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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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FEATURED STORIES

New *Frontline*: DSPs Respond to COVID-19

The new issue of Frontline Initiative shares stories by and for direct support professionals (DSPs) as they navigate longer hours, inadequate pay, grief stemming

from the death of colleagues, and other fallout from the ongoing COVID-19 pandemic.

Already in crisis before the pandemic hit in 2020 due to high turnover and staffing shortages, the DSP workforce has been rocked by the pandemic. One *FI* article reports on a series of three national surveys, completed by more than 18,000 respondents, that show many are working substantially more hours than they did before the pandemic, and more than half indicated their work life had gotten worse or much worse. The study also revealed that Black/African American DSPs were paid less per hour than white DSPs.

Other articles provide public health information on keeping DSPs, their families, and the people they support safe as the pandemic marches on. *Frontline Initiative*, a publication for and about DSPs, is produced through a partnership between the National Alliance for Direct Support Professionals and the Institute's Research and Training Center on Community Living.

"We know there is a lot of misinformation about vaccines causing doubt in people's minds, so we wanted to provide some clear information and resources," said ICI's Julie Kramme, co-editor of *Frontline Initiative*.

Beyond the basic facts, the issue emphasizes the why behind the vaccination message.

"We wanted to make it very personal," said co-editor Chet Tschetter. "The reason many DSPs are doing this work is because they really care about the people they are working with, so we wanted to bring self-advocates into the issue to weave that relationship into the discussion."

In a first for the publication, DSP Kiley Brennan provided editorial support as a guest editor. A DSP guest editor will be hired for future issues of *Frontline Initiative* to provide their perspective and expertise. More information will be available when this opportunity is posted at z.umn.edu/frontlineinitiative.

"I wanted to serve as a guest editor for *FI* because it seemed like a perfect platform for DSPs to spread awareness and bring attention to topics begging to be heard in the DSP workforce," Brennan said. "I really loved the array of voices and perspectives of this issue, and I hope DSPs take away the fact that they are not alone in their struggles and concerns. Recognition of our profession means recognition, funding, better services, and better outreach for the individuals we

serve."

"Kiley has helped us make sure that the articles are authentic to the DSP experience," Tschetter said.

Some articles in the issue are accompanied by videos, including one by BJ Stasio of Buffalo, New York, who shares that he sleeps in his wheelchair because of the staffing shortage in the DSP profession.

"Without their help, we don't live the lives we want, and it's easy to become isolated," Stasio writes in his article. "I think the reason we should all be vaccinated is because it makes our communities better and stronger. It enriches the community when people with disabilities are present instead of being invisible at home. Without the help of DSPs, that doesn't happen."

Sensory-friendly Vaccine Sites

Several of the Institute's MNLEND program fellows—current and past—have played key roles in bringing sensory-friendly vaccine clinics to children and families in the Minneapolis-St. Paul area.

Fatima Molas (MNLEND 2016–17) and Maren Christenson Hofer (MNLEND 2018–19; pictured at an earlier event with her autistic son, Simon) of the

Multicultural Autism Action Network, and Ellie Wilson (MNLEND 2010–11), executive director of the Autism Society of Minnesota, collaborated with several other partners to create COVID-19 vaccination clinics with quiet rooms, music therapy, a drive-thru option, and distraction techniques.

“At most vaccine events, the goal is getting as many shots in arms as possible,” said Hofer. “Our primary goal was creating the best possible experience and to bring some compassion and understanding to children and families, who may have experienced past trauma or have ongoing anxiety in these settings.”

Raniya Yiman and Brittany Miller, current MNLEND fellows, and Alicia Zhang, an ICI graduate assistant, served as volunteer staff at the clinics.

“It was very meaningful work,” Yiman said. “I was really happy to be able to volunteer in this way and talk to the families.”

Hennepin County Healthcare and Spero Academy partnered with the organizations on the most recent clinics in December and January at Spero in northeast Minneapolis, which drew more than 300 participants. The autism organizations held two smaller clinics last summer in St. Paul.

