North Carolina State Consumer and Family Advisory Committee

Annual Report and Recommendations

Nothing About Us, Without Us

Fiscal Year 2023-2024

July 10th, 2024

Special 20th Anniversary Edition

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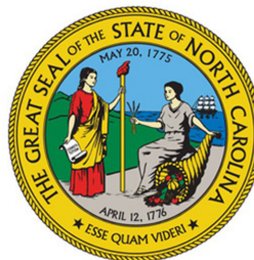


NC DEPARTMENT OF
HEALTH AND
HUMAN SERVICES

Part 1:
Executive Summary

Dear Secretary Kinsley,

Attached is the Annual Report of the North Carolina State Consumer and Family Advisory Committee (SCFAC) covering the period from July 1, 2023 to June 30, 2024. SCFAC members collaborated closely with Local CFACs, MCOs, your staff, and the General Assembly during this time period, focusing on critical initiatives.

As the fiscal year commenced, significant events unfolded, including the tragedy of the unfortunate case of Samantha R., delays in the Tailored Plan launch, anticipation surrounding Medicaid Expansion and, most recently, the proposed changes to NCGS §122C. North Carolina has since experienced a monumental shift in service delivery across mental health, substance use, intellectual and developmental disabilities, and traumatic brain injury sectors. While progress has been made, we remain vigilant about the operational and implementation aspects of the Tailored Plan launch, urging continued monitoring and communication at the highest levels. SCFAC staunchly supports a public system of care and the LME/MCO model, believing that transitioning to a private system would compromise the quality of care statewide.

Furthermore, SCFAC maintains its advocacy for a livable wage for Direct Service Personnel and Peer Support Specialists, statewide TBI waiver expansion, and robust support for our Military and Veterans Community. Despite our focus on these pressing issues, we are committed to fulfilling our mandated responsibilities, which include advising the Department of Health and Human Services (DHHS) and the North Carolina General Assembly (NCGA) on all aspects of the state's public mental health, developmental disabilities, and substance use services.

We commend your efforts toward achieving Medicaid Expansion in North Carolina and eagerly anticipate your continued leadership. You and your staff are always welcome to attend SCFAC meetings as your schedule permits and as you deem necessary.

Finally, we extend our gratitude for your ongoing support of SCFAC and local Consumer and Family Advisory Committees statewide. As we enter into FY 25, the NC SCFAC celebrates its 20th year, and as we stand on the shoulders of so many who blazed the trail for Managed Care. As we look back on the progress we have made, our focus remains on the future state of care.

Respectfully submitted,

Mr. Brandon L. Wilson
SCFAC Chairman

Part 2: Foreword

This report, courteously presented by the North Carolina State Consumer and Family Advisory Committee, serves to provide informed counsel to both the General Assembly and the Department of Health and Human Services, as mandated by legislation. The Committee is optimistic that the insights and recommendations contained within will spur action from the General Assembly and bolster initiatives led by the NC Department of Health and Human Services. Members of this Committee dedicated numerous hours to attending workshops, town halls, conferences, and fulfilling specific tasks. Alongside monthly trips to Raleigh or virtual meetings as per state guidance, the Committee diligently engaged in MH Town Halls, local CFAC meetings, and advocated before the General Assembly on Legislative Day. This ongoing effort aims to ensure that the voices of the citizens we represent are not only heard but also heeded.

The recommendations outlined in this report are directly influenced by the findings, research, and input gathered from individuals affected by mental health, intellectual and developmental disabilities, substance use, and traumatic brain injuries in North Carolina. With unwavering confidence, these recommendations are poised to address identified gaps with practical solutions, benefiting the Department, LME/MCOs, providers, and communities alike.

We look forward to the feedback of these recommendations as a '**Concur**', '**Partially-Concur**' or '**Non-Concur**', with appropriate feedback for each of our recommendations. Additionally, we would like to request that on the 'Concur', and 'Partially Concur' that SCFAC receive quarterly updates on the progress of these recommendations, in order to provide continued support and the help ensure Department accountability for our consumers and families.

In order to provide better communication below are the definitions and implications of responses:

Concur:
Definition: Full agreement with the proposal, or recommendation.
Implications: Indicates complete alignment and support without reservations. All aspects are accepted as presented, and any recommended actions are fully endorsed.

Partially Concur:
Definition: Partial agreement with the proposal, or recommendation.
Implications: Indicates agreement with some aspects but not all. Specific elements are accepted, while others may be contested or require modification. Often includes explanations of the points of agreement and disagreement, along with suggestions for changes or conditions for full concurrence.

Non Concur:
Definition: Full disagreement with the proposal, or recommendation.
Implications: Indicates complete opposition or rejection. The reasons for disagreement are typically provided, along with any alternative suggestions or reasons why the original proposal is not acceptable.

North Carolina State Consumer and Family Advisory Committee 2022-2023

Chairman Mr. Brandon Wilson		Vice Chairman Mr. Bob Crayton	
Ms. April DeSelms		Ms. Crystal Foster	
Ms. Jean Andersen		Ms. Patty Schaeffer	
Ms. Susan Monroe		Ms. Jessica Aguilar	
Rev. Gene McClendon		Mr. Johnnie Thomas	Johnnie Thomas
Ms. Janet Breeding		Ms. Angela-Christine Rainear	Angela-Christine Rainear
Ms. Lorrine Washington		Ms. Heather Johnson	
Ms. Ashley Snyder Miller		Ms. Annette Smith	
Ms. Mamie Hutnick		Mr. Nathan Cartwright	
Ms. Jeannie Irby		Ms. Lilly Parker	
Dr. Michelle Laws			

Part 3:

Celebrating 20 years

The Evolution and Impact of the North Carolina State Consumer and Family Advisory Committee

Over the past 20 years, the North Carolina State Consumer and Family Advisory Committee (SCFAC) has played a pivotal role in advocating for and shaping the state's healthcare landscape. Established to represent the voices of consumers and families within the behavioral healthcare system, SCFAC has been instrumental in driving positive changes and improvements across various facets of service delivery. In 2000, the North Carolina General Assembly took an historic step in advancing the public systems for mental health, developmental disabilities and substance abuse services. During the 2000 Legislative Session, the bipartisan Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services was established to oversee system reform. This led to the 2001 State Plan: Blueprint for Change, which ultimately led to the creation of the North Carolina State Consumer and Family Advisory Committee. The Committee was officially signed into effect on April 15th, 2004 by DHHS Secretary Carmen Hooker Odom and the first meeting was held May 5th, 2004 in the Haywood Room at the Holiday Inn in North Raleigh. Since this time this Committee has been a leading voice and steadfast advocate for thousands of Consumers and Families across NC.

Advocacy and Representation:

SCFAC continues to serve as a crucial advocate for consumers and families, ensuring their perspectives are heard and considered in policy-making and program development. Through active engagement with state leaders, legislators, and healthcare system administrators such as the current LME/MCO's and PHP's, SCFAC has championed initiatives that promote patient/person-centered care, equitable access to services, and improved quality of care for all North Carolinians while ensuring accountability to the Department and the State are held at the highest value.

Policy Influence:

Through its advocacy efforts, SCFAC has influenced state policies and regulations that impact healthcare delivery and accessibility to those with mental health, substance use, intellectual and developmental disabilities and traumatic brain injury. By providing informed insights and recommendations, SCFAC has contributed to the development of policies that prioritize patient safety, care coordination, and effective treatment options tailored to individual needs; often providing strategies that affect system level changes.

Community Engagement:

SCFAC fosters community engagement by hosting forums, meetings, and outreach events that educate and empower consumers and families. These platforms provide opportunities for stakeholders to share experiences, discuss concerns, and collaborate on solutions to improve healthcare outcomes statewide.

Impact on Managed Care:

With the evolution of North Carolina's managed care system, SCFAC has been at the forefront of ensuring consumer and family interests are safeguarded. By advocating for transparency, accountability, and consumer rights within managed care organizations (MCOs), SCFAC has contributed to shaping a more responsive and patient-centered managed care environment through the many changes over the last two decades.

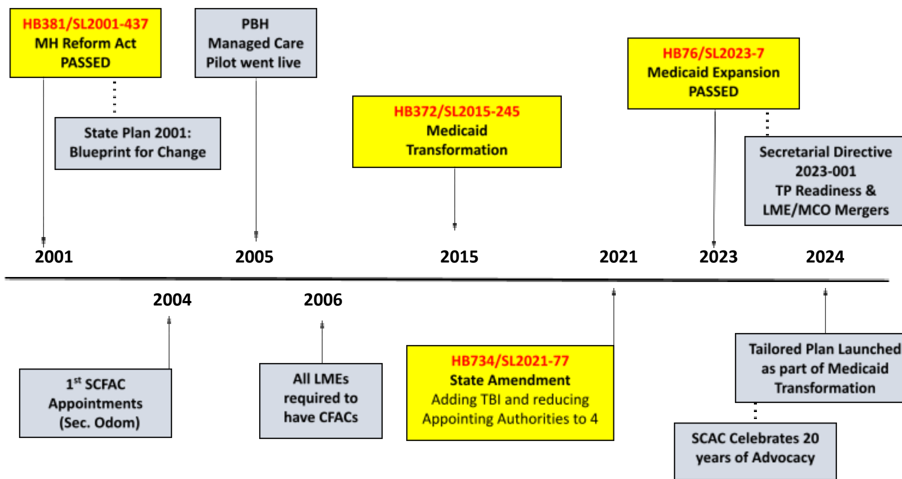
Response to Healthcare Emergencies:

During public health emergencies like the COVID-19 pandemic, SCFAC has demonstrated agility and responsiveness in addressing emerging healthcare challenges. By advocating for flexibilities in service delivery and supportive policies, SCFAC has helped mitigate the impact of crises on vulnerable populations and ensured continuity of care.

Collaboration and Partnerships:

SCFAC collaborates closely with state agencies, healthcare providers, advocacy organizations, and community stakeholders to foster partnerships that enhance healthcare delivery and support services. These collaborations amplify SCFAC's advocacy efforts and broaden its impact across diverse healthcare settings.

In conclusion, over the past two decades, the North Carolina State Consumer and Family Advisory Committee has been a steadfast advocate, influencer, and partner in advancing healthcare quality, accessibility, and patient-centeredness throughout the state. Its ongoing commitment to consumer and family engagement, policy advocacy, and community collaboration underscores its critical role in shaping a more equitable and effective system of care for all North Carolinians. To honor our 20 years this committee would like to recognize all past SCFAC members and Department staff who have worked together to advocate and work together to ensure our motto continues; 'Nothing about us, Without us'.



2005 NC LME/MCO Regions

2024 NC LME/MCO Regions

Celebrating 20 years: The History

This excerpt is the Introduction from the 2001 State Plan: Blueprint for Change – which led to the creation of the North Carolina State Consumer and Family Advisory Committee.

North Carolina's mental health, developmental disabilities and substance abuse services system is at a crossroads. The state's ability to respond to rapidly changing national standards has been severely compromised by reductions in funding, changes in leadership, a lack of consensus regarding how to improve the system, and severe budget problems. Consumers, families, advocates, providers, legislators and administrators recognize that sweeping changes are needed to move the system forward into the 21st century.

The North Carolina General Assembly has taken an increasingly active leadership role in the public system for mental health, developmental disabilities and substance abuse services. During the 2000 Legislative Session, the bipartisan Joint Legislative Oversight Committee on Mental Health, Developmental Disabilities, and Substance Abuse Services was established to oversee system reform. The LOC, chaired by Senator Steven Metcalf and Representative Verla Insko, created the mental health reform bill. Governor Michael F. Easley signed the bill on October 15, 2001. The mental health reform bill (House Bill 381: An Act to Phase in Implementation of Mental Health System Reform at the State and Local Level) provides much of the basis for this state plan, particularly as it relates to coordination of state and local collaboration. The full text of the reform legislation is incorporated by reference as a separate document.

The State Plan 2001: Blueprint for Change is DHHS Secretary Carmen Hooker Buell's plan to transform the present system. It is a living document for a five-year period of time that will be refined as the state plan is implemented. The State Plan will ensure on-going consumer and family involvement and oversight. The State Plan prioritizes services for people with the most disabilities, employs evidence-based best practices, and promotes efficiency. It realigns service priorities and reallocates system resources. It accepts limited funding as a fact and recognizes that the current economic downturn is expected to continue. North Carolina's financial shortfall makes it essential that the service system channel funding to direct services. The State Plan sets clear limits on indirect service costs and opts for the most cost efficient service delivery available.

"When SCFAC was founded in 2004, I had three priorities: First, was to listen and learn. Second, was to ensure that the Chief of Advocacy and Customer Service was someone who had lived experience as a consumer or family member, and third that the committee would report directly to me in order to guarantee meaningful access. Now 20 years later this committee continues to make a difference for the Department and for those we serve."

Ms. Carmen Hooker Odom
Former NC Secretary of Health and Human Services

North Carolina Department of Health and Human Services
Division of Mental Health, Developmental Disabilities and Substance Abuse Services
3009 Mail Service Center • Raleigh, North Carolina 27699-3009
Advocacy and Customer Services
Tel 919-715-3197 • Fax 919-733-4962

Michael F. Easley, Governor
Carmen Hooker Odom, Secretary

Michael Mosley, Director

April 15, 2004

TO: All Concerned

FROM: Carmen Hooker Odom, Secretary
Department of Health and Human Services

RE: State Consumer and Family Advisory Committee (CFAC) Appointments

I am pleased to announce the appointments for the State Consumer and Family Advisory Committee (S-CFAC). The committee is comprised of the following members: Jere W. Annis, III, Carl Britton-Watkins, Derl Bruce, George (Pete) Clary, Zachariah (Zac) Commander, Sandra DuPuy, Ronald Huber, Kathleen Herr, Ed Masters, Doug Michaels, Ellen Perry, Barbara Ann Richards, Katie Chambers Sawyer, Betty Stanberry, Amelia Thorpe, Alejandro Vazquez and Paula Wagner. As outlined in the 2003 State Plan, membership will consist of twenty (20) members who are representative of each of the four disability groups, i.e., mental health, developmental disabilities, substance abuse and co-occurring disorders, of which a minimum of sixteen (16) shall be local CFAC members, but with no more than 1 member from the same local CFAC. An additional member has also been appointed to the committee for voting purposes, which will bring the total representation to twenty-one (21) members. Currently, there are four vacancies for adolescents in each of the four disability groups. The Consumer Empowerment Team will continue to recruit and take applications for these vacant member positions for the state CFAC.

The State CFAC, in conjunction with the Division's Executive Leadership Team (ELT) will provide input and conduct oversight of the Division of Mental Health, Development Disabilities and Substance Abuse Services operations and efforts to accomplish the strategic outcomes of the State Plan. Although the State CFAC works directly with the ELT, they may, at any time, report specific concerns directly to me. The State CFAC will receive support through the Division's Advocacy and Customer Services Consumer Empowerment Team.

The initial meeting location for the State CFAC will in the Haywood Room at the Holiday Inn in North Raleigh on May 5, 2004 from 9:00 a.m. – 4 p.m., where they will begin to develop a work-plan and arrange for future meetings. During this meeting, members will also meet with the new Division Director, Mike Mosley, Chris Phillips, Chief of the Advocacy and Customer Services Section and Ann Remington, Consumer Empowerment Team Leader.

Please join me in congratulating these individuals on their appointments! These individuals have accepted the challenge to assist in the reform efforts by representing their regions and respective disabilities. They need our support to continue the efforts of the reform process.

cc: Lanier Cansler
James Bernstein
DMH/DD/SAS Executive Leadership Team
Carol Duncan-Clayton
Robin Huffman
Fred Waddle
Patrice Roesler
CFACs

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Celebrating 20 years: Voices of Change

Over the past decade, SCFAC has significantly influenced North Carolina's system of care at multiple levels. This includes legislative changes at the General Assembly, policy implementation, and resource allocation at the Department and Division levels, all of which have resulted in enduring, life-changing care for our consumers and families. Many individuals who have served on the committee have witnessed and contributed to these transformative changes in our Communities. Additonally, many of these Committee members have also served on Local CFAC committees and have led to many positive changes within the LME/MCO's. While everyone's efforts are valued, the following list highlights some who have directly experienced SCFAC's impact throught its 20-year history.

"SCFAC is an essential leader in lifting up the voices of consumers and families. As a person with lived experience, I am proud to work closely with SCFAC to improve our public system of care by promoting recovery, reducing stigma, and increasing access to services and supports. I am thankful for SCFAC's twenty years of leadership, and I look forward to our continued partnership in building communities where all are supported to live healthier and happier lives."

Ms. Kelly Crosbie
Division Director of MH/DD/SUS
NCDHHS

"Creating the public managed care system in 2004 stabilized a system in crisis. Mandating independent conusmer and family advocay created true accountability, and I find this to be the most consequential part of the law. I would like to thank all Local and State CFAC members for their pursuit of a better North Carolina."

Mr. Dave Richard
Former Deputy Secretary, Division of Health Benefits
NCDHHS

“The CFAC, both state and local, stand alone among efforts over the years that provide endurance and measurable impact. I am very proud to have had some small role in the drafting of the statute and support for the development of the CFAC. Congratulations to the State and Local CFAC members and all of those who preceded you for a job well done.”

Dr. Pat Porter
Former Chief of Developmental Disabilities
NCDHHS

“For many of us who are family advocates and persons with lived experiences, we have always known that if we didn't have a legitimate place at the table when policies were being made and services were created that our interests would be at risk of either being unmet, minimized, or ignored all together. The State CFAC has given us that place at the table. We are not just at the table for ourselves but for all families and consumers. Our state is better than most because our policymakers and MH/DD/SUD/TBI service administrators understand clearly the meaning of our motto "nothing about us without us."

Dr. Michelle Laws
Former Legislative Liasion, Division of MHDDSAS
NCDHHS

“The system reform efforts of the early 2000’s brought a lot of significant changes to the community system of mental health, intellectual and other developmental disabilities, and addiction services. One of the most important, and long-lasting, has been the creation of State and Local CFACs. I have had the privilege to work with State CFAC as both a DHHS employee and as the CEO of a local management entity. I learned so much through every interaction. Congratulations to State CFAC for making such a positive difference for twenty years! I look forward to the next twenty!”

Ms. Leza Wainwright
Former Division Director of MH/DD/SUS & LME CEO
NCDHHS

Part 4:
North Carolina General Statute

§ 122C-171. State Consumer and Family Advisory Committee.

