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UNIVERSITY OF MINNESOTA  
CEHD COLLEGE OF EDUCATION  
+ HUMAN DEVELOPMENT

**ICI** INSTITUTE *on*  
COMMUNITY INTEGRATION

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

FEBRUARY 2019

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**FEATURE STORIES**

## Do IEP Meetings Relate Well to Students' Goals for Adult Life?



Individualized Education Program (IEP) transition planning meetings are a common event for transition-age students with disabilities. But how do factors such as a student's participation and contribution in those meetings relate to the student's aspirations for postsecondary education, employment, economic independence, and independent living?

To address this question, ICI developed a project called "[Exploring Predictors of Transition Planning Participation and Future Goal Aspirations of Secondary Students with Disabilities.](#)" By reviewing data from the National Longitudinal Transition Study 2012 (NLTS 2012) researchers will identify student, family, and school factors that predict IEP transition planning meeting experiences and examine the relationship between the significant predictors, transition meeting perspectives, and the aspirations for secondary students with disabilities. Funded by a two-year, \$600,000 grant from the U.S. Department of Education, this current study also examines how relations differ by disability category.

NLTS 2012 was a national study of transition-age students with disabilities to identify the challenges they face as they prepare for life after high school, and examined the factors that may improve that transition. Conducted by Mathematica Policy Research with assistance from ICI, the five-year study ended in 2015 and resulted in a [multivolume national report](#) on secondary school students in special education that examined how they compare with their peers. ICI's [David Johnson](#) (current project

director) and [Martha Thurlow](#) were among the authors of this report, and now they and [Yi-Chen Wu](#) and [Xueqin Qian](#) are reviewing this data to explore how factors in IEP transition planning meetings relate to how high school students with disabilities want to live as adults. The researchers will present their findings at conferences and publish them in journal articles.

“Understanding the factors related to participation in the IEP transition planning meeting is important,” says Wu. “Knowing what factors contribute to students taking a leadership role during this process also has a great impact on the quality of transition services provided to students with disabilities and their families.”

## MNLEND Fellows Past and Present Lead Multicultural Autism Action Network



Maren Christenson Hofer (pictured in foreground, second from right), a Fellow in ICI’s [Minnesota Leadership Education in Neurodevelopmental and Related Disabilities \(MNLEND\) program](#), is honing her intercultural

communication and negotiation strategies in a new setting. For 20 years, she worked in international business development. Now, as a MNLEND Fellow, she practices multicultural communication back in Minnesota as a leader in the Multicultural Autism Action Network (MAAN), a nonprofit organization that helps families navigate complex educational, medical, therapeutic, and autism support and service systems. As the parent of a child with autism, she has firsthand knowledge of those complexities, and — thanks to her intercultural experience — knows they can be almost overwhelming when differences in culture, language, and power dynamics are at play. Working at MAAN continues to broaden her intercultural education while expanding the support network of families of children with autism among Minnesota’s underserved communities. Hofer’s interest in the interdisciplinary MNLEND program was sparked by the opportunity to see the world of neurodevelopmental disability through different lenses; her work with MAAN offers similar opportunities to share knowledge from her personal experience and learn from others.

“Working in intercultural communities, we often talk about seeing through another’s lens,” says Hofer. “I see through the eyes of a parent of a child with autism, and MNLEND shares the perspective of practitioners, professionals, and other providers in our community. I learn from others in my cohort and at times teach them about how the world looks from a family’s perspective. Seeing multiple perspectives makes us all stronger in our respective fields.”

In MAAN, Hofer helps to provide safe spaces where families from different cultures can learn from, and support, each other. Together, MAAN families address the information imbalance between families and service providers, develop leadership capacity within under-represented groups, share information about evidence-based practices and how to access them, offer assistance with insurance forms and service applications, attend appointments, and provide in-person support to listen to each

other without judgment or fear of stigma.

Two former MNLEND Fellows also support MAAN's work: Mariam Egal (third from left), a coordinator at the Minnesota Department of Health, and Fatima Molas (right), a respiratory therapist and parent-advocate. Another MAAN member, Dr. Delia Samuel (left), has served as guest faculty for MNLEND.

## Research in Partnership with People with Disabilities, Families, Professionals, and Policymakers



How does a University research center impact the lives of people with disabilities and their families?