“We believe everyone deserves access to healthcare,” Hofer said. “Offering this clinic is one way we can make sure all members of our community can stay safe during the pandemic. We offer a little more patience, flexibility, and an extra dose of compassion for anyone who might need it.”

Hofer said families expressed gratitude at the events.

“We had a really nice response. It was a tough day emotionally for everyone, but to see the relief and gratitude of families who had gone to other events and weren’t able to complete their vaccines, to see them feeling supported and not judged for needing some extra help was really nice,” she said.

ICI Welcomes Visiting International Scholars

Several scholars from Europe, Australia, and central Asia are visiting the Institute on Community Integration as part of a broad-based exchange aimed at increasing the inclusion of people with disabilities around the globe.

The visitors, on campus for varying lengths of stay, are from the Czech Republic, Spain, Kazakhstan, and Australia, and are working with ICI's Global Disability Rights and Inclusion program area, led by Brian Abery and Renáta Tichá (pictured at left).

Roger Stancliffe (not pictured), professor emeritus at University of Sydney, joins ICI as a senior research associate. He is working with an ICI team that is studying the transition to retirement process and served as an editor for the Institute's most recent Impact issue focused on aging and retirement.

Jan Šiška (third from right), a Fulbright-Masaryk scholar from Charles University in Prague, Czech Republic, is building relationships with U.S. disability organizations and gathering information about programs that assist students with disabilities in their transitions to community life after high school. He's also building a framework for assessing the quality of social services across Europe.

"The work also involves studying [ICI's] research and project management methods and learning broadly about the American disability culture," Šiška said.

He will collaborate with Tichá and Abery on specific post-secondary education and independent community living objectives as part of grants their respective institutions have received from the U.S. and Czech governments.

“We are trying to assess to what extent transition programs and education for young adults help them to become active citizens – working in the community and voting, for example – and how we can work together to build a framework for teachers to enhance their expertise,” Šiška said.

Cristina Cardona Moltó (second from right), a professor at the University of Alicante in Alicante, Spain, is developing an index that will be used to assess the quality of inclusive special education instruction.

“I’m very grateful to Renáta and Brian for opening the doors of ICI for this work,” she said. “We have different traditions in our respective countries, so having the opportunity to be here and observe the work you do will help us be successful in creating instruments for measuring the effectiveness of how we are preparing teachers for inclusive education.”

In turn, Tichá and Abery said the international visitors bring fresh ideas and different perspectives to their work in improving the lives of people with disabilities.

“We all come from countries with quite different disability policies and practices, but it has actually been smoother than we thought to find areas where we could collaborate,” Tichá said.

Abery said the work is certainly easier when colleagues are sitting across a table instead of communicating virtually, but it goes deeper than proximity and language translation.

“It’s working through concepts that are slightly different in each country but knowing that the ultimate goal is the same, which is to enrich the possibilities for people with disabilities,” he said.

One example is the time the group spent in discussing the different perspectives of active citizenship and what that means to and for people with disabilities.

“My goal in being here is to understand the methods and evidence-based practices in research within inclusive special education because this is new for my country,”

said Dinara Yertargynkyzy (extreme right), a senior lecturer at Al-Farabi Kazakh University in Kazakhstan. “Our education systems have been segregated in the past, so I’m grateful for this opportunity to observe.”

Šárka Káňová (third from left), a researcher and senior lecturer in disability studies and inclusive education at University of West Bohemia in Pilsen, Czech Republic, leads a research team focusing on the availability and quality of community-based services for people with intellectual disability and autism in the Czech Republic.

“My time at ICI has provided excellent opportunities to observe ongoing research projects and relate them to other work I’ve studied throughout the European Union with the Erasmus program,” she said. Erasmus is the EU’s program supporting education, training, youth, and sport, with an emphasis on social inclusion, environmental and digital advocacy movements, and promoting young people’s participation in democratic life.

Stancliffe, who has worked extensively with ICI since the 1990s, said international exchanges have made a substantial difference in the disability research infrastructure.

