication for at least 210 days and who, in addition to the visit in the initiation phase, had at least two follow-up visits with a practitioner within 270 days (9 months) after the initiation phase ended.	Physical Well-being
Measures Reported Using Electronic Clinical Data Systems	Metabolic Monitoring for Children and Adolescents on Antipsychotics APM-E	The percentage of children and adolescents 1–17 years of age who had two or more antipsychotic prescriptions and had metabolic testing. Three rates are reported: • The percentage of children and adolescents on antipsychotics who received blood glucose testing. • The percentage of children and adolescents on antipsychotics who received cholesterol testing. • The percentage of children and adolescents on antipsychotics who received blood glucose and cholesterol testing.	Physical Well-being

Measures Reported Using Electronic Clinical Data Systems	Depression Screening and Follow-Up for Adolescents and Adults DSF-E	The percentage of members 12 years of age and older who were screened for clinical depression using a standardized instrument and, if screened positive, received follow-up care. • Depression Screening. The percentage of members who were screened for clinical depression using a standardized instrument. • Follow-Up on Positive Screen. The percentage of members who received follow-up care within 30 days of a positive depression screen finding.	Physical Well-being
Measures Reported Using Electronic Clinical Data Systems	Utilization of the PHQ-9 to Monitor Depression Symptoms for Adolescents and Adults DMS-E	The percentage of members 12 years of age and older with a diagnosis of major depression or dysthymia, who had an outpatient encounter with a PHQ-9 score present in their record in the same assessment period as the encounter.	Physical Well-being
Measures Reported Using Electronic Clinical Data Systems	Depression Remission or Response for Adolescents and Adults DRR-E	The percentage of members 12 years of age and older with a diagnosis of depression and an elevated PHQ-9 score, who had evidence of response or remission within 4–8 months of the elevated score. • Follow-Up PHQ-9. The percentage of members who have a follow-up PHQ-9 score documented within 4–8 months after the initial elevated PHQ-9 score. • Depression Remission. The percentage of members who achieved remission within 4–8 months after the initial elevated PHQ-9 score. • Depression Response. The percentage of members who showed response within 4–8 months after the initial elevated PHQ-9 score.	Physical Well-being
Measures Reported Using Electronic Clinical Data Systems	Unhealthy Alcohol Use Screening and Follow-Up ASF-E	The percentage of members 18 years of age and older who were screened for unhealthy alcohol use using a standardized instrument and, if screened positive, received appropriate follow-up care. • Unhealthy Alcohol Use Screening. The percentage of members who had a systematic screening for unhealthy alcohol use. • Follow-Up Care on Positive Screen. The percentage of members receiving brief counseling or other follow-up care within 2 months of screening positive for unhealthy alcohol use.	Physical Well-being
Measures Reported Using Electronic Clinical Data Systems	Adult Immunization Status AIS-E	The percentage of members 19 years of age and older who are up to date on recommended routine vaccines for influenza, tetanus and diphtheria (Td) or tetanus, diphtheria and acellular pertussis (Tdap), zoster and pneumococcal.	Physical Well-being
Measures Reported Using Electronic Clinical Data Systems	Prenatal Immunization Status PRS-E	The percentage of deliveries in the measurement period in which members had received influenza and tetanus, diphtheria toxoids and acellular pertussis (Tdap) vaccinations.	Physical Well-being

Measures Reported Using Electronic Clinical Data Systems	Prenatal Depression Screening and Follow-Up PND-E	The percentage of deliveries in which members were screened for clinical depression while pregnant and, if screened positive, received follow-up care. • Depression Screening. The percentage of deliveries in which members were screened for clinical depression during pregnancy using a standardized instrument. • Follow-Up on Positive Screen. The percentage of deliveries in which members received follow-up care within 30 days of a positive depression screen finding.	Physical Well-being
Measures Reported Using Electronic Clinical Data Systems	Postpartum Depression Screening and Follow-Up PDS-E	The percentage of deliveries in which members were screened for clinical depression during the postpartum period, and if screened positive, received follow-up care. • Depression Screening. The percentage of deliveries in which members were screened for clinical depression using a standardized instrument during the postpartum period. • Follow-Up on Positive Screen. The percentage of deliveries in which members received follow-up care within 30 days of a positive depression screen finding.	Physical Well-being
Measures Reported Using Electronic Clinical Data Systems	Social Need Screening and Intervention SNS-E	The percentage of members who were screened, using prespecified instruments, at least once during the measurement period for unmet food, housing and transportation needs, and received a corresponding intervention if they screened positive. • Food Screening. The percentage of members who were screened for food insecurity. • Food Intervention. The percentage of members who received a corresponding intervention within 1 month of screening positive for food insecurity. • Housing Screening. The percentage of members who were screened for housing instability, homelessness or housing inadequacy. • Housing Intervention. The percentage of members who received a corresponding intervention within 1 month of screening positive for housing instability, homelessness or housing inadequacy. • Transportation Screening. The percentage of members who were screened for transportation insecurity. • Transportation Intervention. The percentage of members who received a corresponding intervention within 1 month of screening positive for transportation insecurity.	Physical Well-being & Material Well-being

(NCQA, HEDIS MY 2023, https://www.ncqa.org/wp-content/uploads/2022/07/HEDIS-MY-2023-Measure-Description.pdf)

APPENDIX I: FINAL MEASURE SET FOR MEDICAID-FUNDED HCBS ALIGNED WITH QOL DOMAINS

Measure	Measure Steward	Assurance	QoL Domain
HCBS CAHPS Choosing the services that matter to you (Q 56, 57)	CMS	Service Plan	Self-Determination
CI-IDD PCP-2: PersonCentered Goals (The proportion of people who report their service plan includes things that are important to them)	NASDDDS, HSRI	Service Plan	Self-Determination
NCI-AD: Percentage of people who can choose or change what kind of services they get	Advancing States, HSRI	Service Plan	Self-Determination
NCI-AD: Percentage of people who can choose or change when and how often they get their services	Advancing States, HSRI	Service Plan	Self-Determination
NCI-AD: Percentage of people whose service plan includes their preferences and choices	Advancing States, HSRI	Service Plan	Self-Determination
POM: People realize personal goals	CQL	Service Plan	Personal Development
MLTSS-1: LTSS Comprehensive Assessment and Update	CMS	Service Plan	Process Measurement (NA)
MLTSS-2: LTSS Comprehensive Care Plan and Update	CMS	Service Plan	Process Measurement (NA)

