

TOGETHER WE CAN CONFERENCE 2024

A STATEWIDE CONFERENCE FOR PEOPLE WITH DISABILITIES, THEIR FAMILIES, AND THE PROFESSIONALS WHO SUPPORT THEM.

Keynote Speaker: Lisa Heddens

Lisa Heddens is a mom with two kids who received a Bachelor of Science Degree in elementary education from Iowa State University. Her career choice changed after the birth of her second child, Paul, who has Down Syndrome. Thirsty for information she got involved on the local boards of directors for The Arc of Story County and Mainstream Living. It didn't take long before her advocacy efforts expanded. She began working for Disability Rights Iowa and then ASK Resource Center, as well as serving on several state boards and commissions. Lisa saw the need to provide support and opportunities for people with disabilities on a larger scale. She ran for the Iowa Legislature in 2002, won, and served 17-1/2 years. Lisa left the legislature in 2019 to become a County Supervisor in Story County. Today, she continues her disability policy advocacy through work, Rotary, and as a mom. She also continues serving on boards and committees in her free time.

CONFERENCE AGENDA

**EXHIBITOR HALL AND BREAKFAST ARE LOCATED THROUGH
THE BANK OF DOORS BEHIND MAIN LOBBY
EXHIBITOR FAIR DRAWING—MUST BE PRESENT TO WIN!**

Over \$2,000 in prizes will be drawn. See the Exhibit Raffle Form in your packet to learn more. Place your completed form in the raffle drawing box located in the Exhibit Hall beside the ASK table by 3:30 pm to be included in the drawing. Drawing is at 4:00 pm.

**THE FI AND FRIENDS SENSORY ROOM IS LOCATED
NEAR THE BOX OFFICE WINDOWS**

See the Registration Desk Attendant for access to the Sensory Room.

8:15 am - 4:00 pm

8:15 - 9:00 am	Lobby	<p>REGISTRATION/CHECK-IN & CHILDCARE DROP-OFF Sign in and pick up your conference packet and name badge. Badges are required to receive a boxed lunch. Those registered for childcare, please check your child(ren) in by 8:45 am.</p>
9:00 - 9:15 am		<p>OPENING REMARKS & KEYNOTE INTRODUCTION</p>
9:15 - 10:15 am	Upper Level West	<p>MORNING KEYNOTE My Journey from Parent to Policymaker <i>Lisa Heddens, first and foremost a mom; and a policymaker</i></p> <p>Lisa's advocacy journey started after the birth of her son, Paul. In this empowering Keynote Session, Lisa will share some of the advocacy tools she learned throughout her evolution from parent to 19-year, veteran policymaker. Her examples encourage audience members to take meaningful action themselves - whether that is by learning how to share their own stories to impact change, or by creating partnerships that result in better lives for people with disabilities.</p>

10:15 - 10:45 am

CONFERENCE BREAK

10:45 - 11:45 am

10:45 AM BREAKOUT SESSIONS

ROOM
A-1

HEALTH & WELLBEING

Navigating the Diagnostic Odyssey
Bharatendu “Bharat” Chandra, MD, FACMG & Moon Ley Tung, MD, FACMG
Rare and undiagnosed diseases affect over 30 million people in United states and over 450 million people globally. Unfortunately, most of these diseases are associated with several years of diagnostic odyssey, resulting in a huge psychosocial and financial burden on the patients and their families. In this session, the speakers will cover a broad overview of undiagnosed diseases and rare diseases, which will set the stage for discussion on this topic and for families to share their experience.

SPECIAL NOTICE— CONFERENCE WITHIN A CONFERENCE
1 - 3 PM IN THE KEYNOTE ROOM (UPPER LEVEL WEST)

Join us for an open forum for patients and families to discuss their challenges with undiagnosed and rare diseases. Participants will share their personal experiences with the diagnostic odyssey.

ROOM
A-2

DISABILITY LAW

Your Right to Accommodations
Catherine E. Johnson, J.D. M.A.
The goal of this workshop is to provide participants with an overview of some of the common questions that arise when individuals with disabilities request accommodations for work, to attend an event, to participate in a club, sports, theatre, etc. Topics discussed will include how do I ask for an accommodation, what are reasonable accommodations for employees with disabilities, can my employer or event sponsor deny my accommodation request, and examples of commonly requested accommodations.

