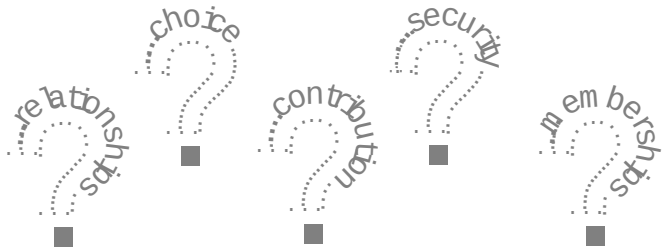
LivingWith the Questions

Notes from a Gathering of People Concerned with Supported Living



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Acknowledgments

Despite a state service system whose implacable commitment to the exclusion and control of people with disabilities parches and hardens the ground, supported living has taken root in Georgia. Small shoots have broken through because of the imagination, courage, and perseverance of a small and growing network of innovators among people with disabilities, family members, service providers, and system managers.

The idea for this gathering grew among the leaders of this network. Mary Kissel conceived the idea and coordinated the meeting as part of her work for the University affiliated Program at the University of Georgia. Pat Puckett assured the participation of Georgians with disabilities through The Community Supported Living Network, a Project of the Georgia Governor's Council on Developmental Disabilities.

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A better idea

Despite much talk about individualization, most people with developmental disabilities either live with their families or live in a place that belongs to someone else: a state service system, a nursing home operator, a residential service agency, or a family care provider. But a growing number of people with disabilities and their families have a better idea. For some people the better idea is, "Get me out of this nursing home or this group home and get me into my own place!" For others it's, "I'm ready to move out of my parents' home and establish myself." Once the threat or the reality of being in an institution or a group residence is gone, other people say "Let's get on with our lives and keep things growing!"

My own place

More and more service workers want to support people to live in their own place, in the way they want to live. They believe that their work means most when…

… plans and decisions are made close to people with disabilities who get the support they need to take increasing responsibility for directing their own lives

… people have the assistance they need to live in their own places

…people have the support they need to contribute as valued members of their communities

Living with hard questions

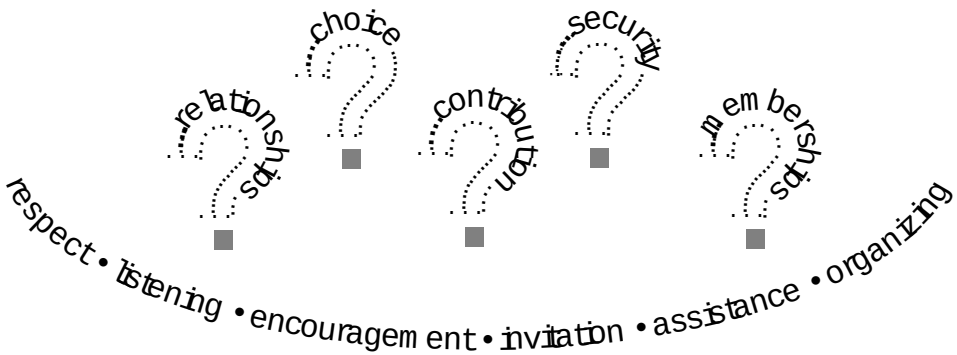
The commitment to offer personalized assistance instead of taking control is based on a clear recognition that each person's story, dreams, and supports is distinct from other people's. The work of assisting people with disabilities as they unfold their own life stories has roots that run down into common issues, issues that we will only resolve when we confront the forces that divide people into "us" and "them" on the basis of disability and deal in a positive way with the forces that keep poor people without decent housing, secure health care, reasonable transportation and access to economic opportunities. In living out this commitment, there are no quick answers; no blueprints, there are only opportunities to join people who want change in creating new answers.

Hard questions

Supporting people calls on us to build relationships and organizations that are strong enough to support us to live well with hard questions. These questions come from the sort of community that we want to create together: a community that recognizes and benefits from the contributions of people with disabilities; a community that welcomes people into memberships; a community the offers people opportunities for good relationships; a community that supports people's choices; a community that provides a reasonable measure of security to all of its members.

These fundamental questions lack final, definite answers because all people grow into them throughout their lives. Often this growth means experiencing uncertainty, fear, incom-

petence, and suffering on the way to greater maturity, capability, and wisdom. Caring relationships make the best container to hold these developmental questions. Caring relationships are characterized by respect, active listening, encouragement, invitations to try new ways, practical assistance, and efforts to organize available resources.



One way to understand supported living agencies is to see them as purposeful and sustained efforts to increase the chances that people at risk of exclusion from community membership can experience caring relationships on a day-to-day basis. These efforts include consciously building a culture of caring that embraces people with disabilities, their families and friends, and agency staff and learning, through action and reflection, how best to know and assist people to negotiate the risks of exclusion and the challenges of individual development.

Some hard questions concern the day to day work of developing organizations that can assist people effectively:

- How do we earn sufficient trust from people with disabilities and their families to allow us to discover enough of their gifts, interests, and vulnerabilities so that we can provide accurate support?
- How do we build the capacity to provide respectful, reliable assistance day after day for years?
- How do we help each person discover and build connections to a community of interest and place that offers opportunities to contribute, to be known, to be valued, and to exchange support?
- How do we deal creatively with a service system that, because it must serve many conflicting interests, is overcommitted, overinvested in services that segregate and control people, and limited in its flexibility?
- How do we confront the pervasive discrimination and prejudice that isolates and discourages people with disabilities and their families?

Some questions arise from our interest in increasing the number of people who enjoy the benefits of supported living.

- What policies should we advocate when there is little interest in supported living among system decision makers and how should we demonstrate the demand for supported living?

- What policies should we advocate when there is strong –if often uninformed– enthusiasm for supported living among system level decision makers?
- What strategies offer the greatest hope of increasing the amount of supported living available without diluting its essential features?
- When should we say 'no' to agency growth in order to maintain the capacity to act with the people we are already committed to?
- When do we say 'no' to system demands and requirements, and how do we maintain our ability to act and be influential while protecting the integrity of our work by resisting?

No excuse for abandoning people

Saying that we must live with questions is no excuse for abandoning people, or for failing to do whatever seems positive and possible to do. It's simply a reminder that

At the level of day to day support…

…what suits a person's situation today may not fit as well tomorrow

…many people live with a history of exclusion and low expectations that hides their identity and their interests; what people want and expect depends on the trust we earn

…many important issues —such as assisting a person to be secure or to make friends— call for learning with people rather than implementing a standard answer

…in many circumstances people have to draw a balance between good things, for example, between security and risk

…people often rely very much on other's assistance to accomplish what they want; this calls for an unusual amount of cooperation, sometimes among people who have different points of view and different values

At the level of positively influencing the development of supported living in our systems…

…there are fundamental uncertainties that come from the newness of supported living, for example,

- how large can a supported living agency grow without compromising its ability to serve people well?
- how, and at what rate, should a supported living agency grow?
- under what conditions can an agency with a history of providing congregate residential services add on supported living services without compromising its quality?
- how can a provider of congregate residential services convert its investment in group residences into high quality supported living?

…very rapid change in policies and resource availability, often changes in contradictory directions, create new opportunities and new problems at a faster tempo.

…many supported living efforts currently get funds and operate by working around

existing policies and regulations; the efforts of system managers who want to rationalize these marginal changes will shift conditions in important, unpredictable ways.

Escape hatches

Dealing with hard questions is difficult and anxiety provoking. At least five escape hatches offer easy ways to duck out of anxiety and hard work:

- *"The person chooses not to…"* Staff who feel uncomfortable about change can strike an implicit bargain with people with disabilities who feel uncomfortable about change. It is as if staff said, "We will pretend that your life is as good as it can be and we won't challenge you to move outside your zone of comfort if you will pretend that your life is as good as it can be and don't push us to help you test new experiences and greater autonomy." This bargain results in many, many video rentals and in staff arguing indignantly against people who want to impose middle class values on people with disabilities. Discriminating choice as escape from choice as a precious achievement involves exploring such questions as…
  - Over time, what experiences have we invited and assisted people to try out? The more invitations we have made the less likely that we are disappearing through an escape hatch.
  - What values are we talking about imposing? Is avoiding the temptation to hurt others only a middle class value? Is participation in civic life only a middle class value? Is working to make a contribution only a middle class value? Is resisting prejudiced treatment only a middle class value? Even more important, how do we know these things aren't important to this person? The more open and productive our discussion of these questions, the less likely we are running away.
  - How are we planning to impose? Do we intend to employ coercive physical force, threat of eviction or dispossession or pain? Or are we informing, encouraging, inviting, arguing, or otherwise struggling to challenge a person to engage one of the hard questions in his or her life?
- *"Community is dead; there is no community to be found. Anywhere."* (This is best delivered as a lament.) There are many hard truths around community: mobility, many more hours of paid work to balance family budgets, powerful media, poor transport, widespread prejudice, individualism, consumerism, and unsafe streets threaten civic life and popular association. But the hard questions of our common development as humans call us to look hard for efforts to build community and to act creatively to contribute to these efforts by assuring the participation of interested citizens, including people with disabilities and their families.
- *"The system isn't supportive."* Systems designed around the therapeutic control and segregation of people with disabilities are full of barriers to choice and participation, so this escape hatch, like the others, has the

virtue of being correct. But reflection suggests that system changes could result from people negotiating for necessary changes in a vigorous, principled, and united fashion.

