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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.

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### FEATURE STORIES

## ***Impact: Designing Lives of Their Own***

The [new issue of ICI's \*Impact\* magazine](#) explores how people with disabilities are experiencing self-determination today, including how they are using Supported Decision-Making (SDM) and other strategies to replace court-appointed guardianship, improve their education, and design lives that better reflect their values.

“The whole concept of self-determination has changed dramatically in the 30 years we’ve been researching it,” said [Brian Abery](#), co-director of ICI’s [Research and Training Center on HCBS Outcome Measurement](#). “Today it is much more complex and includes supporting people with the most significant disabilities to have the amount of control they want over their lives.”

Abery and [Renáta Tichá](#), co-director of ICI’s [Global Resource Center for Inclusive Education](#), served as guest editors for the issue, along with Jonathan Martinis, senior director for law and policy at the Burton Blatt Institute, Syracuse University; and Karrie Shogren, director of Kansas University’s Center on Developmental Disabilities.

Articles include an update on state legislation and trends in using SDM to advance self-determination and other favorable outcomes in the lives of people with disabilities, visions of future directions from leaders in the disability community, and compelling personal stories of both self-determination and self-



advocacy.

“I was told in high school that I could not continue my education because it was a waste of my time and my teachers’ time,” wrote [Roqayah Ajaj](#), originally from Saudi Arabia and now a PhD student at the University of Minnesota. Despite several obstacles, including the challenges associated with blindness, Ajaj is pursuing her dream of improving education for people with disabilities.

The issue’s cover story highlights Ryan King and his family, who fought a lengthy legal battle to end Ryan’s court-appointed guardianship, replacing it with SDM.

Global perspectives on self-determination also are addressed.

“People with disabilities in countries such as Armenia, Russian Federation, Kazakhstan, Tanzania, and Kenya have begun to exercise self-determination in their lives,” writes Tichá, citing influences from the adoption of the 2006 United Nations Convention on the Rights of Persons with Disabilities.

In many areas of the world, however, self-determination and SDM in particular still are fledgling concepts, Tichá said.

“Given their different cultures and histories, you cannot expect self-determination to look the same in every country,” she said. “For many, the focus is still on the physical inclusion of people, and they haven’t moved to the point of advocacy. It’s not going to happen overnight.”

## The DSP Shortage: Think Local



Supporting people with disabilities is rewarding work, and it’s among the nation’s fastest-growing occupations, but the direct-support profession’s low pay and considerable demands are associated with crisis-level labor shortages that are lowering the quality of life of the people with disabilities that DSPs support. Without major changes in how organizations recruit, train, and support these professionals, the problem will only worsen.

Collaborating with state officials and provider organizations across Tennessee, the Institute on Community Integration (ICI) is conducting annual surveys of local wages, benefits, and retention efforts; developing a customized toolkit for organizations to use in recruiting and retaining DSPs; and providing coaching to organizations as they implement the toolkit. The tools include videos with realistic portrayals of a typical day for a DSP that have been effective in recruiting candidates who will stay longer on the job and who view the work as a profession.

“Working with TennCare and Tennessee Community Organizations is allowing us to apply our evidence-based expertise to a broad network of organizations across the state, creating promising strategies for strengthening the pool of DSPs,” said ICI’s [Heidi Eschenbacher](#), principal investigator for the project, known as the TennCare Employment and Community First CHOICES Workforce Initiative. “Partial

implementation of a strategy can lead to organizations concluding it failed, but our teams will work closely with organizations throughout the process, guiding selection and implementation of the hiring and retention tools that work best in each organization.”

Now beginning the second of the three-year project, ICI’s Research Training Center on Community Living shortly will launch a second annual survey as a way to measure short-term progress and expand it to a second cohort of organizations, said [Barb Kleist](#), co-principal investigator.

In September, ICI Director [Amy Hewitt](#), also a co-principal investigator, and TennCare’s Shannon Nehus kicked off the first workshops for participating organizations, along with a team of ICI staff that included Kleist, [Claire Benway](#), [Chet Tschetter](#), [Julie Kramme](#), [Sarah Hall](#), and [MacDonald Metzger](#). In total, fifteen ICI staff members are working on the project.

Readers can [inquire directly](#) about the broader project.

## **Bhutan’s Future Challenge: Meaningful Work for People with Disabilities**

Fewer than half of Bhutanese children with identified disabilities go to school, according to a [recent study](#) conducted by University of Birmingham, ICI, and Royal Thimphu College staff. The resulting lack of skills makes it quite difficult for them to support themselves with jobs as adults and be viewed as full members of the community. As part of a grant awarded to the University of Birmingham, United Kingdom, in collaboration with the University of Minnesota, and the Royal Thimphu College, ICI’s [Global Disability Rights and Inclusion](#) team this month is hosting 18 Bhutanese educators, non-governmental organizational leaders, people with disabilities, and parents of children with disabilities. The group is observing and meeting with a number of Minnesota and Wisconsin organizations committed to supported and customized employment—practices that support people with disabilities developing the personal capacities for work and having opportunities for community-based employment that match their interests.

