Defining the Value of Care Management for Consumers, Families and Individuals with Lived Experience in North Carolina: A Collaborative Approach

i2i CENTER for INTEGRATIVE HEALTH
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NORTH CAROLINA
NCCHCA
Serving Community & Migrant Health Centers
Community Health Center Association

Index

Appendices

Summary of Products and Recommendations

General Theme and Process of Discussion

Throughout the eight Collaborative Meetings, regardless of the specific topic related to care management, one question drove the group through all discussions:

What would make care management valuable and successful from the perspective of the consumer and family?

The answers to this question could serve as the basis for defining value-based care for care management services.

Collaborative Members were provided with information and materials for each topic that included NC DHHS concepts, provider guidance materials and national tools. It is important to note that discussions did not revolve around already existing concepts, lists or tools; rather, these resources served as a baseline to better understand what had already been developed, and also included the products and recommendations created by the Collaborative, which were framed around the driving question. This approach led to very different discussions than would typically occur around policy.

Comprehensive Assessment

- A distinctive theme regarding the comprehensive assessment relates to the importance that the initial assessment take a ***person-driven approach***. The group noted a significant difference between person-driven (i.e., the individual/family is in the driver's seat when defining needs, issues, goals, success) and person-centered (professionals define areas of concern, goals, and success based on information about and discussion with the individual or family) and concluded that the person-driven focus is necessary to know how each individual consumer defines success in their treatment and supports.
- The Collaborative developed a consumer-care manager engagement sheet (see Appendix C) that consumers and families could use to guide the initial contact and help care managers understand them better.

Racial and Health Equity

- The Collaborative reached consensus on a definition for health equity:

Health equity means that everyone has a fair and just opportunity to be healthy in mind, body, spirit and environment and to have adequate access to the supports and services that they need to be healthy. Health is defined by an individual, and may include dealing with past trauma, current conditions, disparities in society and anything else that an individual defines as a barrier to health and wellness.

- The Collaborative provided feedback (see Appendix D) to the NC DHHS Secretary on the Medicaid (ncmedicaidplans.gov) website under the "Search by Provider for a Plan" gender choices for both provider and patient being limited to "male" and "female;" as well as on the need for increased funding of community trusted and community lead wellness centers to address racially driven health disparities.

Data Integration and Outcomes Guiding Principles

Collaborative members reviewed the data points and outcome information available, and made the following suggestions:

1. Collect data that is meaningful to the consumers and families.
2. Reimburse care managers for a focus on the needs of the consumers and families.
3. Build flexibility into the care manager role to attain success as it is defined by the consumers and families.
4. Reframe the system to include incentives for consumers and families as well as providers and payors.

Care Management Qualifications and Training Recommendations

Collaborative Members agreed that this is a significant area requiring a great deal of planning after reviewing available information; the following general gaps were identified:

- The importance of social connections.
- Lack of emphasis on a single plan across providers. Current system remains fragmented, needs alignment.
- Need for the care manager to take a *person-driven* approach to learn what is most important for the individual and assist them in achieving that.
- The need to include advocacy as part of the care manager role.
- Workforce is the major issue as the qualifications are very narrow:
    - The role must be adapted to each family and each situation
    - Beneficial to include peer support or family navigator role because they can build the trust and get to natural and general support issues. Can serve as an advocate more than any other person on a team yet they are not funded.
    - This is the pivotal role in managed care and it has to be done right for the family and will help with not only the success of individuals, but for Medicaid Transformation as a whole
    - This role must have compassion built into it
    - Need enough of a workforce to have cultural competence

Topics/Areas to be considered in Care Manager Training and Qualifications:

- Trauma-informed care and understanding ACEs
- Addressing IMMINENT needs related to SDoH—housing and food that day
- Access to friends, social interaction and relationships—need a structured plan to make this happen
- Structural Determinants of Health

- Facilitating discussions around informed decisions making
- Recovery alternatives to forced treatment
- Individualization
- Strength-based approach in discussions.
- The importance and impact of family for the individual
- Integration between behavioral and physical healthcare—unified plan that can be shared
- Developing natural and culturally responsive supports
- Use encouraging questions of what success would look like
- The ability of peers to serve in meaningful roles in care management, to include monitoring, follow-up, and advocacy.
- Dual eligible and individuals in CAP/DA care management needs
- How are qualifications determined?
- Create a process (potentially an app) for professionals so they know the individual's goals
- Create a quick satisfaction survey for post-contact use to give the care manager immediate feedback. Consider making such feedback public
- Consider creating a state-level training to qualify both professionally degreed and non-degreed individuals as care managers
- Fund peer-run organizations to develop a training for care managers
- Include the parent story in training

I. Overview—Drive to Define the Value of Care Management for Consumers, Families and Peers

Goals for Alumni Grant

Since the Fall of 2018, the i2i Center for Integrative Health (i2i) and the North Carolina Community Health Care Association (NCCHCA) have partnered in a grant effort focused on value-based planning and care (VBPC) across healthcare. This work, covering 2 grant cycles and 3 years, is supported by the Delta Center for a Thriving Public Safety Net. In Phase 1, our work focused on VBPC education and training for behavioral and primary health at the provider level, with an overarching goal to improve understanding of VBPC principles and to establish pathways to support service integration across behavioral and physical healthcare.

Our goal for Delta Center Phase 2, and the topic of this document, was to continue to address VBPC by focusing on the consumer perspective. With the backdrop of our state's Medicaid Transformation, we established a set of objectives in support of a process to impact policy from the consumer perspective. Utilizing a collaborative approach, we established a working group consisting of equal membership of BH/IDD and FQHC/CHC consumers and family members, and we added a small number of provider representatives. We agreed to address issues, planning, and constructs related to care management in Medicaid Transformation, recognizing that care management serves a critical role in service delivery; and, we believed it was critically important to ensure that all stakeholders involved in the collaboration be recognized as equal partners in the discussion and formulation of recommendations.

In order to bring consumers, families and people with lived experience into the policy influencing equation, we committed to the following:

- To define value in the care management role from the perspective of consumers, family members and providers.
- To examine how the global pandemic, systemic bias, issues of racial equity, and Social Determinants of Health impact the value proposition.
- To identify and examine issues of priority and importance for consumers and their family members related to the care management role and to provide resolutions/recommendations for these issues.
- To inform and influence Medicaid managed care policy and implementation by bringing forward a series of recommendations related to care management that address the value proposition in VBPC from the perspective of the consumer.
- To pilot a process to address policy issues across behavioral and physical healthcare that focuses on the perspective of consumers, families and peers.

North Carolina Care Management Landscape

In 2016, driven by the NC General Assembly's concern over several years of increasing financial shortfall in Medicaid, the NC Department of Health and Human Services (NC

DHHS) was given legislative authority to pursue a 1115 Medicaid waiver. The main drivers for the legislature were cost containment, budget stability, increased competition and shared risk. In January 2017, a new NC DHHS Secretary ramped up State efforts to shift North Carolina's Medicaid program to managed care. NC DHHS created a vision with critical roles to achieve managed care through a whole person approach. The vision included development of a strong Advanced Medical Home (AMH) component, building upon a primary care case management model already in place in the North Carolina. As this vision evolved, a historical change was underway to create a Standard Plan, for which the majority of Medicaid beneficiaries would be eligible and that would include mental health and substance use disorder services as well as a BH/IDD Tailored Plan that would be integrated and include a benefit package to meet the needs of individuals with higher mental health and substance use disorder needs, as well as intellectual-developmental disability services and supports (referred to as MH/IDD/SUD). Previously, most Medicaid recipients who qualified for MH/IDD/SUD services received them through a regional service system managed by LME/MCOs. After a series of delays related primarily to technical issues, the Standard Plans were implemented on July 1, 2021. The BH/IDD Tailored Plan is now scheduled to be implemented on December 1, 2022.

Both Plans include the provision of a health home for Medicaid beneficiaries. Standard Plan members with more complex needs are assigned a care manager at the discretion of the Standard Plan, through their designated Advanced Medical Home. Each and every BH/IDD Tailored Plan member will be assigned a care manager through either an entity known as an Advanced Medical Home Plus or a Care Management Agency. Advanced Medical Homes in Standard Plan networks are approved by NC DHHS by way of attestation to fulfill required responsibilities. Advanced Medical Home Plus and Care Management Agencies in the BH/IDD Tailored Plan are required to undergo a more formalized compliance process to receive NC DHHS certification. NC DHHS is currently in the certification process. Because the BH/IDD Tailored Plan care manager role is new, NC DHHS has created a "glidepath" to build care management capacity by allowing the BH/IDD Tailored Plan to serve as the care manager in many instances while physician offices, FQHCs, BH/IDD/SUD providers gain competency in the role. Payment under both plans is based on a per member, per month construct.

NC DHHS has a robust website that includes the vision, contractual responsibilities for Standard and BH/IDD Tailored Plans, resource playbooks for social services/communities and providers, and provider manuals.