- *"Supported living isn't supposed to be like that (so shut up)."* When the first three hatches are barred, more subtle escapes can still be arranged. This escape works by shifting attention from a real struggle to an important, but more abstract principle and then dismissing the struggle as outmoded. For example…

  …Struggle: "Donna is mixed up in this particular thing which I think is dangerous, and I'm worried and want to do some problem solving." Escape: "That's old paradigm thinking. In supported living, people are responsible for the consequences of their own behavior."

  …Struggle: "Frank hangs out at the Elks most every Wednesday night. But he hasn't connected with anybody. What could we do?" Escape: "Friendships have to happen spontaneously. It wouldn't be natural for us to intrude. We're here to get out of the community's way."

- *"**We**, who have the right values, would be able to do whatever is necessary, if only t**hey**, who have the wrong values, would say they agree with us."* This escape works best when it is strongly but silently in the background of a passionate denunciation of some mindless rule or offensive statement. It works by distracting us from what we might disagree about –figuring a way forward when we aren't sure what to do next– to something we can all agree about –they are profoundly less enlightened than we are; so its no wonder we can't take any steps toward what we want. Community members should only be blamed as a last resort; it sounds much more progressive to portray "the system" as the source of the problem.

Living well with the questions

Living well with hard questions means…

- Working to develop an organizational culture which is strong enough to contain the important questions. The signs of such a culture include…

  …relationships with people with disabilities that embody respect and personal concern, even in times of fear, anger, uncertainty, or exasperation

  …investment of time and attention to reflection on what we are learning about the fundamentals of the daily work

  …a clear expectation that people will support each other to deal constructively and creatively with basic questions in their everyday work

  …strong and sustained efforts to build honest, caring relationships among key actors; these relationships will allow people to surface and resolve conflicts before they become poisonous

…regular and substantial investment in helping people deepen their understanding of the values the agency wants to embody

…openness to comments and help

"Good enough" answers

- Cultivating an acute and enduring awareness of the negative consequences of the compromises imposed by system conditions and using the discomfort caused by this awareness as motivation to…

  …work creatively to dissolve the compromise by finding new ways to understand and resolve problems

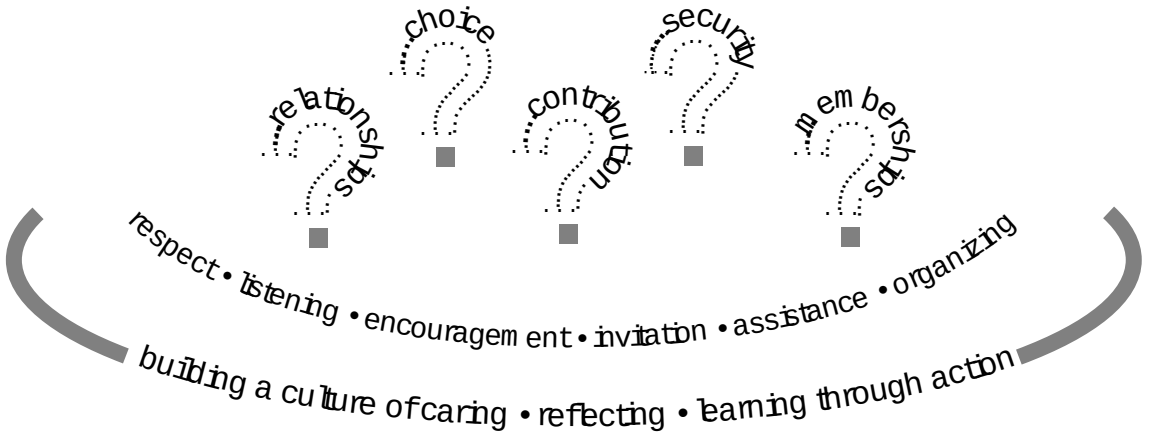
  …avoid justifying compromises by pretending that "this is what people wanted" or "there are no real answers, so anything goes"

  …re-visit compromises at least annually as part of agency planning

  …work creatively to minimize the damage the compromise does

  …advocate vigorously for change in the policies that contribute to the compromise

The search is not for final answers but for "good enough" answers: answers that will strengthen relationships and build capacity for the continuing journey of supporting one another through life.



Contradiction with system rules

We live with these questions and conditions in a service system that follows unwritten rules that make creativity difficult: In practice, the service system typically behaves as if…

- Bigger agencies which are managed as a business bureaucracy are more efficient than smaller agencies that are managed collaboratively.
- Resource allocation decisions made impersonally, far away from people, are better than decisions that are made up close, by involved people.
- Professionally trained people can make better plans for people's lives than people can make with the help of their family and friends.
- Support can be effectively delivered by interchangeable staff performing standardized tasks in 30 minute blocks.
- Relatives can't provide paid support.
- People who receive benefits should expect fewer opportunities for choice than people who do not rely on income transfers.

Multiplying resources can make people more vulnerable

Many of us feel a contradiction between what must be done to comply with our system's written and unwritten rules in order to get necessary resources and what really needs to happen in order for people to live good lives. This contradiction can sometimes feel like guilt, "I have to follow rules I don't believe are right in order to get the money to do what people need."

Some state systems act as though their approach is good enough as is; the only problems they recognize are problems of maintaining compliance, controlling costs, and dealing with rising demand for services without proportionate increases in public funds. Other state systems work to reduce the burden of top-down rules and to create the flexibility for innovation. But our ability to attract political and administrative support is limited because –apart from saying, "We do whatever it takes to support people in their own homes."– we don't have policy answers that fit easily into 30 second sound bites.

Many of us have increased flexibility by helping people to reach outside the developmental disabilities system in order to use a variety of different benefits; but that more complex web of support is fragile. People's housing can be threatened by policy changes which are based on the idea that there are "good poor people" (people with disabilities who are served in special programs for the disabled) and "bad poor people" (people with addictions, teenaged mothers who rely on other kinds of income and housing supports). Measures intended to discipline "bad poor people" can tear the web that supports people with disabilities. And the politics of division can destroy coalitions among people who might otherwise be allies in the quest for affordable housing, safe neighborhoods, decent health care, reliable transportation, cultural richness, and fair economic conditions.

"Even when a state provides funds and flexibility –and my state and my county do– it is still incredibly hard to…

…figure out how to support people to become part of community in ways that really reflect who they are

…be responsive to the people who provide assistance

…be open to work with families

…pay attention to what is going on in our communities

and to do all this every day, through years of people's lives. Sometimes it's really frightening to me to think about what it takes, personally, as a service agency, and as a community to really hang in there. It's easy to think that if only the system were more flexible or if there was more money that somehow all these great things might happen. But even with flexibility and money, things are so complex…"

–Gail Jacob

The core of the work

The core of our work in supporting people with disabilities and their families depends on…

- Belief in people and their future
- Personal commitment over time, as people make different kinds of changes…

  …clear-cut changes ("I'm moving out of the institution," or "I'm leaving my parents' home.")

  …less easily defined changes ("I'm out, now what?")

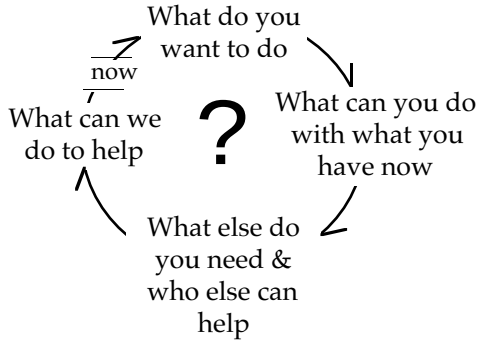
Time in supported living means more than calendar time. There is also the time people need to adjust to different life challenges, the time it takes to heal from hurtful things; the time it takes to build up new skills and interests.

The seed of our strategies

The first cycle: Where do you want to live?

