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ICI

INSTITUTE *on*
COMMUNITY INTEGRATION

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

SEPTEMBER 2021

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FEATURED STORIES



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Impact Launches Arts Issue

The work of nearly three dozen professional artists with disabilities is highlighted in the new issue of [Impact](#), a print and digital publication of the Institute on

Community Integration.

Articles by Leroy Moore, founder of Krip-Hop Nation, and William Britt, a visual artist who spent more than 30 years institutionalized at Willowbrook State School, accompany scholarly articles assessing the progress toward inclusion in the professional arts for people with intellectual, developmental, and other disabilities. Visual and performing artists at all stages of their careers and leading programs working to helping artists develop their professional careers also are featured.

The issue launches at a time when major film and television studios are making public vows to increase diversity in front of and behind the camera. It also comes as day programs for artists with disabilities face changes to their public funding, and as recognition grows that the number of professional artists with disabilities working today is simply too low.

“This issue showcases the complex nature of artistic careers and the seriousness of artists who have traditionally been cast aside,” said [Nik Fernholz](#), program manager for ICI’s Art for All, who served as an issue editor. “It bridges a gap between these artists and the greater arts community, defining an inclusive space for artists at all stages of their careers.”

A talent studio founder in Los Angeles takes readers behind the scenes as he coaches actors with disabilities in their television and film work, including roles in *The Good Doctor*, *Born This Way*, and *Glee*.

And Jeanne Calvit shares the story of how she started Saint Paul’s Interact Center for the Visual and Performing Arts.

“We know that the artistic process has the power to change things, to give us those ‘ah-ha’ moments that can blow your thinking wide open,” she writes.

Other issue editors include Betty Siegel, director of the Office of Accessibility and VSA at the John F. Kennedy Center for the Performing Arts in Washington, D.C.; Olivia Raynor, founder and director of the National Arts and Disability Center and director of the Tarjan Center, University of California, Los Angeles; and Beth Stoffmacher, an arts specialist with NADC and center coordinator for the Tarjan Center at UCLA.

“The creative talent of artists with disabilities warrants greater visibility and recognition,” Raynor said. “There are no limits to this talent, and this issue shows

the progress that is being made in representation and recognition for artistic excellence. It also points out the need for more education and training opportunities for people with disabilities to develop and succeed in professional careers in the arts.”

Other artists and programs featured in the issue include Jimmy Reagan, the Saint Paul painter whose work has been exhibited throughout the United States and in Europe; Jeremy Sicile-Kira, a San Diego-based painter with autism who experiences synesthesia, allowing him to perceive people and their emotions as color; and Mind the Gap, England’s largest theater company working with performers with autism or learning disabilities.

Siegel said advising the feature issue reminded her that access to the arts connects us with one another, and makes us fully human.

“Art allows us to communicate our feelings and fears, our desires and dreams,” she said. “In this odd year of social reckoning and pandemic, climate change, and political change, working on this issue of Impact gave me a sense of purpose and it reminded me of the words of President John F. Kennedy, engraved on the walls of the Kennedy Center:

‘I am certain that after the dust of centuries has passed over our cities, we, too, will be remembered not for victories or defeats in battle or in politics, but for our contribution to the human spirit.’”



Back to School, or Not: What Matters Most in Any Classroom

As schools, students, and families grapple with a pandemic surge just as many classrooms are about to open for fall term, one thing is clear: Parents need more help in supporting their children to navigate both in-person and virtual classrooms.

The [National Center on Educational Outcomes](#) (NCEO) and the TIES Center recently presented a new video series to the Office of Special Education Programs (OSEP), which funds both centers. The free series, [Supporting the Learning of Children with Significant Cognitive Disabilities at Home](#), offers support, tips, and information to parents of students with significant cognitive disabilities as they facilitate learning at home.

“We think these materials continue to stay relevant because they emphasize the importance of collaboration between teachers and parents,” said [Kristin Liu](#), assistant director of NCEO and TIES Center principal investigator. “There are important things parents can do at home, even when students go back to in-person classes.”

