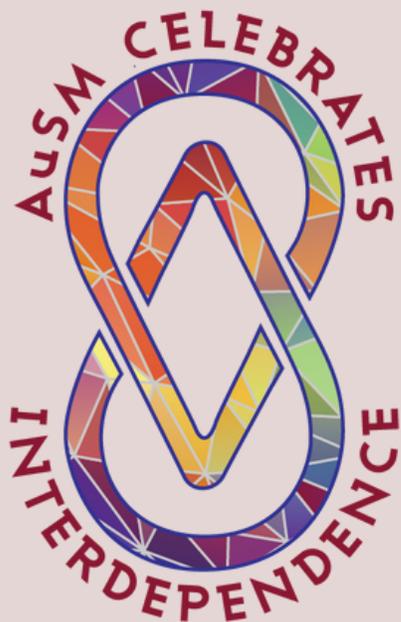# WHAT IS

COLLECTIVE CARE?

To learn more visit www.ausm.org. Questions or suggestion? E-mail zjames@ausm.org.

Collective care is an approach to disability that does not rely on either paid work funneled through organizations or governmental systems nor on family supports. Instead, it frames supports and access as something that people can joyfully give to each other. Supporting a disabled person isn't a chore - it is part of being in community with them. Collective care often focuses on multiple people with a variety of disabilities mutually supporting each other. This concept has been pioneered and articulated by queer, disabled, people of color. This resource is particularly indebted to the work of Leah Lakshmi Piepzna-Samarasinha and Mia Mingus.

AuSM CELEBRATES INTERDEPENDENCE

LET'S LOOK AT SOME EXAMPLES

1 AN AT HOME CARE COLLECTIVE
LOREE ERICKSON, AN EARLY PIONEER OF THE MODEL

Some individuals with disabilities have enacted collective care by building what is called a care web of their friends and community members. Loree Erickson is often cited as a pioneer of this method of care. She is a physically disabled woman who uses a wheelchair and requires support throughout her day. Her community volunteers to take on shifts helping with dressing, bathing, transferring, and administrative work. She uses e-mail, text, and a Facebook group to organize and ask for care. The people who support her find that they get to enjoy her company, have fun, and build a community together while Erickson gets the support she needs. A major benefit is that Erickson is supported by people who accept her, who don't make her feel like a burden, and who aren't judgmental of things like her sexuality. It allows Erickson to be in charge of her own care: sharing how she would like to be treated on her own terms. She has managed her care in this way for many years.

PROS AND CONS OF THIS MODEL

One challenge of this model is that it relies on having a large group of people who love and care for an individual and are willing to share their time and energy without compensation. Not everyone has access to these resources. Some folks also find that they prefer their support people to be professionals rather than personal friends, as it can drastically change a friend relationship.
On the other hand, this model provides the individual receiving care with a great deal of control over their care, and additionally can allow someone access to care that they may not otherwise be able to afford. It also removes a great deal of stigma from receiving care, as it reframes care away from being burdensome.

A WAY FOR GROUPS TO ACCESS SPACES AMP CONFERENCE

Collective care is a powerful tool when there are multiple people with disabilities who all need access to the same spaces. Creative Collective Access was a group of people with a variety of disabilities who were planning to attend the 2010 Allied Media Conference and who were trying to find supports and access. When they realized this, they reached out to each other to build a collective that could support each other and advocate more powerfully. Through Facebook and text chains, they identified other individuals with disabilities who were attending and made plans to meet up and help each other with access needs. Examples of how they built collective care include:

- Those who didn't have mobility problems walked to pick up food and bring it back for those who couldn't walk.
- When they went places as a group, they followed the pace of the slowest individual.
- One individual had an accessible van and used it to transport other wheelchair users.
- Communally advocating for the conference to provide scent-free soap in all of the bathrooms.

This group built solidarity across disabilities, and used the skills of each to help support the areas where others required accommodations.

PROS AND CONS OF THIS MODEL

This model is specific to events that happen at a specific time and place, and only works when a large group of disabled individuals is attending. What the model brings is the power of a group - where one person asking for translation or scent-free options may be ignored, 20 people are more difficult to ignore. It also allows each person to share their abilities to support others.

3 AN ONGOING NETWORK CCA BAY

It is also possible to create something like a combination of the previous two examples. If a group of people decides that they want to mutually support each other, you can use that power of collective access and the variety of skills that exists in any group to support each other. One example of this was a group called CCA Bay, which met in person weekly for over a year. They built relationships, enjoyed each other's company, and learned from each other about how to be supportive. For some people that meant providing physical care, for others it was emotional support.