The strategies we trust begin in concrete, day-to-day situations and focus collective attention on working out answers to this fundamental cycle of questions:

- What do you want to do in your life?
- What can you do about that with the resources you already have?
- What else do you need?
- Who else can help you?
- What can we do to help you?



These questions are for the person, the person's family and friends, and others who want to support the person. They need to be the focus of discussion and shared action.

This cycle of questions can be as big as a year or as small as an hour. Many efforts to do supported living pay a great deal of attention to the first big cycle, which is organized around this question, "Where do you want to live and with whom?" But the effort is deeply incomplete if it stops there. As people get established in their own place and become better able to direct their own lives, whether with words or in other ways, possibilities multiply, situations become more diffuse and staff ability to listen, negotiate, and assist people to explore becomes more and more important. The quality of people's lives depends on many, many day-to-day repetitions of this cycle. The capacity to sustain attention to this cycle tests and strengthens the culture of our organizations and the extent of our individual commitment.

Ordinary wants and an unusual system

While the core questions are simple, creating answers is not. The ordinariness of what most people want –a place of their own with a choice of companions, a chance to contribute, opportunities to pursue personal interests, friends, intimacy– contrasts sharply with the unusualness of the system that provides services and the system's capacity to generate complexity of detail.. Pursuing ordinary wants often brings people up against social barriers sustained by prejudice and ingrained discrimination against people with disabilities. This hurts. It can be tiring and discouraging.

Dealing with discouragement by involving more people

Perhaps the best response to hurt, tiredness, and discouragement can be the hardest. Just when we want to give up and close in on ourselves, we need to acknowledge that we can't do what must be done alone, and use this awareness to invite others to join in the work. Some people will decline to become involved, but the more widely we find the courage to extend our invitations, the more energy becomes available for the work.

The best way is simple, but difficult

Finding good enough answers to get on with happens when people figure out how to support one another and how to enlist others instead of splitting people apart. Important questions often evoke fear, anxiety, anger, and a strong desire to run away or to find someone to blame or to fight with. Anxiety can bring people to highlight differences instead of common direction and common processes for figuring things out. Splits dominate: parents *vs* staff; guardians *vs* wards; board *vs* staff; "clients" *vs* staff; community members *vs* disability insiders. When focus on difference organizes a situation, there is little energy left for listening and problem solving.

Often this focus on difference is a defense against the fear that one single person will be left totally responsible for dealing with a complex and difficult situation. The best response is to redraw the boundaries that divide people by attending to what people can accomplish if they recognize their differences but choose to work together.

"We were over in Alabama, doing some personal futures plans with families. We talked about exclusion and the pain these families had been through. And they invited us to come to their house, but they said come before six o'clock and leave before dark; there are no black folks around where we live after dark. They said it so matter of factly that it took a while for it to dawn on me that they were making no connection between my exclusion and the exclusion of their kids. I don't believe families of children with disabilities can feel the pain for their child and not feel the pain for other groups who are excluded from our society. Democracy just cannot be exclusively applied to one situation. With the whole disability movement, what I am seeing is, 'Welcome to my world!'…

We have this idea in America that you got to pull yourself up by your own bootstraps and make it on your own. 'I'll help you get out of the institution, but after that you're on your own." We don't know how to hang in community all the time and we have to figure that out if we're going to be effective… Some of us don't want to be identified with gays, lesbians, and people of color. We want to say, 'We're different, it's a disability issue.' But really it's community and we have to see those connections and be prepared to stand up for them. You can't run from connections, or only stand up when the issue is specific to disability.

Most of those folks making decisions within the bureaucracy, they are totally isolated from what is going on in community; in people's lives. They don't understand what life is like in a nursing home; they haven't been over there. So we have to figure out how to bring them into our world until they can make the connection.… I'm working to learn how to engage those folks in the struggle with all the rest of us. Just because it is the right thing to do."

—Mike Biggs

Life time work

Supported living can be understood as a life time commitment in two ways. First, many people will need support throughout their lifetime. Supported living is fundamentally different from services that attempt to finish training those people with disabilities who will soon be ready to try living with no support or with very minimal support. Long term commitment to people who will probably require day to day assistance throughout their lives is the foundation of supported living.

Second, the work of supporting people happens in response to the rhythms of peoples' lives more than in response to external time lines. A deinstitutionalization plan can set the target date for a person's move, and service providers can responsibly aim to move on target. But after a person moves in it is harder to predict and control how long important things will take.

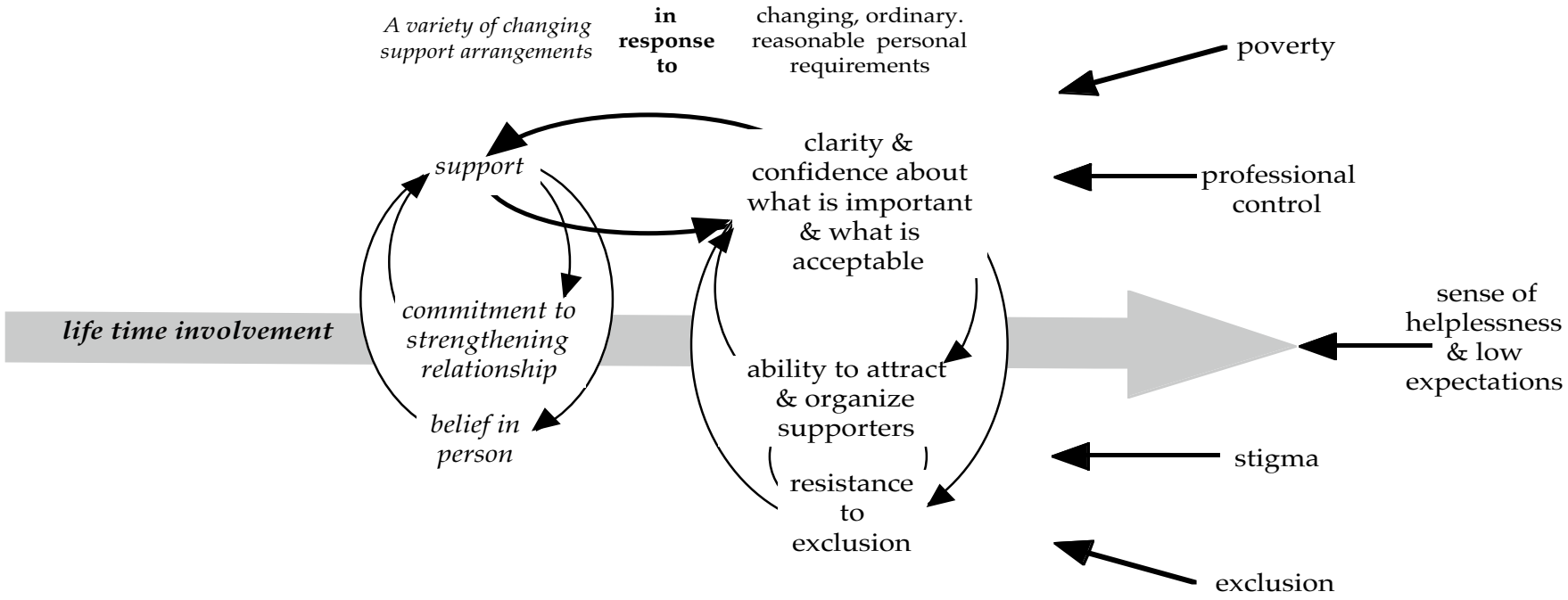
- It takes people's own time to adjust to big changes, like moving in to their own place. Some people are at home immediately; others may take months to get used to the fact that they can leave things in their own living room rather than packing everything into their closets every night.
- It takes people's own time to understand the demands and expectations of directing one's own life. Some people seem to delight in their daily responsibilities and pick up skills at an amazing rate; others emerge very slowly from a kind of passive confusion about everyday life, as if someone else were in complete charge of their lives and responsible for rescuing them from daily demands.
- It takes people's own time to heal from the hurts of institutionalization, isolation, and rejection. Some people forgive and move on confidently; others may struggle for years with fear of being "sent back" or with depression or anger at what they have been through.
- It takes people's own time to trust that other's will listen respectfully and respond honestly to important communications. Some people share their dreams with enthusiasm; others test their listeners over months with silence or with fantastic or ambiguous communications.
- It takes people's own time to discover what makes them feel at home and what interests will structure their work time and leisure time. Some people are clear about what matters to them and find a sense of community with apparent ease; others seem restless, or even aimless, and unattached for long periods.

Workers involved in people's life times deal with understandable, if difficult, desires and problems in the context of particular people's lives. One may or may not know what to do about a person's intense desire for intimacy and for children, but the desire can be understood at a human scale; it need not be primarily a matter for general policies and procedures.

