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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.

SEPTEMBER 2019

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FEATURE STORIES

Getting Kids with Autism and Other NDDs Out into Nature



Despite a brutal late winter and spring in Minneapolis, a hearty team of children with autism and other neurodevelopmental disabilities (NDD) and their families more than doubled their average time outdoors during a six-month project exploring the health benefits of interacting with nature. Mollika “Molly” Sajady (MNLEND Fellow, 2018–19) and her mentor, [Andrew Barnes](#),

M.D., an Assistant Professor of Pediatrics at the University of Minnesota Medical School, co-led the project as part of ICI’s [Minnesota Leadership Education in Neurodevelopmental and Related Disabilities Program](#) (MNLEND). Sajady is the mother of Luca (pictured last fall at age 8–10 months) and is a Developmental-Behavioral Pediatric fellow physician at the University’s Voyager Clinic, a developmental-behavioral clinic. After playing outdoors during the summer months, children are physically and mentally fit, but with the start of fall, it can be difficult for families to keep children healthy and connected to nature when the weather turns cold. Using motivational interviews and goal-setting, Sajady and her Voyager Clinic colleagues coached 28 participants on specific strategies for reaching their targets for outdoor activity.

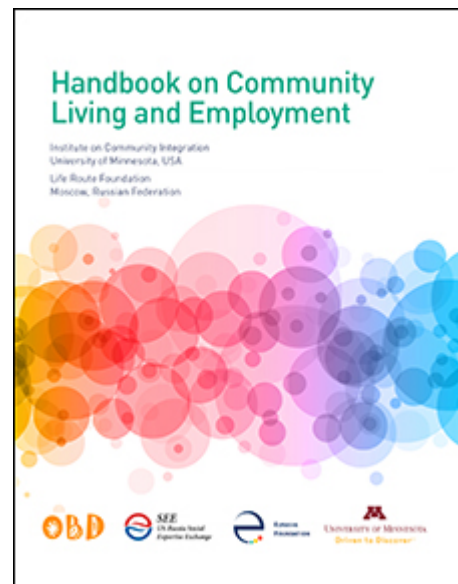
Beginning in February, the team asked families about how much outdoor time they averaged per week over the past year and their new goal. After discussing what participants like to do outside, staff guided them to make a reasonable action plan. If families struggled with ideas, staff offered to search for parks or outdoor spaces close to home. The goal-setting and accountability were motivators, but all participants contributed to the project’s success, Sajady said. For example, some families tied in

educational opportunities when they were outside together, such as discussing the benefits of vitamin D with their children. Others defied the cold winter weather by simply wearing more warm clothes. Some families said they would like the clinic to organize more outdoor activities.

Following up on the families' requests for expanding outdoor opportunities, Sajady is working with the Minnesota Department of Natural Resources to educate health care providers about the developmental and health benefits of encouraging children to spend more time in nature. As part of this community partnership, staff hope to create a database of accessible and sensory-friendly parks in Minnesota. Voyager Clinic also plans to combine nature interventions with anxiety treatment programs for children with NDD. "Children with neurodevelopmental disabilities and their families deserve to take advantage of the health benefits of spending time in nature by finding enjoyable, accessible ways to get outside," says Sajady.

American/Russian Handbook Shares Successes and Struggles of Community Living and Employment

Almost every country gives adults with disabilities the legal right to live in their community of choice, make friends, fall in love, access healthcare and other services, and work in a job that matches their interests, skills, and talents. The reality, however, often falls far short of this ideal. In the U.S., for example, low pay for direct support professionals who help people with disabilities realize those rights is undermining decades of progress in community living. In Russia, the law enshrines everyone's right to community living, but most people with disabilities cannot afford to live independently, leaving overworked families to either care for them at home or send them to harsh, state-run institutions. American and Russian authors share their respective countries' bumpy road to inclusion in [Handbook on Community Living and Employment](#), which is co-published by ICI and Life Route Foundation in Russia. "It is the first resource guide of its kind produced as a collaborative between a U.S. and a Russian partner in both languages, with the hope that users from both countries can learn from each other's initiatives," says editor [Renáta Tichá](#), co-director of the [Global Resource Center for Inclusive Education](#).



Created from the perspective that people with disabilities have the right to positive life outcomes and that societies can and should share their successes in achieving them, the book aims to raise awareness among people with disabilities, family members, employers, neighbors, healthcare providers, co-workers, and others about a wide variety of issues related to the employment and community living of people with disabilities. Each chapter provides readers with basic facts about a given topic and strategies to enhance the quality of life of people with disabilities and support them to

lead valued, meaningful lives, both from the U.S. and Russian perspectives. The handbook is accompanied by learning modules that cover the same topics.

With chapters co-authored by U.S. and Russian experts, the handbook includes case studies and specific examples of innovative approaches to community living and competitive employment. Authors address a wide range of issues, including transition from school to adulthood, working with families, health and wellness, relationships, community-based housing, social networks, self-determination, guardianship, funding for services, and opportunities for supported and customized employment.

