



Enhancing Health Care for People Intellectual and Developmental Disabilities

December 9, 2021

The Arc of Massachusetts

The Arc Oregon



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Overview for Today's Webinar



- Operation House Call Background
- Health Disparities and Access Challenges
- Training & Education for Healthcare Providers in Hospital Emergency Departments
- Barriers & Opportunities
- Overview of Training and Education Resources on the Website

The Arc of Massachusetts

Maura Sullivan, MPA

- Parent Instructor
- Leadership Education in Neurodevelopmental Disabilities (LEND) Fellow, UMASS Medical School
- Director Of Government Affairs
- Director Of Operation House Call
- National Speaker On Health Equity

The Arc Oregon



Em Braman (she/her/hers)

Executive Director, The Arc Oregon

Parent Educator



The Arc of Massachusetts

Operation House Call: Our Impact



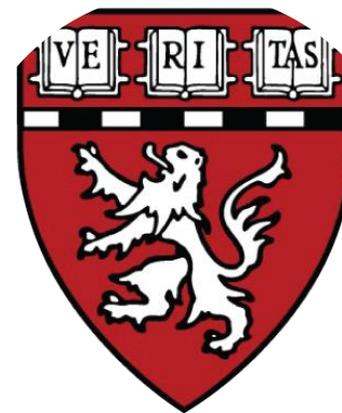
- 1,300 plus medical and graduate nursing students trained each year
- Over 250 volunteer families in Massachusetts welcome students throughout the year for “in home” experiential learning
- Grows confidence and interest in future doctors
- Shifts implicit bias that affects treatment and assessment
- Growing to reach other healthcare professionals



Participating Medical Schools

Four Components

- Didactics
- Panels of individuals and families and experts
- Home visits (now virtual)
- Self-reflections essays on privacy protected forums



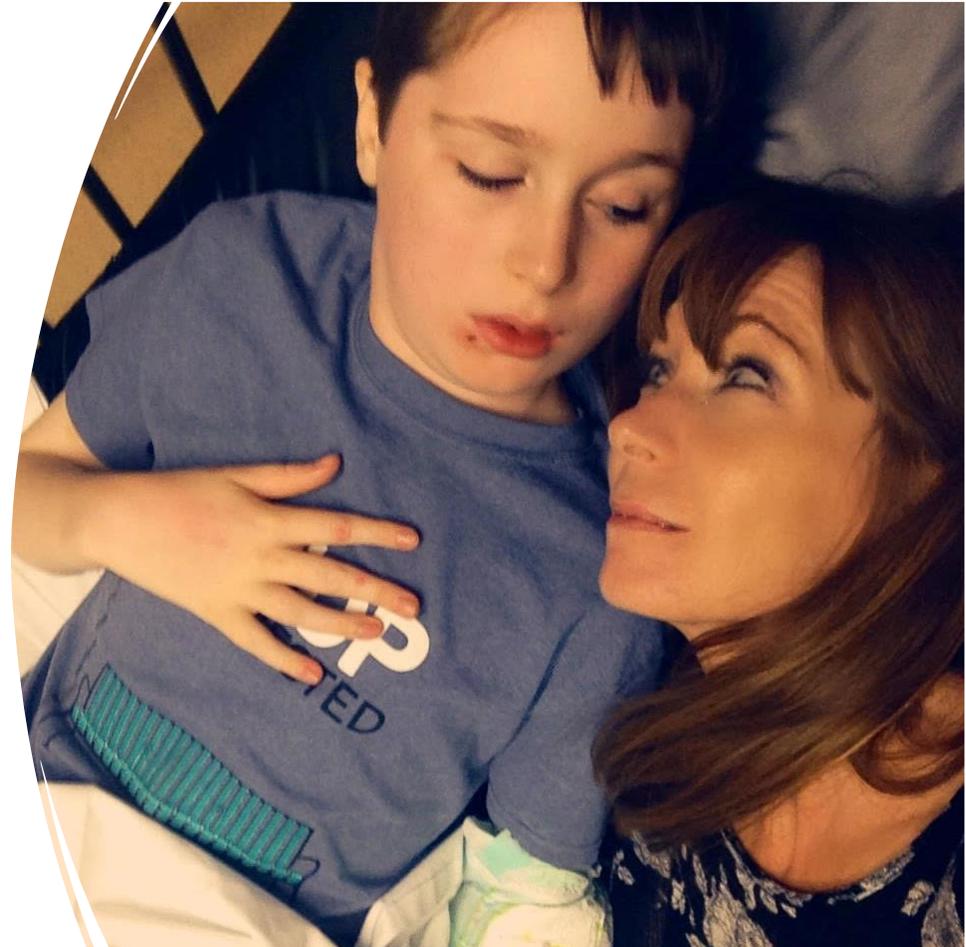
Health Disparities and Access Challenges



