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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.

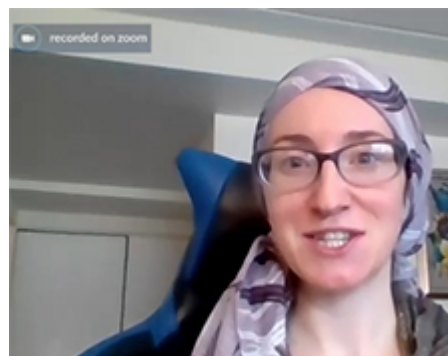
MAY 2020

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FEATURE STORIES

Survey: DSPs in a Time of Crisis

About 8,500 direct support professionals (DSPs), and counting, have responded to a new [survey](#), from ICI designed to measure the impact of the COVID-19 pandemic on the essential employees working with people with disabilities.



Conducted in partnership with the National Alliance for Direct Support Professionals, the online survey captures information about whether DSPs are officially classified as essential workers in their communities, how their work has changed as a result of the pandemic, whether there have been increases or decreases in work hours or layoffs, what types of personal protective equipment and safety training they have received, and what consequences of COVID-19 they have observed in the people they support.

“Hearing from workers themselves is key to changing policy, and this is an excellent time to ask them about their experiences,” said [Amy Hewitt](#), ICI director. “This overwhelming response creates possibly the largest-ever sample of the workforce supporting people with intellectual and developmental disabilities. Through social media and direct outreach to advocates, providers, individuals with disabilities and families who employ DSPs, we have given voice to a group of professionals that has traditionally been difficult to reach.”

Open-ended questions on DSP self-care and employer best practices also are part of the survey, as is wage and demographic data. Some respondents have expressed interest in telling their story about

being a DSP during COVID-19 and are being interviewed and filmed about their experiences via Zoom (pictured). Selections from these interviews are being [posted online](#) and shared across social media.

ICI is a longtime advocate for increasing pay, benefits, and professionalism in the DSP workforce. In a survey last year by [National Core Indicators](#), researchers found that DSPs earn about \$12 per hour, the average annual turnover rate is 51%, and vacancy rates range from 8% to 17%, depending on how many hours the DSP is employed. Their duties typically include administering medications, coordination of multiple services, teaching and training, transportation, social and job skills coaching, counseling, personal and home care, and more.

In a recent [MinnPost article](#) highlighting the severe shortage of DSPs, Hewitt called for greater recognition of the essential nature of the work, higher pay and benefits, and more personal protective equipment.

“As our country responds to the devastation of COVID-19, those of us working for the full inclusion of people with disabilities in all aspects of society will fight any attempt to disregard their safety and rights,” Hewitt wrote. “This includes sins of omission by ignoring people with disabilities in economic stimulus programs and blatant discrimination in care-rationing decisions. It includes demanding that this country finally recognizes the critical nature of DSP work.”

Since that article was published, in addition to the DSP survey, the disability advocacy community has mobilized other critical research in the absence of official government data. The Autistic Self Advocacy Network, for example, has created an [online tool](#) showing more than 18,000 deaths and 90,000 COVID-19 cases in congregate care settings such as nursing homes and institutions for people with developmental disabilities.

And in a May 11 [PBS NewsHour segment](#) featuring a wide range of people with disabilities sharing concerns including medical care rationing, Rebecca Cokley of the Center for American Progress says people with disabilities are simply no longer able to engage with society due to the loss of their support professionals.

“They are worried about the loss of services actually forcing them to be institutionalized or put in a nursing home against their will,” she told PBS. “Any time there’s any sort of health care rationing, it’s the sad truth of history that ... we’re put to the end of the line.”

Latest Issue of *Impact*: Brothers and Sisters

Siblings of people with intellectual and developmental disabilities (IDD) are frequently involved in their brother’s or sister’s life longer than anyone else in their family, but they are often overlooked by service providers, family members, and others. [The new *Impact*](#) issue delves into these important and dynamic relationships over the life course.

Led by guest editors from across the country who are leading voices in the sibling community, the issue explores what we know about siblings' roles and needs across the lifespan, their feelings about themselves and their siblings, and how to support them. It includes their personal stories, profiles of organizations around the world that are giving them a place to connect with one another, strategies and resources for addressing their concerns, and research findings about them. Guest editors from outside ICI were Katie Arnold, executive director of the Sibling Leadership Network and community education director for the Institute on Disability and Human Development at University of Illinois at Chicago; Emily Holl, director of the Sibling Support Project, Bellevue, Washington; and Emily Shea Tanis, co-director for policy and advocacy at the Coleman Institute for Cognitive Disabilities at the University of Colorado, Boulder.



