

BUILDING A RESPITE COOPERATIVE –

WHY IT MAKES SENSE

AND HOW TO MAKE IT HAPPEN

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A coffee break
A lunch break
A break from this project
A break from my boss

“I need a break”

What does this phrase mean to you? To most of us, “a break” is the chance to step away, take a breath. Maybe you run errands on your lunch break, or perhaps you walk around the block. Whatever you do, a break allows most of us the chance to refresh, get some *respite*. Not always so with family caregivers.

Tens of thousands of families all around the country include a member with special needs – from cerebral palsy to AIDS to Alzheimer’s – family caregivers are the backbone of our nation’s long-term care system. And yet many people find themselves in the position of caring for a family member in their home, often without adequate preparation or a support system.

The statistics are sobering. Family caregivers are at risk for elevated blood pressure and increased risk of coronary heart disease. According to the Family Caregiving Alliance, *“full two-thirds of working caregivers providing assistance to a family member or friend aged 65+ decreased their work hours or took unpaid leave in order to meet their caregiving duties.”* In addition, a host of national studies have determined caregivers use prescription drugs for depression and related issues up to three times more often as the balance of the population.

Since 1987 the Respite Care Association of Wisconsin (RCAW) has been providing assistance and information about respite care to people and programs across the lifespan. RCAW provides training and technical assistance to respite care programs, and links caregivers with the tools and support they need to remain a strong, vital part of long-term caregiving.

INTRODUCTION

Cooperatives have been around for centuries. The idea that exchanging a service or product for a like valued product or service is successful and practical. Examples of a shared services cooperative can be groups of individuals or businesses coming together for the purpose of purchasing products, or as complex as businesses forming alliances to negotiate health care insurance.

Lifespan respite care is a service that lends itself well to the idea of a cooperative. Diversity in the needs deepens the pool of potential families, which in turn makes a cooperative more viable.

This document attempts to give a broad approach to creating a successful cooperative, but is by no means complete or absolute. The direction of a respite cooperative remains with the people who will benefit most, family caregivers.

Sources used in the development of this guide include:

- Family Cooperative Respite – a project of United Cerebral Palsy of Southeastern Wisconsin, Inc.
- University of Wisconsin Center for Cooperatives
- National Association for Family Child Care
- National Network for Child Care
- Wisconsin Department of Public Instruction, Families in Education Program
- University of Massachusetts Cooperative Extension / National Network for Child Care

Since 1987, Respite Care Association of Wisconsin (RCAW) has worked to promote, support and expand quality statewide respite care across the lifespan. RCAW serves as a clearinghouse for information about respite care, provides training and technical assistance to respite care programs, and advocates for support of respite care at the state and federal levels.

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HOW TO START – WHERE DO I BEGIN?

The University of Wisconsin Center for Cooperatives suggests seven important steps to forming a cooperative:

- Exploration meeting – find out who is interested
- Establish a steering committee to help guide start of the co-op
- Determine the viability of the co-op
- Determine the structure / guidelines
- Prepare a plan to market and sustain the co-op
- Determine up-front costs and money needed for advertising, web site etc.
- Recruit members
- Recruit personnel

These steps form the blueprint which will guide the operation and success of the co-op.

THE VERY BEGINNING

You have an idea. You talk to another person about your idea. Even if the conversation stops here, you have the workings of a co-op. People with the same understanding of the benefit of collaboration are the bones of a co-op.



But let's take this a little further. Extending the idea to more like-minded families will not only create a deeper pool from which to draw, but will also help stabilize the co-op.

Now, where do you find families?

There are a myriad of avenues open to finding other like-minded families to start the discussion about a co-op. Sometimes the best place to start is with the organization or agency where you may already have a relationship. Don't be shy – now is the best time to talk with your case worker, social worker or health care team members about your idea.

On the flip side, it will be up to agency coordinators to determine which clients may be receptive to the idea. A co-op may not be appropriate for all families, especially considering there is a bit of work up front to get the program off the ground. Be patient as you work with appropriate agency contacts.

