

ECHO Autism Hawai'i

A Pilot Program for Supporting Autism Providers in Family-Centered Care



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Eunice Kennedy Shriver
National Institute of
Child Health and
Human Development



Today's Objectives

- Introduce and describe the ECHO Model
- Describe how ECHO was adapted/implemented for communities of educators and service providers in Hawai'i
- Show data from sessions on feasibility and acceptability of family-centered care strategies
- Show outcome data from post-session surveys
- Discuss future directions

Meet Your ECHO Hub Team



Maya Matheis

- Ph.D., MSW
- Clinical Psychologist; Faculty at Center on Disability Studies



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- Assistant Professor, Special Education



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ECHO Model

“Move knowledge,
not people”



ECHO Guiding Principles

- Democratization of knowledge
- Mutual respect and intellectual honesty
- Non-exclusivity
- Fidelity to the ECHO model
- Empowerment of providers
- Commitment to listening, learning, and service
- Positive communication and empathetic skills
- “All teach, all learn”
- Collective data and community-based research to improve outcomes

ECHO Outcomes

- ECHO model has been successfully used for rheumatoid arthritis, diabetes, chronic pain, HIV/AIDS, hepatitis C, and more
- UH Mānoa also hosts ECHO Geriatrics and ECHO Care Home

ECHO-trained primary care providers offer equivalent outcomes to those of patients managed by specialists. (Arora et al. 2011, New England Journal of Medicine)

Reported outcomes from a systematic review of 39 studies describing ECHO for 17 different medical conditions. (Zhou et al 2016)

- Professional satisfaction
- Knowledge
- Provider competence
- Provider performance
- Patient health

ECHO Autism



- Started by faculty at University of Missouri in 2015
- Currently 36 programs (and counting!) across the world



ECHO Autism Hawai'i: Significance

- Significant need in Hawai'i for effective sharing of autism knowledge and resources across rural, remote, and/or underserved areas
- Children with ASD who are Native Hawaiian or other Pacific Islander have access to the fewest autism resources per child compared to White children with ASD
- Physical geography of Hawai'i leads to many areas having disproportionately low access to autism services
- Many regions have no physical access to services at all



ECHO Autism Hawai'i: Significance

- For example: In the HI Department of Education there are (as of Oct. 2024):
 - **35** employees in Behavior Analyst Positions
 - **17** employees in Behavior Analyst Teacher positions
 - **123** BCBAs under the State ABA contract
 - **2,686** students eligible for IDEA services under the category of ASD

Overarching Goals of ECHO Autism Hawai'i

- By fostering a community of practice, ECHO Autism Hawai'i aims to:
 - **Reduce disparities in access** to autism services
 - More effectively **disseminate knowledge** and resources related to autism
 - **Improve outcomes** for autistic individuals and their families across Hawai'i