ROOM
B

POSTSECONDARY
TRANSITION

Understanding Supplemental Security Income
Suzanne R Paulson, MS, CRC, CPWIC
During this session we will learn the difference between the two disability benefits and share some hints on applying for benefits. There will be time for questions related to working and how benefits are affected by work. We will also talk about waivers, Medicaid and work.

ROOM
C

EDUCATION

What is Being Done to Improve Secondary Transition Outcomes?
Barbara Guy, Ph.D. & Kelsey Teeter, BSW
This session will provide an overview of Iowa’s model for differentiated accountability of the Individuals with Disabilities Education Act, aka IDEA-DA. Discussion will include a description of how the Department of Education assigns districts a level of support, required districts actions and professional learning. Examples will be provided through the lens of improving secondary transition outcomes.

ROOM
D

SELF-ADVOCACY

Putting Advocacy Into Action
Brady Werger, Kris Graves, Hugh Kelly, and Ed Esbeck
Have you ever thought about where your self-advocacy efforts might take you? Do you want to help others advocate for their rights? Do you want to help change a law? Do you want to represent others on a statewide council? In this session you will meet four, adult self-advocates who have influenced many positive changes. Hear their stories and learn about a statewide group they have helped formed called Allies in Advocacy.

LUNCH BREAK

11:45 am - 1:00pm

PICK UP YOUR BOXED LUNCH IN THE EXHIBIT HALL WITH YOUR NAME BADGE VISIBLE

12:00 pm - 12:30 pm

Optional, 30-Minute ASK Each Other Networking Sessions
See the Networking Session Form in your packet to learn more.

Don't forget to make time to visit the Exhibit Hall during lunch!

1:00 pm—2:00 pm

1:00 PM BREAKOUT SESSIONS

ROOM A-1 HEALTH & WELLBEING	Medicaid and Children's Behavioral Health System Updates <i>Director Elizabeth Matney</i> This session will provide an update on current Iowa Medicaid initiatives, the waiver redesign project, and improvements to behavioral health supports for children in the coming year. With these initiatives, Iowa Medicaid's goal is to create systems that provide equity in opportunity and access for individuals regardless of diagnosis; and to support Iowans and their families in clearly understanding how to access the services they need.
ROOM A-2 DISABILITY LAW	Tips and Tricks to Negotiating with Your Team: How to Avoid (or Resolve) Conflict <i>Daniel Van Sant, Director of Disability Policy, The Harkin Institute for Public Policy & Citizen Engagement</i> Join this interactive session lead by a former parent-side special education attorney who will share the tips, tricks and common hang-ups to resolving conflict among IEP team members from his time in the field. This session will include some presentation and some group discussion. Learn from each other, and practice what is shared.
ROOM B EDUCATION	Empowering Conversations: Navigating Bullying with Your Child – A Parent Workshop on Effective Communication Strategies <i>Jordan Mix (they/them), Certified School Culture Advocate</i> In this interactive workshop, parents will gain invaluable insights and practical communication strategies for addressing bullying with their children. Facilitated by experts in anti-bullying advocacy, participants will explore age-appropriate approaches to discussing bullying, fostering open dialogues, and empowering their children to navigate challenging social situations. Through engaging activities and real-life scenarios, parents will leave equipped with the tools to create a supportive environment at home, reinforcing resilience and empathy in their children.
ROOM C POSTSECONDARY TRANSITION	Making it Possible: Innovating the Transition Planning Process with Customized Employment Strategies <i>Kelsey Teeter, BSW and Jessica Kreho, MS, CRC</i> All people, given the right support, can build meaningful and financially rewarding careers. For some people with disabilities, the usual assessment, evaluation, career planning, and job search approaches simply don't work. That's where Customized Employment fits in. Customized Employment (CE) is a strategy to help students meet postsecondary outcomes, including paid work that aligns with their unique skills, interests, learning preferences, and support needs. Embedding this approach into transition planning holds promise for Iowa schools to better support students' development of work skills early in the transition planning process.
ROOM D SELF-ADVOCACY	I Want a Friend, Boyfriend/Girlfriend, Partner, Spouse" – Developing the Self-Advocacy Skills to Help You Make Your Choices and Have Them Respected <i>Judy Warth, BBA, CESP and Joel Wesselink</i> With information and confidence, we know that people with disabilities are safer, less likely to be victims of abuse and have the opportunity to have meaningful relationships. This fun and playful session will look at the issues and skills needed to decide if you want to have a friend or relationship. Topics cover basic skills like identifying different types of relationships, public and private (what is ok in each), friendship, decision making and communication, moving from friend to sweetheart and being in a relationship. PLEASE NOTE: The presenters will tailor this session to be age appropriate for ALL attendees.