Some resources you may want to consider:

- Birth to Three programs
- Family Support Programs
- ARCH (Association for Rights of Citizens with Handicaps)
- Local chapter of the Alzheimer's Association
- County Office on Aging
- Your health insurance provider or HMO

Or other organizations serving individuals with specific disabilities such as:

- ARC (Advocates for Retarded Citizens)
- Autism Society
- Muscular Dystrophy Association
- Spina Bifida Association
- ADD/ADHD
- Behavioral support groups

- Spinal injury support groups
- Any other that makes sense

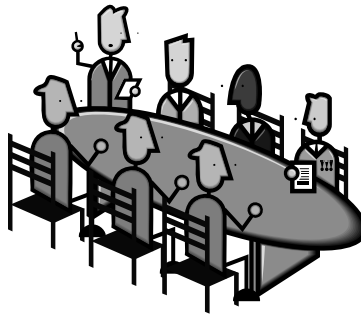
One other path that may be right for your area is through the internet. Websites are the most readily available and resource-friendly tools for communication. Many sites have a message board or chat room making this avenue fast and easy. Some broad, statewide websites to check out include:

- <http://www.caregiversupportnetwork.org/default.asp?id=1>
- <http://www.waisman.wisc.edu/index.html>
- <http://www3.uwm.edu/dept/lefc/>
- <http://www.uwex.edu/ces/flp/caregiving/index.html>

There is always the tried-and-true method of posting fact sheets or flyers touting the initial meeting. Some suggestions for placement include:

- local health clinics – medical and therapy
- hospitals – many have community bulletin boards or clinic boards
- schools – check with the health worker in your school district to help be sure your flyer is appropriate for the venue.
- libraries, book stores
- houses of worship
- preschool and daycare centers
- local co-operatives including food co-ops, pharmacy co-ops, farm co-ops
- grocery stores – don't limit yourself to the local chain store, be sure to include organic health food stores, University community stores, and vitamin stores such as GNC or Community Pharmacy

Once the group of interested families is identified, an initial meeting should be held to test the level of interest in the co-op idea.



Let's talk about the initial, informational meeting.

The first meeting of interested folks will set the tone for a long time to come. Here is where families will meet each other and discuss the who's, what's, why's, where's and how's of a co-op. Taking the time to plan, even just a few things, will not only make the meeting run smoothly but will help establish trust and comfort.

As they say in real estate the three most important things are location, location, location.

For some it makes sense to hold the informational meeting in a home, for others it may be after hours at a daycare, and still others the right location may be a church meeting hall. Wherever you choose, make sure there is safe and adequate parking. You want to make it as easy as possible for people to find the meeting place and not worry about parking challenges.

It goes without saying, physical accessibility is key. If a family member uses a wheelchair, be sure to hold your meeting at a site with ramps and accessible restrooms. If a member is blind or deaf

be prepared to meet those needs. Preplanning is essential for a successful start

Offering childcare or adult care at meetings may give interested folks more option to attend. Caregivers and others will have a chance to meet those who may eventually provide care for their loved one. Here are some tips:

- have toys, games, books and other materials on hand to facilitate provided care for either children or adults.
- Perhaps asking families to bring a helper if an individual has exceptional care needs
- Be sure the care room is close to the meeting room to ease transition
- Snacks and beverages are great – be sure to “police” the room when you are done to insure your group will be invited back!

Providing food – beverages and snacks – can help create a more relaxed environment.

And be sure to invite others who may be able to add to the overall conversation, such as community outreach specialists from the local clinics, teachers, or other community volunteers.

The Meeting Room

Most all of us have at one time or another been frustrated by attending a meeting that was poorly planned. To be sure this doesn't happen to you, take a few minutes and think over these suggestions:

- Get there early! Even 30 minutes ahead of your meeting gives you time to set out materials, arrange chairs, post signs, pre-pour beverages. It's often the little things that count, so bring more than enough pens, paper, name tags, markers, clip boards (it's hard to write on your lap), napkins, etc.
- Arrange chairs in circular pattern to enhance conversation and inclusion – tables and chairs send a message of a “lecture” as opposed to a dialogue.
- Signage and directions – if you are in a public building (a community center for example) be sure to have signs pointing in the direction of your room and the name of your group. This helps folks get to the meeting on time!
- Station a greeter or two at the door to welcome families, point out the coat room, lead them to childcare room, ask them to sign in, and help write out name tags and the like.
- Notes – someone should be charged with this task before the meeting begins.