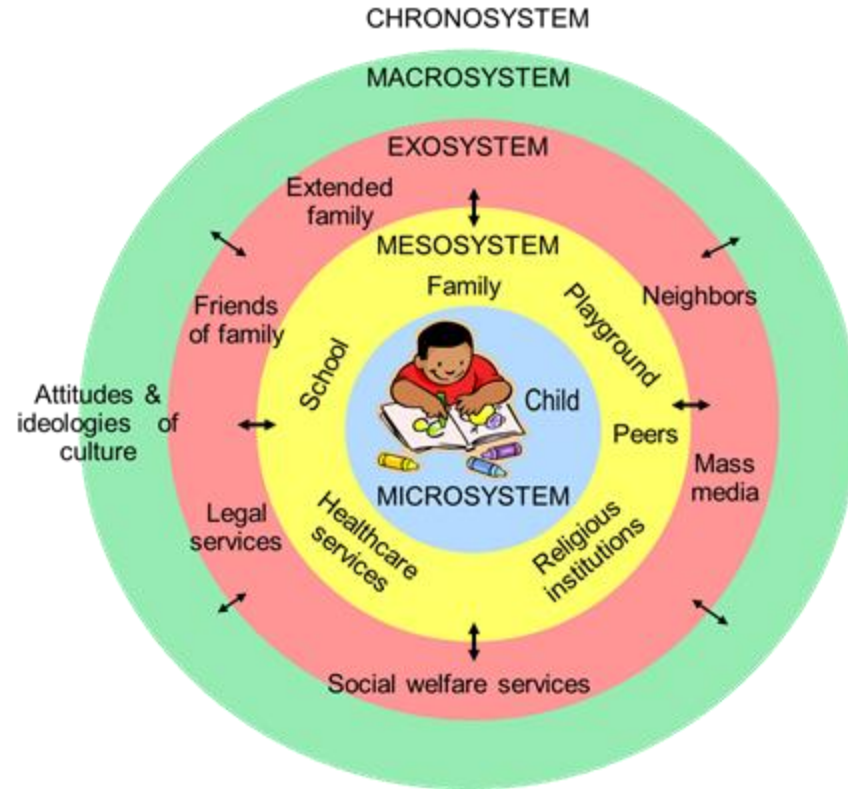
Specific Goals of ECHO Autism Hawai'i

- Increase provider **knowledge and confidence** with implementing **family-centered practices** across the lifespan
- Increase **access to an interdisciplinary network** of providers
- Disseminate **evidence-based resources** and knowledge
- Use **community-partnered research** to collect/analyze data and improve outcomes



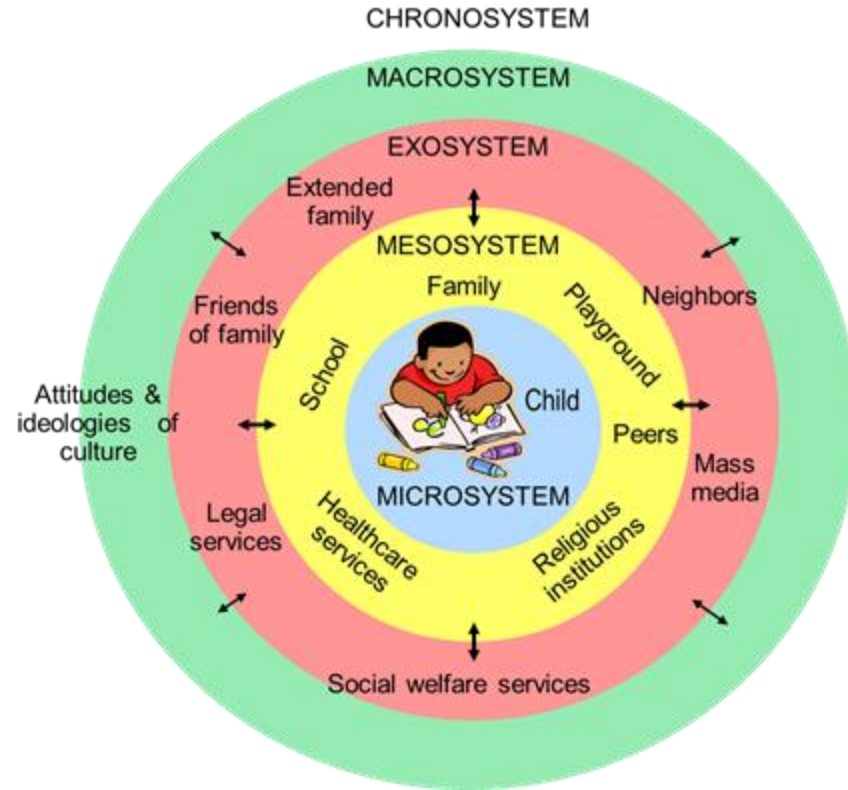
Family-Centered Care

- Service provision and support occurs within multiple contexts/systems
- Caregivers are usually the closest “system” to the individual - they are the experts on their child



Family-Centered Care

- Family-centered care involves families and professionals working together to support the well-being of the child and the family
- “Both parties share their respective knowledge and skills to jointly achieve outcomes chosen by the family”



Outcomes of Family-Centered Care

- Family-centered practices are more likely to build **mutual trust** and **shared effort** in achieving goals
- Family-centered care **increases caregiver self-efficacy and well-being**, contributes to increases in **positive, adaptive child behaviors** and decreases in perceived negative behaviors
- Family-centered partnerships are more likely to contribute to families **viewing services as effective** and **contributing to their quality of life**

Family-Centered Care: ACE Strategies*

- All sessions centered around knowledge/resources that incorporated ACE strategies

Alliance

- Actively listen to caregiver
- Convey a sense of partnership
- Communicate positive regard to caregiver