A view of the process: How support makes a difference

While engagement in people's life times seems fuzzier and more diffuse than highly defined job roles, experience suggests that these fuzzier involvements often sustain people when crisis breaks down formal relationships or makes procedures useless.

People with disabilities, and their families, move through their lives against powerful forces: poverty, stigma, prejudice, exclusion, and the social expectation that professionals who work for a service system will be in control of life's details. This makes it understandable that many feel a sense of helplessness and hold low expectations of what is possible for themselves and their family members. Those who choose to walk with people with disabilities and their families, will walk with them against the pressure of poverty, stigma, prejudice, and the presumption of exclusion.



Walking with some people means simply respecting their desires to contribute and participate, and then figuring out how to assist without taking over the person's life. Other people, who respond to the pressures of prejudice and exclusion by shrinking themselves, need encouragement, information about possibilities, and the knowledge that others believe in them in order to raise their expectations and take action to discover and pursue their interests.

As people experience support, their sense of what is important and what is acceptable grows clearer and their confidence grows stronger. As people can more clearly communicate what matters to them and what works for them, support grows more accurate. As things change in a person's life, supports may get out of phase with what someone needs, but adjustments take place with less risk and disruption as people become better able to communicate what matters and what is working. This positive process is constrained by the flexibility with which support can be offered and by barriers to understanding between the person and support workers.

As people become more clear and more confident about their interests, it becomes progressively easier to for them to recruit others to play complementary and supportive roles. For example, someone with an active interest in a clean, safe neighborhood will want to join in neighborhood association clean up or block watch activities, and this interest will often attract others who are involved in these activities to welcome and to support the person. With greater support, people are better able to speak clearly and confidently about their interests and preferences. This positive process is constrained by the amount of local civic and economic activity and by the accessibility of relevant places and activities to people with low incomes, who often lack automobiles, and who often require accommodation to difficulties with movement, information processing, or dealing with emotion.

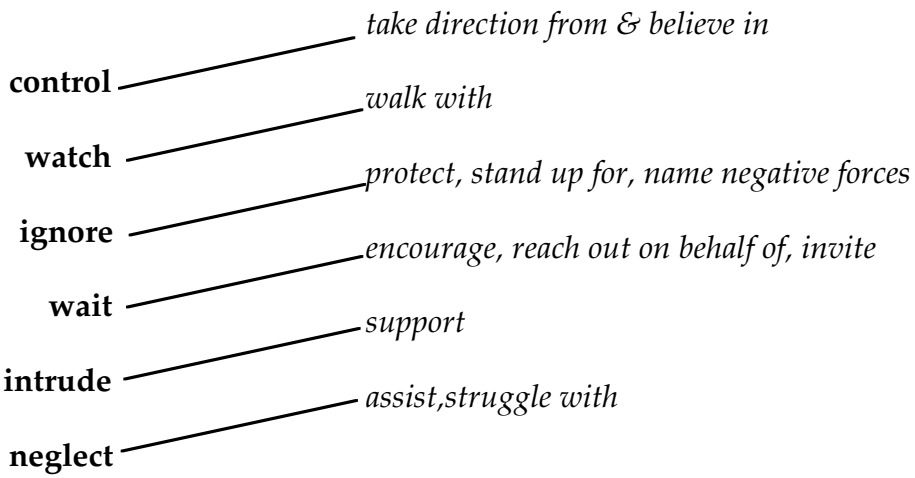
Greater clarity and confidence, and more supporters who are better aligned, raises people's capacity to resist the forces of stigma and exclusion. With a clear sense of what matters and what is acceptable, and some other people on your side, people have greater resilience to deal with negative situations when they cannot figure out ways to avoid them. Greater capacity to resist exclusion increases the number of potential supporters available to a person and strengthens people's sense of justice and what is right. This positive process is constrained by the level of people's and supporters' active commitment to understanding of discrimination and exclusion as matters of justice and the balance of resources between those working for inclusion and those working to exclude people with disabilities.

As support workers develop and modify a variety of practical support arrangements in response to people's changing requirements, they are likely to increase their commitment to

further strengthening their relationships with people with disabilities. This positive process is limited by the extent of other demands on support worker's time and attention and by the level of support available to them to deal with confusing, disappointing, and painful situations.

Workers who experience the benefits people derive from good support are likely to increase their belief in a positive future for them. Stronger belief in what is possible and desirable increases workers' ability to offer encouragement and practical help. This positive process is limited by workers' consciousness of the effects of pervasive social devaluation on people's lives and by their awareness of alternatives for assisting people as well as by the willingness of people with disabilities to collaborate with workers.

An uphill path



Given the history of relationships between people with disabilities and those who provide services, the work of supported living calls on workers, family members, and people themselves to work their way uphill. Without a strong organizational culture and disciplined effort, workers will find themselves settling into a usual pattern of responses. This pattern makes everyone's role more definite and more familiar; being on the uphill side can feel awkward, uncertain, and tentative. And it is easy to slip. But support only happens in relationships where people strive for the uphill qualities.

- Typical patterns set the expectation that "staff" will be in control of "clients" where what is needed is for workers to believe in and take direction from the person they support.
- Staff are often spectators, watching to see if "they" are capable of "making it on their own." When people fail, the watchers dispassionately note that people must bear the "natural consequences" of their failures. What is needed is for workers to walk with people, actively seeking the most positive possible resolutions of conflicts when conflicts arise. This will carry staff into drawing a difficult balance between rescuing people, and thus depriving them of the dignity of risk, and being actively engaged as a person's supporter.
- The uncertainty and discomfort created by encountering 1) the marginal social position

of people with disabilities and 2) the difficulties people have in effectively resisting prejudice, discrimination, neglect, and abuse make it understandable that staff would collude with these unpleasant forces by keeping silence and ignoring injustice when it happens. What is needed is workers who will name negative forces for what they are and stand up with people against them. And sometimes people will be so beaten down or so vulnerable that they will need protection. This will lead staff into the dilemma of balancing respect for people's ability to deal with prejudice and exclusion in a way that suits them and being complicit in allowing prejudiced and discriminatory patterns to win out.

- An understandable reluctance to impose on another's personal affairs can lead staff to neglect to raise difficult questions and to make the challenging invitations that so often play an important part in the development of new patterns of living. The pull of inertia, of waiting, can put staff on the side of passive adjustment to lowering expectations in the name of respecting privacy and individual choice. What is needed is workers who will not only encourage the person to reach out to a wider circle of people but also themselves reach out on people's behalf and invite others into the person's life. This requires staff to productively engage a conflict between two good things: accepting people as they are and respecting privacy on the one hand, and encouraging people to broaden and deepen their base of personal support on the other.
- In some circumstances privacy is far from consciousness as staff, particularly professional and paraprofessional teams, make program plans that intrude into almost every detail of how a person with a disability lives. What is wanted is workers who are…

  …committed to earning sufficient trust so that people will tell them honestly how they would like to live and

  …ready to actively support people toward creating situations that will embody their own sense of a full, rich life.
- When people have low expectations and little voice it is easy to become complacent and to neglect them. When people do things that frighten or dismay staff it is easy to withdraw from them and neglect them in the name of respecting their choices. What is needed is staff who will respectfully and vigorously struggle with people to offer constructive assistance and positive influence.

Concerns in day to day work

Relationships

- As people get better individual support, their isolation can become far more visible. Some critics want to say that it is supported living that causes isolation, but this does not seem like the whole story. Often it is supported living that provides a context in which involved people notice, care about, and talk about a persons isolation. Dealing with this concern involves…
  - Honoring and supporting the friendships people have with other disabled people
  - Assisting people to maintain, expand, or re-build relationships with extended family.
  - Inviting and supporting people to expand their network of friends and acquaintances
- Individualized support and circles of support have many positive features however, one potentially negative consequence of these potentially good things is that people's relationships then become public. The flaws in one's family, the flaws in one's love interests, the flaws in one's friends, all can become matters on the agenda of meetings. These meetings can be important to providing good support: concerned people need to figure out when to step back and let things take their course, when to stand up for a person, and how to be of assistance. These discussions may be more important when people who are vulnerable begin to bring new and unfamiliar people into their lives. For some of us, privacy seems such a fundamental value that any such discussion seems distasteful. Others believe that temptations to voyeurism can be controlled well enough to make the benefits in support outweigh the costs to privacy.

"As we have gotten efficient about assembling the money and the material parts of putting a household together, we have really decreased the time it takes for a person to move in. The only problem with this is that people's support circles don't seem to have the time and the tasks they need to work on to build up strong relationships. So, in a way, the person moves with a bit less support."

