

ACT OLMSTEAD ACADEMY, CLASS OF 2017

2017 DISABILITY INTEGRATION PROJECTS

A REPORT TO THE COMMUNITY

DECEMBER 15, 2017

DECEMBER 2017

*The Olmstead Academy is a program of the
ACT Center for Disability Leadership*

ACT
CENTER for DISABILITY LEADERSHIP
ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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Advocating Change Together
 Advocating Change Together (ACT) is a grass-roots disability rights organization run by and for people with developmental disabilities. ACT's mission is help people across disabilities see themselves as part of larger disability rights moment and make connections to other civil and human rights struggles.

ACT Olmstead Academy
 The Olmstead Academy is a program of ACT. The 2017 class was funded with the generous support of the Minnesota Department of Human Services. Thanks also to the Minnesota Department of Employment and Economic Development for program supports as well as providing a meeting space for the Academy.

ACT Center for Disability Leadership (on Intellectual and Developmental Disabilities) incorporates a number of ACT's longstanding programs, as well as new ones, into a structured framework for equipping groups to understand disability equality, make it happen, and inform others. In addition to the Olmstead Academy, ACT Center for Disability Leadership includes Self-Advocates Minnesota (SAM) network, and ACT's new, multi-level Disability Equality Training Series.

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EVENT PROGRAM

Report to the Community

ACT Olmstead Academy Class of 2017
Public event hosted by Judge Donovan Frank

December 15, 2017

Devitt Ceremonial Courtroom
Warren E. Burger Federal Building & United States Courthouse
316 North Robert Street
St. Paul, MN

1:00 p.m. Program

Opening procession: Academy participants
Welcome: Judge Frank
Academy overview: Mary Kay Kennedy
Presentations of project results: Seven regional teams
Comments by Judge Frank
Closing song

2:00 p.m. Reception

Guests are invited to join Academy participants for project exhibits and light refreshments in the Jury Assembly Room (also on the 1st floor)

Soon and Very Soon

Soon and very soon we'll have human rights for all
Soon and very soon we'll have human rights for all
Soon and very soon we'll have human rights for all
All together, all together, human rights for all

2. Living side by side we'll have human rights for all

3. We will not give up. We'll have human rights for all

by Andre Crouch, with new lyrics by ACT

EXECUTIVE SUMMARY

Building self advocate leaders by working on projects to advance community integration.



TIMELINE

January 2017 through December 2017

ACADEMY GOAL

Create a culture within Minnesota where self-advocacy is a foundational piece in the state's Olmstead plan and self-advocates are playing meaningful roles in its implementation.

ACADEMY STRUCTURE

The ACT Olmstead Academy is a 12- month program featuring eight days of classroom sessions, and 9 months of required field work on Disability Integration Projects. Participants enroll as teams of three

(two self-advocates, one ally) from around the state. Teams learn leadership skills and organizing tools for creating change to advance community integration. Each team develops and implements a project in their home community.

2017 PROGRAM FEATURES

- Team-based participation – two self-advocates and one ally.
- Participatory, innovative, proven methods of Popular Education theory.
- Mentors assist each team to create and complete project.
- Each team receives funds to implement a project in their community.

- Participants build relationships with key state allies during “dinner with leaders.”

DISABILITY INTEGRATION PROJECTS

Each team chooses and leads a local project to advance integration for real people in their community. See pp. 6-19 for results of each of these seven projects.

LONG-TERM IMPACT

Of projects launched by Classes One and Two, over half of the teams have found ways to continue their successful efforts, including using Uber, community gardening, event planning and volunteering in the community.

EXECUTIVE SUMMARY

“Congratulations ACT Olmstead Academy Class Three! You are showing us, through your example, how to be part of community.”

