Health Care Policy and People with Developmental Disabilities:

We All Need To Be Advocates

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The Boggs Center on Developmental Disabilities- A Life Span Program

• A division of the RWJMS Department of Pediatrics

• New Jersey’s federally designated
  University Center for Excellence in Developmental Disabilities Education, Research and Service [UCEDD]
  Leadership Education in Neurodevelopmental Disabilities Program [NJLEND]

• Work with state agencies, including the
  NJ Division of Developmental Disabilities
  NJ Department of Children & Families
  NJ Department of Education
UCEDD Core Functions
The Boggs Center as a UCEDD: A Bridge Between the University and Community
Theme

Health and Disability Policy & [funding] is shaped and/or determined by larger social forces as well as disability considerations.
COVID-19 Pandemic
Health Care for People with Intellectual Disabilities/ IDD

A *medically, socially, and economically disadvantaged population*

- Historically segregated from the mainstream of society
- Often multiple disability conditions
- Limitations in communication & other needs for support
- Complex health & disability conditions
- Complex service systems
- Caregivers
- Reliance on public insurance- Medicaid & Medicare
- Need for care coordination
- Lack of training of health care providers
Paradigm Shift in Service Systems

from systems of residential services

to systems supporting people with their families
How did we get from there to here? Advocacy

• by families
• by people with disabilities: self-advocacy
• by supporters and those who work with and on behalf of people with disabilities, their families, and communities

• by understanding policy

• educating and partnering with policy makers

............. and we still have a long way to go
Medicaid is a joint Federal-State program which pays for health care services for low income families with dependent children, senior citizens, and people with disabilities, as well as some people who are medically needy because their health expenses are high.
Medicaid as a Public Health Insurance Program

“Medicaid’s resilience and flexibility position the program to assume roles that no other insurer can undertake. It’s place in the American health care system is simply foundational”

-Sara Rosenbaum, 2017
National Academy of Social Insurance Panel
Medicaid

• Protections and Due Process
• Stakeholder input
  • NJ Medical Assistance Advisory Committee[MAAC]
  • Public Comment on program changes
• Public health perspective
• Acute care & Long-term care
NJ Department of Human Services

Division of Medical Assistance and Health Services

New Jersey Medicaid
Medicaid

Acute Care

Long Term Care Services
NJ Medicaid HMOs

- Aetna Better Health of NJ
  - All counties
- Amerigroup NJ
  - All counties
- Horizon NJ Health
  - All counties; largest HMO in NJ
- United Healthcare Community Plan
  - All counties
- Wellcare
  - All but Hunterdon County
Early and Periodic Screening, Diagnosis, and Treatment

- **Early**: Identifying problems early, starting at birth
- **Periodic**: Checking children’s health at periodic, age-appropriate intervals
- **Screening**: Doing physical, mental, developmental, dental, hearing, vision, and other screening tests to detect potential problems
- **Diagnosis**: Performing diagnostic tests to follow up when a risk is identified
- **Treatment**: Treating the problems found
NJFamilyCare services covered for individuals with ASD

- Physical therapy, speech therapy and occupational therapy
- Alternative Communication Assessment and Devices
- Sensory Integration
- Applied Behavior Analysis
- Development, Relationship-based Interventions

- When clinically appropriate, CSOC provides Skill Acquisition and Capacity Building for individuals with an I/DD and continues to provide ABA for individuals who meet their requirements, but are not eligible for Medicaid.
Medicaid

Acute Care

Long Term Care Services
Long Term Services & Supports

- Services provided to people with developmental disabilities
  - Through the Division of Developmental Disabilities (DDD) in NJ

- Services provided to older people

- Dual Eligibles
  - people who have Medicaid & Medicare
  - in MLTSS- Managed Long Term Services & Supports
The Aged Blind Disabled-ABD

• A category of Medicaid
• Those Medicaid beneficiaries who are SSI recipients
• People who are clients of DDD are a subset of the ABD population
• Managed Acute Care
• Long Term Services
Medicaid Long-Term Services & Supports