LEADING THE MEETING

Someone needs to lead the meeting. Sounds simple, but awfully important. The person you decide may be yourself or someone else, perfectly fine. Be sure the leader is comfortable with the agenda and clear about the meeting outcomes.



Here are just a few things to help your meeting move well:

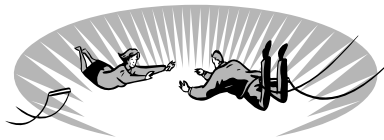
- Introductions – start with yourself if you are leading the meeting, who you are, why you are there, what kinds of resources you use and a bit about your family. You will set the tone from there.
- Description of co-ops – facilitator or presenter explains the concept and benefits of building a cooperative.
- Questions – if the group is slow to start questions have a few questions and answers prepared to spark dialogue, such as:
 - what kind of involvement or time commitment may be required
 - how to train each other
 - general responsibilities, liabilities
 - how many people need to be registered



- Distribute materials – send folks home with printed materials, fact sheets, web sites for example, to share with other family members or friends who may be interested in co-ops (be sure there is a contact name, phone number and e-mail on all materials for follow-up questions.)
- Next steps – identify next steps, including:
 - if there is enough interest and momentum, select a steering committee (there is no magic number of members, allow those who are interested to all participate)

- date for the next meeting or social event
- if there are assignments, review them at this time
- Reminder about the sign-in sheets – be sure people leave their name, phone number, address, e-mail
- Conclude meeting – extend thanks to all who helped make the meeting possible, and of course, be sure your space is cleaned and returned to the original look (put chairs back into place, sweep crumbs, empty trash, take down direction signs, etc.)

And it is from this group a steering committee will be formed.



BUILDING TRUST – THE FOUNDATION OF THE CO-OP

Probably a no-brainer but deserves consideration nevertheless. The most precious asset we have is our family and its members, so confidence and trust in those who may care for them is crucial. As families become more interested in the idea of starting a co-op, it's good to organize some social event to give them opportunities to get to know each other better and see how they give care and interact with their children. Pot lucks, picnics, swim parties and other simple events offer families a relaxed space and more opportunities to become acquainted. Piggy-backing onto existing events means less work and more opportunities to attract like-minded families into the co-op.

STEERING COMMITTEE

A Steering Committee is usually formed from the participants in the informational or initial meeting. This group will examine several critical questions related to the construction of the co-op, but don't let the list intimidate you. Not all of the questions we have outlined will necessarily apply to your group, but it's worth a few minutes to take a look:

- Is there general agreement on the definition of the “need” to be met; or another way to put it, does everyone have a common understanding of respite?
- Are there individuals willing to serve in a leadership role? Just because it may be your idea does not mean you have to do all the work. Some tasks and issues to address include:
 - Managing policies
 - Tracking exchange methods – will you use points, hours/time, etc.
 - What is the “currency” to be used – will the value be tickets worth 30 minutes of care, for example?
 - Will families who have members with “bigger” care needs have a different rate?
- What are the major obstacles and opportunities the co-op will face and how to prepare for them?

- Once you have looked at the feasibility of the co-op (interest levels, barriers, resources), is there still enough interest to keep going?
- Are there enough potential families willing to invest their time to get the concept off the ground – is there critical mass?
- What kind of bylaws or operating structure do you want? Who can be a member – will you require:
 - A referral, application or interview
 - Are there geographical, disability or age considerations
 - Will there be a membership fee
 - Will there be a home visit prior to accepting the family?
- Is the co-op able to identify leaders to take the “first shift” managing the operations, meaning keeping records, being point person for questions, taking calls from interested families?

Whew, lots of questions but if you do the groundwork now, and put the frame or guidelines for the co-op in place you will have less chance for squabbles to erupt.



FAMILY BINDER – THE BRAIN OF THE CO-OP

These will serve as the handbook for your co-op. After you have worked out your structure and guidelines, copy them and include them in your

Family Binder. This binder will hold all important information related to the co-op that will give sitting families what they need to know about the people they are caring for. The binder

should travel with and accompany the child or adult at their respite. The Binder should include but not be limited to:

1. guidelines
2. medical release forms
3. medication charts
4. emergency data sheet
5. personal information sheet
6. special instructions sheet
7. recording sheet (to track the points or hours earned/spent)
8. safety checklist

Samples you may want to review are included in this manual.

