



ICI INSTITUTE *on* COMMUNITY INTEGRATION

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

JUNE 2018

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FEATURE STORIES

New *Impact* Issue Examines the Direct Support Workforce Crisis and People with Disabilities

ICI's flagship publication *Impact* enters its 30th year of publishing by focusing on an issue that is front and center across this country: The crucial role of the direct support workforce in providing daily support to people with intellectual, developmental, and other disabilities as they live and participate in their communities. In the past 40 years, the U.S. has experienced a dramatic shift away from large congregate care facilities to home- and family-based services for people with disabilities needing supports. Advocacy and self-advocacy efforts have led to laws affirming the rights of people with disabilities to be included in all areas of community life. However, those support needs, and rights, are bumping up against limitations in the systems of long-term services and supports for a growing population of individuals with disabilities.



[*Impact: Feature Issue on the Direct Support Workforce and People with Intellectual, Developmental, and Other Disabilities*](#) examines some of the workforce problems in the long-term care system and their consequences for people with disabilities, Direct Support Professionals, families, provider agencies, and communities. It presents data on the direct support workforce, including size, wages, turnover, tenure, and composition; shares personal stories of what is and isn't working for those delivering and receiving supports; looks at creative, bold actions being taken around the country to address workforce issues; and explores ways to be a collective force for change and ensure that quality supports are there for people with disabilities in all communities.

The editors of this issue are ICI's [Amy Hewitt](#) and [Barbara Kleist](#); Joseph Macbeth, Executive Director of the National Alliance for Direct Support Professionals; and Barbara Merrill, CEO of the American Network of Community Options and Resources. The [Impact series](#) is published by ICI and its [Research and Training Center on Community Living](#).

Biggest-Ever Class of MNLEND Fellows Complete "an Incredible Year"

On May 17, 33 MNLEND Fellows (pictured) received their Certificate of Completion, recognizing the culmination of their year-long appointment with the [Minnesota Leadership Education in Neurodevelopmental and Related Disabilities \(MNLEND\) Program](#) at ICI. The MNLEND Fellow class of 2017-



18 was the largest since the fellowships began in 2011, surpassing last year's record of 26 Fellows. Each year the MNLEND, which is funded by the Maternal and Child Health Bureau, U.S. Department of Health and Human Services, selects outstanding graduate/postgraduate students and community members to become Fellows. In partnership with other academic departments at the University, the MNLEND offers Fellows a unique interdisciplinary training experience that prepares them for leadership in serving children with Autism Spectrum Disorders (ASD) and other neurodevelopmental and related disabilities (NDD) and their families in health care, education, human services, and policy settings.

This year's Fellows included Nimo Ahmed, Kathryn ("Katie") Anderson, Kaysie Bergum, Bridget Binstock, Stacey Brandjord, Pang Chaxiong, Eleanor Chenoweth, Rebecca Davis, Beth Dierker, Adele Dimian, Teresa Eide, Emily Furl, Nancy Gonzalez, Jaclyn Gunderson, Libby Hallas-Muchow, Katherine Holzer, Abdi Hussein, Deeqaifrah Hussein, Alice Kraiza, Julia Lang, Emily Mentz, Elise Niedermeier, Kate Onyeneho, Sylvester Onyeneho, Munira Osman, Elizabeth Pittman, John ("Jack") Reagan, Mollika Sajady, Yusuf Samatar, Susan Saunders, Hannah Sterling, Derjuan Strons, and Mariana Walther.

When asked what they gained from their MNLEND experience, this year's cohort had much to say, including:

- "Thanks to MNLEND, it has been an incredible year filled with many opportunities to learn and experience interdisciplinary leadership and advocacy skills, and then immediately I was putting these skills into practice within the community and in the halls of government."
- "MNLEND instilled in me this 'can-do' vibe... this 'I-am-the-one-to-do-it' attitude. As a growing leader, I will continue to think not only of the way things are, but also of the way things could be."
- "Meeting with professional people from different disciplines and fields was the opportunity of a lifetime. I learned about ASD/NDD from different researchers and professors... and each one of them was like a walking library. I also learned how to assess Positive Behavior Supports and how to manage problem behaviors positively."