NCEO and the TIES Center, the national technical assistance center on inclusive practices and policies, are part of the Institute on Community Integration. To develop the series, the team used a collaborative process that included volunteer families filming themselves with cell phones as they engaged in learning activities

at home. OSEP, other technical assistance centers, and parent advocacy groups were among the other contributors to the project. ICI's principal media producer [Pete McCauley](#) edited and narrated the videos.

"The result is an engaging video series that portrays real families of students with significant cognitive disabilities in real homes," said Liu.

The videos share activities families can use to strengthen communication, reading, math, and writing skills, and the types of support they should expect from their schools.

"The series reassures parents that they don't have to be their child's primary teacher when learning from home," said [Gail Ghere](#), TIES Center research associate. "Collaborating with the IEP team, they can support their children to learn in a manner consistent with what's happening at school, which will enhance students' success in standards-based instruction."

In addition to the parent videos, a web-based [distance-learning series](#) for educators and families that was developed by the TIES Center during the early phase of the pandemic is now being adapted with additional content for those who are going back to in-person learning environments this fall, Liu said.

"The lessons of the past year have taught us a great deal about what students and parents need to be successful in learning in general," said [Jennifer Sommerness](#), a TIES Center research associate. "The Pivot to In-Person Instruction series will capture practical examples of what families need from their school teams in order for students to be successful as they return to the classroom."

Further details about the new series will be shared on the [TIES Center Facebook](#) page and in the [TIES newsletter](#).



Building Bridges

Families waiting for diagnostic and intervention services for children exhibiting signs of autism spectrum disorder (ASD) wait even longer if they live in rural areas or come from culturally or linguistically diverse communities. Now, teams from the University of Minnesota's Masonic Institute for the Developing Brain will help bridge the gap with interim telehealth interventions.

Under a \$600,000, three-year grant from the Health Resources & Services Administration, an agency within the U.S. Department of Health and Human Services, researchers from the Institute on Community Integration and the University of Minnesota Medical School's Department of Pediatrics – both part of MIDB – will conduct a large-scale, randomized control trial of Naturalistic Developmental Behavioral Intervention and diagnostic services that are delivered via telehealth. The project aims to improve communication and challenging behavior using a supplemental model of support while families await formal ASD evaluation or intervention.

“The wait time between when a family is concerned about their child's development and when services and supports are actually delivered can last years, which is a significant problem,” said [Jessica Simacek](#), director of the [MIDB TeleOutreach Center](#) and the principal investigator (PI) on the project. “This grant will accomplish a number of important goals, expanding on a model we have been exploring for some time, and doing so on a larger scale.”

The project, [Bridging Barriers to Intervention Access for Waitlisted Children with ASD and Their Families](#), is part of HRSA's Autism Field-Initiated Innovative Research Studies Program (Autism-FIRST).

It builds on work the MIDB TeleOutreach Center originated with a philanthropic grant from the Richard M. Schulze Family Foundation. The Center provides research, training, and technical assistance through innovative and secure technology to address barriers to care for children, youth, families, and professionals in the field.

"Providers lost a lot of staff due to the pandemic and also had to reduce the number of households staff could visit because of COVID precautions, so wait times for intervention services have really increased," said [Amy Esler](#), section head of the UMN Autism and Neurodevelopment Clinic, interim co-director of MIDB Clinic, and Co-PI on the project.

"This collaboration will help families start working on things now as they wait for the more intensive services, and it will help us evaluate how well it is working," Esler said.

Because telehealth services often involve supporting parents to deliver interventions, investigators will also measure caregivers' effectiveness in implementing strategies. Working through evaluation clinics and intervention providers, the project will include a minimum of 50 families with children ranging in age from 1 to 5 years old. The study also involves follow up visits to evaluate the impact of the model on children and families' lives over time.

