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Ensuring that all children, youth, and adults with disabilities, and those receiving educational supports, are valued by and contribute to their communities of choice.

OCTOBER 2019

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**FEATURE STORIES**

## Evaluating the Services that People with Disabilities Receive

Under a recent two-year, \$250,000 supplemental award from the Administration on Community Living/National Institute on Disability, Independent Living, and Rehabilitation Research, [Renata Tichá](#) and [Brian Abery](#) (pictured) and their colleagues within ICI's [Research and Training Center on Home and Community-based Services Outcome Measurement](#) will



develop and field-test measures of person-centered service practices. They will also explore the extent to which people with disabilities themselves are provided with opportunities to develop and evaluate home and community-based services.

“Millions of federal and state dollars are currently invested annually in providing community-based services to people with disabilities,” said Abery. “At this point, however, we have a long way to go with respect to being able to measure, in a reliable and valid manner, the quality of services people receive and the outcomes they experience. That has to change.”

People with all forms of disability receive services through the Center for Medicaid and Medicare Services (CMS) Home and Community-based Services (HCBS) Waiver Programs. These services are designed to support people with disabilities to live high-quality lives and achieve the outcomes that they personally desire. In order to achieve those goals, both the services that recipients receive and the outcomes they experience need to be evaluated and the resulting data used to improve outcomes.

Instead of measuring how many times people with disabilities get out each month, for example, states and service providers should ask them questions to understand whether their experiences in the community lead to them feel included. Instead of asking them how much control they have in their lives, they should be asked about whether they have the degree of control they desire over those things that are most important to them.

“The reliable and accurate measurement of HCBS outcomes is critical in improving the effectiveness of services designed for people with disabilities,” said Tichá. “In the absence of this type of information, service providers, policymakers, and most importantly, people with disabilities, are unable to make informed decisions.”

## Alum Joins Autism Society of Minnesota

The Autism Society of Minnesota has hired Ashwak Hassan, a graduate of both an ICI [Diversity Fellowship](#) and a [MNLEND Fellowship](#), to help multicultural families affected by autism navigate and access services that lead to better lives and communities. Under a two-year Minnesota Department of Human Services Innovations Grant, Hassan will bring the Autism Society of Minnesota (AuSM) together with the Somali American Parent Network and the Multicultural Autism Action Network to streamline how families navigate services and increase their participation and meaningful engagement with culturally appropriate supports.



“I’ve always been interested in looking at the barriers multicultural families encounter on a daily basis in their communities,” said Hassan (MNLEND Fellow, 2015–16). As a Diversity Fellow, Hassan and colleague Sheyhan Gelle created the Al-Rahman (“compassion and kindness”) Center for Muslims with disabilities and their community partners, aiming to enlarge the support network among the various east African and Muslim communities in the metro area.

“[Hassan’s] training as a marriage and family therapist was very interesting to us because of her commitment to the family unit, which is at the crux of what we do,” said AuSM Executive Director Ellie Wilson (MNLEND Fellow, 2010–11). “Her specific training in autism and inclusion of diverse families, including her MNLEND experience, also brings a deep network of contacts and knowledge.”

A third-year doctoral student studying education leadership at the St. Mary’s University Twin Cities Campus, Hassan also speaks three languages (Somali, German, and English).

Her combined experiences create a natural segue into the work she hopes to accomplish at AuSM, she said. “It’s no longer a surprise to walk into a room of leaders in this field and there are more LEND fellows than not. This new opportunity will be an amazing way to continue to work on the

things we all love and feel passionate about.”

Wilson, as a fellow alum, agreed.

“So many times, people say when they complete an education that they’ll never use it in the real world. The LEND program gave us things we use every day.”

## Lazarus Takes Helm at NCEO

[Sheryl Lazarus](#) (pictured addressing the Helsinki Commission in 2018), senior research associate at the [National Center on Educational Outcomes](#) (NCEO), became NCEO’s director on October 1, ICI Director [Amy Hewitt](#) announced.



“We are so fortunate that Sheryl Lazarus has moved into this role,” Hewitt said. “Sheryl has been an NCEO leader for nearly two decades and it is wonderful that ICI can benefit from her wealth of knowledge and experience in carrying on the incredibly important work of ensuring that all students are included and belong in their educational programs. There is no doubt that Sheryl will carry on the legacy of NCEOs founder, [Martha Thurlow](#).”

Lazarus first joined NCEO as a graduate research assistant in 2001. After later serving as a research scientist for the Institute of Education Sciences at the U.S. Department of Education, she returned to the University as a lecturer and NCEO researcher. She has served as the director of the [National Technical Assistance Center on Inclusive Practices and Policies \(TIES Center\)](#) since 2017 and associate director of NCEO since 2016.

