



ICI INSTITUTE *on* COMMUNITY INTEGRATION

Ensuring that all people with disabilities have the opportunity to be participating members in their communities of choice

DECEMBER 2018

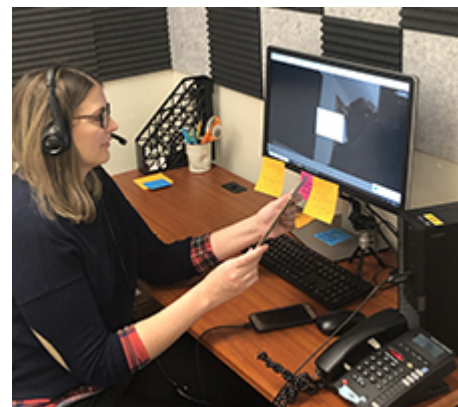
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FEATURE STORIES

ICI's Telehealth Lab Improves Access to Autism Intervention Services

Early identification, treatment, and intervention helps Minnesota's children with autism and other neurodevelopmental disabilities reach their potential, but families can encounter waitlists up to a year for evaluation services. Part of the reason for this long delay is geography and journey time: Autism evaluation clinics are typically located in the Twin Cities, but families of children with ASD live all over the state. Reducing waitlists can be critical for young children with autism because intervention is most effective while the young brain is still developing.



ICI's [Jessica Simacek](#) (pictured), [Adele Dimian](#), and [Jennifer Hall-Lande](#), are collaborating with Amy Esler from the Autism Spectrum and Neurodevelopmental Disorders (ASD) Clinic at the University of Minnesota's Department of Pediatrics to see if ICI's telehealth laboratory can help shorten these waitlists and improve access to early intervention among children with autism. *Telehealth* refers to using telecommunications technology to support long-distance clinical healthcare, health management, and education via devices like smart phones and home computers. Telehealth also reduces the need to schedule appointments with providers; the technology can be synchronous or asynchronous, meaning people with disabilities and their families can either communicate in real time with a medical professional or leave audio-visual messages that professionals can see and hear later.

"Too many children and their families face barriers to accessing needed intervention services," says Simacek, who has managed the lab since it began a year ago. "I investigate innovative interventions that are timely, efficient, and effective for children with neurodevelopmental disabilities. The ICI telehealth

laboratory allows us to leverage technology to reach children and families who may live in rural areas or may be on lengthy waitlists for intervention. We also provide training and technical assistance on the use of telehealth, which allows providers, educators, and researchers to use telehealth to improve and extend their practices."

ICI's telehealth lab is not limited to early intervention and evaluation. Simacek and [Rachel Freeman](#) also use telehealth to train organizations on Positive Behavior Support (PBS) for people with intellectual and/or developmental disabilities. Known as the TelePBS model, it helps connect organizations in Greater Minnesota with ICI trainers and other organizations, most of which are based in the Twin Cities. As a result, many organizations and individuals have been able to participate in TelePBS training.

The telehealth lab also helps train Fellows from ICI's [Minnesota Leadership Education in Neurodevelopmental and Related Disabilities Program \(MNLEND\)](#). MNLEND is helping develop the next generation of knowledgeable, interdisciplinary leaders (known as MNLEND Fellows) in the neurodevelopmental disabilities field -- and telehealth is an emerging part of Fellows' training. Simacek, a former MNLEND Fellow, and Dimian, a current MNLEND Post-Doctoral Fellow, now mentor MNLEND Fellows on research and technical assistance telehealth. MNLEND Fellows who participated in research at the telehealth lab have gone on to present at multiple national conferences and publish articles in research publications, says Simacek.

ICI's TIES Center Marks First Anniversary With New Resources

Marking its recent first anniversary, ICI's [TIES Center](#) has released an array of information and resources for use by educators across the country to improve the quality of education for K-8 students with the most significant cognitive disabilities in inclusive environments. The center helps create sustainable changes in school and district educational systems so that students with the most significant cognitive disabilities can fully engage in the same instructional and non-instructional activities as their general education peers while being instructed in a way that meets individual learning needs.



"The work of TIES Center has the potential to impact important adult outcomes," says center director [Sheryl Lazarus](#) (pictured at right with assistant director [Terri Vandercook](#)). Vandercook agrees, adding, "Students who experience membership, active participation, and learning in inclusive educational settings will be better prepared and more likely to live in inclusive communities of their choice as adults. This increased likelihood comes from the experience and expectation of both individuals with disabilities and their typical classmates."