*Alexandra Bartolic, Director | Disability Services
Minnesota Department of Human Services*



PROGRAM ASSESSMENT

Strategic Consulting and Coaching (SCC) Program effectiveness assessment is now underway with final analysis after the December review of 2017 Disability Integration Projects. SCC consultant facilitated a focus group/discussion with 20 participants from the Olmstead Academy. The consultant also interviewed the participants with their displays of the various Disability Integration projects that will be taking place around the state.



Preliminary findings indicate that participants enthusiastically embraced the leadership experience. There were many learnings which will be elaborated on in the final report. Listed below are the themes for the key findings.

Advocacy- People with disabilities have the power to be their own advocates.

“As people with disabilities we have the right to make decisions about our own lives.”

“We can speak up for ourselves and others in the community.”

“We are the voice of people who cannot speak for themselves.”

Community-Everybody helping each other is important to getting

things done in the community.

“As a team of advocates our voices will be heard.”

“We can make our communities better for everyone.”

Action- taking action and standing up for their rights was important to attendees.

“People with disabilities deserve the same pay as other people with the same jobs.”

“We will show by our actions that people with disabilities have rights.”

[Note: An additional assessment is scheduled to evaluate the process and outcome of the seven Disability Integration Projects. Results will be posted on ACT's website.]

SAM NORTHEAST TEAM

Find eight people with a community job and help them socially connect more deeply with co-workers



WHERE WE LIVE:

Duluth

WHO WE ARE:

Shawn Stanich

Meredith Kujala

Mentor: Melody Johnson

WHAT WE DID

As more and more people with disabilities get competitive, integrated jobs, we wondered if they are also included socially at work. For most typical people, work is not only a job but also a place full of social relationships: coworkers eat lunch together, laugh, celebrate birthdays, and banter about last night's game. We set out to find people with disabilities who have community jobs, find out if they feel socially included at work, and help address a lack they feel, if any.

WHAT HAPPENED

We met with 50+ individuals who have job coaches, interviewed 10 of these individuals in depth, interviewed 3 job coaches, 2 employers, and our 2 agency partners who employ job coaches. Our team first identified some peer mentors--people with disabilities who already have good social relationships with their co-workers. We arranged for this group of people to both provide a model of what others could work toward, and even meet with the people with disabilities who are not included and an ally.



SAM NORTHEAST TEAM

"We found many people unhappy because their job coach operates like a babysitter."

Meredith Kujala



WHAT WE LEARNED

People were mostly satisfied with their level of work friendships. When we started this project, we anticipated that we'd talk to a lot of people with disabilities that weren't socially integrated in their jobs. But we didn't hear that very often. Most of those we talked to love where they work and get what they want socially (some wanting a lot, others only a little).

BARRIERS

The barrier we heard most about was not social isolation on the job, but rather oppressive job coaches. Four of ten interviewees felt their job coach inhibited rather than

enhanced their work and their social integration at work. Many felt they were being "babysat" by the job coach.

NEXT STEPS

We have decided to shift issues and take on the issue of job coaching. People who have a job coach have ideas of how they can best be supported. So we are now talking to these people about what they envision in a "perfect" job coach and how can coaches can be retrained to be better integrators. We will then be partnering with two provider agencies, bringing this new information, looking together at their programs and revising how the job coach operates to best support people.

We are looking for a way to share what we have learned with all agencies who provide job coaches. Videos that feature people demonstrating what a "perfect" job coach looks like in action might be one way to pass this information along.

OWAKIHI TEAM

Offer a tour of homes to inspire people in group homes-- and guardians --by seeing how others with disabilities are living independently



WHERE WE LIVE:

Inver Grove Heights

WHO WE ARE:

- Jessica Ackerman
- Becca Stevenson
- Jessica Skrypez
- Mentor: Beth Fondell

WHAT WE DID

The self-advocates on this team live on our own, in our own apartments and we love our independence. But we know people who want independent living but don't have it. We want to help by showing them examples of what is possible for them.