“There was nothing like ICI in Australia when I first began visiting here in the ‘90s,” he said. “Now, disability research centers exist in Australia and some are very strong, a direct result of university-affiliated programs in the United States and the learning that came from them. The scale and rigor of national U.S. research and the self-determination instruments that have been developed and shared are important. Also, what really impressed me in the ‘90s was that people in the United States with disabilities were working alongside fellow researchers, and today that is much more common in Australia, which is an important change as well.”

Innovation created from spending time with other cultures is something that is still being repeated today, Abery said.

“In the United States we often focus on resources and money,” he said. “Working with international colleagues, we see how innovation doesn’t always have to be based on that. Looking at things from a different perspective stimulates everyone’s thinking.”

In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends 2018

Residential Information Systems Project (RISP)

Near Zero: As Institutional Care Declines, Concerns Remain

The number of people with intellectual and developmental disabilities (IDD) living in large, state-run institutions could approach zero by 2025, according to a new report for the U.S. Department of Health and Human Services by the University of Minnesota's Institute on Community Integration. This represents a remarkable decline from the 194,650 people with IDD who lived in those institutions in 1967.

The report, analyzing the living arrangements of people with IDD from 1977 to 2018, also projects that the number of people with IDD living in privately run large institutions could approach zero by 2037, down from 52,718 in 1977.

Since 1981, when Medicaid Home and Community-based Waiver supports first became available, the number and proportion of people with IDD who receive Medicaid-funded services while living at home has grown dramatically, but critical funding and other issues remain.

"Nearly 1.2 million people with IDD get funded support services in non-institutional settings today," said Sheryl Larson, principal investigator for ICI's National Residential Information Systems Project (RISP), an Administration on Community Living Longitudinal Data Project of National Significance.

"Even if all IDD-specific institutions close, tens of thousands of people with IDD

will remain in nursing homes, and psychiatric and correctional facilities," Larson noted, "but the RISP report documents the government-funded resources that now flow to people living in family homes, their own homes, or smaller settings, where quality of life and self-determination are known to be higher."

Despite increased access to supports, families continue to bear many unreimbursed costs of care. Inadequate funding for Home and Community-Based Services (HCBS) means that families who have resources allocated to them cannot always use the money because they can't find anyone willing to work at prevailing wages, Larson said.

"Finding and keeping people in direct support professional positions is a huge challenge across all home, community, and institutional settings," she said. In 2019, the DSP turnover rate was 42.9%.

"In addition, there are still more than 200,000 people with IDD waiting for services, and for those receiving services, the direct support workforce crisis has deepened," Larson said.

From 1998 to 2018, the number of people with IDD receiving long-term supports and services (LTSS) more than doubled, from 639,691 to 1.3 million. During the same period, the number of people receiving services who live with family increased from 325,650 to 792,650. And those living in their own home increased by 144 percent, to 153,092.

RISP has chronicled the institutionalization and deinstitutionalization of people with IDD and the rise of community-based services across the United States for 45 years, operating in the early years under other names and funding sources. Former University of Minnesota President Robert Bruininks was part of a team that conducted national censuses of residential facilities for people with IDD in 1977 and 1982. The RISP project has reported on HCBS waiver programs since 1982. The project conducts annual surveys of state IDD agencies about the places people with IDD live, and of the remaining state-operated IDD facilities.

The National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI) contribute to RISP data collection, product development and dissemination activities. In addition to Larson, the team includes Brittany van der Salm from HSRI, Mary Sowers from NASDDDS, and Sandra Pettingell, Lynda Lahti Anderson, and Jonathan Neidorf from ICI. Charlie Lakin, a former director of the Research and Training Center on

Community Living at ICI, was the original director of the RISP project.