The new resources and activities include:

- Two publication series: *TIES Center Brief* and *TIES Center Report*. The titles of the first issues are [*10 Reasons to Support Inclusive School Communities for ALL Students \(TIES Center Brief #1\)*](#) and

- The launch of its [Facebook page](#).
- Introducing the TIES Center to a nationwide audience of educators at the TASH conference in late November. Lazarus and Vandercook, along with Diane Ryndak from the University of North Carolina, Greensboro (a TIES Center partner organization) presented a conference session entitled, "Implementation Science and Facilitating Inclusive Education: The TIES Center's Perspective." Lazarus and Vandercook also presented a poster session titled, "TIES Center: Supporting Inclusive Practices and Policies for Students with Significant Cognitive Disabilities."
- Guest-editing ICI's upcoming publication, *Impact: Feature Issue on Inclusive Education for K-8 Students with the Most Significant Cognitive Disabilities* (to receive a free copy of this issue [subscribe here](#)).

The TIES Center -- Increasing Time, Instructional Effectiveness, Engagement, and State Support for Inclusive Practices for Students with Significant Cognitive Disabilities -- began in October 2017 with a five-year, \$10 million grant from the U.S. Department of Education's Office of Special Education Programs.

ICI and Hennepin County Collaborate to Improve Early Screening and Intervention

[Jennifer Hall-Lande](#), on behalf of ICI, has received a \$50,000 Hennepin-University Partnership Fall 2018 Mixer grant for a new project, scheduled to begin January 1, 2019, supporting healthy development and enhancing early intervention outcomes for Hennepin County children. Known as "Building Healthy Children and Strong Families: Increasing Access to Early Screening and Early Intervention," the one-year project -- co-directed by Hall-Lande and Karen Adamson, a Child Well Being Area Manager for Hennepin County -- will study screening rates in Minnesota's largest county and follow up for early intervention services. "Hennepin County and the University of Minnesota both want to empower families and improve health, well-being, and educational outcomes for all children," says ICI's Hall-Lande. The project will connect autism resources and early intervention research from the University with the county's best practices. "This project provides valuable data to evaluate progress on screening rates and early intervention access for Hennepin County children," adds Hall-Lande. "We hope to increase access and improve lives of children and families."



The project will evaluate family perspectives on early screening and intervention in Hennepin County, including cultural and contextual factors that affect access, and learn why families may or may not pursue early screening and early intervention. Finally, the project will determine the impact of the parent-to-parent navigator model on family engagement and participation in early screening and intervention

follow-up, developing a parent-to-parent community support model for future use.

Check & Connect: New Country, New States, New Community Partners

[Eileen Klemm](#) (second from left) and [Maureen Hawes](#) (second from right) from ICI's [Check & Connect](#) (C&C) program are on the Pacific island of Yap in the Federated States of Micronesia (FSM) this month, meeting with lead special education staff for Yap and FSM about conducting a needs assessment of student engagement levels for C&C training and implementation. The



C&C school engagement model, developed at ICI in the 1990s to assist K-12 students who show signs of disengagement from school and learning, has been implemented by educators in 45 U.S. states and several foreign countries, and the partnerships continue to grow. "It's encouraging that Check & Connect's reach is expanding to improve student engagement and ultimately increase graduation rates for students in new locations," says C&C Program Manager Klemm (pictured in Micronesia with staff from the Yap Special Education Department). C&C's current work in Yap follows earlier ICI visits to Micronesia in support of early English literacy (see [story on ICI website](#)).

The current project in Micronesia is part of a growing number of international partnerships for C&C. It has trained mentors to implement the program in schools in Canada, South Africa, and Australia. In addition, C&C has a growing number of statewide implementation projects in the U.S., with cohorts of trainers within states becoming certified local C&C trainers. There are over 200 local certified C&C trainers in Florida, Iowa, Missouri, Montana, North Carolina, Pennsylvania, Utah, and Washington, and Georgia became the newest state by adding two cohorts of trainers in August and September of 2018. And at the local level, many community-based organizations (e.g., Boys & Girls Clubs, Communities in Schools) have chosen the C&C model to meet their goals of improving student engagement and graduation rates. Newly expanded community partnerships include that with the Minnesota Alliance for Youth, which places Americorps Promise Fellows in local school districts, often in the role of a Check & Connect Mentor.

Whatever their location, the program introduced the [Check & Connect App](#) to clients last year. Launched in October 2017, the Check & Connect App is a web-based application that replaces the paper or Excel version of the Check & Connect monitoring form. In early December, C&C showcased the key features of the app in a free webinar and fielded questions from the online audience about using the app to support Check & Connect implementation. Beginning in January 2019, these free webinars will be planned monthly. [Registration is on the C&C website.](#)

SOCIAL MEDIA SPOTLIGHT

Featured on [ICI's Facebook](#) on November 22, 2018



ICI Film About School Inclusion in Armenia Receives Award.