This publication was produced with the support of the Eurasia Foundation by an ICI project known as [Community Participation and Employment as Strategies for Social Inclusion: A U.S.-Russian Dialogue](#).

New Frontline Initiative Promotes Self-Care for Direct Support Professionals

Frontline Initiative, a newsletter for Direct Support Professionals (DSPs), devotes its [latest issue to the vital importance of self-care](#). Jointly published by the National Alliance for Direct Support Professionals and ICI's Research and Training Center on Community Living,

Frontline Initiative provides resources for DSPs in the publication and celebrates practitioners who incorporate self-care into their work and lives. Self-care may be part of the solution to the problems plaguing the direct support workforce: chronically low pay despite high expectations, rampant turnover, and burnout. And unlike pay raises, self-care is a solution that DSPs themselves can control. DSPs are often expected to put the people they support ahead of their own needs, leading to deteriorating DSP health and wellness that often ends in burnout and resignations. Losing those workers exacerbates the shortage of DSPs, further burdening the DSPs who remain on the job.



To assist the people they support, DSPs must also take care of their own needs, health, and wellness. Incorporating self-care practices into their everyday lives helps DSPs in their work and other life areas. This issue of *Frontline Initiative* highlights how this helps them continue in the field and improve professionally.

Emotional intelligence and agility, mindful awareness, resilience, compassion fatigue, and trauma-informed care are addressed, as are important physical components, including good nutrition, hydration, and regular activity. DSPs and others featured in the newsletter emphasize the importance of taking time for themselves to process and unwind. The payoff for DSPs: improved stamina throughout the workday, and the year.

“These self-care practices carry over to how we support people,” write editors [Julie Kramme](#) and

[Laurie “Chet” Tschetter](#), both of whom have worked in direct support. “Self-care practices also help us to better understand ourselves, our colleagues, and the people we support. Understanding, for example, the impact of trauma from our own and others’ experiences helps us to be a more supportive, more compassionate, DSP and colleague.”



SOCIAL MEDIA SPOTLIGHT



Featured on the [Facebook](#) page for ICI’s RTC on Community Living on August 23, 2019

"I would see it as a career if it was a wage I could live off of, but this isn't a wage I could survive on." – DSP Tonya Lenox. z.umn.edu/invaluable



NEW RELEASES

NCEO Report 414: A Review of the Literature on Computerized Speech-to-Text Accommodations

Authors: [Kristin Liu](#), [Martha Thurlow](#), [Anastasia Press](#), and [Michael Dosedel](#)

[This literature review](#) describes what research conducted between 2008 and 2018 tells the field about the use of computerized speech-to-text (STT) technology tools by K–12 and post-secondary students with disabilities.

Speech-to-text tools are often installed on school-provided computers or tablets and thus may be widely available to students for instructional use. The report highlights what the available literature tells us about the characteristics of students who used STT for instruction and assessment, and the methodologies and outcome variables associated with those studies; the implementation of STT tools; and the effect of the technology on academic outcomes for students with different types of disabilities. Published by ICI's National Center on Educational Outcomes (NCEO).



NCEO Report 416: Status of State-Defined Alternate Diplomas in 2018–19

Authors: [Martha Thurlow](#), David Test, [Chris Rogers](#), [Matthew Klare](#), and [Sheryl Lazarus](#)

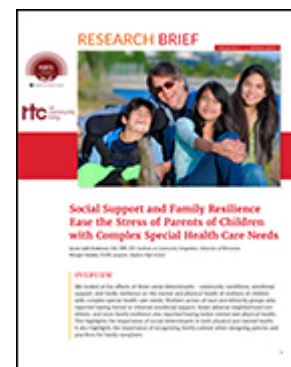
[This report](#) summarizes the status of state-defined alternate diplomas in the 50 U.S. states three years after the Elementary and Secondary Education Act (ESSA) indicated that states could develop these diplomas and use them in accountability calculations. To count this diploma in a graduation measure for accountability, several criteria must be met, including that it must be standards-based, aligned to state requirements for the regular high school diploma, and obtained within the time period for which the state ensures the availability of a free appropriate public education (FAPE). This report documents the status of state-defined alternate diplomas in states in 2018–19 and provides recommendations to states intending to develop a state-defined alternate diploma. Published by NCEO.



FSRTC Research Brief 1: Social Support and Family Resilience Ease the Stress of Parents of Children with Complex Special Health Care Needs

Authors: [Lynda Anderson](#) and [Morgan Hawley](#)

[This brief](#) examines the effects of three social determinants—community conditions, emotional support, and family resilience—on the mental and physical health of mothers of children with complex special health care needs. The researchers analyzed data from the National Survey of Children with Special Health Care Needs, selecting caregivers whose children were identified as having “more complex health care needs.” The three social determinants mentioned above were found to affect the emotional and physical health of mothers of children with more-complex health care needs, regardless of race/ethnic background. However, the exposure to social determinants that may have a negative effect on caregivers does differ by race and ethnicity. Thinking about social determinants and the context in which families live are important considerations when developing policies and practices aimed at supporting family caregivers. Published by the Family Support Research and Training Center at the University of Illinois at Chicago and ICI’s Research and Training Center on Community Living.



