WHAT ARE WE LEARNING ABOUT CIRCLES OF SUPPORT?

A Collection of Tools, Ideas, and Reflections on Building and Facilitating Circles of Support.

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We would like to acknowledge all of the people we have met through the 25 circles of support in Connecticut whose experiences are reflected in this document. Special thanks to Cathy Ludlum for her gift of writing stories, particularly the two stories included in this document. Thanks also to Linda and Kevin Meadows who also contribute their story. We are grateful for the layout work of Chris Page who has helped us portray our ideas. We greatly appreciate the support and encouragement of the members of the Connecticut Developmental Disabilities Council.

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What Are We Learning About Circles of Support?

In January of 1987, Graphic Futures and Northspring Consulting received a grant from the Developmental Disabilities Council to work with five families in Connecticut. The purpose of this work was to help people clarify their goals, to identify obstacles and opportunities, and to bring together friends and community members to help overcome obstacles and find new opportunities. This grant initiated the beginning of five circles of support.

As of June, 1988, 25 circles of support in Connecticut are working toward unique but related goals. Each circle has chosen its own direction based on the wishes of the member with a disability. Some circles are working on housing issues, while others concentrate on improving school or employment situations.

Common to all circles is an emphasis on interdependence among people. Contrary to popular belief, independence is usually not achieved by an "I'm going to do it all by myself" attitude. The key is to establish and nurture relationships in which everyone is able to do something for someone else. Individual strengths and talents are multiplied as circle members join forces. Likewise, weaknesses become less significant because of the combined abilities of the group. People with disabilities and their families acquire more power to influence the direction of their lives through establishing new connections in the community, by changing the systems they depend on for support, and by overcoming personal barriers with the support of the people around them who are committed to the vision.

When we describe our work, people often want to know the details of creating a circle of support. Consequently, this monograph describes the start-up of a circle of support, the composition of a circle, the ongoing process of a circle of support, the proceedings of circle meetings, and other supports we find helpful to keeping the spirit of a circle of support alive. The process we describe outlines our experience in Connecticut and it is not intended to be a "blueprint" for all other circles of support. The spirit of a circle of support is far more important than the details of the process, and we hope that the process we describe will help people invite the spirit of support into the lives of other people.

How Is a Circle of Support Developed?

A circle of support is formed when the focus person, or a spokesperson for that person decides to ask for help from the people they know and they want to call these people together to focus and collaborate to reach a common goal. We begin to identify circle members by asking the focus person to help us make a "relationship map." A relationship map is simply a drawing of the people who are important to the focus person. We usually group these people into three categories; family members, friends and associates, and paid human service workers.

The relationship map is part of the background information collected as part of developing a Personal Futures Plan for the person. This plan is usually developed prior to the first circle meeting to help clarify issues and goals, and to help determine who should be invited to the meeting based on priority issues identified in the plan. A sample Personal Futures Plan for Cathy is included in Appendix A. The plan is continually developed and modified during the circle meeting, but it provides the initial focus for the group.

After the relationship map is complete and a Futures Plan is developed, we ask the person to choose who they would like to invite to the initial meeting. We help people extend invitations if they need support to do so. People have invited from five to 25 people to their first circle meeting. Figure 1 illustrates the people who were part of Cathy's circle in the beginning stages.

We find that circles change over time and that the circle members can be described by three levels of involvement. A small group often becomes the core of the circle. This core group usually attends each meeting, and they may work extra hard between meetings. The second group of circle members may be committed to the circle process, but they may be less involved. We find that resource people may come to a circle meeting once, and they want to stay informed; we know we can call on them if we need their help. They provide the third level of support. Figure 2 illustrates Cathy's circle of support after 18 months of working together.

Cathy's story reflects the intensity of the support circle's activities, and the development of her circle over time.

Figure 1: Cathy's circle of support in February, 1987

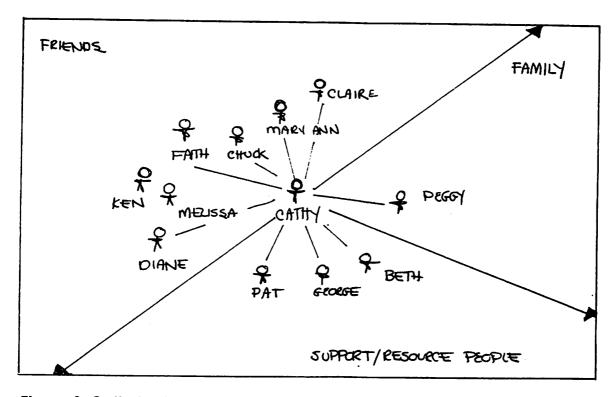
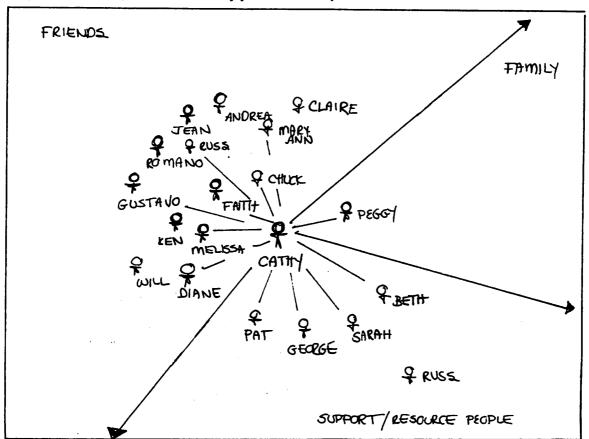