So we organized two bus tours to visit a variety people living independently in their actual homes. First, we recruited hosts: people who would be willing to have others tour their home. Then we recruited riders: people who would like a different living arrangement, and their guardians. We made arrangements

with a technology broker who would demonstrate a variety of devices to assist people living on their own.

WHAT HAPPENED

Eight people came on the first tour and 16 on the second. Our rented coach bus brought people to several different properties run by some local providers. Afterward we had everyone over for dinner and chatting. Two experts talked: one about different funding and program options related to independent living and the other about supportive technology that can help people feel safe in their apartments. One concrete follow-up result: one family contacted Owakihi after the event to set up an intake for services to move their daughter into her own apartment.



OWAKIHI TEAM

“People really enjoyed seeing the different housing options, hearing from the people actually living there.”



WHAT WE LEARNED

People definitely want to live on their own. Many people who had never thought about it before were really excited to see some of the products that can go into people’s homes to support them.

Guardians/families were also supportive of this idea of independent living. Many stated that independent housing is something they will be pursuing in the near future.

Our project was a lot of fun. We got to meet a lot of great people and showed them some fine examples of individualized living.

Recruiting takes work: For each tour, twice as many people signed up compared to those who actually came on tour day.

BARRIERS

Money is a big barrier to independent living. One bedroom apartments rent for about \$1000 per month and the management companies require renters to earn two or three times the rental figure in income to qualify to rent their apartment. This means people must have a roommate or two, or they must live in an area with a lower standard of living.

NEXT STEPS

We would love to find a way to continue to doing this tour several times a year. People really enjoyed seeing the different options, hearing from the people actually living through it, and learning about supportive technology.

In a perfect world everyone who is living at home with their families or in a group home would be given the chance to see what it is like--and how they can be successful --in their own apartment. There would be more options of affordable housing and more understanding landlords.

MAINS'L TEAM

Offer a tour of homes to inspire people in group homes-- and guardians --by seeing how others with disabilities are living independently



WHERE WE LIVE:

Monticello

WHO WE ARE:

Don Neu

Dustin Anderson

Ashlie Arguelles

Mentor: Erin Henry

WHAT WE DID

One of our team members lives on his own, and another would like to live on his own. But to live independently, we need to have supports that are tailored to each person. And we need to have our parents/guardians on board with whatever plan we devise. Well-meaning parents/guardians often prioritize safety over independence, despite our wishes for deeper integration.

So, to inspire both self-advocates and their guardians toward change, we set up a home tour, where

participants could ride a bus and see how several people with disabilities are living successfully on their own.

WHAT HAPPENED

We planned for one tour. We arranged three stops, showing living situations ranging from complete independent living to supported living situations. Our team answered questions about finances, walkable shopping options, and available transportation services. One tour site was a duplex where a person lived fairly independently upstairs and staff live downstairs and are available if needed at night. To recruit riders, we reached out to dozens of self-advocates in our



MAINS'L TEAM

"I know my parents want me safe because they love me, but there should be a way for me to be both safe *and* happy!"



WHAT HAPPENED, CONT.

community over the course of eight weeks. And we rented a bus.

Despite all this preparation, the turnout was disappointing. The only riders on the bus tour were our three team members and one other person. The problem was not lack of self-advocate interest. We found many self-advocates who told us they'd like to come on the bus tour. But then when they talked with their guardians, the guardians said no.

WHAT WE LEARNED

Our project proved to be difficult for one big reason--guardians. Many people wanted to join the tour, but their guardians stopped them from coming. The guardian said they could not move out on their own. The guardians clearly perceived this

information-gathering tour as a threat to the status quo and their control. Now as we look back over the project we see that there is no straight line that takes a person who wants to live on their own to an apartment where they actually are doing so. Even building participation in a simple bus tour needs to start with anticipating guardian resistance and strategizing accordingly.

BARRIERS

Guardians are barriers to living more independently. Guardians are barriers to merely learning about what options exist in the community. Period.

