# ACT CENTER for DISABILITY LEADERSHIP

on intellectual and developmental disabilities

# Biennial Report 2021-2022

Advocating Change Together (ACT) has been Advancing Disability Rights and Building Self-Advocate Leaders Since 1979 www.selfadvocacy.org

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## **ACT** CENTER for DISABILITY LEADERSHIP

#### on intellectual and developmental disabilities

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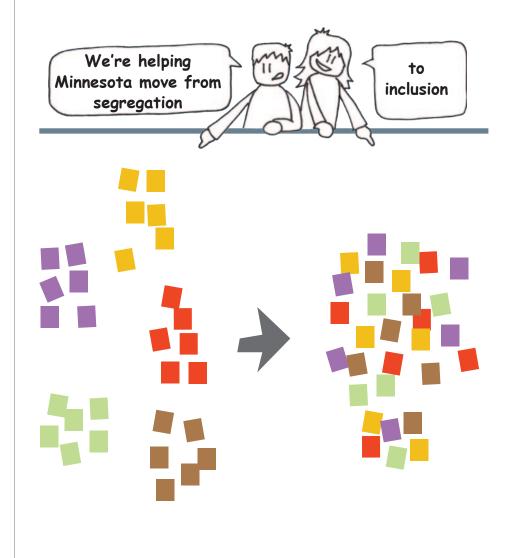
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"Taking risks is part of life. Otherwise, life would be boring." - Adam Kendall, East Grand Forks

# Inclusion:

"During the pandemic. I went to zoom happy hour with my neighbors Kim and Donna, I made soup for a church member with Covid, I zoomed in for weekly Disability Power Days. I joined a remote book club. And I go to zoom dance parties. Now that the pandemic is lifting, I'm using Lyft to get around. My friend from church picks me up for service on Sundays."



Whew! What a couple of years. Funding changes. Pandemic changes. And soon, leadership changes.

The ACT Center has long contended that self-advocacy needs to be a non-negotiable piece of our state's efforts to increase choice and inclusion for people with intellectual and developmental disabilities. Over the past 18 months we have been building a model that will do just that. With the help of Minnesota Department of Human Services, we have established a sustainable business model that allows for self-advocacy training to be included in people's service plans. With the launch of our new Self-Advocacy Academy, any person with a disability who receives waivered support can participate in the self-advocacy programming offered by the ACT Center. In its first year, the Self Advocacy Academy grew from offering three courses to nine courses. As it continues to expand, this new Academy will allow many more people can learn about their rights, practice speaking up for themselves and participate in their communities in a meaningful way.

Like everyone else, the pandemic required us to be creative in order to pursue our mission. Across the state, day programs sent people with disabilities home and residential providers asked them to stay there. Self-advocates were suddenly under a tremendous stress of isolation. ACT Center quickly pivoted, adapting our entire body of work to virtual programming and creating new programs as well.

We first reached out to the most vulnerable. Through our statewide SAM network, we identified selfadvocates who were particularly struggling. For some we started a phone buddy program; we paired 60 people with friends for frequent calls. For others, we sent teddy bears, card games, care packages, and friendship letters. Building from there, we started

several new virtual groups: Coffee Chat, a movie club, a craft club, a dance party club, and a game club. All on zoom. Many hosted by graduates of our ACT Olmstead Academy.

We also adapted our programming content to virtual, creating distance learning versions of each of our program curricula.

These pandemic responses will be a boon for ACT Center, with online options helping us reach the hundreds of future self-advocates who seek a better life for themselves.

Lastly, the upcoming year will bring a change in leadership and new energy to ACT Center. In December 2022, our valued program director, Patrick Mitchell, moved on after eight productive years. (Thank you Patrick!) And this coming March, another change: I am retiring. With our exciting recent changes, and our long body of work, I am confident that the new executive director will guide an organization with a stable financial footing and our reputation as the provider of high quality, highly effective self-advocacy to hundreds of people.

In closing, let me express my gratitude to the many self-advocates, families, supporters, policymakers and grant makers who have put their trust in our work over the years. With Rick Cardenas, my former co-director who we lost last year, we have defined self-



advocacy for our state and laid the groundwork for true, comprehensive transformation for people with disabilities.

