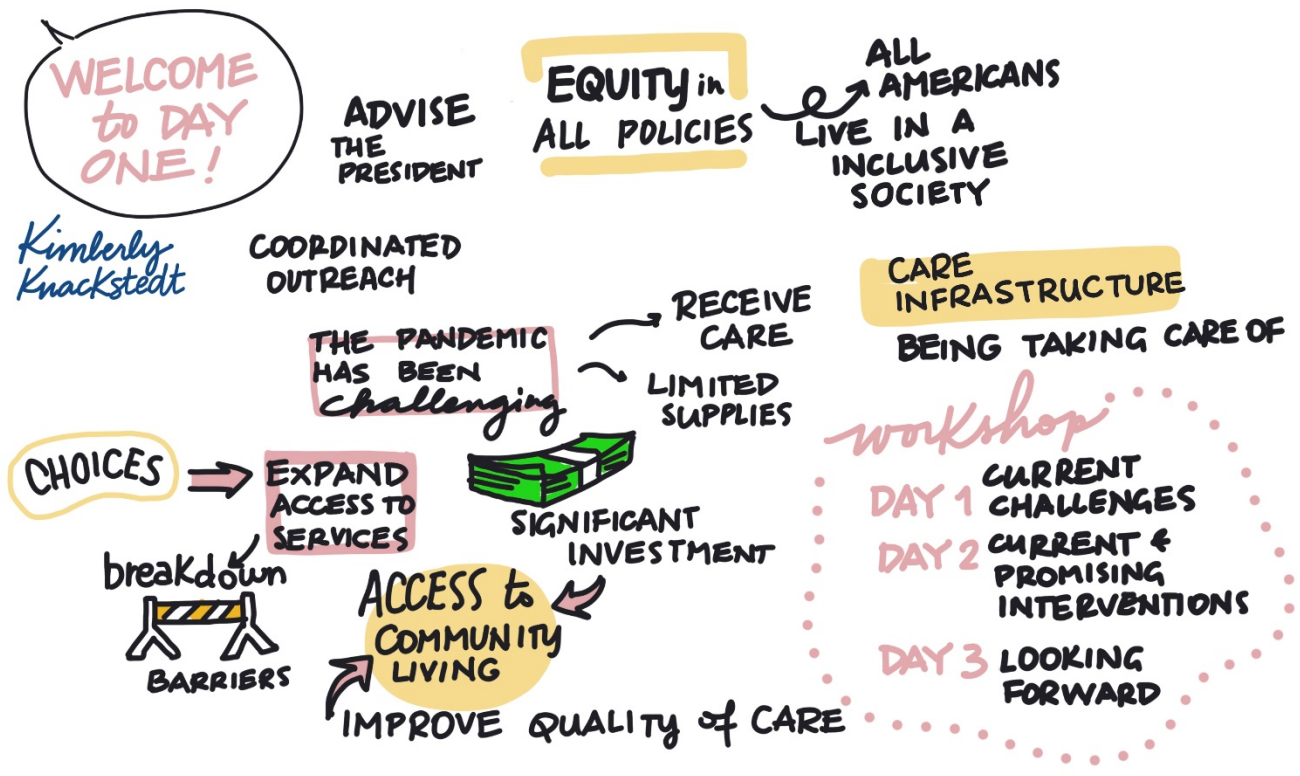


# Optimizing Care Systems For People with Intellectual and Developmental Disabilities



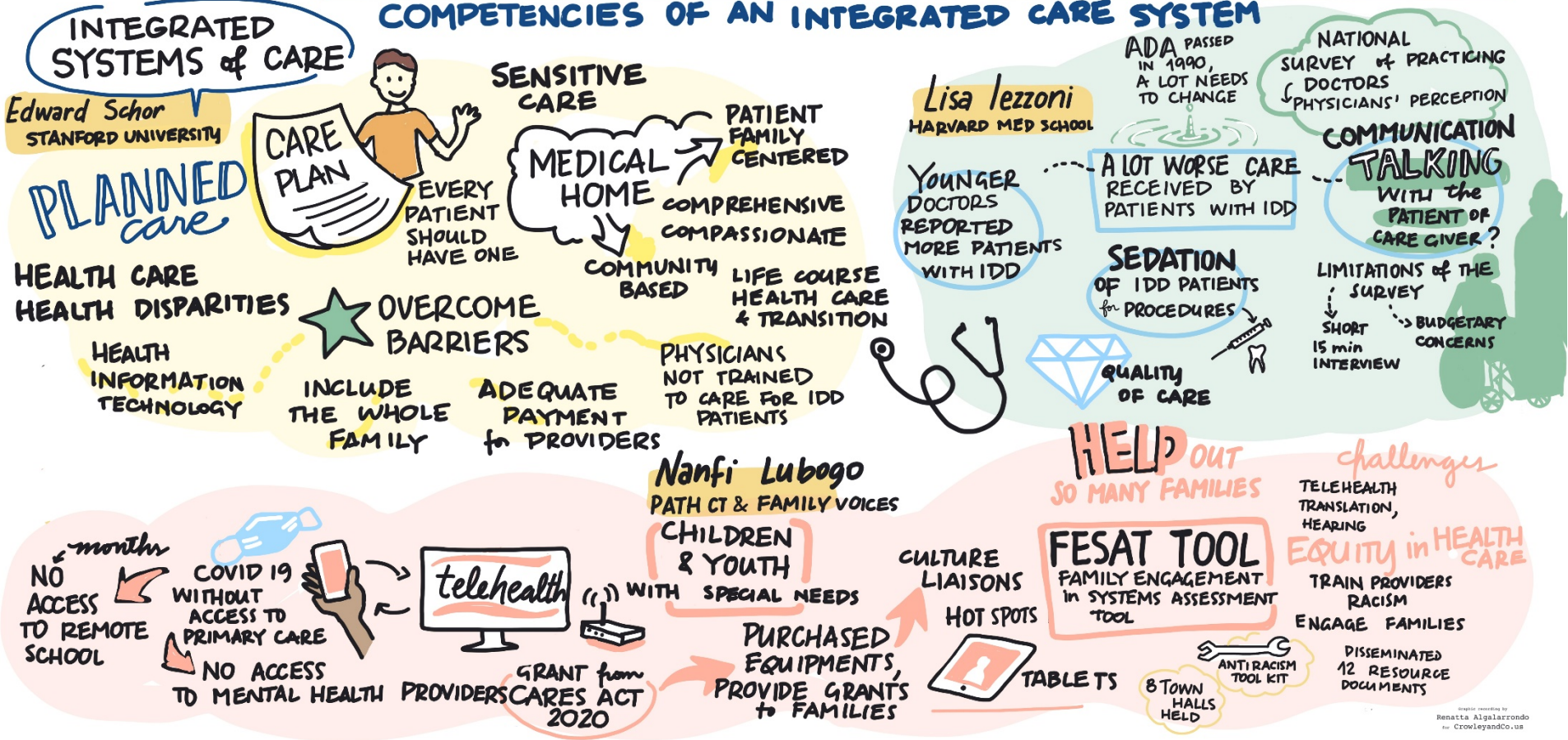
Kimberly Knackstedt

# Optimizing Care Systems

## For People with Intellectual and Developmental Disabilities

Day 1

### COMPETENCIES OF AN INTEGRATED CARE SYSTEM



# Optimizing Care Systems Day 1

## For People with Intellectual and Developmental Disabilities

### Q&A + DISCUSSION

#### COMPETENCIES OF AN INTEGRATED CARE SYSTEM

★ LEARN from PEDIATRICIANS → SPEND MORE TIME WITH PATIENTS → MORE ATTENTION → CARE FOR A BIGGER VARIETY OF PATIENTS

TRANSITION IS DIFFICULT

ADULT vs. CHILD CARE

COLLABORATION & COMMUNICATION TO PREPARE THEM BETTER



COMMUNITY-BASED SERVICES COST MONEY  
CARE GIVERS ARE THE PARENTS

LINKAGE WITH ORGANIZATIONS and SUPPORT SERVICES

BIAS → ENCOURAGE PHYSICIANS TO SPEND MORE TIME WITH PEOPLE WITH ID



OUR CULTURE: PARENTS TAKE CARE OF CHILDREN  
HOW TO CARE FOR ADULT CHILDREN WITH IDD

EDUCATE THE NEXT GENERATION OF PHYSICIANS  
EDUCATE and UNDERSTAND THE COMPLEXITIES

ACCESS TO CARE  
MINORITIES  
WE NEED BETTER TRAINING of PCP PROVIDERS

WE NEED MORE CARE FOR CAREGIVERS

# Optimizing Care Systems

For People with Intellectual and Developmental Disabilities

Day 1