FASI-1: Identification of Person-Centered Priorities10,11	CMS	Service Plan	Self-Determination
FASI-2: Documentation of a Person-Centered Service Plan12,13	CMS	Service Plan	Process Measurement (NA)
HCBS CAHPS Unmet Needs Single-Item Measures (Q 18, 22, 25, 27, 40)14	CMS	Service Plan	Physical Well-being
HCBS CAHPS Staff Are Reliable and Helpful Composite Measure (Q 13, 14, 15, 19, 37, 38)19	CMS	Service Plan	Rights Physical Well-being
HCBS CAHPS Staff Listen and Communicate Well Composite Measure (Q 28, 29, 30, 31, 32, 33, 41, 42, 43, 44, 45)20	CMS	Service Plan	Rights Social Inclusion
NCI-IDD: Percentage of people who report their staff come and leave when they are supposed to	NASDDDS, HSRI	Service Plan	Rights
NCI-AD: Percentage of people whose support staff do things the way they want them done	Advancing States, HSRI	Service Plan	Self-Determination
NCI-AD: Percentage of people whose support staff show up and leave when they are supposed to	Advancing States, HSRI	Service Plan	Rights
HCBS CAHPS Community Inclusion and Empowerment Composite Measure (Q 75, 77, 78, 79, 80, 81)21	CMS	Service Plan	Interpersonal Relations Social Inclusion

NCI-IDD CC-4: Life Decision Composite Measure (The proportion of people who report making choices (independently or with help) in life decisions)	NASDDDS, HSRI	Service Plan	Self-Determination
NCI-IDD: The percentage of people who report that they helped make their service plan	NASDDDS, HSRI	Service Plan	Self-Determination
NCI-AD: Percentage of people who can choose or change what kind of services they get	Advancing States, HSRI	Service Plan	Self-Determination
NCI-AD: Percentage of people who can choose or change when and how often they get their services	ADvancing States, HSRI	Service Plan	Self-Determination
NCI-AD: Percentage of people who can choose or change their support staff	ADvancing States, HSRI	Service Plan	Self-Determination
NCI-AD: Percentage of people whose service plan reflects their preferences and choices	ADvancing States, HSRI	Service Plan	Self-Determination
POM: People choose services	CQL	Service Plan	Self-Determination
HCBS-10: Self-direction of services and supports among Medicaid beneficiaries receiving LTSS through managed care organizations22	CMS	Service Plan	Self-Determination

HCBS CAHPS Personal Safety & Respect Composite Measure (Q 64, 65, 68)24	CMS	Health and Welfare	Physical Well-being Emotional Well-being
HCBS CAHPS Physical Safety Single-Item Measure (Q 71)25	CMS	Health and Welfare	Physical Well-being
NCI-AD: Percentage of people who feel safe around their support staff	ADvancing States, HSRI	Health and Welfare	Emotional Well-being
NCI-AD: Percentage of people who are ever worried for the security of their personal belongings	ADvancing States, HSRI	Health and Welfare	Emotional Well-being Material Well-being
NCI-AD: Percentage of people whose money was taken or used without their permission in the last 12 months	ADvancing States, HSRI	Health and Welfare	Emotional Well-being Material Well-being
POM: People are free from abuse and neglect	CQL	Health and Welfare	Emotional Well-being Physical Well-being
N CI-IDD preventive screening single-item measures: Percentage of people who are reported to have received preventive health screenings within recommended time frames (physical exam, routine dental exam, vision screening, hearing test, mammogram, pap test, colorectal cancer screening)	NASDDDS, HSRI	Health and Welfare	Physical Well-being

NCI-AD: Percentage of people who know how to manage their chronic conditions	ADvancing States, HSRI	Health and Welfare	Physical Well-being
NCI-AD: Percentage of people who had somebody talk or work with them to reduce their risk of falling or being unstable	ADvancing States, HSRI	Health and Welfare	Physical Well-being
MLTSS-3: LTSS Shared Care Plan with Primary Care Practitioner26 HEDIS equivalent available	CMS	Health and Welfare	Physical Well-being
MLTSS-5: Screening, Risk Assessment, and Plan of Care to Prevent Future Falls (NCQA)	NCQA	Health and Welfare	Physical Well-being
MLTSS: Plan All-Cause Readmission (HEDIS)	NCQA	Health and Welfare	Physical Well-being
MLTSS: Flu Vaccination (HEDIS) (adults 18-64 only)	NCQA	Health and Welfare	Physical Well-being
POM: People have the best possible health	CQL	Health and Welfare	Physical Well-being
HCBS CAHPS Choosing the services that matter to you (Q 56, 57)28	CMS	Service Plan	Self-Determination
HCBS CAHPS Unmet Needs Single-Item Measures (Q 18, 22, 25, 27, 40)29	CMS	Service Plan	Physical Well-being
HCBS CAHPS Staff Are Reliable and Helpful Composite Measure (Q 13, 14, 15, 19, 37, 38)30	CMS	Service Plan	Rights Physical Well-being

HCBS CAHPS Transportation to Medical Appointments Composite Measure (Q 59, 61, 62)31	CMS	NA	Physical Well-being
NCI-IDD CI-3: Transportation Availability Scale (The proportion of people who report adequate transportation)	NASDDDS, HSRI	NA	Social Inclusion Material Well-being
CI-IDD PCP-2: PersonCentered Goals (The proportion of people who report their service plan includes things that are important to them)	NASDDDS, HSRI	Service Plan	Self-Determination
NCI-IDD preventive screening single-item measures: Percentage of people who are reported to have received preventive health screenings within recommended time frames (physical exam, routine dental exam, vision screening, hearing test, mammogram, pap test, colorectal cancer screening)	NASDDDS, HSRI	Health and Welfare	Physical Well-being
NCI-AD: Percentage of people whose support staff show up and leave when they are supposed to	ADvancing States, HSRI	Service Plan	Rights

NCI-AD: Percentage of non-English speaking participants who receive information about their services in the language they prefer	ADvancing States, HSRI	NA	Rights
NCI-AD: Percentage of people who have transportation when they want to do things outside of their home	ADvancing States, HSRI	NA	Social Inclusion
NCI-AD: Percentage of people who have transportation to get to medical appointments when they need to	ADvancing States, HSRI	NA	Physical Well-being
NCI-AD: Percentage of people who can choose or change what kind of services they get	ADvancing States, HSRI	Service Plan	Self-Determination
NCI-AD: Percentage of people who can choose or change when and how often they get their services		Service Plan	Self-Determination
NCI-AD: Percentage of people whose service plan reflects their preferences and choices		Service Plan	Self-Determination
HCBS-10: Self-direction of services and supports among Medicaid beneficiaries receiving LTSS through managed care organizations32	CMS	Service Plan	Self-Determination

NCI-AD: Percentage of people who had adequate follow up after being discharged from a hospital or rehabilitation/nursing facility	ADvancing States,. HSRI	NA	Physical Well-being
M LTSS-4: LTSS Reassessment/Care Plan Update after Inpatient Discharge33 HEDIS equivalent available	CMS	Service Plan	Physical Well-being
MLTSS-6: LTSS Admission to a Facility from the Community (MLTSS equivalent of HCBS-1)	CMS	NA	Material Well-being Physical Well-being Social Inclusion
HCBS-1: Admission to a Facility from the Community Among Medicaid Fee-for Service (FFS) HCBS Users (CMS) (FFS equivalent of MLTSS6)34	CMS	NA	Material Well-being Physical Well-being Social Inclusion
MLTSS-7: LTSS Minimizing Facility Length of Stay	CMS	NA	Material Well-being Physical Well-being Social Inclusion
MLTSS-8: LTSS Successful Transition After Long-Term Facility Stay	CMS	NA	Material Well-being Physical Well-being Social Inclusion
HCBS CAHPS Choosing the services that matter to you (Q 56, 57)35	CMS	Service Plan	Self-Determination
HCBS CAHPS Personal Safety & Respect Composite Measure (Q 64, 65, 68)36	CMS	Health and Welfare	Rights Material Well-being Physical Well-being Emotional Well-being

