

Supporting Access for Everyone (SAFE)

safedbp.org

SAFE Initiative Public Forum
October 6 & 7, 2022



SAFE Initiative Overview

- Interprofessional and stakeholder-driven initiative to establish best practices for supporting youth with neurodevelopmental disabilities in medical settings
- Answering key questions:
 - What do medical professionals need to know and do differently?
 - How can hospitals proactively make medical settings more accommodating?
 - How can scheduling, care delivery, and other processes make care more accessible?
 - What systems and policies should change to advance health equity?



SAFE Process



1. **Call for Stakeholder Testimony.** Community advocates and neurodivergent adults, family members, clinicians (including physicians, advanced practice clinicians, nurses, child life specialists, rehab specialists, etc.), researchers, and other stakeholders are invited to share their expertise and lived experience on how medical settings can provide SAFE care.



2. **Public Forum.** Representative testimony submitted by stakeholders will be presented in a live, virtual forum where they can expand on their perspectives and answer questions from the public audience as well as invited experts. The forum will help to consolidate knowledge shared through the testimony process.



3. **Consensus Panel.** An assembled panel of stakeholders will convene to integrate the submitted testimony with published evidence and write a **Consensus Statement on Best Practices for SAFE Care** for children with autism and neurodevelopmental disabilities. This statement can lay the groundwork for disseminating and evaluating SAFE practices, with the overarching goal of improving health outcomes for all children.

SAFE Consensus Panel



Sarah Spence, MD, PhD



Jackie Ward, DNP



Rena Sorensen, PhD



Matthew Siegel, MD



Rachel Honore



Paige Cervantes, PhD



Yetta Myrick



Morénike Giwa Onaiwu, MA



Wendy Ross, MD, FAAP



Lauren Raskin Ramos, MPH



Varleisha Gibbs PhD, OTD



Christina Nicolaidis, MD, MPH



Scott Allen, MS



Mary Rumble, BA, CCLS



Marilyn Augustyn, MD



Carol Weitzman, MD
SAFE Co-Chairs



Cy Nadler, PhD

<https://safedbp.org/consensus-panelists/>



Developmental Behavioral Pediatrics Research Network

- The Developmental Behavioral Pediatrics Research Network (DBPNet) is a multi-center scientific and clinical research network that promotes research activities and addresses health issues for children with developmental and behavioral needs. DBPNet infrastructure also supports the translation of research to practice, as well as training the next generation of developmental behavioral pediatrics researchers.



<https://www.research.chop.edu/dbpnet>



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DBPNet Network Coordinating
Center Director
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Jaclyn Cacia, MS, CCRC

Clinical Research Program
Manager
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Health Resources and Services Administration's Maternal and Child Health Bureau

- HRSA is the primary federal agency focused on improving health care for geographically isolated, economically or medically vulnerable populations.
- MCHB supports training, research, and coordinated and effective system of cares so that all children, youth, and young adults with ASD enjoy a full life, from childhood through adulthood. We aim to help this population thrive in systems that support their families, their social, health, and emotional needs as well as ensure dignity, autonomy, independence, and active participation in their community.



<https://mchb.hrsa.gov/>

Maura Maloney, PhD, MS

Health Scientist and Project Officer

Division of Research, Office of Epidemiology
and Research





AUCD/ITAC Acknowledgment

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Overview of Today

Visit <https://safedbp.org/public-forum-schedule/> to see today's schedule

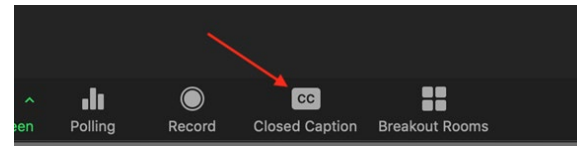
Reminders for all attendees:

- SAFE is committed to supporting a respectful and inclusive dialogue. Language or behavior that is hostile, derogatory, or otherwise disruptive will result in your removal from the meeting.
- If sharing personal experiences, please avoid naming specific people or institutions. Instead, focus on what aspects of your experiences were helpful, problematic, or inform recommendations for improvement.
- By participating in this live session, you agree and acknowledge that your name and participation will be part of the recording that will be archived on the SAFE Initiative public website.
- For those presenting, please be mindful of your assigned time limit. We will let you know when you have about 30 seconds left.