2:00—2:15 pm

CONFERENCE BREAK

2:15—3:15 pm

2:15 PM BREAKOUT SESSIONS

ROOM A-1

HEALTH & WELLBEING

Understanding Medicaid Managed Care Grievance Processes
Donna Wendt: Wellpoint (formerly Amerigroup) of Iowa, Nafissa Egbuonye, PhD, MPH and Jeremy Morgan, BA: Molina Justin Schieffer, LTSS and Malinda Malcolm, RN, BSN: Iowa Total Care
 Iowa’s Medicaid Managed Care organizations utilize what are called “escalation strategies” when someone submits a complaint or grievance. In this session, participants will hear directly from a panel of representatives from each MCO. Learn what the MCO escalation strategies processes and timelines are. Come away with information every family should know about before going that route with a concern.

ROOM A-2

DISABILITY LAW

Bullying of and By Students with Disabilities: The Law's Requirements
Thomas A. Mayes, General Counsel, Iowa Department of Education, JD, MEd, CWLS
 This session will explore the issues surrounding bullying and harassment and students with disabilities. What is bullying? What is harassment? What happens when the student with the disability is the target? What happens when the student is the alleged perpetrator? What are the responsibilities of educators in these circumstances? This session will explore these questions in light of state and federal education law and civil rights law.

ROOM B

POSTSECONDARY TRANSITION

How Does Iowa Workforce Developments' Vocational Rehabilitation (VR) Division Help People with Disabilities?
Dr. James Williams, CRC, ACAS
 In this session, Dr. James Williams, Vocational Rehabilitation Administrator at Iowa Workforce Development, will present a high-level overview of the various services provided by IVRS. As part of those services, Dr. Williams will share the important information that parents/community stakeholders should know, along with ideas for how to utilize them to obtain competitive, integrated employment (CIE). At the end, time will be provided for parents to ask questions that may have about IVRS and how they can sign up individuals for services.

ROOM C

EDUCATION

From IEP to 504: What Should the Transition Look Like?
Jennifer Argo
 What does it look like when your student transitions from an IEP to a 504 due to entering a certificate program or college? In this session attendees will learn about the generalized services available for students with 504s at Iowa’s colleges and universities. Next, the presenter will touch on what specific accommodations might look like in college, in general, when a 504 is in place.

ROOM D

SELF-ADVOCACY

Social Security Benefits and Working
Suzanne R Paulson, MS, CRC, CPWIC
 We will discuss how important working is and answer questions on how to report income to Social Security.

3:15—3:30 pm	CONFERENCE BREAK
<p data-bbox="45 241 243 283">3:30—4:00pm</p> <p data-bbox="45 325 316 367">UPPER LEVEL WEST</p>	<p data-bbox="673 115 1307 157">CLOSING REMARKS AND CALL TO ACTION</p> <p data-bbox="600 157 1380 199"><i>Lisa Heddens, first and foremost a mom; and a policymaker</i></p> <p data-bbox="438 199 1542 273">Wrap up the day of learning with our keynote Lisa Heddens as she shares takeaways from her day of connecting with everyone at the conference.</p> <p data-bbox="560 315 1421 357">EXHIBITOR FAIR DRAWING — MUST BE PRESENT TO WIN!</p> <p data-bbox="422 357 1567 472">Over \$2,000 in prizes will be drawn. See the Exhibit Raffle Form in your packet to learn more. Place your completed form in the raffle drawing box located in the Exhibit Hall beside the ASK table by 3:30 pm to be included in the drawing. Drawing is at 4:00 pm.</p>
<p data-bbox="45 598 251 640">4:00 - 4:30 pm</p>	<p data-bbox="828 504 1153 546">CHILDCARE PICK-UP</p> <p data-bbox="657 556 1323 598">Children must be picked up no later than 4:30 pm.</p> <p data-bbox="414 630 1567 703">THANK YOU Easterseals Bob and Billie Ray Child Development Center staff for providing a fun and inclusive environment!</p>

Conference t-shirts are available in the lobby.

