Nothing About Us, Without Us

NORTH CAROLINA STATE CONSUMER AND FAMILY ADVISORY COMMITTEE

Lilly Parker, Chair
Ashley-Snyder Miller, Vice-Chair

Meeting Minutes
Hybrid Meeting | August 12, 2026, 9:00 AM – 3:00 PM

ATTENDEES					
Council Members					
Name	**In-Person**	**Virtual**	**Name**	**In-Person**	**Virtual**
Lilly Parker (Chair)	x		Flo Stein		
Ashley Snyder-Miller (Vice-Chair)	x		Jeannie Irby		
Amie Brendle		x	Johnnie Thomas		x
Annette Smith	x		Lynn Martin		x
Bob Crayton		x	Nathan Cartwright		
Crystal Foster		x			
Staff/Guests					
Name	**Staff**	**Guest**	**Name**	**Staff**	**Guest**
Jennifer Meade	x		Ann Marie Webb	x	
Badia Henderson			Lisa Jackson	x	
Erica Asbury	x				
Moe Ebson	x				
Crystal Dorsey	x				

Agenda Topic:	**Welcome/Roll Call/ Approval of Agenda and Minutes**
Presenter:	Lilly Parker, Chair

- Roll call was conducted, and a quorum was confirmed. The agenda received a motion to approve, followed by a second, and was unanimously approved. The July meeting minutes were also moved, seconded, and approved unanimously.

Agenda Topic:	**Division of Mental Health, Developmental Disabilities, and Substance Use Services (DMH/DD/SUS) Update**
Presenter:	Ginger Yarborough, Chief Clinical Officer (CCO)-I/DD, TBI and Olmstead

IDD Update Presentation:

- Between January–March 2026, 13,100 people with IDD received 1915(i) services, a 14% increase from 2025.
  - This is a 26% increase since July 2024.
  - As of 3/31/2026, 21,449 people are on the Innovations Waiver Waitlist; growth averages 500 people per quarter (2,000 per year).
- **Questions:**
  - Is there a standard way LME/MCOs report their waitlists? CCO Yarborough receives data. SCFAC requested access to reasons for removals. CCO Yarborough will review the reporting template and consult legal.
  - If individuals move from the Child and Family Specialty Plan to the Tailored Plan (TP), does this mean they are getting a slot? CCO Yarborough will follow up.
- New metric: Average wait time until receiving a slot is 12.26 years (based on data collected over the past 27 months). Tracked by county, not LME/MCO. Excludes Reserve Capacity slots (Money Follows the Person (MFP), Emergency, Military, etc.). Will update annually.
- DMH/DD/SUS will initiate a new Innovations Waiver Waitlist review process.

- **Objectives for the Waitlist Standard Operating Procedure (SOP) include**:
  - o Improve waitlist management with greater transparency, equity, and efficiency; clarify TP roles.
  - o Maximize accuracy of waitlist data.
  - o Ensure people have information and access to services while waiting.
- **Innovations Waiver Waitlist Process (draft):**
  - o Standard Waitlist Management
  - – Onboarding and ongoing engagement defined
  - – Consistent statewide experience
  - – All individuals assessed at entry and annually
  - o Improved Accuracy
  - – Confirms interest, needs, and information
  - – Removes individuals who decline offered slots
  - – Removes individuals unreachable after multiple attempts
  - – Introduces an Inactive Waitlist category
  - o Annual Outreach
  - – Confirm interest/information
  - – Review available services and link individuals, including those without Tailored Care Management
- **Proposed Waitlist Management Process (draft):**
  - o Chart Review: TPs verify accuracy and completeness of information.
  - o Outreach: TPs contact members if information is missing.
  - o Onboarding: Accept referrals via in-person, online, mail, phone, or email.
  - o Assessment of Need & Eligibility: TPs assess needs and make referrals.
  - o Notification of Outcome: TPs provide written notification to all who request waitlist placement.
- **Direct Care Workforce Analysis underway:** The Department and NC Center on the Workforce for Health launched a statewide wage and rate analysis to inform reimbursement strategies & better understand workforce challenges
  - o The analysis will:
  - – Evaluate wages and compensation
  - – Assess workforce supply and service utilization
  - – Review payment rates and methodologies
  - – Develop wage benchmarks and forecasting models
  - o Provider Survey (July 29–August 26, 2026): Participation is voluntary but important. Concern expressed that responses should come from operational or financial leadership to protect data validity. CCO Yarborough will consult Trish Farnham (who's leading this work) regarding safeguards in place to screen for this.
- **36th Anniversary of the ADA (Americans with Disabilities Act):**
  - o DMHDDSUS continues advancing home and community-based supports, employment initiatives, workforce development, person-centered supports, and access to care.
- **OBISS (Online Brain Injury Screening and Support) System** launched 8/1/2026:
  - o DRNC (Disability Rights of NC) began the work; the Division now manages it.
  - o Online, nondiagnostic screener (2–5 minutes) available for anyone age 10+. Provides guidance, tip sheets, and next-step information for potential brain injury.
  - o Training video available August 21, 2026; announced in Hot Topics. Includes screening for acquired brain injuries.
  - o Funding covers 5,000 screenings; no criteria for who may take it. Shared broadly with SU providers, veterans, Certified Community Behavioral Health Centers (CCBHCs), mental health providers, etc.
  - o Individuals already diagnosed do not need to take the screener.