Collaboration

- Give suggestions, not directions
- Ask for caregiver input
- Collaboratively plan for home and community practice

Empowerment

- Acknowledge caregiver strengths and efforts
- Jointly identify and problem solve barriers

Fidelity of Implementation

- ECHO Autism Hawai'i Hub Team completed three-day training on the model from the ECHO Autism hub team at the MIND Institute at UC Davis
- Our fidelity of implementation was scored by an outside observer familiar with the program AND an internal research assistant
- ECHO Autism Hawai'i Hub Team implemented all sessions with fidelity to the original ECHO model

ECHO Autism Hawai'i Schedule

Date/Length	Topic	Didactic Presenter(s)
June 12, 2024 90 min.	Intro to ECHO Model and Family-Centered Care	ECHO Hub Team
June 26, 2024 90 min.	Family-Centered Care in Early Childhood	Erika Phelps (Developmental Behavioral Pediatrician)
July 10, 2024 90 min.	Family-Centered Care and School-Age Children	Naomi Tachera (Professor of Special Education; Parent of autistic children)
July 24, 2024 90 min.	Family-Centered Care and Transition-Age Individuals	Susan Wood (Director of Hilopa'a Family to Family)

Session Structure

Component	Time	Description/Purpose
Welcome, Introductions	5-10 min.	Check-in and connect, review any news or updates
Didactic presentation	15-20 min.	Content expert introduces and describes strategies related to the session topic on Family-Centered Practices
Case presentation	15-20 min.	Real life case example and guiding questions presented by participants to problem-solve and apply key concepts
Q&A	~10 min.	Participants ask clarifying questions about the case
Recommendations and Considerations	10-15 min.	Participants share recommendations, strategies, resources, and considerations
Wrap-Up	~5 min.	Summary of session, reminders of upcoming sessions, etc.

Case Presentation

- **Case description***: age, diagnosis, service setting, current services
- **Family considerations**: language spoken at home, family composition and support systems, cultural considerations, primary caregiver participating in services
- **Individual/family strengths**
- **Current skill levels**
- **Additional medical considerations**
- **Service barriers**: common factors, triggers, and/or stressors that may have kept the individual and/or family from meeting goals
- **Previous strategies**: what has already been tried and how successful was it?
- **Focus of discussion**: Primary Area of Concern (on what specifically would you like ECHO community to provide support/ideas?)

Role of Participants

“All Teach, All Learn”

Actively engage

- Be fully present and ready to learn
- Minimize distractions
- Avoid reading/sending messages, doing other work, or multitasking
- Share your knowledge - your contributions are invaluable!
- Do not share any Protected Health Information (PHI)

Be open-minded to diverse views

- Learn from others
- Adopt the spirit of improving, not proving
- Value and respect all perspectives
- Be mindful of who is not in the room

Culturally Sustaining Practices

- Culturally sustaining practices:

“work that not only respects and honors but intentionally nurtures and expands ethnically and racially minoritized students’ cultures. These practices uplift, center, and sustain Black, Latino, Asian/Pacific Islander, and Indigenous (or Native peoples) cultures”

- It is important for our Hub team, as transplants to the Kingdom of Hawai‘i, to find ways to engage in culturally sustaining practices

Adapting ECHO for Hawai'i

- **“Talk story”**: Hawaiian idiom meaning to informally chat or share stories, often in a relaxed and intimate setting. It's a way to connect with others, share experiences, and build relationships.
- Connections to the land, to elders, and to the community are valued in Hawaiian culture
- ECHO Welcome/Introduction activities included having participants share their **‘Aina** (land) and their **kupuna** (ancestors, elders, mentors) that they bring with them to the learning space
- Sessions included interactive discussions on the following:
 - What are some barriers to providing family-centered care that you have encountered in your work in Hawai'i?
 - What are examples of ACE strategies in your work with families in Hawai'i?