NEXT STEPS

If we were to do this again we might give the tour a less threatening description, perhaps bill it as a fun, progressive supper to meet peers living out in the community. We would present even more living options; for example, we would show two people living together as roommates and an apartment where a person had higher support needs.

SAM NORTHWEST TEAM

Assist eight people who are lacking a basic right to take one concrete step to get it: get a job, make a date or set their own schedule



WHERE WE LIVE:

East Grand Forks

WHO WE ARE:

Adam Kendall

Heidi Cartier

Carla Tice

Mentor: Corbett Laubignat

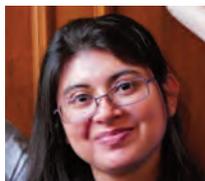
WHAT WE DID

We know that many self-advocates in our area face barriers to full integration. We set out to find six peers and help them to get over specific barriers they face. We named our project the Barrier Busters.

WHAT HAPPENED

Thanks to the longevity of our self-advocacy group in town, we have our finger on the pulse of people's life situations. We quickly found six people who had a human rights barriers we might address. The

starting point for each person was talking over a root beer float. "Let's talk about that problem you said you wanted to work on", "What's the underlying right?", and "What's a doable course of action?" We then took action, with reasonable success. For example, one person was having roommates come into his room when he wasn't there. We discussed privacy and the recent federal ruling that people in group homes may have a lock on their door. The person went to his group home staff, told them of his right to privacy and need for a lock and one was procured. Another example of a more difficult issue: one person had worked well at her jobs for months, (years) with minimal job coach assistance. New regulations came



SAM NORTHWEST TEAM

"Our group's long-term relationships in the community are the #1 reason for our project's success."



WHAT HAPPENED, CONT.

from DHS and now the person has a job coach hovering over her constantly. It has been difficult to find the regulation and the team is bringing in other experts (the Disability Law Center), to sort through if the regulation is being interpreted properly. This issue is still unresolved.

WHAT WE LEARNED

- 1) People with disabilities often do not know that a rights issue might be behind their problems. Realizing this give people power.
- 2) Our long-term relationships in the community are the #1 reason for our success. In the Northwest area of the state, we have a strong self-

advocacy group that is well known, respected and long standing. Because of those long term relationships, people feel safe in sharing their problems. For example, one woman told us of her child and other relatives she had not talked to in many years. We have known this woman for a long time, but did not know she had not had contact with her family or that she had been married and had a child. We don't think she would have asked for Barrier Buster help if she did not have a good relationship with us. We were able to find the relatives and put the woman in touch with them.

3) We have a simple structure that really works well. Rather than start

with a big meeting to bust a barrier, we start with a root beer float; and we often can get quick, satisfying results.

4) The more we have real success with real people in our lives, the more we see ourselves as human rights workers. We feel proud that we are making a difference in the lives of our peers.

NEXT STEPS— Our team will continue to bust barriers in 2018. As we network at self-advocacy events and in the community, new barriers will come to light. And when they do, we'll order a root beer float, listen, and take action together.

LUTHERAN SOCIAL SERVICES TEAM

We set out to demonstrate that with new technology, we could have more time by ourselves.



"We feel run over by staff."

WHERE WE LIVE:

Crosby / Baxter

WHO WE ARE:

David Petersen

Matt Borgstrom

Debra Olander

Mentor: Patrick Mitchell

WHAT WE DID

After learning about our rights at the Olmstead Academy, we knew that our integration project would focus on improving our own lives: having more control over our time and our space. Two of us live in the same house and want more time by ourselves without staff present. We feel "run over" by staff. For us, the right of integration means being treated like equals: we want control and privacy in our lives, just like others in society have.