“As a sibling of a brother with multiple disabilities, I have often felt my situation was too different for others to understand. This issue reminds me that I am connected to a larger group of siblings who really understand my experiences,” said [Sarah Hall](#), an ICI research associate who served as a guest editor for the issue. “This issue is also essential for helping parents and professionals to understand the sibling experience and support siblings throughout their lives.” Another guest editor from within ICI, [Jerry Smith](#), contributed a personal essay about his sister Gayle and her influence on his career.

Published by ICI and the [Research and Training Center on Community Living and Employment](#), *Impact* is supported in part by grants from the U.S. Department of Health and Human Services and the National Institute on Disability, Independent Living, and Rehabilitation Research.

Articles in the issue range from an academic look at how sibling roles and needs change over the course of their lives, to very personal stories of family experiences, to important public policy issues and advice on handling grief and loss issues. Both print and online versions of the issue point readers to multiple sources of further information on sibling issues.

The issue also pays tribute to [Vicki Gaylord](#), *Impact's* managing editor, who is retiring from ICI after nearly 32 years of service. Under her leadership, more than 70 issues of the magazine have been produced, in addition to her other responsibilities.

“This magazine has without question moved us toward greater inclusion, self-determination, and empowerment of people with disabilities,” Smith said in the tribute. “For this, we owe Vicki a tremendous debt of gratitude.”

TIES Center Provides Tips Online to Quarantined Teachers and Families



School districts, teachers, students and families are struggling as they try to close out the academic year online. Districts worry about complying with educational requirements, particularly for students with disabilities. Teachers grapple with students' uneven access to technology and to support at home.

Students try to pick up what learning they can, but there are concerns many of them are sliding backwards in their skills. Parents are overwhelmed balancing work and their new teaching responsibilities at home.

ICI's [TIES Center](#) is responding to these needs with a series of [online articles](#) that give teachers and families practical tips on navigating the educational process under quarantine conditions.

“We’re hearing about a lot of confusion and doubt about whether online learning is even possible, particularly for students with significant cognitive disabilities. We want to make sure educators and families alike know that it is, indeed, possible,” said ICI’s [Kristin Liu](#), co-principal investigator of the TIES Center (TIES stands for Increasing **(T)ime**, **(I)nstructional** Effectiveness, **(E)ngagement**, and **State (S)upport** for Inclusive Practices for students with significant cognitive disabilities). TIES is a national technical assistance center on inclusive educational policies and practices.

The series offers a framework for using online tools to gradually boost students’ access to and engagement in virtual classrooms.

One article in the series shares the story of Olivia, a 13-year-old who loves music, science, and Disney and who also lives with autism. Her mom, Jen, is a fellow in [MNLEND](#), ICI’s leadership development program in the neurodevelopmental disability field.

Jen shares her story of how quarantine life has affected Olivia’s sleep, daily routines, and stress levels. Then, the module offers some practical take-aways for teachers and parents, such as prioritizing lesson concepts, working school lessons into daily household activities, and deciding on a number of times a lesson will be attempted before moving on.

“We understand this is not an easy time for anyone in the field, and it’s been overwhelming for parents to figure out how to do distance learning,” said [Gail Ghere](#), an ICI investigator who helped create the series. Written by a number of TIES Partners, each article is designed to support teachers, students and families. They start with educational activities to link skills with daily routines at home and progress to new online tools for more inclusive and academically rigorous virtual instruction. The series also acknowledges schools’ and families’ varied access to technology, offering hi-tech and low-tech options for learning strategies.

Even though the shift is still in its early stages and was a response to the pandemic, the potential exists to make long-lasting improvements in inclusivity for students with disabilities through the increased use of technology, Ghere said. When all students are using devices to contribute to a classroom discussion, for example, students using alternative and augmentative communication devices may be more

comfortable participating in class discussions or chatting with a classmate without disabilities.

“These changes weren’t planned, but the fact is there is a lot of learning going on at the moment about how kids with disabilities can access curriculum and interact with their classmates,” Ghere said. “We want to build on that and not go backwards.”