Mary Kay Kennedy Executive Director ACT Center for Disability Leadership

NOTE: Mark your calendar for Sept. 29- 30, 2023, Self-Advocacy Conference at Mystic Lake Conference Center in Prior Lake. Mn.



"We're tired, we're gonna fight back and we're gonna keep fighting back until we win our rights."

- Gloria Steinbring (1945 - 2016), ACT founding member

Once again, ACT Center's leadership training programs have been recognized both locally and nationally.

#### Edward O'Brien Human Rights Educator Award

In December of 2020 ACT Center received this human rights education award "in recognition of outstanding achievement in human rights education in the United States". Cynthia Gayles accepted the award at the virtual national HRE conference of over 100 national and international human rights workers. She said that she is "so proud to be part of a human rights movement that respects the rights of every single person, with and without disabilities."

#### Robert Hobbins Community Service Award

ACT Center was also awarded the 2021 Hobbins Award through the Ignatian Volunteer Corps (IVC). We were cited "in grateful appreciation for commitment to empower people with disabilities to speak for themselves, take control of their lives and lead the movement for equal rights for people with disabilities." ACT Center was nominated by our very own IVC volunteers, Michele Gersick and Colleen Curran. "It's been a real privilege to volunteer with ACT Center." said Gersick. "The work we do is all about bolstering self-empowerment. It's about supporting people on their journey to live the lives they want and deserve."



Shaunte Martin, ACT Trainer, displays award alongside Ignatian Volunteer Bob Mendenhall.



"*I just want to be treated like everyone else. That's what they call inclusion.*" - Brian Heuring, Litchfield Minnesota

# ACT CENTER for DISABILITY LEADERSHIP

#### ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

is the only stand-alone self-advocacy organization in the state. Our programs reach every corner of the state; our training materials are used nationally.

### ACT SELF-ADVOCACY ACADEMY

self-advocates have the opportunity to participate in weekly sessions on disability rights and power.

#### act Olmstead ACADEMY

showing by example how to make better community inclusion happen

## ACT Self Advocates MINNESOTA SAM NETWORK

reaches self-advocates in every part of the state with programming, engagement and community-building.

> act MINNESOTA Self Advocacy Conference

brings together hundreds of selfadvocates and supporters to learn and celebrate their lives.

Belonging Clubs Movie Club Book Club Coffee Club

## Disability Power Day

regular gatherings to learn about selfadvocacy

# Peoples Chorus

building community and integration through singing



"The most common barrier to participation in the SAM network was restrictive, inflexible living situations."

- Maggie Treichel, Cambridge

# ACT Self-Advocacy Academy

The new Self-Advocacy Academy provides weekly sessions that support self-advocates in discovering what they want in life and thinking though how to get it.

#### OVERVIEW

After years of discussion between ACT Center, DHS and state lawmakers about how to finance our work, we can now offer participants a way to use funds from their state waivers to pay for participation in our disability rights and leadership programs. Through the new Self-Advocacy Academy (SAA), ACT Center is greatly expanding its audience.

#### Method

Using both in-person and on-line participation, the Self-Advocacy Academy follows the structure and methods of ACT Center's DETS curriculum (see sidebar):

- catalog of 12-session courses on disability rights.
- weekly sessions connected in a longer arc of learning.
- small classes of 8-12 participants.
- two-hour sessions.
- kinesthetic learning culture, featuring stories, music, art, laughter, role-play, hugs and lots of big visuals.
- end-of-trimester celebrations including guests from the broader community.

Academy participants talk about the qualities they have as leaders.

#### LEARNER OUTCOMES

Self-advocates who attend the Academy can expect to:

- Get better at speaking up for ourselves and taking charge of our lives.
- Learning about rights, including laws and policies that support our dreams and choices.
- Find support to get out there and enjoy life, side-by-side with everyone else.
- Make friends, learn about ourselves and build skills though art, games, stories and laughter.
- Take steps to become stronger leaders.





"I didn't know if I would like the classes, but I decided to try. And I really like them! I never did assertiveness training before. Wow, I learned a lot about myself. I'm going to check into joining the Y because I used to like to swim and want to try it again."

- Darcel Battern, self-advocate



Shannon and Ariel practice body language as part of the course Self Advocacy Basics.