ICI's [Research and Training Center on Community Living](#) (RTC-CL) asked itself that question and found many answers. Research conducted in this center is done with a number of critical partnerships including people with disabilities, families, professionals, and policymakers. By viewing themselves as partners with others in the field, RTC-CL researchers focus their attention on questions with "real world" impact that will be used to inform policies and practices in the field. This leads to findings that add to an improved understanding of the needs of people with disabilities.

To share the results of core research conducted from 2013–18 with a broader audience, the RTC-CL created [summaries of the following studies along with short videos](#) featuring researchers discussing the results and impact of their work, and why it matters to people with disabilities and their families:

- [National Core Indicators \(NCI\) Study of Community Living Outcomes](#). In this project, RTC-CL analyzes data from a national survey that is administered annually by Human Services Research Institute (an RTC-CL partner) to collect information about how people with intellectual and developmental disabilities (IDD) are using services and supports.
- [An Updated National Review of Medicaid Home and Community-Based Services \(HCBS\) for Individuals with Autism Spectrum Disorders \(ASD\)](#). More states are using ASD-specific waivers for children and youth, but service delivery and the availability of HCBS waivers varies across states, especially for adults with ASD. Understanding these differences can inform efforts to meet the growing need for services and supports for people with ASD.
- [Self-direction for Individuals with Intellectual and Developmental Disabilities](#). Self-direction is an approach to designing long-term services and supports that aims to provide greater control for individuals with disabilities and their closest supporters.
- [Family and Individual Needs for Disabilities Supports \(FINDS\) Survey](#). RTC-CL developed and conducted this survey in partnership The Arc of the United States to collect information from families about their experiences with caregiving and support. The Center is now analyzing the data.

- [Competency-Based Training Intervention for Direct Support Professionals \(DSPs\) Who Provide Services in Family Home Settings to Improve Outcomes for Individuals with Intellectual and Developmental Disabilities.](#) This study examined a training and coaching model for DSPs working in family homes.
- [A National Study of the Effects, Practices, and Innovations in Employment Support for Adults and Transition-Age Youth.](#) In partnership with the Institute for Community Inclusion at the University of Massachusetts Boston, this project developed a comprehensive model of employment support for job seekers with IDD, published widely on the topic of employment services and supports, and generated new knowledge on the use of technology, micro-learning, and data-based decision making for employment consultants and employment provider agencies.
- [Supporting Self-Determination of Adults and Transition-Age Youth within the Family Context.](#) This project developed a curriculum for caregivers on how to best support the self-determination of a family member with a disability and established feasibility, usability, and effectiveness of the curriculum delivered via a telepractice model.
- [The Effectiveness of Two Approaches to Expand the Social Inclusion of Adults with Intellectual and Development Disabilities Living with Families.](#) Adults with IDD in this study became more active in their communities, their families reported the training as useful, different families shared ideas, and scheduling follow-up meetings with the researchers motivated families to implement their ideas and plans.
- [Identifying the Critical Elements Associated with High Fidelity Adoption of Programs that Support an Enhanced Quality of Life for Persons with Intellectual and Developmental Disabilities.](#) This project developed and piloted a detailed survey to assess an organization's capacity to implement new programming and the resources needed to ensure effective implementation and sustainability.

The RTC-CL strives continually to inform and improve services, systems, and supports so that people with disabilities and their families are fully included in community living. As a result of these studies, one book, 28 book chapters, 114 articles, 61 reports, and 420 presentations have been produced. The current cycle of the RTC-CL (2018–2023) includes studies that extend its research and develop new ways to improve policies and practices. These studies include research on home and community-based services, employment for people with disabilities, testing direct support workforce system interventions, exploring retirement for older adults with IDD, and further expanding FINDS to learn more about family caregiving.

## New Art for All Exhibit Starts March 6

On March 6, ICI's [Art for All: The Stephanie Evelo Fund for Art Inclusion,](#) will install a new exhibit titled “United Practice” in Pattee Hall at the University of Minnesota. The exhibition partner, the Avivo ArtWorks Collective, is a group of 16 artists (including Deborah R. Flye, whose untitled ink



drawing is shown here) who unite to practice art, embrace diversity, build community, and present their work publicly. The Collective is supported by Avivo, a Minneapolis nonprofit specializing in helping individuals and their families who face complex barriers to success—poverty, homelessness, unemployment, chemical addiction or mental health concerns.

The public reception for the show is scheduled for March 14, 4–6:30 pm, with an artist talk at 5:15 pm. The exhibit runs through May 24.