Incorporating the Consumer and Family Voice

Much of the statewide focus in preparation for Medicaid managed care to date has been on building the infrastructure for the service delivery system. There have been many opportunities for all stakeholders (payors, providers, consumers, families, peers and advocates) to provide feedback to drafts of concept papers and proposed structures for functions. NC DHHS convened groups to gather feedback at critical planning times.

They have most recently established a Tailored Care Management Technical Advisory Group that began work in late October 2021. Membership of the groups includes consumer and family representation. Importantly, however, the Advisory Group takes a general perspective and does not focus on service users.

State Leadership Response to Purpose of Grant

In planning for the Alumni Grant and its focus, the i2i/NCCHCA team corresponded with the NC DHHS Deputy Secretary for Medicaid and the Chief Deputy Secretary for Health to inform them of the grant work and to seek support. The team held a Zoom meeting with the Chief Quality Officer for NC Medicaid, Division of Health Benefits as well as her staff. Their response was quite positive. In fact, they noted that their engagement process and the engagement processes of their contractors had not yet included a focus on the consumer, family and peer perspective. They offered support and interaction as appropriate.

II. Process and Membership

To establish the Collaborative Membership, i2i and NCCHCA recruited individuals with lived experience and family members who had experience as Medicaid service recipients. We additionally recruited several service providers who were interested in providing care management under Medicaid Transformation. As potential representatives were named, we held individual meetings with each person to familiarize them with our plan, to determine their willingness and their ability to participate, and to ensure that we were actively supporting principles of diversity to the greatest extent possible. **SEE APPENDIX A: Interview Questions and the Compilation/Trending of Responses**

Reflections on Interviews:

- Interviews provided an opportunity to get to know each person individually, identify their priorities and goals for participation, and for each participant to evaluate the potential merits of the proposed Collaborative.
- Some of the consumer/family members expressed concern that they were not as knowledgeable about the system as they thought they should be to participate. We used the interview time to help them identify their unique strengths and the value that their experiences and first-hand knowledge would bring to the Collaborative.

Collaborative Membership Mix:

The final membership of the Collaborative included ten individuals who are individuals with lived experience, family members of individuals with lived experience or long-term advocates who are not affiliated with a member advocacy organization. Six of these Collaborative members had experience in the BH/IDD/SUD public system in North Carolina and four of these Collaborative members had experience in receiving behavioral healthcare services through the FQHC/Community Health Centers. Five individuals represented provider organizations in the Collaborative. Three of those organization representatives are affiliated with provider agencies that are working to become Care Management Agencies under the BH/IDD Tailored Plan, including **Monarch, Southlight and Homecare Management Corporation**. Two of the organization representatives are affiliated with FQHCs.

Reflections on Membership Mix:

- We chose provider organizations whose plans are to provide care management statewide, whose existing knowledge was beneficial to the Collaborative, and who had demonstrated support for consumer voice.
- Several provider organization representatives stated that they wanted to participate because they believed that understanding what is important to consumers would enhance their organization's capacity.

- Having a larger number of consumer/family Collaborative members than provider organization representatives clearly contributed to keeping the discussions focused on the perspective of consumers and families and what is of value to them.
- The BH/IDD Tailored Plan system often has consumer/family/advocate representatives who have been a part of the system for a long time. Consumer/family representatives who have accessed FQHCs/CHCs are newer to the system and had not served on groups before. The combination of the "seasoned" and new consumer/family/advocate representatives created dynamic discussions and an open environment to new ideas.

Meeting Structure and Logistics:

As referenced throughout this document, the work of the Alumni Grant occurred within the framework of a Collaborative. We chose a model that would support equal interaction among participants and could translate reasonably well to a virtual meeting platform. We were committed to a consumer-directed process, yet also recognized the likely need for some degree of facilitation by the i2i/NCCHCA team. Our use of the Collaborative structure allowed for directed leadership in support of discussion and content when needed, while allowing all members to take on leadership regarding discussion direction, goals for the Collaborative, and products/outcome. As facilitators, the i2i/NCCHCA team was clear from the outset that the work, energy, and success of the Collaborative was dependent on the collective efforts of the group, and that the Collaborative's true expertise was a function of the member participants rather than the facilitators.

The Collaborative did not have a set schedule and regular meeting date and time. Prior to each meeting, a Doodle poll was sent out to determine optimal date and time. The grant team decided to do this each time to accommodate as many Collaborative members as possible and particularly those Collaborative members who do not work in the public health and human services system. The meetings were generally held during the last week of the month and most meetings were held from 3 pm – 5 pm (or 6 pm). This time slot seemed to be the most convenient for most members. The i2i Center grant webpage was developed to provide additional resources for Collaborative members.

Reflections on Logistics:

- Not having a consistently scheduled date and time slot was more difficult for the providers.
- The webpage was developed as a resource at the start of the Collaborative but was not enhanced subsequently.
- Meeting notes were not posted on the webpage and names of Collaborative members were not published to respect Collaborative members privacy.

- There are approaches that could be used to share the meeting notes by not including member names and compiling comments. Recordings would be impossible to redact but it could be done with notes.
- The flow of the agenda and discussion maintenance requires more than one facilitator. This way, prompting and managing can be done by different approaches if one approach is not successful.
- Facilitation included sharing with the Collaborative the policies, concepts and other mechanisms that had already been created around the topic at hand and then allowing the Collaborative to *translate* it into what is most important from their perspectives. The result was that the policies, concepts and other mechanisms were background information but not the basis of their discussion.

Peer Support to Encourage Collaborative Participation:

A critical informal component of success in this collaborative model began organically. As stated previously, the membership mix included individuals who themselves or their family member had been a part of the services system for many years as well as individuals or family members who were new to the public system. The individuals who had been involved in the public system also had prior opportunities to sit at policy tables. Individuals and family members who were newer to the public system had not ever participated in policy discussions. The initial interviews were designed to help newer advocates gain a comfort level in the collaborative process. We have received feedback that the concept of the interview can be overwhelming. In fact, one peer Collaborative member was mentoring and encouraging the newer advocates early in the process, including preparation for the interview and the first Collaborative meetings. It is important to note this informal component and to evaluate whether it should be more formally recognized as a part of the model.

Reflections on Peer Support in Participation:

- There may be a better-received word than “interview” that denotes a more informal and laid-back process.
- A portion of the final survey of Collaborative members should include questions around the user-friendliness of the invitation, interview and collaborative process itself.
- The model may be stronger with a designated peer mentor representative.

Leveling the Knowledge:

The first Collaborative meeting was developed to be a learning opportunity to level the knowledge base of all Collaborative members. To achieve this, the grant team invited the NC DHHS, Division of Health Benefits Chief Quality Officer and Tailored Care Management Program Manager to provide an overview of the care manager role in both the Standard and Tailored Plan for the Collaborative members. Collaborative members were also provided the link to the recording of the overview and the presentation handout was posted on the i2i Center grant webpage. **SEE APPENDIX B: Care Management Overview Presentation**

Reflections on Leveling the Knowledge:

- The webinar was a good way to promote a group dynamic since everyone was given access to the same information and had opportunity to ask questions.
- There was more specific information needed in other meetings and provided either as a part of the agenda or in other materials for the meeting.

Compensation:

The grant team sought donations that allowed compensation for those individuals on the Collaborative who are not affiliated with an organization that would pay for their time. Because payors in the North Carolina Medicaid managed care system oversee the care management role and have a mission and contractual responsibilities to conduct consumer engagement and community outreach, Prepaid Health Plans (Standard Plans) and LME/MCOs that would be applying to become a BH/IDD Tailored Plan were solicited for donations. The $1,000 donations that were received were used to compensate the 10 Collaborative members not affiliated with an organization at a $20/hour rate, 3 hours per month beginning in March when meetings started. Most of the meetings were two-hours in duration, and the additional hour accounted for any homework or education done in preparation for meetings. They also received compensation for the one-hour interviews conducted in January and February.

Our donors are:

- Alliance Health
- AmeriHealth Caritas
- Carolina Complete Health
- Healthy Blue
- Trillium Health Resources
- United
- Wellcare

III. Four Focuses of Collaborative Discussion

Focus of Collaborative Discussion:

Early in the Collaborative process, the group identified key aspects of care management in order to guide the Collaborative's work. This allowed the facilitators to organize meetings, provide background documents and information, and guide discussions in accordance with the intent of the membership. It supported participants in planning meeting times in advance and thus in their preparation for discussion. Given that members frequently reflected on personal experience, the opportunity to learn topics in advance was important and contributed to comfort levels with sharing. The four topic areas guiding our work were:

1. Comprehensive Assessment
2. Racial and Health Equity
3. Whole Person Care Data Integration and Outcomes
4. Care Manager Qualifications and Training.

Comprehensive Assessment:

A distinctive theme in several comments is around the need for the initial assessment to be ***person-driven***. The group distinguished person-driven from person-centered and concluded that the language in "person-driven" is important to understand in terms of how that individual consumer defines success in their treatment and supports. It was noted that many of the service definitions that the State uses include person-centered planning. Collaborative members noted that ***a person-driven approach*** would have wide applicability within the NC DHHS structure for services.