## CHALLENGES IN WORKFORCE STRENGTH AND PREPAREDNESS

**Matt Holder**

AMERICAN ACADEMY OF DEVELOPMENTAL MEDICINE AND DENTISTRY

### CHALLENGES CLINICIANS FACE IN PROVIDING CARE

**IMPROPER REIMBURSEMENT MECHANISMS** ONLY 25%  
**OVERUTILIZATION & POLYPHARMACY**  
**PHYSICIANS SPECIALTY DRIVEN** \$6 MANY GENETIC SYNDROMES  
**ACCESS DO NOT GUARANTEE QUALITY**  
**Plan for THE LEVEL OF COMPLEXITY**

PATIENT COMPLEXITY

INADEQUATE PROFESSIONAL KNOWLEDGE  
 NO OFFICE MODIFICATIONS & NO TRAINING  
**INCREASE OF LIFE EXPECTANCY OF PATIENTS WITH IDD**

\* **BEHAVIOR COMPLAINT**  
 BEHAVIORS INCREASE  
 PROBLEM WORSENS  
 BEHAVIORS DECREASE  
**DIAGNOSTIC OVERSHADOWING**  
**MEDICATE BEHAVIORS WRONG**  
**PRESCRIPTIONS**

**Susan Havercamp**  
OHIO STATE UNIVERSITY

**HEALTHCARE PROVIDERS ARE UNPREPARED & UNCOMFORTABLE**

PEOPLE WITH DISABILITIES CAN'T GET BASIC HEALTHCARE. SO THEY GET SICK. AND DIE.

### NEED for TRAINING

we believe that **DISABILITY CONTENT SHOULD BE REQUIRED for ACCREDITATION of ALL HEALTH CARE TRAINING PROGRAMS**

AGREE ON WHAT NEEDS TO BE TAUGHT

CONSENSUS

GUIDELINES PRINCIPLES

6 CORE COMPETENCIES

OVERLOOK CULTURAL, ECONOMIC, SOCIAL BACKGROUNDS  
 OVERLOOK HEALTH ISSUES

UNDERESTIMATE CAPABILITIES

INACCURATE SYMPTOMS  
 SPEAK TO THE PATIENT  
 NOT ONLY CARE GIVERS