HCBS CAHPS Physical Safety Single-Item Measure (Q 71)37	CMS	Health and Welfare	Physical Well-being
HCBS CAHPS Community Inclusion and Empowerment Composite Measure (Q 75, 77, 78, 79, 80, 81)38	CMS	Health and Welfare	Social Inclusion Interpersonal Relations Self-Determination
NCI-IDD CI-1: Social Connectedness (The proportion of people who report that they do not feel lonely)	NASDDDS, HSRI	NA	Emotional Well-being Interpersonal Relations Social Inclusion
NCI-IDD CI-3: Transportation Availability Scale (The proportion of people who report adequate transportation)	NASDDDS, HSRI	NA	Material Well-being
NCI-IDD: The percentage of people who report that they helped make their service plan	NASDDDS, HSRI	Service Plan	Self-Determination
NCI-IDD CC-3: Can Stay Home When Others Leave (The proportion of people who live with others who report they can stay home if they choose when others in their house/home go somewhere)	NASDDDS, HSRI	NA	Self-Determination Material Well-being

NCI-IDD CC-4: Life Decision Composite Measure (The proportion of people who report making choices (independently or with help) in life decisions)	NASDDDS. HSRI	Service Plan	Self-Determination
NCI-IDD PCP-2: PersonCentered Goals (The proportion of people who report their service plan includes things that are important to them)	NASDDDS. HSRI	Service Plan	Self-Determination
NCI-IDD PCP-5: Satisfaction with Community Inclusion Scale (The proportion of people who report satisfaction with the level of participation in community inclusion activities)	NASDDDS, HSRI	NA	Social Inclusion
NCI-IDD HLR-1: Respect for Personal Space Scale (The proportion of people who report that their personal space is respected in the home)	NASDDDS. HSRI	NA	Rights
NCI-AD: Percentage of people who are as active in their community as they would like to be	ADvancing States, HSRI	NA	Social Inclusion
NCI-AD: Percentage of people who are able to see or talk to their friends and family when they want to	ADvancing States, HSRI	NA	Interpersonal Relations

NCI-AD: Percentage of people who have transportation when they want to do things outside of their home	ADvancing States, HSRI	NA	Social Inclusion Material Well-being
NCI-AD: Percentage of people who feel safe around their support staff	ADvancing States, HSRI	Health and Welfare	Emotional Well-being
NCI-AD: Percentage of people who are ever worried for the security of their personal belongings	ADvancing States, HSRI	Health and Welfare	Emotional Well-being Material Well-being
NCI-AD: Percentage of people whose money was taken or used without their permission in the last 12 months	ADvancing States, HSRI	Health and Welfare	Rights Material Well-being
NCI-AD: Percentage of people in group settings who have enough privacy where they live	ADvancing States, HSRI	NA	Rights
NCI-AD: Percentage of people who can choose or change what kind of services they get	ADvancing States, HSRI	Service Plan	Self-Determination
NCI-AD: Percentage of people who can choose or change when and how often they get their services	ADvancing States, HSRI	Service Plan	Self-Determination
NCI-AD: Percentage of people who can choose or change their support staff	ADvancing States, HSRI	Service Plan	Self-Determination
NCI-AD: Percentage of people whose service plan reflects their preferences and choices	ADvancing States, HSRI	Service Plan	Self-Determination

POM: People are free from abuse and neglect	CQL	Health and Welfare	Rights Emotional Well-being Physical Well-being
POM: People live in integrated environments	CQL	NA	Social Inclusion Material Well-being
POM: People interact with other members of the community	CQL	NA	Social Inclusion
POM: People participate in the life of the community	CQL	NA	Social Inclusion
MLTSS-1: LTSS Comprehensive Assessment and Update39 HEDIS equivalent available40	CMS	Service Plan	Physical Well-being
MLTSS-2: LTSS Comprehensive Care Plan and Update41 HEDIS equivalent available	CMS	Service Plan	Physical Well-being
MLTSS-7: LTSS Minimizing Facility Length of Stay	CMS	NA	Physical Well-being Material Well-being
MLTSS-8: LTSS Successful Transition After Long-Term Facility Stay	CMS	NA	Physical Well-being Material Well-being
FASI-1: Identification of Person-Centered Priorities42,43	CMS	Service Plan	Self-Determination
FASI-2: Documentation of a Person-Centered Service Plan44,45	CMS	Service Plan	NA/ Procedural Measure

(Centers for Medicare and Medicaid, 2022).

APPENDIX J: SOCIAL DETERMINANTS OF HEALTH SCREENING TOOL

Qol Domain	**Description**	**Sub-domains**	**Standardized Social Determinants of Health Screening Questions**
Personal Development	Deals with your education (including lifelong learning) and personal competence (including learning and demonstrating skills).	- Learning about the things you are interested in - Learning skills to become more independent - Being able to take care of yourself - Being able to follow your own interests - Having access to information	Education (ESL, GED) Do you have a high school degree? If NO, would you like help to get a GED? (WE CARE) What is the highest level of school you have completed? (Elementary, High, College, Graduate, Professional) (Health Begins, PRAPARE) What is the highest degree you earned? (High school diploma, GED, Vocational certificate (post high school or GED), Associate's degree (junior college), Bachelor's degree, Master's degree, Doctorate (Health Begins) I don't have enough education. Yes, Somewhat, No (Duke Population Health) Does your child have learning problems at school or have trouble keeping up with other students? (UNC) How is your child doing in school? Is he/she getting the help to learn what he/she needs? (IHELLP) Is your child enrolled in Head Start, preschool or early childhood enrichment? (IHELLP) (Triangle Family Services) Do you read to your child every night? (IHELLP) How happy are you with how you read? (IHELLP)
Self-Determination	Deals with your personal goals and objectives, decision making, and making your own choices.	- Making your own choices - Deciding yourself what to wear - Expressing your own opinion - Acting on your own personal goals and aspirations	

