



# ICI INSTITUTE *on* COMMUNITY INTEGRATION

Ensuring that all people with disabilities have the opportunity to be participating members in their communities of choice

MAY 2018

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## FEATURE STORIES

### ICI Researchers Unveil Minnesota Autism Rates as Part of Nationwide CDC Study

A new study by the [Minnesota-Autism and Developmental Disabilities Monitoring Network](#) (MN-ADDM) at ICI identified 1 in 42 children (2.4%) of the observed population as having autism spectrum disorder (ASD) in Minnesota. Focused on children who were 8 years old, the study relied on 2014 data from the health and special education records of 9,767 children in Hennepin and Ramsey counties.



As part of a nationwide network of studies funded by the Centers for Disease Control and Prevention's (CDC) [Autism and Developmental Disability Monitoring Network](#) (ADDM), the Minnesota-specific study shows the rate of ASD is higher than the national average. The CDC found that, on average, 1 in 59 (1.7%) children was identified as having ASD in communities where prevalence was tracked by the ADDM Network (this is the first time Minnesota has been involved in the ADDM Network). "Minnesota's higher prevalence rates could be due, in part, to the concentration of services and supports in the Minneapolis-St. Paul area," said ICI's [Amy Hewitt](#), the principal investigator for the Minnesota study.

The Minnesota study is unique in relation to other ADDM Network studies because, in addition to examining data from white, black and Hispanic populations, it also collected information on two immigrant groups with large populations in Minnesota -- Somali and Hmong. The study found no significant statistical differences in prevalence rates between Somali and non-Somali children or between Hmong and other children. The prevalence finding was 1 in 26 for Somali children and 1 in 54 for Hmong children. "While both these numbers may look very different from the overall Minnesota average of 1 in 42, the sample sizes were too small to be able to tell if these differences are real or occurred by random chance," Hewitt said. "By being able to expand our study area beyond the borders of

Hennepin and Ramsey counties in future studies, we will be able to gain a better perspective on autism rates among all Minnesotans, including those of Somali and Hmong descent."

"Understanding the prevalence of autism in Minnesota communities is a critical first step as we make plans to ensure access to services from childhood through adulthood," said Hewitt. "We hope that as a result of the MN-ADDM project, the differences uncovered in this study will help us better understand health disparities in our state and to expand Minnesota's autism support services and workforce network."

The MN-ADDM Network collaborates with a wide variety of community ASD organizations and several Minnesota state organizations, including the Minnesota Departments of Education, Human Services, and Health. For more details on the findings see the [full press release about the study](#) and the [full Community Report from the CDC](#). The study was widely reported in the media including [Twin Cities Public Television](#), [Minnesota Public Radio](#), [Hiiraan Online](#), and [KARE11 television](#). The study was also featured on the [Improving Lives CEHD Vision 2020 Blog](#) from the College of Education and Human Development (CEHD), University of Minnesota.

## MNLEND Fellow Leads Creation of Sensory Tents in the Minneapolis Parks

Summer is coming and city parks will soon be filled with crowds, noisy events, excited children, food, and family pets. For most people, this is a celebration of warm weather and a chance to reconnect with family and friends in the great outdoors. But [Elise Niedermeier](#) (far right in photograph), a Fellow in ICI's [Leadership Education in Neurodevelopmental and Related Disabilities \(MNLEND\) program](#), and the ADA Coordinator for the Minneapolis Park and Recreation Board (MPRB), knows that for some people -- such as children with autism -- all this stimulation can become sensory overload.



"We have so many loud, crowded outdoor summer events that I thought it would be great to offer a sensory or escape tent for people to take a break," she says. Sensory tents give people with sensory processing needs a space to soothe or stimulate their senses at crowded park events. Niedermeier's MNLEND training prepared her to think collaboratively so, with an inclusion microgrant from the National Park and Recreation Association, she decided to build a project team to make MPRB events and programs more accessible. She spoke to MNLEND parent trainees after class; approached MNLEND faculty mentor Ellie Wilson, who is now director of the Autism Society of Minnesota (AuSM); contacted Sarah Thorson (left in picture), who is the MPRB's Therapeutic Recreation and Inclusion Coordinator; and reached out to Erica Chua (center), the park board's Community Outreach Event Coordinator.

