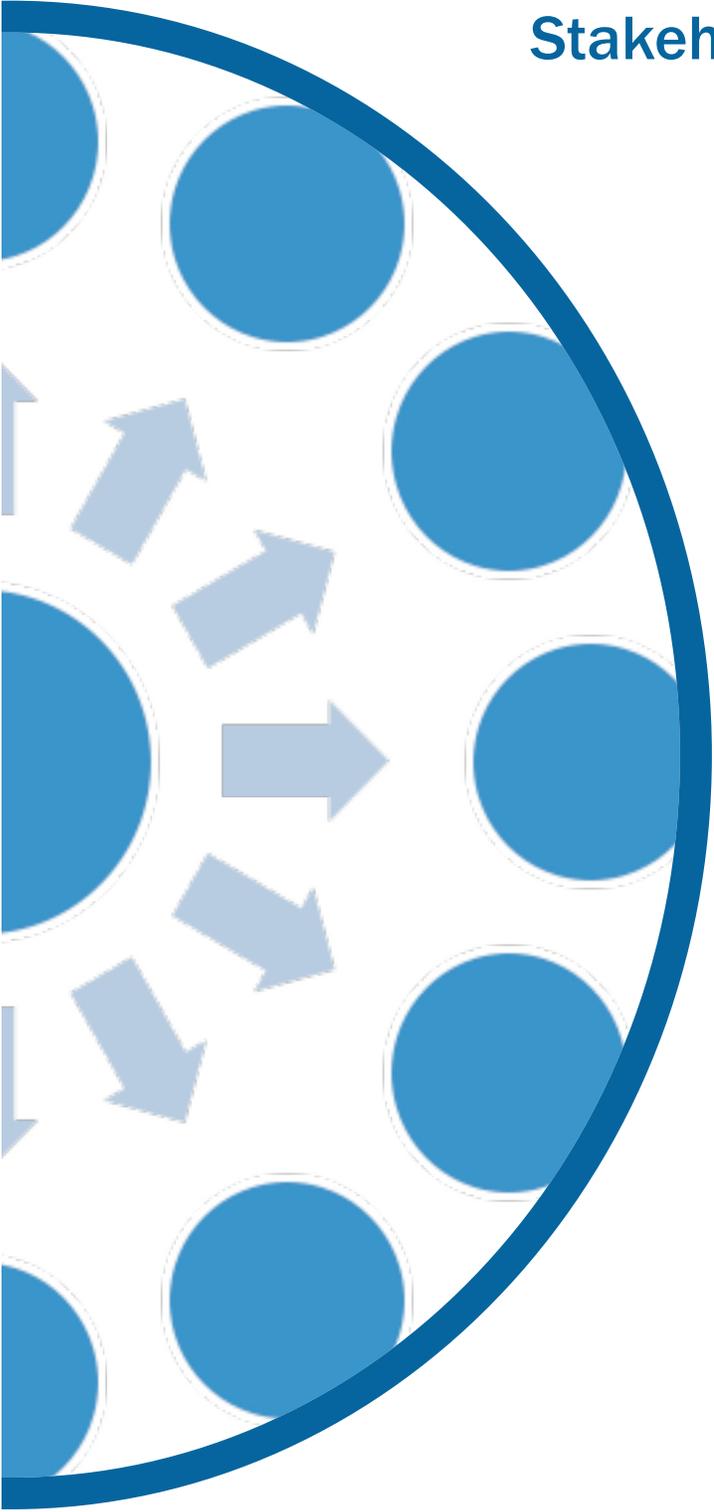
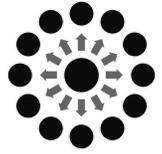