—Myrna Bartlett

- Partnership takes time to grow and then to grow strong. This creates problems:
  - There is money available for people who are in institutions. To many of us, the benefits of moving a person whenever it is possible seem greater than the problems created by our lack of knowledge of them and our lack of relationship with them.
  - We have to deal with our own impatience ("I want it done. I want it done right. And I want it done yesterday.") when things really need time to grow and ripen.
  - We have to be alert to the possibility that we might use the time things take as an excuse to cover timidity or laziness.
- It can be very difficult to talk about relationship issues between service providers and families, especially when we acknowledge that many more possibilities open up when responsibility is shared. Important issues become undiscussible when things that are often true get reduced to slogans which cannot be challenged. One way to spot these issues is to listen for quick shifts from a person reporting what they believe to someone else saying, in effect, "That's not how it's supposed to be." It seems difficult for staff to find productive ways to talk about situations in which…
  - Staff genuinely feel that they know a person, and a person's positive possibilities, better than family members do. Testing this will be impossible if this is felt to be undiscussible because "families know people best" (often, but not always true).
  - Staff feel that in fact they bear final responsibility for what happens to someone because involved family members are free to decide and change how they will be involved while staff have to deal with whatever else must be done. Testing this will be impossible if this is felt to be undiscussible because, "staff come and go, but families are always there." (often but not always true).
  - Staff feel that particular family members understand shared responsibility in a kind of hierarchal fashion: if something goes wrong for a person staff alone will be to blame. Testing this will be impossible if this is felt to be undiscussible because, "We are partners with family members." (often, but not always true).

Choices

- Some people make choices that present us with a conflict or scare us. The conflict may be with people with disabilities themselves or it may be a conflict with family members who see our role as exercising control over people with disabilities. Wherever the conflict or fear comes from, we can only deal with the situation effectively if we engage in an active problem solving process aimed at understanding the situation so that we can figure out ways to decrease the person's vulnerability while promoting the person's autonomy.

– It's hard to share problem-solving with family members who are used to being the only people who care about a person.
– It's hard to share problem solving with people with disabilities who lack experience or are not used to working on things cooperatively. For many people power seems to be either something you have or something I have; not something we share.

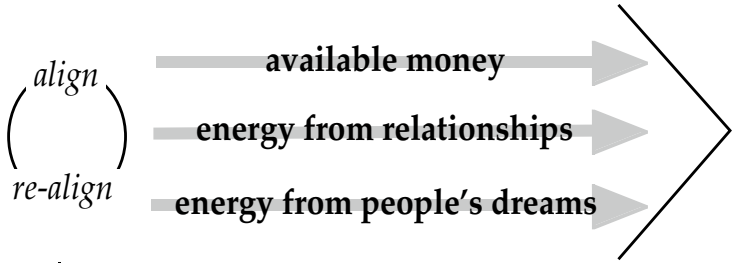
"Some people see solving problems as a distraction from the work. But solving problems is the work. Dealing with a problem together and finding common ground in a real situation is the road to trust." – Viola Perry

- Anxiety about whether we have strong enough relationships to deal with difficult choice issues shows in the way we sometimes talk about choice. Anxiety speaks loudly when…
  – Discussion is immediately drawn to the most extreme situations we have experienced or can imagine.
  – The voices of shame and disapproval for things that have already happened dominate: "How can you have let that happen!"
  – We quickly distance ourselves from potential confusion (and learning) with a slogan: "It's the dignity of risk." or "We are liable for supervising our clients, our insurance carrier would never allow us to…"
  – We hide anger or a desire to punish someone for threatening us with clinical language: "We can't rescue people from the natural consequences of their actions."
- Once our anxiety has had its say, we can focus on deepening our relationships with people so that, over time, chances
  – decrease that people will make foolish or risky decisions alone and without information and feedback
  – decrease that people will hide problems from us until they have become dangerous
  – increase that we can help people develop their skills for avoiding or dealing with difficult situations
  – increase that we will have influence with people without having to get into power struggles with them
  – increase that we will want to be on people's side when they get into conflicts and difficulties
- Staff may lack confidence, skill or experience in negotiating conflicts, in dealing with community members who are threatened or rejecting, in thinking about complicated issues from different points of view, and in engaging people and communities in a creative way. One sign of this lack of staff skill is the emergence of a sort of a little club between the staff and people with disabilities where the charter seems to say, "I won't challenge you much, if you don't challenge me much. We'll just stay in, kick back, and watch TV. If anybody asks, we'll tell them its a perfectly normal choice." This kind of neglect raises issues of staff selection, staff development, and the availability of processes for problem solving and for reflection

which are strong enough to support high expectations.

- When people have a great deal of difficulty communicating and a great deal of difficulty doing things on their own, another dilemma arises. Our values say we take direction from the person, and sometimes we talk about situations as though the person were choosing things that, in fact, we are choosing for the person. That is a way to speak positively about what we are doing, but it can also be confusing if it obscures the need to be explicit, careful, and thoughtful about what we read in people's behavior, or what we sense intuitively, or what we assume.

Aligning energy



- to maintain support as people come & go
- to adapt support as people change
- to reduce anxiety, blaming, & shame to allow problem solving
- to call on 'no choice' creativity

The work of supporting people with disabilities aligns available money with the energy available from people's relationships with family and friends and with the energy generated by people's dreams for a full life. History makes it hard to align these energies. People are alienated from their dreams of a good life together. Families, people with disabilities, community members, staff and system managers are apt to feel that they are opponents rather than being collaborators. Much available money goes for services that control and separate people. Time, changing circumstances, human frailty, and negative social forces will keep pulling these three energies out of alignment. The challenge is to bring people together, and to keep bringing people back together to renew their focus and to clarify and to strengthen their commitments to one another and to making important changes.

"One of the hopeful things about the waiting list is the kind of creativity that emerges when some families face the fact that they are 640 people down the list. This 'no choice' creativity leads people outside their usual patterns into forming new questions, enlisting new kinds of resources, and creating different solutions."

–Sara Page

Problematic effects of current system design

There are so many external barriers and threats arising from the way the service system is structured and from our civic life that it is difficult for many of us to focus on defining the contradictions that come up from the way we actually support people. The presence of outside forces that we can define as the enemy may distract us from improving the quality of the day to day work we do.

The Zen of supported living: designing the 'no-organization'

Moreover, people who want to work for supported living have very different perspectives on the role the developmental disabilities service system can play. These different perspectives emerge in response to a thought experiment: "Design a 'no organization.' That is, a way that people could get the support and assistance they require without the trappings and structures of service agencies."

Different perspectives on the system

- Some people think that the system can scale up supported living by managerial changes in policies and allocations of funds. Providers will respond to policy and price signals and meet the demand for supported living services. It may be difficult to change the paradigm that informs the system's management, but it can be done with effective training and technical support. They think that the 'no organization' exercise is a waste of time.
- Some people think that supported living represents such a fundamental shift in key relationships between people with disabilities, families, community members, service providers, and system managers that there are deep and problematic tensions between the professional-bureaucratic structure of the system and the supported living initiatives that depend on that system for important resources. They worry that efforts to increase the availability of supported living beyond the system's capacity to support fundamental changes will turn supported living into just one more stop on the continuum of services: business as usual, with a new name. They think the 'no organization' exercise could be a source of insight into the challenges of designing new kinds of agencies to offer new kinds of relationships and new kinds of assistance."
- Some people think that the system is the enemy of community, and of people with disabilities and their families. The issue is getting the system out of people's lives and getting service workers, including ourselves, out of the way of people living as they want, with the natural supports that are (or will become) available once people are no longer separated by professionals wearing the mask of care. The 'no organization' exercise embodies something that they yearn to make happen.

These differences in perspective could enrich the possibilities for supported living, or they might weaken and confuse efforts to build up supported living. Whatever one's perspective, the concerns arising from the design of the service system are hard to ignore and finding the next steps will require careful thought and committed action.

Scarcity

We are concerned that the small scale of supported living will continue to result in many people getting left out.