Program Outcomes

- 28 service providers registered on ECHO Platform; 22 participated (average of 13 participants per session)
- Included clinical psychologists, speech-language pathologists, early interventionists, special education teachers, director of organization, Registered Behavior Technician, and service coordinator

Program Outcomes

Reasons for joining ECHO Autism Hawai'i	<i>n</i>
Desire to learn more about autism	6
Desire to increase networking and resource sharing with colleagues	5
Desire to learn more about family-centered care	4
Desire to increase access to specialists and interdisciplinary work	1

Program Outcomes

Reasons for discontinuing and/or not attending sessions	<i>n</i>
Scheduling conflicts	5
Personal/family issues	1
Time commitment for the program	1
Technical difficulties with online sessions	1

Session and Program Outcomes

- After each session, participants completed satisfaction surveys, including feasibility and applicability of strategies
- Post-program survey evaluated the overall acceptability and perceived impact of the program
- Four-point Likert scale rating (Strongly Disagree → Strongly Agree)

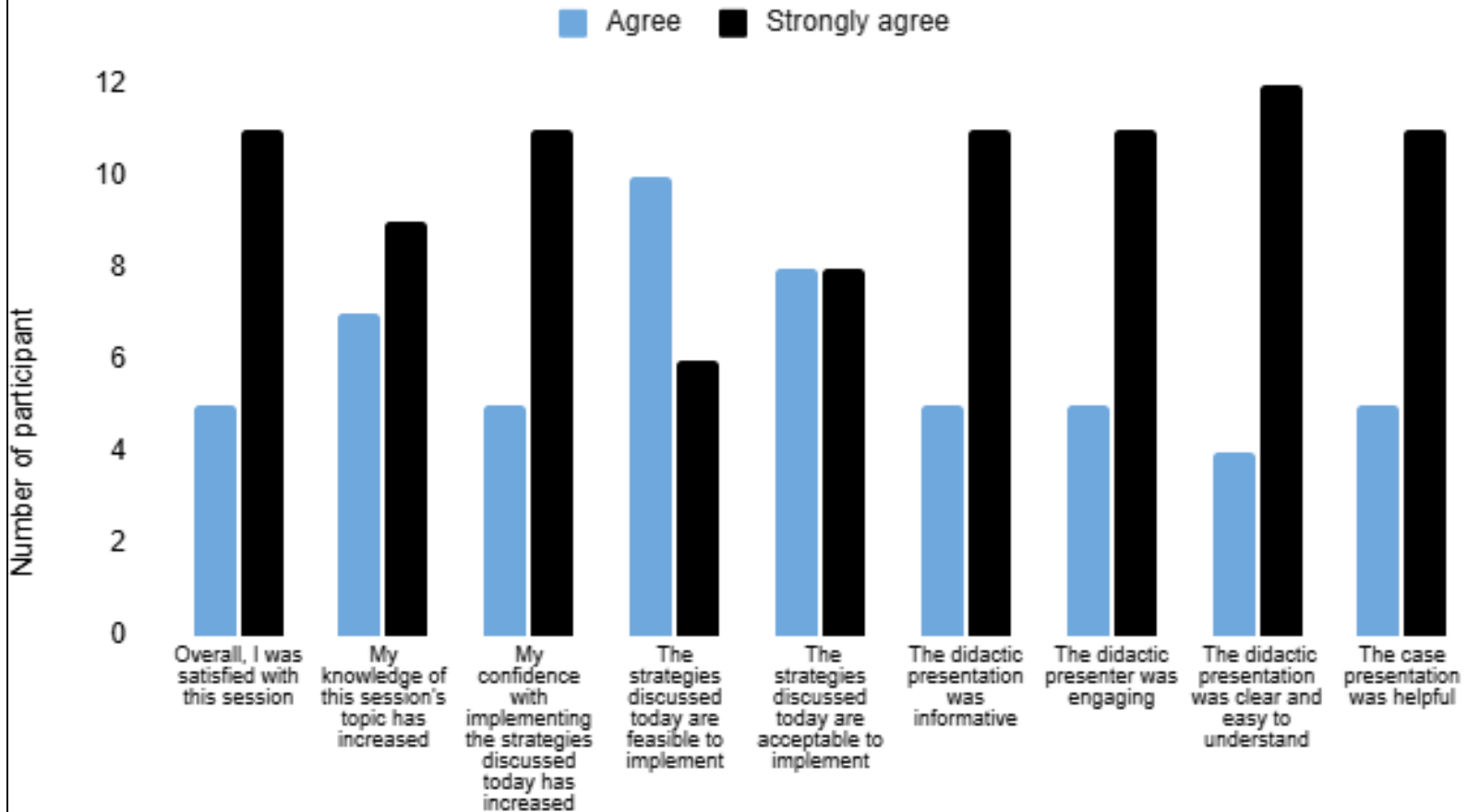
Post-Session Survey Items

- I was satisfied with this session
- My knowledge of this session's topic has increased
- My confidence with implementing strategies discussed today increased
- Strategies discussed today are feasible to implement
- Strategies discussed today are acceptable to implement
- Didactic presentation was informative
- Didactic presenter was engaging
- Didactic presentation was clear and easy to understand
- Case presentation was helpful