Figure 2: Cathy's circle of support in June, 198





For many years it has been my dream to get out on my own and live independently, I started looking into alternative living situations when I was 16 because I already knew it might take a while to find something that met my needs. Since respiratory problems are a side-effect of my disability, I have issues around being left alone for long periods of time. I consider anything over an hour to be a long time.

The first thing I did was to calculate the cost of hiring personal care atendants 24-hours a day. That idea went out pretty fast! It was impossible, both financially, and because I would live in constant dread that the next PCA would not show up, and I would be left alone.

I consulted a counselor who had helped a friend of mine become independent. He listened and understood, but couldn't solve the 24-hour problem either. He referred me to several other places, where everyone was sympathetic, but no one knew what to do. I was told that nothing existed out there for someone whose disability was as severe as mine.

I started writing away to communities where only people with disabilities lived. Some of these places were within Connecticut. Others were in the midwest or the north. I was more than willing to relocate if it meant staying out of a nursing home. I had always lived in neighborhoods where the majority of people were non-disabled, and I feared that

these communities would be isolated, but a nursing home would surely be more isolated. I wanted to live where I could feel free and safe at the same time, but could find no such place.

Next, I tried to start a group home for people with physical disabilities. I thought that 4 or 5 of us together could raise enough money to have someone with us on a 24-hour basis. Wrong again.

At this point, I had been searching for six years, I had graduated from college, but could see no other progress. An incredible sort of numb despair settled over my life. In addition to my housing dilemma, I discovered I was trapped by the financial assistance program that was supposed to be helping me (SSDI). Unable to get off of this program, yet not allowed to do much work while on it, I started a series of short-lived jobs, determined to think no more about my future.

I would continue to live with my mother, working where and when I could, and when she could no longer get me up and dressed and out of bed, I would go and live in a nursing home. I didn't like it, but I could see no other way.

This despair lasted for two years. Then I started working at the Office of Protection and Advocacy, and was invited to a series of workshops on community integration as part of my job. I laughed. Community integration was a

Reprinted from *THE P&A UPDATE* Volume 4, Number 3 Summer 1988 nice idea, but I had been told too many times that it didn't work for everyone.

All three workshops stressed that the only way to really be "safe" is to have people who care about you. All along, I had been thinking that if I only had enough money, I could buy all the help I needed.

During David Wetherow's presentation on the Prairie Housing Cooperative, I saw a woman who appeared to have even more complex needs than I did. Yet she was living happily, successfully — and safely — in a co-op. The people who lived with her and near her were there because they wanted to be. One was paid, but the rest were not. For the first time, I thought, "This could work for me!" I wrote in big letters on the evaluation form, "Call me if anything like this is developed here!"

Three months later, I received a call from George Ducharme of Northspring Consulting, and we began work on my housing cooperative. George introduced me to Pat Beeman, Beth Mount, and Sarah Page, all of whom facilitate different parts of the project. They, in turn, put me in touch with an amazing number of state and local officials, community organizers, co-op developers, and people with and without disabilities who are interested in co-ops.

Even more startling is the effect the project has had on my friends. The first thing I was supposed to do was round up a group of people who would be interested in helping create the co-op. I thought everyone would say, "Sure, I'll help you do research and make phone calls. Hope you find some good people to live there." Instead, three of our ten units were spoken for immediately. A short time later, someone who had joined our group to learn how co-ops could improve the lives of her clients asked if she could live there too.

Although I have many friends, most of them did not know each other until our first co-op meeting. All of a sudden, one member was calling another to say, "Thought you might be interested in this," or "Here's the address of that place I was telling you about." Small

groups met for meals or shopping, and six of us recently went to see Michael Jackson. These people were no longer just my friends — we were all friends.

One of the members of my circle spun off her own circle, and now has her friends working on a co-op with her. Another found a new job through someone else in the group.

Traditionally, a support circle is drawn as a multi-layered ring of people surrounding someone with a disability. We have found, however, that other people are in the center at times when they need encouragement or friendship. I like the idea that the circle isn't solely for my benefit anymore.

The co-op has already made a big difference in my life, and it isn't even built yet. For example, my mother used to be the only one who could drive my van. Now nearly everyone in the circle knows how to drive it. We not only take off for co-op meetings and housing conferences, but for lunch, concerts, or sightseeing.