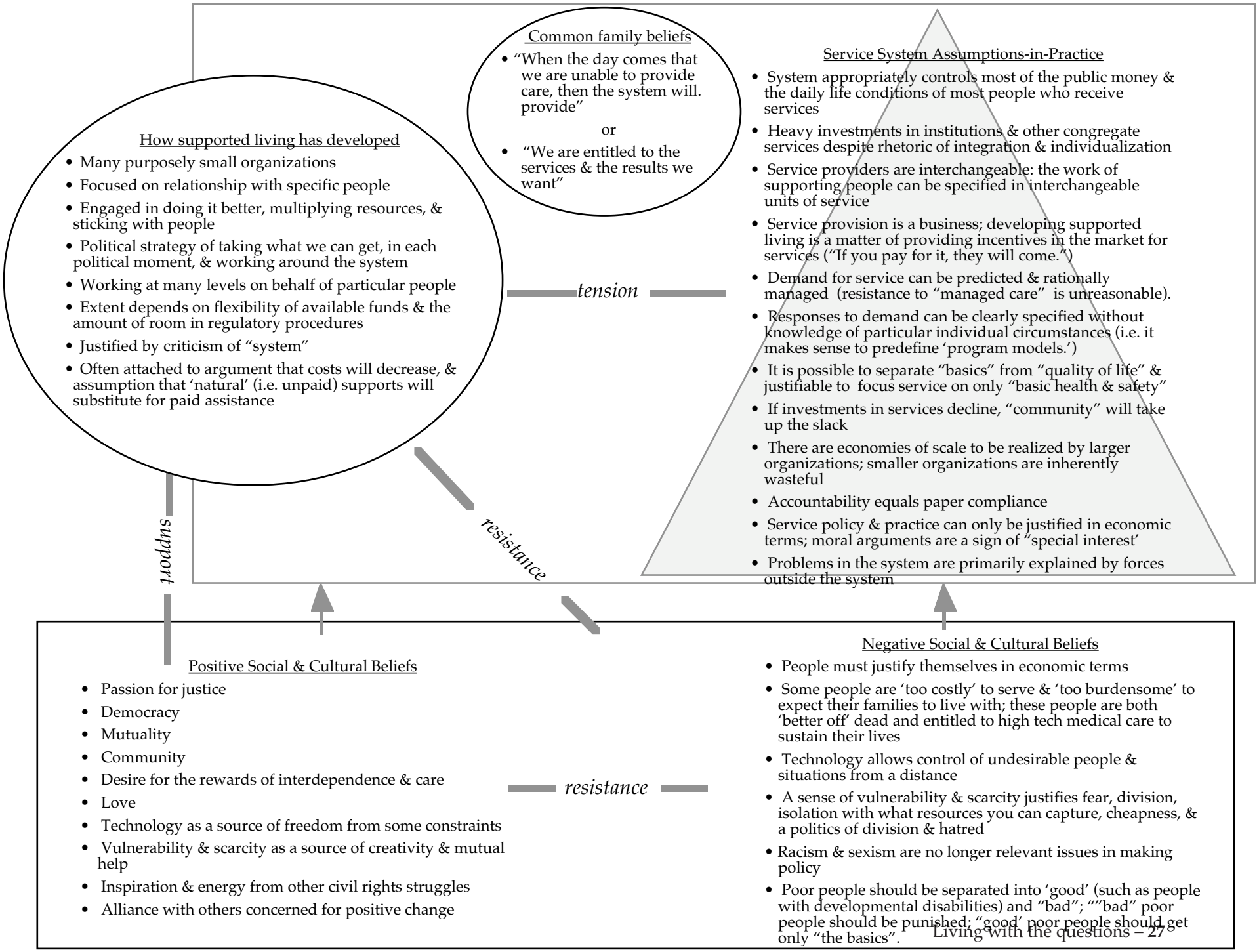
- People will be left in institutions because supported living agencies choose to stay small and committed to specific people. To some of us this seems like ignoring the responsibility to rescue people from institutionalization in order to search for perfection with a few people. To others, this seems like a misunderstanding: people don't have to stay in institutions because a few agencies are working to offer supported living; people have to stay in institutions because backward policies make it economically attractive to segregate and control people.
- Supported living will exclude people who lack the capacity to speak clearly for themselves or people without strong advocates.
- If significant family contribution is necessary, people who have been cut off from their families will be left out; so might people from poor or disorganized families.
- The overall scarcity of residential resources will mean that supported living only becomes available to families when they are exhausted, or when they have broken down or come into acute crisis. This undermines most opportunities for partnership with families and people with disabilities.
- System administrators will arbitrarily decide that supported living is only 'for' a particular group. In some places, supported living is only for people whose difficult behavior makes them unacceptable to group home providers. In other places, it is only for people who demonstrate the ability to direct their own services.

This scarcity of opportunities for supported living can lead some families and people with disabilities to feel guilty because they are among a privileged few. While people shouldn't have to feel guilty –they did not create the shortage even though the fact they have a place may exclude someone else– some people do feel a heathy sense of obligation to keep working to increase the opportunities for others. They do this both by purposely including people who might be left out in existing initiatives and by advocating for and assisting development of more supported living. This is a dilemma for those of us who simply want people to have an ordinary life: it is far from ordinary to be an activist for significant system and social change when being an activist makes the way you live your daily life a matter for public comment.

Compartmentalization

Doing the work of supported living helps us to identify with people and see their lives as a whole. This makes us sensitive (and sometimes angry) about the ways that the service system compartmentalizes and divides things that we experience as integrally connected or lumps things together that would be better separated.

- The design of our system routinely separates day services from residential services. This often results in significant problems when a day service fails to respect people's choices or to support their community membership.
- In some systems it is very complicated to negotiate changes in budgets for individualized services because there is little flexibility built in to the funding process and multiple layers in the system have to sign-off on changes.
- Scarcity and preoccupation with internal issues puts many service systems in the position of dividing people from their families. The rule seems to be, "Family takes almost complete care of a person until completely exhausted, and then the service system takes over completely." This unnecessarily threatens people's active membership in their family at the same time as it undermines family expectations and trust.
- Unaddressed family poverty or near poverty often makes a disabled person's benefit check an important part of balancing the family budget.
- A focus on the value of individualization leads us to talk about and budget and keep accounts for people as isolated individuals. But everyone comes with a rolodex of people attached to them. We are really joining families, even if there is a lot of conflict or distance in a family. In some service systems, working with families is defined as someone else's turf.
- Few service systems are working actively with service providers who need to dispose of the real estate they acquired to house groups of people with disabilities, and some systems even continue to permit agencies to combine support and housing in new developments.
- When income supports are packaged along with treatment and supervision, we hear strong voices telling us that we are accountable for all of the ways a person spends money.


Common family beliefs
• "When the day comes that we are unable to provide care, then the system will. provide"
or
• "We are entitled to the services & the results we want"
Service System Assumptions-in-Practice
• System appropriately controls most of the public money & the daily life conditions of most people who receive services
• Heavy investments in institutions & other congregate services despite rhetoric of integration & individualization
• Service providers are interchangeable: the work of supporting people can be specified in interchangeable units of service
• Service provision is a business; developing supported living is a matter of providing incentives in the market for services ("If you pay for it, they will come.")
• Demand for service can be predicted & rationally managed (resistance to "managed care" is unreasonable).
• Responses to demand can be clearly specified without knowledge of particular individual circumstances (i.e. it makes sense to predefine 'program models.')
• It is possible to separate "basics" from "quality of life" & justifiable to focus service on only "basic health & safety"
• If investments in services decline, "community" will take up the slack
• There are economies of scale to be realized by larger organizations; smaller organizations are inherently wasteful
• Accountability equals paper compliance
• Service policy & practice can only be justified in economic terms; moral arguments are a sign of "special interest'
• Problems in the system are primarily explained by forces outside the system
How supported living has developed
• Many purposely small organizations
• Focused on relationship with specific people
• Engaged in doing it better, multiplying resources, & sticking with people
• Political strategy of taking what we can get, in each political moment, & working around the system
• Working at many levels on behalf of particular people
• Extent depends on flexibility of available funds & the amount of room in regulatory procedures
• Justified by criticism of "system"
• Often attached to argument that costs will decrease, & assumption that 'natural' (i.e. unpaid) supports will substitute for paid assistance
tension
support
resistance
resistance
Positive Social & Cultural Beliefs
• Passion for justice
• Democracy
• Mutuality
• Community
• Desire for the rewards of interdependence & care
• Love
• Technology as a source of freedom from some constraints
• Vulnerability & scarcity as a source of creativity & mutual help
• Inspiration & energy from other civil rights struggles
• Alliance with others concerned for positive change
Negative Social & Cultural Beliefs
• People must justify themselves in economic terms
• Some people are 'too costly' to serve & 'too burdensome' to expect their families to live with; these people are both 'better off' dead and entitled to high tech medical care to sustain their lives
• Technology allows control of undesirable people & situations from a distance
• A sense of vulnerability & scarcity justifies fear, division, isolation with what resources you can capture, cheapness, & a politics of division & hatred
• Racism & sexism are no longer relevant issues in making policy
• Poor people should be separated into 'good' (such as people with developmental disabilities) and "bad"; ""bad" poor people should be punished; "good' poor people should get only "the basics".