Art for All curates ongoing and revolving exhibits of visual art at ICI, celebrating art and diversity while supporting artists with disabilities. “At Art for All, we are excited to expand our inclusive vision around promoting artists living with disabilities to include people who identify as living with a mental health diagnosis,” says project director [Mark Olson](#). “We share with Avivo the belief that those exhibiting their work are artists first and their diagnosis is secondary.”

Art for All: The Stephanie Evelo Fund for Art Inclusion was established to recognize and celebrate artists with disabilities. The Fund was created by Sheryl and David Evelo in partnership with ICI in memory of their daughter, Stephanie (1969–2012), an artist and ICI employee. With fiscal support from the Fund, the Stephanie Award, including a \$100 gift card, is awarded to one artist from each exhibition. ICI also makes a contribution to the organization supporting that artist.

Pattee Hall, the home building of ICI, is at 150 Pillsbury Dr SE in Minneapolis.

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## SOCIAL MEDIA SPOTLIGHT



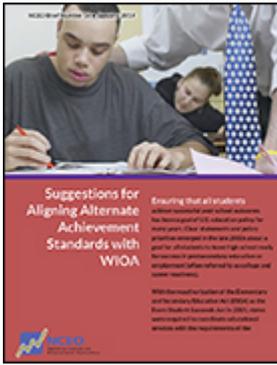
### Featured on [ICI's Facebook](#) on January 25, 2019

"You, teacher, are setting the tone for all of your students to follow. It is you that makes an inclusive classroom work."  
From THEMIGHTY.COM: "Dear General Education Teacher, Thank You for Embracing Inclusion."

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## NEW RELEASES

### **NCEO Brief 16: Suggestions for Aligning Alternate Achievement Standards with WIOA**



Authors: [Martha Thurlow](#), [Kelly Nye-Lengerman](#), and [Sheryl Lazarus](#)

[This Brief](#) provides information on alternate achievement standards and the Workforce Innovation and Opportunity Act (WIOA) of 2014, and makes several suggestions about ways to show that a student who meets a state's alternate academic achievement standards is on track to pursue postsecondary education or competitive integrated employment.

Recommendations are also provided for states on how to build a strong system to support the realization of the intent of the Elementary and Secondary Education Act (ESEA) and WIOA requirements for their students with the most significant cognitive disabilities. Published by the National Center on Educational Outcomes (NCEO).



## NCEO Newsletter February 2019

Editor: [Michael Moore](#)

[This issue](#) highlights recent NCEO publications, including a brief on approaches to examining district alternate assessment participation rates, a proceedings document on the 1% Cap National Convening, and a brief on suggestions for showing that proficiency on a state's alternate achievement standards are consistent with the requirements of the Workforce Innovation and Opportunity Act. Also in this issue is an update on news from the TIES project (including recent publications and the project's Facebook page). Finally, this issue provides information on NCEO sessions at the annual conferences of the Council for Exceptional Children (CEC), the National Association for Bilingual Education (NABE), the American Educational Research Association (AERA), and the National Council on Measurement in Education (NCME).

## Journal Articles Published

"Psychotropic Medication Use for Adults with Autism Spectrum Disorder who Receive Services and Supports Through Adult Developmental Disability Services in the United States." (2019). By [Amy Esler](#), [Amy Hewitt](#), [Jennifer Hall-Lande](#), [Sandra L. Pettingell](#), and [James Houseworth](#). Published in the [Journal of Autism and Developmental Disorders](#).

"Agreement Between Structured Descriptive Assessments and Functional Analyses Conducted Over a Telehealth System." (2019). By Brian K. Martens, Emily Baxter, Jennifer McComas, Samantha J. Sallade, Johanna S. Kester, Miguel Caamano, [Adele Dimian](#), [Jennifer Simacek](#), and Brittany

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## EVENTS

### Deadline for MNLEND Applications Approaches



**March 1, 2019**

ICI's [Minnesota Leadership Education in Neurodevelopmental and Related Disabilities](#) (MNLEND) program is accepting applications for the 2019–20 cohort of MNLEND Fellows through Friday, March 1. This year-long graduate-level interdisciplinary program trains emerging leaders to advocate for, and improve the quality-of-life outcomes of, infants, children, and adolescents with neurodevelopmental disabilities, such as autism spectrum disorders, fetal alcohol spectrum disorders, cerebral palsy, epilepsy, and Down syndrome. MNLEND will offer 28–30 fellowships to self-advocates with disabilities, family members, community practitioners, graduate students, and post-doctoral students. Fellows receive generous award stipends. Applicants from under-represented racial and ethnic/linguistic communities are strongly encouraged to apply. The 2018–19 cohort is pictured.