Other key data points of the 254-page report include:

- There are an estimated 7.43 million people in the United States with IDD, an increase of about 50,000 people since the previous year's report.
- The proportion of people with IDD receiving HCBS services while living with a family member increased from 12% in 1998 to 35% in 2018. Overall, 58% of all LTSS recipients live with a family member.
- Among those 21 years old and younger, less than 11% received services from state agencies in 2018.
- Among adults 22 and older, an estimated 46% received state services.
- From 1988 to 2018, spending for Medicaid intermediate-care facilities for people with IDD and HCBS waiver expenditures grew from an inflation-adjusted $13.44 billion to $51.93 billion. During the same period, the proportion of Medicaid expenditures used for long-term services for people with IDD declined from 12% to 8.9%.

The report also notes wide variability in state service structures, leading to large differences among the states in the proportion of LTSS recipients living with family members, and in the number of LTSS recipients with IDD per 100,000 of the state population.

The decline in the proportion of Medicaid spending used for people with IDD reflects the increasing need for services amongst older adults who make up a growing proportion of Americans. People with IDD now live nearly as long as people in the general population. While all school-age children with IDD are entitled to free publicly-funded education, far fewer receive supports once they leave school.

"Many families, particularly in states with limited HCBS waiver services, describe this as falling off the cliff," Larson said. "This report continues to provide important data that reflects how our country is allocating resources for people with disabilities."

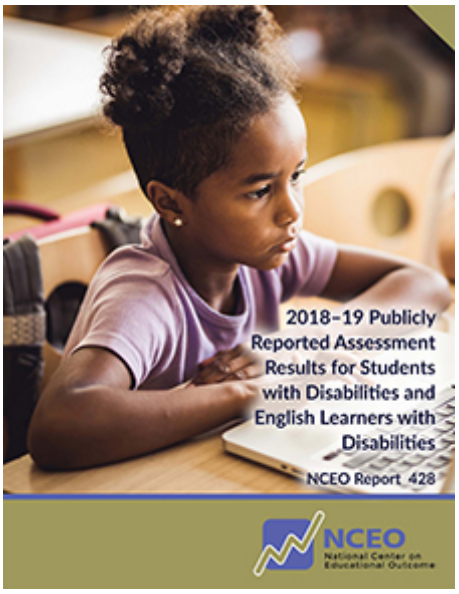
SOCIAL MEDIA SPOTLIGHT

Recently featured on ICI's Facebook

What if retirement didn't happen all in one day? In the new issue of *Impact*, authors Nathan Wilson and Roger Stancliffe share details of their Transition to Retirement program in Australia.

Image: Older woman working on a computer.

NEW RELEASES

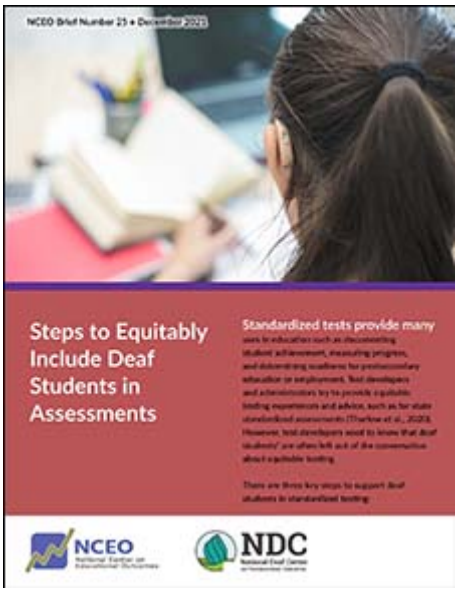


NCEO Report 428: 2018–19 Publicly Reported Assessment Results for Students with Disabilities and English Learners with Disabilities

Authors: Deb Albus, Sheryl Lazarus, and Martha L Thurlow

This is the 22nd report by ICI's National Center on Educational Outcomes (NCEO) that describes how states publicly report assessment data for students with disabilities in K–12 schools in the United States. The purpose of this report is to examine the extent to which states reported 2018–19

assessment data for students with disabilities "to the public with the same frequency and in the same detail as it reports on the assessment of nondisabled children," as required by the Individuals with Disabilities Education Act (IDEA). It also describes how states report assessment participation and performance data to the public online. It summarizes these data for grades 4 and 8, and high school, with additional analyses that focus on average performance gaps across years. The report also summarizes the extent to which states report participation and performance for English learners (ELs) with disabilities and examines public reporting of accommodations.