### MITIGATION

\* INCLUDE PEOPLE WITH DISABILITIES IN THE TRAINING  
 CREATES AWARENESS and MITIGATE BIAS

**Amy Hewitt**

UNIVERSITY OF MINNESOTA

COMMUNITY LIVING

PEOPLE WITH IDD  
**QUALITY OF LIFE HAS BEEN IMPROVED IN THE PAST 30 YRS.**

NOT FOR DIRECT SUPPORT PROFESSIONALS (DSP)



THIS WORKFORCE HAS LOW WAGES, UNAFFORDABLE BENEFITS, LACK OF CAREER ADVANCEMENTS CHALLENGES

LOW QUALITY SERVICES & POOR OUTCOMES

DSP MULTI-DISCIPLINARY SKILLS  
 25% HIGH SCHOOL DIPLOMA  
 75% BEYOND HIGH SCHOOL DIPLOMA  
**HHA ≠ DSP**  
**PCA ≠ DSP**  
**CNA**  
**DSPs ARE A LOT MORE THAN THAT**

BURNOUT 50%  
 ANXIETY 47%  
 SLEEP DIFFICULTIES 38%  
 PHYSICAL HEALTH 18%  
 SUICIDAL 4%

>13 MILLION DSPs in THE US  
 WE NEEDED 18.2 MILLION before the PANDEMIC

WE NEED TO UPLIFT and TRAIN THAT WORKFORCE

POLICIES / CREATE NEW ONES

### CULTURAL AND SYSTEMIC ISSUES

ENCOURAGE INNOVATION in our field

RIGHT PAYMENT and REIMBURSEMENT

REQUIRE TRAINING

POLICY CHANGE

BUILD CAREER

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Day 1

**Michael Monson** **ALTRUM INSTITUTE**

**FINANCING** → INTO THE HEALTHCARE SYSTEM  
**PAYMENT** → \$ DIRECTLY TO PROVIDERS AND PAYERS

**ACCESS ↔ COVERAGE** → **PROVIDERS**  
 INTEGRATED MODEL IS IDEAL  
 MEDICAID STATE PAYS BASED ON POPULATIONS  
 MEDICARE