Interpersonal Relations	Deals with your family, friends, social network, and the supports you receive from others.	- The contacts you have or the time you spend with family and/or friends -The respect or feedback you receive from family and friends -The support you get from family and friends -The respect you receive from others	Family and Social Supports (parent/child attachment, prenatal support, social isolation, care giver support) Parent-Child Relationship Well-being Domain (The Child & Adolescent Health Measurement Initiative Technical Working Group on Screening Young Children for Social Determinants of Health): (VCU-Alliance) How often do you see or talk to people that you care about and feel close to? (For example: talking to friends on the phone, visiting friends or family, going to church or club meetings) (PREPARE) People stress me more than they support me. Yes, Somewhat, No (Duke Population Health) In a typical week, how many times do you: (Health Begins) • talk on the telephone with family, friends, or neighbors? • get together with friends or relatives? • attend religious or faith based services? • attend meetings of the clubs or organizations you belong to? During the past week, how often did you socialize with people (talk or visit with friends or relatives) (Duke) Are you involved with some type of group that causes/forces you to make decisions you are not comfortable with? (Triangle Family Services) Do you have a hard time making friends? (Triangle Family Services) Do you have friends that help you with making decisions? (Triangle Family Services) Child Care Do problems getting child care make it difficult for you to work or study? (Health leads, VCU, Alliance) In the past year, have you or the family members you live with been unable to get child care when it was really needed? Yes, No (PRAPARE) In the past three months, how often have you experienced child care breakdowns? (Survey for Adolescent and Child Wellbeing) Do you need daycare for your child? If yes, would you like help finding it? (WE CARE)

Social Inclusion	Deals with your community integration and participation, the community roles that you play, and the social supports you receive.	- The community activities you participate in - The contacts you have with people in your neighborhood - The help you get from people living in the community - The number of memberships you have in community organizations	In a typical week, how many times do you: (Health Begins) • talk on the telephone with family, friends, or neighbors? • get together with friends or relatives? • attend religious or faith based services? • attend meetings of the clubs or organizations you belong to?
Rights	Deals with both your human rights (respect, dignity, equality) and your legal rights (citizenship, access, and fair treatment).	- Your right to privacy and a private life - How people around you treat you - The opportunity you have to say what you think and being listened to - The right to have a pet - Having a key to your house - Being able to vote	Immigration Do you have concerns about any immigration matters for you or your family? (Health Begins) Do you have questions about your immigration status? Do you need help accessing benefits or services for your family? (IHELLP) At any point in the past 2 years, has seasonal or migrant farm work been your or your family's main source of income? (PRAPARE) Are you a refugee? (PRAPARE) Legal/Correctional In the past year, have you spent more than 2 nights in a row in a jail, prison, detention center or juvenile correctional facility? Yes, No, I choose not to answer this question. (PRAPARE)

Emotional Well-being	Deals with your contentment, self-concept, and lack of stress in your life.	- How you express your feelings - Are there elements of danger in the environment where you spend most of your time - Do you worry or have serious concerns in some matters? In what matters? - How stable and predictable is your environment?	Family and Social Supports (parent/child attachment, prenatal support, social isolation, care giver support) Parent-Child Relationship Well-being Domain (The Child & Adolescent Health Measurement Initiative Technical Working Group on Screening Young Children for Social Determinants of Health): • Are you generally excited and confident, rather than stressed and worried, about your role as a parent? • Do you generally feel you know what to do to take care of your child(ren) and respond to their needs and the way they are growing and behaving? • Have there been any changes in your family life (housing move, change in household membership, relationships) that might affect your role as a parent? Would you have someone to help you if you were sick and needed to be in bed? Yes, No Within the past 12 months, have you been hit, slapped, kicked or otherwise physically hurt by someone? (core screen) Are you in a relationship with a person who threatens or physically hurts you? Has anyone forced you to have sexual activities that made you feel uncomfortable? (Pregnancy Medical Home, ACOG Public Health Title X) Within the last year, have you been: Humiliated or emotionally abused in other ways by your partner or ex-partner? (core screen) Afraid of your partner or your ex-partner? Raped or forced to have any kind of sexual activity by your partner or ex-partner? Kicked, hit, slapped, or otherwise physically hurt by your partner or ex-partner? (HARK) Community Safety Are safety issues quickly addressed by authorities (landlord, community managers, law enforcement)? Is there a visible law enforcement presence in your neighborhood? Is there gang activity in your neighborhood? Have you or your children been approached by gang

			members? Is there visible drug traffic in your neighborhood? Are there instances of gun violence or public fighting in your neighborhood? Mental Health, Substance Use Are you interested in receiving resources for emotional wellness? (Advance Community Health Center) During the past week, how much trouble have you had with feeling depressed or sad? None, Some, A Lot (Duke Population Health) Do you worry about your mental health or drug and alcohol use? (Wake County Human Services) Are you concerned about your child’s learning, performance or behavior in school? (Health Begins) Did any of your parents have a problem with alcohol or other drug use? 17 Do any of your friends have a problem with alcohol or other drug use? Does your partner have a problem with alcohol or other drug use? In the past, have you had difficulties in your life due to alcohol or other drugs, including prescription medications? In the past month, how often did you drink any alcohol, including beer or wine, or use other drugs? Emotional Wellness/Stress/Stressors My illnesses are a heavy burden for me. Yes, Somewhat, No (Duke Population Health) I am basically a healthy person. Yes, Somewhat, No (Duke Population Health) I feel discriminated against. Yes, Somewhat, No (Duke Population Health) Stress is when someone feels tense, nervous, anxious or can’t sleep at night because their mind is troubled. How stressed are you? Not at all, a little bit, somewhat, quite a bit, very much, I choose not to answer this question. (PRAPARE) Do you feel overwhelmed or exhausted? (Triangle Family Services) Do you have problems falling asleep at night? (Triangle Family Services) Do you find that going for a walk

			helps when you are stressed? (Triangle Family Services) How important is exercise? A little, very important, not important (Triangle Family Services) Do you have specific areas in your life that make you stressed over others? For example, your job or lack of education or job skills, bills. (Triangle Family Services) Do you feel stuck in your situation and need help to map out a life strategy or steps to follow? (Triangle Family Services) Do have a vision for yourself and are not sure how to get there? If yes, would you like someone to help you map out your vision? (Triangle Family Services) Do you feel pressure during holidays? (Triangle Family Services) Do you feel uneasy when seasons change? If yes, do you find yourself moodier during these times? (Triangle Family Services)
Physical Well-being	Deals with your health and health care, nutrition, self-care skills, mobility, and recreation.	- Do have the energy to participate in physical activities? - Do you limit how much you eat so you do not gain weight? - Do you participate in recreation and leisure activities and/or sports?	Health Literacy/Communication/Language/Culture How confident are you filling out medical forms by yourself? (Health Leads/The Short Test of Functional Health Literacy in Adults – 7th grade) Do you ever need help reading hospital materials? (Health Leads, VCU-Alliance) How often do you have a problem understanding what is told to you about your medical condition? (Health Leads /The Short Test of Functional Health Literacy in Adults) Do you feel that when you look for help that there is a language barrier issue? (Triangle Family Services) 19 Do people tell you that they cannot understand what you are saying? (It is hard to get help when no one can understand what a person is trying to convey due to language or comprehension deficit) (Triangle Family Services) Are you comfortable providing information? (May get nervous and need someone to help) (Triangle Family Services) Do you understand the information/paperwork that is presented to you? (Triangle Family Services) Are you able to follow through