The SEG Way to a Healthy North Carolina

North Carolina Stakeholder Engagement Group Initiative



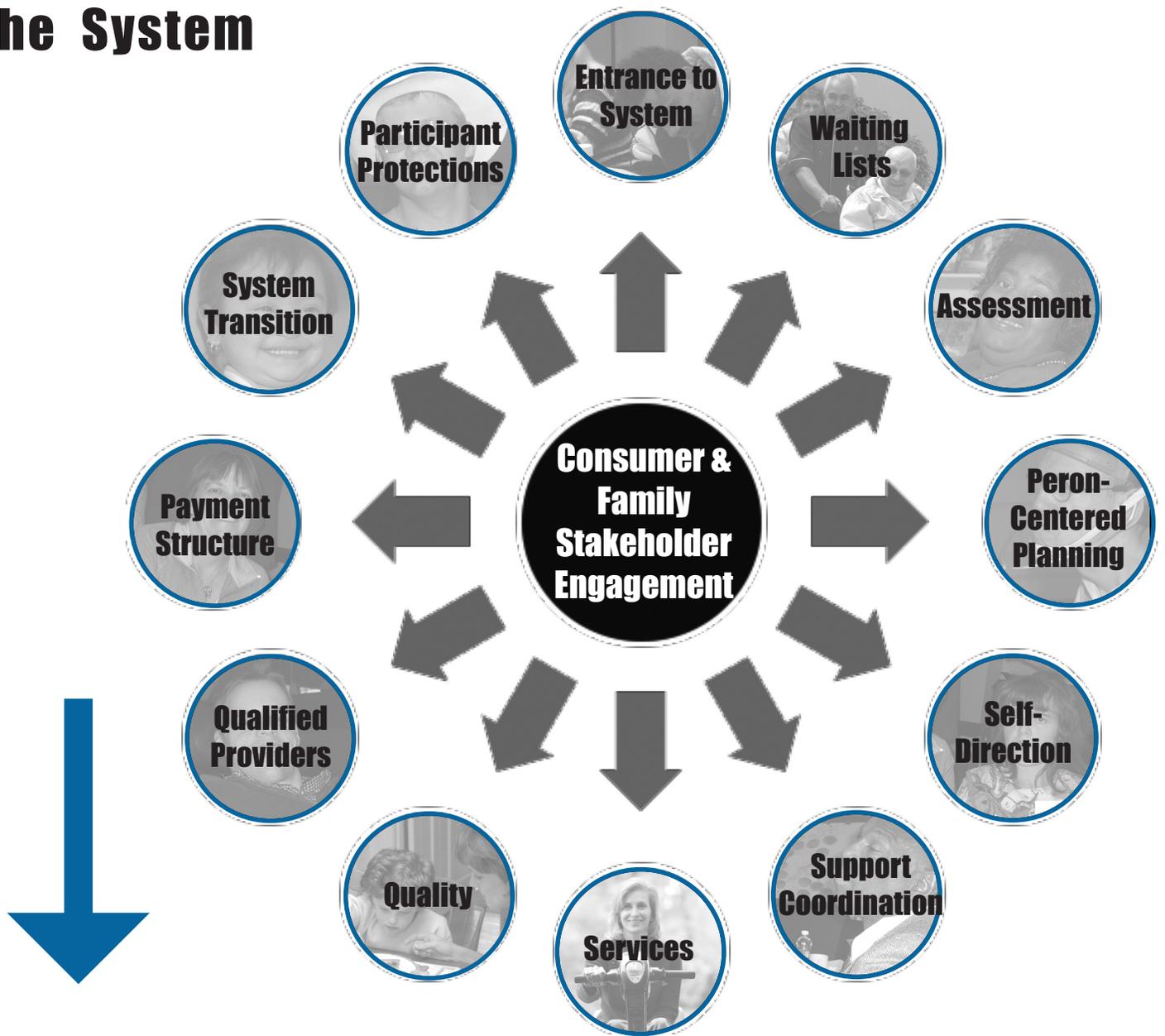
Outcomes and
Expectations for
Managed Long Term
Services and Supports

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Co-Chairs: **Michael Mayer**, Ph.D., President of National Alliance of Mental Illness (NAMI-NC) and **Ron Reeve**, Chairman, North Carolina Council on Developmental Disabilities (NCCDD)

A Consumer & Family Centered Approach for Managed Long Term Services and Supports Implementation

The System



The Outcomes

- No Waiting Lists
- Integrated Employment
- Inclusive Living
- Asset Development
- An Accountable System

For more information, contact Co-Chairs of the Stakeholder Engagement Group **Michael Mayer**, Ph.D., President of National Alliance on Mental Illness (NAMI-NC) at mikem@cra.cc or **Ron Reeve**, Chairman of the North Carolina Council on Developmental Disabilities (NCCDD) at rr77777@carolina.rr.com

Talking Points

Who is the “Stakeholder Engagement Group”?