"We're trying to provide as much support as possible to families early on because they are inundated with a big learning curve to understand what services are out there and what will work best for their family," said [Adele Dimian](#), associate director of the TeleOutreach Center and co-PI on the project. "We tend to work with children who have complex communication needs, and we've been able to fairly quickly give them strategies that work well. By sharing these alternative communication strategies, we've also seen improvements in self-injurious behaviors that interfere with children's and families' quality of life."

A critical piece of the award focuses on health equity and reducing geographic and disproportionate access patterns to services, and related barriers faced by many Minnesota families.

ICI's [Muna Khalif](#) (pictured at right), key personnel on the grant and the project coordinator for the TeleOutreach Center, will serve as a project interventionist in Naturalistic Developmental and Behavioral Intervention and evaluation. As a Qualified Intercultural Development Inventory Administrator, Khalif will also help to support the team and diverse communities involved in the study, including in the Hmong, Somali, and Spanish-speaking communities.

"Telehealth plays a big role in promoting health equity and reducing barriers to service," Khalif said. "As a parent with a child currently on a waiting list for services, I can tell you these barriers have become worse since the start of the pandemic. Without services, these kids and families are losing opportunities for support."



Smith Wins Kennedy Award

On September 13, the National Alliance for Direct Support Professionals (NADSP) presented the John F. Kennedy, Jr. Award for Direct Support Workforce Advocacy & Leadership to [Jerry Smith](#), ICI's marketing and business development manager, who has directed dozens of films about community living for people with disabilities. In a statement coinciding with the organization's annual conference, NADSP President and Chief Executive Officer Joseph Macbeth evoked the Kennedy family's legacy of supporting disability issues through informed public

policies and strategies that strengthen the role of direct support workers.

“We name this prestigious award after our founder, John F. Kennedy, Jr., and bestow it upon those who have dedicated their careers to upholding this noble vision,” Macbeth said.

Smith’s documentary and educational media projects have explored media bias in mainstream coverage of disability issues, created awareness about autism for diverse communities, chronicled DSPs’ critical contributions to people with disabilities in the aftermath of Hurricane Katrina, and told countless other stories that have led to greater inclusion of people with disabilities in their communities.

SOCIAL MEDIA SPOTLIGHT



Featured on [ICI's Facebook](#) page in September 2021

“Protect yourself and protect the person that you’re working for from COVID by all means necessary.” – Ashley, DSP

[#WeCanDoThis](#)

Image: Woman in a wheelchair going down a sidewalk with her direct support professional (DSP).

NEW RELEASES



Accommodations Toolkit

The [Accommodations Toolkit](#) provides easy-to-use summaries of the academic research literature on specific accommodations for students with disabilities as well as policy analyses. The Accommodations Toolkit is organized by accommodation (e.g., tactile graphics, braille, test breaks, extended time, etc.), with a research fact sheet for each accommodation. The toolkit also includes a policy analysis that summarizes how each accommodation was included in states' accessibility policies. The resources in the toolkit are designed to support the work of state education agencies, but may also be helpful to technical assistance providers, researchers, and others. Published by ICI's National Center on Educational Outcomes (NCEO).



HCBS Modules for Person-Centered Organizations

Authors: [Rachel Freeman](#), [Chet Tschetter](#), [Nicole Duchelle](#), [Muna Khalif](#), and [Jessica Simacek](#)

This online training can help providers of Home and Community-Based Services (HCBS) become more person-centered while meeting HCBS regulations. The [modules](#) are for anyone working in or receiving HCBS who want to improve quality of life outcomes for people with disabilities. Using tools and resources, the modules guide organizations through each step of becoming a more person-centered organization. Watch the Overview of HCBS Person-centered and Positive Support Practices Modules video to learn more about the modules and tools. Published by the Minnesota Department of Human Services and ICI.