(a) There is established the State Consumer and Family Advisory Committee (State CFAC). The State CFAC shall be a self-governing and self-directed organization that advises the Department and the General Assembly on the planning and management of the State's public mental health, intellectual and developmental disabilities, substance use disorder, and traumatic brain injury services system.

(b) The State CFAC shall be composed of 21 members. The members shall be composed exclusively of adult consumers of mental health, intellectual and developmental disabilities, substance use disorder, and traumatic brain injury services and family members of consumers of mental health, intellectual and developmental disabilities, substance use disorder, and traumatic brain injury services. The terms of members shall be three years, and no member may serve more than two consecutive terms. Vacancies shall be filled by the appointing authority.

Part 5:
SCFAC Mission & Purpose

Mission

The mission of the State CFAC is to:

- Support the development of consumer services by identifying needs and gaps in services and promoting services that are effective and meet high quality standards.
- Support CFAC growth and development at state and local level.
- Support individual consumer and family participation at state and local level.

Purpose

The State CFAC shall be a self-governing and self-directed organization that advises the Department and the General Assembly on the planning and management of the State's public mental health, developmental disabilities, and substance abuse services system.

The State CFAC shall undertake all the following:

(1) Review, comment on, and monitor the implementation of the State Plan for Mental Health, Developmental Disabilities, and Substance Abuse Services.

(2) Identify service gaps and underserved populations.

(3) Make recommendations regarding the service array and monitor the development of additional services.

(4) Review and comment on the State budget for mental health, intellectual and developmental disabilities, substance use disorder, and traumatic brain injury services.

(5) Review and comment on contract deliverables and the process and outcomes of prepaid health plans in meeting these contract deliverables.

(6) Receive the findings and recommendations by local CFACs regarding ways to improve the delivery of mental health, intellectual and developmental disabilities, substance use disorder, and traumatic brain injury services, including statewide issues.

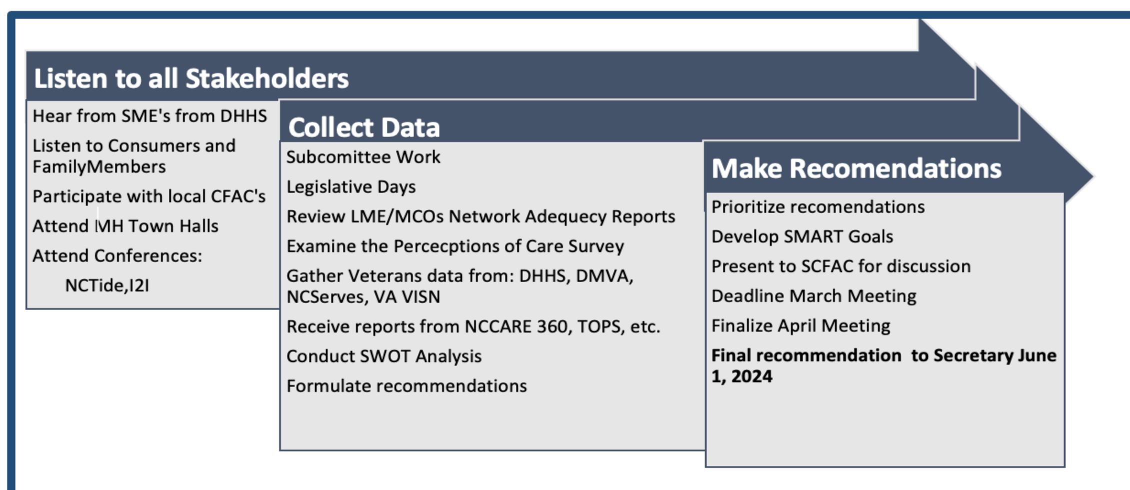
(7) Develop a collaborative and working relationship with the prepaid health plan member advisory committees to obtain input related to service delivery and system change issues

Part 6:
Background of Annual Report

The SCFAC committee continually seeks out dedicated members with strong leadership and advocacy skills, paired with lived experiences that enable them to enabling them to effectively identify challenges and barriers while maintaining a solutions-oriented approach for the Department. This annual report is a culmination of contributions from our subcommittees and members, serving as the voice of North Carolina consumers and families accessing services.

Throughout the year, the committee gathers information from various sources, including Network Adequacy Reports, Consumer Surveys, LME/MCO data, inputs from the NCDMHDDSAS Quality Management Team, as well as insights from speakers, presentations, local CFAC communications, and direct feedback from individuals receiving mental health, substance use disorder, traumatic brain injury, and intellectual and developmental disabilities services. This wealth of data is thoroughly examined by the Optimization subcommittee to pinpoint areas where services are lacking.

This year, the four standing subcommittees: Legislative and State Budget, Contract Deliverables, Community Collaboration, and Optimization (Gaps/Needs), ensured comprehensive coverage of our mandated areas under GS-122 C-171. Each subcommittee worked independently, occasionally collaborating with external subject matter experts, to develop recommendations in the SMART format. By adhering to Specific, Measurable, Attainable, Relevant, and Timely criteria, our recommendations are characterized by strong, clear language consistent with the Committee's mandate outlined in NC General Statute § 122C-171, and are subject to a vote for inclusion in the Annual Report.



Part 7:
Summary of Accomplishments 2023-2024

In 2023-2024 State CFAC, and all North Carolinians, continued to be met with challenges from COVID-19 as well as political and social unrest. Despite these challenges, SCFAC and Local CFACs were able to meet both in person (where applicable) and virtually. We have embraced the many leadership changes during this past year and have worked with each new team member in order to create a solid partnership, founded on transparency and trust. We have palced significant emphasis on improving communication with the department as well as our Legitslators.

With the assistance of DHHS staff, we were able to provide relevant, useful information to our members by presentations from numerous DHHS leaders and those directly involved with the development and implementation of programs directly affecting our citizens receiving mental health, traumatic brain injury, developmental disability, and substance use disorder services.
Some of the major efforts of SCFAC have been on continued Medicaid Transformation, Medicaid expansion, access to services, livable wages for Direct Services Personnel and Peer Support Specialists, the lack of resources available to individuals with TBI and the shortage of staff that provide the needed services to the people of NC. At each meeting we have addressed issues and concerns related to these challenges. During meetings, SCFAC received updates from state leaders. These presentations added significantly to NC SCFAC's ongoing commitment to providing guidance to members of the North Carolina General Assembly and the development of this year's Annual Report.

The four standing subcommittees accomplished many things over the last year, each subcommittee collaborated in coordination to order to ensure we covered all the areas we are mandated to cover in GS-122 C-171. The subcommittees are as follows and their accomplishments are listed below - Legislative Committee, Recovery and Self-Determination Committee, State to Local Collaboration Committee, and Service Gaps and Needs/Veterans Committee.

Medicaid Expansion: A Milestone for Healthcare

In a landmark decision, North Carolina finally embraced Medicaid expansion and launched December 1, 2023. This historical move has already significantly enhanced healthcare access for thousands of residents across the state. SCFAC has supported this expansion from the onset and this crucial step, anticipated for years, marks a turning point in the state's approach to healthcare, promising to provide coverage to many previously uninsured individuals and families. In addition to the estimated 600,000 North Carolinians who will gain access to healthcare coverage there are many other advantages that have already supported the overall health of those we serve. This includes early intervention to include preventative care and mental health services, which yields economic benefits reducing the burden of severe health conditions and decrease in ER visits. Additionally, this is expected to inject billions of federal dollars into the state's economy.

The SCFAC Committee applauds Secretary Kinsley for his staunch advocacy and for working across the aisle for bi-partisan support to get this accomplished; and although this is a significant step forward several challenges still need to be addressed and monitored and SCFAC looks forward to meeting these challenges with the Department moving forward.

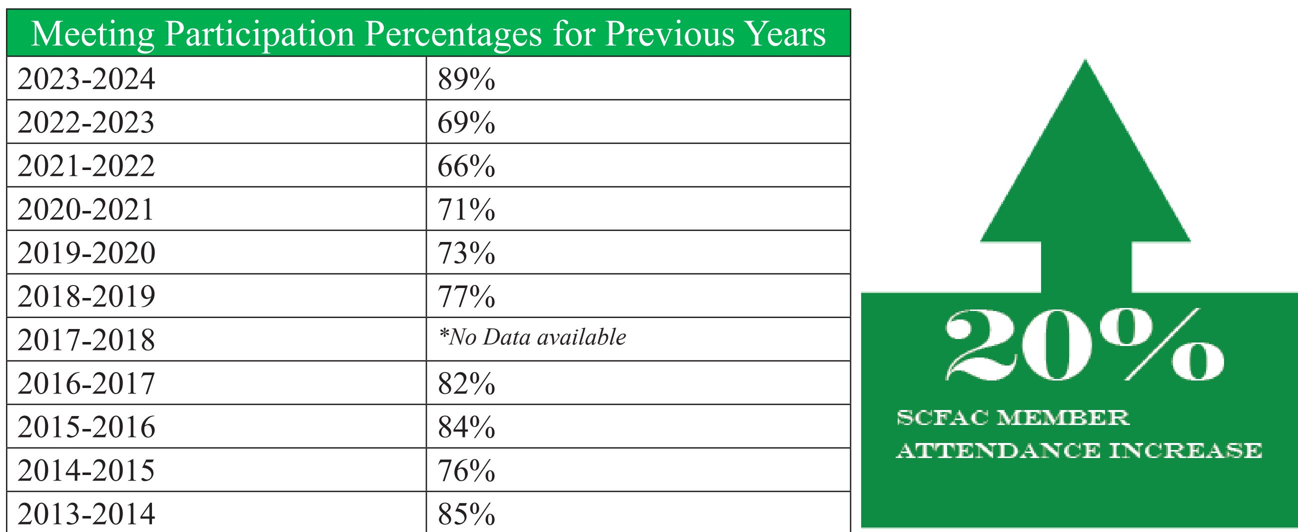
Implementation: Effective implementation requires a coordinated effort between state agencies, healthcare providers to include the LME/MCO's and PHP's, and community organizations to ensure smooth enrollment and service delivery with limited disruption of care. Monitoring and managing Tailored Plan launch in FY25 and its integration is vital.

Provider Capacity: There must be an adequate number of healthcare providers to meet the increased demand for services, particularly in underserved areas. The State must continually address both **Accessibility and Availability**, specifically in our rural areas.

Sustainability: Ensuring the long-term sustainability of the expanded Medicaid program will require ongoing evaluation and potential policy adjustments to address emerging issues that will impact our consumers and families

A Year of Revitalization:
SCFAC's Journey toward Enhanced Engagement

Throughout the past year, the North Carolina State Consumer and Family Advisory Committee has witnessed a remarkable surge in participation, marking its highest attendance at committee meetings in the last decade. The active engagement of SCFAC members has soared to 89%, significantly enhancing communication, inclusivity in decision-making, and the overall sense of purpose. This revitalization has brought about a more focused alignment with our mission under 122C. The table below contrasts SCFAC participation over the past decade with the recent surge, highlighting the committee's renewed vigor and commitment to its role:



Meeting Participation Percentages for Previous Years	
2023-2024	89%
2022-2023	69%
2021-2022	66%
2020-2021	71%
2019-2020	73%
2018-2019	77%
2017-2018	**No Data available*
2016-2017	82%
2015-2016	84%
2014-2015	76%
2013-2014	85%

This surge in participation underscores SCFAC's dedication to amplifying consumer and family voices in shaping policies and initiatives that impact healthcare and support services across North Carolina and can be attributed to the goals set by both Chairman Wilson and Vice-Chair Crayton in order to heighten the visibility of the committee to the community. This result has also strengthened engagement through enhanced participation and encouragement with statewide events that impact mental health, intellectual and developmental disabilities, substance use disorder and traumatic brain injury. One example of this heightened visibility included two highly publicized panel discussions with some of the state's top leaders with both our Managed Care Organizations and Pre-Paid Health Plans.

In summary, increasing participation within an advisory committee has proven important as it has promoted better decision-making, enhanced stakeholder engagement, supported effective problem-solving, improved accountability, ensured long-term sustainability, and strengthened strategic alignment with Department goals. These benefits collectively contribute to the overall success and effectiveness of the advisory committee and has created a more informed voice for our consumers and families.

An Historic Discussion: Insight from the LME/MCO panel

On January 10th, 2024, SCFAC hosted a special monthly meeting at Alliance Health in Morrisville, NC, focusing on "The Future State of Care." The event featured the four CEOs from our Local Management Entities/Managed Care Organizations. The panel discussion delved into topics such as Tailored Plan Readiness, Implementation of Waiver Updates, and Systems-level challenges. Additionally, senior leadership provided insights into the recent MCO consolidation and its impact on North Carolina's managed care landscape.

The discussion revealed significant insights, highlighting instances of communication gaps between the Department level and the MCO level, leading to confusion and mistrust among consumers and families. However, the leaders present demonstrated a commendable commitment to addressing these issues transparently and were receptive to feedback, fostering opportunities for continued collaboration. SCFAC extends its formal gratitude to these leaders for their willingness to engage openly with the committee.

CEO Rob Robinson – Alliance Health

CEO Rhett Melton – Partners Health Management

CEO Tracy Hayes – VAYA Health

CEO Joy Futrell – Trillium Health Resources

Enhancing Collaboration: Insights from Historic PHP/Standard Plan Panel Discussion

Building on the momentum from the Historic LME/MCO panel discussion, the Contract Deliverables subcommittee, led by Dr. Michelle Laws, proposed engaging Prepaid Health Plans (PHPs) in discussions. Given their pivotal role in providing mental health (MH), substance use (SU), and traumatic brain injury (TBI) services under the new managed care system, SCFAC recognized the importance of including PHP leadership to foster collaboration during this transformative period.

SCFAC highlighted concerns regarding accountability with PHPs despite their critical role in healthcare transformation. During the panel discussion, SCFAC gained valuable insights:

- Each PHP's implementation strategies for new services like SAIOP and SACOT, and their efforts to smoothly transition members to Local Management Entities (LMEs).

- The intentional continuity of care strategies each PHP has generated that is aimed at ensuring a seamless transition from Tailored Plans to Standard Plans, prioritizing the well-being of consumers and families.

- Discovery of Member Advisory Committees within PHPs, offering potential for coordinated efforts to enhance system transparency in the upcoming fiscal year and beyond.

- Shared challenges regarding accessible communications, SCFAC was impressed with each PHP's emphasis with community education on Medicaid enrollment, expansion, and flexibility of these services.

In summary, SCFAC remains committed to collaborating with Standard Plans on mutual interests to benefit North Carolina's population. Looking ahead, SCFAC anticipates continued engagement with PHPs and their Member Advisory Committees, fostering transparency and driving positive outcomes in healthcare delivery.

Amplifying Voices: Advocacy with State Leaders at the General Assembly Legislative Day 2024

On May 7th, 2024, members of SCFAC joined forces with local CFAC members from VAYA, Alliance, Partners, and Trillium MCOs to advocate and inform our state leaders at the General Assembly. Throughout the day, we engaged with numerous legislators from both the House and Senate, discussing critical issues within our healthcare system. Our discussions were guided by five specific legislative talking points that are outlined here:

1. North Carolina has a unique and rich history of providing mental health, intellectual & developmental disabilities, behavioral health services to individuals through the public LME/MCO system. This system has proven effective in the delivery of mental health, intellectual and developmental disabilities, substance use and traumatic brain injury services. It is vital to our state that this public system be allowed to continue in order to protect the quality of care being provided. Privatizing these services will only cause a disadvantage to individuals receiving these services by taking away the personal connection, family support, and the foundation of person-centered care. **We strongly support keeping the public LME/MCO system in North Carolina.**
2. In 2023 the statewide TBI waiver was passed, creating the foundation for expanded services for those with Traumatic Brain Injury. However, since this expansion there has not been adequate funding that supports this monumental service need, therefore it is vital for this wavier to be funded to reach across the state. **The General Assembly needs to contribute by matching Federal contributions for this expansion and/or provide the appropriate oversight of funding and resource allocation for the TBI waiver expansion.**
3. **General Assembly through the Department needs to allocate increased funding at an appropriate and sustainable level for substance use services to for the LME/MCO's.** With the continued rise of Opioid related deaths, we must continue to elevate the appropriate resources to combat this epidemic. This includes providing funding for the provision for both prevention (the largest domain cut over the last several years) and treatment.
4. **We must continue to work to increase wages for Direct Care Providers, including Direct Support Professional, Private Duty Nursing, Peer Support Specialists, and Personal Care Workers.** Implementing mandates, improving policies, or creating incentives based strategies will help to combat the workforce shortage and improve the quality of care for consumers, families and providers.
5. In February 2023, the Governor's Budget asked for investments in direct support professional wages and the addition of over 17,000 Innovations with a goal of eliminating the RUN by 2033 (10 years). **Through NCDHHS there needs to be a continuation of additional slots (funding) each fiscal year, while monitoring and tracking to reach this goal by 2033.**

This years' Legislative day was pivotal for many SCFAC and local CFAC members, providing invaluable opportunities to understand the workings of the General Assembly and how to effectively engage with lawmakers to advocate for North Carolina's healthcare needs. Highlights included insights from Representatives Frank Sossamon and Sarah Crawford, as well as Senator Mike Woodard, who emphasized their commitment to improving our system of care through enhanced accountability to the Department amidst historic changes to managed care. Additionally, poignant personal stories shared by consumers and family members underscored both the challenges in accessing care and the successes stemming from Medicaid expansion. Throughout the day, committee members actively participated in various committee meetings, including the Military and Veterans Affairs Commission, where they engaged with the introduction of the new NC Department of Military and Veterans Affairs Secretary, Mr. Grier Martin.

Empowering Support:
The Launch of NC's Peer warmline

On February 20th, the North Carolina Department of Health and Human Services unveiled the Statewide Peer Warmline, an essential complement to the North Carolina 988 Suicide and Crisis Lifeline, offering callers the option to connect with Peer Support Specialists. SCFAC members celebrated this milestone at the ribbon-cutting ceremony, marking the culmination of their advocacy efforts over the years.

The Committee continues to advocate for integrating lived experiences as a cornerstone for navigating the complexities of care transitions.

Annually, SCFAC submits recommendations to the Department aimed at enhancing the Peer Support program through increased funding, expanded resources, and policy improvements. The launch of the Peer Warmline is timely; according to the NCDHHS 988 Performance Dashboard, over 40% of 988 callers are repeat callers who benefit greatly from speaking with someone. By incorporating peers into the support network, the warmline augments the Lifeline's capacity to deliver vital services.