**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

### CHALLENGES in FINANCING AND PAYMENT

**Cheryl Powell MITRE**

SWISS CHEESE OF FINANCING

IDEAL → INDIVIDUAL SUPPORTED HIS/HER GOALS, THEIR NEEDS

THERE IS NO CLEAR PATH

**Lack** OF COHESION OF SHARED VISION OF AGREEMENTS

WE DON'T KNOW WHAT TO PAY AND HOW MUCH TO PAY

HOW TO MEASURE SUCCESS?

**Fragmentation** SYSTEMS FINANCED BY DIFFERENT ORGANIZATIONS

DO NOT TALK WITH EACH OTHER

BRING THE PAYER ACROSS PUBLIC & PRIVATE SECTORS

WE STILL DON'T KNOW HOW TO MEASURE THE OUTCOMES

LEVERAGE PROFIT → CREATE THE RIGHT FRAMEWORK

PEOPLE WITH IDD WILL LIVE FULL LIVES WITH ACCESS AND CARE

IDD IS A TEAM SPORT

**NEED...**

GREATER EMPHASIS ON TRANSITION FROM HOME TO COMMUNITY LIVING

CHOICE and AUTONOMY in FURTHER MEASURE

DAY and EMPLOYMENT SERVICES RIPE GREATER

★ HOLD PROVIDERS ACCOUNTABLE

**Ari Ne'eman** HARVARD UNIVERSITY

**MEDICAL MODEL of DISABILITY**  
 IMPAIRMENT → CHALLENGE

**SOCIAL MODEL of DISABILITY**  
 IMPAIRMENT → STIGMA → BARRIERS → SOCIAL CONTEXT → CHALLENGE

HOW TO MEASURE OUTCOMES?  
 CLOSE THE GAPS

**QUALITY MEASURES**  
 HOME and COMMUNITY SERVICES

SURVEY MEASURE  
 NCI® NATIONAL CORE INDICATORS

RISK ADJUSTMENTS  
 QUALITY MANAGEMENT

**RISKS' ADJUSTMENTS**

- NO PROPER EXPERTISE
- NO VALUE PROVIDED

FINANCIAL INCENTIVES to ACHIEVE QUALITY

EXAMPLE: NEW YORK FIDA-IDD QUALITY MEASURES

outcome-based measures  
 SERVICE PLANS → PROPORTION ENROLLEES

- UNPREPARED HEALTH CARE SYSTEM OFTEN CAUSE HARM
  - FIX THE FINANCE SYSTEM & MOTIVATE PROVIDERS
  - PROFIT STEERED TOWARD GOALS and ACCOUNTABILITY
  - THINK ABOUT PEOPLE'S HOUSTIC NEEDS
- testing → COST RIGHT CARE for EACH CASE
- how TO CREATE THE RIGHT SYSTEM?
- helps the transformation
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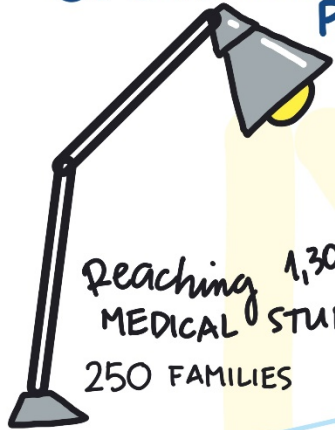
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Day 1

## SPOTLIGHT

PRESENTATION MAURA SULLIVAN



OPERATION  
HOUSE CALL

Reaching 1,300+  
MEDICAL STUDENTS  
250 FAMILIES



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  
of WEBSITE TRAINING  
by END of 2021

PANELS  
of  
INDIVIDUALS  
and FAMILIES

COMMUNICATION  
and TRUST

MONITORING BIAS and  
DIAGNOSTIC OVERSHADOWING

INTERSECTIONALITY and  
CULTURALLY COMPETENT CARE  
ACCOMMODATIONS  
and TIPS

change  
the  
culture

PEOPLE  
IN NEED  
ABOVE ALL

OPPORTUNITIES

★ HEALTH EQUITY  
MOVEMENT

★ ADA COMPLIANCE

★ FAMILIES MAKE  
GREAT TEACHERS