Shaping a strategy for the growth of supported living

We are convinced that supported living should grow. Many more people with disabilities, family members, community members, and service staff can benefit from supported living than currently do. But shaping a strategy for growth meets strong and subtle resistance from a complex field, as the summary chart shows.

Work for change is demanding

Working to change all this is challenging…

- The day to day work is demanding and time consuming. It takes substantial energy to influence the development of supported living.
- We are confident that we are on the right tract and we are capable, but we are a very small group compared to the nursing home industry or the group home industry.
- People with a stake in the developmental disabilities system have to revise deeply held beliefs and interrupt habits of practice that are nearly unconscious. Changing assumptions-in-practice is hard work whether it is families who are faced with re-considering their belief in entitlement or policy maker's beliefs who have to reflect on their belief that support, including "natural" support, can be produced to order in a controlled market.
- The positive growth of supported living depends on development in many spheres, not just in the reform of the developmental disabilities service system. For example we cannot merely access the housing market, we must shape it by influencing housing policy and income support policy. The prejudices that favor the congregation and control of people with disabilities can be as strong in these spheres as they are in the developmental disabilities system.
- The terms of public support have grown uncertain. Proponents of negative social and cultural beliefs seem to have the loudest voices in many forums. Discouragement and fear can keep us from calling on the positive energies that contend with destructive forces.

Increasing political influence

Dwelling with people in the concrete reality of their day-to-day lives provides the energy and direction for our effort to be influential in the many different situations that matter. In political contexts, this leads us to learn:

- How to be organized.
- How to be clear about what we want in terms that will be persuasive. Even when a significant increase in the amount of available public money is uncertain, or impossible, the time may be right to modify rules or procedures. This may be an inconvenient time for people with disabilities to claim the support they deserve, but this is the only time we have.
- How to build coalitions by finding and joining others who demand better housing opportunities, decent health care, reallocation of public funds from the nursing home

and group home industry to personal assistance, effective public transportation, and fair access to economic opportunities.

- How to increase our power in the political process. Success will attract power. Annoying powerful people who get in the way will attract power.
- How to avoid compromise on fundamental principles. This means staying out of the traps set by those who believe that people can only justify their worth in economic terms and that support is the same as any other commodity in the marketplace. This makes debate among ourselves important so that we can come to one mind about what principles we stand for and what we want to achieve.

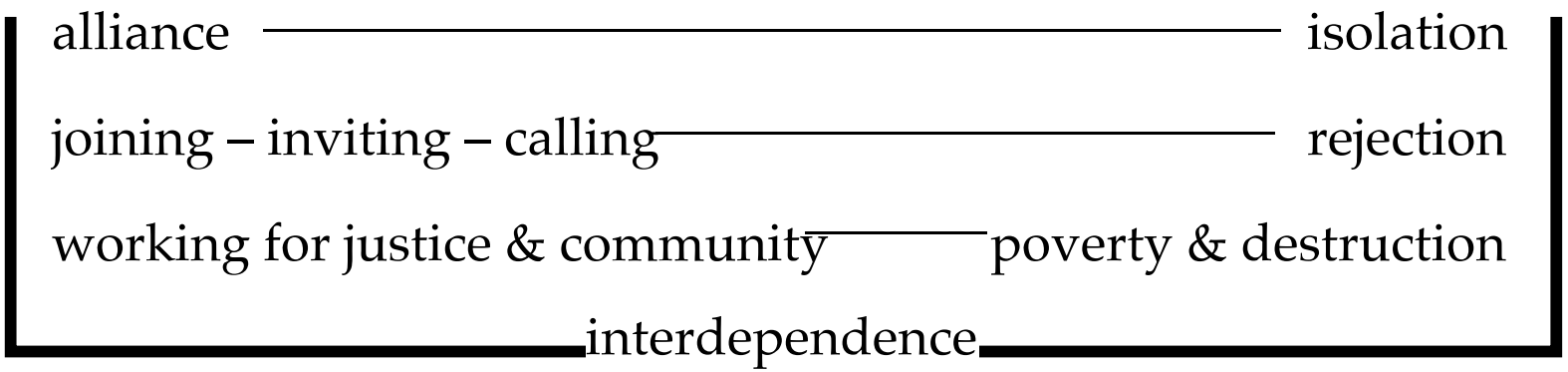
The context is interdependence

The ordinary desires of people with disabilities to have their own place to live catch us all in the middle of three great polarities. Our actions influence, and are influenced by, a social and cultural field that is shaped by contending forces:

- We want to pursue our individual lives and we feel the fear that if we don't get and protect what we need for ourselves as individuals, or as separated families, or as distinct interest groups we will lose out to others willing to be more self-concerned and competitive. At almost the same moment, we recognize the practical possibilities of working through alliances.
- We recognize the pervasiveness of discrimination, prejudice, and rejection of people with disabilities and, in justified anger or in pain or in fear, we want to reject the rejectors and to build up our own enclave behind walls of our own making. At almost the same moment, we recognize the practical possibilities of calling others into relationship, inviting others to share our lives, and joining in other people's concerns.
- We see that poverty and a real possibility for the destruction of devalued people endures despite generations of hopeful rhetoric and decades of rationally administered programs and, discouraged, we want to withdraw into cynicism and denial that any real change is possible. At almost the same moment, we recognize the practical necessity of working, wherever we can, for justice and community.

These polarities grow from the fact of our interdependence; our fundamental relatedness. Isolation, pre-emptive rejection, and cynicism are ways to hide from interdependence. Alliance, inviting, and working for justice and community are ways to face interdependence. Most people find themselves pulled between these poles, closer to one or the other at different times.

Supported living offers a concrete opportunity to recognize interdependence as the context of our individual lives by assisting one another to discover and pursue our own individual lives in ways that contribute to common good.


alliance
isolation
joining – inviting – calling
rejection
working for justice & community
poverty & destruction
interdependence

Six participants with long experience in supported living offer their reflections on our discussions.

Gail Jacob –

"Our rhetoric can keep us from getting down to the basic questions…'What is our real day to day experience of supporting people and what are we learning from that?' "

It is wonderful to be part of a group of people who are really serious about the work and thinking about it in different ways. We have discussed commitment, and deepening commitment. I realized during that discussion that there are not a lot of places where I can say what I can say here about how my commitment to the work evolves and changes over time. When you are not a family member, and you don't have someone that you deeply love in the way you do when you have a child, commitment is something that you question more than you do if the person is your son or daughter or your brother or sister. You make a choice to be involved in the work and in the relationship.

On a lot of levels, rhetoric gets in the way by setting up an expectation that you work and work and work and then you finally reach this point of commitment and understanding: "You've arrived." And then you bring everyone else along. In this rhetoric commitment is a place you get to, and you stay there, and it's way up there. But my experience of commitment to our work has been much more variable. I question a lot: do I still believe in this enough to do it? And my personal situation has changed; I don't feel the same as I did 20 years ago. There have been many times when I've had a lot of doubt about whether I should be doing this work.

This is a very hard thing to talk about with people who have the idea that you have to be in a sort of religious place all the time. I have questioned myself a lot about my level of commitment. I have had a lot of doubt. It's hard to find places where you can be honest when people look to you as a leader in the work, but the truth is that commitment ebbs and flows for me.

The other thing that came up for me was the question, when do we ever get beyond the clichés? Rhetoric can just get in the way of really talking about the day to day experience of it. The rhetoric of "choice" and "listening to people" and "own homes" is a valuable common language, but to me generalities are not the same as being involved in the work, and doing it day to day, and struggling with how these terms apply in the lives of specific people. It's dangerous to deal in generalities

These clichés are also boring because discussion that never moves deeper gets very repetitive. It seems like anybody could be saying these things about anyone. It loses meaning. We need to continuously remind ourselves of what we are trying to get at and avoid language that makes the discussion sound like a prayer meeting. Sometimes this kind of rhetorical discussion is a smoke screen for really getting to the heart of what we need to talk about.

"We need to dwell in concreteness, and yet we need to make opportunities to reflect."

The escape hatch, "it's not supposed to be like that", relates to these clichés. For example, we have had this idea that community building or community connections is supposed to be part of everyone's work. It's a good idea, but at Options, we tried for 15 years to make community building part of everyone's work and we just couldn't do it. So we had to decide that this is a myth and that believing in this myth is keeping people from making connections; so we now have someone specializing in doing community building. But still, in my head, "it's not supposed to be like that."