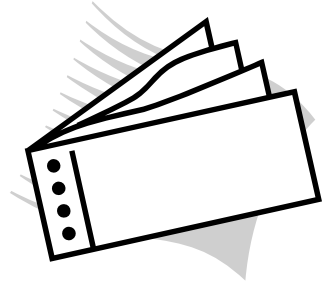
Directory

Create a directory listing of all addresses, phone numbers, cell phones, email of the families involved in your co-op. Each family must receive a copy, too. If you are using the internet, posting this on your co-op website in a secure manner is also a good idea. We also strongly encourage using Family and Child/Adult Profile forms as well as photos.

Tracking Credits

If your group chooses a system that keeps track of the points, hours or credits you may want to have a “bookkeeper” track them in a master ledger. The system can be as rudimentary as calling them in to the designated person, or as part of the co-ops website. When the books are balanced – meaning the provider and the recipient have submitted their information – then the books are “balanced” and everyone gets credit for the care given and received. (See form titled “*Master Point Record Sheet-Sample*”.)

When groups decide to pay each other with tickets or coupons, they need to start off with this “currency” to begin exchange. Some groups may give in-coming members 20 tickets to begin their exchanges and when they run out, they will need to provide respite for other families to earn tickets. Be sure to assign a value to each coupon or ticket, just like paper money. Each coupon could be good for 30 minutes, 1 hour and so on.



Training Sessions

It is important for families to know all about each other’s family member so they can give the best care, and have confidence to do it well. The best way to train and be trained is through direct experience. Set up a training session where a parent or caregiver will be able to give hands-on demonstrations on how to properly give care to their family member. A separate training before giving care affords people the time to learn, ask questions, get hands-on instruction and feel comfortable about giving their care – and for those receiving it.

Actual Exchanges of “Respite”

As soon as members have been trained, exchanging can begin.

Either the bookkeeper or family member will call and ask another



member to give respite. Both parties need to make sure dates and times are clear and reserved. Families agree on a time and location of the care (their home, your home or another location). After the respite, both

members confirm the amount of payment. If you are using tickets or coupons, they are given at this time. If you are giving points or hours, record those on your tally sheet right away before anyone forgets. Here is an example of the exchange:

The Jones family gave respite to the Smith family for 3 hours. Each family had 10 hours on their account. The transaction is recorded as follows:

Jones family account - 10 hours
3 hours added for the respite
Jones family balance = 13 hours

Smith Family account - 10 hours
3 hours deducted for the respite
Smith family balance = 7 hours

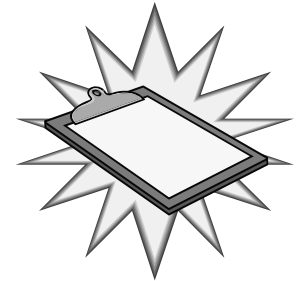
See “Master Point Record Sheet” as an example.

KEEP THE GOOD TIMES ROLLING

As families hear about and become interested in joining your co-op, regular meetings or socials can allow them to ease into the organization and get comfortable. Economically co-ops are a good program but for caregivers the co-op may become a source of greater support than simply giving a break – some refer to their co-

op as an extended family. Each co-op will develop according to its own interests, needs and culture. There are many paths to take and because co-op members are willing to extend themselves to other families it can sometimes become easier to ask for help.

Family Co-op Application – SAMPLE



Applicant Parent/Guardian Name(s) : _____

Who will be the primary contact: _____?

Address: _____

City: _____

Home phone: _____

Primary Contact Work Phone: _____ Cell: _____

Email: _____

Our Family:

Sibling: _____ DOB: _____

Sibling: _____ DOB: _____

Sibling: _____ DOB: _____

Other family members: _____

Home is wheelchair accessible [circle one] Yes No

Number of steps into the house: _____

We are willing to care for others in OUR home [circle one] Yes No

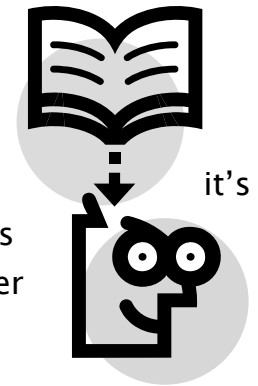
We are willing to care for others in THEIR home [circle one] Yes No

We can take care of the siblings in the family [circle one] Yes No

Family User Manual – All About Us

Keep in your family binder

Don't let this sheet scare you. Yes there is a lot of information to be gathered but once all down this will actually be a useful document to share with healthcare providers, schools and other family members. Remember, the more information you can write down the better prepared everyone will be.