Operated by the Promise Resource Network (PRN) in Charlotte, NC, following a competitive bidding process, the Peer Warmline is staffed by Peer Support Specialists who provide non-clinical support and resources around the clock. Their unique perspective reduces stigma and enhances engagement in care, potentially reducing hospitalizations, emergency department visits, and behavioral health symptoms recurrence.

The successful launch owes much to the dedication of advocacy groups, Peer Support Specialists, and lawmakers who have championed this initiative over the past decade. SCFAC is proud to have played a role in bringing this invaluable resource to the community, poised to make a significant impact on crisis intervention and mental health support in North Carolina.

Petitioning for what is Right: The Appendix K Flexibilities Extension

During the COVID-19 public health emergency in March 2020, CMS implemented various Innovations Waiver flexibilities to ensure the safety of waiver members in their communities. While some of these flexibilities were integrated into the Waiver, others were scheduled to expire on September 1, 2023. Recognizing the urgency and impact of these changes, SCFAC swiftly prioritized the issue for several months. We engaged NC Medicaid Deputy Secretary Jay Ludlam and his team through formal letters of inquiry, urging action which included filing to CMS for extension and for making flexibilities permanent.

As a result of these efforts, North Carolina successfully petitioned for an extension of the sunset date for these flexibilities, allowing consumers and families more time to prepare. Additionally, NC advocated for permanent flexibilities to be retained, ensuring ongoing support for those affected by the changes. SCFAC was grateful for the NC Medicaid team for their willingness to include committee members in this decision making process and for truly advocating to CMS for these critical changes.

Success Happened:

- Extension Granted: To avoid a disruption in care and support consumers and their families, NC Medicaid successfully extended Appendix K temporary flexibilities until Feb. 29, 2024, while the Centers for Medicare & Medicaid Services (CMS) reviews additional changes with the Innovations and Traumatic Brain Injury Waiver amendments.
- The Innovations Waiver Cap Increase: The Innovations Waiver Cap set to $135,000 was increased to $184,000
- Relative as Provider (Adults) increased to 84 hours

While many flexibilities ended February 29th, 2024, many other flexibilities were made permanent specifically for service providers, which also impacted Employer of Record (EOR). To review this entire list please visit the NC Department of Health and Human Services website of visit: https://medicaid.ncdhhs.gov/blog/2024/01/30/nc-medicaid-guidance-sunsetting-innovations-waiver-appendix-k-flexibilities

Forging the Future:
COLLABORATION OF NC'S STRATEGIC PLAN

SCFAC has focused on and pushed the Department to not only be more transparent in communication but to also implement more 'Intentional' strategies. In the last year members from the SCFAC committee were fortunate to participate and provide feedback with the build of the Draft 2024-2029 Strategic Plan for the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Use Services (DMH/DD/SUS). This critical 5 comprehensive plan shares the Division's mission, vision, guiding principles, priorities, and goals for the next five years.
The Draft DMH/DD/SUS Strategic Plan was developed in collaboration with Division staff and SCFAC; that included monthly Side-by-Side webinars, and discussions with providers and LME/MCOs over the last 7 months. This inclusive strategy provided opportunities to be involved with six different work groups that included:

- Strengthening the Workforce
- Promote Wellness and Recovery
- Strengthening the Crisis System
- Expand Access to Quality I/DD and TBI Services
- Prevent Substance Misuse and Overdose
- Expanding Services for Individuals in the Justice System

In addition to these focus areas DMHDDSUS are developing Advisory Committees to discuss five key priority areas; Child Behavioral Health, Crisis Systems, Supports for Justice-Involved Individuals, Peer Support Workforce, and Direct Support Professional Workforce. SCFAC is proud to be a part of these Advisory Committees as Side by side, we will brainstorm together to develop a list of priorities for the funding we've received. Members will share ideas, provide feedback and help DMHDDSUS leadership develop strategic priorities to improve our system.

To learn more visit www.ncdhhs.gov

To view the draft strategic plan

To get involved

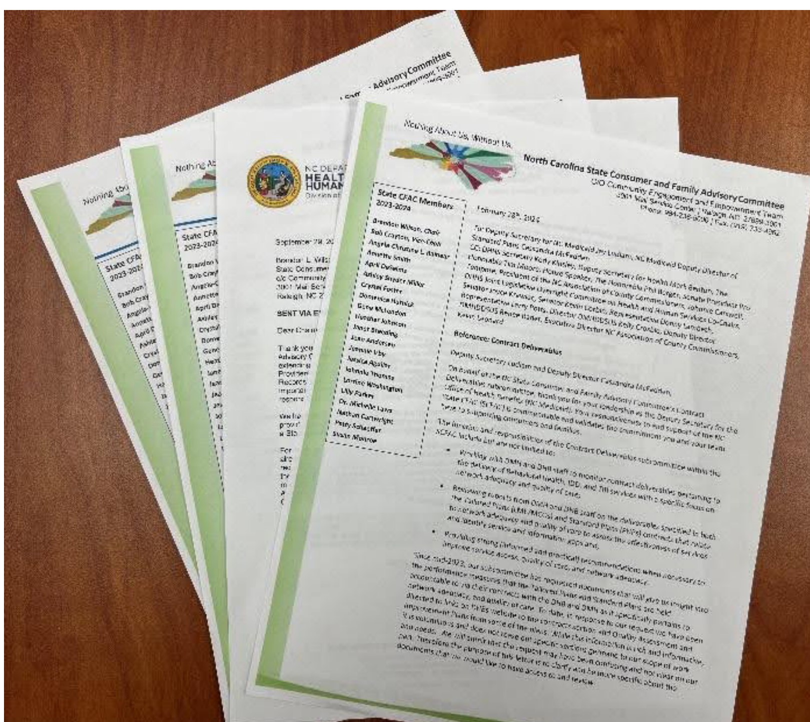
Expanding Communication: The Impact of 11 Advocacy Letters

Over the past several years, this committee has worked to enhance communication between Department leadership and staff with both the committee and consumer voices. In 2022, under the leadership of SCFAC Chairperson April DeSelms, SCFAC committed to a more transparent approach by addressing issues, concerns, and solutions throughout the year, rather than relying solely on the annual report. Consequently, the committee wrote five official letters to the Department that year.

Building on this momentum, the committee penned 11 letters over the past year, addressing a range of concerns including the Statewide TBI Waiver, LME/MCO consolidation, and changes to 122C. These letters were often discussed and voted on during our monthly meetings, although some were prompted by urgent issues. As a result, SCFAC received four response letters from the Department outlining direct actions taken in response to our concerns. Additionally, the committee unanimously voted to include Department Leadership, appointing authorities, and the General Assembly's Joint Oversight Committee on Health and Human Services in our communications, thereby deepening our efforts.

The committee is hopeful that these letters provide a platform to voice concerns, communicate potential challenges, and support the Department's stance on various issues, from operational to strategic. We appreciate the Department's openness to these letters and hope they assist in decision-making throughout the year. Some of our formal recommendations stem from the content of these letters and align with overarching issues.

These complete letters can be found in Appendix A.



Date	Recipients	Subject
September 6th, 2023	DMHDDSUS Director Kelly Crosbie Deputy Secretary of Medicaid Jay Ludlam	SCFAC Subcommittees for FY 2024 Medicaid Reporting Template
September 15th, 2023	Deputy Secretary of Medicaid Jay Ludlam DMHDDSUS Director Kelly Crosbie	Appendix K Flexibilities
October 27th, 2023	Secretary Kody Kinsley, Deputy Secretary Mark Benton, Deputy Secretary Jay Ludlam	SCFAC Response on the Appropriations Act of 2023 (H259), Section 9G.7A(a1)
November 3rd, 2023	DMHDDSUS Director Kelly Crosbie, DMHDDSUS Deputy Director Renee Rader	Concerns over qualification requirements of the TBI waiver.
November 20th, 2023	LME/MCO CEO's Rob Robinson Alliance Health, Sarah Stroud EastPointe, Rhett Melton Partners Health, Anthony Ward Sandhills Center, Joy Futrell Trillium Health Resources Resources, Tracey Hayes Vaya Health Secretary Kody Kinsley, Deputy Secretary Jay Ludlam, Deputy Secretary Mark Benton, DMHDDSUS Director Kelly Crosbie	Formal Invitation to the 'State of Future' Panel Discussion for January 10th
December 28th, 2023	Secretary Kody Kinsley, Deputy Secretary Jay Ludlam, Deputy Secretary Mark Benton, DMHDDSUS Director Kelly Crosbie, DMHDDSUS Deputy Director Renee Rader, Chief Medical Officer Dr. Elizabeth Tilson	Formal Invitation to the 'State of Future' Panel Discussion for January 10th
December 29th, 2023	Standard Plan Member Advisory Committee Leads Brenda Radford AmeriHealth Caritas, Gina Howard HealthyBlue, Lori Keane Carolina Complete Health, Paige Hales United Health Care, Shaleel Johnson WellCare	Formal Invitation to the 'State of Future' Panel Discussion for January 10th and solicited invitation for February 14th Panel Discussion
January 24th, 2024	Deputy Secretary Jay Ludlam, DMHDDSUS Director Kelly Crosbie, DMHDDSUS Deputy Director Renee Rader, Chief Clinical Officer NC Medicaid Sandy Terrell, NC TBI Team Lead Scott Pokorny	Response to the invited participation to the TBI Waiver Advisory Committee that include the nomination for SCFAC member Crystal Foster.

Date	Recipients	Subject
February 21st, 2024	DHHS Secretary Kody Kinsley, Chief Deputy Secretary for Health Mark Benton, Deputy Secretary for NC Medicaid Jay Ludlam, The Honorable Tim Moore, House Speaker, The Honorable Phil Berger, Senate President Pro Tempore, President of the NC Association of County Commissioners Johnnie Carswell, DHHS Joint Legislative Oversight Committee on Health and Human Services Co-Chairs, Senator Joyce Krawiec, Senator Kevin Corbin, Representative Donny Lambeth, Representative Larry Potts, Director DMHDDSUS Kelly Crosbie, Deputy Director DMHDDSUS Renee Rader, Executive Director NC Association of County Commissioners Kevin Leonard	Letter to announce that all correspondence moving forward will include all SCFAC appointing authorities, as well as cc the DHHS Joint Legislative oversight Committee Chairs. Invitation to Legislative Day.
February 28th, 2024	DHHS Secretary Kody Kinsley, KarenWade, DHHS Policy Director, Lisa Corbett, Deputy Secretary for NC Medicaid Jay Ludlam, Deputy Secretary for Health Mark Benton, The Honorable Tim Moore, House Speaker, The Honorable Phil Berger, Senate President Pro Tempore, President of the NC Association of County Commissioners, Johnnie Carswell, DHHS Joint Legislative Oversight Committee on Health and Human Services Co-Chairs, Senator Joyce Krawiec, Senator Kevin Corbin, Representative Donny Lambeth, Representative Larry Potts, Director DMHDDSUS Kelly Crosbie, Deputy Director DMHDDSUS Renee Rader, Executive Director NC Association of County Commissioners, Kevin Leonard, Vaya Health CEO Tracy Hayes, Trillium Health Resources CEO Joy Futrell, Alliance Health CEO, Rob Robinson, Partners Health CEO Rhett Melton	Letter 1: Formal Response to the proposed 122C Changes; Letter 2: Contract Deliverables

A Presence in Community: SCFAC's Statewide Involvement

The SCFAC Committee is composed of members who represent diverse disabilities and live, work, and play throughout North Carolina. This diversity, combined with a strong commitment to community involvement, enables SCFAC to effectively advocate across the state. Our ability to be present in multiple locations simultaeously enhances our understanding of challenges and best practices in various domains of care.

One of our key strategies is to leverage the unique experiences, professional roles, and strengths of each Committe member. This comprehensive approach allows us to offer well-rounded recommendations. As a result, SCFAC has participated in over 100 conferences, town hall meetings, and community training sessions. Additionally, our members are involved in over 25 local, regional, and national committees focused on improving health outcomes and processes for those we serve.

The strength of SCFAC and ability to employ extensive engagement across NC significantly benefits the Department. Below are highlights some of the deep involvement in serving the community.

2023-2024 Community Events

- NCTide Conference
- NAMI NC Conference
- 46th Annual Legislative Breakfast on Mental Health
- NC Guardianship Conference
- Bring It Home -- NC Housing Coalition Conference
- NC Summit on Suicide Prevention
- 5-- NC Mental Health Town Halls
- 6 Veteran Stand downs
- I2i Winter Conference
- BenCHmarks Desitination 2023
- NCDMVA Spring Conference
- NC Governors Working Group on Veterans
- I2i Spring Conference
- BenCHmarks Public/Private BH Forum
- NC One Community in Recovery
- Conference for Hispanic Families
- Statewide Suicide Prevention Summit
- Sweeten Creek Mental Health Ribbon Cutting
- Peer Warm Line Ribbon Cutting
- Alamance Behavioral Health Center Ribbon Cutting

A Presence in Community: SCFAC's Statewide Involvement

Boards, Collaboratives, Comissions, and Comittees

- Vaya Health Local Consumer and Family Advisory Committee
- Alliance Health Local Consumer and Family Advisory Committee
- Partners Health Management Local Consumer and Family Advisory Committee
- Trillium Health Resources Local Consumer and Family Advisory Committee
- LME/MCO Regional Advisory Boards
- Olmstead Plan Stakeholder Advisory Committee
- Tailored Care Management Technical Advisory Group
- NC Collaborative for Children, Youth & Families
- Workforce Advisory Committee (Peers)
- Workforce Advisory Committee (DSP's)
- Supporting Justice Involved Individuals Advisory Committee
- Crisis Systems Advisory Board
- Brain Injury Association
- Direct Support Professionals Workgroup
- Brain Injury Association Legislative Sub-Committee
- Novant Health Brain Injury Support Group
- Commission on Children with Special Health Care Needs
- Stakeholder Engagement Advisory Group (SEA-G) SPARK
- Brunswick Interagency Program (BIP) Advisory Committee
- NC Governors Working Group on Veterans
- Advocates for Medically fragile kids NC
- Exceptional Children Assistance Center
- Wake Consumer and Family Advocacy
- SIS Advisory Committee
- Central Appalachian Peer Partnership/S.T.A.R.S (Regional Committee)
- Opioid Research Consortium of Central Appalachia
- Governor´s Advisory Council for Hispanic and Latino Affairs
- TCM Member Education & Community Awareness Workgroup
- Child Behavioral Health Advisory Committee
- DHHS I/DD Stakeholder Workgroup
- Advisory Committee on Homeless Veterans (Federal Committee)
- White House Task Force on 'Sync for Social Needs Collaborative' (Federal Committee)

A United Front:
The Effort on changes to 122(c)

As the General Assembly and the Department manage changes to how North Carolinians receive healthcare, there is always a certain level of risk associated with opportunity. NCGS § 122C, which governs mental health, developmental disabilities, and substance abuse services across North Carolina, is the statute under which the Committee is mandated and operates. This past year, the Department saw the opportunity to make necessary changes to this statute. While many changes to 122C were needed, some changes in the 101-page proposal would have been detrimental to both State and Local CFACs.

While we appreciated that state leaders included both SCFAC and our communities in discussions, public meetings, and webinars, the timing and delivery of the proposed changes did not allow us and other stakeholders to provide the informed, comprehensive feedback that the citizens of our state deserve. SCFAC, along with local CFACs from across the state, held meetings to discuss the complexities of the proposed changes and their impact. In the spirit of collaboration and unity, SCFAC, local CFACs, and other advocacy groups wrote supporting letters against the proposed changes to 122C. While the letters varied, the core message was clear.

In a letter dated February 28th, SCFAC respectfully requested that the legislative proposals to facilitate further Medicaid managed care implementation, including changes to GS 122C, not be introduced in the upcoming 2024 short session but rather in the long session of 2025. In response on May 1, 2024 teh Department agreed not to make any changes to sections 170 and 171 of 122C, which directly impacted both State and Local Consumer and Family Advisory Committees and their structure.

This request provided adequate time for Providers, MCOs, and, more importantly, both State and Local CFACs to comprehensively understand the entirety of this legislation. Through persistent and coordinated efforts, the CFAC aimed to ensure that any legislative revisions would align with the best interests of the community they serve.

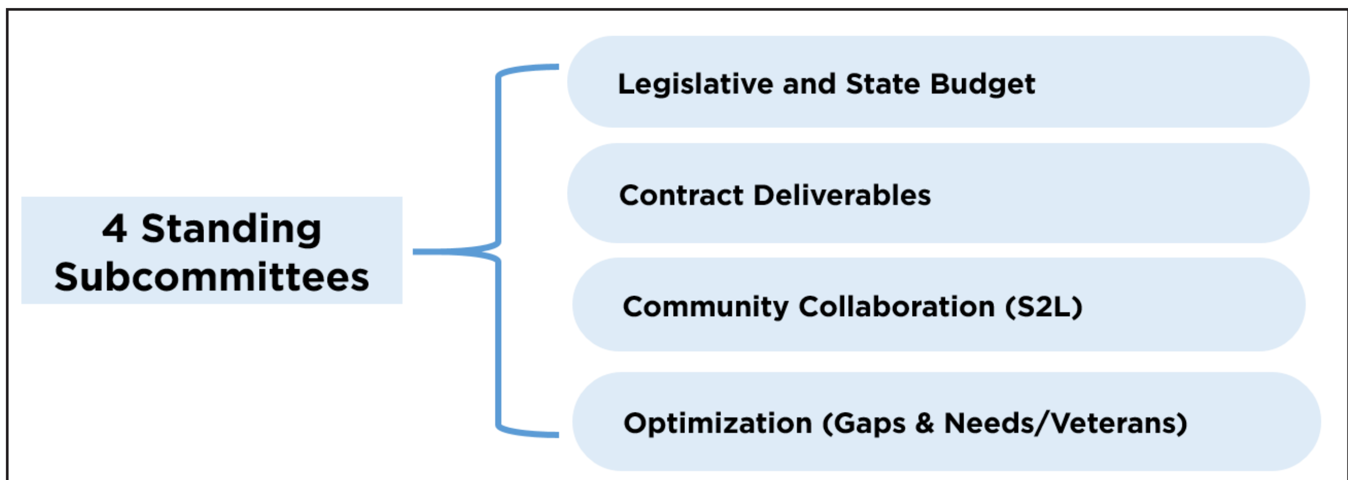
We appreciate that the DHHS has responded to much of the input and removed or amended proposed revisions. Unfortunately, there are still revisions in this proposal that are not in the best interest of those with BH and especially for people with IDD and their families, in our view.