- **Rural Health Transformation Program Advisory Committee**: 40 members representing tribal groups, healthcare, community organizations, local government, and people with lived experience.
- **New Workforce Data Snapshot** released by UNC Sheps Center: Focuses on Behavioral Health workforce, licensed clinicians, geographic distribution, and trends.
- Question: Will each LME/MCO have a list of individuals who self-direct?
- Joint Vaya Partners EOR (Employer of Record) Meeting next week; information should be shared there and with the Self-Direction Coalition.

Agenda Topic:	**Annual Retreat/October Meeting SCFAC/Medicaid Shared Agenda Discussion**
Presenter:	Lilly Parker, Chair

- While awaiting the next speaker, the Chair facilitated discussion on the Annual Retreat (October 13) and SCFAC attendance at the Annual Medicaid Quality Forum (October 14).
- **Retreat:**
    - Instead of forming a Retreat Committee, the Chair and Vice-Chair will meet with staff to review issues from last year through to the present.
    - Members may email suggestions to the Chair and Vice-Chair.
    - The By-Laws Ad Hoc Committee, previously paused, needs to be reinstated to complete the Annual Review before the retreat and to identify any needed updates. The retreat should strengthen SCFAC's collective voice.
    - A suggestion was made to invite Mark Botts from the UNC School of Government to present on SCFAC rules and responsibilities.
    - SCFAC members should copy all members when submitting retreat discussion ideas.
- **Sixth Annual Statewide Medicaid Quality Forum** (Presented by NC Medicaid and the Medicaid Managed Care Plans)
    - The forum will be held from 11:00 AM to 1:00 PM, overlapping with part of the SCFAC meeting. Attendees include providers and quality managers, with a focus on improving outcomes for Medicaid beneficiaries.
    - Questions raised: Will the forum be recorded? Would information from the Medicaid Advisory Committee (MAC) be more relevant than content aimed at quality managers?
    - State staff later confirmed SCFAC can join the virtual meeting on October 14. A request was made to table the vote on whether SCFAC will attend; the group agreed.
    - Action items may emerge from the retreat on October 13 (one day prior to the forum), which should be considered when deciding SCFAC participation in the forum.

Agenda Topic:	**Trillium Health Resources**
Presenter:	Cindy Ehlers, Chief Strategy and Innovations Officer

- The Innovations Waiver Waitlist has existed for ~30 years and continues to evolve. Key factors to measure if redesigning the waitlist include severity and risk of institutionalization.
  • A prior weighted tool examined those on the waitlist without services or Medicaid eligibility, looking at length of time waiting, and severity.
  • Earlier assessments are critical and should involve the educational system and physicians; reassessment every five years is recommended for those still waiting.
  • Current policy assigns slots based solely on time on the waitlist within each LME/MCO region; equity across counties is needed.
  • Some individuals may be better served by services outside the Innovations Waiver, including nursing-level care. Ms. Ehlers noted her 30+ years of experience and her lived experience as a parent of two children with intellectual and developmental disabilities.
  • Some children placed on the waitlist at age three and still waiting at age twelve may miss critical developmental opportunities for habilitative services.
  • SCFAC should consider policy changes that could drive real system improvements.