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EVENTS

Screenings of *Invaluable: The Unrecognized Profession of Direct Support*

[October 11: The Arc National Convention, Washington, DC](#)

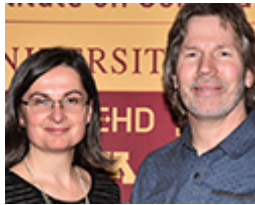
[October 22: The Council on Quality and Leadership \(CQL\) Conference, Baltimore, MD](#)



[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](#).

STAFF UPDATES



Renáta Tichá and **Brian Abery**: On July 13–17, [Tichá](#) and [Abery](#) presented on their international work at the International Association of Special Education Biannual Conference in Lushoto, Tanzania. They presented on both the ADA Fellowship program and “The Importance of International Collaboration to Enhance Educational Inclusion,” highlighting their work in Armenia, Ukraine, and India. They also conducted a workshop supporting new researchers on the criteria needed for publication of their “on-the-ground” research on inclusive and special education in international journals.

Jennifer Hall-Lande and **Libby Hallas Muchow**: On July 31–August 1, [Hall-Lande](#) and [Hallas Muchow](#) delivered two presentations on MN ADDM and MN Act Early project at the Minnesota Department of Human Services’ Age and Disabilities Odyssey Conference in Duluth, Minnesota. On August 18–21, Hall-Lande traveled with the Minnesota Early Childhood Personnel Development (CSPD) team to Connecticut to work together as a team to plan, organize, and build a competent early childhood workforce in Minnesota.

Julie Kramme, **Laurie (“Chet”) Tschetter**, **Amy Hewitt**, and **Jerry Smith**: On September 6, [Kramme](#) and [Tschetter](#) presented, “Always Fresh, Always Relevant, *Frontline Initiative*,” at the National Alliance of Direct Support Professionals (NADSP) conference in Cleveland, Ohio. Kramme and Tschetter shared the mission and history of *Frontline Initiative* with DSPs, frontline supervisors, family members, and administrators of community service providers from all over the U.S. The

following day, Tschetter hosted the first “Always Fresh, Always Relevant, *Frontline Initiative*,” appreciation event at the conference. Authors spoke about their experience and motivation to contribute to *Frontline Initiative*.

Also at the NADSP conference, [Hewitt](#) and [Smith](#) presented the film *Invaluable: The Unrecognized Profession of Direct Support* as a plenary session. Hewitt also delivered the pre-conference workshop, "Advocating for Effective Public Policy Reform: It's Time for Direct Support Professionals to Take the Lead."

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ALUMNI UPDATE

Julia Lang: Lang ([MNLEND Fellow](#) and [Certificate in Disability Policy and Services](#), 2017–18) is a pediatric registered dietitian at Gillette Children’s Hospital in St. Paul, Minnesota. While a MNLEND Fellow and Certificate student, she interned at Gillette and the hospital hired her in July 2018. Her Gillette internship counted as MNLEND clinical observation hours and she saw lessons from her MNLEND training come to life at the hospital: patient- and family-centered care, the complexities of navigating the healthcare system for people with disabilities and their families, and the need to hear and advocate for them.



Lang had previously worked with adults as a Direct Support Professional but, when interning on an interdisciplinary care team, she immediately warmed to her young patients—many of whom are on feeding tubes or have very specialized diets—and their families. MNLEND trained her to give as much weight to their lived experiences, stories, and preferences as to evidenced-based practice. Research on medical nutrition therapy for individuals with complex conditions is limited and relatively few dietitians specialize in this area. “Standard nutrition practice for general pediatrics is not appropriate for many of our patients and this is an inclusion issue on a systems level,” she observes. The scarcity of relevant evidenced-based practice sparks Lang’s creativity and advocacy. She enjoys the challenge of creating (and, when necessary, advocating for) diets that suit the preferences of patients and families while still ensuring that children get the nutrition they need.

And MNLEND’s tradition of advocacy and systems critique may be opening new avenues in Lang’s career. “Topics discussed in MNLEND, as well as among my cohort, also gave me more insight on how oppressive, discriminatory systems are created and allowed to stay in place,” she recalls. “MNLEND reinforced the importance and power of advocacy both on the policy level and in my personal and professional life. I also pull a lot from what I learned in the Certificate program on things like the history and evolution of disability policy, and understanding how to contribute to systems change. It was always so interesting to hear which pieces of legislation were on the table, and learning how easy it is to get involved in changing these policies and laws. All this has helped me consider future education and practice in ethics, health policy, and law.”

This email was sent to ICI staff by Institute on Community Integration, 109 Pattee Hall, 150 Pillsbury Drive

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