1. Name and relationship of Family Member needing care: [husband, wife, son, daughter, niece, etc.]_____
 2. Our address: _____
 - a. Cross streets: _____ and _____
 3. Parent / Guardian Name and relationship: _____
 - a. Phones
 - i. cell: _____
 - ii. work/daytime: _____
 - iii. evening: _____
 - b. email address: _____
- Parent / Guardian Name and relationship: _____
- c. Phones:
 - i. cell: _____
 - ii. work/daytime: _____
 - iii. evening: _____
 - b. email address: _____

Other members of the household [siblings, grandparents, exchange student, renter, etc.]

Name / Relationship: _____

Name / Relationship: _____

Name / Relationship: _____

Television, computer and internet rules: _____

We do / do not [circle one] allow smoking in our home.

What kind of pet / pet name: _____

- o Treats and activities:

For our *young children* here's how we handle:

1. Rest times: _____

2. When doing messy activities, our child should (i.e. wash own hands) : _____

3. Outdoor activities are: _____

4. Indoor activities are: _____

5. Our philosophy on behavior management (if applicable) is: _____

Our House – what you need to know

Keep in your family binder

Every house has sounds, smells and particular peculiarities that may be unfamiliar to new friends. Little things can matter – like handle needs to be jiggled, or the house groans when the hot water is turned on. As you go through this exercise you will be reminded of all the idiosyncrasies that make your house a home.



make it your home – and the downstairs bathroom

Designate a space in the kitchen where your co-op member can find note paper and pens for phone messages, written house rules (i.e. dog is not allowed on couch) and other tips will all help make the exchange go smoothly.

Finally be sure to leave a set of house keys with a neighbor, because you never know.

- Normal house sounds, noises

- Toilet, shower, plumbing tips [jiggle the downstairs toilet handle, etc.]:

- Door and lock tricks: -----
- Appliance quirks: -----
- Security instructions: -----
- Remote control tips: -----
- Trash and recycling specifics: -----
- Phone message instructions: -----
- Circuit breakers [location]: -----

- Smoke detectors [location]: _____
- We do / do not [circle one] have a pool. Rules for the pool include:

Other Notes

Medical Release Form

Keep a master/blank copy in your family binder



I, _____ hereby authorize
[print name]

[print name]

to seek emergency medical care or treatment for my
child/spouse/partner (circle one)

[print name]

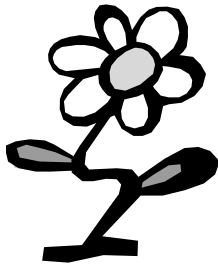
In the event of accident, injury or sickness etc. until such time as
I may be contacted. I also assume the responsibility of payment
of any such treatment.

Signature:

Date: _____

This release is valid for one year from the date of signature.

Checklist to help keep older adults safe ¹



Poor vision or less stability in walking can increase an older adult's chance of stumbling and being injured. Having a house that takes into account these frailties and offers easy accessibility to light fixtures and supportive devices can help prevent injuries and make life easier for an older adult. It can also give peace of mind when you are away from the person you care about.

The checklist below can be useful in reviewing any home, including your own for safety.

