

This is an Excerpt from *Members of Each Other*.
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The complementary and creative nature of these polarities can be described by mapping them onto the *Ta Ki*-symbol of the balance of the two great forces of *yin-yang*.

Reflections on Support Circles

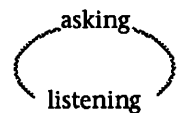
Circles arise from consciousness of our great need for each other.

Sometimes circles begin by attaching this need for others firmly to the person in the center: "She is isolated and needs us." Unless this narrow beginning leads to a dawning awareness of interdependence, of our deep reliance on one another for a good life, the circle will turn into a sort of a square. It will become a soulless project about disability which is motivated by pity, or by an abstract desire to perfect an impersonal system for processing deficiencies.

Circles arise from action that grows out of awareness of our great need for each other. The flow of this energy between holding questions and creating answers energizes circles. As the picture on the facing page suggests, circle facilitators work with the flow of energy between at least five sets of poles. On the light side of the circle are processes for creating. On the dark side of the circle are processes for holding. Each process calls for its opposite, and thus the circle is animated.

Circles begin with **asking** people to come together and then **listening** carefully to the life story of the person in the center: past experiences, present realities, and future aspirations. Listening together feelingly, intuitively, thoughtfully, and with each of the senses leads to a shared glimpse of the person's dream: the threads that give this particular life significance and meaning; the threads that animate this person's particular contribution to our common life; the threads that glow when this person is passionately engaged. A glimpse of someone's dream organizes and motivates efforts to help that person to establish the living conditions and develop the opportunities necessary to allow the person's identity to unfold.

Listening leads back to asking: asking circle members to move through fears and uncertainties to say clearly what they most want to create for themselves and for one another; asking one another for commitments to the action steps that will trace a path toward what they most want; asking others for cooperation, for resources, for access to opportunities.



The Support Circle Mentoring Project, which is funded by the Pennsylvania Developmental Disabilities Planning Council, gathered people involved with facilitating circles to share what they are learning. This chapter is a reflection of their thinking.

Asking leads back to listening. What more can we sense, think, feel, and intuit now that we have come this far? What more can we ask?

inviting
following

The circle follows the person in the center by accommodating particular preferences about how this person wants others to listen, and by making agreements about which aspects of how this person wants to live that circle members will work to make happen. **Following** leads to **inviting** out of an honest wish to broaden this person's horizons or an insight into a gift or ability whose possibilities this person may not realize.

Inviting leads back to following as the circle asks: "What does this person make of a new experience?" "What does an opportunity to exercise an unrealized possibility draw out of this person and those this person relies upon?" This move back to listening is especially important when a person is vulnerable to other's impositions -maybe because this person depends on others for assistance, or because this person has very limited experiences and ability to clearly communicate preferences.

reaching out
gathering

Circles **gather** those who know and care about a person within their circumference. As those within the circle gain clarity about their goals, they usually discover the need for additional members. Sometimes they will **reach out** to people from the person in the center's past: lost or estranged family members or friends who have gotten out of touch. Sometimes they will reach out to people with the knowledge, skills, resources, and gifts to help the person at the center build strength, explore an emerging interest, or gain access to a needed opportunity. Circle members may locate these new people among their own families, friends, or acquaintances or they may go looking for them on the person in the center's behalf.

Reaching out leads back to gathering as the members of the circle become scattered into diverse activities, or lose touch with one another, or with the circle's purpose and focus. This can happen when the work becomes hard, or after a success.

impatience
endurance

The circumstances of many people with disabilities cry out for **action against the injustice** that constrains their lives. From childhood, many people with disabilities suffer enforced exclusion from ordinary places, activities, and experiences; arbitrary control that restricts elementary liberty; poor support and second class service; and, too frequently, neglect and abuse. Some circles act directly to confront unjust treatment and demand changed behavior or different services (as when a circle helps a child gain access to an inclusive school experience); others work to help the person in the center to create new circumstances (as when a circle helps someone establish their own home instead of trying to reform a nursing home).