#### 2022 RESULTS

The Self-Advocacy Academy has quickly grown. The January 2022 launch had three courses. One year later, the SAA has nine courses; 62 selfadvocates have committed to attending an entire 12-session course.

My Thoughts and Reflections on This Course SO I CAN MOVE EUT ON MY OWN THE FUTURE. I LEARNED IF I SET COALS THEN I CAN MOVE ON MY OUD ADE BEUNISE TETIS MORE RESPECTFULC WAY TO PEOPLE Like THE CLASS AND THE PEOPLE IN THE CLASS. I WON'T GIVE THE IDEA OF MOVING OUT. I LEARNED THAT I CAN HAVE HELP

Take-away learning from the Self Advocacy Academy is documented in participant comments.

#### CURRICULUM

The Academy uses the Disability Equality Training Series (DETS) curriculum. DETS is a catalog of 12 session courses. Each course spans the range of skills needed to move forward: building personal power, connecting to disability rights, and building better communities. This rich and growing package of content builds from ACT Center's 43 years of input and experience by persons with disabilities. Topics include self-advocacy, strengthening leadership, deepening your self advocacy, building communities of support, making good housing choices.



"I didn't always know that I had rights, but now I do. I spoke up and said I wanted more privacy and now I have a lock on my bedroom door."

- Heidi Cartier, East Grand Forks



(since 2015)

This leadership program requires a 12-month commitment from participants. Attending as a team of three, participants show by example how to make more and better disability community inclusion happen in communities across Minnesota.

#### **OVERVIEW**

The 2022 Class of the ACT Center's groundbreaking ACT Olmstead Academy gathered in January to learn leadership skills, and plan for a disability integration project in their home community. Preports presented at a virtual gathering with Judge Donovan Frank Sept 14th.

#### **METHODS**

ACT Center knows what it takes for people with disabilities to fully engage as disability inclusion leaders: a kinesthetic learning culture of stories, music, art, laughter, role-play, hugs and lots of big visuals.

#### **2022 DISABILITY INTEGRATION PROJECTS**

All seven teams pursued the same project: buying laptops for peers without one. These teams realized that especially during the pandemic, having a computer means being connected to others in the community. Teams each fundraised in their home community, pitching their project to local service clubs, business associations and service providers, until they met their budget goal.

#### 2022 RESULTS

Seven teams raised \$6000, and purchased a laptop for 15 peers in Cambridge, Mankato, East Grand Forks, St. Cloud, and the Metro area.

Nathan Miller talks in July to a Cambridge business leader about selfadvocacy, raising money to purchase laptops.





Tasha talks at a January training session about how and why supporting each other and sharing ideas is part of being a selfadvocate.



"I use my new computer to do video chats with my mom and sisters. I also use it for virtual doctor appointments. Sometimes when the weather is bad, Options does remote programs so I can still see my friends and learn stuff. The computer has been really helpful. Thank you." - Diana Robinson, recipient of computer, made possible by the class of 2022

## Self Advocates Minnesota

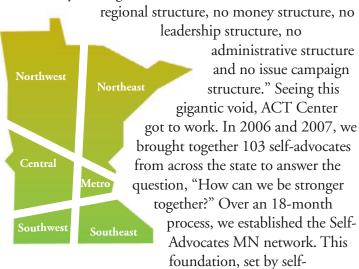
## SAM NETWORK

(Since 2007)

ACT Center founded and continues to administer a statewide network of groups working on 1) building personal power 2) connecting to disability rights and 3) building more inclusive communities, side-by-side with everyone else.

#### **OVERVIEW - THE FIRST 15 YEARS**

Back in 2005 we conducted an environmental scan (Dr. Susan O'Connor) assessing the position of the self-advocacy movement in Minnesota. The key finding, "There is no statewide structure, no



advocates over 15 years ago, gets stronger every year.

Once the network was up and running, we noticed its members were feeling the power. We heard things like, "There are disability people in Bemidji, too." And "It's cool. We are part of a big movement. It's not just our East Grand Forks group." And "Let's present at the national conference. We've got a story to tell." Clearly, ACT Center's SAM Network successfully connects people to a larger disability rights movement: regionally, statewide, nationally.

#### 2022 RESULTS

High engagement and enthusiasm continues for SAM members in six regions statewide.