### Minnesota Self-Advocacy Conference

**March 8–9, 2019**

**Mystic Lake Casino**

**Prior Lake, Minnesota**



This [biennial conference](#) brings together 400–500 self-advocates and allies to make friends, learn about self-advocacy issues, and become connected to the larger self-advocacy movement. Co-sponsored by ICI's [Research and Training Center on Community Living](#), this year's conference includes ICI's [Jody Van Ness](#) and her son Andy presenting, "Living a Life that is Meaningful to Me: Using Person-Centered Practices to Achieve My Dreams." There will also be 40 workshops on disability rights, housing, getting out in the community, transportation, and more. Finally, the conference will have an awards banquet, DJ dance, art projects, photo booth, and door prizes. [Registration is open.](#)

## ICI Staff Present AAIDD Webinar on Community Living



April 16, 3–4 p.m. CST

### "Being 'Of the Community': Exploring and Celebrating Community Living for Adults with IDD"

This free webinar from the American Association on Intellectual and Developmental Disabilities (AAIDD) focuses on [Community Living and Participation for People with Intellectual and Developmental Disabilities](#), a new book edited by the webinar's presenters: ICI's [Amy Hewitt](#) and [Kelly Nye-Lengerman](#). The book is an exploration of how to create the ideal conditions to facilitate community living and participation for people with intellectual and developmental disabilities (IDD). The editors/presenters will share a model of community living for adults with IDD that includes ever-evolving dimensions related to both the place of community and the feeling of community. Several of the book's core topics will be discussed in detail, including using person-centered and positive support practices, social inclusion and relationships, practices that promote quality outcomes, and the direct support workforce. Join the conversation from being "in the community" to being "of the community." [Registration for this webinar is open.](#)

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#### STAFF UPDATES



#### **Susan O'Neil, Chet Tschetter, Nicole Duchelle, and Jody Van Ness:**

Beginning in Bemidji on January 10, [O'Neil](#), [Tschetter](#), [Duchelle](#), and [Van Ness](#) (pictured) conducted six trainings around Minnesota in January and February. Known as "Next Steps in Person and Family-Centered Approaches in Mental Health and Co-Occurring Disorders," these trainings were part of a contract with the Behavioral Health Division of the Minnesota Department of Human Services to support outcomes related to the Minnesota Olmstead Plan.



**David R. Johnson and Barbara A. Kleist:** On January 17, the American Association on Intellectual and Developmental Disabilities (AAIDD) named [Johnson](#) and [Kleist](#) among its cohort of Fellows for 2019. The formal ceremony of preferment to Fellow will be held at AAIDD's 143rd Annual

Meeting in St. Paul, June 24–27.



**Linda Goldstone, David R. Johnson, Kristin Liu, Sheryl Lazarus, Kathy Strunk, Martha Thurlow, and Yi-Chen Wu:** On January 29–February 2, numerous NCEO staff members presented at the Council for Exceptional Children Conference in Indianapolis. [Thurlow](#) moderated, "Emerging Issues

in Serving Students with Disabilities”; presented, “Meeting the Educational Needs of ELs with Significant Cognitive Disabilities”; co-presented lectures, “Pros and Cons of Alternate Diplomas: Benefits for Student Transition Success?”, “Planning for Successfully Including and Accommodating Your Students in Assessments (with [Wu](#) and [Goldstone](#)), and “Accommodations Considerations in Pre-College and Postsecondary Assessments for Deaf Individuals” (with Goldstone and another presenter); and co-presented posters “Diplomas That Matter: Ensuring Equity of Opportunity for Students with Disabilities” (with [Johnson](#)) and “Alternate ELP Assessment of English Learners with Significant Cognitive Disabilities.” [Lazarus](#) and [Strunk](#) presented, “Successfully Making Decisions about the Use of Scribing and Speech-to-Text.” [Liu](#) and Anastasia Press, a former Graduate Research Assistant, presented the poster, “English Language Proficiency Growth of ELs with Disabilities: How to Measure It.”