			with required information, e.g., returning documents or filling out applications, forms? Within the past 12 months, have you been hit, slapped, kicked or otherwise physically hurt by someone? (core screen) Are you in a relationship with a person who threatens or physically hurts you? Has anyone forced you to have sexual activities that made you feel uncomfortable? (Pregnancy Medical Home, ACOG Public Health Title X) Within the last year, have you been: Humiliated or emotionally abused in other ways by your partner or ex-partner? (core screen) Afraid of your partner or your ex-partner? Raped or forced to have any kind of sexual activity by your partner or ex-partner? Kicked, hit, slapped, or otherwise physically hurt by your partner or ex-partner? (HARK) Health Care/Medicine In the past year, have you or the family members you live with been unable to get medicines or health care (medical, dental, mental health, vision) when it was really needed? Yes, No (PRAPARE) Do you need help to get health insurance for you and your family? (Wake County Human Services) In the last month, have you needed to see a doctor, but could not because of cost? Yes, No (VCU-Alliance) I receive good health care. Yes, Somewhat, No (Duke Population Health) Mental Health, Substance Use Are you interested in receiving resources for emotional wellness? (Advance Community Health Center) During the past week, how much trouble have you had with feeling depressed or sad? None, Some, A Lot (Duke Population Health) Do you worry about your mental health or drug and alcohol use? (Wake County Human Services) Are you concerned about your

			child's learning, performance or behavior in school? (Health Begins) Did any of your parents have a problem with alcohol or other drug use? 17 Do any of your friends have a problem with alcohol or other drug use? Does your partner have a problem with alcohol or other drug use? In the past, have you had difficulties in your life due to alcohol or other drugs, including prescription medications? In the past month, how often did you drink any alcohol, including beer or wine, or use other drugs?
Materials Well-being	Deals with your financial status, employment status, living arrangements, and personal possessions	- What is your monthly income? - Do you have personal possessions that are important to you? - Do you have a paid job? - Are there things or goods that you cannot afford to buy because of lack of money?	During the past two years have you had a child care subsidy taken away? (Children's HealthWatch Survey) Would availability of child care affect hours spent/attendance at schooling, training, employment or job search? (National Longitudinal Survey of Youth) Question 1: Where did you stay last night? • Literally Homeless Unsheltered: (Go to Question 2) o Place not meant for human habitation • Literally Homeless Sheltered: (Go to Question 3) o Emergency shelter o Hotel or motel paid for with emergency shelter/by another organization o Transitional housing for homeless persons o VA Grant Per Diem Programs • At Risk: (Go to Question 4) o Psychiatric hospital/facility o Substance abuse treatment facility/detox center o Hospital/residential medical facility o Jail/prison/juvenile detention facility o Foster care home/group home o Long-term care facility/nursing home o Residential program/halfway house that is non-homeless specific o Hotel/motel paid for by individual o Staying or living with friends or family in room, apartment or house o Permanent supportive housing program through homeless system, VA (long-term rental assistance) o Rental or owned by individual with housing subsidy (long-term and short-term rental assistance) o Rental

			or owned by individual with no housing subsidy Question 2: Do you need assistance in accessing shelter? • Yes (Link to appropriate services and shelters in region and Go to Question 3) o Shelter information o Transportation o Other: __________________ • No (Go to Question 3) Question 3: Do you know how to access housing services in your community? Are you currently working with someone to access housing services? • Yes = No referral needed • No = Refer to coordinated entry process in community Question 4: What assistance do you need to stabilize or make more secure your current housing or find other housing? (Referrals made based on needs) • Rental assistance • Utilities assistance • Legal aid services • Medical services • Mental health services • Weatherization assistance • Employment services • Assistance with accessing other benefits (SSA disability benefits, SNAP, WIC) • Other: ________ Housing Quality My living conditions are bad – Yes, Somewhat, No – (Duke Population Health) In the last month, have you had concerns about the condition or quality of your housing? (Health Begins) Are you worried that something in your home might be making people sick? For example, problems with mold, cockroaches, rodents, or other safety issues? (UNC) Think about the place you live. Do you have any problems with any of the following (check all that apply)? • Bug infestation • Mold • Lead paint or pipes • Inadequate heat • Oven or stove not working • No or not working smoke detectors • Water leaks • None of the above (Accountable Health Community) My air is clean and my water is safe. Yes, Somewhat, No (Duke Population Health) Employment During the last four weeks, have you been actively looking for work?

			(Health Leads) Do you have a job? If No, would you like help with finding employment and/or job training? (WE CARE) Do you have a disability that prevents you from accepting any kind of work during the next 6 months (US Census - Health Leads) Last week, did you work for pay at a job? (US Census – Health Leads) What is your current work situation? Unemployed and seeking work; Part time or temporary work; Full time work; Otherwise unemployed, but not seeking work (ex-student, retired, disabled, unpaid primary care giver); I choose to not answer this questions (PRAPARE) Which best describes your current occupation? (Homemaker, not working outside the home; Employed (or self-employed) full time; Employed (or self-employed) part time; Employed, but on leave for health reasons; Employed but temporarily away from my job (other than health reasons); Unemployed or laid off 6 months or less; Unemployed or laid off more than 6 months; Unemployed due to a disability; Retired from my usual occupation and not working; Retired from my usual occupation but working for pay; Retired from my usual occupation but volunteering (Health Begins) I want to work but cannot find a job. (Duke Population Health) Income Do you have trouble making ends meet? (IHELLP) I don’t have enough money to pay my bills. (Aldana & Liljenquist) Sometimes people find that their income does not quite cover their living costs. In the last 12 months, has this happened to you? (The Organisation for Economic Co-operation and Development) Do you ever have problems making ends meet at the end of the month? (Health Begins) I have enough money for my basic needs. (Duke Population Health) How hard is it for you to pay for the very basics like food, housing, medical care and heating? (Health Begins) In the last 12 months, was there a

			time when you needed to see a doctor but could not because of cost? (Health Leads) In the last 12 months, have you skipped doses of medication to make it last longer? (Advance Community Health Center) 20 In the last 12 months, did you skip medications to save money? (Medical Expenditure Panel Survey – Health Leads) Suppose that you have an emergency expense that costs $400. Based on your current financial situation, how would you pay for this expense? If you would use more than one method to cover this expense, please select all that apply. (Federal Reserve) a. Put it on my credit card and pay it off in full at the next statement b. Put it on my credit card and pay it off over time c. With the money currently in my checking/savings account or with cash d. Using money from a bank loan or line of credit e. By borrowing from a friend or family member f. Using a payday loan, deposit advance, or overdraft g. By selling something h. I wouldn't be able to pay for the expense right now Do you have a budget? (Triangle Family Services) Does the thought of bills overwhelm you? (Triangle Family Services) Do you have a problem juggling bills and not sure what to pay and how? (Triangle Family Services) Do you spend more money when you are not feeling good about yourself or situation? (Triangle Family Services) Do you find that you have to borrow money from friends and family? (Triangle Family Services)

Centers for Medicaid Services (2020). Request for Information: Recommended Measure

Set for Medicaid-Funded Home and Community-Based Services.