\$15 for Small— Extra Large

\$20 for 2x & 3x

100% of the proceeds from t-shirts sales support the TWC Conference

All available presentation materials (PowerPoints, handouts, etc.) will be posted to

<https://www.askresource.org/togetherwecan> after the conference.

All conference attendees will receive email notice when the items are available.

ACKNOWLEDGEMENTS

A **HUGE THANK YOU** to the partner organizations, sponsors, volunteers, exhibitors and attendees for being a part of the 12th Annual Together We Can Conference!

CONFERENCE PLANNING COMMITTEE

Listed alphabetically by member type and last name

Parents

Marwan Alabed, Parent

Cynthia Blackard, Parent

Leila Hussein, Parent

Summer Murdock, Parent

Stacy Senneff-Briggs, Parent

Diane Thacker, Parent

Self-Advocates

Evan Murdock, Self-Advocate

Robert Thacker, Self-Advocate

Mike Vratsinas, Self-Advocate

ASK Staff

Karen Thompson, Executive Director

on Planning Committee

Alicia Karwal, Family Support Supervisor

Mari Brown, Data & Evaluation Manager

Erin Farquhar, Graphic Design & Media Specialist



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ASK RESOURCE CENTER'S 12th ANNUAL

TOGETHER WE CAN CONFERENCE 2024

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&

Thom & Patty Hotka

PRESENTER BIOGRAPHIES

Listed alphabetically by last name

Jennifer Argo has worked in higher education for over 20 years and has served as the Des Moines Area Community College Disability Services Coordinator since 2014. Prior to Jennifer's current role she began her career with the Federal TRIO Programs Student Support Services and Upward Bound providing services for individuals from disadvantaged backgrounds with the goal to enroll in and graduate from postsecondary education institutions. In 2005 she began her role as the Disability Support Services Coordinator at the Metropolitan Community College of Kansas City. She is a longtime member of the Association on Higher Education and Disability (AHEAD) and has served as a state board member. Jennifer frequently presents to the community about the transition from an IEP or 504 in high school to accommodations at college. Jennifer is dedicated to providing equal access to students with disabilities at DMACC.

Bharatendu "Bharat" Chandra a Neurogeneticist specializing in rare and ultra-rare neurological disorders. He is an Assistant Professor at the University of Iowa. He is the director of the Undiagnosed Diseases Program housed in the Division of Medical Genetics and Genomics at the Stead Family Children's Hospital. He is also a member of the N=1 collaborative working group focusing on therapeutics development for ultrarare diseases. His laboratory focuses on disease modeling for rare diseases using stem cells and organoid systems.

Nafissa Egbuonye is the Associate Vice President of Growth and Community Engagement at Molina Healthcare of Iowa. She holds a Master's degree in public health from San Diego State University and a Doctorate in Public Health Education from Texas A&M University. She has more than 15 years of experience in public health and a passion for improving population health outcomes.

Edward Esbeck serves as a Self-advocacy Coordinator for the University of Iowa Center for Disabilities and Development. In the fall of 2017, he became ILEND's first self-advocacy trainee. He drafted a series of recommendations for improving curriculum accessibility and created a self-advocacy trainee handbook. Edward became the first non-clinical ILEND trainee to win the prestigious Alfred Healy Leadership Award. He used funds from this award to travel to his native country, Uganda, where he shared his lived experience and taught classes about self-advocacy to families and students. Edward works on a variety of UCEDD projects related to health care, education, and transition, and is active on many boards and councils.

Kristine Graves is a Peer Support Specialist and an Advanced Level Wellness Recovery Action Plan Facilitator. She is a fierce advocate in the disability world. Kris hopes by being involved in different aspects of disability advocacy she can help make Iowa a better place for people with disabilities to live, work and thrive.

Dr. Barbara Guy is the Director of Special Education at the Iowa Department of Education. In this role she has worked with regional and local special educators to build state infrastructures and capacity to provide quality special education services and supports. Prior to her current work, Barb was Iowa's education consultant for secondary transition. Her broad perspectives of secondary transition derive from her work at the University of Minnesota with state systems change grants on transition, her experiences at the University of Kansas and teaching students with severe and profound disabilities. This background has led to her recognition of the diverse needs of learners with disabilities and the belief that services and practices need to be flexible and broad enough to meet that diversity. She is the author of several articles and book chapters on secondary transition of youth with disabilities. In 2009 she was honored with the Mark Gold Innovative Practices in Transition Award from DCDT.