Read more about this story and other ICI news from our monthly e-communication at <https://z.umn.edu/FYI-November-2018>

NEW RELEASES



The Effectiveness of Engaging Parents and Family Members to Expand the Social Inclusion of Adults with Intellectual/Developmental Disabilities Living with Families

Authors: Angela Amado, [Kelly Ortenblad](#), and Kathleen O'Donnell

Since most individuals with intellectual and/or developmental disabilities live in their family home, engaging families in social inclusion helps build more inclusive communities. [This new report](#) explains the findings of a research project about supporting families in how to expand social inclusion for their adult children living at home. The study found that families can successfully use the same strategies that human services agency staff use to expand social inclusion for group home residents. Families discovered the openness and willingness of community members to include and befriend their children. The project also helped family members see their children's gifts and possible relationships with the larger community. Besides the challenges of connecting individuals with disabilities with other community members, the study's main challenges were measuring and tracking social relationships, family recruitment, and type of project structure. Similarities and differences found between training families and agency staff may also be useful for those engaged in training families in future endeavors. Many families expressed a need for different types of social inclusion ideas or tactics. Published by ICI's Research and Training Center on Community Living (RTC-CL).

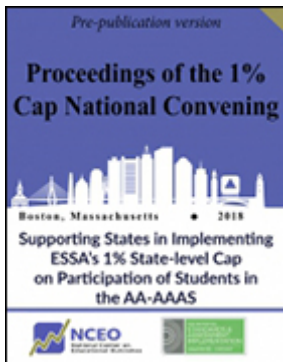


FSRTC Research Brief 8: Family Caregivers of Family Members with IDD Differ from Other Caregivers in the Kinds and Duration of Supports They Provide

Author: [Lynda Lahti Anderson](#)

[This brief](#) compares experiences of family caregivers for adults with intellectual and developmental disabilities (IDD) with those of caregivers who responded to the

Caregiving in the U.S. (CUS) survey in 2015. The brief helps readers understand the experiences of people providing care to family members with lifelong disabilities compared to the experiences of caregivers of those who are aging or have acquired disabilities in adulthood. The more recent survey was known as the *Family and Individual Needs for Disability Supports* (FINDS) survey and it was conducted online by ICI's [Research and Training Center on Community Living](#) (RTC-CL) and The Arc of the United States (The Arc) in 2017. The purpose of FINDS is to better understand the experiences of families who provide supports to a family member with IDD. There were some important differences between the groups, including the duration of caregiving and the types of supports provided. Published by University of Illinois at Chicago's Family Support Research and Training Center (FSRTC), The Arc, and RTC-CL.



Proceedings of the 1% Cap National Convening: Supporting States in Implementing ESSA's 1% State-level Cap on Participation of Students in the AA-AAAS

Authors: [National Center on Educational Outcomes](#) (NCEO) and the Center on Standards & Assessment Implementation (CSAI)

This [Proceedings document](#) was developed to provide a summary of the 1% National Convening that took place in Boston on October 18 and 19, 2018. More than 200 individuals gathered to listen to each other, share ideas, and develop state-level action plans. The purpose of the Convening was to support states as they work with local education agencies to implement the Every Student Succeeds Act (ESSA) requirement of a 1% cap on the participation of students with the most significant cognitive disabilities in the alternate assessment aligned with alternate academic achievement standards (AA-AAAS). The Proceedings document includes appendices and links to resources that were shared by states and others at the Convening. Published by NCEO and CSAI.

Journal Article Published

"Exploring Gaps in the Online Economic Inclusion of Persons with Disabilities in Korea." (2018). By [Kyung Mee Kim](#) and Ju Hee Hwang. Published in [Information, Communication & Society](#).

EVENTS

Responses Sought for Online Survey About ICI Website



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The ICI Web Team is asking our friends and colleagues around the world to take a moment today to let us know what you think of the [ICI Website](#) and how it can better serve you

in the future. The short survey takes only a few moments to complete and can be found [here](#). We would love to hear from you. Thank you!

STAFF UPDATES

Lynda Lahti Anderson and **Jody Van Ness**: On November 5, [Anderson's](#) blog post, "[Parents of Disabled Children Face Impossible Choices: Paid Family Leave can Make Them Easier](#)," was published on *Apolitical*. On November 30, she co-presented at the TASH conference in Portland, Oregon on, "Advancing Community Living -- A Presentation of Current Policy and Practice in Medicaid, Employment, and Family Supports," co-written by [Van Ness](#).

Amy Hewitt and **Kelly Nye-Lengerman**: On November 5, [Hewitt](#) and [Nye-Lengerman](#) presented to the Minnesota Organization for Habilitation and Rehabilitation (MOHR) on the work and activities of ICI and the [Research and Training Center on Community Living](#).