DSP Professionalism: The Art of Relationships

Making friends, staying professional in a work relationship, talking about sexuality—it’s all in a day’s work for direct support professionals, who assist people with intellectual and developmental disabilities in living the lives they choose.



The latest issue of [Frontline Initiative](#), the newsletter for DSPs produced by the National Alliance for Direct Support Professionals and ICI’s [Research and Training Center on Community Living](#), focuses on developing awareness, knowledge, and skills for supporting healthy relationships. It’s just one component of DSPs’ work—they assist with many other essential tasks of daily living—but it’s a critical one.

“Healthy relationships of all kinds are important to people with IDD,” said [Julie Kramme](#), *FI*’s co-editor, along with [Chet Tschetter](#). Kramme and Tschetter, both of the Institute on Community Integration, said the issue marks an important step forward in acknowledging the level of professionalism required of DSPs.

“We’re excited about this issue because it speaks to some of the important tools DSPs need to do their jobs at a high level,” Tschetter said.

Articles cover a broad range of professional and personal relationships. Balancing differing priorities from people with IDD and their families, creating and supporting opportunities for friendships to develop, building self-awareness skills that can lead to healthier connections, and more are included in the issue.

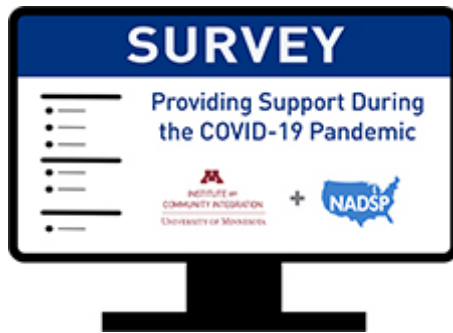
“Feelings of isolation are quite common among people with intellectual disabilities,” said Kramme. “This issue assembles a number of experienced professionals who talk about the ramifications of that. It also offers very specific tools and strategies for professionals to use, and there’s some great storytelling about what’s possible for people when they stick to their guns and say they want real relationships in their lives.”

With the issue release happening amid the COVID-19 pandemic, it also delivers an “a-ha” moment for everyone, Tschetter said.

“We’re now feeling the isolation that people with disabilities feel on a regular basis, as well as the feeling

of not being able to do the things we want to do and to see people whenever we want,” Tschetter said. “These are lessons in empathy that are important for DSPs and today’s environment provides important context around these issues.”

SOCIAL MEDIA SPOTLIGHT



Featured on ICI's [Facebook](#) page on April 23, 2020

"If you provide direct support to people with disabilities, please complete this survey. Your answers, which will be anonymous, will help us better understand how to support and keep safe DSPs and the people you support." [#DSPsAreEssential](#), [#COVID19](#) <http://z.umn.edu/dsp-covid19>

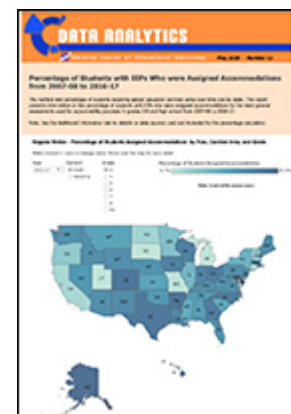
Image description: Computer screen containing the headings "Survey" and "Providing Support During the COVID-19 Pandemic." The screen also shows the logos of ICI and NADSP.

NEW RELEASES

NCEO Data Analytics 13: Percentage of Students with IEPs Who Were Assigned Accommodations from 2007–08 to 2016–17

Authors: [Yi-Chen Wu](#), [Sheryl Lazarus](#), [Deb Albus](#), and [Kristin K. Liu](#)

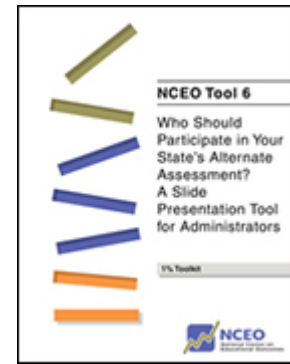
[This interactive report](#) presents data on the number and percentage of students receiving special education services who were assigned accommodations for the state general assessments used for accountability purposes in grades 3–8 and high school from 2007–08 to 2016–17. This report displays data on content area differences, grade level differences, trends over time, accommodations vs. performance, and state profiles. Published by ICI's National Center on Educational Outcomes (NCEO).



