Promoting Integrated Care for People with Intellectual and Developmental Disabilities

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“It is difficult to live with independence and dignity in the community if you are not healthy.”

Adult with a Disability
Medical Health Homes for People with Intellectual and Other Developmental Disabilities and Their Families

• 1-year planning grant funded by the NC Council on Developmental Disabilities

• Goal: To ensure people with intellectual and developmental disabilities receive the right care at the right time in the right setting
Year One Activities

• Establish Community-Academic –Provider Consortium & Work Groups:
  • Outcomes, Data, Provider Education, Finance and Policy
• Engage and gather input from stakeholders across the state
• Review national and state models, best practices, and lessons learned
• Identify and review NC data sources on access to care, cost, gaps and needs
• Develop consumer profiles
• Identify recommended provider competencies
• Develop summary report, actionable model, recommendations and solutions for North Carolina
Stakeholders

• Individuals with disabilities and families
• Advocates
• Health care providers
• MCO LMEs
• Long term service and support providers
• Government
• Business
• Educators
• Community
• Technology and Data
CMS Triple Aim

• Improving the health of the population

• Enhancing the patient experience of care

• Reducing the cost of care
NC DHHS Medicaid Reform Aims

• **Putting patients / people first to** improve quality of care and health outcomes for Medicaid beneficiaries

• **Securing budget predictability and cost savings** for the Medicaid program

• **Building on what we have in North Carolina** and partnering with the healthcare community
## Core Values and Principles

<table>
<thead>
<tr>
<th>Focus on Individual and Family</th>
<th>Quality and Safety</th>
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<tbody>
<tr>
<td>Person Centeredness</td>
<td>Accountability</td>
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<tr>
<td>Self direction</td>
<td>Coordination of Care and Services</td>
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<tr>
<td>Choice</td>
<td>Community Partnerships</td>
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<tr>
<td>Stakeholder engagement</td>
<td>Inclusive and integrated settings</td>
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<td>Equity and Fairness</td>
<td>Stable statewide infrastructure</td>
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<td>Values based outcomes</td>
<td>Balancing Flexibility and Predictability</td>
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Terminology Matters

• Definitions are
  – Complex and evolving
  – Mean different things to different audiences

• Confusing definitions can lead to:
  – Misunderstanding
  – Discounting viewpoint of some stakeholders
  – Faulty planning and conclusions
Patient Centered Medical Home

Comprehensive primary care that replaces episodic care with coordinated care and a long-term healing relationship.

Core elements:
- Personal physician
- Physician/provider directed medical practice
- Whole person orientation
- Care is coordinated and/or integrated across all elements of the complex health care system
- Quality and safety
- Enhanced access
- Payment structure recognizes and pays for value
Health Home (as defined by ACA and CMS)

An integrated, person-centered, and coordinated service delivery system that links primary, dental, acute, specialists, behavioral health, and long-term services and supports.

Core elements:
- Comprehensive care management
- Care coordination
- Health promotion
- Comprehensive transitional care and follow-up
- Patient and family support
- Referral to community and social support services
- Use of health information technology to link services
Definition of Integrated Care  (AHRQ)

• A team of primary care and behavioral health clinicians, working together with patients and families, using a systematic and cost-effective approach to provide patient-centered care for a defined population.

• May address mental health and substance abuse conditions, health behaviors (including their contribution to chronic medical illnesses), life stressors and crises, stress-related physical symptoms, and ineffective patterns of health care utilization.
Integrated Care for People with DD (Kastner)

- Multiple services and supports are integrated into a unified plan
- Services are comprehensive, provided in accessible and natural environments in the community
- Coordinated array of services and supports that integrates primary and acute medical and dental care needs, behavioral health needs, and long-term services and supports

- **Re-engineered Practices**: Teams of Nurse Practitioners/Physicians
  - Case Loads: 250 vs 2000
  - Visits/Year: 1000 to 1500 vs 6000 to 8000
  - Visit Length: 50 minutes vs 8 minutes
  - Care Coordination: 10 – 15 hours per week
  - Same Day Availability
  - 24/7/365 Coverage
  - ADA Accommodations
Health
• Receives primary care at family medicine practice
• Medicaid insurance
• Family history of HTN
• New HTN medication with side effects: dry mouth and gum px.
• Dislikes brushing teeth

Family & Community
• Lives with brother, aged 57, his wife and teenage son
• Works 10 hours a week at grocery store
• At home when not working
• Attends church on a regular basis

Disability Services & Supports
• Innovations Waiver
• Receives Supported Employment