APPENDIX K: HCBS SETTINGS FINAL RULE

Quality of Life Domain	Home and Community-Based Setting Requirements
Personal Development	
Self-Determination	- The setting is selected by the individual among options; the setting options are identified within the person-centered service plan - The setting should optimize individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact - Facilitates and supports individual choice regarding services and supports, and who provides them - Individuals can have visitors at any time - Individuals should have the freedom to furnish and decorate their sleeping/living units - Individuals have the freedom to control their own schedules, activities, and have access to food at all times
Interpersonal Relations	- Individuals are able to have visitors at any time
Social Inclusion	- The setting is integrated in and supports full access of individuals to the greater community, including opportunities to seek employment, engage in community life, control personal resources, and receive services within the community
Rights	- The setting ensures individual rights of privacy, dignity and respect, and freedom from coercion and restraint - Each individual has privacy in their sleeping or living unit
Emotional Well-Being	
Physical Well-Being	- Living units have doors lockable by the individual; appropriate staff should have keys to doors as needed - The setting is physically accessible to the individual
Material Well-Being	- Individual has a lease or other legal contract with protections.

(Centers for Medicare and Medicaid, 2014)

Quality of Life Domain	HCB Living Standards
Personal Development	
Self-Determination	- If residents share a room, they should have a choice to decide their roommate - Residents must be provided choice(s) in the structure of their service delivery - Provide appropriate support to ensure the individual has an active role in directing their care planning process - Residents must have input on food options provided - Residents must be allowed to choose who to eat meals with including the ability to eat alone if preferred - Residents must be able to choose with whom and when to participate in recreational activities
Interpersonal Relations	- Telephones must be accessible by residents 24/7/365 - Residents should be allowed to have and maintain personal phones in their rooms
Social Inclusion	- Visitors must be allowed anytime 24/7/365 - Residents must be given the choice to participate in facility’s recreational activities and pursing activities of their interest - Residents must be given opportunities to participate in community activities of their choosing - Residents must be continuously encouraged to remain active in their community - Residents should be supported in pursuing activities of interest, and not be restricted from participating in community activities of their choosing
Rights	- Residents must have the ability to lock their rooms - Residents must be able to file anonymous complaints - Residents must be able to come and go at any hour - Residents must have a personal lockable storage space available to them at any time - Residents must be given maximum privacy in the delivery of their services - Include the individual within the care planning process, and the people chosen by the individual to attend care plan meetings
Emotional Well-Being	
Physical Well-Being	- Residents must have the ability to lock their rooms

Material Well-Being	- Residents should be allowed to have and maintain personal phones in their rooms - Residents must be allowed to decorate and keep personal items within their rooms - Residents must be able to have personal appliances and devices in their room (that do not violate safety codes or rules)

(North Carolina DHHS, 2015)

APPENDIX M: CMS STATE OPERATIONS MANUAL- APPENDIX J ALIGNMENT WITH QOL DOMAINS

Quality of Life Domain	Interpretive Guidelines-Responsibilities of ICF/IID
Personal Development	- CFA: the adaptive behaviors or independent living skills portion refers to assessing the client's personal independence, social responsibility, and community orientation/integration; examples of independent skills include food shopping, meal prep, housekeeping, laundry, bed making and budgeting. (W224 §483.440(c)(3)(v)) - IPP objectives are identified by the CFA to improve the client's ability to independently function in their daily life, determined by the IDT (W227 §483.440(c)(4)) - IPP objectives should be organized in a logical sequence that will assist the client in attaining skills in greater self-choice, independence, and community integration (W228 §483.440(c)(4)) - IPP must include relevant interventions to support the client toward independence (W240 §483.440(c)(6)(i)) - Policies and procedures for the management of conduct between staff and clients must promote the growth, development, and independence of the client (W268 §483.450(a)(1)(i)) - The facility must ensure that each client eats in a manner that is consistent with their developmental level, which should promote acquisition of skills that lead to greater independence in eating (W488 §483.480(d)(4))
Self-Determination	- Clients should be offered opportunities to participate in social, religious, or group activities within the community based on their interests/choices (W136 §483.420(a)(11)) - Encourage clients to use/display their possessions of their choice in a culturally normative manner (W137 §483.420(a)(12)) - Active treatment must be directed toward acquisition of behaviors for the client to function with as much self-determination and independence as possible (W196 §483.440(a)(1)(i)) - IPP objectives should be organized in a logical sequence that will assist the client in attaining skills in greater *self-choice*, independence, and community integration (W228 §483.440(c)(4))

	- IPPs should include opportunities for client choice and self-management; examples include choosing housing or roommates, clothing to purchase or wear, and or choosing what, where, and how to eat (W247 §483.440(c)(6)(vi)) - Conduct policies/procedures between staff and the client should promote and emphasize client choice in the areas of decision-making, self-determination and self-management (W269 §483.450(a)(1)(ii))
Interpersonal Relations	- Ensure clients the opportunity to communicate and meet privately with whomever they choose (W133 §483.420(a)(9)) - Provide clients privacy for face-to-face and electronic interactions (W133 483.420(a)(9)) - CFA: the speech and language development portion involves identifying how the client communicates, present barriers, and programs and services that are available to the client in order for them to go out and fully participate in the world (W220 §483.440(c)(3)(v))
Social Inclusion	- Clients should be offered opportunities to participate in social, religious, or group activities within the community based on their interests/choices (W136 §483.420(a)(11)) - The CFA must address behavioral management needs that interfere with progress, assimilation into the community, decrease freedom or increase the need for restriction of activities (W214 §483.440(c)(3)(iii)) - CFA: the social development portion refers to the formation of self-help, recreation and development, and interpersonal skills that enables the client to develop roles and fulfilling relationships with others (W223 §483.440(c)(3)(v))
Rights	- Facility must ensure the client of their rights and does not wait for them to claim a right (W122 §483.420(a)) - Facility is actively engaged in activities that protect and advocate the client’s rights and include training programs for clients and staff to understand protection of client rights (W122 §483.420(a)) - Clients and their families must be informed of their rights in a manner in which they can understand (W123 §483.420(a)(1)) - Each client, parent, and/or legal guardian must bet informed of the client’s medical condition, developmental and behavioral status, risks of treatment, and the right to refuse treatment (W124 §483.420(a)(2))

	- Clients and their families/guardians have the right to be notified of changes in treatment, as well as have the right to refuse recommended treatments or interventions (W124 §483.420(a)(2)) - Each client has autonomy of decision making and choice; they must be allowed to exercise their rights of the facility and as a citizen of the US (W125 §483.420(a)(3))
Emotional Well-Being	- CFA: the affective emotional development portion includes the development of behaviors that relates to the client's interests, attitudes, values, morals, emotional feelings, and emotional expressions (W219 483.440(c)(3)(v))
Physical Well-Being	- Clients are free to move about without limitations imposed due to staff preferences or convenience (W124 §483.420(a)(3)) - CFA: the physical development/health portion should include developmental history, physical exam results, health assessment data, laboratory results since the previous CFA, medical interventions, and admin/scheduling of one's own medical treatments (W126 §483.440(c)(3)(v)) - Appropriate materials, adaptations and modifications to equipment and the environment should be available to support training programs. Examples include, but are not limited to, built-up toilet seats, adaptive eating utensils, extended reach devices, and wheelchair accommodations. (W240 §483.440(c)(6)(i)) - IPP must identify mechanical supports based on the client's needs, used to support proper body position or alignment to prevent contractures or deformities; clients should be released from the mechanical support periodically for exercise and free movement. (W242 §483.440(c)(6)(iv)) - The facility must have procedures in place to ensure that the clients receive general health care services to assure optimal levels of wellness (W322 §483.460(a)(3)) - The facility should have a preventative health program in place to address screenings that will be performed periodically relevant to all clients, and screenings related to gender, age, or vulnerability (W322 §483.460(a)(3)) - Annual physical exams should be performed on each client that includes: evaluation of vision and hearing, immunizations, routine laboratory screenings (necessary by the physicians), and special studies when needed (W322-326 §483.460(a)(3)(i-iii))