PRESENTER BIOGRAPHIES CONTINUED

Listed alphabetically by last name

Catherine E. Johnson received her Bachelors of Business Administration, Juris Doctor and Master's in Higher Education degrees from the University of Iowa. Prior to joining the great team at Disability Rights Iowa, Catherine's work included serving as the Assistant Dean of Students at St. Louis University School of Law, the Director of Student Legal Services at University of Iowa, and a disability rights attorney at Disability Rights Center of Kansas. Before becoming the Executive Director of DRI, she was the Director of the ADA Resource Center for Equity and Accessibility at the University of Kansas. Catherine has devoted her career to impactful civil rights work on behalf of individuals with disabilities.

Hugh Kelly was born and raised in Southeastern Iowa. Hugh is currently employed by Goodwill Industries of Central Iowa's retail store in Ottumwa, Iowa. He has been employed for almost 14 years with Goodwill. He enjoys his job, because he believes he is contributing to his employer's overall mission to help people in all sorts of circumstances. Hugh is a pretty active person. Hugh enjoys watching University of Iowa football, as well as Iowa Men's and Women's basketball. He also enjoys Major League baseball, where the Houston Astros are his favorite team. He enjoys listening to Public Radio. He enjoys watching British mysteries, dramas, and comedies. Doctor Who is his favorite television show. He also enjoys animals. He has two cats, a black cat named Ginger, and a ginger kitty named JJ, which he absolutely spoils and dotes on. Hugh is also current Vice-Chair of Iowa's DD Council.

Jessica Kreho currently serves as a Senior Associate with Griffin-Hammis Associates, an award-winning, internationally recognized pioneer in the field of customized employment services for people with disabilities. In her current role at Griffin-Hammis, Jessica provides training, mentoring, and technical assistance in Customized Employment to government agencies, employment providers, business leaders, family members, and job seekers to transform systems, lives, and communities.

Malinda Malcolm, RN, BSN is the director of Grievances and Appeals for Iowa Total Care. She has been a registered nurse for 18 years and truly loves what she does. Her role allows her the opportunity to leverage her skills and knowledge to ensure fair resolutions while advocating to the improvement of healthcare outcomes for vulnerable populations.

Elizabeth Matney was appointed as Iowa's Medicaid Director in April 2021. In June 2023 she was appointed to also lead the division of Administration as the Department's Deputy Director. As Medicaid Director, Matney oversees Iowa's \$6.4 billion medical assistance program, which serves more than 760,000 Iowans. Prior to returning to Iowa Medicaid, she served as health policy advisor for Iowa Governor Kim Reynolds, where she worked closely with HHS programs and services on a broad range of critical issues. As the Director of Administration, Matney oversees HHS' budget and accounting functions and information technology services.

Jordan Mix serves as the Director of Educational Programming at Iowa Safe Schools, leveraging their expertise to create inclusive learning environments. A 2016 graduate of Drake University with degrees in Law, Politics, and Society; Sociology; and Women and Gender Studies, Jordan's journey began with transformative leadership as the president of Rainbow Union. Their commitment to inclusivity extended to pioneering efforts, including the establishment of the first all-gender bathroom on campus and contributing significantly to Drake's Transgender Inclusion Statement.

PRESENTER BIOGRAPHIES CONTINUED

Listed alphabetically by last name

Jeremy Morgan is the Director of Operations for Molina Healthcare of Iowa. He has more than 20 years of experience working in a variety of roles with Iowa Medicaid. Jeremy has a BA degree from Iowa State University.

Suzanne R Paulson, MS, CRC, CPWIC has been a certified Social Security benefits planner since 2007. Suzie has her Master's Degree from Drake University in Rehabilitation/Mental Health Counseling and is a Certified Rehabilitation Counselor (CRC). Suzie also has a daughter Lucy, who has Down syndrome and is nonverbal. The personal experience as a parent, guardian and representative payee gives Suzie a unique insight into the systems that impact individuals with disabilities the best ways to get the services necessary for them to be successfully integrated into their communities.