My job situation is even improving, gradually, as I am asked to speak and write about the co-op, and do editing for some of the members. I am now thinking that after I finish writing my book, I would like to start my own business doing writing and editing.

Of course, being part of a circle does not eliminate individual tears or collective frustrations. But as we work together and share the good and bad times, we know the group is there to support us.

No amount of money could have bought the combination of freedom and safety I wanted. Creating a network of people who care seems like such a simple solution. But it works. And it doesn't only apply to me. We are all making each other safe.

Presented by Cathy Ludlum at "One Candle Power," an introduction to circling, which was held at the Gengras Center at St. Joseph's College on May 11.

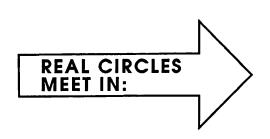
When and Where Do Circles of Support Meet?

Meeting time and location is essential to support the participation of circle members. We typically meet in people's living rooms, church meeting rooms, library meeting rooms, and other spaces that make it easy for everyone to attend. These spaces are selected because they are most convenient for everyone and they are accessible. We always meet in community meeting places and we rarely meet in human service settings.

Meeting times and places are based on individual preference.

We often meet at night or on the weekends in order to include everyone and to not interfere with day time commitments. Evening meetings and informal settings set the tone for a lively meeting. People often prepare snacks, and we celebrate a lot as part of these meetings. Children attend, and pets can spark up a meeting as well. The meetings have a set format, but they are also fun and intense at the same time. We laugh a lot. We also struggle a lot as we work our way through the obstacles people face and the complexities of each situation. The formal meeting requires about two hours. Often people stay much longer once the formal meeting is over.

Circles meet about once a month. Some circles have sub-committee meetings in-between large meetings in which much work gets accomplished. The process is intense, requiring numerous meetings, phone calls, and excursions. The focus person or spokesperson often leads these small meetings. Some circles take a vacation during the summer depending on the activities of the group.



- Living Rooms, Patio's, Back yards
- Church Meeting Rooms
- Library Meeting Rooms
- Civic/Town Hall Meeting Rooms
- Diners, Cafe's
- Other Places Close to Home

Observations From Circle Members and Circle Builders

"The circle building process is "elliptical." By elliptical I mean that the path a circle takes is not a straight line, that at times we move away from the dream or vision we are searching for as surely as we move back again toward it in another direction. No matter how intently we set upon the path, there are bound to be detours and dry places, stretches of darkness we fear we might never emerge from. Such doubts and distractions are not unusual. In fact, these difficulties are built into the very process of our growth together as a circle supporting the vision for an individual."

Pat Beeman

"The circle brings me new insights and visions from others that enrich and illuminate my own way."

Cathy Ludlum

"The work is more an art than a science. The solution is as likely to come from your imagination as from your rational mind. It's not a matter of designing programs but of creating visions; not of following protocols but fulfilling dreams. And believing in those dreams; believing that a woman who has been isolated could still have friends, or that a man whose life has been controlled could still escape and be free. Trusting that kind of vision means learning to hope."

From the Gift of Hospitality
Mary O'Connell

"As a result of my circle of support, I am more confident in making some waves rather than being status quo about a situation I would like to change."

Raymond Kilroy

What Happens During a Circle of Support Meeting?

A facilitator is essential to an effective circle meeting. The facilitator agrees to conduct the meeting by beginning the activities, keeping a record of the meeting, summarizing the discussion, and helping people make commitments to action.

The first circle meeting helps the group to focus. The facilitator has already met with the person with a disability prior to the first group meeting to summarize the current themes in the focus person's life, to clarify the goals of the person, and to gain an understanding of the obstacles and opportunities facing the person. We call this summary a "graphic future" because it provides diagrams and pictures of a person's life. Appendix A provides an example of this document.

We distribute and review this document with the members of the group. We discuss the role of the support circle and describe the process by telling stories. We identify a focus for the group, and spend the rest of the meeting brainstorming strategies for action. In the last ten minutes of the meeting, the facilitator reviews the strategies and circle members make commitments to act on the strategies that seem most important. Five to ten action items with commitments are the result of a productive meeting. The group decides on the next meeting time and place before the group adjourns. Figure 3 summarizes the steps of the first meeting.

The first meetings are a time of reflection and clarification while follow-up meetings provide an on-going opportunity to strategize. The first meetings are very revealing because circle members become aware of the barriers faced by the person with a disability. The first meetings provide an opportunity for members to clarify their values and share their experiences. This first meeting is critical because it clarifies a focus and creates solidarity and commitment from participants.

Agenda for the First Support Circle Meeting

1. Introductions of all circle members.

How long has each person known the focus person and how did you meet? Other questions that help people get to know each other.

2. Review the Profile.

Clarify current patterns. Add to existing information.

- 3. Clarify the ideas about the future. Review Obstacles and Opportunities. Discuss these directions and select a priority.
- 4. Brainstorm strategies for action.
- 5. Record obstacles and opportunities as they arise.
- 6. Make commitments for action.
- 7. Set the next meeting time and place.