- 10-16 million individuals are living with autism and IDD.
- Access to primary care and specialist is lacking especially for adults. These factors lead to poor health and life outcomes, increased rates of physical and mental comorbidities, and mortality.
- Outcomes are worse for racial minorities and people with other marginalized identities.

Health Disparities and Access Challenges

- In a survey of 3500 people with IDD/autism, nearly 1/3 of respondents noted a traumatic or negative experience and unwanted outcome in the ED.



Clinician Training and Confidence

Most clinicians receive little to no training in autism or IDD.

78% want to understand more about IDD.

Only 40% feel prepared to treat patients with IDD.

Pandemic Impact on Autism and IDD: Breaking the Bias and Building Trust



§ Crisis Standards of Care (CSC)

Many individuals with autism and IDD face negative biases and inaccurate assumptions about their quality of life, the value of their life, even their capacity for survival and all of this can have deadly consequences.

COVID-19 impact on our community has been enormous and affecting all aspects of their typical services and supports.

Live 1-hour Virtual Webinar / Recorded Webinar on Training Website



- The Arc: Leading advocacy organization in Massachusetts for ppl with autism and IDD

- Autism, IDD, Health Disparities, access, COVID-19 impact

- Communication, implicit bias, accommodations, culturally competent care

- Experiences, tips and perspective

Examples of Learning Objectives

Communication
and Trust

Intersectionality
and Culturally
Competent Care

Monitoring Bias
and Diagnostic
Overshadowing

Accommodations
and Tips

Shifting Culture and Attitudes



- The importance of language you use
 - Remember that language shapes our beliefs and our attitudes!
- Respect.
- Modeling “person first language and behavior”