We expect we will continue to urge legislators to hold off on any vote to approve these until the long session. There simply is no good reason to rush these through and many reasons not to do so.

Part 8:
Subcommittees and Focus Areas 2024

As the committee entered the new fiscal year, the team convened in August for a strategic planning session. The goal was to refine our focus and ensure intentional alignment with our 122C mandate. Key issues were to determine the re-set of our subcommittees. These subcommittees are vital as they keep the focus for our members on what we are charged with in 122C. We reviewed this charter and our mission and decided to target some systems level challenges through our subcommittee makeup.

SCFAC established four standing subcommittees that actively worked throughout FY 2024 to provide feedback, conduct research, and facilitate advocacy with both LME/MCOs and members of the General Assembly. Each subcommittee was chaired by a SCFAC member, included State and Local CFAC members, and involved Subject Matter Experts (SMEs) from the community. In addition, SCFAC created an Ad Hoc committee lead by member Heather Johnson to explore the scope within the Employer of Record challenges.



Subcommittees and Focus Areas 2024

Legislative and State Budget Subcommittee

The Legislative and State Budget Subcommittee exists to support our General Statue Mandate. This committee is charged with monitoring proposed State legislation for bills that impact DHHS, Medicaid and behavioral health. In addition this committee will explore and review both current and proposed state budgets that may impact the behavioral health system; and in order to make future recommendations for the Department to consider during their strategic planning in reference to their budget requests.

Responsibilities

- Plan SCFAC participation with the Mental Health Legislative Breakfast.
- Review and understand the state budget.
- Develop Schedule for Legislative Day
- Generate SCFAC One-Pager with talking points for SCFAC members
- Provide a list of GA members to target on day
- Provide strong recommendation(s) in SMART format to the Optimization subcommittee
- Compile a monitor a list of bills that impact the behavioral health system.

Chairperson: Lorrine Washington, Co-Chair: April DeSelms

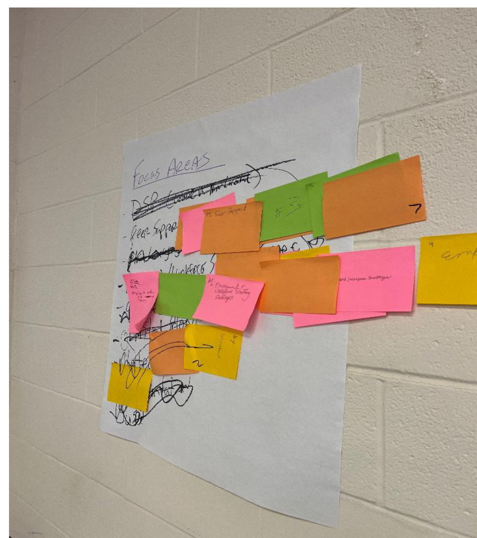
Contract Deliverables Subcommittee

The Contract Deliverables Subcommittee works with DMH staff and DHB staff to ensure that state contracts for services are performing in compliance as it pertains to contract deliverables.
The contracts reviewed include: Standard Plans, Tailored Plans, LME/MCO's, Vendors and Providers.
Two primary focus areas for FY 24 included: Network adequacy and Quality of care buckets.

Responsibilities

- Work with DMH and DHB staff to monitor list of deliverables per respected contracts.
- Review Reports from staff on the deliverables in order to gauge both implementation and execution of the aforementioned contracts.
- Provide strong recommendations in SMART format to the Optimization subcommittee every March.

Chairperson: Dr. Michelle Laws: Co-Chair: Johnnie Thomas



Subcommittees and Focus Areas 2024

Community Collaboration Subcommittee

The Community Collaboration Subcommittee previously the State to Local sub-committee has been a vital part of communication & transparency between the State and Local CFACs. A standing monthly call allows exchange of information, education and collection of benchmarks and outcomes, which promotes community collaboration through working with other committees and councils such as the Brain Injury Association, IDD Council, and etc. In addition, working alongside local CFAC committees, respective LME/MCO's and providers that employ services at a local level. This Subcommittee is charged with creating a strong relationship with the Standard Plan Member Advisory Committee.

Responsibilities

- Facilitate the Monthly State to Local Calls every month
- Development of the reporting, agenda and attendance of the State to local Call
- Provides report to the SCFAC committee monthly on any issues or trends.
- Develop a new and working relationship with the Standard Plan Member Advisory Committee and promote participation with the Standard Plan MACProvide strong recommendations in SMART format to the Optimization subcommittee

Chairperson: Jean Andersen, Co-Chairs: Jeannie Irby, Annette Smith

Optimization Subcommittee

Optimization Subcommittee (formerly Gaps and Needs) works to identify significant gaps and needs in the services array across Mental Health, Traumatic Brain Injury, Intellectual and Developmental Disabilities and Substance Use Disorder domains. In addition, this subcommittee also works to provide recommendations that address the needs of North Carolina's military connected communities that may be affected in the same ecosystem of care. This committee also works to submit letters to the Department on a needed basis, while also compile the other sub-committees SMART goals in order to formulate the Annual Report.

Responsibilities

- Review reports and surveys from DMHDQ staff to ensure that all relevant data is provided and reviewed and aligns with yearly focus areas, subcommittees and legislation.
- Identifies challenges and gaps of services within the Military and Veterans communities.
- Manage public comment concerns and submit necessary letters to the Department.
- Collates subcommittees SMART goals and develops the Annual Report and Recommendations

Chairperson: Brandon Wilson: Co-Chairs: Bob Crayton, Crystal Foster

Special Thanks

This report would not have been possible without the dedicated efforts of all SCFAC committee members. Their invaluable contributions, both as a group and as individuals, have been instrumental in our advocacy work. We would also like to extend our gratitude to the many others who went above and beyond this year to support the creation of this report. SCFAC would like to thank Mr. Brian Powers for his efforts in the design and editing of this year's report. With so many organizations, groups and individuals who define advocacy it would be impossible to name them all without leaving some out. For all those who continue to be the voice for so many SCFAC would like to thank each of you for supporting and continuing to fight for what is right.

Additionally, the Committee would like to formally acknowledge and thank SCFAC members Janet Breeding and Susan Monroe for their tireless commitment to SCFAC and the system over the years. Their work has been invaluable, driven by their knowledge, persistence, and passion for helping others.

Ms. Susan Monroe has been a voice of reason and a model of diplomacy on the committee. Her relentless efforts to elevate Peer Support Specialists have led to many new initiatives in North Carolina.

Ms. Janet Breeding's deep experience with the system of care has brought a high level of professionalism and understanding. Her dedication to all committee writing and public-facing correspondence has been invaluable.

The SCFAC committee has been privileged to have these two leaders. Their dedication and unwavering passion for people have made a lasting impact on those we serve. We wish them the best of luck as they transition off the Committee.

Part 9:

Recommendations

*Recommendation 1: Traumatic Brain Injury

Expand Traumatic Brain Injury Services

Note: Recommendation from last year with partial concur:

DHHS Response from last year's recommendation: DHHS has determined that a comprehensive analysis of this request can be completed by the end of July 2024.

The Subcommittee recommends adding Extended State Plan Allied Health Services to the Innovation waiver, so those with TBI can receive ongoing therapies. Through this expansion TBI consumers will receive needed rehabilitative therapies to maximize recovery and independence. This recommendation's plan should include a phased implementation approach. (This will also be beneficial for the IDD population.)

SCFAC remains resilient with this recommendation as the committee feels that with the rollout with the statewide TBI waiver, a more comprehensive understanding paralleled with extending these services will greatly enhance the overall care for this population.

Since the Department did not fully concur with this recommendation last year and only partially concurred, we are making this recommendation again, hopeful that the comprehensive analysis completed in July 2024 can lead to a phased implementation that will begin October 2024.

*Recommendation 2: Comprehensive Reporting

Provide an Annual Statewide Comprehensive Gaps and Needs Report

Note: Recommendation from last year with Full concur:

Last Year's Recommendation Narrative

In 2019 the state CFAC committee presented this recommendation to the Department, in order to align LME/MCO reporting and survey results that were outlined in their 'Network Adequacy Reports. In the last two years the LME/MCOs have failed to provide their Gaps and Needs or Network Adequacy Reports in a timely manner. This shortfall has created windfall effect for this committee to review critical reports, thus handcuffing our ability to provide strong recommendations and fulfill our charge. Unfortunately, there has been no major movement or change since this recommendation in 2019; and it is our strong belief that we are making this strategy a priority moving forward. We strongly believe that the Department can work to create some common language and require (or even mandate) these reports to be completed in a more consistent manner. By producing an annual statewide comprehensive gaps and needs report that includes the LME/MCO Network Adequacy reports it will create a broader sense of transparency across the continuum, which will impact providers, consumers, advocates and lawmakers. This will also ensure that as a state we are accurately measuring reported gaps in services, which will help create strategies and viable solutions. This report should also include other data sources: NC Care 360 data, Healthy Opportunities Pilot data, NC-TOPPS to name a few.

*We recommend that the Department provide an annual Statewide Comprehensive Gaps and Needs Report from the NC Quality Improvement Team, which encompasses all Tailored Care Plan Providers (LME's). This report should be published by January 1 succeeding the Fiscal Year. *This formal recommendation was previously submitted by State CFAC in 2019.*

We believe that this recommendation can be established by August 1, 2023, while producing the first comprehensive report by January 2025.

DMHDDSUS will provide comprehensive data to SCFAC on an annual basis after the start of the Tailored Plans. By September 1, 2023 DMHDDSUS will share a plan for sharing available data prior to Tailored Plan launch. This data will include:

We recommend that the Department provide an annual Statewide Comprehensive Gaps and Needs Report from the NC Quality Improvement Team, which encompasses all Tailored Care Plan Providers (LME's). This report should be published by January 1 succeeding the Fiscal Year. *This formal recommendation was previously submitted by State CFAC in 2019.

We believe that this recommendation's new deadline is September 1, 2024, while producing the first comprehensive report by January 2025.

Recommendation 3:
Substance Use Disorder and Opioid Use:

Additional Funding

Despite Medicaid Expansion, adult substance use services in our state are still primarily funded by federal, state, and county dollars. Overdose deaths continue to rise across many regions statewide. Many counties lack access to essential substance use treatment services due to the limited availability of federal and state funds. Additionally, there are very few inpatient treatment beds available statewide, and local LME/MCOs have insufficient funds to support new programs.

Over the past year, the State Consumer and Family Advisory Committee (SCFAC) has participated in numerous conferences, listening sessions, and local CFAC committee calls, and facilitated two panel discussions with top leaders of both the LME/MCOs and the PHPs. These engagements provided a unique perspective on the secondary effects of inadequate resources and funding in our communities. Interviewing DSS Directors from across the state, the primary reason for children entering custody is parental substance use. This ripple effect of loss of funding to the LME/MCO's as created a despairing result of children ending up sleeping on couches in DSS offices or with providers, which can lead to further mental health challenges. This ripple effect will continue to impact families, leading to a multitude of additional challenges that harm North Carolina at a macro level.

We recommend the Department provide additional funding to the LME/MCO's and/or community-based organziations to develop and sustain new and existing substance abuse programs. This should also include funding to expand access to residential treatment options through targeted halfway house funding, and access to recovery level options at all levels of SAMSHA's recovery housing spectrum; including halfway to longterm residential treatment. Furthermore, allowing flexibilities with this additional funding that can pilot new treatment models like the Sobriety Treatment and Recovery Teams (START), UNC Horizons, and evidence-based child welfare service delivery model for families that is aimed at keeping children safely with their parent(s) whenever possible. This funding also supports programs for youth and young adults in recovery.

SCFAC believes that this recommendation can be accomplished within the scope of the Department's existing budget by prioritizing this need ahead of others with less consequence. We believe that this can be explored and that additional funding allocated to the LME/MCO's by January 1st, 2025 if not earlier.

Recommendation 4: Veterans and Military Families

Veterans Care Coordination Department Integration

As NCServes enters into its 10th year of providing extensive care coordination for NC Veterans and their families, it is imperative that the Department to not only continue funding and resources to this initiative but to deepen its role in these critical services. In addition to continuing the funding which provides the coordination of services to over 7,000 families annually; complimented with the NCCare360 initiative, NC will truly provide comprehensive and holistic care for Veterans while leveraging public, private and non-profit organizations. NCServes has been the national thought leader and innovator, not only serving the Military-Connected Community but has impacted healthcare at a systems level through, data informed strategies, predictive analytics by maximizing the Unite Us technology.

We recommend the Department take deliberate steps to enhance support for Veterans and their families by fostering closer collaboration with DHHS staff and programs through the intentional alignment with the NCServes Program. This alignment includes integrating resources on the NCDHHS website. This proposal involves leveraging the Department's backing of the NCServes program by assigning dedicated division staff to utilize the platform via NCCARE360. This will enhance the exchange of referrals, ensuring Veterans and their families receive timely assistance tailored to their specific needs. Furthermore, we advocate for the inclusion of direct links on the Department's website, facilitating easy access for Veterans to resources such as the NCserves website and Assistance Page.

SCFAC believes that this recommendation can be adopted and established as early as November 11th, 2025 – Veterans Day.

Recommendation 5: Peer Support Services

Standardize a Universal Peer Support Certification Program

SCFAC is grateful for the continued investment and utilization of Peers within all facets of care and programs. However, it has been made evident that an overhaul of the certification process and need for accessibility of training is long overdue. Therefore SCFAC believes that there is a need for a statewide universal peer support training curriculum.
In the heart of our communities, where the fight against substance use, mental health challenges, and social disparities is most intense, there lies a potent yet underutilized resource: peer support. Individuals who have walked the path of recovery and transformation possess an unparalleled ability to connect with and uplift others facing similar struggles. However, the power of peer support is only as effective as the training and support these peers receive. SCFAC imagines NC as a place where every peer supporter, regardless of their location, has access to consistent, high-quality training. This training not only equips them with the necessary skills to provide empathetic and effective support but also ensures that they adhere to best practices and ethical guidelines. A universal curriculum would create a standardized framework, fostering a cohesive and coordinated approach to peer support across the entire state. The impact of such a curriculum would be profound. For individuals battling addiction, mental health issues, or the aftermath of trauma, peer supporters can serve as a beacon of hope and a tangible proof that recovery is possible. Their unique perspective and shared experiences allow them to build trust and rapport in ways that traditional professionals may not be able to. However, without proper training, these peer supporters might struggle with boundaries, effective communication, or the complexities of guiding someone through the recovery process.

A statewide universal peer support training curriculum would ensure that all peer supporters have a deep understanding of their roles and responsibilities. It would cover essential topics such as active listening, crisis intervention, and self-care for the peer supporter. Furthermore, it would emphasize the importance of cultural competence, recognizing and respecting the diverse backgrounds and experiences of those they support. Beyond individual interactions, a standardized curriculum would also enhance the broader support ecosystem. It would enable peer supporters to integrate more seamlessly with healthcare providers, social workers, and other professionals, fostering a more collaborative and holistic approach to care. This interconnected network could share resources, strategies, and insights, creating a more resilient and responsive support system for all individuals in need. Moreover, the implementation of a universal training program would provide a clear pathway for credentialing and professional development for peer supporters. This recognition would not only validate their essential contributions but also open up opportunities for career advancement and stability, attracting more individuals to this vital field.
The call for a statewide universal peer support training curriculum is not just about improving the effectiveness of peer support—it is about recognizing and harnessing the full potential of those who have turned their personal trials into a source of strength and inspiration for others. Additionally it would vastly improve the accessibility of certification regardless of challenges.
By investing in this recommendation we are investing in a future where recovery is not a distant hope, but a shared journey supported by a robust and unified network of peer supporters. It is a commitment to ensuring that no one has to face their battles alone and that every path to recovery is illuminated by the guiding light of those who have walked it before.

SCFAC recommends the Department develop a standardized Peer Support Specialist Curriculum. By establishing a statewide curriculum under the Department's management, we can enhance training consistency and ensure a cohesive approach to the Peer Support Model of Care across the state. This curriculum shall include a hybrid delivery system, strong oversight on continuing education requirements, and an ethics board to address issues with clients, providers and peers.

We believe that with recent efforts within this system of care that the Department can execute this recommendation by January 1st, 2025.

Recommendation 6:
Private Duty Nursing (PDN):

Note: This recommendation has two parts, SCFAC would like to extend the option that the Department can independently respond to each of these recommendations

The healthcare landscape in North Carolina is undergoing significant changes, influenced by an aging population, rising medical costs, and increasing demand for specialized care. One critical aspect of this landscape is private duty nursing, a service essential for providing high-quality, and customized care to patients with chronic illnesses, disabilities, or post-operative needs across all ages. However, this Medicaid current reimbursement rates for private duty nursing in North Carolina do not adequately reflect the complexities and demands of the profession. This proposal advocates for a necessary increase in these rates to ensure sustainability, quality of care, and the retention of skilled nursing professionals.

Private duty nurses (PDNs) deliver personalized care to patients in their homes, enabling better health outcomes and reducing the burden on hospitals and long-term care facilities. Despite their crucial role, PDNs in North Carolina face several challenges which include inadequate compensation, high demand and low supply of providers, and transparency of reporting; all which impact quality of care.

The table below (presented to SCFAC during May 2024 meeting) compares the number of authorized hours versus the number actual staffed hours over the last two years. In SFY 23 only 556 individuals received PDN and only had 39% of their authorized hours staffed. This puts consumers and families at risk.

