



Massachusetts Statewide NDD Transition Summit 2023: Deepening Engagement with Stakeholders

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Introduction

The Massachusetts Initiative to Improve Healthcare Transition for Individuals with Neurodevelopmental Disabilities (NDD) began in 2018 and developed into a multiyear quality improvement collaborative. An initial statewide summit was held in 2020 to engage stakeholders. Building partnerships is an ongoing, primary aim of the initiative and an updated summit was held in 2023.

Process/Methods

- Interdisciplinary planning committee convened included pediatricians, parents, adult providers, subspecialists and policy makers.
- Summit participation from broad, diverse set of stakeholders, including families, was encouraged.
- Surveys were collected from participants to evaluate the Summit.

Summit Objectives:

Identify barriers and facilitators of equitable access to quality healthcare for transition-age youth with NDD

Develop shared understanding of perspectives of diverse stakeholders, with particular attention to patient and family experience of the transition process

Develop at least one action step to improve the transition process in their setting.

Results

Summit Topics/Speakers:

Keynote: Supported Decision Making

- Anna Krieger, JD, *Executive Director, Mass Advocates for Children*; Jonathan Gardner, *Self-Advocate*; Nancy Gardner, *Parent*

State of the State: Transition Ideas in the State of Massachusetts

- Elaine Gabovitch, MPA, *Director, Division for Children & Youth with Special Health Needs (DCYSHN), DPH*

Partnering with Families: Overview of the NDD Transition Initiative

- Sarah Spence, MD, PhD; Nancy Wagman, Parent

Improving the Transition Process: Lessons learned from the NDD Learning Collaborative

- Team Leads

Breakout Round Table Discussions

- Training Innovations and Engaging Medical Residents
- Optimizing the Transfer Process
- Leveraging Transition Resources

Success in Adult Practice: How They Do It

- Facilitator: Ahmet Uluer, DO, MPH
- James Bath, MD, *Family Practitioner MGH*; Kate Nolan, Gyn NP, *KIND clinic BIDMC*; Margaret Threadgill, MD, MBA, *Internist BWH*; Rangsun Silthichai, MD, *Psychiatrist, UMass*

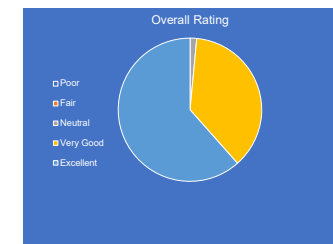
In Allyship: What Can Be Learned from Making People with Disabilities Visible in 'Big Data'

- Alyna Chien, MD, MS

Leaders Learning and Learning In

- Facilitator: Jason Fogler, PhD; Deborah Dreyfus, MD, *Medical Director, DDS*; Cindy Friedman, *MA State Senator* Victor Hernandez, *Deputy Assistant Commissioner, DDS*; John Lawn, *MA State Rep*; Christine Pace, MD, *Population Health Management, Boston Medical Center*; Maura Sullivan, *MA ARC, Operation House Call, Parent*; Madi Wachman, *MassHealth*

- 170 registrants.
- 65 evaluation surveys received, **100% reported summit met learning objectives.**



- Important for a summit built on inspiring action, **89% of respondents stated that they would make clinical, teaching, or administrative changes as a result of the summit.**
- **98% expressed interest in further courses on the topic.**
- **75% agreed (14% neutral) that the summit helped to address, overcome or remove barriers to change in professional practice.**
- **Themes from participant comments:**
 - High cost, lack of time and resources, and the medical insurance system impede progress
 - Personal experiences stories from families and providers were particularly helpful
 - Scarcity of adult providers comfortable with caring for these young adults is major barrier
 - More opportunities for more cross-pollination of ideas and networking are needed

Conclusions

The summit, with the opportunities to engage with other collaborators from multiple perspectives, was valuable to participants. New stakeholders were engaged and partnerships created.

Future Directions

Summit participants generated many potential change ideas to implement:

- Increasing networking and referrals to adult providers
- Creating a transition policy
- Educating colleagues about supported decision making
- Obtaining leadership buy in
- Collecting data about resources required

NDD Transition Initiative Next Steps:

- Continue connection via monthly collaborative meetings
- Disseminate findings via presentations and manuscripts
- Ensure sustainability by obtaining funding