- "I learned there are multiple forms of advocacy -- from educating individuals to influencing policy -- and that each form of advocacy is important to bettering the lives of individuals with neurodevelopmental disabilities. I have learned the value of working in a group of individuals with different abilities; I will share this valuable knowledge with other healthcare professionals and the community."

NCEO Publishes and Presents on Accommodations and Assessments



Assessments (i.e., tests) are an integral part of today's educational system, for informing instruction and for documenting the achievement of students and groups of students. For decades, ICI's [National Center on Educational Outcomes](#) (NCEO) has been a national leader in documenting the accessibility and accommodations of state tests, as well as exploring the challenges that educators face in making decisions about appropriate accessibility and accommodations, and in providing suggestions for addressing those challenges. "For students with disabilities and English learners, appropriate accessibility and accommodations are an important part of ensuring that students are able to show what they know and can do," says NCEO director [Martha Thurlow](#).

This spring/summer, NCEO is publishing and presenting on two of its core research areas: accommodations and assessments. In May, the center's Data Informed Accessibility -- Making Optimal Needs-based Decisions (DIAMOND) project published [Educators' Perspectives on Classroom Implementation of Accessibility Features and Accommodations](#) (see "New Releases" section below), a report written by [Deb Albus](#), Thurlow, [Kristin Liu](#), [Sheryl Lazarus](#), and [Erik Larson](#). Further, during this month and in early July, NCEO staff present on accommodations and assessments at conferences in California and Canada:

- On June 26, NCEO and the Assessing Special Education Students State Collaborative on Assessment and Student Standards host a pre-session at the National Conference on Student Assessment (NCSA) in San Diego titled, "Speech to Text and Scribing -- Getting a Handle on What it Means." This NCSA pre-session will bring together states, assessment vendors, and other educational stakeholders to clarify implementation of speech-to-text and scribe accessibility features and accommodations. During instruction, all students commonly use speech to text on their phones, so it is becoming an issue in testing.
- On June 27-29, NCEO staff members participate in several sessions at the 2018 NCSA in San Diego. This conference is the premiere forum for assessment practitioners to discuss what is happening in the real world of educational assessment -- what is new, what is going on at the state and federal level, what works, and what doesn't.
- On July 3, [Yi-Chen Wu](#), Thurlow, and Larson will present on research from the DIAMOND project at the International Test Commission conference in Montreal. Wu and Martha Thurlow will present, "Who is Benefiting from Increased Access to Large Scale Assessments?" Larson and Thurlow will present, "Educator Perspectives on Assessment Accessibility Features and

Accommodations."

FINDS Report Reveals Stress on Caregivers of People with Intellectual and Developmental Disabilities

In 2017, ICI's [Research and Training Center on Community Living](#) conducted an online survey in collaboration with The Arc of the United States in order to better understand the status of family caregivers of individuals with intellectual and developmental disabilities (I/DD) in the United States. Known as the Family & Individual Needs for Disability Support (FINDS) study, the survey and resulting [Community Report](#) (pictured) shed light on the experiences of families who provide supports to a family member with I/DD. They are a follow-up to the first FINDS survey, which was released in 2011.



"Participants in the FINDS study reflect the ever-increasing reliance on families to provide the bulk of supports to individuals with IDD," notes lead author [Lynda Lahti Anderson](#). The workforce crisis and lack of supports such as respite can challenge both the caregivers and the individuals receiving supports. Caregivers reported economic stresses such as needing to quit work, reduce hours, or turn down promotions in order to provide care, as well as impacts on their own health and well-being. Compounding the reliance on families to provide long-term supports is the aging population of caregivers. "One of the primary roles of families has always been to provide support and care to family members," says Anderson. "The results of the FINDS survey highlight the scope, intensity, and duration of the supports provided family members, particularly parents, of both children and adults with intellectual or developmental disabilities. Policies that support family caregivers to reduce economic and other impacts are critical."

Anderson's co-authors on the report were [Amy Hewitt](#), [Sandra Pettingell](#), Amie Lulinski, Marianne Taylor, and [John \("Jack"\) Reagan](#).