• NF (Nursing Facility)
• ICF (Intermediate Care Facility)
• ICF/DD (ICF/MR)
• 1915C Waiver Programs & Services
  - Home & Community Based Services
  - DDD: Community Care Waiver “CCW”
• 1115 Comprehensive Waiver
  • DDD: Supports Program & Community Care Program (CCP)
Medicaid

• “Institutional bias”

• Waivers
Waivers Driving Service Delivery

• DDD- requiring Medicaid eligibility to receive DDD services

• Entire Medicaid program:
  
  **NJ Comprehensive Medicaid Waiver**
NJ Comprehensive Waiver (CMW)

Renewal in Process

- Section 1115 A “demonstration” waiver
- Putting together all waiver programs
- More coordinated care
  - MLTSS
- Home & Community Based Services “HCBS”
- Federal Medicaid requirements
  - Stakeholder input
  - Readiness reviews
  - Due Process Protections
- Opportunity for Input & Advocacy
Home & Community Based Services

Policy direction

• American Rescue Plan March 2021

• COVID HCBS Relief Act 2021

• ?Build Back Better Jobs Act?
Patient Protection and Affordable Care Act
Patient Protection and Affordable Care Act

• “Health Care Reform” “Obama care”
• March 23, 2010-signed into law by President Obama
• Coverage for Pre-existing Conditions
• Acute care & Long-term Services & Supports
• Presumption for Community
• Eliminates Annual & lifetime Caps

• Medicaid embedded in ACA
Theme

Health and Disability Policy & [funding] is shaped and/or determined by larger social forces as well as disability considerations.
COVID-19 Pandemic
Larger Social Forces

• Differing views of the role of government in people’s lives
• Differing views of the role of government and the nature of the economy
• Elections-Control of Congress
• Elections-Executive Branch
• Supreme Court
The present social, political, & policy climate
Threats to Care & Supports for People with Disabilities

• Protections for PRE-EXISTING Conditions
• CAPS on Expenditures
• Changes to MEDICAID
• Court challenges to ACA
• Federal deficit
Threats to Medicaid

• Reducing how much $ the federal government spends on Medicaid

• Who gets Medicaid?

• Structure of Medicaid

• Waivers: Flexibility or weakening?

What is the nature of the Medicaid program as a safety net?
Program Changes that would Threaten Medicaid

• **Block grants**
  
  State gets one lump sum of $  
  - usually less than total present federal $  
  - might be based on past year[s] spending  

States decided how to spend  
- fewer requirements or protections  
- competition among eligible groups
Program Changes that would Threaten Medicaid

• Block grants

• Caps
  • Per Capita Caps
    Federal government puts a limit on the amount it spends per person enrolled and a
    State is responsible for any costs that exceed the limit
  • Annual caps
  • Lifetime caps
2017 Tax Bill

• Repealed individual coverage mandate of the ACA beginning in 2019
  • Estimated that 4 million fewer people will have coverage in 2019
  • 13 million fewer would be covered by 2025
• Insurance premiums could increase as much as 10% as young, healthy individuals are likely to exit the insurance market
• Changes in medical expense deduction; worsens over time
• Makes research on drugs for rare conditions more expensive


Continuing Threats to the ACA & Medicaid

- District court—which parts of ACA?
- Supreme Court

- Instability in Insurance Markets

- Political shifts in DC= Policy shifts

- Changes that followed ACA:
  - NJ  elimination of Charity Care
Staying Informed

• Kaiser Family Foundation- provides trusted information on national health issues
  • https://www.kff.org/

• Center for American Progress- independent nonpartisan policy institute that is dedicated to improving the lives of all Americans
  • https://www.americanprogress.org

• National Health Law Program- protects and advances the health rights of low-income and underserved individuals and families
  • http://www.healthlaw.org/

• Center on Budget and Policy Priorities- nonpartisan research and policy institute focused on reducing poverty and inequality
  • https://www.cbpp.org/

• NJFamilyCare
  • https://www.state.nj.us/humanservices/dmahs/home/
“I did then what I knew how to do. Now that I know better, I do better.”

Maya Angelou
Thank you!

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The Boggs Center on Developmental Disabilities
https://rwjms.rutgers.edu/boggscenter/