“As director, I seek to ensure that NCEO continues to be the go-to place for states and federal agencies regarding the inclusion of all students in instruction and assessments,” Lazarus said. “NCEO will build upon its strong foundation and provide continued national leadership on how to include students with disabilities, English learners (ELs) and ELs with disabilities, moving the field forward in providing rich academic learning opportunities for all students.”

Increasingly, she said, NCEO is using technological advances to improve technical assistance and create high-quality learning experiences.

Reflecting on her longtime colleague Thurlow, who recently stepped down as NCEO director, Lazarus credited Thurlow as a major force contributing to NCEO’s growth in stature as a national leader on inclusion of students with disabilities.

“I cannot help but be struck by the magnitude of Martha’s legacy,” she said. “She knows how to inspire those around her to grow as professionals, and has served as a mentor to many.”

Together, the NCEO team works from the perspective that assessments can provide a window into instruction, and that when students have the opportunity to learn rigorous academic content, there will be improved outcomes.

“Today, there is an increasing recognition that it is vital to address inclusion and accessibility issues across the comprehensive assessment system. This includes formative assessments, classroom tests, and benchmark or interim assessments as well as state tests,” Lazarus said.

NCEO, a center within ICI, provides national leadership in designing and building educational assessments and accountability systems that appropriately monitor educational results for all students.

### SOCIAL MEDIA SPOTLIGHT



### Featured on the [Facebook](#) page for ICI's RTC on Community Living on September 24, 2019

Alex Bartolic, director of the Disability Services division of the Minnesota Department of Human Services, was recognized today for her visionary and iconoclastic leadership at the MN Gathering for Person-Centered Practices.

### NEW RELEASES

## NCEO Brief 18: Examining Disproportionality of Student Group Participation in Alternate Assessments

Authors: [Carla M. Evans](#) and [Chris Domaleski](#)

[This brief](#) examines disproportionality with respect to student group participation in Alternate Assessments aligned with Alternate Academic Achievement Standards (AA-AAAS). It is a companion to the NCEO brief, *Guidance for Examining District Alternate Assessment Participation Rates*. Disproportionality, according to the current brief, exists when there are atypical differences in the proportions of participants from a student group who



take the alternate assessment in comparison to the general assessment. This current brief provides a more detailed examination and illustration of disproportionality. Jointly published by ICI's National Center on Educational Outcomes (NCEO) and the National Center for the Improvement of Educational Assessment.

## NCEO Newsletter, October 2019

Editor: [Michael Moore](#)

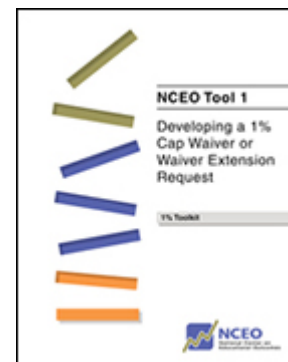
[This newsletter](#) includes articles on a variety of NCEO topics. First, a Brief on examining disproportionality is highlighted, including ideas for looking at data when sample sizes are small; this brief also provides a link to a video on producing confidence intervals. Following that is an article highlighting a study of guidance manuals; it describes ideas and lessons learned from leaders who developed state education agency and local education agency guidance manuals for identifying, assessing, and referring English learners (ELs) to special education. Presentations that will be made by NCEO staff in November in St. Paul, Minnesota (MELEd) and February in Portland, Oregon (CEC) are also listed in this newsletter. Finally information on products from two NCEO affiliated projects is presented—first, several products from the TIES Center are shown, followed by a description of a [module that is now publicly available](#) from the DIAMOND project. Published by NCEO.



## NCEO Tool 1: Developing a 1% Cap Waiver or Waiver Extension Request

Authors: [Kathy Strunk](#) and [Martha Thurlow](#)

The Every Student Succeeds Act allows for states to request a waiver from the 1% cap on alternate assessment participation requirements. Waiver request requirements are described in [this Tool](#) (the first of several 1% tools that NCEO is developing), along with examples of how states responded to each requirement. The Tool also includes a section on Additional Considerations (reporting on stakeholder involvement; addressing approaches to take when the 95% participation requirement for requesting a waiver is not met). This Tool was developed through a collaborative process with the 44 states participating in the 1% Cap Community of Practice (CoP) during its bi-weekly webinar calls in 2018. Although the CoP was formed at the request of states to be for private state conversations, it was with mutual agreement that this Tool should be shared publicly. Published by NCEO.