ICI to Co-host Minnesota Gathering for Person-Centered Practices in September

On September 25-26, ICI and its [Research and Training Center on Community Living \(RTC-CL\)](#), the Minnesota Department of Human Services, and The Learning Community for Person Centered Practices will host the 2018 Minnesota Gathering for Person-Centered Practices at the Egan [Minnesota] Community Center. [Registration is now open](#). "The Gathering is meant to bring all persons from various facets of life -- advocates, self-advocates, family members of persons with disabilities,



providers, and community members -- together from all over the state to meet face-to-face and engage with one another about their lives and work regarding person-centered practices," says [Claire Benway](#), ICI's lead for the Gathering. "It's a time to learn from one another versus just from a training manual, to share stories to help one another become more inspired, to deliver resources and ideas, to enrich the network, and to dive deeper into the practice."

Rather than call it a conference, event organizers purposely use the term "gathering" to convey a more casual atmosphere that encourages participants to share intimate stories, feel closer to the people they meet, and have deep conversations about person-centered practices. Alex Bartolic, the Director of Disability Services at the Minnesota Department Human Services, will welcome participants to the two-day event and the keynote speakers will be Michael Steinbruck, who is executive director of The Learning Community, and [Amy Hewitt](#), director of RTC-CL. Other event organizers from ICI include committee members [Beth Fondell](#), [Mark Olson](#), and Nicole Duchelle. [Nik Fernholz](#), who is event coordinator for all person-centered initiatives at ICI, has a co-lead role at the Gathering and heads the event's marketing committee.

SOCIAL MEDIA SPOTLIGHT



Featured on [ICI's Facebook](#) on May 18, 2018

We invite you to visit [Maeve's Cafe](#) during Art-a-Whirl festivities the weekend of May 18-20 to see our current [Art for All: The Stephanie Evelo Fund for Art Inclusion](#) exhibit featuring the art of four talented individuals: Ingrid Hansen, Jimmy Reagan, Katharine Fitzgerald and Jon Leverentz (his painting, "Stormy Barn," is pictured). We know you will enjoy their talented perspective on the world! [#artforall](#)

[#ici](#) [#maeve's](#) [#artawhirl](#)

NEW RELEASES

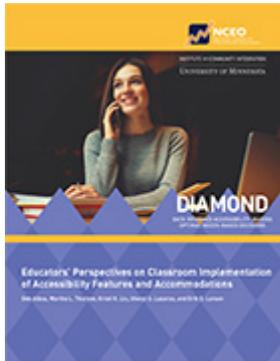


Policy Research Brief: **Employment First: An Update on National Progress**

Authors: [Amy Gunty](#), [Kristin Dean](#), Derek Nord, David Hoff, and [Kelly Nye-Lengerman](#)

Employment First identifies employment as the preferred outcome for people with disabilities and encourages those supporting people with disabilities to promote employment as an outcome first, before considering alternatives. Central to Employment First

is work in integrated settings in the community, with access to the same wages and benefits as people without disabilities. This [brief](#) is a progress update on the Employment First field. It reports that the number of job seekers with disabilities is greater than the number who are actually employed. For people with intellectual and developmental disabilities, the integrated employment rate has been stagnant for the past ten years, but rates of facility-based and non-work have risen. The Employment First philosophy has gained momentum to address this gap. *Policy Research Brief* is a [series](#) that is published by ICI's [Research and Training Center on Community Living](#).



Educators' Perspectives on Classroom Implementation of Accessibility Features and Accommodations

Authors: [Deb Albus](#), [Martha Thurlow](#), [Kristin Liu](#), [Sheryl Lazarus](#), and [Erik Larson](#)

This [report](#), from NCEO's [DIAMOND project](#), summarizes the results of telephone interviews of educators that highlight the effective practices they use to implement accessibility features and accommodations in their classrooms during instruction and assessments. Educators were asked about two kinds of accessibility features (universal features and designated features) and about accommodations.



FYI Monthly

Editor: [Tom Donaghy](#)

Readers can now find [past issues](#) of *FYI*, ICI's monthly e-communication, on the Institute's website going back to December 2017. Every month, *FYI* features news of recent ICI activities, accomplishments, and resources. Free [subscriptions are available](#).