	- The facility must provide diagnostic and treatment dental services from community dentists/dental hygienists whenever possible. (W348 §483.460(e)(1))) - Dental care for relief of pain and infections, restoration of teeth, and maintenance of dental health should be provided as needed. (W356 §483.460(g)(2)) - The facility must provide a sanitary environment to avoid sources and transmission of infections (W454 §483.470(l)(1)) - Facilities should maintain a surveillance program of communicable disease control and infections. The program should include procedures for: identification of the extent of the infection, protection of clients, treatment of clients, notification of family/guardians, reporting to the health department (as indicated), and continued follow-up. (W455 §483.470(l)(1)) - Each client should receive a well-balanced and nourished diet modified to their specifically prescribed needs. (W460 §483.480(a)(1)) - Each client must receive at least three meals daily, and be given the choice of not participating in a meal (W467 §483.480(b)(1))
Material Well-Being	- Allow and teach clients how to manage their finances to the best of their capabilities (W126 §483.420(a)(4)) - Clients should have personal possessions and clothing which meet their needs, interests and choices (W137 §483.420(a)(12)) - CFA: vocational development refers to work interests, skills, attitudes, work-related behaviors, and employment options. The vocational assessment should only be used as applicable. (W225 §483.440(c)(3)(v)) - Clients with multiple disabling conditions should spend a major portion of the waking day out of bed and outside of the bedroom area, moving about using various methods and device as possible (W246 §483.440(c)(6)(v))

(CMS. State Operations Manual Appendix J. Retrieved on 6-14-2021)

APPENDIX N: NATIONAL QUALITY FORUM AND QUALITY OF LIFE DOMAINS

ALIGNMENT

QoL Domain	**Description**	**Sub-Domains**	**NQF Domain**	**Description**	**Sub-Domains**
Personal Development	Deals with your education (including lifelong learning) and personal competence (including learning and demonstrating skills).	-Learning about the things you are interested in -Learning skills to become more independent -Being able to take care of yourself -Being able to follow your own interests -Having access to information	Service Delivery and Effectiveness	The level to which services and supports are provided in a manner consistent with a person's needs, goals, preferences, and values that help the person to achieve desired outcomes.52	Subdomains include: •**Delivery:** The level to which the individuals who use HCBS receive person-centered services and supports. Important aspects of delivery include timely initiation, the degree to which the delivered services and supports correspond with the plan of care, the ongoing assessment of the correlation of delivery and the plan of care, adequacy of the provider network to deliver needed services, and the capacity of the system to meet existing and future demands. •**Person's needs met and goals realized:** The level to which individuals who use HCBS receive services and supports sufficient to meet their needs and to support them in achieving their goals. • **Person's identified goals realized** (Additional subdomain added by the University of Minnesota. See https://rtcom.umn.edu/database/domains.)
Self-Determination	Deals with your personal goals and objectives, decision making, and making your own choices.	-Making your own choices -Deciding yourself what to wear -Expressing your own opinion -Acting on your own personal goals and aspirations	Person-Centered Planning and Coordination	An approach to assessment, planning, and coordination of services and supports that is focused on the individual's goals, needs, preferences, and values. The person directs the development	Subdomains include: •**Assessment:** The level to which the HCBS system and providers support persons in identifying their goals, needs, preferences, and values. This process should gather all of the information needed to inform the person-centered planning process. Re-assessments should occur on a regular basis to assure that changes in consumer goals and needs are captured and

				of the plan, which describes the life they want to live in the community. Services and supports are coordinated across providers and systems to carry out the plan and ensure fidelity with the person's expressed goals, needs, preferences, and values.57	appropriate adjustments to services and supports are made. •**Person-centered planning:** The level to which the planning process is directed by the person, with support as needed, and results in an executable plan for achieving goals and meeting needs that the person deems important. The plan includes the role of the paid and unpaid services or supports needed to reach those goals. •**Coordination:** The level to which the services and supports an individual receives across the healthcare and social service system are complementary, integrated, and fully support the HCBS consumer in meeting his or her needs and achieving his or her goals.
Self-Determination	Deals with your personal goals and objectives, decision making, and making your own choices.	-Making your own choices -Deciding yourself what to wear -Expressing your own opinion -Acting on your own personal goals and aspirations	Choice and Control	The level to which individuals who use HCBS, on their own or with support, make life choices, choose their services and supports, and control how those services and supports are delivered.71	Subdomains include: •**Personal choices and goals:** The level to which services and plans describe, develop, and support individual choices and life goals. •**Choice of services and supports:** The level to which individuals who use HCBS have a choice, and are supported in making that choice, in selecting and self-directing their program delivery models, services and supports, provider(s), and setting(s) •**Personal freedoms and dignity of risk:** The level to which individuals who use HCBS have personal freedoms and the ability to take risks. •**Self-direction:** The level to which individuals who use HCBS, on their own or with support, have decision-making authority over their services and take direct responsibility to manage their services with the assistance

					of a system of available supports.
Social Inclusion	Deals with your community integration and participation, the community roles that you play, and the social supports you receive.	-The community activities you participate in -The contacts you have with people in your neighborhood -The help you get from people living in the community -The number of memberships you have in community organizations	Community Inclusion	The level to which people who use HCBS are integrated into their communities and are socially connected, in accordance with personal preferences.81	Subdomains include: •**Social connectedness and relationships:** The level to which individuals who use HCBS develop and maintain relationships with others. •**Meaningful activity:** The level to which individuals who use HCBS engage in desired activities (e.g., employment, education, volunteering, etc.). •**Resources and settings to facilitate inclusion:** The level to which resources and involvement in community integrated settings are available to individuals who use HCBS. •**Employment** (Additional subdomain added by the University of Minnesota RTC/OM. See https://rtcom.umn.edu/database/domains.) •**Transportation** (Additional subdomain added by the University of Minnesota RTC/OM. See https://rtcom.umn.edu/database/domains.)
Interpersonal Relations	Deals with your family, friends, social network, and the supports you receive from others.	-The contacts you have or the time you spend with family and/or friends -The respect or feedback you receive from family and friends -The support you get from family and friends -The respect you receive from others	Caregiver Support	The level of support (e.g., financial, emotional, technical) available to and received by family caregivers or natural supports of individuals who use HCBS.90	Subdomains include: •**Family caregiver/natural support well-being:** The level to which the family caregiver/natural support is assisted in terms of physical, emotional, mental, social, and financial well-being. •**Training and skill-building:** The level to which the appropriate training and skill-building activities are available to caregivers/natural supports who desire such activities. •**Family caregiver/natural support involvement:** The level to which family caregivers/natural supports are involved in developing and executing the HCBS consumer’s person-centered care plan in accordance with