The Collaborative reviewed the requirements for the Comprehensive Assessment that are available in NC DHHS documents for both the Standard and BH/IDD Tailored Plans. They discussed the opportunity that the Comprehensive Assessment presents for the care manager, consumer and family to begin a relationship and to build trust. As the discussion progressed, they formulated a plan to develop a question sheet that consumers and families could use to help the care manager understand them and their individual/family situation better. The questions are framed as if they are asked by the care manager, and they address topics that the consumer and family may want the care manager to know about them. The Collaborative members have discussed distributing the question sheet through various groups, and the i2i Center and NCCHCA will also publish them.

Key Points from the Discussion around Comprehensive Assessment:

- On the Standard Plan care manager list, physical healthcare and I/DD services are together. They are different and require different approaches, therefore, should be separated.
- Person-driven is more sustainable than person-centered .

- The assessment should be individualized.
- Data collection requirements need to support the person-driven perspective, which will necessitate some adjustments to balance data and person driven concepts.
- Utilize soft skills (includes organization hiring people who have soft skills)
- Ensure technological capacity for planning
- Offer choice
- Use person-driven language in their policies and writing so the individual and family can remember it and use it.
- Match the consumer/family with the “most authentic” peer support at the beginning.
- Important to have clear parts of assessment related to equity, justice and inclusion.
- Encourage consumers to bring in more people to help the individual in assessments.
- Reinforce person-driven behavior.
- Peer support/Family partners --
    - No service definition for peer support in I/DD and TBI
    - Can offer key supports

Comments about the Consumer-Care Manager Engagement Sheet:

- Try to make the questions as short as possible and phrased in language a consumer would use.
- Provide clear examples of phrases, “You might want to ask your care manager…”
- Translate to Spanish
- Should be available in print and electronic versions. A YouTube video could provide further technical assistance. (Use a range of focus group members to develop)
- Address how we equip the care manager to improve the quality of care through these enhanced discussions with consumers/families.
- Can the CMAs have a chat feature?
- Make it clear how to access interpretive services:
    - CMA agency is responsible for making the request.
    - Plan manager is responsible for getting the service.
- Point of entry should be where the consumer/family gets the information so family can be empowered.
- This is a large enough change that it should be explained in different ways and multiple times so families know how they can be a part of this.
- Include questions about anything the family uses as wellness strategies/supports and uses as community supports.
- Consider how families can connect with CMAs and it remains confidential.

- Address ensuring informed decision-making.
- Is there a way to track responses to identify gaps in services? Can there be a feedback loop about SDoHs that are outside of the four domains?
- Ensure community inclusion to support successful care management.

Observations and Recommendations:

- Typically plans only require that we list guardians, but you may have cousins, aunts, friends, other people with I/DD/BH needs that are not typically included in the record listings.) Include these individuals.
- Crisis plans should include early options – call a friend, deep breathing, etc., and providers should know what calms someone down [as determined by the consumer and care manager].
- When something "bad" happens that triggers a stress response for an individual, it is important to understand what the auto response is for that person. The care managers should ask questions about and teach staff to watch for this.
- Crisis plans should include both what others will do to help you, but also how you can learn to manage a crisis yourself.

Product:

Consumer-Care Manager Engagement Sheet **SEE APPENDIX C: Empowering Consumers and Families in Care Management: Questions and Statements Consumers/Families Can Use During the Comprehensive Assessment and Beyond**

Health and Racial Equity:

Discussion:

Defining Health and Racial Equity

- After lengthy, rich discussion regarding definition of health and racial equity, the Collaborative was most comfortable using concepts from the Robert Wood Johnson document definition of equity *as a starting point* and adding key components they deemed necessary to be a wholistic definition.
- One of the good things about the RWJ definition is that it includes power. However, the phrase "fair, just and **impartial**" is concerning because to be just, can't be impartial, sometimes must give more to certain people.
- Equity is not the same as equality. The White House focuses too much on equality and treating everyone the same.
- Access to services should be included.
- Should be culturally relevant, culturally competent.

- Support and services OR support services.
- It is important to identify what is behaviorally different for care managers who think they have been doing this for a long time
- Health disparities in context of racial and neurodivergent disparities.
- Include trauma informed care.
- The group discussed how to acknowledge additional important issues including trauma, neurodevelopmental, racial and neurodivergent disparities.
- E-mail comment from Collaborative member that was valued and supported by others: "The Unity Wellness Center of East Winston-Salem has been denied funding for two years in a row now while they are continuing to do incredible work in WS to educate the Winston-Salem community about health disparities in Eastern most part of their city, in particular. They have researched the detailed history of health disparities unique to East Winston-Salem and how they trace back to racial disparities in the city. They share information with the community and with government leaders as they seek to open a space to deliver services that are desperately needed, and acknowledged by those local leaders in charge of our city budgets. If our local leaders are not willing to put dollars into the pockets of people doing work like this to directly battle health disparities, it will be a very long road for all of us. I am encouraged by the language of health and racial disparities reaching a national platform, but I am concerned with how this broad message will impact local governments as they manage budgets.

  Understanding the incremental and more pervasive ways that racial disparities impact our communities here will require a cultural shift in thinking that will take time. Defining the terms that we speak of is vital and sharing definitions we make together about what it means to consider racial and health disparities in care management will be crucial as well. We must shift the language from an overarching desire for racial and health equity to a more detailed and difficult discussion of the challenges that have traditionally been met when attempting to achieve it. The lack of access to trauma-informed care is something that cannot be ignored if addressing racial and health equities and should be something we want to engage in long term – because we have to - in order to move forward as a human race. Trauma-informed doctors and services are not yet mainstream.

Racial and Health Equity Data Collection Discussion with NC DHHS Leaders:

- NC DHHS representatives indicated they are early in efforts regarding equity in data collection. Noted that minority providers are under-represented, and this is something the Dept is looking into. Current data collection on providers does not provide information to do this so the Dept is working to adjust fields. Working with a UNC group that does have more provider data (based on billing) to increase information; This is in early stages
- NC DHHS is digging more into this data to compare it against 'expected utilization' or how to get at what expected utilization is and to determine what the benchmarks should be

- They are working to expand this UNC committee and make it more representative, though not clear if consumers will be invited
- It would be helpful to have a write up from the UNC committee so we know what their methods and criteria are, to help process.
- Health equity payments are being made to some primary healthcare providers between April and June. There is a feedback requirement that most have followed, and she expects this will help with increasing information about the provider pool
- It was suggested that the Minority Coalition of Behavioral Health Providers could be engaged

Products:

After discussion, the Collaborative members reached consensus on a definition of racial and health equity:

Health equity means that everyone has a fair and just opportunity to be healthy in mind, body, spirit and environment and to have adequate access to support and services that they need to be healthier. Being healthy is defined by an individual, and may include dealing with past trauma, current conditions, disparities in society and anything else that an individual defines as a barrier to health and wellness.

A Collaborative member brought to the attention of the group that the options to respond to "gender" on ncmedicaidplans.gov, the NC DHHS website for Medicaid managed care, were limited to "male" and "female." After discussion and review of gender classifications used by the federal government, the group agreed to express support to NC DHHS Secretary Cohen for the addition of a gender category of "other" for providers and patients. They conveyed this recommendation through a letter to Secretary Cohen. **SEE APPENDIX D: Letter to NC DHHS Secretary Cohen re: Gender options on ncmedicaidplans.gov website**

Resources shared by Collaborative members related to racial and health equity:

1. **5 Key Questions and Answers Figure 1**--https://www.kff.org/racial-equity-and-health-policy/issue-brief/disparities-in-health-and-health-care-5-key-question-and-answers/.