"We're so used to disabled care being professionalized, to assuming that medical and therapeutic professionals are the only ones qualified to intersect with our terrifying bodies...Able-bodied folks can of course engage in care work with disabled folks, by listening and following the lead of the person they are engaging in care with, but they are arguably the least qualified to give care and able to understand the kind of care sick, disabled, and neurodivergent folks need. It has been drilled into us so thoroughly that we do not possess adequate knowledge of our own bodies because we have not had the proper training or do not possess the proper degrees. "
Leah Lakshmi Piepzna-Smarasinha

Outside of these meetings they helped each other with care needs: everything from transportation to sharing resources to helping each other move. This kind of ongoing network can take a wide variety of forms. Maybe you only want to provide limited support to each other. Maybe you hope to live together and meet all of each other's support needs.

PROS AND CONS OF THIS MODEL

One important thing to remember about this kind of care collective is that there will be interpersonal conflict. Not everyone will understand each other's needs. People will get tired and burn out from providing care. Some people will feel they are contributing more than others. Think about how you will address these potential concerns before you work to build a network. What this model offers is the benefits of the at home care collective but across a wider group of people, and without relying on someone's personality to entice others to give them care.

Creating a Care Web

- What are the goals of the group?
- Who needs care?
- What kind of care?
- How does the person prefer to receive care?
- Do others need training?
- Who can train, and what does that look like?
- How much time will it take?
- Does it require resources?

Potential Roles:
- Caregiver
- Care receiver
- Administrator
- Fundraiser
- Communicator
- Conflict resolver
- Funder

Consider asking:
- What do the caregivers receive from this web?
- What makes it fun? What can you celebrate? What can you enjoy?
- How can caregivers feel supported and in community?

Step One
Identify your needs or the needs of the person at the center of the care web. This could be a group of people if you want to provide care mutually.

Step Two
Brainstorm the roles that may exist in the web and who will take on each role. People may have multiple roles within the web.

You'll need to invite people to join you in your care web. You may want to think in advance about what type of people make you feel comfortable in receiving care. Perhaps you have a gender preference if you need help with toileting. Maybe you would prefer your network to include other disabled people. This is your life. You can make the choices.

Step Three
Get practical. Once you have a group of people identified, it's time to make more concrete plans.

- What physical resources do you need?
- Do you need money or financial support?
- What kind of administration will it require and who will do that work?
- How will you all communicate and how often?
- How are you going to build a schedule for care needs? How do people get time off? What is the process if someone is sick or has an emergency?
- What is your plan for managing conflicts?
- Do you want documentation of your work? This could be a spreadsheet of the schedule or keeping receipts from those who purchase resources.

The last step is to get started! That could be as small as having a friend come over and do your dishes or as large as a weeklong schedule for personal care. Your first attempt at creating a care web will probably not be perfect. Sometimes it can be most helpful to try something and make adjustments as you go.

Required Reading

AuSM recognizes that these concepts were pioneered by queer, disabled people of color and we are forever grateful to them for their work. To recognize their contributions, we strongly recommend that anyone using this guide spend time with the books and articles they have written.

To learn more visit www.ausm.org. Questions or suggestion? E-mail zjames@ausm.org.
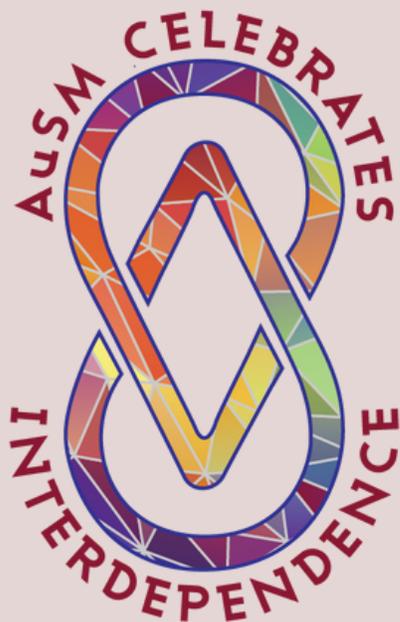
Care Work: Dreaming Disability Justice
by Leah Lakshmi Piepzna-Samarasinha

Creating Collective Access

Reflections on an Opening
by Mia Mingus

Sins Invalid

Brilliant Imperfection
by Eli Clare

Access Intimacy
by Mia Mingus

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It can be challenging to know what words to use when asking for help. For a great example, check out the Creating Collective Access blog.