WHAT HAPPENED

We brought together friends, advocates and provider staff (LSS) to make a plan: remove night staff so that all of us in our house would be on our own at night. We called the plan, "Leave Me Alone, I'll Be Fine." Security cameras would be installed to monitor the house for safety, and a nearby LSS home would provide backup emergency coverage. The team and all at LSS were excited about the project and ready to go when they talked to the last group of decision makers: the parents. One set of parents/guardians would not give approval--they felt their son would not be safe. Plan A aborted. There was disappointment and sadness.



LUTHERAN SOCIAL SERVICES TEAM

"As a staff person, the ACT Olmstead Academy opened my eyes to how to respectfully support someone and honor their human rights."



PLAN B

So we got together again and had conversations on how we could make some alone time happen. Three of the people who live at this home, including the team members, went to our annual meetings and said we wanted four hours of time alone. We got it; now there are several days a week when no staff are scheduled. Now each of us has privacy to play the guitar and sing or dance to Wii Fit without an audience. We like being in our home when it is totally quiet.

WHAT WE LEARNED

Shifting gears after disappointment is an important skill. We found an alternate plan that helped us salvage some progress toward the values of Olmstead.

Educating staff on human rights has a big impact. This project has brought new understandings and a big behavior shift for staff and our provider organization. Knowing the rights of people has opened staff's eyes on how to respectfully support people. They are better able to really listen to the people they serve and then offer positive options that help people balance not only safety but also independence.

NEXT STEPS

We would like to move forward with the "leave me alone" theme and advocate for getting more time in the community by ourselves without staff—going where we want when we want.

SAM SOUTHWEST TEAM

“We found that guardians and staff were thwarting self-advocates from integrating in the community.”



WHAT HAPPENED, CONT.

- One person is now calling Bingo at the local Senior Residence
- Another person is getting assistance from a community member as she studies for her learners permit.
- Another person wanted to go to church and two pastors are working to find him transportation to services.
- Some community leaders began reaching out for coffee with self-advocates.

WHAT WE LEARNED

Our project clearly demonstrates that when people with disabilities

socialize with people in the larger community, these new relationships lead to new opportunities and continuing social connections: both sides benefit. We also learned that patience and perseverance pays off when recruiting; the second dinner was better attended than the first.

BARRIERS

Recruiting was hard. Guardians and staff were thwarting self-advocates from integrating in the community--both before and after the events. Two self-advocates had guardians who would not allow them to attend our dinner. One self-advocate had a staff who said she (the self-advocate) had already used her allotted “alone time” and could not

attend the dinner. After the two dinners, as a few community leaders began reaching out for coffee dates with self-advocates, they found that sometimes the guardian would say "No," or perhaps "I'm coming to coffee too". The project shows that staff policies and guardians who are unwilling to moderate their stance are often barriers to a person having a full life in the community.

NEXT STEPS

Some of our results (see bullet points above) are still emerging. We expect these connections to continue bearing fruit, to deepen our integration and interdependence here in this small southern Minnesota town of ours.

MERIDIAN TEAM

Host two dinners, at our group homes, to build connections with our next door neighbors



WHERE WE LIVE:

Anoka / New Brighton

WHO WE ARE:

Cassidy Link

Jason Gysberrs

Barbara Thomas

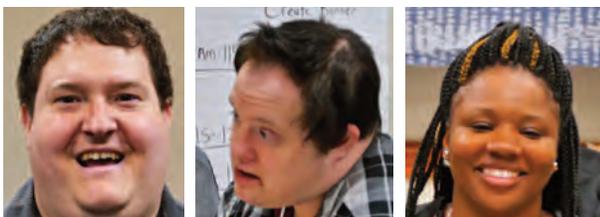
Mentor: Pat Salmi

WHAT WE DID

We live in group homes in suburban neighborhoods, and are isolated from our next-door neighbors. They don't know us, we don't know them. Since we love to cook and eat, we decided to host a neighborhood BBQ at each of our homes. To help the dinners be successful, we did extensive planning and practice in advance, including role-plays and a trial meal. And of course, we shared the work of cooking and serving.