George Ducharme

[&]quot;The gifts of each person participating in a circle can make a difference. It is possible for anyone to contribute to achieving a vision."

Follow-Along Meetings

The follow-along meetings are equally important in a different way.

We begin the follow-along meetings by reviewing the priorities from the last meeting. Members then share their activities and accomplishments. We record the actions of the group into two categories: "Things that work: new opportunities, positive findings" and "Things that don't work: new barriers, negative findings, more obstacles." Following this reflection on group activities, the group re-strategizes, makes new commitments, sets another meeting date, and begins the cycle again.

Agenda for Follow-Along Meetings

- 1. Review commitments from last meeting.
- 2. Members report on progress. Information is sorted into new opportunities and new obstacles.
- 3. Brainstorm new strategies.
- 4. Record obstacles and opportunities as they arise.
- 5. Make commitments to action.
- 6. Set next meeting time and date.

What Do The Members of a Support Circle Actually Do on Behalf of People with Disabilities?

Circle members contribute many gifts to the process of building a better future for the focus person. Circle members contribute whatever support they can and these contributions vary greatly from circle to circle.

The following examples of circle member activities provide a sample of the many ways circle members provide support. It is easy to see from these examples that a variety of resources become available when the group members are quite diverse, representing a variety of connections, perspectives, and ideas. Circle members help people by:

- Bringing their ideas to the group and their connections to the community.
- Finding jobs and arranging job supports.
- Helping people find respite providers and personal care attendant supports.
- Helping people acquire the furniture they need to move into their own apartment.
- Helping someone learn to read. They help a young person do his homework.
- Helping a person join community associations.
- Helping children become part of the public school scene.
- Helping children ride the school bus with other children.
- Programming communication boards with hip words.
- Helping people move out of nursing homes.
- Helping people start up their own business.
- Helping people build or join housing co-operatives.
- Asking local reporters to write stories about the circle.
- Representing people's interest in town meetings and school boards.
- Sharing rides to important events.
- Helping people interpret policy. They go with people to interview policy makers about benefits.
- Helping human services be more responsive to people.
- Talking on the phone a lot.
- Sharing the frustrations people feel as well as celebrate accomplishments.
- Deepening the friendships and commitments made between each other.
- They help people celebrate their birthdays as well.

What Do Support Circles Accomplish Over Time?

The actual accomplishments of each support circle also vary greatly. Some circles solve problems right away with the extra support and a different focus. However, many circles are working on complex issues that take a long time to change. Many circles work to integrate children into public school. This requires constant and continual collaboration with school systems. Other people are working to move into Housing Co-operatives. These housing options do not exist, or when they do exist, people must identify and arrange for Personal Care Attendant support. Many people need services that do not exist. They must work at a policy level to support change.

Focus people and circle members certainly become discouraged. We find that "circles have cycles." Circle members go through periods of great struggle and long periods of hard work when opportunities are hard to see. These periods of struggle are often followed by "breakthrough" opportunities in which positive outcomes occur at a rapid rate, and then people are faced with new sets of problems.

Consequently, we look for small wins along the way. We try to find ways to renew the vision and the work of the group. The following story of Kevin reflects the outcomes of an on-going process of struggle and celebration. Both adults and children meeting together in Kevin's living room and at high school worked together with school officials to make Kevin and his brother Jason's vision for the future into a reality.

"Small successes keep us going, and sometimes may be the most important thing. We must always remember to celebrate the small wins to give us energy to go forward."

Pat Beeman



Kevin attended Newington Children's Hospital School for 13 years. But because the students all came from different towns, they tended to scatter as soon as school was out. So Kevin never had the opportunity to make friends or to form any lasting relationships at this school.

After awhile we had to make a move, so we sent Kevin to the Regional Occupational Training Center in Manchester. But again, the kids were bussed in from all over, and he couldn't make any friends.

When we started our circle, we invited some close friends who had kids, and asked the kids what they thought Kevin needed. Our younger son, Jason, said that if Kevin thought his school was rough, he ought to try going to a regular school. All the kids agreed that Kevin should go to our local high school, RHAM.

At our meetings, the kids told us who the best teachers were, and figured out who could help Kevin with different things during the school day. The school psychologist was on our side, and he took down all their ideas. At first, we were only able to get Kevin into RHAM once a semester. But when it was time for the PPT, we invited so many people that we almost couldn't get everyone into the room. Students spoke about how good it would be to have Kevin in school with them, and explained how they thought it could work. By now, not only

the psychologist, but all the special ed and regular ed teachers, administrators, and other team members were becoming enthusiastic.

Now Kev is attending RHAM full time, and he is working above the capacity anyone thought he had. He has made friends on the basketball team, so he is always going to games. He has joined Peer Leadership, an afterschool club involved in community service.

People want to help if you just tell them how. We never could have done this without the support of our friends.