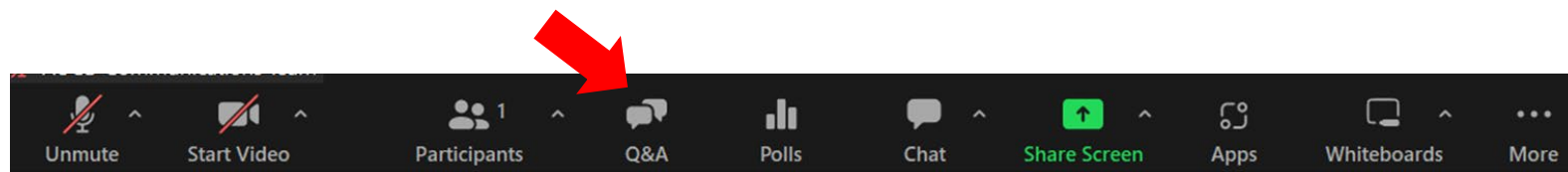
Housekeeping

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- Closed captioning is available:



- Participants are muted/video off throughout sessions
- Use Q&A function to ask questions:





Identifying Components of Autism-Friendly Healthcare

Belinda O'Hagan

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Q&A



Public Testimony

Mary Anne Hammond

Beth Dehoff

Lina Patel (Written Submission)

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Q&A

Break



Public Testimony

Shayla Sullivant
Natalie Monfort
Deepa Menon

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Q&A



Public Testimony

Hari Srinivasan
Donnie Denome

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Q&A

Break



Public Testimony

Kathleen Williamson

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Q&A



Public Testimony

Matt Snell
Alex Friedman
Jenni Gretzema (Video)

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Q&A

Break



Public Testimony

Patrick Forgey

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Q&A



Public Testimony

Doreen Bestolarides
Janet Shouse
Shannon Rosa

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Q&A



Public Testimony

Jo Dienst
Rachel Santiago
Bob Williams

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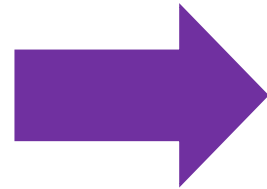



Q&A

Thank You!

Please take 1 minute to provide feedback on today's meeting:
<https://www.surveymonkey.com/r/SAFEforum>

*or scan the
QR Code*





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SAFE Initiative Overview

- We value diversity, equity and inclusion and hearing all voices with respect and integrity.
- If you are presenting on behalf of a program or an organization, feel free to state your affiliation.
- We ask that you not name specific programs or individuals in the content of your presentation or questions/response to protect individual privacy.

SAFE Day 1 Recap

Key themes included:

- Communication is key
- Representation, respect, and equity
- Proactive, collaborative, and individualized accommodations and supports

Overview of Today

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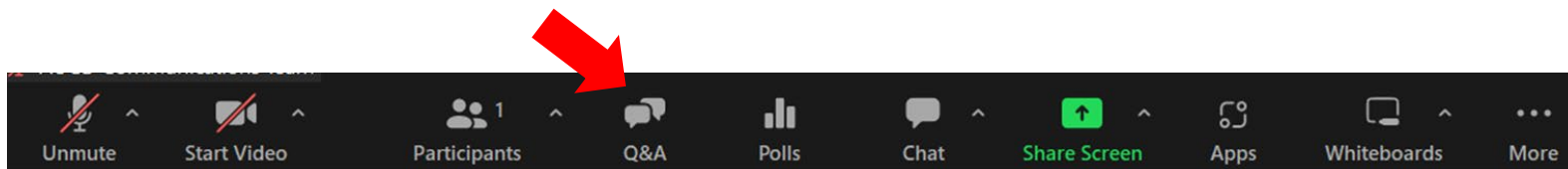
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Evidence-Based Strategies for Supporting Youth in Medical Settings

Holly Harris
Alec Bernstein

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Q&A



Public Testimony

Emma Bouza
Marty Skemp Brown
Katie Sullenbrand

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Q&A

Break



Public Testimony

Syma Khan
Kristen Coffey & Theresa McCarthy
Tamara Rosen

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Q&A



Public Testimony

Bethany Ziss (Video)
Adnan Qadeer
Sean Inderbitzen (Video)

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Q&A

Break



Public Testimony

Clarissa Kripke (Video)

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Public Testimony

Nasuh Malas
David Childers
Julianna Rava

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Q&A

Break



Public Testimony

Ellen Bannister

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Q&A



Public Testimony

Alice Zhang
Kashia Rosenau
Lauren Frederick

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Q&A

Q&A

Bethany Ziss & Clarissa Kripke

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