- 24 members on statewide Leadership Circle
- 53 members on Regional leadership councils
- 13 Rights courses led members for peers (12 sessions each!) with 117 graduates
- 138 members attend virtual state conference.
- 16 members on State Conference planning committee for 2023



Leadership Circle Celebrates SAM Action Poster



"My old place felt like a prison. I had to do the same things everyone else did and I was not happy. It took three years, but I kept standing up for myself. Now I'm able to go where I want, when I want."

- Nate Clark, Mankato

## ACT Minnesota Self Advocacy CONFERENCE

(Since 1994)

This biennial conference is the epitomy of "nothing about us without us"; it's planned, led, and attended by people with disabilities from across Minnesota.

#### **OVERVIEW**

ACT Center brings together self-advocates from across the state to plan and implement this event. In 2020 and 2022, this conference went virtual. It featured the same array of keynote speakers, door prizes, breakout sessions, Bingo, award ceremonies and dances. The mix of both large and small group sessions, as well as a box of program materials mailed to each attendee make these conference successful. Great fun was on full display. Following the closing ceremony of the 2022 cnoference, self-advocates stayed on the zoom link for a full half-hour waving and saying goodbye to each other and sending notes in the chat. Nobody complaining about zoom. Everyone smiling. It was a strong community of folks, pledging to keep in touch.

#### **2022 RESULTS**

- 138 self-advocates from across the state.
- 11 Sessions offered: Assertiveness Training, Power Poses, creative writing class, mediation, Disability History, and more.
- Breakout rooms for all sessions, allowed smaller cohorts to connect
- Integrated leadership at all 11 sessions: both self-advocates and support allies
- Olmstead Implementation Office co-sponsored the conference.



Participants show the values they bring to their lives in a distance learning session.



"I didn't even know I had rights. I knew I had the right to vote, but that's about it." - Jonathan Wolner, Fairmount

# **Disability Power Day**

(Since 2015) ACT Center's wide-open gateway into the world of disability pride and power

#### **OVERVIEW**

Disability Power Day is a weekly gathering of people from different circles. It's a drop-in opportunity for people to meet new friends and learn about aspects of self-advocacy. The classes are most often virtual, but offered in-person once each month. Besides large group interactions, Power Day uses smaller breakout groups to dig deeper into the topic and hear personal experiences.

#### 2022 RESULTS

- **43** Power Day Sessions offered
- 38 self-advocates per session, on average.
- 102 total self-advocates attended
- 47 attendees went on to participate in other ACT programs, including Side-by-Side Chorus, Self-Advocacy Academy, and the MN Self-Advocacy Conference.



Folks made collages showing their core values at an April 2022 session.



"The zoom did not work for us all to hear each other's voices, but that did not stop us. We all sang and could feel the power of everyone singing the same song together. We took turns singing where everyone could hear us. It worked."

- Thomas Robinson, Minneapolis

# Building Belonging

Movie Club • Book Club • Coffee Club

(New in 2021)

ACT Center created a variety of new clubs to help our members stay connected and survive the isolation of the pandemic.

#### **OVERVIEW**

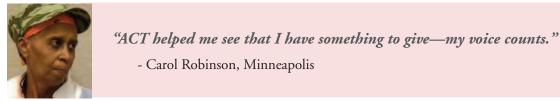
During the early days of the pandemic, our focus shifted to anything we thought would help selfadvocates get though the days and weeks of aloneness. We sent care packages, we visited people on their sidewalks, we made countless phone calls. We started several virtual social groups: coffee chats, movie clubs, birthday parties, dance parties, cooking clubs, podcasts and craft clubs. We paired people up with phone buddy for regular chats. Our goal was to help members feel that we still belong to each other. Now that in-person gatherings are returning, we are scaling back our remote options. But looking back, these virtual connections were a lifeline for many of our members during a difficult time.

#### 2021-22 RESULTS

- 5 clubs met virutally 67 times, averaging 10 people per time
- 60 pairs of phone buddies
- 12 books read by book club
- 12 podcasts made



We sent craft materials and art supplies to self-advocates and got on Zoom to work on the projects together.



# People's Chorus

(Since 2015) This unique chorus is integrated by design: people with and without disabilities gather regularly to sing together, building community and pride.