Jody Van Ness: On November 8, Jody and Dr. Brian Van Ness presented, "A Family's Journey into Autism Genetics" for ICI's [Minnesota Leadership Education in Neurodevelopmental and Related Disabilities Program \(MNLEND\)](#). They discussed their son's regression and their journey in finding answers that ultimately led to a return to baseline. Brian wrapped up the conversation by discussing how the research and outcomes described can serve as a prototype for the use of individualized genotyping and pharmacogenomics-guided directed therapies in developmental syndromes. On November 12, [Jody Van Ness](#) traveled to Hibbing, Minnesota to provide technical support for Minnesota Diversified Industries; she presented a training to employment specialists titled, "Autism... Tools and Strategies in the Context of Employment."

Brian Abery, Jerry Smith, and Renáta Tichá: On November 11, [Abery](#), [Smith](#), and [Tichá](#) presented the ICI film, "[Education for Every Child: Armenia's Path to Inclusion](#)," at St. Sahag Armenian Church in St. Paul. The film explores ICI's [Global Resource Center for Inclusive Education](#) work with UNICEF Armenia and Armenian State Pedagogical University in helping make Armenia's schools inclusive for all students with disabilities. On November 18, "[Valuing Lives: Wolf Wolfensberger and the Principle of Normalization](#)," a documentary film directed by Smith, aired on WITF public television in Harrisburg, Pennsylvania.



Amy Hewitt: On November 11-14, [Hewitt](#) became President of the Association for University Centers on Disabilities (AUCD) during the association's annual conference in Washington, DC.

Sheryl Larson: On November 11-14, [Larson](#) co-presented twice at the AUCD 2018 Conference in Washington, DC. The presentations were titled, "Longitudinal Data Projects of National Significance: What Does the Data Tell Us?" and "Working Through the Intellectual and Developmental Disability Data



Conundrum: Strategies for Collecting Better Data to Inform Program and Policy."

Claire Benway and **Laura ("Chet") Tschetter**: On November 14, [Benway](#) and [Tschetter](#) traveled to Iowa to conduct a Senior Leadership Training on "Effective Strategies and Solutions for Addressing Workforce Issues" for the Iowa Association of Community Providers.



Kristin Liu and **Jennifer Hall-Lande**: On November 15, [Liu](#) and [Hall-Lande](#) were selected to present their work at the University of Minnesota Gallery of Excellence, which highlights faculty who address issues of equity, diversity, and social justice through innovative and groundbreaking research. The annual event brings together the University community and external stakeholders -- alumni, donors, community organizations, and corporate entities -- to recognize the students, staff, and faculty that exemplify the University's commitment to equity and diversity. In a separate development, Minnesota State Senator Jim Abeler recently appointed Hall-Lande to the Minnesota Autism Council, a state group that informs policy and program priorities to improve the lives of individuals with autism and their families in Minnesota.



David Johnson: On November 27, the [Minnesota Daily](#) quoted [Johnson](#) in an article describing the University of Minnesota Disabilities Issues Committee draft resolution requiring that all employees working with students receive training on accommodating and supporting students with disabilities. Johnson is a former member of the committee.

Claire Benway and **Barb Kleist**: On November 28, [Benway](#) and [Kleist](#) traveled to Missouri for a panel presentation to state health and human services leadership on maximizing implementation of DirectCourse's College of Direct Support as a workforce solution.



Rachel Freeman: On December 3, [Freeman](#) co-presented a Home and Community Positive Behavior Support webinar titled, "Creating Buy-in with Positive Behavior Support Teams: Using Person-centered Practices and PBS to Support Team-based Strategies."

ALUMNI UPDATES

Paruj Acharya: Acharya is a senior data analyst at UnitedHealth Group, but thanks to his graduate assistantship at ICI in 2012-13, he is always aware of what data represent. "I now work with millions of rows of data, but am reminded every moment that each row is an individual and not just cold-hard 'data,'" he says.



While Acharya pursued his master's degree in Public Policy at the Humphrey School of Public Affairs, he was part of a team doing a longitudinal study on whether Active Support or hand-over-hand practices made a difference on the independence levels of people with varying degrees of disability. "We were a strong team of highly intellectual individuals such as [Sheryl Larson](#) and [Renáta Tichá](#), along with graduate assistants such as myself," he recalls. "Among many other things, this experience at ICI permanently instilled in me the sense to treat data as the individuals they represent. As a part of my duties at ICI, I went out into the field record data by observing individuals in their own setting. Later on, I transcribed the findings into a database."

"As someone just starting out, being under the wings of such seasoned researchers allowed me to learn much about the industry as well as about myself. Thank you, ICI, for helping me constructively shape my professional as well as personal worldview."

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