WHAT HAPPENED

To prepare both staff and ourselves, we met with a consultant from Hamline University's Making Waves Theater Group for Social Change, who designed and led us in some role-plays. We practiced what we would say when guests arrived, how we would keep conversations going, and staff practiced their role (support, not leadership; act as if it's our home, not theirs). Before the BBQ, we did a trial run: we hosted a practice meal with family members. Lucky we did; we found that one of the grills did not work. Repairs were made.



MERIDIAN TEAM

“Since the dinners we hosted, we’re getting a lot more waves as we walk around the neighborhood.”



WHAT HAPPENED, CONT.

The meals were a hit. Each BBQ had 15 or more people: us, our staff, and four to five neighbor families. With good food, (hot dogs, burgers, chips, pop, veggies, dessert), there was good conversation, even a little volleyball. Neighbors were so happy for the invitation and there was lots of talk about how life is so busy these days that we don't slow down to know our neighbors.

WHAT WE LEARNED

The role-play practice was really important. Because of HIPPA fears, staff didn't know what was allowed in casual conversation: the practice put them at ease. Self-advocates took a much stronger lead in the socializing, thanks to the prior role-plays. There

were a few awkward moments that came up during the BBQs and it helped that we had anticipated them.

The simple fact of having had a meal together has quickly strengthened our connections in the neighborhood. One neighbor now goes out of her way to come over and say "Hi."

BARRIERS

This neighborhood isolation is not unique to people with disabilities--people these days don't know their neighbors. But we noticed further forces in play. The staff, with high turnover and rotating shifts, have no particular investment in the neighborhood or in noticing this need of residents to connect. Add to that

HIPPA concerns, perhaps making staff reluctant to connect with neighbors.

We also faced stigma: one of our houses had an incident 8 years ago, and still today neighbors are suspicious and even a bit fearful, supported perhaps by the deep seated stereotype of disability as something to be feared.

NEXT STEPS

Everyone is proudly planning to make the BBQs an annual event.

Also, after experiencing the transforming power of role-play, our service provider realized that this type of training would be important for their whole staff to receive, and are exploring a further partnership with the ACT to make it happen.

NOTE FROM THE DIRECTOR

The Class of 2017 is the third class of ACT's Olmstead Academy. Twenty integration projects have now been launched since we started in 2015. Dozens of emerging leaders have take part in each project. The Academy and its projects have set the stage for hundreds of people with and without disabilities to work side-by-side, building more inclusive and stronger communities.

People clearly leave the ACT Olmstead Academy experience asserting, "As people with disabilities, we have the right to make choices about our lives." When asked what stops them from getting what they want out of life, the response is overwhelmingly related to a power-over dynamic with service providers, parents and guardians. As one self-advocate said, "You know, my life would be pretty good if it weren't for my staff and parents." It is a tough road for self-advocates to carry the message of disability as a human and civil rights issue to those who see their primary role as keeping their loved one or client safe and away harm's way. We all agree that being safe is a good thing. But when safety is the lens from which life decisions are made, it can limit options and create a narrow view of what is possible.

Service providers, families and guardians are the gate-keepers to opportunity. These gate-keepers often have a world-view that does not include disability as a human and civil rights issue. Many of them stand in the way of allowing self-advocates to rise to a higher level of liberation. As more people with developmental disabilities learn about and begin to advocate for their rights, it is becoming increasingly important that gate-keepers also change: to learn more about the tenets of human and civil rights and to start building knowledge and skills to support people to achieve more integration. This change must start with changing the frame within which gatekeepers view their authority to give the thumbs up or down to the dreams and goals of the people they love/work with.

The work ahead is daunting, but it is also very exciting. Minnesota is poised on the brink of a huge opportunity for advancing independent living and dignity for people with disabilities. ACT, and its Olmstead Academy, are very interested in conversation around the work that needs to be done to create a culture of disability inclusion. If you have ideas, please invite us for coffee! We'd love to talk and plan together.