NCEO Tool 6: Who Should Participate in Your State’s Alternate Assessment? A Slide Presentation Tool for Administrators

Authors: [Maureen E. Hawes](#), [Martha L. Thurlow](#), Cesar D'Agord, [Charity N Funfe Tatah Mentan](#), [Kathy J. Strunk](#), and [Sheryl Lazarus](#)

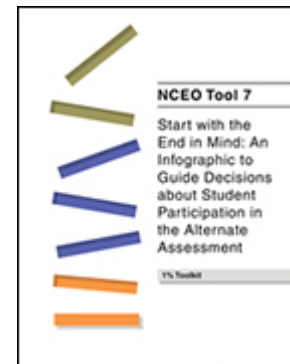
[This slide presentation tool](#), which is part of [NCEO's 1% Toolkit series](#), is designed to support the needs that administrators have for brief but substantive information about who should participate in the state's alternate assessment on academic achievement standards (AA-AAAS). In addition to serving as an information resource for administrators, it may be used for in-person or webinar trainings for educators, and as a handout for educators and parents. Developed during NCEO's Peer Learning Group 3 (PLG 3), they highlight the purpose of the AA-AAAS, the implications of a student taking the AA-AAAS, strategies for talking with parents, and identification of students who should participate in this assessment. The slides may be customized. Published by NCEO.



NCEO Tool 7: Start with the End in Mind: An Infographic to Guide Decisions about Student Participation in the Alternate Assessment

Authors: Katherine Nagle, [Charity N Funfe Tatah Mentan](#), Anthea Brady, [Kathy J. Strunk](#), [Martha L. Thurlow](#), and [Sheryl Lazarus](#)

[This infographic tool](#), which is part of [NCEO's 1% Toolkit series](#), is designed to provide guidance about IEP team decision making for a student's participation in the state's alternate assessment on academic achievement standards (AA-AAAS), which is meant for a very small number of students with significant cognitive disabilities. Developed during NCEO's Peer Learning Group 3 (PLG 3), the tool explains how this important decision can affect the future opportunities available to a student with a disability. The infographic may be given to teachers in IEP trainings, provided to parents and guardians to read before an IEP team meeting, and used to talk with parents and guardians during an IEP team meeting. Published by NCEO.



Bringing Employment First to Scale: Supports Planning, Finding Tasks and Jobs, and Support After Hire

Authors: [Kelly Nye-Lengerman](#), [Amy L Gunty](#), John Butterworth, Alberto Migliore, Oliver Lyons, Jill Eastman, and Agnes Zalewska

[This series of one-page briefs](#) highlights the effective employment practices of employment consultants who promote the Employment First philosophy. *Employment First* sees employment as the preferred outcome for people with disabilities and encourages those supporting people with disabilities to promote employment as an outcome first, before considering alternatives. Employment First means integrated settings in the community with the same wages and benefits as people without disabilities. However, the community employment rate among job seekers with



disabilities remains low while rates of facility-based and non-work have risen. Employment First aims to reduce this gap and these briefs offer employment consultants practical advice on how to accomplish that. The last three briefs of this five-issue series are: [Supports Planning](#), [Finding Tasks and Jobs](#), and [Support After Hire](#). All issues are published by [ThinkWork!](#), a partnership of the University of Massachusetts Boston's Institute for Community Inclusion and the Research and Training Center for Community Living here at the University of Minnesota's Institute on Community Integration.

Book Chapters Published

Various ICI researchers authored chapters in [Choice, preference, and disability: Supporting self-determination across the lifespan](#) (2020), a book published by Springer in London, England, and edited by [Roger J. Stancliffe](#), Michael L. Wehmeyer, Karrie A. Shogren, and [Brian H. Abery](#). Stancliffe wrote the chapter, "Choice availability and people with intellectual disability," and along with Abery and others, co-authored, "Policies and practices to support preference, choice, and self-determination: An ecological understanding." Abery and [Lynda L. Anderson](#) wrote, "Preference, choice, and self-determination in the healthcare context." [Renáta Tichá](#) and others authored, "Choices, preferences, and disability: A view from Central and Eastern Europe." [John G. Smith](#) was among the authors of, "Reflections on choice: The stories of self-advocates."