Videos Addressing COVID-19 Vaccine Access and Confidence

Editor: [Pete McCauley](#)

The COVID-19 pandemic has had serious implications and difficult outcomes for people with intellectual and developmental disabilities (IDD) and the organizations and direct support professionals that support them. There have been high rates of COVID-19 for people with IDD and they remain among the most likely to die from the disease. A recent study by ICI and the National Alliance for Direct Support Professionals ([Direct Support Workforce and COVID-19 Survey: Providing Support During the COVID-19 Pandemic. 2021](#)) reports that 26% of support workers remain unvaccinated.

To address the significant health risks for people with IDD and direct support workers, ICI, in partnership with ARRM and support from the Association of University Centers on Disabilities, produced these [public service announcements](#) (PSAs), encouraging direct support workers to get vaccinated.

Book Chapters Published

[Tichá, R.](#), & [Abery, B.](#) (2021). Measuring outcomes of people with disabilities in the US: Current challenges and opportunities. In J. Šiška & J. Beadle-Brown (Eds.), [The Development, Conceptualisation and Implementation of Quality in Disability Support Services](#) (1st ed.).

Gallagher, A., [Lee, S.](#), [Houseworth, J.](#), & [Cakir-Dilek, B.](#) (2021). Promoting independence and safety with medication technology for people with disabilities. In J. Šiška & J. Beadle-Brown (Eds.), [The Development, Conceptualisation and Implementation of Quality in Disability Support Services](#) (1st ed.).

EVENTS AND ANNOUNCEMENTS



2021 Minnesota Gathering Goes Virtual

October 27–28

The Minnesota Gathering is entering its 7th year of providing person-centered, family-centered, and organization-centered tools through networking, presentations, group conversation, and activities to further expand our knowledge to support all people through person-centered practices. [Registration for this virtual event is coming soon.](#)

Seeking Participants with Disabilities for Research Study of New HCBS Outcome Measures

Getting services at home or in the community is important for people with disabilities and their providers. ICI's Research and Training Center on HCBS Outcome Measurement (RTC-OM) is developing measures that include questions about how well Home and Community-Based Services (HCBS) help people with disabilities live the lives they want and be leaders. RTC-OM researchers want to talk to people with disabilities over video conference (Zoom) to make sure these measures provide information that improves services in ways that matter (e.g., social connectedness, meaningful activities). The researchers will ask the questions and then talk with participants about what they were thinking about when they answered. Participants must be 18 years or older, have a disability and receive services or supports for it, provide participation consent or assent (if not their own legal guardian), and be willing to take part in a 60–90 minute interview. Participants may be interviewed up to three times. Each participant will receive a \$20 gift card.



If you think some of the people you support might be interested or have questions about this work, please contact [Matt Roberts](#). The study is overseen by RTC-OM's co-directors [Dr. Brian Abery](#) and [Dr. Renáta Tichá](#). They are recruiting participants for interviews right now.

Seeking Service Provider Organizations for Research Studies

Workforce

ICI's Research and Training Center on Community Living (RTC-CL) is seeking interested provider organizations that serve adults with IDD to take part in a study to evaluate training approaches and interventions for direct support professionals (DSPs) and supervisors. The study aims to find out which training approaches (customized with technical assistance vs. standard protocol) and interventions (for staff recruitment, selection, and retention) are more



effective in reducing the turnover and vacancy rates among direct support staff and supervisors as well as improving staff job satisfaction, intent to stay on the job, and staff competencies.

The study would provide your organization with an opportunity for your staff (DSPs and supervisors) to be a part of an online training and technical assistance intended to improve the above-listed outcomes. All study activities (including data collection and training) have moved online because of the pandemic. Interested? Contact [Renáta Tichá](#).

Technology

RTC-CL is seeking interested provider organizations that serve adults with IDD to take part in a study to evaluate the use of smart living technologies (e.g., motion sensors, communication technologies, assistive technologies) on outcomes of adults with IDD. The study aims to find out what types of technologies are now being used to support people with IDD and how they improve the well-being, independence, self-determination, and social connectedness of adults with IDD.