Mary Kay Kennedy, Executive Director



OLMSTEAD ACADEMY LEADERS

Program Design

Mary Kay Kennedy
Bret Hesla

Program Facilitation

Mary Kay Kennedy
Bret Hesla

Session Leaders

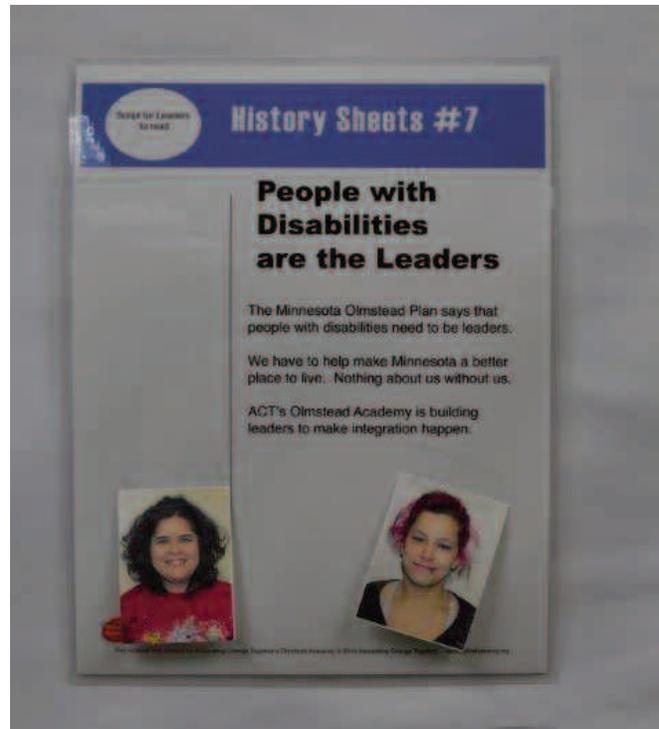
Mary Kay Kennedy
Bret Hesla
Mary Fenske: Self-Advocates Minnesota
Linda Breitag: Professional artist/musician
Carolyn Levy: Hamline University
Laura Mann Hill: Hamline University
Patrick Mitchell: Advocating Change Together
Katie Thune: Yoga Calm
Carla Tice: Self-Advocates Minnesota
Maggie Treichel: Self-Advocates Minnesota
Lynne Lindholm: Catering
Deni Berigan-Pirro: Catering
Paul Rogers: Photography
John Anderson: Photography
Cheryl Jensen: Program evaluation

Team Project Mentors

Melody Johnson, Olmstead Implementation Office
Corbett Laubignat, Access Consultant, Univ. of Minn.
Les Bauer, MN Quality Council
Patrick Mitchell, Advocating Change Together
Pat Salmi, Access Design Consultant
Erin Henry, Center for Independent Living
Beth Fondell, Institute on Community Integration

Dinner Hosts

Rebecca Dosch Brown: Minnesota Leadership Education in Dis.
Carol Anthony: Dept of Human Services
Deb Holtz: Disability Rights Activist
Katie and Dusty Thune: Arts and Disability Educators
Rick Cardenas: Independent consultant
Jo Erbes: Minnesota Consortium for Citizens with Disabilities
Sean Burke: MN Disability Law Center
Joan Willshire: MN State Council on Disability
Darlene Zangara: Olmstead Implementation Office
Alex Bartolic: MN Dept. of Human Services
John Anderson: MN Dept. of Human Services
Pat Siebert: Disability Law Center
Lori Dablow: Service and Standards Supervisor, DHS