- Approximately 21,000 people are on the Registry of Unmet Needs; at current rates, it would take over 200 years to serve all if no one else were added.
- LME/MCOs do not manage the waitlist due to policy restrictions; even with additional slots funded by the General Assembly, policy changes would still be required.
- No diagnosis is required to be added to the waitlist, contributing to inflated numbers; current policy does not require an I/DD diagnosis or verification of Intermediate Care Facility (ICF) level of care.
- Maryland announced a 50% rate reduction for parents serving as caregivers under the relatives-as-providers model.
- IDD diagnosis is broad under state policy and differs from diagnosing intellectual disability, which requires psychological testing; the Waiver also includes physical disabilities such as cerebral palsy.

Trillium Data (5,551 people on the waitlist):

o 2,602 are age 18+ with Medicaid and access to services including 1915(i); those ineligible for 1915(i) also do not meet ICF level of care.

o About 2,422 are under age 18; ~65% (≈1,500) have Medicaid and access to EPSDT (Early and Periodic Screening Diagnostic and Treatment) and therapies.

o 4,105 have Medicaid; 1,446 do not.

o Only 867 currently receive 1915(i) services.

o Approximately 919 without Medicaid may be eligible but have not applied—highlighting an education need.

o About 10% (527 people) cannot be located after multiple outreach attempts; policy does not allow removal.

Additional LME/MCO waitlist numbers (from the Innovations Waiver Waitlist Dashboard):

– Alliance: 8,128

– Partners: 5,217

– Vaya: 2,409

- Approximately 81% of individuals on the statewide waitlist have Medicaid. Waitlist size is influenced in part by policies that prevent active management.
- Most Innovations Waiver services are already accessible to standard Medicaid beneficiaries. However, nursing-level care is not available in Innovations Waiver group homes and is instead limited to Intermediate Care Facilities (ICFs). Individuals living in their own homes may receive nursing through LTSS or private duty nursing.
- Clarification: The Innovations Waiver and Residential Supports do not include nursing as a service.
- Clarification on ICF types: Community ICFs provide bundled services such as therapies, behavioral support, and equipment. Skilled nursing ICFs provide higher-level medical care, including respiratory support and complex medical interventions. The O'Berry Center is the highest-level skilled nursing facility serving people with IDD.
- Enhanced coordination between State Plan services and the Innovations Waiver is needed. While "Relative as Provider" is included in updated state funded I/DD services, state funding has remained largely stagnant for nearly three decades despite population growth.
- Ms. Ehlers emphasized updating policy so the Waivers better meet current population needs, including reconsidering whether nursing should be integrated into the Innovations Waiver. Clarification: She was not suggesting that community residents should move to ICF-MRs; rather, she highlighted that current policies do not adequately support individuals' needs and must be modernized.
- The waitlist signals an urgent need for SCFAC to improve waitlist management, ensure accurate documentation of needs, and build an infrastructure that sustains service delivery without jeopardizing existing supports.

Agenda Topic:	**SCFAC Annual Report and Recommendations**
Presenter:	Lilly Parker, Chair