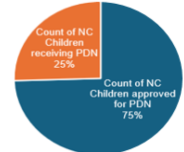
Total PDN Population SFY 2023

Sources: DR# 2024.2475, DR# 2024.2776

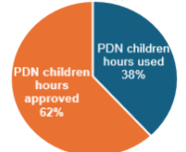
Data Element	PDN PEDIATRICS	PDN ADULTS	Total
NC population approved for PDN	1,234	437	1,671
NC population receiving PDN	422	134	556
PDN Hours Used	1,433,035	570,585	2,003,620
PDN Hours Approved	2,330,030	867,450	3,197,480
Hourly payment rates for PDN to agencies	$52.00 per hour	$52.00 per hour	N/A

PDN Pediatrics Data SFY 2023

% of NC Children receiving and approved for PDN

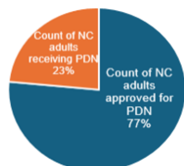


% PDN Children hours used and approved

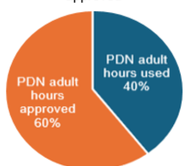


PDN Adults Data SFY 2023

% of NC adults receiving and approved for PDN



% PDN adults hours used and approved



Recommendation 6(a):
Increase in PDN Reimbursement Rates

Increasing the reimbursement rates for private duty nursing in North Carolina is not just a financial necessity but a moral imperative. It ensures that those who dedicate their lives to caring for the most vulnerable members of our community are adequately compensated and valued. Private Duty Nursing (PDN) is substantial, complex, and continuous skilled nursing care provided in the home for medically fragile Medicaid beneficiaries. Prior approval (PA) is required for PDN services, and is granted based on the beneficiary's medical necessity. PDN recipients are NC's most vulnerable population; without these services individuals face institutionalization, hospitalization, and possibly death.

To address these challenges, we propose the Department increase private duty nursing rates. This adjustment is based on an analysis of current economic trends, cost of living adjustments, and comparison with rates in similar regions. Additionally we propose that the Department also implement a procedural policy that would ensure PDN nurses receive the appropriate portion of the reimbursement rate. This rate increase needs to be equivalent to other PDN payer sources in NC (such as Veterans Administration). This policy would also include the oversight of providers to safeguard the quality of services rendered and appropriate pay occurred to safeguard this system of care.

A Department committee and policy can be established and implemented by January 1, 2025.

Recommendation 6(b):
PDN Dashboard

The need for transparency and accountability in healthcare has never been greater. In North Carolina, private duty nursing (PDN) is a critical component of care for Medicaid beneficiaries with complex medical needs. However, the current system lacks a centralized, public-facing platform to track and present data on PDN services. This proposal advocates for the development and implementation of a PDN Dashboard, which will provide accessible, real-time information on various aspects of private duty nursing for Medicaid plans.

SCFAC believes that the need for this dashboard is built on three foundational values:

- Enhanced Transparency: Built upon trust this action will create true public accountability. This dashboard would offer visibility into how Medicaid funds are allocated and spent, specifically on PDN services. A user-friendly interface will make complex data accessible and understandable to all North Carolinians.
- Improve Quality of Care: The dashboard will track key performance indicators (KPIs) related to quality of care to include patient outcomes. This will also lead to identifying trends and outcomes fostering the groundwork for sharing best practices.
- Data-Driven Strategies: Both the Department and Policymakers can utilize this data to make informed decisions around future funding, regulations and support.

This precedence of this type of dashboard exists as the Department has established dashboards for Innovations Waitlist, Payments to Providers, and PHP Claims monitoring; all which can be found at www.Medicaid.ncdhhs.gov/reports/dashboards. By leveraging modern technology and data analytics, North Carolina can lead the way in setting a new standard for transparency and quality in Medicaid services. The PDN Dashboard is not just a tool but a commitment to better care and accountability for our most vulnerable populations.

We recommend that the Department develop a PDN dashboard to track specific data from Medicaid Direct, Tailored Plans, and Standard Plans. This data should include availability of PDN Providers per county, service types, and average reimbursement paid. Number of individuals receiving PDN pediatric/adult, number of authorized hour's pediatric/adult, number of staffed hours pediatric/adult. We believe this dashboard can be built and operational by January 1, 2025.

Recommendation 7:
Traumatic Brain Injury (TBI)
TBI Dashboard

Traumatic brain injuries (TBIs) are a major public health concern, often leading to long-term or permanent disabilities. The SCFAC has repeatedly requested specific data from the Department over the years, but the results have been suboptimal. Reports are often delayed, contain conflicting information, or lack data altogether. Despite the prevalence and significant impact of TBIs, there is a current lack of comprehensive, easily accessible data to guide policy decisions, resource allocation, and care strategies.

For Medicaid and state services, a TBI dashboard would greatly enhance the ability to monitor and evaluate the care provided to TBI patients. This centralized repository is crucial for ensuring that Medicaid programs effectively meet the needs of TBI patients and for identifying opportunities to improve service delivery, including diagnosis, treatments, and services provided. Additionally, a TBI dashboard would promote transparency and accountability. By making data publicly available, it empowers patients, families, and advocacy groups like SCFAC and local CFACs to make informed recommendations about care and advocate for necessary services and support. It also holds providers and state agencies accountable for the quality and effectiveness of their programs, fostering a culture of continuous improvement.

Although the State provides an annual TBI State Funds Expenditure report, a more detailed and regularly updated dashboard would improve care quality, optimize resource allocation, and ensure that individuals with TBIs receive the support they need to lead fulfilling lives. Establishing such a dashboard would demonstrate a commitment to transparency, accountability, and continuous improvement in the care and services provided to some of the most vulnerable members of our community. Based upon legislative appropriation, the State funded TBI program operates on approximately $3.9 million dollars for the purposes of services, supports, education and awareness. Out of this appropriation, each Local Management Entity-Managed Care Organization (LME-MCO) is allocated funding to provide TBI specific services and supports to individuals living with TBI in their respective catchment area. The Brain Injury Association of NC (BIANC) also receives funding out of the same legislative appropriation.

A statewide Traumatic Brain Injury (TBI) dashboard in North Carolina is critical for enhancing Medicaid and state services for individuals affected by TBIs. Therefore, SCFAC recommends that the Department develop a TBI dashboard to track specific data from Medicaid Direct, Tailored Plans, and Standard Plans. This dashboard should include information on race, gender, ethnicity, age, and the following metrics:

- **Number of individuals with TBI receiving Medicaid**
- **Number of individuals with TBI enrolled in CAP/C, CAP/DA, Innovation, or TBI waiver programs**
- **Number of individuals with TBI receiving Private Duty Nursing**
- **Number of individuals accessing TBI state funds and TBI state funding programing**
    - **Breakdown of TBI state funds for each MCO and the Brain Injury Association of NC, including:**
        - **Number of individuals served**
        - **Specific services funded**

We believe this dashboard can be developed and operational by January 1, 2025.

Recommendation 8: CAP Waivers

RELATIVE AS PROVIDER OPTION

As outlined and reported in the 2023 North Carolina Medicaid Annual Report (page 29), there are four 1915(c) waivers, CAP/C, CAP/DA, Innovations, and Traumatic Brain Injury. This recommendation is primarily focusing on the two CAP waivers.

- The Community Alternatives Program for Children (CAP/C) waiver is an alternative to institutionalization, which may be needed if services aren't in place. CAP/C operates under the 1915(c) waiver to provide Medicaid Home and Community-Based Services (HCBS). It's authorized by Centers for Medicare & Medicaid Services (CMS) although the state has freedom to request changes.

- Community Alternatives Program for Disabled Adults (CAP/DA), is a Medicaid waiver program in North Carolina designed to provide home and community-based services to adults with disabilities who require long-term care. The primary goal of CAP/DA is to offer an alternative to institutional care, allowing individuals to receive the necessary services and support in their own homes or community settings.

Supporting the inclusion of "Relative as Provider" under the CAP Waivers (CAP/C and CAP/DA) is crucial for enhancing the quality of care and support for individuals in their homes. Allowing relatives to act as providers recognizes the valuable role they play in delivering personalized, compassionate care. This recommendation addresses the growing demand for home-based care, aligning with best practices that prioritize patient comfort and well-being. By ensuring relatives receive fair compensation, we also promote equity and sustainability within the caregiving workforce. This approach not only reduces the financial and emotional burdens on families but also mitigates the risk of institutionalization, leading to better health outcomes and cost savings for the healthcare system.

This recommendation will also prevent consumers and families from being forced to relinquish their already approved Medicaid services in order to access waiver services. ***"Services offered through CAP waivers supplement rather than replace the formal and informal services and supports already available to an approved Medicaid beneficiary"*** as dictated in the Medicaid Annual Report.

A phased implementation may allow for careful evaluation and adjustments, ensuring that the transition is smooth and effective. This policy change reflects our commitment to supporting families and enhancing the home care system, ultimately benefiting the entire community.
In addition, the current workforce shortage is significantly affecting our ability to provide essential care. By implementing this recommendation, we can effectively address this shortage and build a stronger foundation for a healthier North Carolina. Furthermore, this would ensure a fair and equitable rate of pay to all without discrepancies based on prior employment certifications, licenses and experience.

We recommend that the Department include the option of "Relative as Provider" under the CAP Waivers. This addition will provide essential services to help individuals remain in their homes, thereby reducing the need for institutionalization. It will also ensure that all relatives serving as providers receive a fair hourly rate for their services under this waiver provision. It is imperative that added language be included in the CAP Waivers Clinical Coverage Policies to ensure the Coordination of Waiver services and state plan Medicaid services are met. Such language currently exists in the Innovations Waiver Clinical Coverage Policy 8P.Given the nature of this recommendation, we propose a phased approach to assess feasibility, as consultation from CMS may be required.

The implementation of this recommendation can be established by October 1, 2025.

Recommendation 9 Interpersonal Violence and Intellectual and Developmental Disability:

Implement a comprehensive plan to reduce IPV in the IDD population

Note: This recommendation has three parts, SCFAC would like to extend the option that the Department can independently respond to each of these recommendations

Interpersonal Violence (IPV) is an umbrella term encompassing sexual violence as well as domestic, intimate-partner, family, caregiver, and community violence. IPV can include physical, sexual, psychological, and emotional abuse, as well as neglect and deprivation.
People with intellectual and developmental disabilities (IDD) are at risk of IPV at significantly elevated rates compared to almost all other demographic populations: People with IDD are sexually assaulted at a rate at least 7 times the rate of people without any disability.

- 83 percent of women and girls with IDD are sexually assaulted during their lifetimes—and half of those women and girls are sexually assaulted more than 10 times
- Approximately 30 percent of men with IDD are sexually assaulted
- 41.9 percent of sexual assault cases involve someone with a cognitive disability
- Children with disabilities are three times more likely than children without them to be victims of sexual abuse—and the likelihood is even higher for children with intellectual or mental-health disabilities
- Sexual violence disproportionately impacts the IDD LGBTQ+ community, which has even greater challenges disclosing victimization or reporting crimes, with trans and non-binary intellectually and developmentally disabled people facing even higher rates of sexual violence
- An estimated 70 to 85 percent of cases of abuse against adults with disabilities go unreported

People with IDD face significantly elevated risks of sexual assault. However, reporting such abuse is filled with challenges due to a lack of adequate training for service providers; a lack of accessible services; societal biases about IDD, which includes questioning the credibility of intellectually and developmentally disabled survivors; and the risk of retaliation from abusers, who sometimes are caregivers and very often are known to and trusted by victims.

Additionally, intersections between IDD and mental-health and substance-use-recovery needs and traumatic brain injury create further challenges for survivors. IPV-exposed individuals are at heightened risk of substance-use disorders and brain injury, exacerbating cycles of abuse and risk of victimization. Survivors often have an increased need for mental-health services and support. Most service providers lack adequate training to address these complex issues, leaving intellectually and developmentally disabled survivors facing deep systemic barriers. North Carolina lacks a concerted strategy for reducing IPV and the trauma and harm it causes in our IDD population.

SCFAC recommends the Department adopt a multi-pronged strategy for reducing IPV among people with IDD and that this strategy focus on three significant steps:

1. **Recommendation 8(a) - Requiring that all frontline IDD service providers and their supervisors complete a mandatory annual training on IPV prevention and healthy relationships;**
2. **Recommendation 8(b) - Making available an accessible curriculum with IPV prevention, healthy relationship, and sexual health information for people with IDD and their families;**
3. **Recommendation 8(c) - Requiring collaborative engagement and relationships of IDD provider agencies with IPV providers and networks in reciprocal resource and referral partnerships.**

This multi-pronged strategy is being presented with different timeframes and specific recommendations and the Department can review and report on these all independently.

Abused and Betrayed (2018), NPR
https://www.npr.org/series/575502633/abused-and-betrayed

Domestic Violence and Disabilities (2017), National Coalition Against Domestic Violence (NCADV), https://drive.google.com/file/d/1udt0aeq3lxwAkjQ0BxJjW7GZQEJyrcwh/view

Talk About Sexual Violence (2017–2023), The Arc of the United States,
https://thearc.org/wp-content/uploads/2023/11/Talk-About-Sexual-Violence-Final-Report-2023.pdf, page 8

Sexual Abuse of Children with Disabilities (2013), Vera Institute of Justice,
https://www.vera.org/publications/sexual-abuse-of-children-with-disabilities-a-national-snapshot

Talk About Sexual Violence (2017–2023), The Arc of the United States
https://thearc.org/wp-content/uploads/2023/11/Talk-About-Sexual-Violence-Final-Report-2023.pdf, page 8

T.C. Weiss, People with disabilities and sexual assault (updated 2023)
https://www.disabled-world.com/disability/sexuality/assaults.php

T.C. Weiss, People with disabilities and sexual assault (updated 2023)
https://www.disabled-world.com/disability/sexuality/assaults.php

Recommendation 9(a):
Mandatory annual training on IPV prevention and healthy relationships

SCFAC believes that in order to bring awareness and increase effectiveness the Department must provide and require mandatory trainings. By doing so, we can create a more secure and empowering environment for people with IDD in North Carolina. Training staff to handle complex situations better may enhance job satisfaction and performance. Trauma-informed practices will foster greater trust with clients and promote a safer environment. An accessible healthy-relationship and IPV-prevention curriculum will better equip people with IDD with the understanding, knowledge, and skills to build healthy relationships and identify and prevent potential abuse and harm. And partnerships between IDD agencies and IPV agencies will ensure victims have access to specialized support services.

A well-trained workforce, accessible prevention information, and strong partnerships with IPV service providers are crucial steps toward dismantling the cycles of silence and violence and promoting greater safety and justice for people with IDD.

We recommend the Department require all frontline IDD service providers (including DSPs/care workers, Qualified Professionals [QPs], care managers, care-manager extenders, and care coordinators) to complete an annual minimum 2-hour training that includes:

- **Understanding healthy relationships and sexual health;**
- **Understanding the forms and dynamics of IPV and the cycles of abuse;**
- **Identifying the signs and symptoms of IPV, including abuse by caregivers and/or staff;**
- **Learning trauma-responsive practices to support survivors appropriately;**
- **Learning how to make an effective referral to IPV resources and supports**

This recommendation can be employed by implementing mandatory training within the scope of services outlined in contracts with organizations providing services.

This recommendation can be completed by January 1st, 2025.

Recommendation 9 (b):

Availability of an accessible curriculum for IPV prevention

Creating and providing accessible curriculum on IPV prevention, healthy relationships, and sexual health for individuals with intellectual and developmental disabilities (IDD) and their families is essential. Such resources raise awareness and educate our community about these critical issues. By prioritizing education and awareness, we can implement a cost-effective strategy to reduce trauma. An accessible curriculum ensures transparency across the entire care ecosystem, fostering better communication among consumers, their families, providers, and the broader community.

We recommend the Department require that all IDD providers offer consumers and family members or guardians an accessible IPV prevention curriculum, including information addressing healthy relationship dynamics, communication, and sexual health. We endorse the curriculum be made available in multiple formats (including easy-to-read text, audio recording, and visual aids/picture-assisted, as well as in Spanish language) to cater to diverse communication and learning needs and styles. We trust that the Department can identify a course, whether customizing a new curriculum, modifying a present or simply employing an existing program.

SCFAC believes that this recommendation can be completed by June 30th, 2025 and statewide implementation begin July 1st, 2025.

Recommendation 9 (c):

Requiring Collaborative Engagement

Lastly, we recommend the Department require that all IDD providers establish a reciprocal partnership with at least one IPV service provider to ensure effective responses to IPV referrals from IDD provider agencies; to help IPV organizations develop curriculum, resources, and programming that are accessible, tailored for people with IDD, and responsive to individual needs; and to ensure IPV-organization staff training is IDD-informed—all ensuring a coordinated, comprehensive approach to IPV prevention and response.

We would like to suggest as part of this recommendation to track and report the implementation of these steps, including:

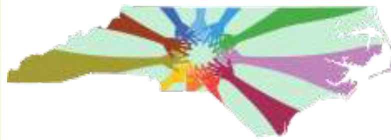
- Tracking the number of IPV incidents, reports, and referrals submitted
- Collecting and tracking feedback from frontline IDD service providers and their managers about their satisfaction with the IPV prevention and healthy relationships training and their perception of knowledge gained and its usefulness
- Tracking the number and percentage of consumers and family members or guardians receiving the prevention curriculum
- Collecting and tracking feedback from consumers and family members about their satisfaction
- with the curriculum provided and their perception of knowledge gained and the curriculum's value
- Monitor the number of partnership agreements between IDD and IPV providers

With this information, improvements to implementing these recommendations can be achieved over time to further reduce IPV in North Carolina's IDD population. We would also suggest that the Department work with IPV associations including the North Carolina Coalition Against Domestic Violence (NCCADV) and the North Carolina Coalition Against Sexual Assault (NCCASA), as well as other IPV organizations and stakeholders, to meet these recommendations.

The committee believes this recommendation be implemented in its entirety by May 1, 2025.

Part 10:
APPENDIX A LETTERS

Nothing About Us, Without Us.



North Carolina State Consumer and Family Advisory Committee
C/O Community Engagement and Empowerment Team
3001 Mail Service Center | Raleigh, NC 27699-3001
Phone: 984-236-5000 | Fax: (919) 733-4962

State CFAC Members 2023-2024

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Bob Crayton, *Vice-Chair*
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Janet Breeding
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Jeanie Irby
Jessica Aguilar
Johnnie Thomas
Lorrine Washington
Lily Parker
Dr. Michelle Laws
Nathan Cartwright
Patty Schaeffer
Susan Monroe

September 6th, 2023

To: DMH Director Kelly Crosbie
Cc: Deputy Secretary for Medicaid Jay Ludlam

First I would like to thank you and the Department for their attendance and deep participation during our July 12th SCFAC meeting in Raleigh, NC. It was great to have you, Secretary Kody Kinsley, Deputy Secretary Mark Benton, Deputy Secretary for Medicaid Jay Ludlam and Deputy Director Renee Rader present. We are grateful for your responses to our formal recommendations, and are excited that some of these may move forward. The committee would like to request that we receive updates quarterly on the recommendations that you concurred and will be implementing in the coming year.