NCEO Brief 25: Steps to Equitably Include Deaf Students in Assessments

Authors: Stephanie Cawthon, Martha L Thurlow, Linda S Goldstone, and Jennifer Higgins

Standardized tests have many uses in education. For example, they are used to document student achievement, measure progress, and determine readiness for postsecondary education or employment. However, deaf students often do not have equitable access to standardized tests. This Brief is jointly written by ICI's National Center on Educational Outcomes (NCEO) and the National Deaf Center on Postsecondary Education (NDC). It provides three key steps to support deaf students in standardized testing. Part of an NCEO series.

Journal Articles Published

Stancliffe, R. J., Pettingell, S. L., Tichá, R., & Houseworth, J. (2021). Mothers and fathers with intellectual and developmental disabilities who use U.S. disability services: Prevalence and living arrangements. *Journal of Intellectual Disability Research*.

Johnson, D. R., Thurlow, M. L., Wu, Y.-C., Qian, X., Davenport, E., & Matthias, C. (2022). Youth and parent participation in transition planning in the U.S.A.:

Findings from the National Longitudinal Transition Study 2012 (NLTS 2012). *Journal of International Special Needs Education*.

Book Chapter Published

Burke, M., Lee, C., Rossetti, Z., & Hall, S. (2021). Parent and sibling roles in decision making with individuals with intellectual and developmental disabilities. In I. Khemka, & L. Hickson (Eds.), *Decision making by individuals with intellectual and developmental disabilities: Integrating research into practice* (pp. 95–113). Springer.

EVENTS AND ANNOUNCEMENTS

Policy Forum: "Wage Compression Among Direct Support Professionals"

January 26, 2022
1 pm–2:30 pm Central Time

Wage compression among direct support professionals—the subject of the current *Policy Research Brief*—is a major problem in U.S. disability support services. Wage compression is when there is little difference in pay between new and more experienced staff. While the pay raise among all U.S. hourly workers now averages 3–5% per year, it is nowhere near that for the direct support workforce. Join us as we look at the data and discuss the implications. ICI's Julie Bershadsky will moderate. The discussants will include Mary Lou Bourne from Person Centered Consulting, Sharon Lewis and Stephen Pawlowski from Health Management Associates, and Michelle Murphy from The Arc Mid-Hudson. Registration is free but required.

2022 Virtual Check & Connect Conference:

Attend, Engage, Invest!

February 23–24, 2022
11:30 am–3:00 pm Central Time

The conference aims to support the needs of the Check & Connect implementation community. Topics include promoting mentor development, deepening the understanding of student engagement, strengthening program implementation, sharing successful strategies, and lessons learned.

CHECK & CONNECT

The keynote speakers will be Drs. Adam Sáenz and Jean Rhodes. Sáenz, a psychologist and the CEO of Applied EQ Group, will speak about the power of relationships. Rhodes is the Frank L. Boyden Professor at the University of Massachusetts, Boston, and the lead researcher for the *Chronicle for Evidence-Based Mentoring*. She will share her findings and conclusions on the future of mentoring. Registration is open.

Seeking Participants from Anywhere in U.S. for IDD Retirement Study

ICI is seeking retirees with intellectual or developmental disabilities (IDD) from anywhere in the U.S. who are 45 years old and older, and who would like to talk about their retirement. The study aims to learn about how, why, and when adults with IDD retire. Information from this study can help other individuals, families, providers, and policymakers understand the important ingredients that are meaningful in retirement. Retired adults with IDD and an ally of their choice (e.g., family member, friend, significant other, direct support professional) will participate in a Zoom or phone interview together about the steps they took to retire, what they are doing in retirement now, and their thoughts about retirement. Individuals and their ally who complete an interview will each receive a $50 gift card.