"The connections and conversations through my participation in MNLEND all sparked this vision for what could be," Niedermeier says. The tent provides materials including scented crayons, a mini trampoline, hammock swing, calming light, and noise-cancelling headphones -- all materials suggested

and selected in consultation with AuSM. The tent will appear this summer at outdoor concerts and movies in the parks. A schedule for "sensory-friendly Sundays" is being developed, and MPRB staff are collaborating with MNLEND alumna Julia Anderson at the Walker Art Center and Twin Cities Public Television (TPT) to share successes and learning about creating inclusive events. MPRB also is collaborating to make sure sensory-friendly event dates do not overlap, so families have multiple options to explore this summer.

The sensory tent is tentatively scheduled to be at Music in the Parks at the Lake Harriet Bandshell on Sundays, 2-3:30 p.m., starting June 10 and running through August 19. The tent is also tentatively scheduled to be at the Monarch Festival at Lake Nokomis on September 8.

## RTC-CL Co-hosts National Reinventing Quality Conference in July

ICI's [Research and Training Center on Community Living \(RTC-CL\)](#) will jointly host the [2018 Reinventing Quality conference](#) in Baltimore, July 29-31. Reinventing Quality is a biennial conference that gathers and disseminates "best practice" information on individualized, person-centered supports and related quality management activities. The theme of this year's conference is, "Building an Infrastructure that Promotes Equity and Diversity." RTC-CL was instrumental in starting these conferences in 1991 and the center has supported them ever since, often providing funding and/or talent.



Eight ICI staffers will co-present at this year's conference with other collaborators from around the country:

- [Brian Abery](#) and [Renáta Tichá](#): "Next Steps in Quality Measurement"
- [Heidi Eschenbacher](#), [Jerry Smith](#), and [John Smith](#): "Communicating Community Inclusion Through Media and Advocacy"
- [Rachel Freeman](#): "Collaboration on Policy and System Issues in Positive Behavior Support"
- [Amy Hewitt](#): "Elevating the Crisis: Leveraging Data and National Reports to Effect Change"
- [Kelly Nye-Lengerman](#): "The Care and Feeding of the Workforce: Supporting Quality Employment Consultants in Optimizing Employment Outcomes."

"Reinventing Quality brings together advocates, policymakers, providers, and state agencies to share and exchange ideas about some of the most promising practices in the field of intellectual and developmental disabilities," says Nye-Lengerman. "Reinventing Quality highlights many of the 'bright spots' of creative and inclusive practices and policies that are happening within states and communities."

The other hosts of this year's conference are the National Association of State Directors of

Developmental Disabilities Services (NASDDDS), Human Services Research Institute (HSRI), University of Delaware National Leadership Consortium, American Network of Community Options and Resources (ANCOR), American Association on Intellectual and Developmental Disabilities (AAIDD), and TASH. The conference is at the Baltimore Renaissance Harborplace Hotel (pictured) and [registration is open](#).

## RTC Policy Forums: Speaking with Community Members on Policies that Affect Them



Families of people with disabilities often seek guardianship or conservatorship because they are worried about a loved one's ability to make choices about healthcare or other matters. However, guardianship and conservatorship are not the only tool available. On May 2, ICI's [Research and Training Center on Community Living](#) (RTC) held a public discussion at the Rondo Community Library in St. Paul on supported decision-making and presumed competence as an alternative to guardianship. This event was one of dozens of RTC Policy Forums that have been held in the Twin Cities since their launch in 1992, each one an invitation to interested community members to learn more about and discuss policies that affect the lives of individuals with disabilities and their families.

Held three or four times a year, the RTC Policy Forum series brings together people with disabilities, their families, staff from provider agencies, policymakers, and researchers in timely conversations that can make a difference in people's lives. "There are a lot of policy changes and initiatives under way at the state and federal level," says organizer [Lynda Lahti Anderson](#). "Our recent topics include employment first policies, the HCBS [Home and Community Based Services] rule changes, and supported decision-making. We're planning another forum this fall about the effect of school safety policies on students with disabilities. It's important to provide an opportunity for people to learn how changing policies may affect the services and supports for people with disabilities."