EVENTS

Event Changes, Postponements, and Cancellations Due to Coronavirus

The COVID-19 pandemic has made it unsafe for people to gather in large groups. As a result, many ICI-related events have been changed, postponed or canceled, including the AAIDD Annual Meeting 2020, originally scheduled for June 1–4 in Pittsburgh, PA, and the ADA 30th Anniversary, originally scheduled for July 27 in St. Paul. Watch for other event changes in the weeks and months to come.

Check & Connect Mentor Training

August 19–20

University of Minnesota Continuing Education and Conference Center

1890 Buford Avenue

St. Paul, MN



[Check & Connect](#)'s two-day Mentor Training provides participants with the information, competencies, and skills needed to be an effective Check & Connect mentor at their local site. Check & Connect is an ICI-developed intervention used with K–12 students who show warning signs of disengagement with

school and who are at risk of dropping out. At the core of Check & Connect is a trusting relationship between the student and a caring, trained mentor who both advocates for and challenges the student to keep education salient. This training is designed for those assigned the role of Check & Connect mentor as well as those interested in Check & Connect mentoring principles and practices. Check & Connect site coordinators and administrators are also encouraged to attend. [Registration is open.](#)

STAFF UPDATES

Susan O'Neill: On April 8, [O'Neill](#) co-facilitated a workshop on, "Using your WRAP(r) Wellness Tools and Turning Negative Thoughts into Positive Ones," with Stan Schmidt from Community Integrated Work Program. The workshop encouraged people living with intellectual and developmental disabilities and their staff (many of whom have developed their own Wellness Recovery Action Plan) to consider accessing this wellness tool to stay well during the isolation of COVID-19. O'Neill is also editor of "Health Insurance Portability and Accountability Act (Version 2.1)," a course that was updated on April 20 for DirectCourse, which is a partnership of ICI's Research and Training Center on Community Living (RTC-CL) and Elsevier, a world-leading provider of scientific, technical, and medical information.



Jennifer Hall-Lande and Amy Esler: [Hall-Lande](#) (left) and [Esler](#) (right) presented on the Minnesota Autism Prevalence project and the Learn the Signs, Act Early project to the EIDBI Learning Collaborative on April 16 and at the Autism Society of Minnesota virtual conference on April 17. Hall-Lande presented alone on these projects at the Minnesota Department of Health Lunch and Learn on April 14 and was interviewed about the early identification/intervention of autism during the April 20 podcast of *Mom Enough*. Also, "Disparities in Documented Diagnoses of Autism Spectrum Disorder Based on Demographic, Individual, and Service Factors," an article that Hall-Lande and Esler published last year in *Autism Research*, was recently selected by the Interagency Autism Coordinating Committee as one of 2019's top research advances in autism research.



Amy Hewitt: On April 17, *MinnPost* published, "[It's time to recognize the essential value of direct support professionals.](#)" an opinion piece written by [Hewitt](#). And on April 28, she and [Kelly Nye-Lengerman](#) presented an AAIDD webinar titled, "Critical Issues in Community Living: Supporting High Expectations and Workforce Investment."



Barb Kleist: On April 23, [Kleist](#) presented the webinar, "Professionalizing DSPs and Their Career Path." It is part of a series of webinars on best practices in implementing workforce tools and strategies that are presented by the Employment and Community First CHOICES Workforce QuILTSS Initiative, which is sponsored by TennCare, TNCO, and ICI. On May 1, Kleist's \$10,000, 16-month CEHD Global Signature Grant began for her project, Journey Toward Inclusion for All: A University of Minnesota—Zambia Disability Collaboration.



Danielle Mahoehney: On April 24, [Mahoehney](#) was appointed to the Interagency Employment First Advisory Committee, which is part of the Minnesota Department of Employment and Economic Development (DEED) – Vocational Rehabilitation Services (VRS) and State Services for the Blind (SSB). The committee is composed of 14 volunteers who represent the perspectives of diverse stakeholders from around the state. The committee provides strategic advice and consultation to DHS and DEED-VRS/SSB as they work together to implement Minnesota’s Employment First policy and fulfill its agreements in the [September 2019 joint memorandum of understanding](#).



Katrina Simons: On April 27, *The Wall Street Journal* pictured and profiled [Simons](#) in the feature story, "Demand for In-Home Care Rises During Coronavirus." The article shows how the pandemic has increased the already-high turnover among direct support staff, which worsens home-care arrangements for seniors and people with disabilities like Simons, who lost four staff members within 48 hours.