Because many injustices are systemic, and entrenched behind unconscious myths of people's inability and inequality, many changes which seem self-evidently right to circle members turn out to be much more difficult to make than they predict. The ability to **endure what remains unyielding** in the face of even the most disciplined action is fundamental to the continuing life of the circle.

structuring
uncertainty

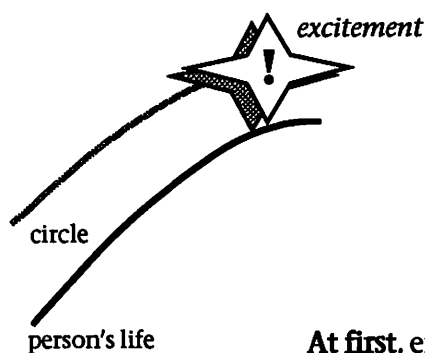
Circle members create **structure** when they set goals, gather and organize information, make and revise plans, construct time lines, accept assignments, and act purposefully to implement their plans. However, circles are not agencies: they don't control staff and budgets that they can deploy to achieve their goals. Their ability to act depends on their ability to enlist cooperation by enrolling people in their vision. Furthermore, the focus of a circle is on the life of the person at the center, not on the completion of a project. New information, new contacts, new experiences, and new relationships can lead to unpredictable changes in direction. So can unexpected barriers and intractable problems.

Structure calls out the capacity to **tolerate uncertainty** and surprise. If circle members need a guarantee that their plans will work before they set out, they will be paralyzed by their lack of formal authority. If circle members judge their efforts solely in terms of objectives achieved on time, they will often be plunged into disappointment. What is wanted is the courage to walk together into uncertainty and the openness to seek new possibilities as things change.

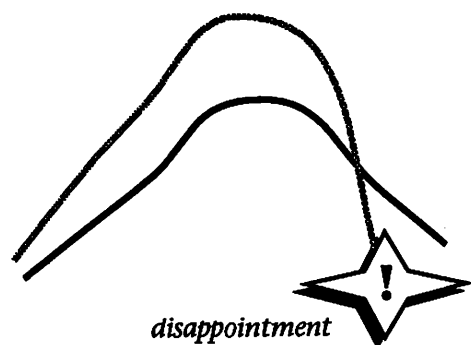
Tolerance of uncertainty and openness to surprise lead back to structure as circle members organize and re-organize around new defeats and new possibilities.

Sustained interdependence calls for many turns into the holding processes to find and re-find direction, to collect and recollect relationships that have become scattered, to discover and rediscover meaning, to sustain and renew energy. The difficulties imposed by the pervasive effects of the social devaluation of people with disabilities make listening, following, gathering, enduring, and tolerating uncertain outcomes particularly important in walking and standing with people with disabilities.

Finding the rhythm

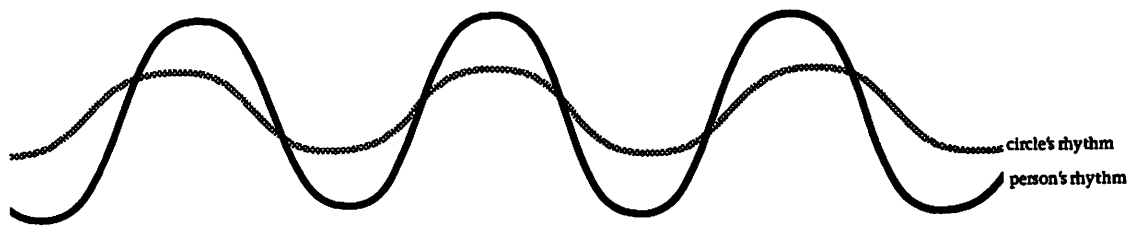


At first, enthusiasm for the circle rises rapidly, as members see the possibility of positive changes for the person at the center and some first steps improve things for the person.



But, a downturn in the person's situation can cause initial enthusiasm for the circle to crash. The same excitement that took circle members up, brings them down as inflated expectations hit real life barriers. Some of the signs of this crash include, circle members feeling...