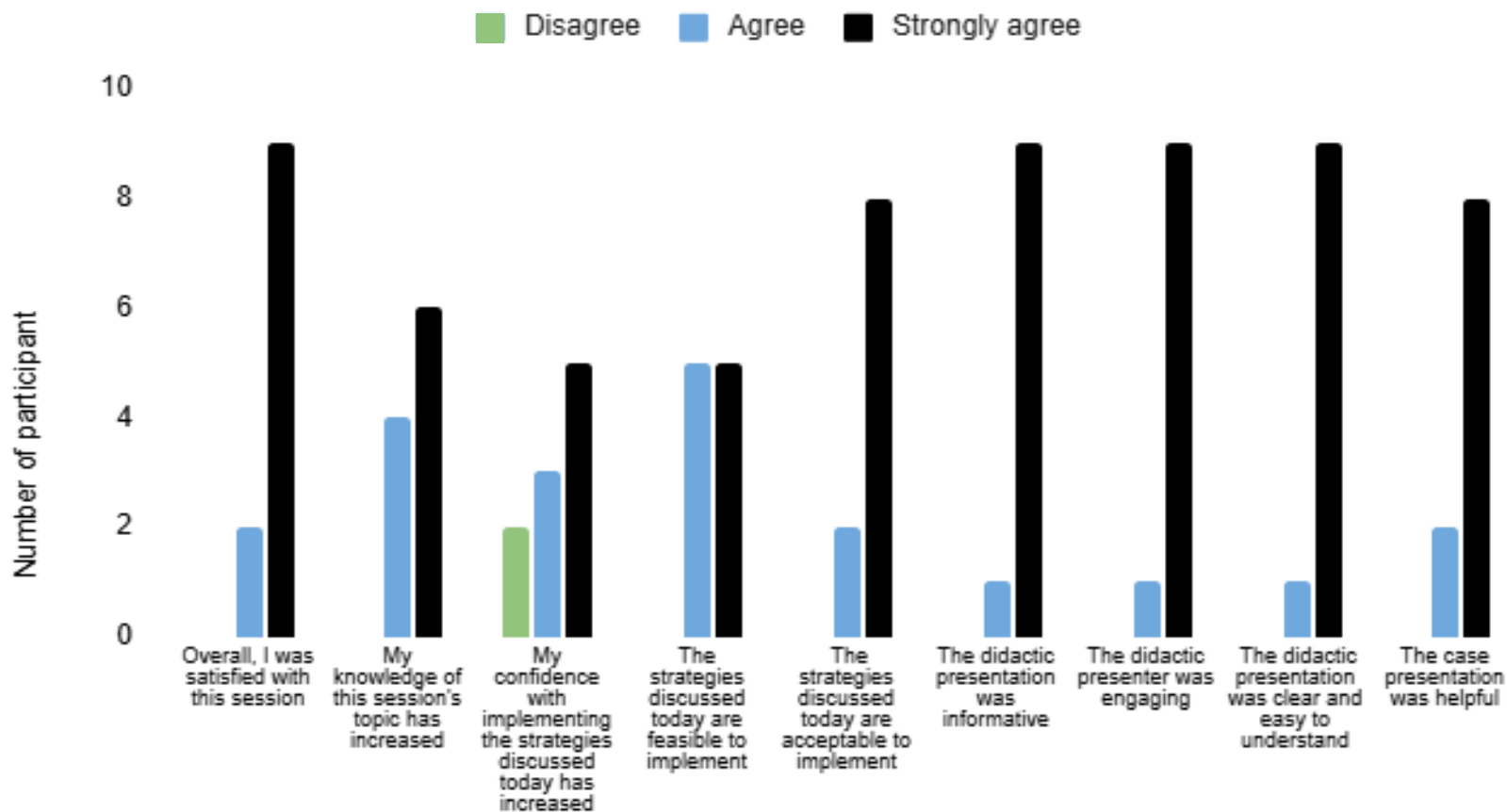
Post-Program Survey Items

- Overall, I was satisfied with the ECHO Program
- I would recommend ECHO Autism Hawai'i to others
- The ECHO Team created a supportive learning environment
- I felt comfortable expressing my questions and ideas
- My knowledge of family-centered practices has increased as a result of ECHO Autism Hawai'i