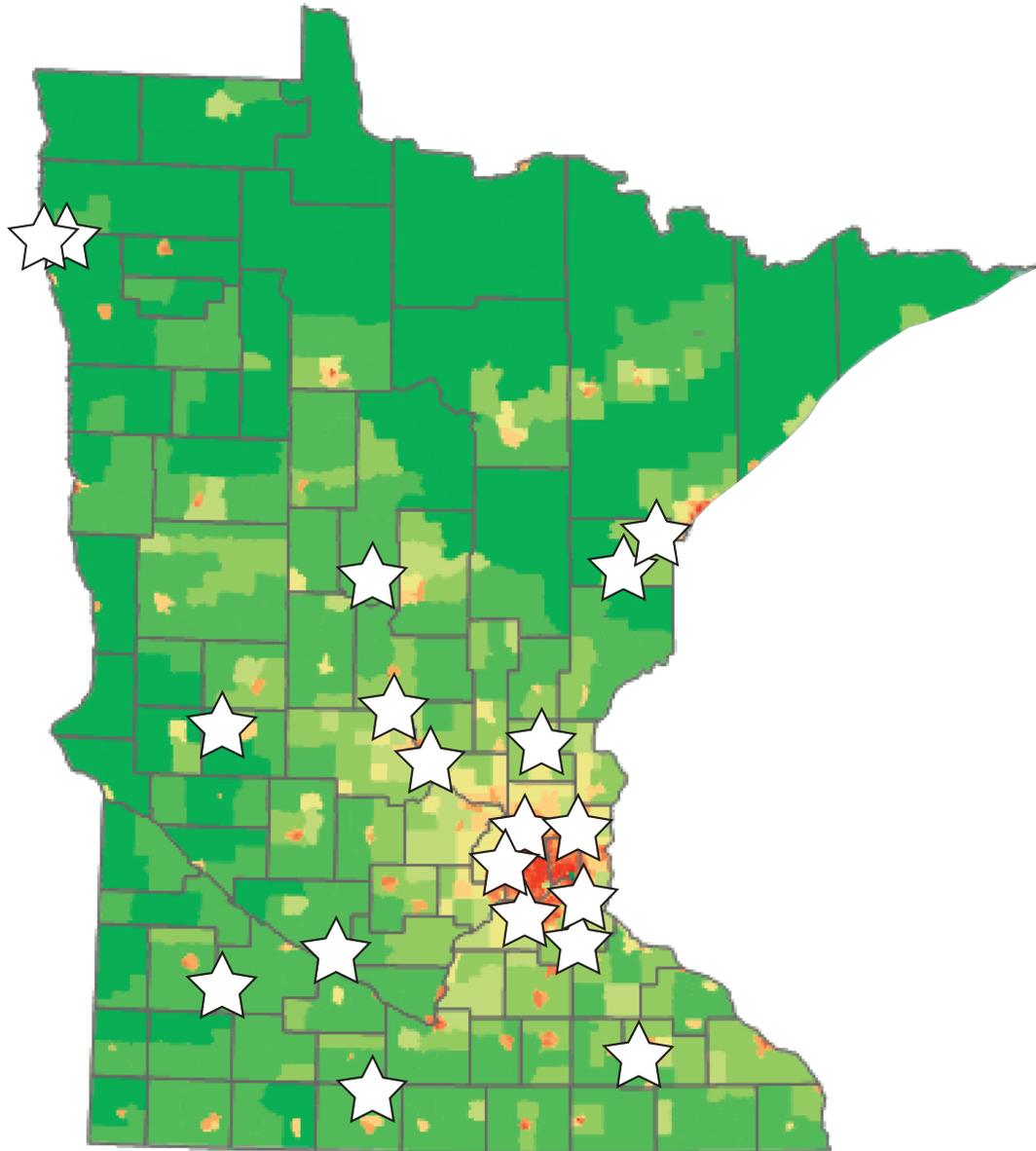


DIVERSE METHODS



STATEWIDE IMPACT

20 Integration Projects since 2015



ACT Olmstead Academy:
Disability Leadership to
Advance Integration In Minnesota

ACT Olmstead Academy, Class of 2017



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ACADEMY

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