2. **National Standards for Culturally and Linguistically Appropriate Services in Health and Health Care: A Blueprint for Advancing and Sustaining CLAS Policy and Practice**. U.S. Department of Health and Human Services, Office of Minority Health (OMH). Washington, DC: U.S. Department of Health and Human Services, Office of Minority Health (OMH), 2013. vi, 192 p.
3. https://www.thinkculturalhealth.hhs.gov/assets/pdfs/EnhancedCLASStandardsBlueprint.pdf;
https://archive.org/details/nationalstandard00unse [See Appendix A: Glossary]

4. **Community Conversations about Mental Health: Information Brief**. Rockville, MD: Substance Abuse and Mental Health Services Administration (SAMHSA)|U.S. Department of Health & Human Services, 2013. 36 p. Includes bibliographic references and appendix.
https://store.samhsa.gov/sites/default/files/d7/priv/sma13-4763.pdf

5. **Health Disparities in Racial/Ethnic and Sexual Minority Boys and Men**. American Psychological Association (APA); APA Working Group on Health Disparities in Boys and Men. Washington, DC: American Psychological Association (APA), 2018. 78 p. Includes bibliographic references and glossary.
http://www.apa.org/pi/health-disparities/resources/race-sexuality-men-report.pdf

6. **What Is Health Equity?: And What Difference Does a Definition Make?**. Braveman, P.; Arkin, E.; Orleans, T.; Proctor, D.; Plough, A. Princeton, NJ: Robert Wood Johnson Foundation, 2017. 21 p. Includes bibliographic references.
https://www.rwjf.org/en/library/research/2017/05/what-is-health-equity-.html

7. **WHO Health Promotion Glossary**. World Health Organization (WHO). Geneva, Switzerland: World Health Organization (WHO), 1998; 1999; 2006. viii, 24 p. Includes bibliographic references. https://www.who.int/healthpromotion/about/HPR%20Glossary%201998.pdf?ua=1
https://www.who.int/healthpromotion/about/HP%20Glossay%20in%20HPI.pdf?ua=1

Data Integration and Outcomes:

The discussion around data integration and outcomes was threaded throughout each topic and particularly within the racial and health equity discussion. By the time the Collaborative reached this topic, they quickly recognized the outcomes being defined through the lens of the overarching question, "***What would make care management valuable and successful from the perspective of the consumer and family?"*** The Collaborative members discussed current mechanisms used to collect statewide data and outcomes and opted not to evaluate them. Rather, they focused their discussion on the need to strongly connect consumer and family satisfaction with performance measures, incentives, and reimbursement for providers and payors. The Collaborative members discussed having reimbursement that include time to build a strong relationship with each consumer and family.

Key Questions and Discussion:

- What are we measuring? What outcome are we going for? Are we moving the needle on people's health outcomes? Are we making the system more accessible, user-friendly?
- How do we make the conversation about data collection be from the perspective of the individual? Inequity begins when the data collection is only considered

from the perspective of the providers, State governments and does not account for important data fields for users of services.

- Collaborate and know what other groups are doing to pull together the data, e.g. NC Olmstead Plan.
- Outsource the Perception of Care consumer survey to a consumer group to get more consumer-focused perspective in the data analysis.
- Ask if people get what they wanted. Were they asked about it in a non-biased way?
- Ensure the data collected is useful. Ensure that the data is connected to future action. Ensure that consumers and families see a difference based on data collection.
- Does the data show that consumers are able to access providers who resonate with the consumer, i.e. similar backgrounds, cultural sensitivity?
- Does the data show that consumers are able to access the things they need?
- Lean into the data that shows we are focusing on the four non-medical drivers of health that the State has identified.
- Use technology for follow-ups on care and services.
- Get data that is meaningful to a user of services, have the collection done by a third-party, connect this data with the quantitative data that is collected for accountability, and show that the data transfers to system improvements.
- Do the professionals (i.e., care managers, doctors, providers) have the time (reimbursed) to value data around what is important to a consumer or family member?
- PAID TIME TO FOCUS ON CONSUMER/FAMILY NEEDS! Focus on the initial relationship and have that be billable. Carve time out in the visit that includes the consumer/family leading the dialogue.
- Standard Plan AMH is not set-up to develop much of a relationship with the consumer/family. It is based on an assessment where higher needs are identified to determine if the individual has the higher needs. Then there will be referral for additional services needed. This is not sufficient.
- Cost savings is not a direct line back to the organizations that provide the most benefit. Ex: someone does not show up at the ER because they have received preventative services. The savings at ER does not go back to the preventative providers.
- Reimbursement is not necessarily directed at the most effective outcome. Ex: prescribing pharmaceuticals is reimbursed where alternative methods are not.
- Savings back to the consumer/family? There is greater awareness around incentives.
- Reframe the funding discussion to focus on incentives and resources for consumers/families.
- Incentives at all levels. Incentives for the consumers/families. Incentives for the providers.

- FLEXIBILITY for care management organizations. Flexible dollars to use with consumers/families for them to use as a tool to find success. Is there an acuity factor that will make a difference in what incentives are meaningful? How do we find what is valuable to consumers/families at different acuity levels?
- Flexibility in Standard Plans "value-added" benefits to fit consumers/family needs, e.g. martial arts, non-pharmaceutical treatments, etc.
- Investment of funding should be where it matters the most for the consumer/family.

Recommendations/Guiding Principles in Data and Outcomes:

- Collect data that is meaningful to the consumers and families.
- Reimburse care managers for a focus on the needs of the consumers and families.
- Build flexibility into the care manager role to attain success as it is defined by the consumers and families.
- Reframe the system to include incentives for consumers and families as well as providers and payors.

Resources:

1. "A Toolkit for Centering Racial Equity Throughout Data Integration", University of Pennsylvania: https://www.aisp.upenn.edu/wp-content/uploads/2020/08/AISP-Toolkit_5.27.20.pdf, *see examples of initiatives in North Carolina, page 20 for Mecklenburg County, page 32 for City of Asheville.*
2. List of resources through Urban Institute: https://www.urban.org/elevate-data-equity/resources-elevate-data-equity/equitable-data-practice

Care Management Training and Qualifications:

Discussion:

The Collaborative members reviewed a summation of the requirements for training and qualifications of care managers under the Standard Plan and the BH/IDD Tailored Plan (See AMH Manual 2.1, Tailored Care Management Provider Manual) . Collaborative members noted that the requirements appeared to be driven by clinical and business processes. For that reason, the discussion turned to what *should* be included in training and qualifications from the perspective of consumers, families and peers.

Recommendations:

1. Overall Missing Concepts in Care Manager Training and Qualifications:
    - Importance of Social Connections
    - One integrated plan for individual and families rather than different plans that aren't aligned

- As a part of accountability, the care manager needs to ask what is most important for the individual and assist them in achieving that.
- The role of the care manager as an advocate
- Workforce is the major issue as the qualifications are very narrow:
    - The role must be adapted to each family and each situation
    - Beneficial to include peer support or family navigator role because they can build the trust and get to natural and general support issues; Can serve as an advocate more than any other person on a team yet they are not funded
    - This is the pivotal role in managed care and it has to be done right for the family and will help with not only the success of individuals, but for Medicaid Transformation as a whole
    - This role has to have compassion built into it. Can that be trained?
    - Need enough of a workforce to ensure cultural competence

2. Things that Should be Included in Care Manager Training and Qualifications:

- Trauma-informed care and understanding ACEs
- Addressing IMMINENT needs related to SDoH—housing and food that day
- The significance of access to friends, social interaction and relationships—need a structured plan to make this happen
- Structural Determinants of Health
- Discussions around informed decisions making
- Recovery alternatives to forced treatment
- Individualization
- Strengths-based approach
- The importance of the family and how it influences the individual
- Integration between BH and physical healthcare—unified plan that can be shared
- Developing natural and culturally responsive supports
- How to use encouraging questions of what success would look like
- Very narrow qualifications for the TP care manager create a workforce issue.
- Peers can play a meaningful role in care management. A part of monitoring and follow-up role and to facilitate advocacy
- Is it better to make qualifications less strenuous rather than more strenuous?
- Use an app for professionals before a meeting with the individual so that they know the goals of the individual going into the meeting
- Offer consumers a brief satisfaction survey after the interaction so that the care manager would get immediate feedback and feedback is published
- Could there be a there a state-level training developed that can qualify you to be a care manager so that the professional degree is not the driving factor?
- State allocate money to peer-run organizations to develop a training for care managers

- Include the parent story in training. Suggested that this should come later after the care manager has had a chance to acclimate to the job.

IV. Summary

This Collaborative had two groundbreaking achievements:

1. Defined the value of care management to consumers and families through the comprehensive assessment, racial and health equity, data integration and outcomes and the care manager training and qualifications by considering *"What would make care management valuable and successful from the perspective of the consumer and family?"*
2. Piloted a collaborative model that can be replicated and that brings consumers, families, persons with lived experience, advocates, and professionals to the same table with a focused and equal value on each perspective.

Each Collaborative member, as well as the facilitators, has committed to carrying the work of the Collaborative forward through their individual advocacy work. The goal is for the products, recommendations and lessons learned from this collaborative experience to be **a starting point** for greater consumer, family and peer impact and involvement in policy making.

Thank you to the Delta Center for a Thriving Public Safety Net for recognizing the importance of this grant initiative.

Appendix A

Participant Initial Interview Delta Alumni Grant:

Our grant proposes to convene a collaborative group that will work to define the value of care management as it is structured within Medicaid Transformation. We plan to use this opportunity to consider care management in a larger context and as a role that is crucial to addressing racial and health equity issues as well as the pandemic.

Interview Process (1 hour)

1. Background (15 minutes)
    - Introductions, the grant goals/timeline, how/why this person was chosen to be a participant
    - Ask person to talk a bit about themselves, their interface with Medicaid (primary, behavioral), and general experience with the Medicaid system to date.
    - Ask about their understanding of new Medicaid system in general
    - Ask about involvement with care management
2. Questions (35-40 minutes)
    - What is your definition of care management? How would you explain it to a service user? How can we ensure that we are focusing on racial and health equity in care management?
    - Based on your experience/knowledge as an advocate, how important is care management in treatment?
    - Please give an example of good care management, both in terms of the “how” or provision (process) and the “who” or role (qualities of good case managers).
    - If you have had no involvement in care management, what do you imagine it should involve?
    - State Goal: The goal of this collaborative is to make policy recommendations to DHHS and Medicaid regarding the care management function in NC’s managed care system from the perspective of consumers/service users. The Department is currently shaping its care management plans. What advice would you offer to leadership today to get things on the right track?
    - What would you consider to be an important goal or outcome of this collaborative that would make this beneficial to you?