- Chair Parker noted that recommendations for the Annual Report are not yet finalized and will be added to the report originally sent by former SCFAC Chair Dr. Michelle Laws before being shared with all members. Recommendations must follow correct numerical order.
- **Editorial Note**: Although recommendations were discussed in the July SCFAC Meeting, no vote was taken. This clarification responds to questions about whether recommendations had been previously approved.
- Intermediate Care Facilities (ICFs) were discussed in earlier meetings. The related recommendation seeks a comprehensive study of housing options—including ICFs, supported living, community waiver homes, and additional models—for individuals wanting community living when parents are no longer available. The request is to amend the current recommendation to indicate that all models of housing, not just the group settings, will be looked at. Chair Parker requested additional wording from Member Martin; she agreed to submit it.
- Concern raised that some members feel their voices are not being heard, including members serving on committees, such as the Gaps and Needs Committee.
- **Point of Order** (Member Crayton): According to SCFAC bylaws, Article 6, Section 7, provides that full SCFAC decides by consensus or by majority of members attending. He stated that in April of 2025 (the vote is believed to have taken place in 2026), the committee unanimously approved the set of 12 recommendations. Article 7, Section 4 requires the Chair to reflect the will & intention of the committee. Article 8 indicates that standing subcommittees hold no independent authority to change any decisions already made by this full committee. His summary in calling the Point of Order is that the previously adopted 12 recommendations remain in effect.
- Discussion included clarification of Attorney Joonu-Noel Coste's role with SCFAC.
- Additional discussion: The April recommendations were not final due to placeholders. Between April and June, the number of recommendations was reduced from 12 to 10 with input from Dr. Laws. They were intended for June but were presented in July. Concern expressed about being asked to approve recommendations that will be edited later without timely access to the final version.
- Vice-Chair Snyder-Miller will send out Dr. Laws' portion of the Annual Report. She has made some edits; more are needed (adding committee member names, committee letters, etc.). Support Staff Erica Asbury shared the draft report during the meeting; although labeled "final," it is not the final version.
- Chair Parker requested submission of all recommendations—especially from Members Crayton and Martin—and asked that they include SMART (Specific, Measurable, Achievable, Relevant, and Time-Bound) goals. After completing the report, the final version will be shared for member review. SCFAC is awaiting responses from the divisions/department and will continue following up.

Agenda Topic:	**Public Comments (total of 25)**
Presenter:	Lilly Parker, Chair

- Chair Parker opened the floor for public comments:
  - A question was raised regarding whether written public comments from the previous month's meeting had been distributed. They had not been shared due to the presence of personally identifiable information and the need for staff to receive guidance on whether distribution was permissible. Individuals requesting copies were advised to submit a public records request.
  - Additional discussion highlighted that liability for public comments rests with the commenter. A suggestion was made to create a dedicated email account for submitting public comments and for communication related to Gaps and Needs work. Members discussed whether SCFAC could establish such an account and whether bylaws permit it.
  - Motion: A motion was introduced to create a dedicated Gmail account (publiccomments.scfac@gmail.com), contingent on no conflicts with existing bylaws. The Chair or Gaps and Needs Co-Chair would manage the inbox and forward relevant messages to the SCFAC Chair, Co-Chair (Vice Chair), and Community Engagement as appropriate. The motion was seconded and passed unanimously. Chair Parker agreed to set up the account and reiterated that public comments must not be shared on social media or outside SCFAC.