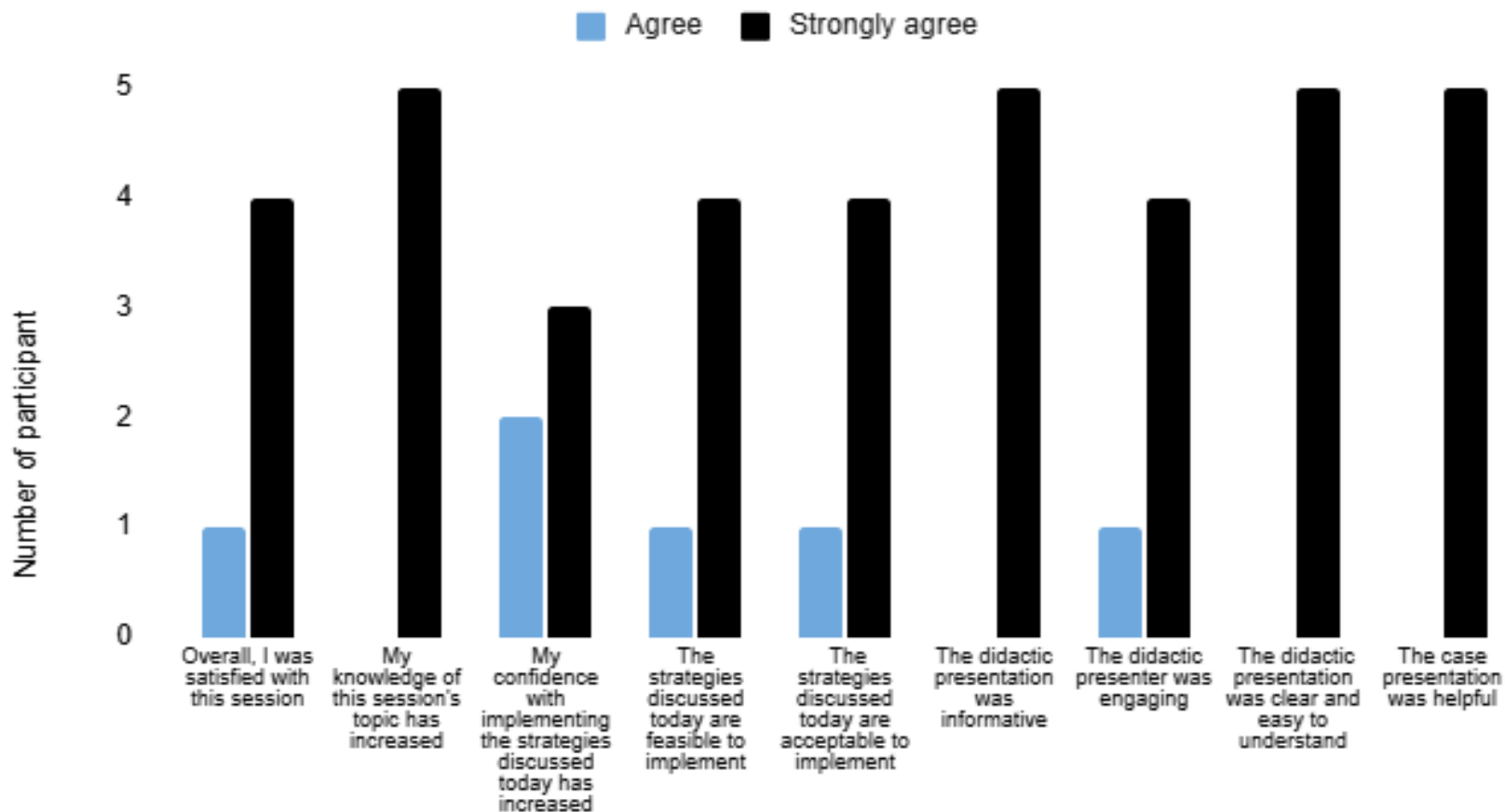
Session 1; Participants = 18; Completed Survey = 16