3. Next Steps (5 minutes)
    - Confirm individual’s commitment to Collaborative.
    - Identify schedule or at least 1st zoom meeting date.

Trending Issues Identified in Interviews

1. Systemic Issues

Distinguish between Standard Plan and Tailored Plan Care Management:

- Include both Medicaid and State funding
- Statewide group of consumers/families having authority to provide some direction to DHHS
- Statewide risk stratification for amount of care management needed
- Standard Plan Consistency in Eligibility Definitions--who is eligible, how do they get it, time period you are eligible
- Statewide weighted fields that determine who will be eligible for care management
- Emphasis should be on outcomes and not processes

Transitions of Care:

- Cannot be long wait times when things happen, e.g. medication non-compliance should not mean that an individual starts from zero and has to wait to get services

Needed Education Materials/Info Sharing/Getting the Word Out:

- Hits different levels of understanding

Person Centered Planning/Individual Support Plan/Service Coordination:

- Outcomes should focus on the individual and not the care manager
- Also need for it to be a Family Centered Plan when appropriate
- Connection to the schools

2. Organizational/Individual Care Managers

Organization/Care Team:

- Must be about the organizational culture that promotes consistency across care managers because cannot rely on the same care manager for long-term
- Focus on what the consumer/family want to achieve
- Caseload Size for each Care Manager
- Peer Support Specialists to support care manager
- Choice of Providers and Care Managers
- Customer Service is a priority
- Allow care managers to help consumers and not try to talk consumer down to fit UM
- Frequent consumer surveys to rate services
- Philosophy should be working toward resiliency

- Value-based interviewing when developing teams
- Using technology to engage consumers through texts, emails, etc.
- Emphasis on outcomes and not on processes

Training:

- Needs to understand the system as a whole in order to make referrals and know resources available
- Expectation that a care manager has an understanding/vision for success going forward for the individual
- Communication skills training
- Diversity training to respect how individuals want to be identified.
- Address workforce issues
- Recruiting case managers who look like their clients, share cultures
- Whole person care
- Goals must be goals of the individuals. Problem-solving is based on the goals of the individuals
- Being able to interact socially with other people, educating about keeping appts, connecting them to resources to get to those appts, showing how to fill out applications, teaching them how to lead productive life with their disability, wellness recovery action plan, identify triggers, eating better, WRAP plan

Building trust:

- Allow initial time for trust building
- Peer Support Specialists to support care manager
- Built-in time to discuss more than medication monitoring
- Having time to talk to families/parents
- Honoring self-determination
- Create strong understanding that there is a firewall between utilization management and care management
- Care managers responsibility is to not say no to the consumer

Outreach and Engagement with Consumers and Families:

- Education geared toward parents
- Use Engagement strategies and not just motivational interviewing
- Using technology to fullest extent

Addressing Unmet Health Needs:

- Life skills training
- Natural support development
- Going beyond the traditional medical model
- Understanding the community-based resources available near that consumer/family

Person Centered Planning/Individual Support Plan/Service Coordination:

- Outcomes should focus on the individual and not the care manager
- Also need for it to be a Family Centered Plan when appropriate
- Connection to the schools

3. Interaction with Other Practitioners and Community Resources

Reimbursement for Multi-disciplinary providers:

- Need for primary care docs, psychiatrists, LMFT, etc. to get paid for their time work with the care manager
- Using MOAs across practitioners to formalize relationships
- Education and inclusion of primary care in how to promote care management process with consumers/families

Link to Community-based resources:

- Network adequacy in rural areas
- Centralized locations needed for services, e.g. wellness centers

Appendix B: Care Management Overview Handout obtained at this link

Appendix C: Consumer-Care Manager Engagement Sheet

Empowering Consumers and Families in Care Management: Questions and Statements Consumers/Families Can Use During the Comprehensive Assessment and Beyond

Background Information: As a Medicaid member of a Standard Plan you may or may not have a care manager and as a Medicaid member of a BH/IDD Tailored Plan you are automatically assigned a care manager. Care management provides Medicaid beneficiaries with a multi-disciplinary approach to coordinating physical healthcare, mental health, substance use disorder services, pharmacy needs and long-term services and supports (I wonder here if we should explain what LTSS is? Maybe add, long term services and supports such as staff to provide respite or services in your home; day programs, residential supports, or other needs. Care management also provides you direct linkages to programs and services that address unmet health-related resource needs affecting social determinants of health (I don't think most families know what this is – perhaps we should add, such as education, housing, food needs, transportation and so on), along with follow-up and ongoing planning.

Care managers are required to conduct a comprehensive assessment of your needs when you begin to receive services and update that assessment every year. Below are questions and statements that you can use to:

- make the comprehensive assessment process as productive for you as possible;
- give your care manager an opportunity to get to know you better;
- formulate goals to meet your needs.

Plan ahead for your first meeting with your care manager by choosing the questions/statements that mean the most to you. Think about how you want to approach those questions/statements with the care manager and how you want to respond to those questions and statements.

What's Important to Me:

- What name or nickname would you like to be called? What pronoun(s) do you use? Do you go by he/him/his, she/her/hers, they/theirs?
- In understanding barriers to your primary care, and other goals for your life, what intersections of your identity (we typically write things at a 5-7 grade reading level. Many people that I talk to would not understand "intersections of your identity) do you want your care manager to better understand?
- What are the three most important things we should know about you or your family member?
- Who else do you want here or talking to the care manager? Who knows you better than anyone? (typically plans only require that we list guardians, but you may have cousins, aunts, friends, other people with I/DD/BH needs that are not typically included in the record listings.)
- Who/what are people/things (resources) you would want to include as we move forward with planning? OR who do you trust?
- What are the things you are already doing that have been helpful?
- In what ways do you want to celebrate your community; what communities do you feel responsible to, connected to?

- Tell me what makes you most able to cope when you are very upset and in a crisis? (crisis plans should include early options – call a friend, deep breathing, etc., and providers should know what calms someone down.)
- When something bad happens, what is your first response likely to be? This question helps us understand what the auto response is for the person and teaches staff to watch for this.
- Will there be opportunity for us to meet face-to-face?
- What is NOT working in your life right now? Do you have ideas how to make that better? What needs to happen so this is not a problem for you?

Getting to Know Your Goals in Treatment and Supports:

- My goals for the next 6 months/year or so are….
- My most important goal right now is ….
- How will we know if we are successful? What would guarantee failure?
- What can a care manager do to help you achieve those goals?
- What has worked best for you in the past to improve your situation?
- Think of a time when you have felt most alive and invigorated. What are you doing? What is in your hands? What are you looking at? How does your body feel? After thinking about this, is there a way for you to do this thing that makes you feel good? If not, what barriers are in the way? A) Time B) Money C) Support in your community D) Transportation E) All of the above
- What are you most worried about now?
- What are you most looking forward to in the future?
- What are some possible roadblocks /challenges that might get in the way of you achieving your goals? OR what has happened in the past that you want to avoid happening in the future?
- Do you use technology? Have a cell phone, computer, smart watch or tablet? Do you need help with any of that? Do you have Alexa?

Consumer/Family and Care Management Agency Communication:

- What is the best way for us to communicate when we are not together in-person? Phone? Email? Text?
- If the care manager sees you are having difficulty doing something, would you like for that individual to ask if you need help or just step in and help you without asking?
- When the care manager is with you in the community, do you want that individual to be a part of the conversation with your family/friends or would you rather that individual hangs back away from the conversation?

Building Resilience Prevention:

- What supports can shore you up in your life? Ex: financial assistance; emotional support; education from physician; more time with my doctor.
- If you could have access to any service that you feel would benefit your care and recovery, what would it be? Ex: Mindfulness Training - Learning how to be in the now; Talk Therapy - Talking with someone about your recovery; Art Therapy - Using art/writing/photography/etc as a way of processing emotions; Financial Support -

Financial Resources to help you get and remain financially stable; Trauma Therapy - Addressing past and present traumas and healing through them

- How would you like to know about OR what is your perspective on connecting with someone with similar lived experiences (i.e., certified peer support/family advocate/partner, youth advocate etc.)?

For Your Information:

What is care management? A 2019 concept paper published by the NC Department of Health and Human Services distinguishes between care management, care coordination and case management:

For the purposes of its care management strategy, North Carolina has developed the following definitions.