- Discussion emphasized that public comments are intended to surface issues needing attention. When comments indicate a need for action, state staff may direct individuals to appropriate resources, or the Chair may request a member to follow up if a question or concern requires further review. A question was raised about who would print comments from the new public comment inbox for meetings; it was agreed that this requires additional discussion pending confirmation that SCFAC may proceed with establishing the separate email account. Chair Parker will submit a public records request for outstanding public comments and will share them only with the Gaps and Needs Committee.
- Public Comment: A question was raised regarding the new North Carolina Traumatic Brain Injury (TBI) law. The commenter referred to the earlier presentation by Ginger Yarborough, Chief Clinical Officer for I/DD, TBI, and Olmstead at DMH/DD/SUS. Another member committed to providing a link to recent Hot Topics information.
- Due to the high volume of public comments submitted for the July and August meetings, an additional 12 comments were read aloud by Chair Parker and Vice Chair Snyder Miller before lunch. These comments focused on recent policy changes to the North Carolina Medicaid Community Alternatives Program for Children (CAP-C), which helps medically fragile children live at home rather than in a hospital or nursing facility.
    - Reported impacts of these changes (summarized list, not all-inclusive) have resulted in critically negative repercussions for the families caring for their loved ones with complex medical needs:
        - New rules are confusing
        - Approval for services/supports is dangerously slow with delayed reviews
        - Denials are highly subjective and arbitrary
        - Lengthy appeal timelines
        - Parents/family members leaving employment to care for children
        - Loss of outside caregiving staff
        - Seemingly unnecessary documentation requirements, sometimes repeated
        - Increased appeals and mediation to maintain services
        - Blanket denials
        - Renewal eligibility process is frustrating and increasingly difficult
        - Gap between theoretical provider availability and actual appropriate care
        - Inability to access the services needed while the plan of care is under review
- The North Carolina General Assembly needs to address the CAP-C denial crisis.
- During the SCFAC Work afternoon agenda item discussion, 11 additional public comments were read by Chair Parker and Vice-Chair Snyder-Miller, all concerning current issues with CAP-C, as summarized earlier. Chair Parker announced that public comments from last month and this month will be sent to committee members on 8/17/26, and this distribution will continue monthly; therefore, a separate email account is no longer needed.
- After these comments, Elaine Neal of Advocates for Medically Fragile Children and Alessandra Fabrello (both attending virtually) were asked to condense family concerns into major themes as talking points. They agreed**.**
- In total, 25 public comments were made today. After the request for condensed caregiver themes to be written up, the floor closed for further public comment.

Agenda Topic:	**Division of Health Benefits (DHB)/NC Medicaid: Employer of Record (EOR)**
Presenter:	Racine Allen, I/DD Policy Consultant, LTSS (Long Term Services and Supports) Team

- Ms. Allen presented on self-direction, also known as Employer of Record (EOR). The formal term in the Innovations Waiver is Individual and Family Directed Services (IFDS). Other terms include Participant Direction, Self-Direction, and Consumer Direction.
    - Self-direction allows individuals to have greater flexibility and decision-making authority over their Waiver services, including hiring and recruiting their own staff.
    - The Innovations Waiver offers two self-direction options:
        - **Budget Authority (Employer of Record or EOR)**
            - o Participant selects and supervises workers for certain Waiver services

- o Sets worker pays wages (may exceed provider agency wages)
- o Manages the self-directed budget
- o Works with a Financial Support Service Agency for fund management

-Financial Support Service Agencies:

- process timesheets
- issue paychecks
- handle tax deductions
- conduct background checks, and
- assist with budgeting

- o Working with a Financial Support Service Agency is required
- o Health Plans/Tailored Plans contract with two agencies: Acumen and North Carolina Secure Direction
- o A representative may be appointed to assist the EOR (not someone affiliated with an agency or Limited Liability Company and without financial gain)

- **Agency with Choice (less common)**
  - o Participant works with a provider agency that manages wages, benefits, and timesheets
  - o Participant still chooses their staff but has fewer responsibilities

- Waiver rules for self-direction vary. Ms. Allen noted that CAP-C and CAP-DA (Community Alternatives Program for Disabled Adults) also offer self-direction, referred to as Consumer Direction.
- Ms. Allen and her team meet monthly with the health plans to review how the IFDS program is progressing, identify issues, and discuss solutions. They are also addressing the transition from the Community Alternatives Program (CAP) to Innovations. When asked whether people with lived experience could serve on this committee, Ms. Allen stated this is possible, though not currently scheduled, but not off the table.
- Oversight of IFDS is conducted by the health plans, with additional oversight from the State and North Carolina Medicaid, which reports to the Centers for Medicare and Medicaid Services (CMS). Ms. Allen asked if any concerns about inappropriate spending be reported to her. She doesn't want the idea to be spread that there is no oversight and that people are utilizing this program to do things of a questionable nature. Participants receive an annual audit, and serious issues can result in removal from the program; less serious issues may lead to training or technical assistance.
- Individuals use their Innovations Waiver budget funds. Any remaining funds accumulate in a balance that can be used over time to support staff (for example, bonuses or paid time off). Health plans have protocols for this, and the Department is developing processes that will be included in the upcoming DHB Clinical Coverage Policy (CCP), (to be posted soon).
- Regarding CCP 8P: Hours can't be split between a traditional provider and an Employer of Record (EOR)-this has not changed. If someone self-directs Community Living and Supports, all hours for that service must be self-directed and cannot be split. An individual can be self-direct with just one service.
- When asked whether EOR can be used to backfill hours that a traditional provider cannot fill, Ms. Allen will follow up. She noted that her initial opinion is that this may create confusion.