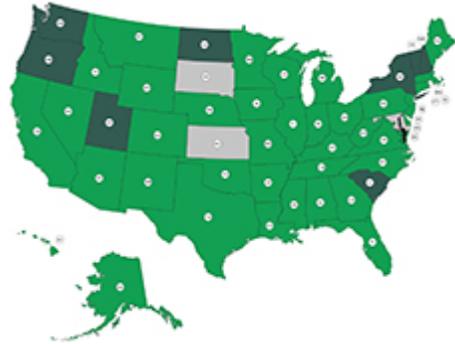


“We have a lot of constraints and challenges, but this trip gives us the opportunity to see how things are developed here,” said one Bhutanese visitor serving as a project liaison. “Our group will go back home and become advocates for change.”

The visit to Minnesota includes an open exhibit of artwork titled [“Symbolic Art from the Land of the Dragon”](#) from Bhutanese artists with disabilities affiliated with Draktsho Vocational Training Centre for Special Children and Youth, January 10 through March 5, at ICI’s Pattee Hall, 150 Pillsbury Dr. SE, Minneapolis. [Directions to Pattee Hall and parking.](#)

[See full story here.](#)

## Mapping More Cohesive Services for People with Disabilities



To qualify for vital public services, people with disabilities must demonstrate they need help with certain activities of daily living. But states have different ways of assessing these needs, and the process for qualifying for benefits is often opaque.

ICI's Research and Training Center on Home and Community Based Services (HCBS) Outcome Measurement (RTC-OM) recently launched a free, interactive national map of state service eligibility requirements, called the HCBS Assessment Tools database. [The map appears on the RTC-OM website.](#)

"Several states are redesigning their Medicaid waivers programs and they want to see what other states are doing," said [Matthew Roberts](#), an ICI research coordinator who is working on the project. The database is also viewed as important by staff at the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), who suggested its development; the Administration on Community Living; and the Center for Medicaid and Medicare Services, which funds home and community-based services so that they can track the manner in which states are making eligibility and funding decisions. This database will be updated frequently, which will help all stakeholders better understand the processes and tools that are being used to support equitable service provision.

To build the database, researchers spent several months digging into state applications for Medicaid waivers, comparing them to the actual processes states are currently using to determine eligibility for services. They examined both eligibility for receiving services and the level of funding for which individuals qualify. Then they verified the findings with state officials, Roberts said. Users can easily click through the states to see how officials determine eligibility, funding and support needs of people receiving services. Data on service quality and outcomes also is available.

"We believe this will help people start a conversation about the best way to assess needs, rather than each state operating independently," he said. "This is the first time a resource has been developed to identify specific measurement tools being used within state HCBS programs across the United States."



### SOCIAL MEDIA SPOTLIGHT

Featured on the [Facebook](#) page for ICI's RTC on Community Living on December 27, 2019



“One of the things I learned as the mom of a person with complex developmental disabilities is that it was better for me, psychologically and morally, if I did everything I could to put Charlie in charge of his own life,” says Sue Swenson. Read her reflections in the article, [“The Future of Self-Determination: Four Visions,”](#) found in the [new issue of \*Impact magazine\*](#) from the Institute on Community Integration, University of Minnesota.

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## NEW RELEASES

### NCEO Data Analytics 10: State Assessment Participation and Performance of Students with IEPs, 2016–2017

Authors: [Yi-Chen Wu](#), [Deb Albus](#), [Kristin Liu](#), and [Martha Thurlow](#)

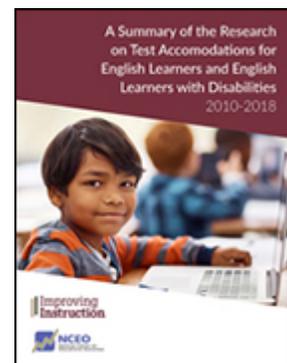
This [interactive report](#) presents data on the participation and performance of students receiving special education services in statewide assessments used for Elementary and Secondary Education Act (ESEA) accountability. Using federally submitted data from the 2016–17 school year, the researchers present information on participation and performance in reading and mathematics statewide assessments. This report includes state profiles for students with disabilities’ participation rates and performance. Published by ICI’s National Center on Educational Outcomes (NCEO).



### A Summary of the Research on Test Accommodations for English Learners and English Learners with Disabilities: 2010–2018

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

The purpose of [this literature review](#) is to examine the published English learner (EL) accommodations literature between 2010 and 2018 to provide an updated overview of research trends on this subject. Providing accommodations during assessments for students with disabilities has long been a standard requirement in federal education legislation. Providing assessment accommodations for English learners (ELs), on the other hand, is a newer requirement appearing only over the past few decades. As such, state assessment policies vary widely in terms of what



accommodations are permitted for ELs on state assessments. Further, many of the allowable accommodations do not address students' linguistic needs and there is not a large research base to document their effectiveness. In this review, the researchers examine the purpose of each study, the type of assessment measured, the content area assessed, the type of linguistic support accommodation examined, the characteristics of the research sample and the participants, the type of research design, the findings, and the author-identified limitations. Published by Improving Instruction and NCEO.