Care Management: A team-based, person-centered approach to effectively managing patients' medical, social and behavioral conditions, which includes:

- Management of rare diseases and high-cost procedures (e.g., transplant, specialty drugs)
- Management of beneficiary needs during transitions of care (e.g., from hospital to home)
- High-risk care management (e.g., high utilizers, high-cost beneficiaries)
- Chronic care management (e.g., management of multiple chronic conditions)
- Management of high-risk social environments (e.g., adverse childhood events, domestic violence)
- Identification of beneficiaries in need of care management (e.g., screening, risk stratification, priority populations)
- Development of care management assessments/care plans (across targeted populations)
- Development and deployment of prevention and population health programs
- Coordination of services (e.g., appointment/wellness reminders, social services coordination/referrals)

Care Coordination: The process of organizing patient care activities and sharing information among all the participants concerned with a beneficiary's care to achieve safer and more effective care. Through organized care coordination, beneficiaries' needs, and preferences are known ahead of time and communicated at the right time to the right people to provide safe, appropriate and effective care. Local Management Entities-Managed Care Organizations (LME-MCOs) currently provide care coordination to select groups of beneficiaries. As described below, Tailored Care Management is broader than and inclusive of care coordination.

Case Management: Federal regulations define case management as "services furnished to assist individuals eligible under the [Medicaid] State Plan who reside in a community setting or who are transitioning to a community setting, in gaining access to needed medical, social, and other services" (42 CFR 44.169). See section II for information on avoiding duplication between care management and case management embedded in enhanced behavioral health services. Case management provided within the Innovations and TBI waivers, which currently addresses only waiver services, will be incorporated into Tailored Care Management.

Appendix D

i2i CENTER for INTEGRATIVE HEALTH
insight to innovation

NORTH CAROLINA
NCCHCA
Serving Community & Migrant Health Centers
Community Health Center Association

July 12, 2021

Mandy Cohen, MD, MPH
Secretary, NC DHHS
2001 Mail Service Center Raleigh,
NC 27699-2000

Dear Secretary Cohen:

The i2i Center for Integrative Health in partnership with the NC Community Health Center Association, with funding from the Delta Center for a Thriving Public Safety Net, has convened a group of Medicaid recipients to support the development of care management under the Standard and Tailored Plans. Our commitment is to offer suggestions and recommendations that truly speak to the value of care management from the critical perspective of service users, and we look forward to sharing our findings with you in several months.

One of the areas discussed recently relates to options for consumer and provider choice. The search criteria both for choosing providers and for patients accepted by providers include a "gender" indicator, and in both cases the options are male or female. This creates a dilemma for service users who are transgender, both in terms of accurately identifying themselves and in terms of having adequate information about and for a provider.

To correct this oversight, we suggest, at a minimum, that a 3rd box be available on the provider search. That box could simply note an "Other" category, which would not force service users to identify as "Male" or "Female", would allow providers to more correctly indicate patients treated, and will reflect inclusivity and diversity.

While we are hopeful that this is something the Department is already working to address, our Collaborative wanted to ensure that it is, indeed, on your radar, and we respectfully request that NCDHHS actively work to make a change. We recognize that such a change requires technical and system changes, and we appreciate the necessary work.

On behalf of the Collaborative, I thank you for your attention to this request.
Sincerely,

Ann Rodriguez, MHA	Chris Shank
Executive Director	CEO and President
i2i Center for Integrative Health	NC Community Health Centers Assn.

cc: Dave Richard
Kody Kinsley
Shannon Dowler, MD

Appendix E
Templates for Soliciting Collaborative Members and Donors

1. Delta Alumni Collaborative Member Request

TO: Potential Collaborative Members

FROM: Ann Rodriguez, Executive Director, i2i Center for integrative Health

Chris Shank, Chief Executive Officer and President, NC Community Health Centers Association

RE: **Participation in Collaborative to Define the Value of Care Management**

The i2i Center for Integrative Health and the NC Community Health Centers Association have recently been awarded a one-year Delta Center for a Thriving Public Safety Net alumni grant related to value-based care. Our grant proposal is to convene a collaborative group that will work to define the value of care management as it is structured within Medicaid Transformation. We plan to use this opportunity to consider care management in a larger context, as a role that is crucial to addressing racial and health equity issues and the pandemic. Here is a link to a newsletter article recently published by i2i that gives you a little more detail about the grant. The product will be recommendations that are published and sent to NC DHHS leaders as well as PHPs and LME/MCOs. Our collaborative will consist of:

- 7 Consumer/Family members familiar with the LME/MCO system
- 7 Consumer/Family members who either serve on FQHC/CHC boards or have used a FQHC/CHC for services
- 3 providers within the LME/MCO system
- 3 providers within the FQHC/CHC system
- Ad Hoc representation from NC DHHS

We are writing today to invite you to participate in this collaborative. We expect the collaborative to begin in March 2021 and continue through October 2021. It will require approximately three hours of your time to participate in a once-a-month, virtual meeting. We will also ask you to participate in a one-hour interview between just you and the grant staff to talk through your goals in your participating in this endeavor and your general thoughts around care management. This interview will occur right away and we will seek a time that is convenient to you.

We are pleased to offer compensation to consumer/family representatives on the collaborative. This compensation will be provided at the end of the collaborative process and is a means of acknowledging the time you have devoted to this process.

Please let us know if you are willing to participate in this important collaborative. You can contact Ann Rodriguez at ann@i2icenter.org for more information.

Thank you so much!

2. Delta Alumni Collaborative Provider Member Request

TO: Potential Collaborative Provider Members

FROM: Ann Rodriguez, Executive Director, i2i Center for integrative Health

RE: **Participation in Collaborative to Define the Value of Care Management**

The i2i Center for Integrative Health and the NC Community Health Centers Association have recently been awarded a one-year Delta Center for a Thriving Public Safety Net alumni grant related to value-based care. Our grant proposal is to convene a collaborative group that will work to define the value of care management as it is structured within Medicaid Transformation. We plan to use this opportunity to consider care management in a larger context, as a role that is crucial to addressing racial and health equity issues and the pandemic. Here is a link to a newsletter article recently published by i2i that gives you a little more detail about the grant. The product will be recommendations that are published and sent to NC DHHS leaders as well as PHPs and LME/MCOs. Our collaborative will consist of:

- 7 Consumer/Family members familiar with the LME/MCO system
- 7 Consumer/Family members who serve on FQHC/CHC boards
- 3 providers within the LME/MCO system
- 3 providers within the FQHC/CHC system
- Ad Hoc representation from NC DHHS.

We are writing today to invite you to nominate an individual from your organization to participate in the collaborative. We expect the collaborative to begin in March 2021 and continue through October 2021. It will require approximately three hours of your time to participate in a once-a-month, virtual meeting. We will also ask you to participate in a one-time only, one-hour interview between just you and the grant staff prior to the beginning of the collaborative to talk through your goals in your participation in this endeavor and your general thoughts around care management. This interview will occur in late January 2021 – February 2021 and we will seek a time that is convenient to you.

The yellow highlighted positions are the ones we are seeking to fill through this correspondence. We are seeking organizations that intend to serve as Advance Medical Home Tier 3, Advanced Medical Home Plus or Care Management Agencies. If your organization fits this criteria and you would like to have a representative at the table, we would welcome this nomination.

This is an exciting opportunity to impact the care management role in Medicaid managed care! Please let us know as soon as possible and no later than January 15, 2021. You can contact Ann Rodriguez at ann@i2icenter.org for more information.

Thank you so much!

3. Delta Alumni Donation Request

TO: LME/MCOs and Prepaid Health Plans

FROM: Ann Rodriguez, Executive Director, i2i Center for integrative Health

Chris Shank, Chief Executive Officer and President, NC Community Health Centers Association

RE: **Consumer/Family Compensation to Participate in Collaborative on the Value of Care Management**

The i2i Center for Integrative Health and the NC Community Health Centers Association have recently been awarded a one-year Delta Center for a Thriving Public Safety Net alumni grant related to value-based care. Our grant proposal is to convene a collaborative group that will work to define the value of care management as it is structured within Medicaid Transformation. We plan to use this opportunity to consider care management in a larger context, as a role that is crucial to addressing racial and health equity issues and the pandemic. Here is a link to a newsletter article recently published by i2i that gives you a little more detail about the grant.

We are writing today to request a donation for a very important aspect of the collaborative. Representatives within the collaborative will be predominantly consumers and family members – 14 of the 20 members. As you know, consumers and family members often have a more difficult time participating in statewide groups because they have unrelated jobs or simply do not have the financial means to participate. We would like to offer compensation to consumer/family representatives on the collaborative for their involvement and time. Unfortunately, the alumni grant amount did not account for adequate compensation.

For this reason, we are seeking donations of $1,000 or more from LME/MCOs and PHPs and that donation will only be used for compensation to consumer/family representatives. In return for your generosity, we would like to provide your organization with a pre-release copy of the final recommendations that are made by the collaborative as well as an acknowledgement of your contribution during a webinar we will offer to all stakeholders who are interested in the recommendations of the collaborative and any publications related to the grant.