During our recent CFAC Board Retreat in August, the committee worked through several white board sessions to identify major focus areas for upcoming year. These focus areas will be integrated within the four major sub-committees for 2023-24. This year we are more closely aligning with our charge of G.S §122C-171 and is evident with this year's sub-committees. The sub-committees are as follows:

- Optimization (Gaps/Needs & Veterans)
- Contract Deliverables (Both Standard and Tailored Plans)
- Community Collaboration (Local CFACs and MACs)
- Legislative and State Budget

The committee would like to request that we receive ***quarterly*** updates on the specific recommendations that the Department concurred and is taking action on this year.

In aid of these subcommittees we would first like to request the following documents that can be utilized to support our work throughout the year; as well as guide our additional requests and presenters.

1) Standard Plan contract ***sections*** directly associated with mental health and substance use in order to explore the deliverables within these plans.
2) Updated DMHDDSUS State Plan for CFAC review.
3) Most recent proposed Department Budget.

In addition, to these appeals we would also like to make a request to Medicaid Director Jay Ludlam to provide monthly accounts during monthly CFAC meetings. We are providing a list of which can serve as a template for reporting that provides structure and consistency for the pressing questions at hand.

1.) Comprehensive update on the 1915i Option Services
2.) Updates on Innovations Waiver
3.) TBI Waiver updates (with data)
4.) LME/MCO Performance Measures
    a.) Tailored Plans Readiness
    b.) Network Adequacy
5.) Update on Contract Deliverables on Standard Plans MH and SUD services
6.) Dashboard Report on PDN

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The committee would also like to share the growing concern with the delay of Tailored Plans launch. This delay has resulted in increased anxiety and has contributed confusion for all North Carolinians and has caused a great deal of strain on the members and their families of services. This committee supports Medicaid Expansion and is grateful for the stance the Department has taken with advocating publicly for General Assembly to pass this critical piece of legislation.

With the many new members, the committee has a renewed energy this year and is looking forward to our upcoming meetings. We remain honored to work alongside the Department to help provide guidance on systemic issues and drive impact for the community. Please reply with any questions and comments at the next CFAC Meeting, September 13th, 2023.

Respectfully, on behalf of the State Consumer and Family Advisory Committee,

Brandon L. Wilson
Chairman
State Consumer and Family Advisory Committee

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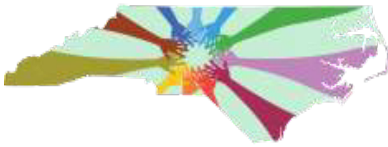

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Nathan Cartwright
Patty Schaeffer
Susan Monroe

September 15th, 2023

To: Deputy Secretary Jay Ludlam
Cc: Director Kelly Crosbie

Happy Friday Deputy Secretary Ludlam. First and foremost I would like to thank you and your teams work with Medicaid Transformation and Expansion over the last several months. Due to the **Urgency** of the following matter, I am writing this letter to support some significant concerns with the Appendix K flexibilities.

In the last 30 days and most recently at our last SCFAC meeting public comments portion a major concerns from families and parent caregivers of consumers was identified that this committee would like to bring to your attention both which are related to Relative as Provider/Relative as Direct Support Employee's and EORs. (These could be either contracted with provider or employees.)

During COVID Appendix K was allowed certain flexibilities, which included to allow family members to work as paid caregivers, as well as provide these services to minor children under the age of 18. It is understood that these flexibilities will end on November 11th, 2023.
On behalf of SCFAC we are requesting that the Appendix K flexibilities be extended ASAP and at least through February 11th, 2024 in order to give families and parent members of consumers deeply affected more time to transition; and/or provide an opportunity for the Department to produce an improved alternative to this challenge. It is *estimated* that as much as 45% of all care and services are provided by family members.
One example of this issue with no Appendix K flexibilities, exists with family members or parent caregivers not being able to attend day programs with their child, even if child needs assistance. This causes unneeded isolation for those needing care and prevents participation in social networking or events, resulting in a decrease in health and may even result in unnecessary institutionalizations.
The ripple effect also creates financial instability due to the loss of hours of care as well as the inability for the parents to work. In addition, this will cause increased anxiety and may lead to additional mental health crisis for our families and consumers.

SCFAC is requesting a written response no later than Friday 9/23/2023 to this letter and our concerns regarding Appendix K.

Respectfully, on behalf of the State Consumer and Family Advisory Committee,

Brandon L. Wilson
Chairman
State Consumer and Family Advisory Committee

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Nathan Cartwright
Patty Schaeffer
Susan Monroe

October 27th, 2023

To: DMH Director Kelly Crosbie

Cc: Secretary Kody Kinsley
Deputy Secretary Mark Benton
Deputy Secretary Jay Ludlam

First, we would like to thank you for requesting feedback on some impactful decisions that the Department must make in the coming weeks. We, as a committee, hold ourselves to a high standard while representing consumers and their families that will be impacted by some of these decisions, and remain humbled that our voices matter. While we also recognize that our recommendations may not always be implemented, it is our great responsibility that we advocate in a manner that remains inclusive for all.

In response to the October 10th, 2023 email we would like to respond to your questions from the Appropriations Act of 2023 (H259), Section 9G.7A.(a1). We hope that our feedback helps to shape the Department's considerations and guide decisions in filling this section and provide enhanced care and services for those most in need.

- What is best for the people we serve and for the providers who deliver services?
Continuity of Care. We believe that LME/MCOs' emphasis on quality of care is instrumental for Tailored Plans and must not only be protected but enhanced for our consumers and families moving forward. Consistency of care, clear communication and accessibility of services must be attained. Additionally, service metrics must continually be improving and accountability must be held at a higher level of excellence.

- What will move us to tailored plans faster and promote the value of whole-person care?
Decisiveness and Execution. Tailored plans launch delays caused confusion and uncertainty for our stakeholders, providers, and consumers. This additionally has caused concern for the ability and readiness for the system of care. With the expansion of Medicaid finally upon us, we know that it is necessary that the Department make an informed decision on the LME/MCO landscape that includes local and regional considerations and commit to provide support to the LME/MCOs while also holding them accountable for their work to our consumers and families.

- What will reduce complexity, create less disruption, and make things easier for everyone involved?
Communication and Transparency. With a lack of resources in many regions that include critical providers for care, there should be a priority for LME/MCOs to have a strong(er) presence in these communities. Encouraging or even mandating regional hubs (physical locations) or when LME/MCOs merge will provide both support of and recruitment of providers as well as provide a consistent presence and resources improving transparency across the ecosystem of care. SCFAC strongly advocates that a public system of care be maintained to help ensure any decrease in service interruption. We also would like to recommend to fully execute the Accessible Communication Plan that the Department fully concurred with and outlined in the SCFAC 2022-23 Annual Report.

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C/O Community Engagement and Empowerment Team
3001 Mail Service Center | Raleigh, NC 27699-3001
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In summary SCFAC believes that the state should take advantage of this opportunity to re-align counties in an organized manner that consumers and providers can understand thus creating a much needed stable behavioral health system structure. We support that the state move to an equitable number of LME/MCOs to a number of 3 or 4 that comprehensively covers North Carolina. We also infer that all four NC 1915(c) HCBS waivers (TBI, Innovations, CAP/DA, and CAP/C) are managed by these LME/MCOs and through Tailored Plans. This summary encompasses what we agree is best for our consumers, families and providers, which will improve whole-person care across all domains. In conclusion, we believe that this will reduce complexities, uncertainties and enhance care for our state.

We are grateful for the opportunity for SCFAC to provide feedback to you and your team and the partnership with General Assembly for their investment into our behavioral health system. We are confident that these responses will re-inforce and/or guide your decisions in these unprecedented times.

Respectfully, on behalf of the State Consumer and Family Advisory Committee,

Brandon L. Wilson
Chairman
State Consumer and Family Advisory Committee

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November 3rd, 2023

To: DMHDDSUS Director Kelly Crosbie
Cc: DMHDDSUS Deputy Director Renee Rader

Kelly,

We hope you are well, on behalf of the SCFAC I would like to extend thanks and appreciation to Deputy Director Renee Rader's attendance and report last month, along with Deputy Secretary Jay Ludlam's presentation on Medicaid. In addition, our committee is receiving extremely valuable information from consumers and providers, and will continue to work within our scope and timeline as we will begin drafting our recommendations in early 2024.

However some concerns have been raised over the qualification requirements of the TBI waiver based on the severity of disability. In the past few months Alliance Health has stated in two separate presentations that some consumers with severe TBI do not qualify for the HCBS rehabilitative waiver or services; and that these consumers are better served in an institutional setting. These statements and practices do not align with the Olmstead plan, as well as the expressed needs of consumers, as well as their family members. Furthermore, this Committee feels that this language and tone is hurtful and damaging to families struggling to navigate the system. We ask that you explore these concerns and take necessary actions to mitigate any further instances. We are also thankful that the General Assembly is moving forward with the TBI waiver expansion statewide. With that said there is a lot of work ahead that needs to be done. SCFAC is requesting to be involved with all of these processes in real-time.

As part of our charge and in depth work across our delta and specifically with our 'Contract Deliverables' subcommittee, we would also like to formally request the behavioral health sections outlined in the Standard Plan contracts for review from the Department. We feel that these sections can support a more comprehensive understanding of the landscape of behavioral health expectations in addition to being a part of our general statute charge.

We hope that our letter last week was helpful for the Department as we will be discussing the Secretary's Directive dated November 1, 2023 which outlined Tailored Plan Readiness & LME/MCO Streamlining Pursuant to SL 2023-134. Once again we thank you for your hard work and transparency with this committee and look forward to the meeting you in next week.

Respectfully, on behalf of the State Consumer and Family Advisory Committee,

Brandon L. Wilson

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November 20th, 2023

To: LME-MCO CEOs
Rob Robinson-Alliance Health, Sarah Stroud-Eastpointe, Rhett Melton-Partners Health Management, Anthony Ward-Sandhills Center, Joy Futrell-Trillium Health Resources, Tracy Hayes-Vaya Health
Cc: Secretary of Health and Human Services Kody Kinsley
DMHDDSUS Director Kelly Crosbie, Deputy Secretary Jay Ludlam, Deputy Secretary Mark Benton

We hope you all are well and are managing the ever-changing landscape of mental health, developmental disabilities, traumatic brain injury, and substance use disorder services across NC; specifically surrounding Tailored Plans Readiness and the recent Secretarial Directive 2023-001.

In an effort to gain a better understanding and to provide solid recommendations (per GS 122C) to the Department we would like to extend an invitation to each of you to join our monthly SCFAC meeting in Raleigh *(location TBD)* January 10th, 2024 for a panel discussion during the afternoon session from 1:00 – 3:00 p.m. The monthly meeting is public, however only SCFAC members will be engaging with the panel. We will begin with questions that each of you will have an opportunity to respond in reference to Tailored Plans and the Secretarial Directive 2023-001. The questions will be provided in advance of the meeting. In addition, we are requesting an opportunity for an open dialogue between the SCFAC and each of you. As there is so much apprehensiveness and concern around the transition to Tailored Plans, this opportunity for candid conversation with the LME-MCO CEOs will provide much needed feedback. The outcome of this discussion will empower/enable SCFAC to better inform consumers and their families, as well as help develop our recommendations. The importance of this cannot be overstated as this systemic change, at the end of the day, may have a catastrophic impact for so very many to include those represented on this Committee, as well as so many others whose stories are heart wrenching to say the very least.

We do not want to deviate from or lose the primary focus of this outreach, but as we are committed to our charge in accordance with General Statute, we are more than willing to share information regarding our annual goals inclusive of our 2022 report as well as our subcommittee work for the current fiscal year. We desire to engage in further dialogue regarding the future of services and supports in North Carolina as it pertains to policies and programs that impact the MH/IDD/SU/TBI community.
Please respond no later than close of business on December 1st, 2023, regarding your availability for the January 2024 SCFAC meeting. Thank you, in advance, for making this a priority in your 2024 schedule.

Respectfully, on behalf of the State Consumer and Family Advisory Committee,

Brandon L. Wilson
Chairman
State Consumer and Family Advisory Committee

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Patty Schaeffer
Susan Monroe

December 28th, 2023

To: DHHS Secretary Kody Kinsley, Deputy Secretary for Health Mark Benton, Deputy Secretary for Medicaid Jay Ludlam, DMHDDSUS Director Kelly Crosbie, DMHDDSUS Deputy Director and Chief Operating Officer Renee Rader, State Health Director and DHHS Chief Medical Officer Dr. Elizabeth Tilson
Cc: Rob Robinson, Tracy Hayes, Rhett Melton, Joy Futrell

North Carolina Department of Health and Human Services Leadership,

Happy Holidays! We hope you are having a wonderful holiday season. On behalf of the North Carolina State Consumer and Family Advisory Committee, we would like to invite you to a special monthly meeting on January 10th, 2024 at Alliance Health in Morrisville, NC. We will be having our normal scheduled morning session that will include updates from Director Crosbie as well as updates from the DBH Medicaid team.

We have also scheduled a meet and greet lunch with the CEO's from the four LME/MCO's from 11:30 – 12:30. Afterward, we will hold a panel discussion with the CEO's: Rob Robinson, Rhett Melton, Tracy Hayes, and Joy Futrell from 12:30 – 3:00pm. This panel discussion will address the following topic areas: Tailored Plan Readiness, Implementation of Waiver Updates, MCO consolidation and Systems level challenges.
The intent of this panel discussion is based on three focus areas: 1.) Creating a clearer sense of transparency specific to the behavioral health system during the very challenging t changes that are occurring, 2) Ascertaining a better working knowledge of the specific challenges and gaps of services each LME/MCO is facing, 3) Providing an opportunity for consumers and families to hear firsthand from the LME/MCOs.

We look forward to this panel discussion and are grateful for the willingness of these leaders from these vitally important organizations. Please advise Stacey Harward of your availability to join the SCFAC for this critically important meeting by COB on January 4th if you plan on attending. It is our hope to see each of you in Morrisville for this important meeting.

Respectfully, on behalf of the State Consumer and Family Advisory Committee,

Brandon L. Wilson
SCFAC Chairman

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December 29th, 2023

To: Standard Plan Member Advisory Committee Leads
Brenda Radford – AmeriHealth, Gina Howard – Healthy Blue, Lori Keane – Carolina Complete Health, Paige Hales – United Health Care, Shaleel Johnson – WellCare
Cc: Secretary of Health and Human Services Kody Kinsley
DMHDDSUS Director Kelly Crosbie, Deputy Secretary for NC Medicaid, Jay Ludlam, Chief Deputy Secretary for Health, Mark Benton

Happy Holidays. I would like to introduce myself as the Chairman of the North Carolina State Consumer and Family Advisory Committee. Under G.S. 122C our Committee is charged with providing recommendations to the Department of Health and Human Services that support all consumers of mental health, traumatic brain injury, intellectual/developmental disabilities and substance use services. I have attached the 2022 annual report inclusive of recommendations in an effort to provide some context to our Committee.

Our membership would like to invite you or a designee to our January 10th meeting that will include a panel discussion from 12:30 -3:00pm. This panel will include the CEO's from our four LME/MCO's in North Carolina. This is timely with regard to the recent consolidation and will allow opportunity to discuss tailored plan readiness, waiver updates, and the new managed care system.

In addition and in an effort to gain a better understanding of the Standard Plans and to provide solid recommendations (per GS 122C) to the Department, we would like to extend an invitation to each of you to join our February 14th, 2024 SCFAC meeting at Alliance Health in Morrisville, NC for a panel discussion during the afternoon session from 1:00 – 3:00 p.m. The monthly meeting is public, however only SCFAC members will be engaging with the panel for the afternoon session. We will begin with questions that each of you will have an opportunity to respond in reference to the Behavioral Health system of care specific to Standard Plans. The questions, for review, will be provided in advance of the meeting. Furthermore, we are requesting an opportunity for an open dialogue between the SCFAC members and each of you. As there has been so much change in the landscape of care and with Medicaid Expansion in full implementation this opportunity for candid conversation will provide much needed feedback. The outcome of this discussion will empower/enable SCFAC to better inform consumers and their families, as well as help develop our recommendations.

We do not want to deviate from or lose the primary focus of this outreach, but we are committed to our charge in accordance with General Statute. To reiterate our only desire is to engage in further dialogue regarding the future of services and supports in North Carolina as it pertains to policies and programs that impact the MH/IDD/SU/TBI community.
Please respond no later than close of business on January 9th, 2024, regarding your availability for the February 2024 SCFAC meeting. Thank you, in advance.

Respectfully, on behalf of the State Consumer and Family Advisory Committee,

Chairman
State Consumer and Family Advisory Committee

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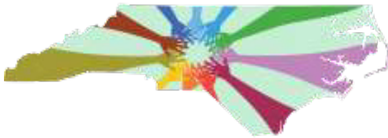

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Nathan Cartwright
Patty Schaeffer
Susan Monroe

January 24th, 2024

To: Deputy Secretary NC Medicaid Jay Ludlam, Chief Clinical Officer NC Medicaid DHB Sandy Terrell, NC Traumatic Brain Injury Team Lead Scott Pokorny
Cc: DMHDDSUS Director Kelly Crosbie, DMHDDSUS Deputy Director Renee Rader
General Assembly Member

Allow us to begin by sharing that we are looking forward to what 2024 holds and the continued partnership between SCFAC and NCDHHS.

On behalf of the SCFAC, I would like to extend thanks and appreciation to Sandy Terrell on the Medicaid Report during last month's SCFAC monthly meeting. We would also like to report that the LME/MCO panel discussion went extremely well as the CEO's and our Committee gained valuable insights and many questions were answered.

During the morning session of our meeting, questions arose specific to the statewide TBI waiver plan and the NCDHHS advisory committees dedicated to TBI services. As part of this process, we were informed that the Department was reforming the TBI Waiver Advisory Committee. We applaud this effort, however we want to reemphasize the importance and urgency specific to expansion of the waiver and ensure that we all in one accord. While we recognize there are competing priorities our correspondence from November 3rd, clearly conveys our position. We believe that this committee can play a significant role in providing "lived experience" as waiver expansion moves forward. We welcome the opportunity to participate in this committee and gladly accept Mr. Pokorny's invitation (email 1/16/2024) as a key participant. In follow up to this email request, SCFAC would like to name Ms. Crystal Foster (ddjunkee@yahoo.com) as the SCFAC representative to this critical committee.