Justin Schieffer, Senior Director, Long Term Care (LTSS) has been working in Long Term Services and Supports since 2005 in various roles. He started at a provider agency and moved into various case management roles. Justin is currently a Senior Director at Iowa Total Care for the LTSS program. He really enjoys working with members and providers to help our members be as independent as possible.

Kelsey Teeter currently serves as the Secondary Special Education Program Consultant with the Iowa Department of Education. Previously, Kelsey worked in the secondary school setting providing transition services. With 15+ years of experience in the field of disability, education, and employment; Kelsey maintains a strong commitment and passions for improving the outcomes, equity, and inclusion of individuals who experience disabilities.

Moon Ley Tung is an Assistant Professor within the Division of Medical Genetics and Genomics at the University of Iowa. She is an adult hematologist with advanced training in medical genetics and currently specializes in the genetics of rare hematological disorder. Dr Tung's research focuses on germline genetic predisposition to hematological cancers and inherited bone marrow failure syndromes.

Judy Warth, BBA, CESP is a Behavior Health Consultant and Employment Training Specialist at Iowa's University Center for Excellent in Developmental Disabilities (UCEDD) at the University of Iowa. Coming to the University in 1994, Warth combines over 30 years of supporting people with disabilities to meet labor needs of Colorado, Illinois and Iowa businesses. Some areas of emphasis include: transition from school to work, job coaching and job coach development, person-centered services, employer relationship building & job development, self-advocacy training, and staff development and technical assistance to community rehabilitation & transition programs. Current projects

Donna Wendt has worked with individuals with disabilities throughout her career. After graduating from Iowa State University, she worked in direct care and family centered services assisting those in crisis and needing assistance, most of whom had a disability. This work led her to working with individuals receiving Medicaid waiver programs and, in 1998, she became the Director of Targeted Case Management Services for Boone and Madison Counties until late 2015; and Dallas County from 1998 until 2006. In 2015, Ms. Wendt joined the LTSS program at Amerigroup Iowa as the manager for utilization management team. In 2023, she implemented a new provider experience team dedicated to LTSS providers with Amerigroup and in March of 2024, she transitioned to her current role as the LTSS Strategy and Program Development Director at Wellpoint (formerly known as Amerigroup). Ms. Wendt resides in Ankeny, Iowa with her two children.

PRESENTER BIOGRAPHIES CONTINUED

Listed alphabetically by last name

Brady Werger was born in 1992. Today, he lives in a Goodwill Group Home in Waverley, Iowa. He is currently employed by the city of Waverly, and works at the city golf course. He is involved in Special Olympics and serves on the Iowa Developmental Disabilities Council, where he is currently the chair. He is very involved in his church, where he is a worship leader in the Praise Band.

Joel Wesselink is an Administrative Assistant for a nonprofit, and ILEND Trainee and an active participant in Access2Independence of the Eastern Iowa Corridor. Joel has a Bachelor Degree in Journalism and Mass Communication along with a certificate in Leadership and Nonprofit Philanthropy from the University of Iowa. Joel is also a public speaker and an advocate and activist for Autism and Disability.

Dr. James Williams is the Administrator for Iowa Vocational Rehabilitation Services (IVRS), a division of Iowa Workforce Development (IWD). Prior to serving as the Administrator of IVRS, Dr. Williams was the Chief Executive Officer of Bloom Consulting, a national provider organization specializing in providing vocational services, evaluations, and training to individuals with disabilities, particularly those diagnosed with Autism Spectrum Disorder (ASD). He is also a Certified Rehabilitation Counselor, an Advanced Certified Autism Specialist, and a Certified Special Education Teacher. He obtained his Bachelor's in Special Education from Sam Houston State University, his Master's in Rehabilitation Counseling from Texas Tech University Health Science Center, and his Doctorate of Education in Educational Leadership from Lamar University. He has had the wonderful opportunity to work in both public and private special education with students of all ages in both teaching and administrative roles. His passion for the last 18 years has been, and always will be, providing transitional and vocational Pre-ETS services to students with disabilities. He strives to use his professional and personal experience with ASD as a catalyst to inspire and educate others to believe in the incredible possibilities for adults and children with disabilities when they receive the appropriate services and accommodations.

NOTES