Interested? Please contact ICI's Julie Kramme or Lynda Lahti Anderson. They will work with you to make sure you meet the study requirements and talk about the study process.

STAFF UPDATES

Jolene Thibedeau Boyd and **Michelle Smith**. On December 2, Thibedeau Boyd and Smith presented a breakout session at the 38th Annual NADD Virtual Conference: "A Changing World: Leading, Learning, and Adapting." Their interactive, virtual session, "Managing Employee Burnout and Increasing Retention," was presented to conference attendees ranging from clinicians, organizational leaders, and training/development leaders to managers, supervisors, and frontline workers.

Jennifer Hall-Lande, Amy Esler, and **Libby Hallas**. On December 2, Hall-Lande (pictured), Esler, Hallas, and the ADDM team held a data release with community stakeholders, and partners. On December 13, Hall-Lande presented the Minnesota team's SCOPE (Supporting Children of the Opioid Epidemic) project to the SCOPE national community of practice. Hall-Lande presented ADDM data to the Early Intensive Developmental and Behavioral Intervention learning collaborative team on December 16 with state agency partners, community stakeholders, partners, and providers.

Rachel Freeman and **Seunghee Lee**. On December 7, Freeman (pictured) and Lee presented the first of three webinars for small organizations interested in implementing person-centered practices and positive behavior support. Later, Freeman and Lee virtually delivered two full-day awareness trainings (on December 12 and 19) to South Korean rehabilitation centers on organization-wide person-centered practices and positive behavior support.

Barb Kleist. On December 9, Kleist (pictured) and Olivia Sullivan from DirectCourse/Elsevier hosted a screening and post-film Q & A of the ICI documentary film *Invaluable – The Unrecognized Profession of Direct Support* to more than 100 in-person and virtual attendees at the 2022 HCBS Conference in Baltimore, Maryland.

ALUMNI UPDATE

MNLEND Fellow Expands Practice

Amal Mohumed (MNLEND 2019–20) recently opened a second location for her multi-lingual mental health therapy practice, Comfort Therapeutic Services LLC.

The new location in northeast Minneapolis offers center-based Early Intensive Developmental and Behavioral Intervention services for children with autism

spectrum disorder or related conditions who are served by Minnesota Care or other qualifying health care programs. Comfort Therapeutic's other location in Brooklyn Center will remain open, offering Children's Therapeutic Services and Supports and adult psychotherapy services.

"Seeing the lack of providers who looked like the families they were serving was what drove us to open. Growing up in Cedar-Riverside, I've long seen the lack of services in the community," Mohumed said.

Another part of Mohumed's background served her well in the venture. The University of Minnesota graduate worked in human resources and recruiting for a variety of companies, including Medtronic, before founding her company in 2018. That experience helped prepare her for the difficult task of recruiting therapy providers in a tight labor market.

"Lately, finding providers has been the biggest struggle," she said. "There was also a time when it was difficult to find families to sign up for services, but with this move we will have a larger space and are excited about what we can offer. We are planning to provide internship opportunities in 2022 for students who are in applied behavior analysis programs, as well as students who are planning to become mental health professionals."

She said her MNLEND experience helped her view each family as a unique entity, a perspective that helped form the mission of her practice, which is to provide person-centered care and a tailored service plan to each family, so that they feel heard and understood by their provider.

"It's easy to say you're providing services to the Somali community or the African American community, but my time at LEND allowed me to look at each individual and each family and tailor services that fit them from their own perspective," she said. "My experience allowed me to broaden my understanding of neurodevelopmental disorders and working in interdisciplinary teams. It also provided an opportunity to build a professional network of individuals who are passionate about providing care to underprivileged communities."

The University of Minnesota stands on *Miní Sóta Makhóčhe*, the rightful homelands of the *Dakhóta Oyáte*. ICI recognizes that the U.S. did not uphold its end of these land treaties. It is the current and continued displacement of the *Dakhóta Oyáte* that allows the University to remain today. At ICI, we affirm our commitment to address systemic racism, ableism and all other inequalities and forms of oppression to ensure inclusive communities.