- Discouraged, "Nothing can really happen."
- Resentful or angry because people who 'should' help refuse to respond as expected or fail to follow through.



- Alone, like “I have to walk up this steep hill all by myself because I’m the only one the person in the center of the circle can really count on.”

Our hope is to renew ourselves by seeking a kind of consistency in the life of the circle: highs that aren’t so high; lows that aren’t so low. As circle members learn to count on each other, the circle can be one source of stability as life goes through its upturns and downturns for the person at the center. This can only happen if circle members learn and practice the arts of renewal...

- Letting our disappointments and our sense of aloneness exist openly between us.
- Offering each other mutual support and encouragement.
- Challenging one another to live up to our commitments and follow through on what we agree to do.
- Sticking with one another in hard times.
- Forgiving and reconciling when members let one another down or offend one another.
- Reaching out to include others who can help.
- Being careful about making final judgements about outcomes. Many good things have come out of -or at least after- discouraging times.
- Remembering the values that brought the circle together and deepening our understanding of them in the shadow of difficult times.
- Celebrating what has happened and the relationships that have grown and endured.

Metaphors for the work of facilitating circles

This work is like...

- Organizing a **quilting bee** -bits and pieces come together through shared efforts... the whole pattern emerges from the vision of a pattern whose final appearance depends on the pieces each person contributes... lots of gossip is exchanged
- **Midwifery** -low tech/high touch support to a natural process... intimate and respectful... a position of services... position and intensity of support varies as needed, based on care-filled listening and watching... competition from others who want to professionalize and mechanize
- **Uncovering** buried treasure; treasure whose value some people will be unable to sense, even when it is uncovered
- **Teaching fearful people to use fire** for heat, light, and uplift (as in filling a hot air balloon) when, out of fear, they want to pour water on the fire
- **Weaving** a spider web
- **Gardening**... planning (and not necessarily following the plans exactly), planting, weeding (and procrastinating about weeding), fertilizing, waiting, harvesting, nourishing, sharing
- **Joining a family**
- Creating **ripples** in a pond by throwing in a stone... or several stones to see the patterns of ripples overlap
- Following in the path of "The Man Who Planted Seeds"
- Riding a **roller coaster** with a loop-the-loop ...thrill and fear are right next to each other
- Being a **juggler** keeping seven plates spinning on top of sticks... but remembering that I don't have to do the act alone -if I ask others to help and make room for them instead of pushing them out of the way
- Being **alone** on a boat in the middle of the ocean (no one I work with seems to get it)
- **Baking brownies** - the recipe says "beat until slightly lumpy"... you can bake all kinds from hard to soft depending on what different people like

Circles and Agency Change

Jay Nolen Community Services in Los Angeles, CA transformed its residential services between 1993 and 1996 by assisting more than sixty people with autism to move from its group homes into their own homes and apartments and then closing its group homes. Circles of support planned and managed each person's transition and maintain responsibility for assuring that people receive adequate services. Their experience provides important insight into the ways circles function when an agency is serious about following their direction.

Circles were an important part of the development of supported living in at least two ways: they provided a forum for decisions about individual supported living arrangements and they gave people a way to contain the anxiety and uncertainty of major change. The requirements of moving have set the circle's agenda. Where should the person live... with whom... with what assistance... how should the place be furnished and decorated? In the period just after the move problems -sometimes big problems- of establishing a household and a support system, and sharing good news about the effects of the move, paced the circle's meetings. These practical issues provided the context for sharing and organizing knowledge about the person's preferences and capabilities and needs and the resources available to the person.

A new constitution

Once a person has moved and things are reasonably stable, the circle needs to re-constitute itself. Its members need to agree on a new constitution by discussing and coming to agreement on these questions:

- What is the purpose of the circle? What contributions does the circle want to make to the life of the person with autism?