Implicit Bias: Screening & Diagnostic Overshadowing



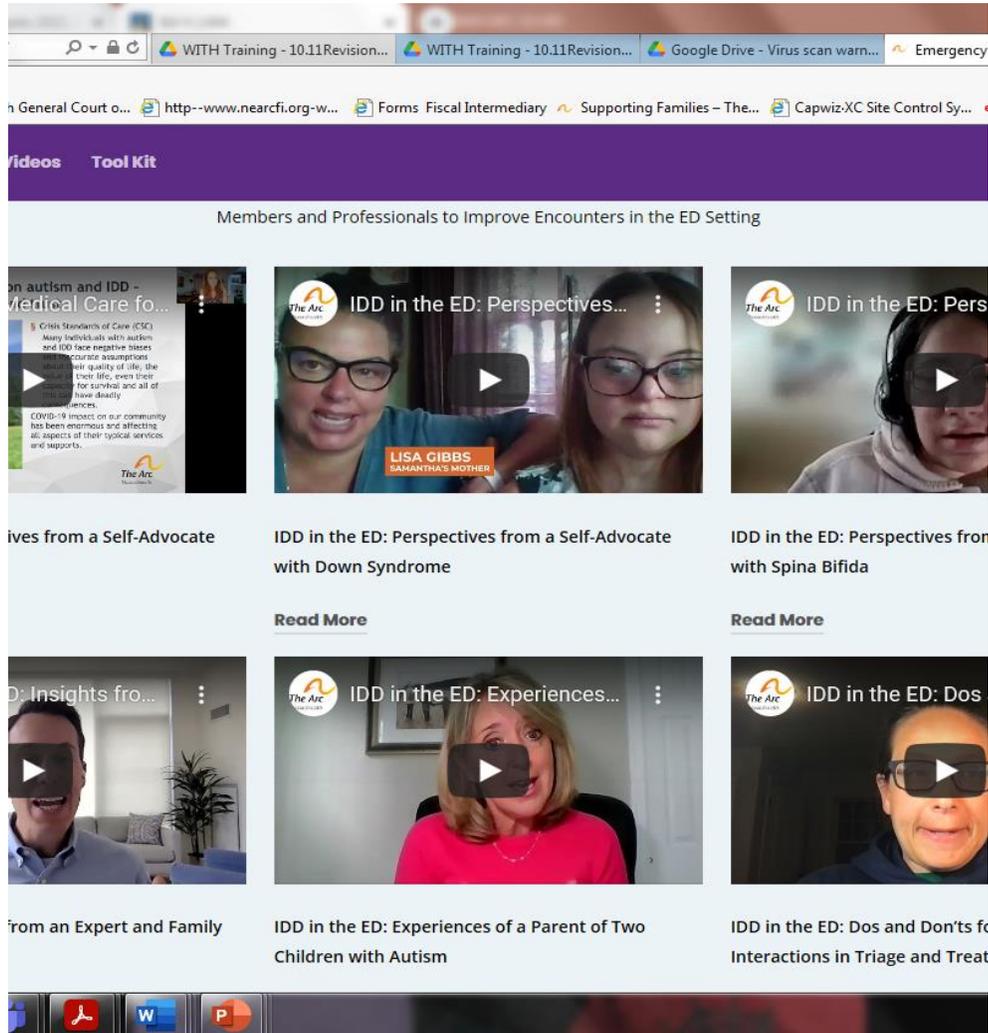
- Recognize bias and stigma and how it affects treatment and assessment.
- People of color face all the well recognized health disparities but are also diagnosed later, misdiagnosed - can lead to less services and supports and worse outcomes

Implicit Bias & Stigma



- Recognize the value and quality of life, expectations, capabilities and accommodations
- Take action! Commit to learning and teaching through modeling language and behavior.

Free Website Training Access



- 10 training videos from self-advocates, parents, MD Experts, and other professionals in the field
- Online toolkit for quick access to resources and pertinent research

Barriers and Opportunities

Covid-19

- Capacity and accessibility of hospital staff
- Availability of interviewees due to quarantines



Covid-19 highlighted the problems of health equity and access

Adverse experiences generated complaints and corrective actions

The virtual training platform allowed for big numbers to attend and a wider variety of interviews and self-advocates

DEI is high priority

Families and individuals were inspired to contribute

How To Get Started



- Developing a list of your known contacts
- Develop a list of ADA/DEI Coordinators, Patient Experience Directors and ED Directors both clinical and administrative
- Script a letter/email that educates
- Provide letters of support
- Stick to 1 hour training
- Include management of patients who present with significant behavior challenges
- Include a range of self-advocates, family members, experts
- Provide hands on tools
- Be sensitive in training the duress and pressure of our healthcare system
- Training should consider an in-person option



The Arc Oregon

What we've been up to in Oregon



- SB 1606
- Advocacy with SDM
- Focus on relationships building, rural outreach, collaboration with UCEDD and Family to Family
- Medical Advocacy
 - GAPS Program
 - HCA Support
 - WITH Project

Health Disparities and Access Challenges



Other factors to consider:

- Access in rural and frontier regions of your state

A Positive Trajectory: Emergency Room Visit Feedback from Self Advocates and Family Members

What people with IDD and their families want...

- To get fair, adequate, person-centered care when going to the Emergency Room
- For the role of the supporter to be understood by ER doctors and personnel
- Emergency room professionals to be confident and equipped to support people with IDD, their families and supporters
- Easy to access resources and tools to support people with IDD in Emergency settings

What People with IDD and Their Families Want to Avoid

- Being misunderstood in emergency settings
- Navigating emergency care without a chosen supporter available
- Being excluded from making important decisions related to their own health
- Person's rights not being understood or supported
- Being discriminated against

Online Toolkit



- Disability and Autism Resources
- Communication Tools
- Human and Health Care Rights
- Cultural Competency and Intersectionality
- Emergency Preparedness Tools/Abuse Reporting

Thank You!



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