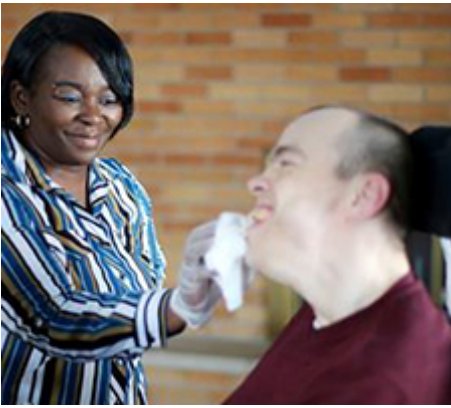
RTC Policy Forum has always been an outreach expression of the RTC's mission to provide research, evaluation, training, technical assistance, and dissemination to support the aspirations of persons with intellectual and developmental disabilities to live full, productive, and included lives in their communities. [Anderson](#) welcomes suggestions for future forum topics. For information about upcoming forums, watch future issues of *FYI*, and follow [ICI on Facebook](#).

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### SOCIAL MEDIA SPOTLIGHT

#### Featured on [ICI's Facebook](#) on May 1, 2018

"You will hear providers talk about the workforce crisis, and they use that word," said ICI's Amy Hewitt. "It's far worse than a crisis. Look it up in the dictionary -- crises don't last 30 years. This is a systemic failure that we've been dealing with for more than 30 years." <http://www.dispatch.com/news/20180429/crisis-in-care--number-of-support-workers-for-disabled-plummets-as-demand-rises>



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## NEW RELEASES



### NCEO Brief 15: Students with Disabilities and Chronic Absenteeism

Authors: Candace Cortiella and Kathleen B. Boundy

This [brief](#) provides information about chronic absenteeism and possible implications for students with disabilities when a state selects it as a measure of school quality or student success. The brief highlights both the benefits and potential risks in light of requirements in the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act of 1973 (Section 504), and the Americans with Disabilities Act (ADA). The brief also suggests actions that states might consider taking to address chronic absences among students with disabilities at the state and local levels as they work to include this new measure in accountability systems. Published by ICI's [National Center on Educational Outcomes](#) (NCEO).

## Journal Article Published

"Maintenance and Generalization in School-based Functional Behavior Assessment/Behavior Intervention Plan Literature." (2018). By Brittany Pennington, [Jessica Simacek](#), Jennifer McComas, Kristen McMaster, and Marianne Elmquist. Published in the [Journal of Behavioral Education](#).

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## EVENTS

### Check & Connect Trainings

June 19 and 20-21

University of Minnesota Continuing Education and Conference Center



**1890 Buford Avenue  
St. Paul, Minnesota**

Check & Connect's day-long Preparation & Implementation Training on June 19 provides education administrators and lead staff with a thorough overview of Check & Connect and its background and how to prepare sites for implementing Check & Connect. This training precedes the Check & Connect Mentor Training on June 20-21 which provides Check & Connect mentors with the information, competencies, and skills needed to succeed at their local sites. Check & Connect is an intervention used with K-12 students who show warning signs of disengagement with school and who are at risk of dropping out. At the core of Check & Connect is a trusting relationship between the student and a caring, trained mentor who both advocates for and challenges the student to keep education salient.

## Responses Sought for Online Autism Survey

ICI is partnering on a survey looking at community needs for young adults with autism spectrum disorder (ASD). We invite you to participate. The survey takes approximately 15-30 minutes to complete. Responses will be used to inform service providers of needed supports and services for young adults with ASD, and may lead to the development and provision of these services within your community. Questions? Please contact Rebekah Hudock at [kale0040@umn.edu](mailto:kale0040@umn.edu) or 612-626-3538.



## Seeking Minnesota Service Provider Organizations for Study

ICI is seeking service provider organizations in Minnesota who are interested in participating in a study to evaluate the effectiveness of a CareProfiler training intervention for direct support workforce supervisors. CareProfiler, Inc. is an organization that assists human service and health care providers to build workplace culture that leads to the development of effective relationships throughout the workforce and service delivery systems. This study focuses on Minnesota organizations that support adults with intellectual and/or developmental disabilities, as well as persons with age-related disabilities. Participating organizations will receive a free supervisor training program that includes screening of potential Direct Support Professionals, onboarding, and situational management components; plus 3-6 months of individual coaching. Participation in this study also involves completing several data collection tools, e.g. on-line survey. Interested? Contact ICI's [Brian Abery](#) or [Renáta Tichá](#).







their communities.