- Who is the focus of the circle? This is not as silly a question as it may first appear. Sometimes the actual focus people in a circle are the person's parents in their role as key decision makers and resource people for their son or daughter. If this is so, it should be clear.
- Who belongs to the circle and what are the obligations of membership? The process of moving brought people into the circle as issues arose. Are all of those people circle members; do they want to be active contributors? Does the circle want to have a "reserve list" -people who don't want to be active unless a particular need arises? Are all of the staff involved with the person circle members? If not, who will link the circle's work with them? Are there other people to invite into the circle?
- How does the person with autism participate in the circle?
- If the person has a conservator, how does the conservator see the role of the circle in assisting them with their legal responsibility of making decisions in the person's interest?
- What ground rules does the circle want to adopt, and what skills do its members want to develop, in order to build honest communication, creative problem solving, and the capacity to understand and negotiate conflicts?
- considering these questions, circles should first take time to carefully answer two questions,
- Now that the person lives in his or her own home, what is most important to work on now in order improve the person's life?
- What are our markers and measures that the person is experiencing a good quality of life? What signs will show us that there is a problem we must attend to?

The circle's answers to these questions will provide a foundation for the circle's renewed constitution, so in answering them it is important to think beyond just keeping the person from harm. The skills in personal futures planning and group planning (PATH) that the agency has invested in developing will be helpful to circles in this work.

It will be important for each circle to ask, "How can we adapt the way the circle meets and works to accommodate the person's strongest ways of participating and communicating?"

The politics of circles

Some involved people speak negatively of “politics” in circles. But politics doesn’t have to be a negative term. In an important way circle meetings are political meetings: they bring people together who have different points of view and different interests and provide a forum for them to discover common ground and organize shared action. The politics of circles only turn destructive if members are dishonest or manipulative.

One way to make circle politics healthier is to surface important disagreements among circle members. Discussions around a renewed personal futures plan provide a good context for mapping such disagreements. Seven common kinds of disagreements can arise:

- Disagreements about people’s vulnerabilities. For example, some people believe that imprecision in administering prescribed medication has severe consequences for a person and others believe that occasional variations in timing or dosage make relatively little difference.
- Disagreements about what staff activities must be performed (“non-negotiables”) and what staff practices are optional, depending on circumstances and individual preferences.. For example, some people believe that systematic effort to assist the person to develop friendships is a necessary part of the job; others see this as much less important or even a waste of time because the person with autism is disinterested in friendships.
- Disagreements about a person’s strong preferences. For example, some people believe that work matters very much to a person; others believe that the person would rather not work and that the desire is being imposed on the person.
- Disagreements about preferred and reliable methods of communication. Some people believe that a person communicates effectively with facilitated communication; others believe that the person is or was being manipulated by facilitation.
- Disagreements about a person’s ability to provide meaningful direction of assistants, regardless of the communication system the person uses.
- Disagreements about how to interpret people’s behavior. Some people read a person’s difficult behavior as an attempt at manipulation; others read the same behavior as a request for a different sort of relationship.
- Disagreements about how the agency’s organizational structure should function: “Who is, or should be, responsible for handling what.”

- Disagreements about the future role of the circle and the future responsibility of parents and family members in the person's life. Some people see substantial family involvement as necessary throughout the person's life; others see it as finishing now that the transition is finished.

These disagreements are based on real uncertainties or real differences in perspective; no outside judge or expert can provide a final or objective answer. The circle's obligation is to be clear about the important disagreements they have and explicit about the ways in which they will negotiate these differences. It is not necessary to make an idol of consistency: some disagreements might be resolved by accepting that "when he is with me, this is what happens; when he is with you, that is what happens." Other issues will require negotiation ("How can we discover a way to proceed that will satisfy all of our interests?") or the willing acceptance of authority ("We do it this way because this is the way his mother wants it.") If these disagreements remain unspoken, or if circle members don't accept a common way of dealing with differences, the differences will poison and paralyze the circle.

