REIMAGING HEALTH CARE ACCESS IN NORTH CAROLINA

A COMMUNITY-INFORMED ROADMAP FOR ACCESSIBILITY, ADVOCACY, AND IMPLEMENTATION

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POLICY OVERVIEW

Americans with Disabilities Act (ADA)
- Ensures physical and communication accessibility by mandating equal access to public services and health care environments

Affordable Care Act (ACA)
- Expands health care coverage and includes Section 1557 protections against discrimination

Title VI of the Civil Rights Act
- Prohibits discrimination based on race, color, or national origin
- Requires meaningful language access for individuals with limited English proficiency

CENTERING LIVED EXPERIENCE

Who we engaged:
- Individuals with disabilities
- Caregivers and community members
- Health care professionals and advocates
- Individuals navigating the system personally or in support roles

Approach:
- Community-engaged, qualitative methodology
- Designed to elevate perspectives often excluded from policy development

Key Insight:
This approach captures real-world challenges not reflected in quantitative data alone, including communication barriers, system navigation, and care delivery in North Carolina.

KEY THEMES FROM COMMUNITY INTERVIEWS

What We Heard from North Carolinians About Accessing Care

Across interviews, participants described gaps between legal protections and everyday reality. Access depends on persistence, support networks, and luck rather than on accessible health care systems that work for everyone.

Theme 1: Health Care Systems are Hard to Navigate and Shift the Burden to Patients

Patients are expected to solve system problems on their own. Interviewees described confusing insurance rules, multiple patient portals, billing issues, and repeating their story to many providers.

Many people rely on family, friends, or community organizations to help them navigate care.

"It takes so much out of me to figure out how to do it."

"Other parents' support is what gets you through all of this."

"I manage about 15 different health care portals."

Why it Matters for Policymakers

Complex systems delay care, increase stress, and disproportionately harm people with fewer resources or less support.

Theme 2: Accessibility Is Inconsistent and Treated as Optional

Participants described barriers with clinic buildings, parking, forms, digital check-in systems, telehealth platforms, interpreters, and accessible communication. Insurance coverage helped many people, but coverage alone did not guarantee real access to care.

"They both fail on...effective communication and accessibility."

"I just don't pick it up, and I don't take it." [about unaffordable medication]

"I was given instructions in a format I couldn't read." [Participant is blind].

Why it Matters for Policymakers

Legal protections mean little if patients cannot physically enter care, communicate effectively, or afford to use their coverage.

Theme 3: Quality Care Must Be Person-Centered, Respectful, and Responsive

Participants said quality care is more than treatment; it includes trust, dignity, listening, continuity, and understanding the whole person. Bias, stigma, and lack of provider training continue to shape negative care experiences.

"Quality care is being able to build rapport with my physician."

"My son's not just a seizure disorder... I need for the health care system to see him as a person first."

"Harm is not always overt discrimination."

Why it Matters for Policymakers

Care quality improves when systems invest in respectful communication, disability competency, and culturally responsive care.

POLICY RECOMMENDATIONS

Make accessibility a standard feature of health care delivery

- Embed accessibility in all care settings (physical, digital, communication, scheduling) as a default standard
- Require core features: interpreters, captioning, accessible materials, flexible scheduling, accessible telehealth, and usable facilities
- Shift from complaint-based to proactive monitoring through contracts, quality metrics, and performance standards
- Invest in rural North Carolina access and expand Medicaid reimbursement to strengthen provider networks

Reduce administrative burden and improve navigation supports

- Fund centralized patient navigation and care coordination systems statewide
- Support enrollment, scheduling, referrals, benefits, transportation, and communication needs
- Reduce fragmentation through streamlined, interoperable health records
- Implement a unified patient record system across providers in North Carolina
- Allow secure provider access to shared records to improve continuity of care

Expand disability-inclusive, person centered, and culturally responsive work-force training

- Require recurring training in disability care, communication access, cultural humility, trauma-informed care, and interpreter use
- Co-design training with people with disabilities and diverse lived experiences
- Embed training into medical education and continuing education (not optional modules)
- Tie competencies to licensure renewal, Medicaid contracts, and performance standards

Create stronger statewide coordination and implementation support

- Align implementation of Affordable Care Act (Section 1557), Americans with Disabilities Act, and Title VI of the Civil Rights Act
- Establish advisory board within North Carolina Department of Health and Human Services to set and monitor statewide accessibility standards
- Provide plain-language (8th grade), multilingual public education on health care rights

Strengthen accountability and shift away from complaint-driven enforcement alone

- Shift to proactive enforcement using system-level monitoring and oversight
- Identify and address barriers without relying on patient complaints alone
- Conduct statewide assessment of what accessible, high-quality care should look like in North Carolina
- Use findings to set clear standards and continuous improvement goals

ACTION STEPS: A ROADMAP FOR IMPLEMENTATION

SHORT-TERM (0-2 YEARS)

- **Launch NC rights awareness campaign:** Create plain-language, multilingual, accessible materials explaining rights under the ACA, ADA, and Title VI for patients, providers, and policymakers.
- **Create state advisory board/coalition**: Bring together disability advocates, clinicians, public health leaders, legislators, and people with lived experience to guide accessibility policy and implementation.
- **Implement provider trainings**: Require training in disability-competent, trauma-informed, person-centered care, including Deaf/Hard of Hearing culture, interpreter use, and inclusive communication.

MID-TERM (3-5 YEARS)

- **Establish an Accessibility Fund:** Support facility upgrades, accessible equipment, interpreter services, transportation, and assistive technology, with priority for rural and safety-net providers.
- **Expand navigator programs statewide:** Strengthen patient navigation and care coordination, especially for Medicaid and behavioral health enrollees.
- **Build accessibility into Medicaid contracts:** Include language, digital, and physical access measures in managed care oversight and provider performance standards.

LONG-TERM (5+ YEARS)

- **Make accessibility a statewide standard:** Update facility, equipment, and telehealth requirements to reflect current accessibility needs.
- **Shift to proactive compliance:** Move beyond complaint-based enforcement with routine monitoring and stronger federal-state coordination.
- **Strengthen language access and equity protections:** Expand interpreter funding, bilingual staffing, community health workers, and data collection on language needs and access barriers.