Please let us know if we can count on your organization to donate toward this worthy endeavor. You can contact Ann Rodriguez at ann@i2icenter.org for more information and/or to let us know of your donation. We will be glad to send an invoice for the donation.

Thank you so much!

Delta Alumni Grant Collaborative Representation Factors:

- Consumer/Family/Peer Experience (LME/MCO or FQHC/CHC)
- Provider Intending to be a Care Manager (LME/MCO or FQHC/CHC)
- Geographical Representation
- Diversity Representation (People of Color, LGBTQIA+ Community Members)
- Standard Plan or BH/IDD Tailored Plan Experience
- MH
- IDD
- SUD

Appendix F

Redacted and Compiled Interview Responses:

General experience with Medicaid in the past:

- Experienced frustration in not being able to have full conversations with providers. Has wanted to have services focused on life skills rather than just medication. Hard to know that, as a parent, your financial standing is impacting the care of your child. Has worked in health care insurance. Government processes are overwhelming to comply with.
- Has a legal background in the medical field. Has experience in out-of-home placement of kids and case management for those children. Is now an educator and case manages his special education students. State CFAC Chair. Wrote the CFAC proposal for consumer advisory councils for PHPs.
- See similarities across child and adult services for the same needs when an individual is long-term requiring services and supports.
- Dual enrollee did get a letter to enroll in the Standard Plan even though she isn't eligible. Parent of children on Medicaid with a lot of disabilities. I/DD/Autism. "Clustered family" with multiple family members having needs. ADHD, autism, neuro-diversity advocate. They have physical disabilities that qualifies them for Medicaid. Took 10 years to get official diagnosis of autism. Worked with autistic individuals.
- Population that they support are children and adults with I/DD. Mostly Medicaid. A small part is state funding. Did provide targeted case management—mostly home care. Are submitting application to be a statewide CMA. Approaching it by starting with one region of the state and then ramp up to statewide. Philosophy of organization is to serve communities well because they are in the communities. Developing what the firewall has to look like since they also provide treatment services. Know that they will not care manage those individuals who they serve.
- Had to seek crisis care in the public system. Social workers in the hospital set up Medicaid to help cover at least some of the costs. Also on a Medicare Advantage plan. Has experienced that there are services that can help her but those new services aren't funded through Medicaid and Medicare. She has been served under integrated care with case managers and primary care physician and psychiatrist. Not a lot of options for primary care person.
- No real experience directly with care management, but hears lots of stories about good old days of case management, how lost people are today because it's not there. People don't know what to do. Re: equity…impossible to find adequate services in some areas. Latino community constantly left out….nothing in their language.
- Nothing for parents who come in thru primary care. Not enough staff or resources to pull everything together. We are not ready for wholesale Medicaid change. Back in the old days when we had case management it was so much easier to find help. Access issues.
- Has been involved in Medicaid and has family members on Medicaid. Also did not qualify for full Medicaid. Provider but not a Medicaid provider. Created a wellness center.

Understanding of new Medicaid system in general:

- Hopeful that it will expand services because it is being run by private insurance companies. The materials have been extensive and not necessarily easy to understand.
- Struggling in the traditional medical model. Met other people who were seeking other options that focus on whole person care. Ex. A psychiatrist might recognize that some things like nutrient deficiency may help patient's health. Gave example of Duke having a good integrated system. Rehabilitation physician at UNC is primary care physician. Would appreciate having someone from her background, e.g race. Having choice in practitioners who can connect with patient more.
- The care management vision sounds like reorganizing what has happened historically, and the dynamic remains the same. Case management as a separate service went away and the assumption was that it was being done as a part of other services. Leap of faith that what was case management can still exist for a certain number of times a year but concerns that this isn't enough.

Past experience/involvement with care management:

- Psychiatrist and counselor do not talk to each other. Bridge becomes the parent. Told that there is not a billing code for the doctors/counselors to talk to each other.
- Never saw a care coordinator. She knew more about resources than the case manager lots of times because she spent time with person. Role more meaningful if involved and less clinical. Supported providers more than young person. Not always prepared. Not focused on self-determination. As much as they should be. It was about what is Medicaid billable.
- Been a participant observer of system from case to care management. Bringing people in to try to explain differences and nuances. Dynamic stays the same, case management is so needed but then it changed to be done in the context of services which didn't make sense to him. Now care management will happen in little shots of this thru a touch maybe 4 times/year. Not what we thought case management to be.
- Agency has been conducting care management for individuals with IDD for a long time. In residential have always done primary care integration as care management function. Boots on the ground. Later started tracking primary issues with non-residential, not as case managers but would connect with others to recommend needed services. Now not everything is integrated but if there is an issue then will share notes and information.
  On behavioral health side, doing the same connecting in residential, but may vary according to level of need/involvement. Higher level folks more focused on self-determination. Moderate to severe it's boots on the ground. Agency has formalized their doctor-to-primary-healthcare-doctor interactions. Not much back and forth except in CCBHC where their care managers facilitate work…more integrated.
  They do risk stratification to determine level of care management need in CCBHC. SDOH are critical. Risk stratification drives the level of involvement. Stratification requires some flexibility and should be a guide not an absolute. Levels shouldn't have rates…should be case mix and provider gets an amount of $ to do their work. Technology is extremely important (ex: Patient Ping).
- A lot of experience with case management. Most important for a case manager to not be overloaded with cases. Can be determined by frequency of visits. If overloaded, not effective. Having that point of contact is crucial for complicated care. Helps parents learn skills and strategies to assist the child. Care can change from day-to-day. Care

manager can get in touch with professionals sometimes easier than a parent can. Case manager at school has been very good at advocated for them.
- Finding a way to support disadvantaged providers to make sure that they have what's needed to want to participate and want to be qualified. Ensuring true integrated care management.
- Is a peer support specialist. Has seen the short-term care benefit when there is long-term need for this kind of support. Being able to interact socially with other people, educating about keeping appts, connecting them to resources to get to those appts, showing how to fill out applications, teaching them how to lead productive life with their disability, wellness recovery action plan, identify triggers, eating better.

Definition of care management/ensuring that we are focusing on racial and health equity in care management:

- Liaison between the schools and the health care system and the parent. Someone who knows resources that are covered and can assist parents navigate. Providers don't see the bigger picture so they cannot respond with that bigger view. Good to have a role where the child is at the center of what they do. The whole picture of a child is not just the hour that they are in the doctor's office. People around them need to be educated on what the child needs (what is learned at the doctor's office).
- Care management has person who needs the care and the family in the center of your thinking. The people around as "touch points" who can talk to each other and share info. Someone who gets the person and can share about your child to figure out the best way to support the person and their family. Do you see what has been available and care management differently? Case management is nuts and bolts. Care management identifies what the individual needs to be successful going forward. May not be just the evidence-based tools but also family understanding what care management is and what their rights are around that. Need support for the family/caregivers
- Care management is more definition different than case management only by the government. Case management is so much more than care management. Case management difficult and see it as lacking. In their personal situation, as knowledgeable as they are about the system, they have problems with navigating. Integrated care, coordination of benefits, closer touch. Not sure they will get this in care management. Seems to be a focus on the money. Is the vision really possible in reality? How do we identify outcomes? He has mixed feelings about surveys. Outcomes should focus on the individual and not the work of the care manager. Workforce must be sufficient, pay must be livable, training has to be available. Especially must be considered in rural areas. Need to be able to spend time with the consumer and family and build up trust.
- Connecting with provider in community. Getting authorizations, Meeting medical necessity. Should look like a peer or have a peer who would be a bridge.
- Person who gets your child can advocate, take some of the burden off the parent. Case management is nuts and bolts. Care management is what the person needs, may not be specific services. Family needs to understand what care management is and what their rights are. Parents need support, don't need this system to give them PTSD.
- Definitional differences from bureaucratic end. Some complex needs individuals need both care and case management. Case management is very difficult…has waiver and private insurance plans…. very difficult. Family can manage care pretty well. But they see case management lacking….so tough so many handicaps on case managers.