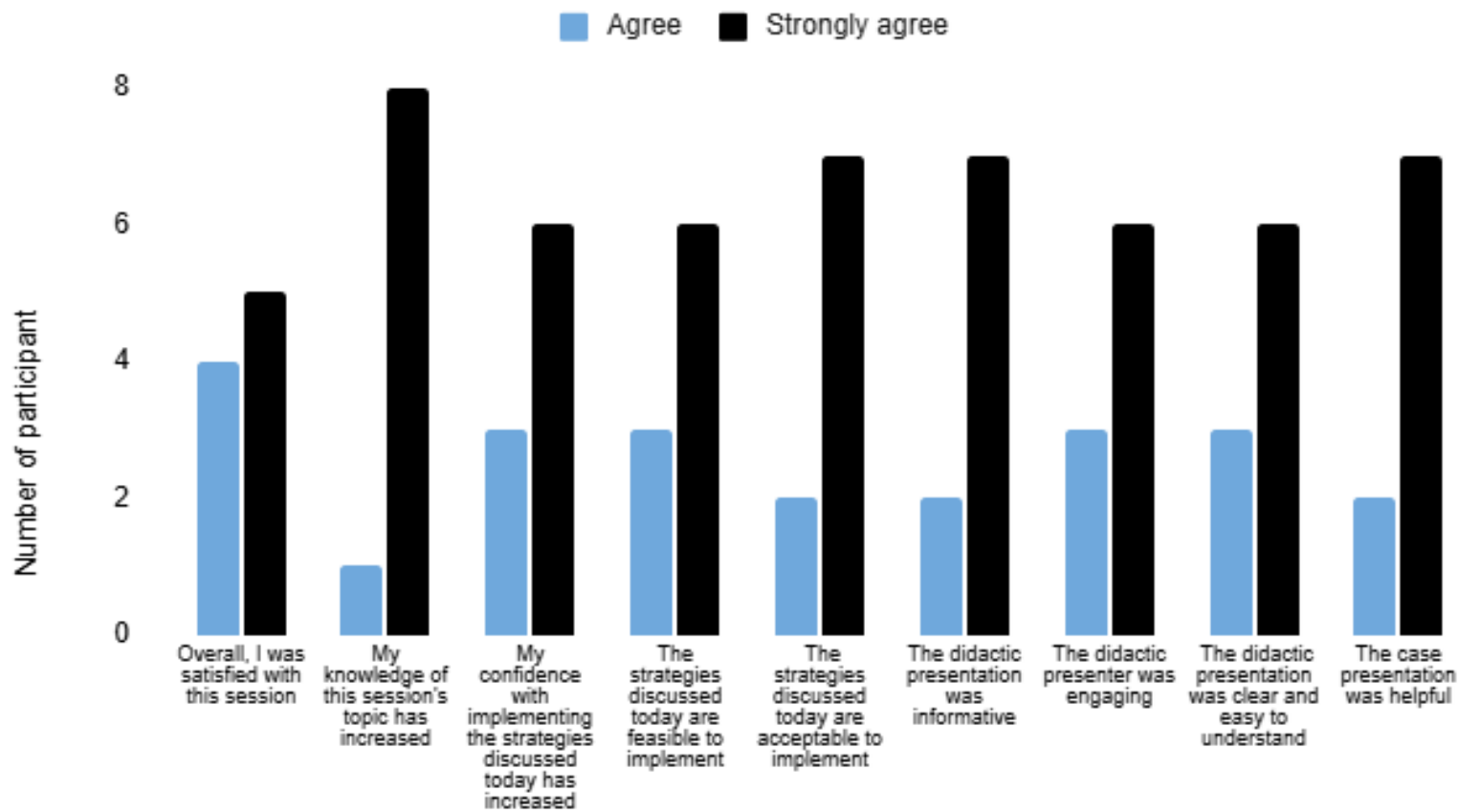
Session 2; Participants = 15; Completed Survey = 11