Services available for Self-Direction:

- o Community Networking Services
- o Community Living and Supports
- o Individual Goods and Services (must be paired with at least one other self-directed service)
- o Natural Supports Education
- o Respite Services
- o Supported Employment

- Supported Living
- A Community Navigator is added during onboarding for individuals who choose to be self-direct; they may later decide whether to continue using this support.
- After completing self-direction training, an assessment is conducted to determine readiness, followed by referral to a financial service provider. The Individual Support Plan (ISP) is then updated, and the individual may begin EOR duties. Individuals may stop self-directing at any time. Involuntary termination is possible for health or safety concerns, misuse of funds, or confirmed fraud, waste, or abuse.
- Each Tailored Plan provides an IFDS manual on its website outlining the details of its model.
- Ms. Allen provided the unit's shared email address for questions: IDDlisteningsessions@dhhs.nc.gov. She requested that messages/questions to her include "Attention: Racine Allen."

Agenda Topic:	**SCFAC Work**
Presenter:	Lilly Parker, Chair

- The group discussed adding all members' names to the side of the SCFAC letterhead. Chair Parker emphasized that names would remain on the letterhead even if members disagreed with the content of a majority-approved letter; names are removed only if a member resigns or is no longer on SCFAC.
- A formal motion to add all member names was made, seconded, and approved with no opposition.
- Letter regarding SCFAC concerns Senate Bill (SB) 257, Section 9L.2, the Division of State Operated Healthcare Facilities (DSOHF), and the LME/MCO Study Request for Proposal (RFP):
- The letter's purpose is to communicate SCFAC concerns about a study evaluating potential cost savings:
  - From eliminating the LME/MCOs and
  - From selling or leasing state-operated healthcare facilities to private entities.
- Chair Parker sent an updated version of the letter yesterday. Members requested that it be viewed during the meeting for final edits & while some edits were made during the meeting, Vice-Chair Snyder-Miller will complete the remaining revisions and send the letter to SCFAC for final review. The letter will be published on Friday, August 14th, with the updated letterhead listing all SCFAC members.
- Chair Parker reminded the group that Vice-Chair Snyder-Miller will chair the September SCFAC meeting in her absence.

Adjournment

- Chair Parker adjourned the meeting at 2:34 PM.

Action Items	**Responsible**	**Deadline**
• SCFAC request for access to reasons for Innovations Waiver Waitlist removals	Ginger Yarborough	Not Specified
• If a child moves from the Child and Family Specialty Plan to the Tailored Plan, do they get an Innovations Waiver slot?	Ginger Yarborough	Not Specified
• SCFAC concern that Provider Survey responses should come from operational or financial leadership to protect data validity; follow up needed with staff working on this (Trish Farnham)	Ginger Yarborough	Not Specified
• Request made for members to submit recommendations with SMART (Specific, Measurable, Achievable, Relevant, & Time-Bound) goals for the Annual Report	SCFAC Members	As soon as possible
• Annual Report Recommendation responses are needed from the divisions/department	SCFAC Leadership	As soon as possible
• SCFAC request that family concerns re: CAP-C comments received during Public Comment be condensed into caregiver themes (as possible talking points)	Elaine Neal & Alessandra Fabrello	Not Specified

• Can Employer of Record or EOR be used to backfill hours that a traditional provider cannot fill?	Racine Allen	Not Specified
• Final revisions for letter concerning Senate Bill 257 will be completed and letter sent to SCFAC members for final review prior to going out	Vice Chair Ashley Snyder-Miller	As soon as possible due to letter send out happening on 8/14/26