We are currently the only group in North Carolina who is made up of only **individuals receiving services and their family members** and *no provider organizations with a potential for a conflict of interest*. We are called “Stakeholders” because we are affected by the decisions the state makes about long term care. We are called “cross-disability” because we represent developmental disabilities, mental health, addictive diseases, individuals with physical disabilities, and family caregivers. Our members came from all areas of the state.

What do we Want to do With This Information?

We want the leaders at DHHS, at Medicaid, and our state legislators to know what is important to us! As they develop plans for consolidating LME/MCOs, as they make plans for medical care, as they make plans for how we get services, we hope they will seriously consider what we have said, that they will carefully look at these outcomes and expectations, and discuss real ways to make improvements today and in the future that make these outcomes and expectations reality.

What Did we Discuss?

Our group very quickly defined five outcomes that were important to individuals and families from all disability groups. We want a system that helps us be more independent—a system that: 1) has **no waiting lists**; 2) **where individuals have jobs in integrated employment settings**; 3) **that individuals live inclusively in their communities**; 4) **that people with disabilities have the ability to develop assets**, and; 5) **that the system is accountable for meaningful outcomes**. We spent a lot of time

discussing our important expectations of the system such as: getting services for the first time, assessment, support coordination, assuring the availability of qualified providers, and protecting our rights.

Why Did We Get Together?

North Carolina wants to make changes to the way Medicaid services are delivered. **We met to develop a consensus about what we want from a long term care system--the values, principles, needs, and outcomes important to us – and then to communicate that consensus to key decision makers**. Because the results of the system re-design was our focus we did not focus on “how” the state should get there - such as who is in charge and how the money flows. We met for **six days over the past six months** and learned from state and national experts about how Medicaid works and the expectations of the Federal Government, options for what the future system might look like, and how we could best get our consensus message to the right people – or, put another way,” get our voices heard”.

How do we Talk About the Handout?

Here we are – the “**Consumer and Family Stakeholder**” – in the middle and at the heart of the entire system! We talked about **13 specific areas of the system** that were important to our ability to get the supports and services we need. Of course all of these things help us get to our outcomes – **no waiting lists, integrated employment, inclusive living, asset development, and an accountable system**. We hope you will use these materials too to talk about your experiences and expectations. **Nothing about us without us!**



Stakeholder Engagement Group (SEG): Meaningful Outcomes for Managed Long Term Services and Supports

We are a unique group comprised entirely of individuals receiving services and family members. We are the only cross-disability stakeholder group representing developmental disabilities, mental health, addictive diseases, individuals with physical disabilities, and family caregivers.

The Stakeholder Engagement Group worked for six months to reach consensus on outcomes - **“WHAT”** is needed in the long-term support system, rather than **“HOW”** to get there in terms of administration.

The **outcomes important** in a person’s life are: **inclusive living, integrated employment, asset development, no waiting lists, and an accountable system.**

Stakeholders identified 13 common areas of the long term services and support system and their expectations for each



Consumer & Family Expectations

Entrance into the System

- Utilize only one application to get all public services.
- Employ a person who helps with enrollment and has nothing to gain from the choice of services.
- Maintain a similar array of services across the state.
- Allow individuals to move from one part of the state to another and keep services.

Waiting Lists

- Provide everyone with the service they need, at the right amount, at the right time and in the right place.
- Serve everyone – no individual waits for services.
- Move people from the waiting list based on urgency and severity of need.

Assessment

- Guide but do not predict what services are received.
- Build on what is important to person and is working in their life.
- Utilize a whole person approach that addresses individual life needs.
- Implement process for ongoing review and development as person will change and grow.
- Require consistent process and tools across the state and MCOs.

Self-Direction

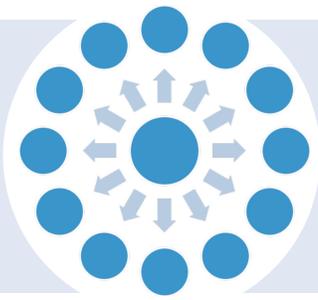
- Individual control and flexibility of funds to meet needs with services within an allowable budget.
- Educate person and providers about self-direction and support them to use it.
- Provide financial and business management supports.