How you know when your circle isn't round

Before a circle considers what matters most for the person and what its constitution will be, the circle should take time to review its own functioning. Based on our interviews, we constructed this checklist of potential problems in the functioning of circles:

- ▲ Circle members see the circle as belonging to someone else: "We have these meetings because they are important to _____" Staff say, "parents". Parents say, "staff." Anybody says, "We have them because the executive director says we have to."
- ▲ Important decisions about a person's life happen without the circle's participation, for example: a circle member says "It's not like we work together or anything" when explaining why someone who is not a circle member is creating a plan for the person the circle supports.
- ▲ The circle turns to a pyramid with a parent at the top. Parents review the details of staff performance. Parents feel, "Agency leaders expect us to do what agency supervisors are paid to do." Staff feel, "The parent wants to use me to control every detail of the person's life."
- ▲ The circle turns to a pyramid with no one at the top. Staff try to get parents to act like supervisors or representatives of their agenda to JNCS administrators.

- ▲ The circle spends time on activities that would be much more efficiently done in other ways, for example: paying the person's bills, explaining JNCS policies, reviewing the details of staff schedules when there is no major issue at stake.
- ▲ Circle meetings focus mostly on "How things were done" rather than on "What we have learned" and "What it is important for the person for us to do."
- ▲ A parent feels, "I am the only advocate for my daughter or son."
- ▲ Staff people are disengaged during the meeting and feel frustrated or angry after the meeting.
- ▲ The circle gets stuck in polarization: its "staff against parents" or "circle members against support staff" or "administrative team members against support staff", or "outsider parents against insiders on the board."
- ▲ Some circle members treat other circle members in a disrespectful way but the issue is never raised and people do not make amends for the offense.
- ▲ Conversations about circle problems happen outside the circle, in pairs or other groups, and do not result in changes in the way the circle works.
- ▲ The only thing that gets a circle unstuck is when a person in authority (often the executive director or board president) shows up and assumes responsibility for dealing with the problem, perhaps by delegating action to a staff person.

Because circles deal with difficult issues and because their work is organizing action on important issues, all circles will lose their roundness from time to time. This issue is whether the circle has the strength to notice that it is stuck and find a way to get unstuck that makes the circle stronger.

The agency role in making circles stronger

The agency can do several things that will make circles stronger:

- Invest in training and supervision in facilitation, creative problem solving, conflict negotiation, and personal futures planning for anyone who wants to learn. Assure that each circle has more than one member interested in improving their skills in these critical areas.
- Identify and share the variety of ways members of different circles have of listening to a person and making decisions about the person's priorities and preferences. Approaches may include: stories about shared experiences, observations on the way a

person responded during a private discussion, rituals that have meaning to the person or in a particular relationship, responses to photographs or drawings, and unconventional methods the person has invented in order to communicate.

- Make facilitators who are not members of a circle available for personal futures planning, PATH, or circle reviews. Facilitators can be members of other circles: staff, family members, others who are interested and willing to get training and supervision.
- Make consultation available to circles that are deeply stuck (what some people call “The Circle Doctor”). The emotional work involved can sometimes overwhelm even capable people. Consultants focus on process rather than having an organizational authority role or a stake in the outcomes of a circle’s decisions.
- Find ways to make information about routine agency business available to circle members without taking up circle meeting time.
- Much confusion and conflict comes from lack of clarity about the responsibility of circles, parents, and agency supervisors. Ask each circle to go through a systematic process of identifying responsibility for key tasks. One way to do this is sketched below.
- The agency can gather and share its experience with circles: benefits, disappointments, what has worked, what has not worked as expected, guidelines from experience. *The circle cookbook* might be a nice title.

This process of re-constituting circles should be carried out systematically, for each circle. It should raise a number of important questions whose answers have implications for the agency as a whole:

- Is it acceptable for a person the agency supports to have no circle, either around the person or around the person’s parents? If so, how will the planning, decision making, and safeguarding functions of the circle happen for the person?
- Is it acceptable for a person to have a circle when the person’s parents do not participate; if the person’s conservator does not participate? If so, how will agency respond to conflicts between the person’s circle and the person’s parent/conservator?
- Is it acceptable to have a circle in which the person with autism does not participate?
- Do staff participate as circle members as an expected part of their job responsibilities or can they choose not to be members of a person’s circle? Can a circle exclude a staff member?