Presented by Linda and Kevin Meadows at "One Candle Power," an introduction to circling, which was held at the Gengras Center at St. Joseph's College on May 11.

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What Are We Learning About Building Circles?

We have changed many of our initial assumptions during the 18 months we have worked with circles of support. Our experience mirrors the "seven truths about circles" identified by Marsha Forest and Judith Snow.

We summarize these truths below and add a few from our own experience.

- 1. "Circles often form around two people who are in a strong relationship, where the advocate speaks for the challenged person. This is certainly true for parents who speak for a young child with a challenging need. The ideals of the circle are more likely to be achieved when an advocate or special partnership exists within the circle."
- 2. "Strong circles usually form around a person who herself/himself want to change. Such people make phenomenal changes in their own lives once they have the required circle of support. On the other hand, you cannot force a circle on someone who is content with life or afraid to change."
- 3. "The person who is the focus of the circle will grow in direct relationship to the honesty and commitment of circle members. Her/his vision is shaped and brought into reality by a combination of deep listening, caring, challenge and committed effort on the part of each circle member."
- 4. "The purpose and direction of the circle is defined by the dream of the focus person. When a circle loses touch with the dream of the "circled" individual, she/he will subvert or stall the process by getting sick, behaving badly, or otherwise holding up the process until real listening happens again."
- 5. "If a circle is too small, everyone will feel under pressure. Invite more people to join! If a circle is too big, people will quit because they don't have enough to do. The size of the circle is dependent on how much the "circled" person wants to change and how fast. Small circles form around little dreams; big ones are needed for big changes."

- 6. "Circles often come into being first during a crisis because this is when the "circled" person figures out what they really need instead of tolerating and adjusting to things as they are. A circle can form without a crisis if the central person is prepared to ask for what she/he really needs."
- 7. "Because it is often difficult for a person who is devalued or his/her advocate to tell the dream or ask for what they really need, it is often necessary for a facilitator to work with the person (s) during the formation of the circle, or at other times when the groups gets stuck. Such a person must be deeply committed to the value of relationships instead of therapy in a person's life. She/he must be a good listener, ready to love and challenge the circled person to reveal the empowering dream. The facilitator must trust the circle members, helping them to value the story and the person behind the story. The facilitator must also be clear about the amount of time and the number of meetings she/he can spend with each circle in order to maintain everyone's trust."

Other truths about circles we have observed:

- 1. Most circles find a focus over time. They may begin with a big vision that includes change in many areas of life, but they sharpen the vision over time by choosing one area of life that is a priority. This is particularly important when change is very complex people can face greater levels of complexity when they look at one piece of the picture at a time.
- 2. We spend a lot of time supporting people to make decisions. We often work together with focus people to make "decisional balance sheets," a process where we lay out the advantages and disadvantages of each option. This is often done visually to help all of us make sense out of many diverse alternatives.
- 3. Most available service supports do not "fit" people's needs. The circle helps people hang onto their desires even when services do not exist, or when they are mismatched to need. An informed, responsive service provider willing to work to shape services to fit people is a real resource in a circle.

How Are Circles of Support Different From Other Planning Groups?

Planning futures for people has become fashionable in the field of disabilities. Many human service workers are seeking to improve the individual planning process so that plans reflect the preferences and interests of people with disabilities. They are working to change human service organizations to be more supportive of quality of life experiences determined by the focus person and people who know him/her well. We refer to these efforts as "person-centered planning" and strongly support these new directions.

However, building circles is very different from other types of individual planning in human services. A circle of support forms and operates totally in the interest of the focus person.

The focus person and/or his/her spokesperson determine every aspect of the circle including membership, setting, image of the future, frequency of meetings, etc. The circle does not "belong to the system." The circle is located and depends on local community for its effectiveness.

We have provided two forms of comparison to illustrate the differences we see between various types of planning. The first compares traditional, interdisciplinary team planning, person-centered planning, and circles of support. The second lists what we have found is and is not a circle of support

Traditional Planning	Person-Centered Teams	Circles of Support
Purpose of the Planning	Meeting:	
To coordinate services across disciplinary lines. To clarify staff roles in the implementation of training programs.	To establish a common vision for all staff. To discover information needed to focus organizational change.	To establish and support a personal vision for an individual. To build community support and action on the behalf of the focus person.
Composition of the Tean	n:	
Professionals and specialists.	Professionals, direct service workers. May include focus person and family.	Focus person and his spokesperson, family, friends, and associates. May include some human service workers.
Where Does the Team M	eet?	
Human service setting conference room: centralized site.	Human Service Setting close to direct service workers: group home, workshop: decentralized site.	Community setting: living room, church room, library meeting room Places close to where members live.
How Often Does the Gro	up Meet?	
Once a year with quarterly reviews.	Major investment in initial sessions. Quarterly or monthly reviews.	Once a month with many sub-meetings in between for on-going problem solving.
Who Initiates the Meeting	g for What Purpose?	·
Team Leader initiates to meet requirements of regulations.	Organizational change agent initiates to find new directions for the organization.	Focus person or spokes- person initiates to reach goals they are unable to accomplish working alone.
What Motivates People t	o Attend the Meeting?	
Avoidance of punishment by regulators. Interest in coordination of departmental units.	Interest in organizational innovation and finding new directions for focus person.	Voluntary commitment by people who are interested in helping someone they care for.