Person-centered Planning

- Drive plan by the personal goals and desired outcomes as indicated by the individual
- Create an on-going living document that changes as person changes – not just paper
- Involve team that is valued and is selected by the person to include family, support professionals planners, and any others.
- Allow the plan to drive the authorization of services – the authorizers do not drive the plan.

Support Coordination

- Develop a personal and consistent relationship between the person and the support coordinator.
- Require coordinators to have a working (best practice) knowledge of local resources and how to connect people to communities.
- Advocate for individual rights, responsibilities, and choices in an independent appeals process.



Our Partners: The Stakeholder Engagement Group is supported by the North Carolina Department of Health and Human Services, (DHHS), the North Carolina Council on Developmental Disabilities (NCCDD), the National Association of State Directors of Developmental Disabilities Services (NASDDDS)—the professional association for the State’s I/DD state authority, Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMH/DD/SAS).

Services

- Promote independence and community inclusion through all services.
- Make employment and careers the preferred outcome of all education and services (“Employment First”).
- Pay for the desired outcomes, not just units of service.
- Allow flexibility to meet the unique needs of each person and family.
- Make outcome expectations and service access consistent across the state.

Quality

- Focus the Comprehensive Quality Strategy on the valued outcomes versus the quality of the process.
- Involve participants and their families in independent oversight.
- Communicate the results of the oversight process in a timely, accurate, and is easily accessible and understood formats.
- Evaluate success in all areas of a person’s life through meaningful outcome measures.
- Enforce requirements and maintain standards statewide.

Qualified Providers

- Provide participant choice by having multiple providers in each specialty area of service.
- Require provider to be qualified, trained and monitored to achieve outcomes for people they support.
- Recruit and retain providers by paying for the actual costs and rewarding good performance.
- Encourage certification and recognition of direct support workers.

Payment Structure

- Move from fee-for-service to incentive payments for outcomes; assist providers to change business models.
- Allow flexibility to better match services with individual needs.
- Share costs of services and the outcomes providers report with consumers.
- Provide timely payments for approved services and outcomes to all providers.

System Transition

- Involve cross disability consumers and families in all levels of strategy development and implementation through recognized advisory boards; provide sufficient time for review of concepts and proposals.
- Determine readiness of the state; managed care entities; providers, consumers, families for new management structures. Readiness includes enough staff, the right skills competencies, the right values.
- Implement and standardize operational and IT systems across the state to assure continuity of service.
- Communicate information to enrolled participants and families – and to those not yet enrolled – about the new program, their rights and responsibilities.
- Develop a process for transferring participants to new system to prevent gaps in service; plan for rapid identification and resolution of problems.

Participant Protections

- Educate individuals, families and support providers about participants rights and responsibilities.
- Assure safety and support for individuals and families when reporting concerns or making claims.
- Investigate, track, and provide prompt follow up on critical incidents (including abuse, neglect and exploitation) and make results clear to all.
- Continue services during disputes and appeals.



Stakeholder Involvement “Nothing About Us Without Us”

- Sustain cross-disability, culturally diverse, and geographically representative consumer and family involvement in state and LME/MCO governance structures
- Provide funds directly to independent peer and family networks and consumer/family advisory committees to involve members, educate and disseminate information.

Spreading the Word

Possible Activities



- **Present this information** to the local groups and organizations in which you are a member. Share the information you learned about Medicaid and this consensus agreement in these meetings.



- **Write a letter** to your local **LME/MCO** telling them about the Stakeholder Engagement Group and your agreement with the consensus statements of the Stakeholder Engagement Group. This letter could be from you, from an advocacy group you belong to, from friends, from family members, or all of these. *If you would like a sample letter, please contact the DD Council Office.*



- **Write a letter** to your **State Representative or Senator, LME/MCO provider, agency provider and/or local organizations**, telling them about your agreement with the Stakeholder Engagement Group statements. Again, this letter could be from you, from an advocacy group you belong to, from friends, from family members, or all of these. *If you would like a sample letter, please contact the DD Council Office.*



- **Set up a meeting** with your **State Representative or Senator, LME/MCO provider, agency provider and/or local organizations** telling them about your agreement with the Stakeholder Engagement Group, and the outcomes and expectations from the group. You could meet alone, with friends or family members, or with several members of an advocacy group you participate in. You can give them this information so they have it in their hands.