Outdoors

- Sidewalks and steps are in good repair
- Railings full-length of any steps
- Yard free of loose boards, ground holes and other hazards

Housekeeping

- Clutter-free clear paths to cross within rooms and from room-to-room
- Frequently used items on shelves are within easy reach
- Sturdy ladders/step stools with grip bars

Lighting/Electrical Equipment

- Light switches near every doorway
- Good lighting to eliminate shadowy areas
- All stairways are well lighted
- Light switches at the top and bottom of stairways

Stairways

- Securely fastened handrails extending the full stairway
- Stairways with no broken or sloping steps
- Stairways free of any stored items
- Non-skid plastic covering on stairway carpeting
- Stair steps with no extruding metal edges
- Rug-free area at top and bottom of stairs

¹ Source: Family Caregivers Support Network, www.caregiversupportnetwork.org

Living Space/Lifestyle

- Doorways adequately wide, especially for walker or wheelchair needs
- Chair seats sufficiently tall for ease of sitting down and get up
- Shoes, boots and slippers with low heels and non-slip soles

Floors

- Non-skid wax used on wax floors
- Non-skid backs on rugs
- Slope-free floors and carpet
- All carpet edges tacked down
- All carpet and rugs free of worn spots and drips
- All carpet with short, dense pile

Bathroom

- Grab bars in bathtub, shower and around toilet
- Toilet seats high enough to get on and off easily
- Rubber mat or non-slip decals in tub or shower
- Night light in bathrooms
- Soap and wash cloths within easy reach

Bedroom

- Bed at good height to easily get in and out
- Light and telephone within reach of bed
- Night light in bedroom
- Obstacle-free, well lighted path to bathroom

Authorization to Administer Medicine

Keep a blank/master copy in your family binder



I hereby authorize administration of the following medication(s)

Recipient: _____
 [print name]

Medication	Type	Dosage	Prescription	Special instructions

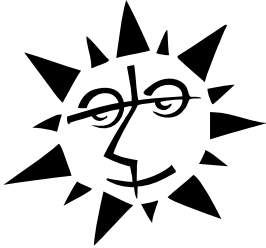
Signature – parent or guardian

_____ Date: _____

Medication Log

Date	Time	Medication and dose given	Person administering

Special Instructions – Getting to know Your Remarkable Family Member



This is a chance to help communicate the very unique personality and needs of your family member. While a form rarely captures the nuances and personality that make your family member special, it is a start. This information should be shared strictly within the co-op and is CONFIDENTIAL. Please use this as a start as the more information you can provide, the better the experience.

Child/adult to be cared for: _____ DOB: _____

Diagnosis/condition:

Equipment used:

Wheelchair ___ G-tube ___ Ventilator ___ Catheter ___ Other ___

Special instructions:

Special likes:

Dislikes :

Communication – methods of:

Food and feeding preferences:

Toileting routine and procedures:

Evening or Bedtime routine:

Behaviors – what they mean, how to respond:

Prompting – reminders:

“Pet phrases”:

Other suggestions:



Master Point Record Sheet – BLANK MASTER

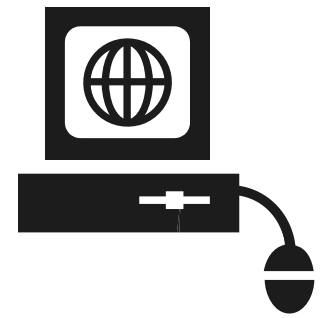
This is an example of how the co-op may keep record of care exchanged. Encourage members to notify the co-op bookkeeper immediately after respite care or exchange occurs to avoid mistakes.

Family Name: _____

Address: _____

Phone: _____

Date	We provided care for them (name)	Points earned (add)	They provided care for us (name)	Points spent (deduct)	Balance	Date /initials entered
	Starting balance					



Resources and suggested sites

There is a wealth of help available via the internet, including access to blogs (web logs), research, bulletin boards and news.

Respite Care Association of Wisconsin

<http://www.respitecarewi.org/>

Family Caregiver Support Network

<http://www.caregiversupportnetwork.org>

ARCH Respite Project

<http://www.archrespite.org/>

Wisconsin Department of Health and Family Services

<http://dhfs.wisconsin.gov/bdds/kbp/index.htm>

National Family Caregivers Association

<http://www.nfcacares.org/>

University of Wisconsin–Madison Waisman Center

<http://www.waisman.wisc.edu/index.html>

Wisconsin Family Caregivers Alliance

<http://www.uwex.edu/ces/flp/caregiving/>

Family Caregiver Alliance

<http://www.caregiver.org/caregiver/jsp/home.jsp>

University of Wisconsin Center for Cooperatives

<http://www.wisc.edu/uwcc/>

United States Department of Agriculture–Cooperatives

<http://cooperative.n4h.org/home.asp>