Optimizing Care Systems
For People with Intellectual and Developmental Disabilities

Technical and Policy Opportunities in Financing and Payment

- Alyna Chien, Boston Children’s Hospital
- Colleen Kidney, Human Services Research Institute
- Joan Alker, Georgetown University Health Policy Institute
- Joshua Sharfstein, Johns Hopkins Bloomberg School of Public Health

Risk Adjustment: Need to understand the whole population
Disabilities: Underidentified
Societal Perspective: Make the invisible visible

Kids: Medicaid does not require the kid to be insured

Policy Development: Data as a tool for measurement
Assurance: Population Health 
Population Health Framework

HCBS vs. Equity: Blend them

Assessment: Support needed based on age, living setting

Machine Learning: Define metrics on care quality and outcomes

Litigations due to abusive use of it

New Ways Demonstrations

Section 1115 Waivers: Applies to Medicaid and CHIP or to spend/receive federal $ in different ways

To waive certain parts of the law

Budget Neutral: Spending lower amounts
Optimizing Care Systems
For People with Intellectual and Developmental Disabilities

Day 3

Technical and Policy Opportunities in Financing and Payment

Discussion

Waivers: The reality is that a lot of kids weren't receiving the care they need.

Policy Conversations: A lot of self-insured employers are including autism.

Budget Neutrality: States are passing several legislations.

States are the way to bring down barriers.

Collect Equity Data: Structure the disaggregation of data at the end of the waiver.

Early Periodic Screening, Diagnostic, and Treatment for Children Under 21 (EPSDT)

A lot more should be done.

Kids going to private insurers and losing Medicaid benefits.

Think Holistically:
Non traditional health intervention.

HCBS look across work in 2 levels.
Wide range of services who make those decisions?

Data Benefits: Equity.

Risk:

More opportunities here.
Optimizing Care Systems
For People with Intellectual and Developmental Disabilities

SCALING WORKFORCE SOLUTIONS

Helen Burstin
Council of Medical Specialty Societies

Kari Shogren
Kansas University Center on Developmental Disabilities

Andrés Gallegos
National Council on Disability

Guidelines
COVID-19

CRISIS MOMENT

How can we corral all available resources?

PAIN

EDUCATION

Journey Map of Chronic Pain

Opioids

THINK BIG

AND FRAME PROBLEMS AS SOLVABLE

WHAT ARE THE RESOURCES NEEDED TO APPROACH IN A BETTER WAY?

WHAT ARE THE IMPACTS OF SOCIAL DETERMINATION OF HEALTH

QUALITY AND EQUITY

SYSTEMS ARE COMPLEX

COLLABORATION IS ESSENTIAL

EFFECTIVE SUPPORT

SYSTEM DESIGNED FOR COLLABORATION

EMPOWER PEOPLE WITH IDD

“Nothing about us without us”

BE PART OF THE SOLUTION

BE PART OF THE DESIGN OF SYSTEMS

BE CO-TRAINED AND LEAD WORK AND INTERVENTIONS

ENHANCED FUNDING FOR HOME AND COMMUNITY-BASED SERVICES

TRAIN HEALTH PROFESSIONALS AND MANAGEMENT SCHOOLS

CLOSE THE GAP ON HEALTH DISPARITIES

ACCESS TO FEDERAL MONEY

ENHANCED MEDICARE AND MEDICAID REIMBURSEMENT

SBC 5307
ADOPTION OF DISABILITY CULTURAL COMPETENCY CURRICULA

Special Medically Underserved Population (SMUP)

“Providers see us. How they will treat us is fellowship and residency programs.”

People with IDD

“Train people who are ID and autism.”

DAY 3
Optimizing Care Systems
For People with Intellectual and Developmental Disabilities

**DISCUSSION**

- Communicate between systems
- We need collaboration between systems

**SCALING WORKFORCE SOLUTIONS**

- Medical students are homogeneous
- Diversify the workforce
- Panels with people with IDD presenting to medical students is just the beginning

**INCLUDE PEOPLE WITH DISABILITIES AS PART OF THE SURVEY DESIGN**

- Build supportive systems for all
- Share evidence and patient stories

**INTEGRATE PROVIDERS WITH PATIENTS SHOW & TELL**

- Create new roles and systems
- Create trust and respect
- Bring medical students and practitioners into the community

**DEVELOP COLLABORATIVE STANDARDS**

- Congress monitor curricula development

- Promote change on multiple levels
Optimizing Care Systems for People with Intellectual and Developmental Disabilities

Day 3

Discussion

A New Vision for Model of Care

Electronic Systems of Medical Records

Secure the Right Investment

Responsibility

25% of a Dollar Invested in Health Care

Consumers

Select a System

Break the Silos

Pure-Based Family-Based Models Are Key

Support System in Place is Needed

Fair Compensation
Optimizing Care Systems
For People with Intellectual and Developmental Disabilities

**Spotlight Presentation**

Maulik Trivedi, StationMD

85% of calls treat the patient in place

Telehealth providing great value

Fosters independence

Needs of this population

Elevate quality of medical care for people with IDD

13 states

Patients, families

Clinicians that understand the needs of this population

Payers, group home support
Optimizing Care Systems
For People with Intellectual and Developmental Disabilities

Dr. Rick Gilfillan
Former Director of the CMS Innovation Center

Incredible progress in the last 30 years

CARE MODELS ARE NOT SCALABLE

800,000+ people
The only waiting list on healthcare is people with IDD

We need to make this population visible

Community-based systems

Who should be?
Find a way to address this

Is it an unifier?

Rethinking our safety net system

Strong coalition to put those voices together

People with IDD and families

Address the workforce issue

Financing fragmented not in optimal position

Addressing

We are hiring