Sam
61 yr. old male with ASD
## Sam’s Need for Integrated Care

<table>
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<tr>
<th>Medical Home</th>
<th>Health Home</th>
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</thead>
<tbody>
<tr>
<td>Checks patient’s blood pressure at each appointment and reviews risk factors (family history).</td>
<td>Identifies HTN as health issue in Individual Service Plan. Includes record of blood pressure readings and risk factors, incl. family history and weight gain. Notes difficulty with oral health (preventive and annual appt.).</td>
</tr>
<tr>
<td>Prescribes medication for HTN. Talks to Sam and family about healthy diet, physical activity, healthy weight. Documents BP, weight, and health behaviors in patient record. Files billing claims.</td>
<td>Helps family contact Medical Home/Practice to schedule annual physical. Informs PCMH of accommodation needs (preference for early morning appts., immediate placement in treatment room rather than reception area). Helps Sam and family prepare for appointment. Reviews appointment to discuss follow-up actions.</td>
</tr>
<tr>
<td>Care manager contacts Sam and family periodically to monitor BP readings and any medication side effects.</td>
<td>Reviews HTN medication side effects with Sam and family. Records date of medical appts..and results in Integrated Plan of Care, notes health promotion strategies that will address HTN and health behaviors. Discusses daily oral health with SE staff.</td>
</tr>
<tr>
<td>Dental appointment: to address medication side effects (dry mouth and potential for gum disease). Contacts PCMH to discuss medication options. Explores difficulty with daily teeth brushing, and offers accommodation strategies.</td>
<td>Arranges for dental appt. Supports family to discuss medication questions. Checks in with Sam and family on periodic basis to monitor HTN, meds, oral health status and health needs. Notes oral health issues and strategies on ISP.</td>
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“I want to know how to advocate (with the system) but still be his mother.”

Mother of Young Adult with a Disability
Challenges and Gaps

• Person-Centered Services and Supports

• Access to and Continuity of Health Care

• Administrative and System Issues
Person Centered Service and Support Needs

• Person–centered principles and practices are essential

• LME MCO care coordination is not case management

• Few persons with IDD receive CCNC active care management

• Many individuals and families need help navigating across systems of care so they can get the right services at the right time and not “fall through the cracks”

• Family and LTSS providers spend the most time with the individual with DD and need to play a central role
Person Centered Service and Support Needs

• Respite services promote family stability and quality of life, but are difficult to access

• Community living and residential services are becoming “medicalized”

• Aging in place is important but difficult

• Confusion and anxiety about on-going changes on a community, regional and state level
Access to Health Care Issues

• Mental health services are in desperate need
• Dental care is difficult to access
• Nurses have a valuable role to play in the coordination and delivery of healthcare
• Health care professionals need more education about DD, living with a disability, family needs, and disability service system(s)
• Health Care professionals want to consult with providers knowledgeable about DD
• Too many records and plans that are not connected
• Concise health summaries that can be used in medical home, ED, hospital, and home
System Issues

• Lack of communication, shared information, and real time data between primary care, dental, specialty care, and disability services

• Service definitions are not flexible enough to meet individual and family needs over time and do not focus on valued or relevant outcomes

• Technology is under-utilized in providing care and services to people with DD

• Financial reimbursement does not align with quality care
Key Recommendations

• Establish a service that provides navigation across systems of care
• Strengthen the focus on health and wellness across the life course in Person Centered Planning and Individual Support Plans
• Standardize MCO LME policies and practices
• Support people to age in place
• Provide education for families and DSP about health across the life course and the role of a medical home
• Expand the # of people with IDD with chronic health conditions who receive active care management through CCNC, with an emphasis on persons not on Innovations Waiver
• Develop a template for an integrated plan of care that links primary health and dental care and LTSS needs
• Improve access to mental health services: expand NC START, provide multiple access options
Key Recommendations

• Improve access to preventive and emergency dental care
• Establish a statewide health care consultation network
• Establish statewide health information technology standards, maximize NC Health Information Exchange opportunities
• Streamlined all-payer and provider data base that can be accessed in real time
• Align payment and incentives with valued outcomes and quality improvement; link incentives to quality and education
• Expand use of technology in primary and specialty care and in-home supports
Challenges Reported by Other States

• Outreach & engagement of high-cost, high-risk individuals takes high-touch and time

• Building relationships and defining roles within an adequate network of physicians, dentists, specialty and other providers

• Availability of timely, accurate health data exchange

• Hiring, training and retaining right people for health home and integrated care

• Incorporating people with IDD into the health home model

• Establishing payment structures

• Measuring quality outcomes
NC’s Unique Assets and Opportunities

• Stakeholder Engagement
• MCO LME network
• CCNC network and leadership on PCMH
• NC Center of Excellence for Integrated Care
• NC Medicaid Reform
• University and Community College System
• Provider Network and Leadership
Moving Forward

• Leverage existing resources
• Identify and utilize expertise in our state
• Engage stakeholders throughout the process
• Commit to transparency, equity, and fairness
• Align incentives
• Focus on accountability
• Implement demonstration activities
“Of all the forms of inequality, injustice in health care is the most shocking and inhumane.”

Martin Luther King Jr.