- Take this information to your local CFAC group and share it with them and encourage them to become active in supporting the work of the Stakeholder Engagement Group.



- **Tell your local paper** about your participation in this group and why it is so important to people who have disabilities and their families. If you are interested in getting the information into your local paper, *let NCCDD know and we can help you with a sample.*

The SEG Way to a Healthy North Carolina

North Carolina Stakeholder Engagement

Group Members

● **Jean Anderson, Stanfield, NC**

Governor's Advisory Council on Brain Injury member; Partners in Policymaking graduate; BIANC member

● **Crystal Bowe, Belmont, NC**

NCCDD member; Family Physician; Family member with I/DD

● **Chris Campu, Raleigh, NC**

NC State Student; Governors Institute on Substance Abuse and Mental Health member; Founder of the Collegiate Recovery Community at NC State; Peer Support for Substance Abuse

● **Eric Chavis, Greensboro, NC**

NCCDD member; Arc of Greensboro member

● **Ben Coggins, Gastonia, NC**

Partners Behavioral Health CFAC member, State CFAC member, Partner's BHM board member; Peer Support Specialist

● **Anna Cunningham, Raleigh, NC**

NCCDD member; NC State CFAC member; Alliance CFAC member; NC Commission on MHDDSA member; The Power of the Dream, Inc / HANDmeUPs president; First in Families Lifetime Connections charter member; FIFNC member; Parent of 2 daughters with I/DD

● **Jonathan Ellis, Murfreesboro, NC**

NCCDD member; FIFNC member; UCEDD Keller Institute on DD member; Advocacy Ambassador NCCDD

● **Monica Foster, Landis, NC**

The Life Beyond Limits Coach® & Inclusionista, founder; Professional Blogger/Writer for the Riot; Advocacy Ambassador NCCDD, Arc of NC and US, member; Spina Bifida Association of the Carolina's member

● **Sue Guy, Goldsboro, NC**

State CFAC Chair; Local Consumer Family Advisory Committee member

● **Merlie Jackson, North Wilkesboro, NC**

Smokey Mountain CFAC member; FIFNC member; High Country First-In-Families member; Parent of a daughter with I/DD

● **Valerie King, Yadainville, NC**

Mended Little Hearts National Advocacy chair, Congenital Heart Public Health Consortium member; National Birth Defects Prevention Network, member; Pediatric Congenital Heart Association, member; Parent of daughter with I/DD

● **Susie Lenfestey, Lenior, NC**

The Arc NC board member; The Breakfast Club Org Co-founder and President

● **Mike Mayer, Mebane, NC**

NAMI-NC President; Arc NC member; Cardinal Innovations Best Practices Workgroup; Seeing Is Believing Initiative Director; Self Advocacy Ambassador Initiative Advisor; Family member of a person with a disability

● **Pat McGinnis, Marion, NC**

PAIMI Vice Chair; DRNC member; Smoky CFAC Chair; NCCANSO member; NCMHCO member

● **Sam Miller, Greensboro, NC**

NCCDD member; Arc of Greensboro member; UNCG Associate Dean of the School of Education; Father of a son with I/DD

● **Matt Potter, Pfafftown, NC**

Centerpoint Humans Services board of directors member; Wake Forest Athletic Department consultant; CRA Ambassador

● **Ron Reeve, Charlotte, NC**

NCCDD Chair; Father of a son with I/DD

● **Tony Sowards, Raleigh, NC**

DWAC member; Sunrise Recovery Center, board member; Oxford House Outreach Worker; A person in long-term recovery

● **Nessie Siler, Manteo, NC**

Partners in Policymaking graduate; Pathways to an Accessible College Experience at College of the Albemarle in Dare Co., Mentor; Monarch Voices of Power, Facilitator

● **Teresa Staley, Greensboro, NC**

NC Independent Living Centers, board member; Joy A. Shabazz Center for Independent Living, board member