					the preferences of the consumer and family caregiver/natural support. This involvement includes direct assessment of caregiver/natural support needs, not just their ability to provide care, and is an ongoing part of the provision of HCBS. •**Access to resources:** The level to which the family caregiver/natural support is aware of and able to access resources (e.g., peer support, respite, crisis support, information and referral) that support overall well-being.
Emotional Well-being	Deals with your contentment, self-concept, and lack of stress in your life.	-How you express your feelings -Are there elements of danger in the environment where you spend most of your time -Do you worry or have serious concerns in some matters? In what matters? -How stable and predictable is your environment?	Workforce	The adequacy, availability, and appropriateness of the paid HCBS workforce.91	Subdomains include: •**Person-centered approach to services:** The level to which the workforce's approach to the delivery of services is tailored to the preferences and values of the consumer. This includes the use of good communication skills to solicit those preferences and values while also demonstrating respect for consumer privacy and boundaries. •**Demonstrated competencies, when appropriate:** The level to which the workforce is able to demonstrate that services are provided in a skilled and competent manner. These skills and competencies are fostered in the workforce through the use of competency-based approaches to training and skill development. •**Safety of and respect for the worker:** The level to which the HCBS delivery system monitors, protects, and supports the safety and well-being of the workforce. •**Sufficient workforce numbers, dispersion, and availability:** The level to which the supply of and the demand for the HCBS

					workforce are aligned in terms of numbers, geographic dispersion, and availability. •**Adequately compensated, with benefits:** The level to which the HCBS workforce is provided compensation, benefits, and opportunities for skill development as a means for ensuring a stable supply of qualified workers to meet the service and support needs of HCBS consumers. •**Culturally competent:** The level to which the workforce is able to deliver services that are aligned with the cultural background, values, and principles of the HCBS consumer (i.e., cultural competency of the workforce) and the level to which the HCBS system trains and supports the workforce in a manner that is aligned with the cultural background, values, and principles of the HCBS workforce (i.e., cultural competency of the HCBS system). •**Workforce engagement and participation:** The level to which front-line workers and service providers have meaningful involvement in care planning and execution when desired by the consumer; program development and evaluation; and the design, implementation, and evaluation of the HCBS system and policies. •**Staff turnover** (Additional subdomain added by the University of Minnesota Research and Training Center on HCBS Outcome Measurement. See https://rtcom.umn.edu/database/domains.)

Rights	Deals with both your human rights (respect, dignity, equality) and your legal rights (citizenship, access, and fair treatment).	-Your right to privacy and a private life -How people around you treat you -The opportunity you have to say what you think and being listened to -The right to have a pet -Having a key to your house -Being able to vote	Human and Legal Rights	The level to which the human and legal rights of individuals who use HCBS are promoted and protected.100	Subdomains include: •**Freedom from abuse and neglect:** The level to which the HCBS consumer is free from abuse and neglect and the HCBS system implements appropriate prevention and intervention strategies to ensure that the HCBS consumer is free from the threat of harm, actual harm, or disregard of basic needs. •**Optimizing the preservation of legal and human rights:** The level to which the HCBS system ensures HCBS consumers are accorded their full legal and human rights and are afforded due process in the delivery of HCBS. The preservation of these rights includes the system's ability to detect and respond to potential violations in a timely and effective manner. •**Informed decision making:** The level to which HCBS consumers, on their own or with support, are provided sufficient, understandable information in order to make decisions. •**Privacy:** The level to which the HCBS consumer is able to maintain the desired level of privacy in terms of information sharing, access to private space, and developing and maintaining private relationships. •**Supporting individuals in exercising their human and legal rights:** The level to which the HCBS system supports individuals in exercising their human and legal rights.
Materials Well-being	Deals with your financial status, employment status, living arrangements, and personal possessions	-What is your monthly income? -Do you have personal possessions that are important to you?	Equity	The level to which HCBS are equitably available to all individuals who need long-term services and supports.109	Subdomains include: •**Equitable access and resource allocation:** The extent to which consumers of HCBS have equitable access and ability to obtain needed services and supports (e.g., housing, transportation, employment services) and the

		-Do you have a paid job? -Are there things or goods that you cannot afford to buy because of lack of money?			extent to which the HCBS system is able to support that access through equitable allocation of resources and minimization of barriers (e.g., environmental, geographic) to access. •**Transparency and consistency:** The extent to which laws, regulations, and policies are equitably administered and information is publicly available. •**Availability:** The extent to which a service or support is equitably available to individuals seeking or receiving HCBS. •**Reduction in health disparities and service disparities:** The extent to which the HCBS system minimizes disparities in health outcomes and services.
Physical Well-being	Deals with your health and health care, nutrition, self-care skills, mobility, and recreation.	-Do have the energy to participate in physical activities? -Do you limit how much you eat so you do not gain weight? -Do you participate in recreation and leisure activities and/or sports?	Holistic Health and Functioning	The extent to which all dimensions of holistic health are assessed and supported.111	Subdomains include: •**Individual health and functioning:** The level to which all aspects of an HCBS consumer's health and functioning (including physical, emotional, mental, behavioral, cognitive, and social) are assessed and supported. •**Health promotion and prevention:** The level to which the HCBS system focuses on the prevention of adverse health and functional outcomes and promotes the highest levels of health and functioning, across all dimensions of holistic health.
NA			System Performance and Accountability	The extent to which the system operates efficiently, ethically, transparently, and effectively in achieving desired outcomes.120	Subdomains include: •**Financing and service delivery structures:** The level to which the system is appropriately financed and has the infrastructure in place to increase the proportion of people served in home and community settings and to meet the needs of consumers. •**Evidence-based practice:** The level to which services are delivered in a manner that

					is consistent with the best available evidence. •**Data management and use:** The level to which the system collects data in a manner that is consistent with best practices (i.e., complete, reliable, and valid), makes data publicly available, and uses data for performance improvement.
NA			Consumer Leadership in System Development	The level to which individuals who use HCBS are well supported to actively participate in the design, implementation, and evaluation of the system at all levels.125	Subdomains include: •**System supports meaningful consumer involvement:** The level to which the HCBS system facilitates and provides supports for active consumer participation in the design, implementation, and evaluation of the HCBS system. •**Evidence of meaningful consumer involvement:** The level to which individuals who use HCBS have meaningful involvement in the design, implementation, and evaluation of the HCBS system. •**Evidence of meaningful caregiver involvement:** The level to which family caregivers/natural supports of individuals who use HCBS have meaningful involvement in the design, implementation, and evaluation of the HCBS system.

(University of Minnesota, 2022) & (Schalock and Ketih, 2016)