#### **OVERVIEW**

The pandemic brought changes to the Side by Side People's Chorus. First, we went virtual. Second, we transitioned from being a performing chorus to being strictly a social singing group. The monthly virtual sing-alongs have mimicked the pre-pandemic rehearsal structure. Each session began with some Zoombased chat and check-in, followed by singing. Long-time director Larry Dittberner led songs on a mix of topics, from community to disability rights, from pop hits to traditional favorites.

The People's Chorus has helped members stay connected. Connected with their pals, connected with disability rights, and connected with that deep part of the spirit that singing reaches.



#### 2022 RESULTS

- 10 sing-alongs (8 virtual, 2 outdoors at the park)
- 56 attendees



Larry Dittberner leads the People's Chorus with his guitar,. Here he leades singers at a picnic.



"I've been to programs at Hamline for more than 25 years, and the chorus that opened the program tonight was the most powerful thing I've ever seen."

Audience member at the People's Chorus performance

#### **BOARD MEMBERS**

Jenny

Johnson



Thomas

Robinson

President



Denise E.

Cady



Kenisha

Conditt







Carrie O'Keefe

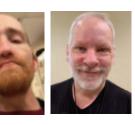
Shaunte Martin



Carol Robinson Lori Rohovit



Kris Jacobs



DJ Fischer, Vice President

Guy Freitag

#### VOLUNTEERS

Mary Kay Kennedy: Executive Director Patrick Mitchell: Program Director Adam Ruff: Program and Communications Manager Albert Lee,: Curriculum Development Cynthia Gayles: Trainer Donn Poll: Consultant Sandy Moore: Grant Writer Bob Brick: Consultant Elizabeth Daskal: Intern/Archivist Larry Dittberner: Choir Director/Academy Trainer Marco Montermini: Accountant

LEADERSHIP TEAM

Mary Fenske: Book Club Lynn Ruff Ellen Surbrook Kristin Lisor Kern Lynn Krupp: Trainer Michelle Gersich: Ignatian Volunteer Corps Colleen Curran: Ignatian Volunteer Corps Bob Mendenhall: Ignatian Volunteer Corps John Kleweno: Ignatian Volunteer Corps Kris Jacobs: Academy Trainer, Board Member

"It's a two-way street. Treat others how you want to be treated." - Richard Schultz, St. Paul

## How is the work financed?

The Minnesota Council on Developmental Disabilities supports the Central and Northwest regions of the Self-Advocates Minnesota (SAM) network with a \$100,000 annual grant.

The Minnesota Department of Human Services supports the Northeast and Southeast and Southwest regions of the Self-Advocates Minnesota (SAM) network with a \$130,000 annual grant.

The Minnesota Department of Human Services supports the Olmstead Academy with a Moving Home Minnesota grant of \$75,000

A 2019 legislative appropriation (administered thought DHS) of \$248,000 supports the ACT Center's work to include 1) maintain state network infrastructure, 2) outreach and conferences 3) support annual leadership programs and 4) program coordination and evaluation. Of the \$248,000, \$105,000 is used statewide to conduct outreach to persons in each region of the Self-Advocates Minnesota network.

Foundation grants include Borealis Foundation, St. Paul Foundation and Bigelow Foundation.

Program income includes fee for service and Waiver Service agreements.

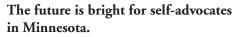
Advocating Change Together Profit & Loss July 2021 through June 2022 Ordinary Income/Expense (accrual basis) Jul '21 - Jun '22 Income **Government Grants** 686,578.19 Foundation Contributions 79,178.08 **Program Income** 91,482.00 Contributions 38,308.16 **Conference Revenue** 9,030.00 **Restricted Revenue** -4,178.08**Total Income** 900,398.35 Gross Profit 900,398.35 Expense Personnel 264,207.00 **Contract Services** 14,531.58 Operations 18,075.08 **Program Expenses** 407,783.23 Conference 58.27 Penalties & Fees 2,260.00 **Total Expense** 706,915.16 Net Ordinary Income 193,483.19 Other Income/Expense Other Income -1,600.17 Other Expense -670.76 Net Other Income -929.41 Net Income 192,553.78



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

- Don Neu, Monticello





#### ACT

CENTER for DISABILITY LEADERSHIP on intellectual and developmental disabilities