In addition, we would like to recommend that both consumers and their families continue to be asked to participate in state initiatives and strategies in order to keep the needs of our communities' at the fore front of all conversations and subsequent actions. SCFAC believes that these committees are vital to the success of services, and that the Department continue in its commitment to ensure our voices are always "at the table". We would also like to recommend reaching out to the local CFACs as well to support these committees. We are most appreciative that the General Assembly is moving forward with the TBI waiver expansion statewide. With that said there is much work ahead that needs to be accomplished and SCFAC is grateful for the opportunity to work alongside the Department as we roll out these life-changing and life-saving initiatives statewide.

Respectfully, on behalf of the State Consumer and Family Advisory Committee,

Brandon L. Wilson
Chairman
State Consumer and Family Advisory Committee

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February 21st, 2024

To: DHHS Secretary Kody Kinsley, Chief Deputy Secretary for Health Mark Benton, Deputy Secretary for NC Medicaid Jay Ludlam, The Honorable Tim Moore, House Speaker, The Honorable Phil Berger, Senate President Pro Tempore, President of the NC Association of County Commissioners Johnnie Carswell, DHHS Joint Legislative Oversight Committee on Health and Human Services Co-Chairs, Senator Joyce Krawiec, Senator Kevin Corbin, Representative Donny Lambeth, Representative Larry Potts, Director DMHDDSUS Kelly Crosbie, Deputy Director DMHDDSUS Renee Rader
Cc: Executive Director NC Association of County Commissioners Kevin Leonard

On behalf of the North Carolina State Consumer and Family Advisory Committee (NC SCFAC), we would first like to commend each of you for all the exemplary work for all North Carolinians throughout the year. Since July of 2023, this Committee has worked to strengthen communication, and ensure our feedback is not only delivered professionally, but is value added for the General Assembly and DHHS as it relates to the voice of consumers and their families. This work has been approached with greater responsibility and accountability by all our Committee members. While working diligently with HHS Department leadership and the General Assembly, we believe it is imperative to increase our level of transparency in an effort to create better communication of our concerns and recommendations to our appointing authorities.

During our February 14th monthly meeting our Committee voted to include all SCFAC appointing authorities (DHHS Secretary, Speaker of the House, President of the Senate Pro Tempore, and President of the NC Association of County Commissioners) on all correspondence that involves our work to ensure we better inform all entities regarding our activities and concerns. Additionally, we will Cc the DHHS Joint Legislative Oversight Committee Co-Chairs to add a level of accountability for both our Committee and the Department moving forward.

Lastly, we would like to invite you all to the press conference for Legislative Day on Tuesday May 7th. We are working with several Representatives to identify the room at the Legislative Building and our subcommittee is developing a robust agenda. A formal invitation will be shared in the coming weeks.

Respectfully, on behalf of the State Consumer and Family Advisory Committee,

Brandon L. Wilson
Chairman

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February 28th, 2024

To: Deputy Secretary for NC Medicaid Jay Ludlam, NC Medicaid Deputy Director of Standard Plans Cassandra McFadden
CC: DHHS Secretary Kody Kinsley, Deputy Secretary for Health Mark Benton, The Honorable Tim Moore, House Speaker, The Honorable Phil Berger, Senate President Pro Tempore, President of the NC Association of County Commissioners, Johnnie Carswell, DHHS Joint Legislative Oversight Committee on Health and Human Services Co-Chairs, Senator Joyce Krawiec, Senator Kevin Corbin, Representative Donny Lambeth, Representative Larry Potts, Director DMHDDSUS Kelly Crosbie, Deputy Director DMHDDSUS Renee Rader, Executive Director NC Association of County Commissioners, Kevin Leonard

Reference: Contract Deliverables

Deputy Secretary Ludlam and Deputy Director Cassandra McFadden,

On behalf of the NC State Consumer and Family Advisory Committee's Contract Deliverables subcommittee, thank you for your leadership as the Deputy Secretary for the Office of Health Benefits (NC Medicaid). Your responsiveness to and support of the NC State CFAC (SCFAC) is commendable and validates the commitment you and your team have to supporting consumers and families.

The function and responsibilities of the Contract Deliverables subcommittee within the SCFAC include but are not limited to:

- Working with DMH and DHB staff to monitor contract deliverables pertaining to the delivery of Behavioral Health, IDD, and TBI services with a specific focus on network adequacy and quality of care;
- Reviewing reports from DMH and DHB staff on the deliverables specified in both the Tailored Plans (LME/MCOs) and Standard Plans (PHPs) contracts that relate to network adequacy and quality of care to assess the effectiveness of services and identify service and information gaps and;
- Providing strong (informed and practical) recommendations when necessary to improve service access, quality of care, and network adequacy.

Since mid-2023, our subcommittee has requested documents that will give us insight into the performance measures that the Tailored Plans and Standard Plans are held accountable to via their contracts with the DHB and DMH as it specifically pertains to network adequacy, and quality of care. To date, in response to our request we have been directed to links on DHBs website to the contracts section and Quality Assessment and Improvement Plans from some of the plans. While this information is rich and informative, it is voluminous and does not tease out specific sections germane to our scope of work and needs. We will admit that the request may have been confusing and not clear on our part. Therefore the purpose of this letter is to clarify and be more specific about the documents that we would like to have access to and review.

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We would like to formally request specific sections on these contracts and their deliverables, in order to provide a more comprehensive view of the current systems and their performance.

1.) We would like the sections from the contracts for both types of plans (Tailored Plans and Standard Plans) that ONLY speak to the network adequacy and quality of care deliverables for Behavioral Health (mental health and substance use) and Intellectual and Developmental Services (including traumatic brain injury).

2.) We would also like to review the sections of the contracts that ONLY speak to the performance metrics or indicators that the plans are being held accountable for as it relates to network adequacy and quality of care.

It is not our desire to be burdensome or to submit unrealistic requests, therefore, please let us know if we still need to drill down to further explicate our request. We would like to humbly request this information by April 10th, 2024.

Thank you again for your time and responsiveness. We really appreciate your willingness to collaborate with us and respond to our multiple requests. We wish you and your team continued success and stamina as we all work together to transform our Medicaid system into a state-of-the-art model that places consumers and families first and at the center of DHB policies and practices.

Respectfully Submitted,

Brandon L. Wilson
Chairman
North Carolina State Consumer and Family Advisory Committee

Dr. Michelle Laws
Chair
State Budget and Contract Deliverables Subcommittee - NCSCFAC

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February 28th, 2024

To: DHHS Secretary Kody Kinsley, Karen Wade, DHHS Policy Director, Lisa Corbett
CC: Deputy Secretary for NC Medicaid Jay Ludlam, Deputy Secretary for Health Mark Benton, The Honorable Tim Moore, House Speaker, The Honorable Phil Berger, Senate President Pro Tempore, President of the NC Association of County Commissioners, Johnnie Carswell, DHHS Joint Legislative Oversight Committee on Health and Human Services Co-Chairs, Senator Joyce Krawiec, Senator Kevin Corbin, Representative Donny Lambeth, Representative Larry Potts, Director DMHDDSUS Kelly Crosbie, Deputy Director DMHDDSUS Renee Rader, Executive Director NC Association of County Commissioners, Kevin Leonard, Vaya Health CEO Tracy Hayes, Trillium Health CEO Joy Futrell, Alliance Health CEO, Rob Robinson, Partners Health CEO Rhett Melton,

In Response to the 122C Proposed Changes

This correspondence serves as the State Consumer and Family Advisory Committee's formal response to the proposed changes to the 'Legislative Proposals to Facilitate Further Medicaid Managed Care Implementation'; including NCGS § 122C. We are grateful for the opportunity to provide feedback to the proposed changes. However, we want to convey that the timeliness and delivery in which we and other stakeholders received the proposed changes does not align with our ability to provide informed comprehensive feedback that the citizens of our state deserve. With the complexities in the system paired with Medicaid expansion, MCO re-alignment and Tailored Plans potential launch we feel strongly that the changes in the 101-page proposal must be reviewed with due diligence, understanding and responsibility. The sweeping changes may directly impact many who receive services currently and in the future. **Therefore, we respectfully request that the Legislative Proposals to Facilitate Further Medicaid Managed Care Implementation which includes GS 122C not be introduced into this upcoming 2024 short session, but rather be introduced in the long session of 2025.** This request would provide adequate time for Providers, MCO's and more importantly both State and Local CFAC's to comprehensively understand the entirety of this legislation (not just sections 170 and 171 of 122C). As both appointed and volunteer representation of the voices of our consumers and family members across NC we take seriously this response and wish to provide solutions to improve the challenges faced. One recommendation to help address this would be a statewide task force to be utilized that would include representation from SCFAC, Local CFAC's, and MCO's that in lieu of the delay would support the dissection and understanding in the proposed changes over the next 10 months in order to be better stewards of changing state legislation.

However, should the changes and proposal be introduced in the upcoming short session, we do wish to provide formal responses that specifically impact the voices of consumers and family members with both the State Consumer and Family Advisory Committee (outlined in NCGS § 122C-171) and the Local Consumer and Family Advisory Committees (outlined in NCGS § 122C-170).

In regard to *NCGS §* 122C-171 which directly impacts the State Consumer and Family Advisory Committee, we cannot agree or disagree with any of the proposed changes due to the issues previously mentioned; furthermore we would like to voice our discontent

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State CFAC Members 2023-2024

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Bob Crayton, *Vice-Chair*
Angela-Christine L. Rainear
Annette Smith
April DeSelms
Ashley Snyder Miller
Crystal Foster
Domenica Hutnick
Gene McClendon
Heather Johnson
Janet Breeding
Jean Andersen
Jeannie Irby
Jessica Aguilar
Johnnie Thomas
Lorrine Washington
Lilly Parker
Dr. Michelle Laws
Nathan Cartwright
Patty Schaeffer
Susan Monroe

-NCGS § 122C-171(b)…….A member can serve for additional terms after a three-year break in service.
As difficult as it is to recruit members this would create many challenges in SCFAC's ability to maintain a consistent and powerful voice. Even with staggered terms and with a proposed increase of SCFAC appointments (21-28 members) we feel that a one year break from appointment is appropriate after serving initial terms.

With regard to NCGS § 122C section 170 we wish to show our support for the Local Consumer and Family Advisory Committees (CFACs) and their responses specifically surrounding NCGS § 122C section 170. The SCFAC's strong stance is to allow these CFACs to maintain full autonomy as self-governing committees. These committees provide invaluable knowledge to the Managed Care Organizations, and the system of care. Many of these committees have generated their formal response that also aligns with our firm recommendation to delay any changes to ~~§~~ NCGS § 122C in the upcoming session these aligned responses include but are not limited to the following:

-NCGS § 122C-170 (a) area authorities shall establish committees made up of consumers and family members in their catchment areas to be known as regional Consumer and Family Advisory Committees (CFACs).
Currently these committees are called local CFACs and we feel this does not need to be changed. Each CFAC should decide how they want to be established and what they want to be called. The LME/MCOs may establish a CFAC steering committee comprised how this region can best be supported. This would allow these regions to recruit, engage and retain membership and structure.

--NCGS § 122C-170 (b) The CFAC shall be composed exclusively of individuals as set out below who are actively receiving services from the area authority for which they serve, or who are family members or guardians of consumers who are actively receiving services.
This statement would exclude anyone in long-term recovery. Who best to serve on CFAC than an individual in long term recovery. We would suggest the language say, "individuals, family members or guardians that are currently or that have received services in the public sector."

-- NCGS § 122C-170 (b) the terms of members shall be three years, and no member may serve more than two consecutive terms. A member can serve additional terms after a break of three years.
CFAC is self-governing and should have the authority to set their own membership terms. We believe each CFAC should adopt by-laws that stipulate length of terms and number of consecutive terms. By-laws should provide for a staggered rotation of members to ensure the committee does not become controlled by a single disability area.

Nothing About Us, Without Us.

North Carolina State Consumer and Family Advisory Committee
C/O Community Engagement and Empowerment Team
3001 Mail Service Center | Raleigh, NC 27699-3001
Phone: 984-236-5000 | Fax: (919) 733-4962

State CFAC Members 2023-2024

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Susan Monroe

Lastly, we do wish to show our support to some of the proposed changes, this list does not reflect the entirety, as there are still many unanswered questions:

--NCGS § 108D-1(26) Mental health, intellectual or developmental disabilities, traumatic brain injury, and substance use services or MH/IDD/TBI/SU services. — Those mental health, intellectual or developmental disabilities, traumatic brain injury, and substance use services covered by a local management entity/managed care organization under a contract with the Department of Health and Human Services to operate Medicaid waiver programs authorized by the Centers for Medicare and Medicaid Services, a BH IDD tailored plan or a PIHP.
This provision aligns with SCFAC's strong stance on inclusion and updating language in the statute. Adding Traumatic Brain Injury and Intellectual Disabilities here in addition to changing the verbiage of "abuse" to "use" supports this system of care more accurately. This provision also adds the other waivers and plans to the definition.

--NCGS § 122C- 118.1 (Structure of Area Board)….. four members of the regional CFACs as recommended by the reginal CFAC steering committees, comprised of two openly declared consumers and two family or guardian members. There shall be representation of all four disability areas: mental health, intellectual and developmental disability, substance use disorder, and traumatic brain injury.
We support this language that includes CFAC representation on these boards and that *we encourage the Departments enforcement of section* (b) parts 5-11 to ensure that these boards have the much needed expertise to function as a Tailored Plan.

Thank you again for providing this opportunity for response and feedback and hope that our recommendation **to delay** the Legislative Proposals to Facilitate Further Medicaid Managed Care Implementation be strongly considered. I would like to request that our appointing authorities provide feedback to the committee in writing before our March 13th meeting, any other feedback for the committee is also welcomed. We remain steadfast to work with the Department, General Assembly, and stakeholders to provide better alternatives with this ever-changing landscape as our community deserves better.

Respectfully Submitted,

Brandon L. Wilson
Chairman
North Carolina State Consumer and Family Advisory Committee

NC DEPARTMENT OF
HEALTH AND HUMAN SERVICES
Division of Health Benefits

ROY COOPER • Governor
KODY H. KINSLEY • Secretary
JAY LUDLAM • Deputy Secretary, NC Medicaid

September 29, 2023

Brandon L. Wilson, Chairman
State Consumer and Family Advisory Committee
c/o Community Engagement and Empowerment Team
3001 Mail Service Center
Raleigh, NC 27699-3001

SENT VIA EMAIL

Dear Chairman Wilson:

Thank you for reaching out to share the concerns of the North Carolina State Consumer and Family Advisory Committee (SCFAC) regarding the soon expiring "Appendix K" flexibilities and the request for extending those flexibilities until February 2024. Your letter expressed concerns regarding Relatives as Provider/Relatives as Direct Support Employee's providing care to minors, adults, and Employer of Records and the need to keep these flexibilities. NC Medicaid acknowledges your concerns, shares the important role that Direct Support Staff provide and appreciates parents who have taken on the responsibility of caring for their family members.

We have been in communication with the Centers for Medicare and Medicaid Services (CMS) which has provided guidance to States regarding possible extensions and the continuation of particular flexibilities if a State has not received Amendment approval by November 11, 2023.

For more context and to provide the SCFAC with greater insights into what actions NC Medicaid has already taken, in August 2023, NC Medicaid submitted an Innovation Waiver Amendment to CMS requesting certain Appendix K flexibilities be made permanent. At the time, NC Medicaid did not include the request for caregivers to continue providing 84 hours per week; our rationale at the time was not to make the 84 hour/week flexibility permanent due to concerns of caregiver burnout and isolation. Since the Amendment submission, NC Medicaid has received additional comments in support of extending Kinship Care.

In support of the SCFAC, the request, and the requests of others, NC Medicaid has engaged CMS to understand whether they would be supportive of an increase of allowing Kinship Care to 84 hours/week and whether they would want us to explore particular "guardrails" to protect caregivers. We will continue those conversations with CMS next week, even during the Federal shutdown.

Thank you again for expressing concerns on behalf of the State Consumer and Family Advisory Committee. On October 6, 2023, we will provide a written update regarding our conversations with CMS about extending the flexibility you are seeking.

Sincerely,

Jay Ludlam

cc: Kelly Crosbie, Director, DMH

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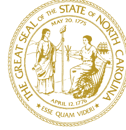

STATE OF NORTH CAROLINA
DEPARTMENT OF HEALTH AND HUMAN SERVICES

ROY COOPER
GOVERNOR

KODY H. KINSLEY
SECRETARY

SECRETARIAL DIRECTIVE 2023-001

DATE: November 1, 2023

SUBJECT: Tailored Plan Readiness & LME/MCO Streamlining Pursuant to SL 2023-134

The State of North Carolina and local governments under Chapter 122C of the North Carolina General Statutes have developed and maintained a unified system for the provision of mental health, developmental disabilities, and substance use disorder services through area authorities. There are currently six such area authorities operating as local management entities/managed care organizations (LME/MCOs).

In effort to improve delivery of care, stabilize the system, and launch Tailored Plans, the North Carolina General Assembly, through Section 9G.7A.(a20) of Session Law 2023-134 (the legislation) directed the Secretary for the North Carolina Department of Health and Human Services to reduce the number of LME/MCOs to a total of no more than five, and at least four. In deciding how to best reduce the number of LME/MCOs, I have solicited input from consumers and beneficiaries, providers, county leadership, associations, and LME/MCO leadership.

As always, my goal is to support a strong public system for the delivery of mental health, intellectual and developmental disabilities, and substance use services and have used the following guiding questions in reaching a decision:

- **What is best for the people we serve and for the providers who deliver services?** This takes into consideration health regions, where people live, and where people go to seek care. It also includes reviewing LME/MCO performance metrics and existing capacities of their provider networks, their systems, and their staff.

- **What will promote the value of whole-person care and move us to tailored plans faster?** This considers reviewing Tailored Plan readiness, the capacities of each LME/MCO, and how their strengths complement one another as part of a larger public system of care. It also includes the federal expectations of a managed care system, which is centered on the need for comprehensive access to care and choice, wherever-possible.

- **What will reduce complexity, create less disruption, and make things easier for everyone involved?** This will include how any change will be adopted by those we serve and other partners – with the goal of finding balance at a time when the system has been under immense change. It will also consider how we streamline efforts for providers and counties that need stability and consistency.