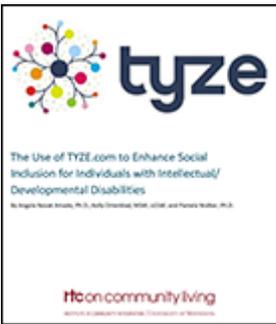
NCEO Newsletter: June 2018 issue

Editor: [Martha Thurlow](#)

The newsletter of ICI's [National Center on Educational Outcomes](#) (NCEO) is published several times a year and this [issue](#) features several upcoming events and a couple of the center's new reports. First, the upcoming pre-conference session to the National Conference on Student Assessment (NCSA) in June in



San Diego. The pre-conference session will focus on the use of speech-to-text. Following that is a listing of the sessions in which NCEO staff are participating during the NCSA conference, as well as at the International Test Commission Conference in Montreal at the beginning of July. Also highlighted in this issue are two new reports from NCEO.



The Use of TYZE.com to Enhance Social Inclusion for Individuals with Intellectual/Developmental Disabilities

Authors: Angela Amado, [Kelly Ortenblad](#), and [Pamela M Walker](#)

Families who have teens and young adults with intellectual/developmental disabilities have used the TYZE.com website and [this report](#) evaluates the site's usefulness in connecting and enhancing the social network of young people. The Arc Greater Twin Cities in the Minneapolis-St. Paul area of Minnesota sent surveys to 22 families who were introduced to the site. Nine families responded, in focus groups, phone interviews, and email surveys. Most families found the technical aspects and site interface too challenging, especially after site ownership and design changed. There were also issues of insufficient technical assistance and training, and confusion about the site administrator role. For those who used TYZE, the site was useful for the young person to stay in more frequent contact and communication with their friends and family members about what was happening in their lives, but TYZE did not help expand their social network. Published by ICI's [Research and Training Center on Community Living](#).

EVENTS

Responses Sought for Online Survey About ICI Website

The ICI Web Team is asking our friends and colleagues around the country to take a moment today to let us know what you think of the [ICI Website](#) and how it can better serve you in the future. The short, four-question survey takes only a few moments to complete and can be found at https://umn.qualtrics.com/jfe/form/SV_0D4v82keKDehnV3. We would love to hear from you by June 30. Thank you!



ICI Staff to Present at AAIDD Annual Meeting

June 25-28
St. Louis, Missouri



The American Association on Intellectual and Developmental Disabilities (AAIDD) is holding its 142nd annual meeting in St. Louis and ICI staff are there presenting lectures and posters, and participating in panel discussions. [Sheryl Larson](#) and [Lynda Anderson](#) are among the presenters of "Status and Trends in Indicators of Community Inclusion: Data Projects of National Significance;" and Anderson and [Amy Hewitt](#) will present, "Caregiver Experiences: What We Learned from the 2017 FINDS." ICI's poster presenters include: [Julie Kramme](#), [Roger Stancliffe](#), and [Kelly Nye-Lengerman](#) ("Exploring Retirement Among Individuals with IDD in 32 States"); Nye-Lengerman, [Sandra Pettingell](#), and [Jody Van Ness](#) ("Inclusion Starts at Home: The Role of Direct Support Professionals (DSPs) in Family Homes"); and Kramme, Erin Watts, and [Rachel Freeman](#) ("Using www.mnpsp.org for Minnesota Statewide Positive Support Implementation"). Kramme, Hewitt, and [Barbara Kleist](#) are the panelists on a discussion of "Addressing the Workforce Crisis With Statewide Credentialing: Retaining Competent and Committed Direct Support Professionals"; and Hewitt and [Renáta Tichá](#) are among the panelists discussing, "The DSP Workforce: Strategies for Improving Stability and Quality." [Registration is on-site.](#)

Reinventing Quality 2018 Conference



July 29-31
Baltimore, Maryland

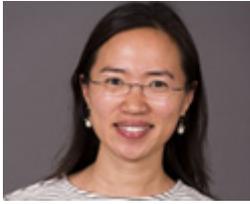
ICI's [Research and Training Center on Community Living](#) (RTC-CL) will jointly host the [Reinventing Quality 2018](#) conference in Baltimore in late July. Reinventing Quality is a biennial conference that gathers and disseminates "best practice" information on individualized, person-centered supports 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 expertise. [Registration is open.](#)

STAFF UPDATES



Kelly Nye-Lengerman: In April, [Nye-Lengerman](#) was elected an at-large director on APSE's national board; APSE is a membership organization that promotes integrated employment and self-sufficiency for all people with disabilities. On June 1, Nye-Lengerman was a guest presenter on "Employment First Across the Nation" at the nTIDE Lunch & Learn Webinar, which was hosted by the Kessler

Foundation and the University of New Hampshire's Institute on Disability.