Traditional Planning	Person-Centered Teams	Circles of Support			
Nature of the Images for t					
Goals will fit within existing program options.	Goals will reflect new program models and options yet to be developed.	Vision will reflect desire of focus person and family.			
Roles of Members and Bo	undaries of Action:				
Members have specific roles and clear boundaries for action. Plans do not change roles or boundaries. Members act within formal existing organizational channels of authority.	Members roles will change based on new directions. Old boundaries for action may be changed to allow for new action. Plans may change roles and create new agendas for action. Members create new channels and connections to accomplish their goals.	Participant roles are constantly changing based on tasks. Boundaries for action are defined by personal vision and commitment of group members. Members use informal networks and contacts to open doors in community.			
Product of an Effective Gre	oup Meeting:				
Completed forms, paperwork. Specific goals to use to evaluate program effectiveness	An agenda for organizational change. A shared understanding of new directions for change.	Commitments to action by community members. Significant quality of life changes for the focus person.			
Role of Human Service Wo	orker:				
Set all direction. Organize all activity. Coordinate direct service worker activities.	Mediate interests of providers and focus person. Lead organizational change efforts. Listen to direct service workers.	Support directions defined by group. Increase knowledge of available resources. Provide direct services to focus person.			
Role of Community Memb	Role of Community Members:				
Not involved in the process.	May help implement some ideas.	Generate and implement plan and action steps.			
Role of Person with a Disal					
Comply with the plan.	Cooperate in the development of the plan.	Direct plan and activities.			

A Circle Building Process Is —Is Not:

IS	IS NOT
• About capacity	About deficiency
• A hope for something better with more options and possibilities	An answer to the service system
• Empowerment of individuals	Control of individuals
• Person—centered	Service—centered
• Shared roles within circles	Not singular control
• Building gifts/connections of people to make things happen	About relying on one overworked manager
 A network of people consisting of friends, families, neighbors and those who know the person best 	 People who have never seen or been a part of the person's life but may be on paper only
• All members are equal, contrib- uting members to the circle	About titles, power or position
• Interdependent	• Dependent
• Role as about facilitation enabling, empowering	About group control
• Flexible	• Rigid
• Bound up in relationships	Bound in a paper process

What Do Facilitators Do?

We have been trying to understand our roles in the circle of support process. Each of us, Pat Beeman, George Ducharme, and Beth Mount, have shared our individual gifts to accomplish a unified goal of assisting as many people and families as possible to articulate their visions and build the circles of support to make the vision real. We recognize that the support we provide outside the support circle helps stimulate the activities of each group. This section outlines a number of roles we provide to facilitate the circles of support.

The overriding theme of our role is to be present and to be responsive to each person and family with whom we are associated. Listening carefully with all our senses is fundamental to our process. We must listen to the individual and family and focus our efforts to support them, rather than projecting our views and our ideas onto people and expecting them to follow our plan. What people really want matters to us, and they don't have to dress up their ideas to fit what they know is currently available. We find that listening is the essential role for one who wishes to empower and enable another

The following list outlines many of the roles we assume as part of this process.

- 1. Catalyst: We plan with people not for them. We may influence the development of new options for people by providing additional ideas related to the vision of each person, but we start with what people want first, then see what else we can add to enhance the original vision.
- 2. Enabler: We facilitate the circle activities but we do not direct these efforts. We do not take responsibility for most action steps, but we provide support and encouragement for those who make commitments to action. We back up these action efforts when needed. We will go to meetings with people, make phone calls, build connections, and open doors also, but we wait to see what commitments the circle members have the energy to make before stepping in to action ourselves.
- 3. Broker: We do assist people to locate and use various resources. When someone is not "eligible" for a needed service or a needed service does not exist, the broker seeks to change those conditions so people can get what they need.

- 4. Bridge-builder: Our role as bridge-builders is discussed in detail in the monograph "What are we learning about community bridge-building?" As bridge-builders we help people make new connections to new opportunities, new people, and new places that may help people accomplish their goals. We stimulate other circle members to use their connections to make things happen.
- 5. Advocate: We do provide leadership and take a stand with people when they need information and resources. Twice a year we publish a policy analysis statement to summarize the system's issues that block people from reaching their goals. We work to stimulate policy change in the identified areas.
- 6. Circle Facilitator: We are active at most meetings calling meetings to order, taking minutes, organizing information at meetings, recording strategies and getting commitments from group members.
- 7. Leadership Developer: We are always seeking to increase the capacity of the group to become autonomous. We identify circle members who can facilitate meetings, and work with these people to support them in a leadership role.
- 8. Forum Organizer: We plan and coordinate four forums a year based on the issues people face in their groups. The purpose of the forums is to bring a number of people together with external resource people to strengthen the vision people have and find new strategies for implementation. We include important policy makers in these forums to build support for the ideals we are seeking to accomplish.
- 9. Troubleshooter: We try to work with difficulties that arise within the circle or with the individuals as they encounter obstacles. We provide on-going presence between circle meetings to ensure that people feel movement toward their goals. We meet individually with people to discuss frustrations or conduct problem-solving sessions.