## Forum on States and Districts Working Together on the 1.0% Threshold

Authors: Sandra Warren, [Kathy Strunk](#), [Sheryl Lazarus](#), and [Martha Thurlow](#)

[A report](#) on a forum held on June 26, 2019 in Orlando, Florida to discuss how states and districts can work together to meet the 1.0% threshold on participation in the alternate assessment aligned to alternate academic achievement standards (AA-AAAS). The forum was a post-session to the Council of Chief State School Officers (CCSSO) National Conference on Student Assessment (NCSA), and was a collaboration of the Assessing Special Education Students (ASES) State Collaborative on Assessment and Student Standards (SCASS) and the National Center on Educational Outcomes (NCEO). This report summarizes both the introductory information provided to forum participants, and the facilitated forum discussions that followed. Published by NCEO, CCSSO, and ASES.



## Journal Articles Published

["Identifying people with intellectual and developmental disabilities in national population surveys."](#)

(2019). By Susan M. Havercamp, Gloria L. Krahn, [Sheryl A. Larson](#), Glenn Fujiura, Tawara D. Goode, Barbara L. Kornblau, and the National Health Surveillance for IDD Workgroup. Published in *Intellectual and Developmental Disabilities*, 57(5), 376–389.

["A systematic review of U.S. studies on the prevalence of intellectual or developmental disabilities since 2000."](#) (2019). By [Lynda Lahti Anderson](#), [Sheryl A. Larson](#), Sarah Mapellentz, and [Jennifer Hall-Lande](#).

Published in *Intellectual and Developmental Disabilities*, 57(5), 421–438.

["What matters: Lessons learned from the implementation of PROMISE Model Demonstration Projects."](#)

(2019). By [Kelly Nye-Lengerman](#), [Amy Guntz](#), [David Johnson](#), and [Maureen Hawes](#). Published in the *Journal of Vocational Rehabilitation*, 51(2), 275–284.

### EVENTS

## Screening of *Invaluable: The Unrecognized Profession of Direct Support*

[October 22: The Council on Quality and Leadership \(CQL\) Conference, Baltimore, MD](#)

[November 5: The Capitol Theatre, Arlington, MA](#)



[\*Invaluable: The Unrecognized Profession of Direct Support\*](#) is a documentary film by ICI's Research and Training Center on Community Living that explores the underappreciated and underfunded work of direct support professionals (DSPs), the people who support individuals with intellectual and developmental disabilities in living full lives as members of their communities. The film is being screened at various conferences and locations around the country.

Through stories and interviews with DSPs, family members, advocates, and people with disabilities, the film honors the complexity of the work and the immense value it provides to individuals receiving support. And it asks us to take action now in strengthening the DSP workforce before the system collapses. The film is also [available for purchase and rental](#).

## AUCD Conference 2019: Leading Change Together



**November 17–20**  
**Washington, DC**

This is the annual conference of the Association of University Centers on Disabilities (AUCD), a membership organization that supports and promotes a national network of university-based interdisciplinary programs across the United States known as University Centers for Excellence in Developmental Disabilities (UCEDDs) and Leadership Education in Neurodevelopmental and Related Disabilities (LENDs). ICI is the UCEDD and LEND for Minnesota and ICI Director [Amy Hewitt](#) is AUCD's board president. ICI will have a booth at the conference. AUCD 2019 will celebrate the many ways UCEDDs and LENDs lead change as they work with diverse communities and people, create programming, conduct research, practice, and advocate for people with disabilities. The conference welcomes network members, non-network organizational partners, experts from all across the disability field, individuals with disabilities, family members, and trainees to learn and grow together. [Registration will close November 1.](#)

## Pilot Study of New HCBS Outcome Measures Launched—Participants Needed!



Getting services at home or in the community is important for people with disabilities and all providers desire to provide the best services possible to the people they serve. To improve services, researchers have to know how well services work for the people who receive them. ICI's [Rehabilitation Research and Training Center on HCBS Outcome Measurement \(RTC-OM\)](#) has developed surveys that ask how well home and community-based services (HCBS) help people with various disabilities live high-quality lives. RTC-OM needs the help of people with disabilities to make sure the surveys provide valuable information and their results used to improve services. In this study, interviewers will talk in person with people with disabilities about

their services and important areas of their lives (e.g., social connectedness, meaningful activities). Everyone interviewed will receive a \$20 gift card. RTC-OM is recruiting participants for immediate interviews; the study ends in December 2019.

To take part, a person must:

- be 18 years of age or older,
- have a disability and receive services or supports for the disability,
- provide consent or assent (if not own legal guardian),
- be willing to take part in a 60–90-minute interview, and
- **live in Minnesota, western Wisconsin, northern Iowa, or Pennsylvania.**

If you think some of the people you support might be interested or have questions about this work, please contact [Matthew Roberts](mailto:Matthew.Roberts@umn.edu) at 612-624-1489 or [rtcom@umn.edu](mailto:rtcom@umn.edu).

