Optimizing Care Systems
For People with Intellectual and Developmental Disabilities

- WELCOME to DAY ONE!
  - ADVISE THE PRESIDENT
  - EQUITY in ALL POLICIES
  - ALL AMERICANS LIVE IN A INCLUSIVE SOCIETY

- CHOICES
  - EXPAND ACCESS TO SERVICES
  - ACCESS to COMMUNITY LIVING
  - IMPROVE QUALITY of CARE

- COORDINATED OUTREACH
- THE PANDEMIC HAS BEEN CHALLENGING
- RECEIVE CARE LIMITED SUPPLIES

- CARE INFRASTRUCTURE
- BEING TAKING CARE OF

- WORKSHOP
- DAY 1 CURRENT CHALLENGES
- DAY 2 CURRENT & PROMISING INTERVENTIONS
- DAY 3 LOOKING FORWARD
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Q&A + DISCUSSION

- Learn from pediatricians
- Spend more time with patients
- More attention
- Care for a bigger variety of patients
- Collaboration & communication to prepare them better

ADULT vs. CHILD CARE

- Transition is difficult
- Community-based services cost money
- Caregivers are the parents

BIAS
- Encourage physicians to spend more time with people with IDD
- Linkage with organizations and support services

EDUCATE THE NEXT GENERATION OF PHYSICIANS

- Educate and understand the complexities
- Access to care
- Race
- Minorities

OUR CULTURE:
Parents take care of children
How to care for adult children with IDD

WE NEED MORE CARE FOR CAREGIVERS

WE NEED BETTER TRAINING OF PCP PROVIDERS
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CHALLENGES IN WORKFORCE STRENGTH AND PREPAREDNESS

Matt Holder
American Academy of Developmental Medicine and Dentistry

Challenges Clinicians Face in Providing Care

- Improper Reimbursement
- lnadequate professional knowledge
- No office modifications & no training
- Access do not guarantee quality
- Many genetic syndromes

Susan Harercamp
Ohio State University

Increase of Life Expectancy of Patients with IDD

Patient Complexity

- Plan for the level of complexity
- Behaviors increase
- Behaviors worsen
- Behaviors decrease

Diagnostic overshadowing

Medicate behaviors

Susan Harercamp
Ohio State University

Healthcare providers are unprepared & uncomfortable

People with disabilities can't get basic healthcare. So they get sick and die.

- Overlook cultural, economic, social backgrounds
- Inadequate training
- Speak to the patient not only care givers

Agree on what needs to be taught

Consensus

Guidelines & principles

Core competencies

Mitigation

- Include people with disabilities in the training
- Creates awareness and mitigate bias

Cultural and systemic issues

Right payment and reimbursement

Pathways

Build career

AMENDMENT

Policy change

Chiara Santoro

People with IDD

Quality of life has been improved in the past 30 years.

Amy Hewitt
University of Minnesota

Community living

Not for direct support professionals (DSP)

DSP Multi-disciplinary skills

13 Million DSP's in the US. We needed 8.2 million before the pandemic

Low quality services & poor outcomes

Cultural and systemic issues

- Unaffordable housing
- Lack of career opportunities
- Challenging skills

DSF, Ph.D.

HHA + DSP

- 26% High School Diploma
- 75% Beyond High School Diploma
- 50% Burnout
- 47% Anxiety
- 41% Sleep difficulties
- 38% Physical health
- 18% Suicide risk

We need to uplift and train that workforce

- Encourage innovation in our field

Policies create new ones

- Require training

Pathways

Build career

The National Academies of Sciences, Engineering, Medicine
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Day 1

CHALLENGES in FINANCING AND PAYMENT
- Financing $ into the healthcare system
- Payment $ directly to providers and payers

What can we do?
- Restructures for IDD
- Create more integrated entities
- Capture appropriate data
- It takes longer for patients with IDD to inform payments to providers

Lack of cohesion of shared vision of agreements

Individual supported living
His/her goals, their needs

NEED...
- Greater emphasis on transition from home to community living
- Choice and autonomy in further measure
- Day and employment services
- People with IDD will live full lives with access and care

RISKS’ ADJUSTMENTS
- No proper expertise
- No value provided

QUALITY MEASURES
- Home and community services
- Survey measure
- NCI National Core Indicators

FUNCTIONALITY
- Outcome-based measures
- Service plans
- Proportion enrollees

FINANCIAL INCENTIVES to achieve quality

CHOICE AND AUTONOMY
- New York FIDA IDD quality measures
- Example: "Fix the finance system - private providers"
- How to measure outcomes

LEVERAGE PROFIT
- Create the right framework
- People with IDD will live full lives with access and care

SYSTEMS FINANCED BY DIFFERENT ORGANIZATIONS
- Do not talk with each other
- How to measure success?
- How to measure profit?
- How we will all make money
- How to generate profit and quality of care
- How to create the right system?
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Day 1

SPOTLIGHT PRESENTATION
MAURA SULLIVAN

OPERATION HOUSE CALL

GROWS CONFIDENCE and INTEREST in future DOCTORS

STUDENTS PAIRED UP with FAMILIES and WRITING about THE EXPERIENCE

EXPOSURE LEADS TO LESS BIAS

WITH FOUNDATION GRANT
NATIONAL DISSEMINATION
and WEBSITE TRAINING
by END of 2021

OPPORTUNITIES

HEALTH EQUITY MOVEMENT
ADA COMPLIANCE
FAMILIES MAKE GREAT TEACHERS

Panels of INDIVIDUALS and FAMILIES

COMMUNICATION and TRUST
MONITORING BIAS and DIAGNOSTIC OVERSHADOWING
INTERSECTIONALITY and CULTURALLY COMPETENT CARE
ACCOMMODATIONS and TIPS

Reaching 1,300+ MEDICAL STUDENTS
and 250 FAMILIES

Change the culture

PEOPLE in NEED ABOVE ALL