Conclusion

This concludes an overview of the ideals, processes, and experiences that are teaching us how to help people with disabilities build a community of support that ultimately benefits all members. We hope these ideas provide a menu of tools to help people on their journey of building circles of support. Each situation is unique and must be approached individually. Each circle developed in Connecticut adapts these suggestions and materials to fit the dynamics of each situation.

It is difficult to describe the most important quality of a circle of support which is the real essence of a support circle. There is a spirit to these circles which is enlivening to all of us, even if we face great obstacles to reaching certain goals. This is the spirit of cooperation, of reaching out to one another to accomplish something that truly benefits the quality of life of another person. We have all been inspired by our work together for we feel deeply that we are building a stronger and more responsive community for all of us.

George Ducharme helps express the essence of a support circle by his image called "One Candle Power." One candle alone has the power to give light, and we empower one another by passing the flame. If we give our gift or flame to another, our flame will not be diminished, but there will be more light. The circle of support helps us ignite and inflame the desire and will in all of us to bring out the best in each other. By working together we overcome obstacles that we are unable to change by working alone. By giving our gifts, or energy, and our hearts to each other we become empowered to build a future we desire. This is the gift of a circle of support.

Ar	pendix:	

PERSONAL FUTURES PLANNING for Cathy Ludlum, Family and Friends.

FINDING DIRECTIONS FOR CHANGE AND LEARNING TOGETHER HOW TO MAKE THINGS HAPPEN for Cathy and for the Community of Wethersfield

Beginning worksheets, March 4, 1987 Planning Meeting: March 21 Cathy Ludlum and Mrs. Ludlum

Claire, Mary Ann, Lynn

Ken Butler and Melissa Marshall

George Ducharme and Pat Beeman Andrea Clark and Diane Berlinski Chuck Hulburt and Beth Mount

Discover capacities.

Find directions for change.

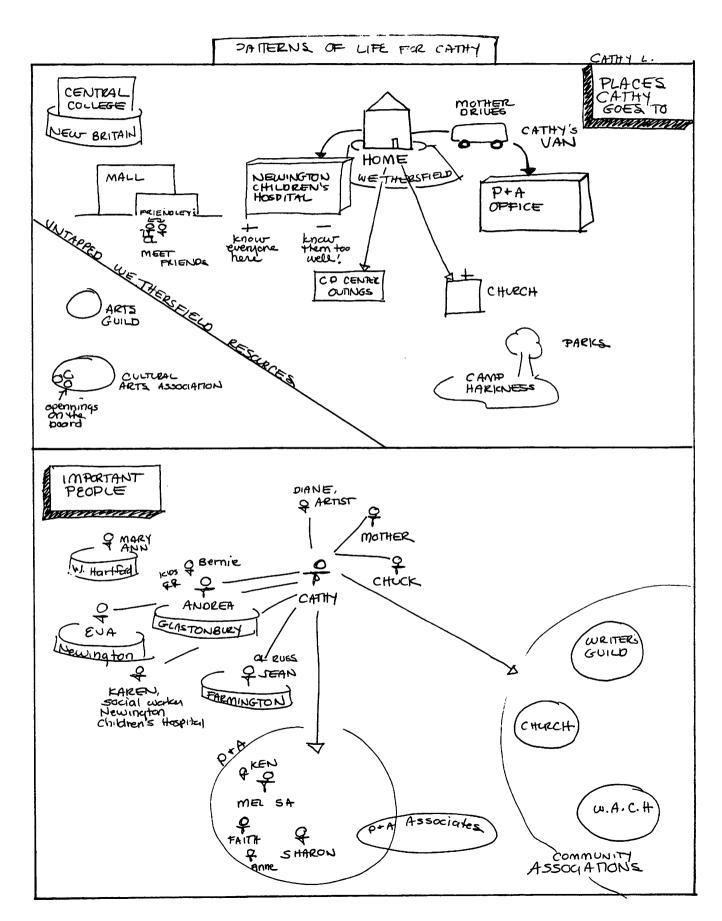
Identify obstacles and opportunities.

Generate strategies.

Make commitments.

Reflect on what we are learning together.