**Ann Romine** and **Ann Thompson**: On January 30–February 1, [Romine](#) and [Thompson](#) attended the 2019 National Mentoring Summit in Washington, D.C. Romine led a session at the summit on, "Check & Connect: Strengthening School and Community Mentoring Collaborations with an Evidence-Based Model." She and Thompson staffed the Check & Connect booth at the summit.

**Claire Benway** and **Chet Tschetter**: On January 31, [Benway](#) and [Tschetter](#) presented a webinar titled the ANCOR-ICI DSP Toolkit Series.



**MacDonald Metzger**: On February 2, [Metzger](#) was selected as the 2019 AUCD Emerging Leader for the Minnesota University Centers for Excellence in Developmental Disabilities (UCEDD). He will be featured on the AUCD Emerging Leaders map along with colleagues from other UCEDDs.



**Jennifer Hall-Lande**: On February 4, [Hall-Lande](#) was invited to serve on a new special advisory committee, the Minnesota Early Intensive Developmental Behavioral Intervention (EIDBI) Learning Collaborative. This committee works to improve access to clinical interventions and EIDBI for families in Minnesota. She was also reappointed to another two-year term on the larger, EIDBI Advisory Group.

**Jessica Simacek**: On February 4, [Simacek](#), along with her University colleagues Jason Wolff (Educational Psychology) and Jed Ellison (Institute on Child Development), were awarded the CEHD Research Acceleration Development Grant for their study, Presymptomatic Intervention for Autism in Infants. The two-year, \$200,000 award began January 2019. The study aims to screen infants and test the feasibility of parent-implemented behavioral intervention with infants.



**James Taborda-Whitt:** In 2016–17, Taborda-Whitt was a Fellow in ICI’s [Minnesota Leadership Education in Neurodevelopmental and related Disabilities \(MNLEND\) Program](#). MNLEND Fellows are often graduate students preparing for a career in medicine or education, but he was a community-based professional motivated to serve the families he meets in his job at East Side

Neighborhood Services in Minneapolis. “I saw that families with a child impacted by disability face two major impediments to accessing timely, relevant, and well-rounded medical support: finding resources and learning how to navigate the medical system,” he recalls. “The MNLEND program is set up to help Fellows do exactly that. In fact, if I summed up my learning and experiential outcomes in three words they would be empathy, networks, and adaptation.”

“My ability to empathize with families and individuals impacted by disability grew tremendously during the fellowship. Interactions with families during the clinic visits helped me see how disability truly shapes whole families’ lived experiences, and in-depth conversations with clinicians helped me understand constraints that many providers face. These new perspectives helped me realize how external folks like myself and other community members can serve families struggling to identify/navigate care systems, which can be complicated and intimidating, especially for caregivers further marginalized by language barriers, citizenship concerns, homelessness, or written language processing disabilities.

“The clinic visits and collegiate relationships with other Fellows helped me identify providers, clinics, and other support systems at the local and national level, and they also helped me build out my own networks within those systems. These experiences helped me establish a robust medical and legal network that I now offer to families I serve. As the saying goes, ‘your network’s network is your network, too.’ Well, now my network’s network can be my community’s network, too.

“My increased knowledge about neurodevelopment and developmental differences impacts how I adapt the environments I’m responsible for creating. MNLEND’s weekly seminars, conversations with new colleagues, and collaboration with faculty taught me about neurodevelopmental, factors that impact neurobiology, and behavioral indicators of developmental differences. In my line of work (Director of Camp Bovey, a nature-centered residential summer camp in Wisconsin), this largely boils down to laying out environments where young people gather or learn, and adapting our program structure to prioritize the potential needs of the most vulnerable young person present, rather than insisting the vulnerable among us adapt to our style. This small-scale change approach was modeled for me by other MNLEND Fellows, especially the parents and caregivers of people with disabilities. Large-scale change and meaningful movements to equity begin at the individual level in our immediate areas of influence.”

His advice to potential MNLEND applicants unsure whether their career is the right fit?

“I was in a similar place before applying. I wondered whether MNLEND reviewers and my supervisors would validate the program’s relevance to my career path as much as they might for an applicant directly connected to medicine and/or traditional education systems. Those of us in careers at the peripheries of medical and educational systems can be of greater benefit to our community when we understand the broad impact of disability on whole families. We can play an important collaborative role with medical and educational systems on behalf of individuals and families impacted by disability to

reduce barriers because we can use our knowledge to shape or change the environments we're responsible for maintaining. I encourage you to think creatively about how MNLEND could help you address equity gaps in your community.”

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