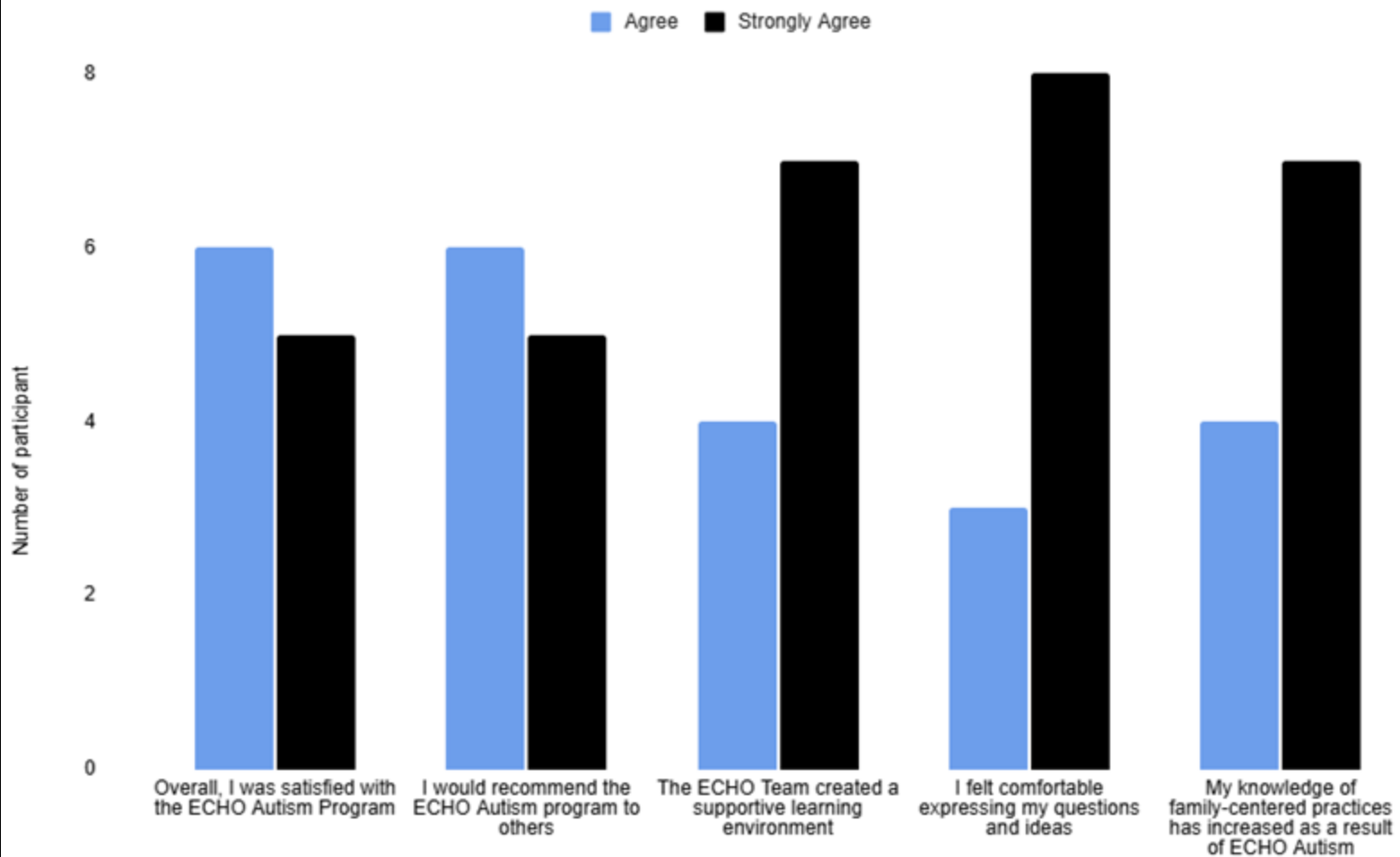


Session 3; Participants = 10; Completed Survey = 5



Session 4; Participants = 9; Completed Survey = 9





Conclusions

- Session content and overall program was well-received by participants
- ECHO Autism Hawai'i has potential to bridge service gaps for autism providers in underserved, rural, and/or remote areas across the islands
- Culturally relevant approaches are important for effectively disseminating information and resources

Next Steps

- Manuscript in preparation to submit to research journal
- Pilot study presented at the International Society for Autism Research (INSAR) Conference in May 2025
- Cohort two: Fall 2025
 - Received IRB approval for an in-depth study for cohort two
- Expanding to additional ECHO Autism topics
 - e.g., ECHO Autism specifically for ‘Ohana (family), inclusive educational practices

Mahalo!

Questions/Thoughts/Feedback?

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