Kelly Nye-Lengerman: On May 1, [Nye-Lengerman](#) was the keynote speaker for the last session of the 2019–2020 Employment Capacity Building Cohort, which promotes competitive integrated employment for graduates with disabilities, ages 19–21. On May 8, Nye-Lengerman, along with Maya Cox from Public Consulting Group, presented the National APSE webinar, "Align Your Stars: Manage Your Journey Ahead." On May 13, Nye-Lengerman joined partners from National APSE (which promotes competitive integrated employment for people with disabilities) and My Quillo in a webinar titled, "Surviving to Thriving: New Tools/Same Values." On May 20, Nye-Lengerman will leave ICI to become director of the New Hampshire Institute on Disability at the University of New Hampshire in Durham. Like ICI, the New Hampshire Institute on Disability is a University Center on Excellence in Developmental Disabilities.



Sherri Larson: On April 29, the U.S. Department of Labor’s Office of Disability Employment Policy (ODEP) announced funding for, “Improving Outcomes for Transition Aged Youth on SSI by Delaying Application of SSI’s Substantial Gainful Activity Eligibility Criteria from Age 18 to 22,” a project led by [Larson](#) and Judy Geyer. This was one of only 12 awards granted nationwide under ODEP’s Supplemental Security Income (SSI) Youth Solutions initiative, which aims to identify and evaluate strategies for improving employment outcomes for young adults from ages 14 to 24 who apply for or receive SSI.



Adele Dimian, Jessica Simacek, and Jennifer McComas: On May 13, [Dimian](#), [Simacek](#), and [McComas](#) presented, “CEHD Remote Research Roundtable: Applications of Telehealth Approaches for Research and Training.”

ALUMNI UPDATE

Katharine Hill: University of St. Thomas has tapped Katharine Hill to become director of the School of



Social Work in the new Morrison Family College of Health. Hill, a former ICI staffer, currently directs St. Thomas' BSW program and will formally step into the new role in July.

In a welcome letter announcing the appointment, MayKao Y. Hang, founding dean of the College, praised Hill's commitment to advocacy, along with her policy and research experience.

"Hill's passion for social change to benefit those most disadvantaged in society and her commitment to nurturing the bonds of human connection to advance the common good makes her the perfect person to lead us courageously into the future," Hang said.

The College brings together multiple disciplines within the University, including public health, exercise science, social work, and psychology, with plans to create a nursing school.

"It is really thinking about health more holistically, inclusively, and globally than a traditional college of health might," Hill said. "Physical health is a part of it, but we've been intentional about setting a broader definition of health that includes communities, economic systems, and schools, the social determinants of health."

Social work plays a critical role in bridging those disciplines, she said.

"We won't have healthy individuals if we don't have healthy communities," she said. "We're building a new system of health that includes both the personal and the environmental and exploring what role social work has in that system. Knowing I'll be part of shaping that is really intriguing and exciting to me."

Hill arrived at St. Thomas in 2009. She holds masters' and doctoral degrees from the University of Minnesota. From 2002 to 2006, she was program coordinator for ICI's Connecting to Success, a multi-state collaboration to provide mentoring to adolescents with disabilities, among other projects.

Traci LaLiberte, executive director of the University of Minnesota's Center for Advanced Studies in Child Welfare, who sat on Hill's dissertation committee, praised Hill's research into the gaps in disability services in the child welfare system.

"One of the things I appreciate most in Katharine is her ability to understand complex systems and to translate that research into practice. She's quite skillful at that," said LaLiberte.

ICI provided foundational skills in grant writing and in developing partnerships, skills she continues to use today, Hill said.

"I learned how to include the thinking of all the partners in building a product or working toward an outcome," she said. "You can't just say, 'Here's how we're going to do it.' You have to think collaboratively and bring everyone's ideas forward."

Beyond the practical skills, Hill cited some intangibles she picked up along the way.

“A lot of how I think about leadership was formed by my work for David [Johnson, ICI’s director during her tenure]. He really modeled letting people bring their best talents to work. He created a format where people could be creative and pursue their interests but he kept us more or less pointed in the same direction, and that’s tricky business,” she said. “Come back and ask me in a couple years if I’m managing to do it, but thinking like that is something I learned at ICI.”

This email was sent to ICI staff by Institute on Community Integration, 109 Pattee Hall, 150 Pillsbury Drive SE, Minneapolis, MN, 55455, USA. The University of Minnesota is an equal opportunity educator and employer.

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