- Care managers are responsible to make sure person is connected with their provider, resources in the community, getting what they medically need or getting medically needed services, more in-person, very important role and should be more present, less clinical, more to support the consumer rather than the provider, having resources to assist a person with things that are not billable, i.e. things that keep a person connected with their communities. Peer could be the bridge. When the peer is no longer there, the person's drive can go away and changes the dynamic. Natural supports are important—helping the person to build those. Natural supports are more sustainable so create more stability for an individual.
- How courageous is DHHS willing to be in looking at systemic racism and policies that may contribute to it? Crisis response, for example, how is that handled to overcome systemic racism? Racial healing and community healing is needed. Investments made in local communities in healing practices—addressing health, trust, how to work with communities and the roots of those communities. Creating safer outdoor spaces in local communities.
- Ample time to do the pre-work before meeting with the consumer/family. Reaching out to all of the people who are connected to that person as a part of reimbursable work. Takes a level of frequency and intensity. Allow flexibility for the communication pieces. Not concerned with overlapping roles. Everyone must experience successes to get buy-in. Care managers must embrace the system of care and the value of coordinating. Culture must be there for it to be focused on the person and not the process. Flexibility in the role.
- LGBTQ understanding of pronouns. Respect for the name to be used, e.g. medical records, forms. Suggests a choice of race to "mixed."
- Get rid of the "siloes." Coordinating all the various providers who work with this same individual. Includes education. View the person as a whole person rather than in categories. Care manager sees each domain of that person's life as equally important as another. What are the other resources that can really add value to that person's life? Focus on what the consumer wants to achieve.
- How can we make sure a consumer is matched with a care manager who connects well with them so that the individual and family are not having to do so much leg work? In a perfect world, the hospital would communicate with your current providers (hospital assumes that you have been non-compliant, so they start from ground zero instead of talking to the current providers). So, hospitals can become disruptive to care by changing medications and services. There is some lack of education about being able to get hospital care/crisis care that it can be covered by public funds. Some people don't seek care early enough because they are afraid of the cost on them. Often providers don't acknowledge how much the consumer knows about their own care. So, having providers who can listen to a consumer that he/she/they are escalating to a potential crisis. Valuing the lived experience. How does peer support/community health workers interact with care management? Professionals need to be educated on how not to make assumptions about individuals that effect their decisions on the level of need for that consumer. Making sure the care manager role is fluid so they can come in when it matters rather than a structured process of touches.
- Implication that the care manager is going to have a relationship with the person. Could be very important. If that is true, with these brief exposures to someone, basis of connection is customer service. Need to build trust, believe that care manager is

interested in making sure getting what you need/appropriate healthcare. Predicated on a relationship. Turnover will be a difficult challenge. Educate care managers on engagement strategies—not just motivational interviewing. Cannot have perception that the care manager has the connection to utilization management to decide how much services the person will get. Clarity that the care manager's job is not to tell them "no." Care managers offer other opportunities to consumers, e.g. wellness talks, etc.) as a chance for the care manager to build relationships with the individuals. Ideas of ways to evaluate the effectiveness of care management. Immediate text to consumer about how helpful contact is to care and coordination of services.

- Care management would reduce stress. Ex: people with disabilities are in lowest vaccination group. Family navigator role is genius but usually volunteer.
- Care management vs. case management. Confusing between the two. Case management personal, developed a relationship, person always available. Care management thinks more of a care coordinator to pull together all services family needs, not as personal. Background in social work and thinks term "case" indicates a more personal touch. Families aren't clear about what care management entails so don't know what to ask for.
- Network adequacy is a problem in rural areas. No choice of providers. Need to be able to go somewhere in a crisis. Should not have to wait for services. Example is medication non-compliance and then told have to get an appt before med can be prescribed again.
- Consumers need a wellness center in each community. Wellness center is a place where they can go to get everything: therapy, med management, exercise, NC WORKS programs, supported employment. Centralized location. Medicaid should be paying for more of those services. Peer respite should be paid for Medicaid. Need more non-traditional services that are evidence-based.

Importance of care management in treatment and what the role can mean for consumers and families:

- Care manager can provide the insight and understanding about the needs of the consumer, child, family. This can free-up time for providers and save money over time.
- Care manager should provide support and validation for parent and education. Son would benefit from a mother who is less stressed. Someone to help organize all of the different aspects of their lives. Someone youth can check in with to remind him of strategies and supports. Someone to have resources, educational materials, to provide to parents.
- Good care management has occurred only through individuals that understand it. It hasn't helped through a systemic way. Many practitioners don't seem to understand the family perspective. Communication that goes beyond "siloes." The ability for any provider to help you the family navigate the system. Having a system in place so that the success of navigating isn't contingent on the individual's and the family's information and knowledge or to coordinate their services. Primary care practitioners understanding appropriate referrals out to community providers that are available and appropriate (e.g. beyond developmental pediatrician)
- Could be very important. Implication is that care manager will have relationship with individual. The extent to which care managers are trained and are really good at engagement strategies will impact, especially with care manager turnover. Care

manager shouldn't be someone who is going to tell the person NO…and there is a sense that if the consumer says, "I'm doing better," the care manager will decide that services will decrease. Care manager should work on behalf of the individual. Care managers should see information as tools to offer individual to support their health.

- Care management should include communications that goes beyond siloes. Ability to take things from a family perspective and can think from perspective and understand. Ability to help you navigate the system. Right now, it's word of mouth.
- Looking at how they can take the informal relationships they have had with practices in the past and make them more formalized, e.g. MOAs. Using NCCARE360. Closing the circle to know that the person got what they needed.
- Has time to get to know the consumer. Has created a trust with him/her. Able to look at non-medical drivers. Isn't a person to say no to having services.
- Know the racial mix of the constituency and ensure that care managers represent that mix and the same for health equity. Recruiting so the care management team has a ratio that reflects the community. Train those care managers who do represent that community other care managers on their team.
- Solving so many issues, time, energy and money if you can direct families to what they need instead of trial and error. Have an opportunity for families to put energy into where it is needed. Lack of guidance and explanation of expectations. Concern that it will be different across LME/MCOs. Parents need more resources.

Advice to NC DHHS on care management:

- There has to be a balance between honesty that the bottom line is important and that the needs being met are important.
- Listen to families. Understand the scenarios and who the important people are touching the lives of the kids. Know how to communicate with groups that have different levels of understanding and not just educate but also communicate. Need to address this at many different levels, e.g. helping people to turn the page to this new way of doing things.
- We do have motivated and good leadership to keep this vision going. It will all be about the implementation of this. Keep focus on what consumers and families need.
- Focus on natural support development which comes before peer support. Natural supports also help with crisis planning.
- Managed care has a yes and a no side. Care managers should be trained to be on the yes side.
- Care management teams should reflect diversity/equity of the community where they work. Variations should reflect community. Care managers can use racially similar folks on their teams to help them be sensitive.
- Don't be overall prescriptive. Be prescriptive with larger issues and tracking. Identify minimums. Floors not ceilings. Emphasize SDOH. Not paper over people…plan writing instead of outcomes/getting what the person needs.
- Where is the money going to come from to make this a robust model? Will there be enough money for the care managers to really work with families. Using descriptors or words, what values are most important? Value descriptors that are practical enough to move them into policy. How does that translate to meet in the middle with the operational framework?

- Total lives served—look at the number of people who are receiving supports/care management, statewide 30,000, glidepath eases people out but will that really support providers who are gearing up to be care managers. Is this plan sustainable right now? Do we need to look at the PMPM differently? How will we compensate, and does it support the initial years?
- Managed care has two big administrative functions of saying "yes" and saying "no". Care manager should be on the saying "yes" side.
- Piece of advice for NC DHHS—what would it be? Person centered plan move to family-centered plan. Personal exchange and relationship. Family feels comfortable. Care manager knows the family. If this is done upfront, the rest of the relationship will come more easily. Spend more time getting to know the family and their situation. So many people have complicated physical needs. This seems like a big lift because we haven't adequately dealt with the MHIDDSAS system. Gaps in the system. Give family a sense of security and empowerment. As they feel empowered, they feel they are in a position to give feedback. Underfunded system. Gaps in the service system. Taking time to get to know the consumers/families is part of the value proposition.
- Has not had the best experiences with DHHS listening and valuing consumers. Build a committee or subcommittee of consumers, families. People of lived experience. DHHS really standing behind what the committee says.

What would you consider to be an important goal or outcome of this collaborative that would make this beneficial to you?

- [NC DHHS} Wants to hear from other consumer/family members to get other perspectives.
- Ensuring choice for individuals. Quality data. Increasing accountability in the system. Weighted metrics that reflect individuals and that the PHP must respond to.
- To be a voice that keeps system recs on what human beings rather than the administrative side whose goal is to run a smooth managed care service.
- Begin by focus on establishing common definition of care management. Send list of descriptors and ask them to circle top 3 things that are characteristics of care manager to support getting to definition.
- Wants to understand other people's points of view. Wants this to be a positive environment that we're working towards common outcomes and goals together. Do something, don't just talk about it…be action oriented.
- Understanding what hasn't worked in past and what would work in the future.
- Choice. Educated on choices. Making sure there is a way the individual to be focused on. Not cookie cutter. Responsive systems. Quality measurement—data, ways to hold the system is accountable. Metrics that balance so they are not just clinical. Feedback/surveys that come from independent organizations working with consumers.
- Helping everyone to push forward with actionable steps.
- Knowing that there will be family members and consumers will help them to develop their care management practice. This will be invaluable. Having the insights of consumer and family members.
- Be one more voice keeping it focused less on bureaucratic and more calibrated toward what the users need. Care management is not the purpose to have a well-run organization but instead to meet consumers needs.

- Positive change, focus on families, focus on roadblocks to families having “life well lived”. A system that works. Have a huge barrier. Philosophies about budgets and “rainy day funds” are barriers to improving the system. Must be allowed to talk about the funding inadequacies of the system and how funding can assist in improvement.
- Change has been small and slow. Need to see bigger steps taken to bring consumers and family members in.