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In addition, I have taken into account the request by Sandhills Center and Eastpointe to approve their Agreement and Plan of Consolidation dated August 1, 2023 (Consolidation Agreement) and other subsequent consolidation recommendations. The Consolidation Agreement is based on the philosophy that consolidation would be in the best interest of the State of North Carolina and the individuals served by them given the substantial value of the respective organizations and the strength of long-standing consumer relationships, service delivery, and its management/leadership teams. The value and strength that the two organizations bring to the public system is acknowledged under this Directive and consistent with the proposed Consolidation Agreement, and Eastpointe will be recognized as a surviving entity for the purpose of further consolidation with Trillium Health Resources. The area authority resulting from this consolidation will build on the strengths of each organization to better meet the needs of the population of the new catchment area, prepare for Tailored Plan launch, and streamline operations.

As Secretary, based on the information received from stakeholders and in order to best support a strong public system for the delivery of mental health, intellectual and developmental disabilities, I am directing that the catchment areas of Sandhills Center, Eastpointe, and Trillium Health Resources be combined except for the counties of Davidson, Harnett, and Rockingham. To achieve this realignment I hereby direct:

1. Consistent with the proposed consolidation agreement between Sandhills Center and Eastpointe and in recognition of the value of mutually agreeable consolidations, self-determination for local communities, and in effort to move toward more contiguous health regions, Sandhills Center will be dissolved and Eastpointe will be the surviving entity with all counties in the Sandhills Center catchment area aligned to Eastpointe except as follows: Davidson county will align with Partners Health Management; Harnett County will align with Alliance Health; and Rockingham County will align with Vaya Health.

2. In recognition of complimentary resources, provider networks, and individuals served, and also in effort to achieve four Tailored Plan regions to build market power, diversified risk pools and simplify systems for providers, Eastpointe shall consolidate with Trillium Health Resources. A consolidation agreement shall be crafted by the parties and presented to the Department for consultation and approval no later than thirty (30) days from the date of this Directive.

3. To ensure the expeditious launch of Tailored Plans and to minimize duplicative work such as transferring assets and other efforts related to multiple consolidations:

    a. The final dissolution of Sandhills Center and consolidation of Eastpointe and Trillium Health Resources shall occur on the date identified in the approved Consolidation Agreement between Eastpointe and Trillium Health Resources. Work toward consolidation should begin immediately and expectations for the Consolidation Plan are described further below.
    b. The realignment of Davidson County to Partners Health Management; Harnett County with Alliance Health; and Rockingham County with Vaya Health shall occur immediately.

4. It is advised that LME/MCOs take every effort to rapidly stabilize the system of care in readiness for Tailored Plan launch. Advised actions include but are not limited to:
    a. honoring legacy provider programs, project, and service contracts (state, federal, Medicaid) including, but not limited to 3-way beds and all crisis services;
    b. maximizing to the greatest extent possible consistent offerings of in lieu of services and other alternative service arrangements;
    c. honoring current provider choice and tailored care management choice and assignment;
    d. supporting the stability of staff and the institutional knowledge critical for the performance of essential functions; and
    e. maintaining and supporting local consumer and family advisory councils during the transition.

To support this directive:

1. The Division of Health Benefits shall provide a proposed Consolidation Plan to the area authorities directed to consolidate within seven (7) days of the date of this Directive. The purpose of this proposed Consolidation Plan is to set expectations for the area authorities as it relates to ensuring smooth transitions of care for beneficiaries of services and Tailored Care Management, establishing clear provider contract and reimbursement approaches, maintaining staff experienced in serving their population, and ensuring financial stability of the consolidated entity. The consolidating area authorities must provide a Consolidation Plan seven (7) days after receipt of DHB's proposed Consolidation Plan which incorporates guidance from DHB.

2. The Division of Health Benefits shall provide a proposed Consolidation Plan to the receiving LME/MCOs for Davidson, Harnett, and Rockingham counties within seven (7) days of the date of this Directive. The purpose of this proposed Consolidation Plan is to set expectations for the area authorities as it relates to member engagement and transition of care for services and Tailored Care Management, provider contracting and reimbursement, staffing expectations, and asset distribution. The receiving LME/MCO shall provide a Consolidation Plan seven (7) days after receipt of DHB's proposed Consolidation Plan which incorporates guidance from DHB.

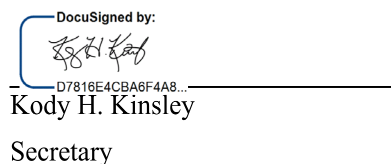
3. All contract amendments or assignments of contracts for the operation of the Tailored Plans and Prepaid Inpatient Hospital Plans between the applicable area authorities and the Division of Health Benefits that are required to meet the mandate of this directive shall be completed within thirty (30) days of the approval of the consolidation agreement for Eastpointe and Trillium and approval of the Consolidation Plan required under Paragraph 2.

4. All contract amendments or assignments for contracts for State-funded services, programs, and projects, federally-funded services, programs, and projects (i.e. MHBG funds, AARPA funds, SOR grant, SUPTR funds), 3-Way Beds, between the applicable area authorities and the Division of Mental Health, Developmental Disabilities, and Substance Use Services that are required to meet the mandate of this directive shall be completed within thirty (30) days of the approval of the consolidation agreement for Eastpointe and Trillium and approval of the Consolidation Plan required under Paragraph 2.

5. Risk reserves and other funds of the area authority for the county realignments resulting from the within ordered consolidation and realignments shall be transferred in accordance with G.S. 122C-115.6.

Pursuant to SL 2023-134, Section 9G.7A.(a20) (7), relevant actions, including the dissolution and consolidations ordered under this Secretarial Directive, are not appealable in any forum.

This Secretarial Directive is effective as of the date signed and shall remain in effect until rescinded or superseded by another applicable Secretarial Directive. This Secretarial Directive may be rescinded, or another Directive issued if any of the parties fail to meet the requirements of this Directive, or the proposed Consolidation Agreement is not approved.



Kody H. Kinsley

Secretary

NC DEPARTMENT OF
HEALTH AND HUMAN SERVICES
Division of Health Benefits

ROY COOPER • Governor
KODY H. KINSLEY • Secretary
JAY LUDLAM • Deputy Secretary, NC Medicaid

November 14, 2023

Brandon L. Wilson, Chairman
State Consumer and Family Advisory Committee
c/o Community Engagement and Empowerment Team
3001 Mail Service Center
Raleigh, NC 27699-3001

SENT VIA EMAIL

Dear Chairman Wilson:

It was a pleasure meeting with you and speaking to the North Carolina State Consumer and Family Advisory Committee (SCFAC) members yesterday morning. I wanted to make sure that the following response was included in the SCFAC minutes, as promised.

I. Comprehensive update on the 1915i option Services (TP 1915(i))

As part of NC Medicaid's commitment to a smooth transition from 1915(b)(3) services to 1915(i) services, NC Medicaid is continuing to work with plans, providers and the broader community to expand access to these services to members in a responsible way that ensures the best outcomes for our members and our providers.

NC Medicaid is aware that the expansion of the availability of Home and Community Based Services (HCBS) through the 1915(i) has been long awaited.

- As NC Medicaid focuses on the smooth transition of current members receiving 1915(b)(3) services, it's important to understand that it will take time for providers in the community to build capacity to provide these much-needed services.

NC Medicaid is incredibly excited about the approval of the 1915(i) services and is looking forward to supporting the LME/MCOs, providers and members in working to make these services more available to all members who could benefit from them.

- The first priority remains to smoothly transition to these services currently receiving services to avoid disruption in care.

II. Update on the Innovations Waiver and Appendix K Flexibilities

Appendix K flexibilities were implemented during the Public Health Emergency and were scheduled to end effective November 11, 2023. The Centers for Medicare and Medicaid Services (CMS) is allowing states to continue Appendix K flexibilities beyond November 11, 2023, if the state submits a 1915(c) waiver amendment making some or all the Appendix K flexibilities permanent.

To that end, NC Medicaid submitted an amended 1915(c) Innovations Waiver to CMS and is awaiting a response; thus, if approved by CMS, Innovations Waiver Appendix K flexibilities will continue beyond November 11, 2023, until the amended waiver is approved and becomes effective.

Once the amended 1915(c) Innovations Waiver becomes effective, only the flexibilities which are

LOCATION: 801 Ruggles Drive, Hoey Building, Raleigh NC 27603
MAILING ADDRESS: 2501 Mail Service Center, Raleigh NC 27699-2501
www.ncdhhs.gov • TEL: 919-855-4066 • FAX: 919-715-0801

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permanently added to the 1915(c) Innovations Waiver will continue. NC Medicaid recognizes the need for time to transition from the various flexibilities ending and is requesting CMS to make North Carolina's 1915(c) Innovations Waiver amendment effective March 31, 2024. NC Medicaid will communicate formal approval of this extension request as soon as it is available from CMS.

NC Medicaid submitted a 1915(c) Innovations Waiver amendment to (CMS) to make the following Appendix K flexibilities permanent:

- Allow home delivered meals (up to seven meals per week/one per day).

- Allow real time, two-way interactive audio and video telehealth for Community Living Support; Day Support, Supported Employment; Supported Living and Community Networking to be delivered via telehealth.

- Allow waiver individuals to receive services in alternative locations: hotel, shelter, church or alternative facility-based settings.

- Remove the requirement for the beneficiary to attend the day supports provider once per week.

- Allow the Community Navigator to note individuals may not receive this support unless they are self-directing one or more of their services through the agency with choice or employer of record model.

- Increase the Innovations waiver cap from $135,000 to $157,000 per waiver year.

- Allow parents of minor children receiving Community Living and Support to provide this service to their child who has been indicated as having extraordinary support needs up to 40 hours/week.

- Allow Supported Living to be provided by relatives.

- Allow relatives as providers for adult waiver individuals to provide above 56 hours/week, not exceeding 84 hours/week of Community Living and Supports.

III. Update on the TBI Waiver and Appendix K Flexibilities

Appendix K flexibilities were implemented during the Public Health Emergency and were scheduled to end effective November 11, 2023. The Centers for Medicare and Medicaid Services (CMS) is allowing states to continue Appendix K flexibilities beyond November 11, 2023, if the state submits a 1915(c) waiver amendment making some or all of the Appendix K flexibilities permanent.

To that end, the NC Medicaid has submitted an amended 1915(c) TBI Waiver to CMS and is awaiting a response; thus, if approved by CMS, TBI Waiver Appendix K flexibilities will continue beyond November 11, 2023, until the amended waiver is approved and becomes effective.

After the amended 1915(c) TBI Waiver becomes effective, only the flexibilities which are permanently added to the 1915(c) TBI Waiver will continue. NC Medicaid recognizes the need for time to transition from the various flexibilities ending and is requesting CMS to make North Carolina's 1915(c) TBI Waiver amendment effective March 1, 2024. NC Medicaid will communicate formal approval of this extension request as soon it is available from CMS.

NC Medicaid has submitted a 1915(c) TBI Waiver amendment to (CMS) to make the following Appendix K flexibilities permanent:

- Allow home delivered meals (up to seven meals per week/one per day)

- Allow real time two-way interactive audio and video telehealth for Life Skills Training,

Cognitive Rehabilitation, Day Support, Supported Employment; Supported Living and Community Networking to be delivered via telehealth.

- Allow waiver individuals to receive services in alternative locations: hotel, shelter, church, or alternative facility-based settings.

- Remove the requirement for the beneficiary to attend the day supports provider once per week.

- Allow relatives as providers for TBI waiver individuals to provide Personal Care and/or Life Skills Training (or a combination of those two services) up to 40 hours/week total.

- Resource Facilitation will no longer be a separate TBI Waiver service; however, the activities that were included in this service are available through Tailored Care Management.

IV. LME/MCO Performance measures

• LME-MCO Dashboard: https://www.ncdhhs.gov/divisions/mental-health-developmental-disabilities-and-substance-use-services/reports

V. Dashboard report on PDN • Please see attached.

VI. LME/MCO Consolidation

The Secretaries priorities for guiding this decision –

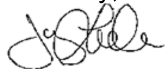
What is best for the people we serve and for the providers who deliver services? This takes into consideration health regions, where people live, and where people go to seek care. It also includes reviewing LME/MCO performance metrics and existing capacities of their provider networks, their systems, and their staff.

What will promote the value of whole-person care and move us to tailored plans faster? This considers reviewing Tailored Plan readiness, the capacities of each LME/MCO, and how their strengths complement one another as part of a larger public system of care. It also includes the federal expectations of a managed care system, which is centered on the need for comprehensive access to care and choice, wherever possible.

What will reduce complexity, create less disruption, and make things easier for everyone involved? This will include how any change will be adopted by those we serve and other partners – with the goal of finding balance at a time when the system has been under immense change. It will also consider how we streamline efforts for providers and counties that need stability and consistency.

Thank you for everything you do on behalf of the State Consumer and Family Advisory Committee!

Sincerely,



Jay Ludlam

cc: Kelly Crosbie, Director, Division of MH/DD/SUS

Attachment: PDN Data Results CY 2021 & 2022

NC DEPARTMENT OF
HEALTH AND
HUMAN SERVICES
Division of Mental Health, Developmental
Disabilities and Substance Use Services

ROY COOPER • Governor
KODY H. KINSLEY • Secretary
MARK T. BENTON • Chief Deputy Secretary for Health
KELLY CROSBIE • Director

May 1, 2024

Dear SFAC and Local CFAC Members,

I am reaching out in response to your written feedback on the proposed changes to the North Carolina General Statues 122C. First and foremost, I want to express my appreciation for the time and attention given by State and Local CFAC to reviewing and discussing the proposed changes and crafting such a thoughtful response. Hearing your initial concerns, we met together with State and Local CFAC in March to discuss areas of concern. All feedback generated during those meetings, as well as written input we received, was shared with the Secretary and key DHHS leadership.

Based on that meeting and your feedback, we are not moving forward with any proposed changes to 122C regarding CFAC structure. As discussed, if CFACs are interested in making changes to statute around CFAC structure in the future, we agree that this should be driven by CFAC members. Consumer and family voice is incredibly important; when we are aligned, we have our strongest, best system. In addition, DHHS spent time streamlining recommendation changes to a very narrow set of changes that we feel are critical to move our system forward now. We appreciate your feedback that greater amounts of changes would require more time and discussion.

As the General Assembly short session is now in progress, I would like to dedicate time to reviewing with you the limited 122C changes the Secretary is recommending after reviewing all feedback. The purpose of this meeting is to share the recommended changes, provide an opportunity for feedback, and answer any questions you may have. During our time together, we will:

- Review the recommended small, but key changes and the impact
- Answer questions and clarify understanding when needed
- Offer an additional opportunity for your feedback to be heard by NCDHHS

The upcoming time together on May 1st, and a second meeting that is being scheduled, is an opportunity for us to work together on a shared goal--ensuring our public mental health, substance use, intellectual and developmental disability, and traumatic brain injury system is as strong as it can be!

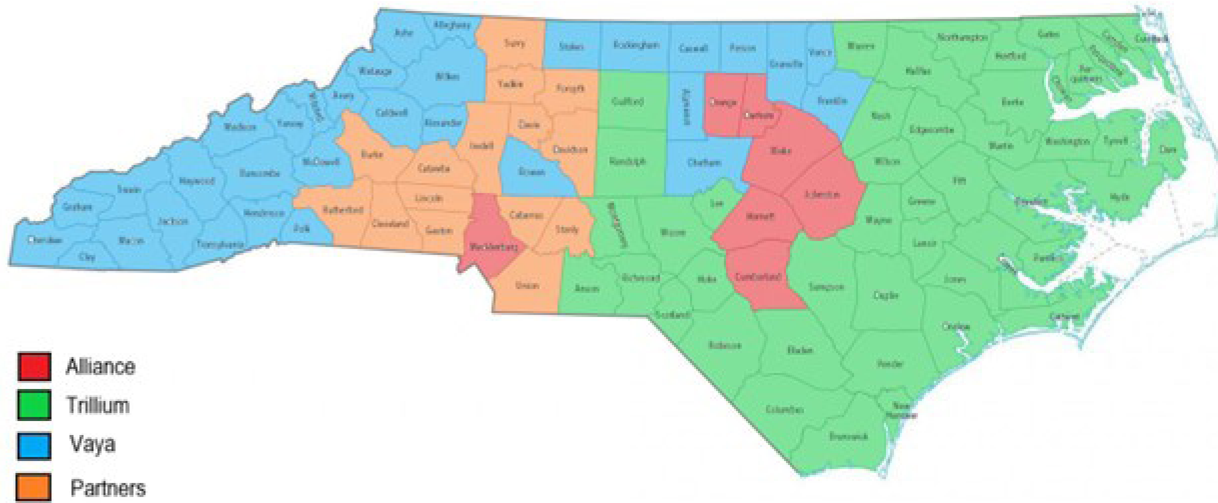
Sincerely,

Kelly Crosbie, MSW, LCSW
Director, DMHDDSUS

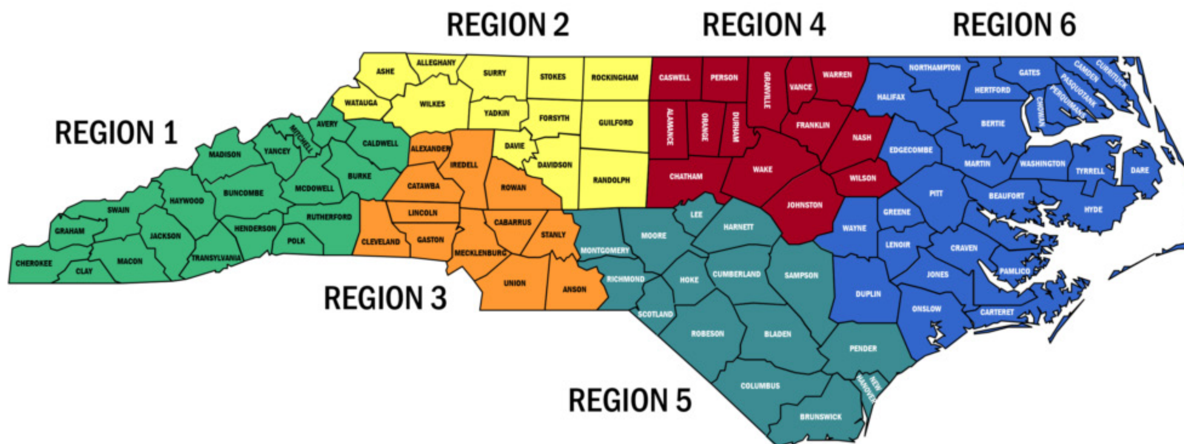
Part 11

MCO/Medicaid Maps

LME/MCO Map, 2024



NC Medicaid Map, 2024



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