## STAFF UPDATES

**Lynda Lahti Anderson, Nik Fernholz, Nichole Meyer, Kelly Nye-Lengerman, Katrina Simons, John Smith, and Jody Van Ness:** [Anderson](#) and [Van Ness](#) are leading a training team that is kicking off a new round of statewide in-person training events targeting direct care workers who provide self-directed services in Minnesota homes. Training topics include caregiver wellness, independent living, communication strategies, supporting choice and control, and more. Sessions will be offered in the metro area and in greater Minnesota. This work is funded through the Minnesota Department of Human Services and SEIU. The team also includes [Fernholz](#), [Meyer](#), [Nye-Lengerman](#), [Simons](#), and [Smith](#).



**Kimberly Baker:** On September 19, [Baker](#) organized a disability resource fair and screened the documentary *Intelligent Lives* for Lakeville Community Schools in Minnesota.



**Claire Benway, Nicole Duchelle, Nik Fernholz, Beth Fondell, Amy Hewitt, Julie Kramme, Pete McCauley, Mark Olson, Susan O’Neill, and Jerry Smith:** On September 24–25, seventeen ICI staff participated in the fifth Minnesota Gathering for Person-Centered Practices, an annual event co-sponsored by ICI’s Research and Training Center on Community Living (RTC-CL). ICI director [Hewitt](#) delivered a welcome message at the Gathering. [O’Neill](#) led, “Person- and Family-Centered Practices in Mental Health and Co-Occurring Disorders: Outcomes and Panel Discussion.” [Fondell](#) presented panel discussion sessions with families, allies and self-advocates. [Benway](#) co-presented, “The Minnesota Community of Practice—Working Sessions.” [Smith](#) was present for the screening of [Of the Community](#), an RTC-CL film he directed, [McCauley](#) and [Kramme](#) interviewed and recorded multiple professionals, self-advocates, and allies. The ICI committee



members were Benway, [Duchelle](#), [Fernholz](#), Fondell, and [Olson](#).



**Kelly Nye-Lengerman:** On October 4, [Nye-Lengerman](#) presented, "Best Practices in Employment Supports: Where Do We Go with What We Know?" at the Boggs Center Developmental Disabilities Lecture Series at Rutgers, The State University of New Jersey.



**Sheryl Lazarus and Maureen Hawes:** On October 7–11, [Lazarus](#) and [Hawes](#) were in Guam, presenting on assessment-related state identified measurable results at the "Pacific State Systemic Improvement Plan Collaborative: Our Journey for Improvement Meeting." Meeting participants came from all six of the Pacific entities: American Samoa, Federal States of Micronesia, Guam, Marshall Islands, Northern Mariana Islands, and Palau.



**Jennifer Reiter:** On October 14, [Reiter](#) recruited for Communities Engaging Autism's (CEA) mindfulness program—a centerpiece of her [MNLEND Fellowship](#) project—at the Osseo School District Special Education Community Fair, a free public event that helped families locate sensory-friendly activities for all ages and abilities. A parent representative for the school district's Special Education Advisory Council with a background in the arts community, Reiter secured Walker Art Center, CEA, Guthrie Theater, Toneworks Music Therapy, and other organizations for the event. Beth Dierker (MNLEND Fellow, 2017–18) is executive director of CEA.

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## ALUMNI UPDATE

**Barite Gemada:** Gemada is a social worker at PrairieCare, a multidisciplinary psychiatric care provider, in Brooklyn Park, Minnesota. She works with children and adolescents from diverse backgrounds, who are admitted to the hospital typically due to safety concerns.



Throughout her career in mental health services, Gemada (MNLEND Fellow, 2015–16) has adhered to a personal mission of meeting people where they are.

"Being a great social worker involves understanding someone's environment and what they truly need," she said. "I constantly advocate for patients' involvement in their treatment planning instead of just creating goals that seem right to me."

Gemada's experience at ICI's [Minnesota Leadership Education in Neurodevelopmental and Related Disabilities Program](#) (MNLEND) capitalized on those values.

"One of the most important concepts I learned while in the LEND program was the importance of person-centered care," she said. "Understanding patients' needs, their first language, and focusing on their humanity rather than only seeing their problems helps me stay grounded and provide the care that

people truly need.”

Even outside her work, as a community member, some of the same insights stick with her today.

“About a year ago, I lived in a three-story apartment building that did not have elevators and the building doors were not wheelchair accessible. Every time I entered that building, I thought about how challenging it would be for people with physical disabilities to live there. And I never saw anyone with a wheelchair even visit anyone in that building,” she said.

Continuing to call out injustice and advocate for all patients adds a sense of mission to her work.

“I’m more attuned to my surroundings now,” she said. “I am forever grateful for everything I learned in LEND, from learning about resources to understanding social justice issues impacting people with disabilities.”

This email was sent to ICI staff by Institute on Community Integration, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN, 55455, USA. The University of Minnesota is an equal opportunity educator and employer.

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