Patterns of Life for Cathy



Cathy's Preferences

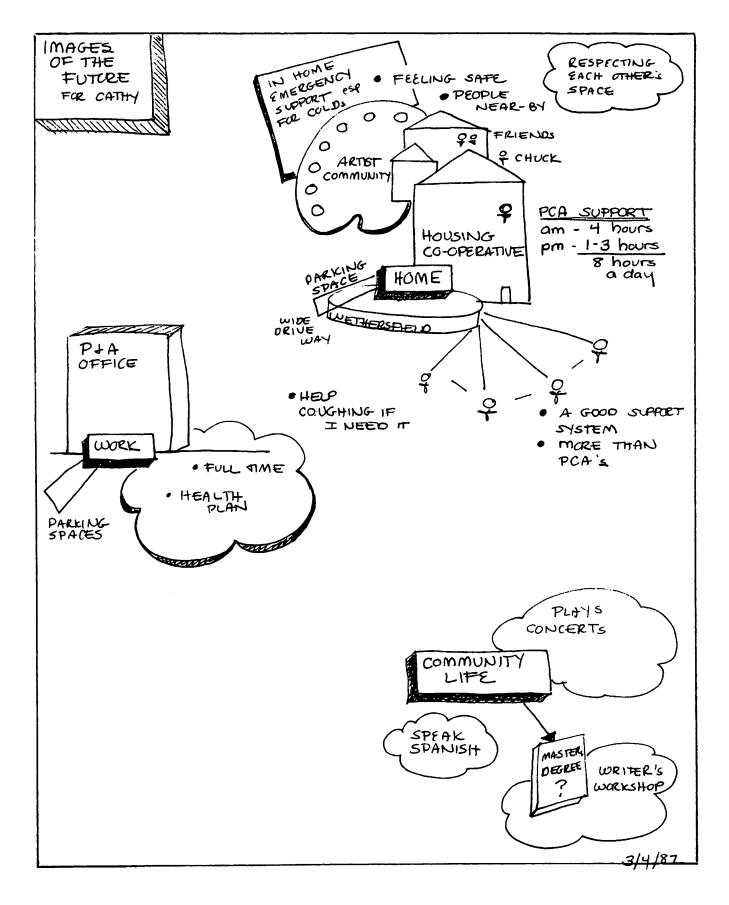
THINGS THAT WORK Engaging, enjoyable, motivating:

- Being a writer.
- Being with people.
- Disability issues including participating in advocacy groups, writing and public speaking.
- Politics, politics!
- Public speaking.
- Having a slow and flexible pace.
- Going to meetings and conferences, and other places.
- The job at Protection and Advocacy.
- Relatively secure work with benefits.
- Room to grow and change.
- A job with insurance, or having a Medicare and Blue Cross supplement. (i.e. I need one or the other).
- Having a good van.
- Increasing numbers of people who can drive the van.

THINGS THAT DON'T WORK Frustrating, upsetting, boring:

- Having weak lungs; I have to have help if I need to cough.
- I can do a lot, but not very fast. For example, it takes about 2 hours to eat.
- I have to remember and plan to eat, because it takes so long and I'd rather be doing other things.
- When everything takes a long time, people often don't understand.
- Not having parking spaces at home or at work.

Images of the Future for Cathy



THINGS THAT WILL HELP; OPPORTUNITIES:

- The housing co-operative idea.
- David Wetherow's vision of an artist's co-operative.
- Ed Preneta is looking into government loans for co-ops.
- Sarah Page in Belchertown, Mass. is becoming an expert on co-ops.
- Cathy has received the PCA program from DHR that pays \$7,300 a year.
- P and A is attempting to get Cathy a full time job with benefits.
- George knows people in the artist/ writer community; Bob Perske, Ted B., Tot Avis, Judy in New Canaan.
- Having a good job at P and A.
- Cathy has Medicare and SSDI tied to father's work record.
- Blue Cross Supplement.

OBSTACLES AND FEARS:

- The co-op idea is very complex. How do we do it? How do we get the money?
- Personal Care Attendant costs, building trust and accountability in PCAs. Learning how to manage PCAs.
- If anything happens to my mom, I have no where to go.
- DHR PCA program is not enough we need about \$18,000 a year.
- If Cathy lost her job, or couldn't work, she would lose the PCA support.
- If Cathy gets sick, she needs a lot of help. A cold can put her out of work for two weeks or more.
- Will have to have insurance to pay for in-home nursing care if she gets sick.
- The current P and A contract arrangement enables Cathy to keep
 Medicare. Consequently, it is a small contract, with low pay.
- Cathy faces the possibility of becoming more dependent over time.
- If she lost father's SSDI benefits, she would not have enough of a work record to get back on.
- Using community medical resources is hard.
- If we use a 3 family house to create a co-op, we would have a problem with parking for 6 cars and those of guests and PCA's.
- Someone has to drive the van back and forth to work.

Strategies from March 21 meeting at Cathy's house

Strategies reflect the brainstorming during one group meeting. The headings are included to provide a guide to the actual discussion. Commitments are made to focus the action of the group.

- Insurance
- Personal Care attendant (P.C.A.) Issues
- Housing Co-op Issues
- COMMITMENTS FOR GETTING STARTED Next meeting date: May 2, at 2:00.