The study would provide your organization with an opportunity to learn more about how smart living technologies support the people your organization serves. All study activities have moved online because of the pandemic. Interested? Contact [Brian Abery](#).

STAFF UPDATES



Jennifer Hall-Lande and **Lynda Lahti Anderson**: On July 14, [Hall-Lande](#) (pictured) presented a report by MN Act Early on COVID's impact on Minnesota's early childhood systems to the Prenatal to 3 Policy Forum (summer forum); over 275 people were in the audience, including policymakers, state legislators, providers, community organizations, pediatricians, and family members. In July and August, Hall-Lande and [Lahti Anderson](#), along with Grant Anderson from UMD's School of Pharmacy, developed and distributed COVID-19 flyers about COVID-19 vaccines and disability for summer county

fairs around the state, especially in Greater Minnesota and rural communities. This outreach focused on providing support for vaccine access for people with disabilities, their family members, and support staff.



Macdonald Metzger: The ICI-led project, [Economic Empowerment for People with Disabilities in Kenya](#), culminated in August when over 20 Kenyan entrepreneurs with disabilities pitched their business plans to—and received expert feedback from—a panel of judges in Nairobi on August 18 and in Mombasa on August 24. Funded by the U.S. State Department via the U.S. Embassy in Kenya, ICI, in collaboration with local partners Daystar University and CAP Youth Empowerment Inc., launched the year-long project in October 2020.

The project aims to increase the capacity of Kenyan entrepreneurs with disabilities to do business with the United States and improve the business environment for Kenyans with disabilities. [Metzger](#) is the co-PI and project director; he represented ICI at both events. The Acting Public Affairs Director at the U.S. Embassy in Kenya represented the U.S. State Department.



Barb Kleist: On August 26, [Kleist](#) facilitated the Lewin HCBS Special Projects Direct Support Workforce (DSW) Learning Collaborative Session on Diversity and Inclusion. This interactive session was the fourth in a series of seven learning collaborative sessions for state Medicaid agency staff from 30 states.



James Returns to LEND a Perspective

Inspired by an actual individualized education plan (IEP) that coldly reduced a student to a list of deficits, Zephyr James ([MNLEND](#), 2018–19) begins an autism presentation with a tongue-in-cheek clinical explanation of a neurotypical person with shallow interests.

“Any trait can be seen as a deficit if you frame it a certain way,” said James, who will address the current class of Minnesota Leadership Education in Neurodevelopmental Disabilities fellows next month. “There are different ways of framing and understanding disability, and embracing this can make a difference. It changes how you approach people and the amount of respect you give them. How we talk about disability and how we talk to people with disabilities affects their options and their lives.”

Earlier this year, James was promoted to a new position, community engagement manager, at the Autism Society of Minnesota (AuSM), from previous marketing and communications roles held since 2015.

Ellie Wilson, AuSM’s executive director, calls James “an all-around MVP.”

“Zephyr articulates ideas, frameworks, and stories that are inherently so well-informed of the autistic experience that they resonate meaningfully with our organizational following,” Wilson said.

One current project supports the organization's new information initiative, [AuSM Celebrates Interdependence](#), a year-long campaign of resources and events dedicated to celebrating neurodiversity in relationships, workplaces, and communities.

Just one example: Web resources that break down the red, yellow, and green flags in relationships, giving people on the autism spectrum tools to build better ones.

"For my first few years at AuSM I was behind a computer writing my social media posts and designing flyers. LEND said, 'No, you have to go out and talk to people,'" said James, who was diagnosed with autism after learning more about it through work. "It's given me a more diverse and deeper group of people to draw on for perspective and connections, and it forced me to accept that I can actually be a leader. I'm going to speak up and challenge people, and that has absolutely become part of my professional life, to push for more perspectives."

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The University of Minnesota stands on *Miní Sóta Makhóche*, the rightful homelands of the *Dakhóta Oyáte*. I recognize 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.