## NCEO Data Analytics 12: AA-AAS Participation Rate from 2007–08 to 2016–2017

Authors: [Yi-Chen Wu](#), [Martha Thurlow](#), [Deb Albus](#), and [Kristin Liu](#)

This [interactive report](#) presents data on the participation rate and percent proficient on the alternate assessment based on alternate achievement standards (AA-AAS) by grade and content across years. This report provides the data with an interactive performance map, trends over time, and state profiles. Published by NCEO.



## Journal Article Published

Wiggins, L. D., Durkin, M., Esler, A., Lee, L. C., Zahorodny, W., Rice, C., Yeargin-Allsopp, M., Dowling, N. F., [Hall-Lande, J.](#), Morrier, M. J., Christensen, D., Shenouda, J., & Baio, J. (2019). [Disparities in Documented Diagnoses of Autism Spectrum Disorder Based on Demographic, Individual, and Service Factors](#). *Autism Research*.

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### EVENTS

## Check & Connect Offers Online Preparation & Implementation Training

**March 3 and 5, and April 7 and 9**  
**1–4 pm Central Time**



Designed for administrators and lead staff interested in preparing for and implementing [Check & Connect](#), an ICI-developed 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. This two-day training option is ideally suited for sites that are exploring Check & Connect, preparing to implement it, currently implementing the program and

seeking formal training, onboarding new team members, training leadership teams of 10 or fewer members, and training leadership teams unable to attend in-person. The registration deadline for the March training is February 11. [Registration is open.](#)

## 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.

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](#) at 612-624-1489 or [rtcom@umn.edu](mailto:rtcom@umn.edu).

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### STAFF UPDATES

**Jessica Bowman, Amy Gunty, Sarah Hall, Amy Hewitt, Barb Kleist, Martha Thurlow, Jody Van Ness, Terri Vandercook, and Yi-Chen Wu:** On December 5–7, 2019, ICI staff presented lectures and posters at the TASH conference in Phoenix, Arizona. Also, during the conference, [Vandercook](#) and TIES Center colleagues from around the country facilitated a focus group of national experts to hear their feedback on a new set of tools that TIES is creating to support the creation and sustainability of inclusive school communities. During TASH, [Bowman](#) presented, “Meaningful Mathematics Instruction for Students with Intellectual Disability.” [Hall](#) and [Van Ness](#) presented, “Purposely Involving Family Members in Employment Planning and Supports.” Hall also co-presented, “Using Dyadic Interviews to Include Adults with IDD and Their Siblings in Qualitative Research.” [Gunty](#) co-presented, “The Time is Now: APSE Universal Employment Competencies” and “Exploring Employment Support: Using Data to

Inform Effective Practice.” [Thurlow](#) and Wu co-presented the posters, “Constructs Related to Transition Planning Meetings Participation for ELs with Disabilities” and “Alternate Assessment Participation Rates: Implications for IEP Teams and Inclusion Efforts.”

**Kelly Nye-Lengerman** and **Jody Van Ness**: On January 1, [Nye-Lengerman](#) began a one-year, \$75,000 contract with employment provider MRCI, Inc., to provide specialized consultation on integrated day services and staff training. Nye-Lengerman will work with [Van Ness](#) and Danielle Mahoehney to develop new tools for staff training to support increased community inclusion and participation for individuals with disabilities in MRCI's day services programs in greater Minnesota.

**Barb Kleist** and **Susan O'Neil**: On January 10, [Kleist](#) and [O'Neil](#) presented on Person-Centered Thinking and Practices to 22 Bhutanese Fellows as part a visit organized by ICI's Global Resource Center for Inclusive Education.

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## ALUMNI UPDATE

**Joe Timmons**: Timmons ( [MNLEND Fellow](#), 2010–11) has devoted his career to teaching, researching, writing about, counseling and working with people with several types of disabilities, but he describes his current position as a social worker at Lionsgate Academy, a charter school designed for students with Autism Spectrum Disorder, as the most satisfying.



Timmons worked at ICI for 15 years in a variety of roles, and was part of the Institute's second MNLEND cohort in 2010–11. The fellowship experience develops future interdisciplinary leaders in the neurodevelopmental disabilities field.

That experience a decade ago, paired with a master's degree in social work, formed his calling to work directly with students on the spectrum. He joined Lionsgate about three years ago and has also served on the board of the Autism Society of Minnesota.

“I learn so much every day,” he said. “The students are so interesting and they really are the best teachers.”

He credits his Lionsgate faculty colleagues—several of whom are ICI alums—with making his transition and his ongoing work go smoothly and with helping students navigate myriad challenges.

“It's been great to see such growth in the time I've been here,” he said. “My experiences at ICI and LEND were incredibly valuable.”

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.