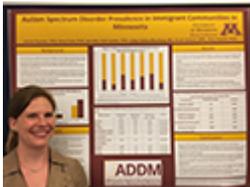
Xueqin Qian: In May, [Qian](#) traveled to China on a CEHD Professional and Administrative Council Professional Development Grant. She visited public schools, both regular and segregated schools for students with disabilities, in seven major Chinese cities (Nanjing, Guangzhou, Shenzhen, Beijing, Nanning, Chengdu, and Wuhan), gaining a greater understanding about services for students with special needs in China. She also lectured at Central China Normal University in Wuhan and at South China Normal University in Guangzhou to about 400 students and faculty, sharing about ICI's work.



Jerry Smith: In May, [Smith](#) received two Hermes Creative Awards for two films he made. The Hermes Creative Awards is an annual international competition recognizing excellence in marketing and communications. Smith received a platinum award for ICI's "Valuing Lives: Wolf Wolfensberger and the Principle of Normalization" and a gold award for "On the Autism Spectrum," a series he produced for the Minnesota Department of Human Services.



Jody Van Ness: On May 11, [Van Ness](#) provided the University of Minnesota Dental School with a training developed to support residents in their work with individuals on the autism spectrum. On May 18, she was appointed to serve on the Community First Services and Supports Development and Implementation Council through the Minnesota Department of Human Services. Her term begins immediately and will run through January 2019.



Libby Hallas-Muchow: On May 12, [Hallas-Muchow](#) presented the poster, "Autism Spectrum Disorder Prevalence in Immigrant Communities in Minnesota," at the International Society for Autism Research Annual Meeting in Rotterdam, the Netherlands. The other authors of the poster were Jen Poynter, Amy Esler, Jennifer Hall-Lande, Anab Gulaid, and Amy Hewitt.



Amy Guntz: On May 22, [Guntz](#) presented a poster on Employment First at Wisconsin's Best Practices in Vocational Rehabilitation conference in Madison, Wisconsin.



Jennifer Hall-Lande: On May 24, [Hall-Lande](#) was among the presenters of a paper, "Children with ASD in the Child Protection System," at the University of Minnesota's Center for Advanced Studies in Child Welfare sponsored conference. Hall-Lande also recently received an additional year of funding on the Association of Maternal Child Health Programs State Systems grant.

Amy Hewitt: On May 25, [Hewitt](#) facilitated a half-day workshop at the Nisonger Institute about the



direct support workforce and systems and organizational level interventions to address turnover and recruitment. She also presented a plenary at the National Association of State Directors of Developmental Disabilities Services (NASDDDS) conference on the same topic the following week. Both events were in Columbus, Ohio.

Katrina Simons and **Jerry Smith**: On June 7, [Smith](#) filmed interviews with more than 25 individuals for ICI's Self-Advocacy Online at the Self Advocates Becoming Empowered (SABE) national conference in Birmingham, Alabama. [Simons](#) attended the conference to learn more about the self-advocacy movement.

ALUMNI UPDATES



Anica Bowe: Assistant Professor Anica Bowe prepares teachers at Oakland University in southeast Michigan, but before that she spent a year working as a Graduate Research Assistant (GRA) at ICI in 2011-12. The experience broadened her academic vision. "It has made me consider the absence of research on English language learners (ELLs) with disabilities," she observes. "I now look for references to such research within the educational psychology textbooks I use in my course. It has also made me comfortable using SAS [analytics software], and mindful of what the general public wants in terms of data reports."

Bowe notes that her background at ICI has sparked some interesting class discussions. "During my courses, I introduce discussion on teachers being able to recognize ELL students with disabilities. I also draw attention to the fact that states have different standards on newly-arrived immigrants taking standardized tests if English is not their first language. We discuss why some states then may have lower averages than others in reference to language diversity."

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