**Renáta Tichá** and **Jennifer Hall-Lande**: On April 19, [Tichá](#) (left) and [Hall-Lande](#) (right) were among a select group who were presented with CEHD Rising Alumni awards at the McNamara Alumni Center. These "rising alumni" were chosen by the College of Education and Human Development (CEHD) Alumni Society Board because they have achieved early distinction in their careers, demonstrated emerging leadership, or shown exceptional volunteer service in



**Tom Donaghy**: On April 24, [Donaghy](#) was appointed to the University of Minnesota's Civil Service Senate for a three-year term, beginning July 1, 2018. The Civil Service Senate is part of the University Senate governance system, which advises the University's Central Administration and Board of Regents. The Civil Service Senate's responsibilities include, but are not limited to, matters concerning the employment conditions of Civil Service employees.

**Claire Benway** and **Jerry Smith**: On April 24, [Benway](#) and [Smith](#) presented a Webinar for The Arc of the United States on the use of the [Realistic Job Preview video](#) that ICI developed last year in partnership with The Arc. This is part of a series of four webinars for The Arc on maximizing the customized Arc DSP toolkit that was led by the team of Benway, Smith, [Barb Kleist](#), and [Chet Tschetter](#).



**Pang Chaxiong**, **Amy Gunty**, **Mark Olson**, and **Jody Van Ness**: On April 26-28, [Chaxiong](#) (left), [Gunty](#) (right), [Olson](#), and [Van Ness](#) presented at the annual Minnesota Autism Conference in St. Louis Park. Chaxiong and Gunty presented, "Promoting Resilience in Families of Children with Autism." Olson and Van Ness presented, "Matchmaker, Matchmaker, Find Me a Career."

**Jennifer Hall-Lande**, **Amy Esler**, and **Amy Hewitt**: On April 27, [Hall-Lande](#), [Esler](#), and [Hewitt](#) presented findings from the [MN-ADDM](#) study mentioned above at the annual Autism Society of Minnesota (AuSM) conference. AuSM also presented a "magic within" award to ICI's [MNLEND program](#).

**Jessica Simacek**, **Adele Dimian**, **Jennifer Hall-Lande**, and **Kelly Nye-Lengerman**: On May 4, ICI staff participated in the University of Minnesota Autism Initiative Day. [Simacek](#) and [Dimian](#) presented, "The Use of Telehealth to Reach Children with Neurodevelopmental Disabilities and Families Experiencing Barriers to Early and Intensive Intervention." [Hall-Lande](#) presented findings from the [MN-ADDM](#) study mentioned above. In addition, [Nye-Lengerman](#) and Simacek served on a multidisciplinary panel of researchers and practitioners who answered questions and shared their experiences with the audience.



**Kelly Nye-Lengerman**: On May 15, [Nye-Lengerman](#) presented, "Untapped Potential: The Hidden Workforce," at the Workforce Research Symposium hosted by the U of M Extension Center for Community Vitality at Coffman Memorial Union. The "hidden workforce" in the title of her presentation refers to workers with disabilities.

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## ALUMNI UPDATES



**Diane Restorff:** Since 2009, Restorff (formerly Halpin) has been executive director of Lionsgate Academy, a Twin Cities' public charter school that is open to all students in grades 7 through 12, yet inclusively designed to address students with autism and other learning differences. But for three years before that, she worked as a Graduate Research Assistant (GRA) at ICI while developing the Minnesota Visual Autism Symptom Scale -- an online assessment/Individualized Education Program planning tool for teachers of children with autism -- for her doctorate in educational psychology/special education from the University of Minnesota. "My time at ICI expanded my awareness of the broader needs of individuals with disabilities and the need to put self-determination in the hands of the individual to the greatest extent possible," she recalls.

This awareness has helped shape her school. "At Lionsgate this influence brought a change to include 'fostering self-determination' as a central tenet in Lionsgate's mission. While Lionsgate Academy has a concentrated population of students receiving special education services, in many ways the students at Lionsgate are offered opportunities for leadership and friendships that in their home schools might not have been possible. My time at ICI, especially my work on the National Inclusion Project, helped me understand that inclusion is more than geography. It's more than being around people who don't have disabilities -- it is having the choice to determine where and how you wish to live."

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