It's important to get down to the basic questions, "What is our real day to day experience of supporting people and what are we learning from that? " For me as a manager, this means that somehow I have to be involved in the work. Even if I am not doing direct support, I have to be connected enough on a day to day basis that whatever I say or do is rooted into the real experiences of particular people's lives. It's really easy to drift away from that.

We need to dwell in concreteness, and yet we need to make opportunities to reflect. This reflection has to be structured. We have to insist on finding ways to talk about how we feel about the work and what it means to us. Those of us in roles of directing things have the biggest responsibility to make that happen. There is a lot of energy working against making time to reflect: we are all so busy and the work is so demanding. But we pay a high price if we don't put time aside day to day, week to week, to really think about what we are doing.

"Generalities about choice and listening are never the same as being involved in the work, and doing it day to day, and struggling with how these terms apply in the lives of specific people."

Kim Turner–

"Both individually and organizationally we have to figure out, 'What's my part in this system and what's our organization's part in this system?' If we hate the system, we hate ourselves."

The value of what's happened here for me has to do with stepping back; taking time to stop and reflect on the day to day work. I already know how important that is, and I know how important it is to find ways to build that into the day to day work and to be so intentional about it, and not to assume that it is just going to happen without making the time and the space for it. Because nobody has time to do it. We have to be so conscious about why it is important and figure out ways to make the space for reflection.

There has been so much worry and fear about the danger "the system" poses to people. My concern comes from the fact the we organize ourselves in some sort of agency structure in order to help people live their lives; doing that means being part of the system. Well, if we think the system is bad, then we are bad. I don't think it has to be that way, but we probably have to come to terms with being a part of the system. Just kind of owning our part in it, and figuring out what that means.

Everybody has different relationships to the system, but as long as you see it only as a big bad thing, and then you see that you are a part of it, there is conflict that gets in the way of being in relationship with people and supporting people to live the lives they want to live. Some of the discussion about the expectations that we as providers might have for individuals versus the expectations they might have for their own lives, relates to this. The system thinks people's lives should look like this, and that's not necessarily what the individual thinks.

There is not an answer to this, it's just something to really pay attention to. Both individually and organizationally we have to figure out, "What's my part in this system and what's our organization's part in this system?" If we hate the system, we hate ourselves.

A lot people came here looking for "the answer" or maybe even a whole bunch of answers. For those of us looking for "the answer", it doesn't exist. But there are thousands and thousands of particular answers. For me it's just remembering that the answer is the process: in just sticking with people and figuring it out. Remembering that it is going to be hard. Every one of our lives is hard and we don't know what is going to happen next year. And that's true for everyone we are trying to support. We don't know how it will go, but we are going to be with the people through it. Being with people is what is going to make a difference.

Our relationship may be one of friendship, but it may be something totally different from that. I think it's really easy to get the support relationship confused with friendship, with a life time personal commitment to an individual, but it's not necessarily about friendship or life long commitment, although it might be sometimes.

Rebecca Shuman–

"We'll find the answers to the money problem once we generate energy by asking, 'What do you want in your life?' and, 'What is not there that you need?' and then helping people to come together to work to find what they want with others who are looking for what they want."

This is a very diverse group in terms of where people are in their involvement with supported living. Some folks are just getting going, others are still trying to figure how to get going; others are involved with small groups of people; and others are involved with larger groups of people. Midland, in its achievement of supporting about 100 people, is one of the larger groups. But there are things that I think apply no matter where we're at.

One thing that applies no matter where you are is generating energy. The energy that it takes to get started, or continue, or to grow, whichever place you are at the moment. Energy seems related to several different things. It is about building up a different culture –a culture that is more supportive and more caring than the one we have now. Where people could get things that they needed in an easier way. This might seem like a romantic way to look at it, but it is kind of a tribal idea of living together. But think about it. We are changing the culture by changing the situation of individuals and building organizations that embody the different culture. This is changing the culture of our communities and the culture of our country. And it all takes energy sources.

One source of energy is that we can't ever know everything. We have to learn how to constantly keep asking questions about what we are doing.

Another source of energy is acting on the belief that people throughout our communities have to get actively engaged. in one another's lives.

Working as if we had a waiting list is exactly the opposite of an energy source. It saps energy from people. Thinking of people as on a waiting list is such a passive thing: you sit, you wait, you do nothing with your life. In our community we face what we have thought about as a waiting list of people who want their own places and the support to live there, and we don't have the resources from the service system. It's easy to say to these people who don't have what they want,"All you need to do is wait and look at the system and say, 'OK system, what are you going to do for us?' And then something will happen." But that is absolutely not going to be the case. There is going to have to be an energy that drives the change and that energy has to come from and with the people who are waiting.

There are questions that we have to ask. We can't just say, "Yes, we know how to do supported living, and when it's your turn, we will do it for you." We have to say, "Yes, we do some supported living, but we don't know how to do it for you. And that is something you and I are going to have to work on. You are going to have to help us figure out how that is going to happen. Right now there might not be the resources that you are going to need, but you still need to get involved in

what happens and in helping to generate the energy to solve this problem."

There is some collective work that can go on here.

So that's where the energy comes from, it comes from people. That's the only source of energy we are ever going to have. We have to invite and engage people in the process of defining and then working to get what they want. It is very clear to me that it is not simply a matter of more money. We can't sit here and say, "Oh, if we just had more money." We can't look at scarcity of money as the problem and focus our attention on money as the solution. Scarcity of money is one problem. We do need more money, but we'll find the answers to the money problem once we generate energy by asking, "What do you want in your life?" and, "What is not there that you need?" Then helping people to come together to work to find what they want with others who are looking for what they want.

"We are changing the culture by changing the situation of individuals and building organizations that embody the different culture. "

One of the dilemmas in generating forward momentum: do we say to people, "If you want support for your son or daughter or for yourself, you must do this or you must do that; if you have resources you have to invest them this way." We can't set those kinds of expectations on people. But we can't turn around on the other hand and say, "We will just do this for you and you don't have to do anything." Somehow we have to find a way for each person to say what is it they can contribute so we can work out what can we do together. We can't do either of the extremes, we have to take the path in between.

Art LeTourneau –

"Instead of looking for one absolute answer, we have to first decide who we are answering the question for. Then we have to make sure that the answer comes out in a way that is sensible, logical, and understandable for that group."

I arrived with lots of questions and the desire for lots of answers. What I heard was lots of questions and the desire for lots of answers. I have to admit that was very frustrating for me. I thought, "If we represent the best there is, the most experienced, and most knowledgeable... " But as we started talking about some of the very difficult questions –issues of choice, issues of scarcity, issues or relationship, and so on– it struck me that there is not going to be one answer that is going to work everytime. I resolved my feelings by going to the bar with the understanding that there were not going to be any good answers.

Then as I listened more and more I started thinking, maybe there are answers, but we have to look at them from slightly different positions, from slightly different points in space.

When I think about these issues in terms of politics, I can frame an answer from that point in space. When I think about these issues in terms of community, I can frame an answer from that point in space. So maybe instead of looking for one absolute answer, we have to first decide who we are answering the question for. Then we have to make sure that the answer comes out in a way that is sensible, logical, and understandable for that group.

There are many difficult issues that we'll never settle from the point of view of the many individuals we work to support. Discussion will have to continue there. But there are political answers and community answers and accounting answers that we can discover and stand up for.

We have to take some of the mystery we have created for ourselves out of the discussion. We still have a great deal of confusion over how to balance issues of disability with issues of poverty, politics, and issues of public perception. We still need to continue those discussions in terms of separating out some issues as not necessarily disability issues at all, but as rights issues, or issues of poverty or gender or race.

I've observed that many of the folks who are here have very different perceptions of what supported living is. We are not of one mind when we think about what it is that we should be doing or trying to achieve. I think that deserves more discussion.

I also learned that when I get really uncomfortable, I have to go back to the process: Focus on an individual, and try to seek some degree of comfort in that process. When the comfort level starts to go away, I can always regain focus by going back to that level of being very, very person centered, and very involved and in touch with the lives of individuals.

Ed Bartlett –

One of the things I've noticed is that a lot of people are trying to defend what I, from industry, would call the "best available technology".

I know of no other way to support people that provides more dignity and more rights or the possibility of blending people back into the communities which they come from and which they deserve to live in.

"There's no final answer on what's good enough, but we can always strive, each time, to do it better."

People who hold the money strings have become defenders of a lot of less effective methods. I see them needing to slip back into the role of being one of a group of people who manage in a way that helps this person to live in the community.

I can't see that there is any other way besides supported living that we could justify supporting a person. The most benefit for the buck goes directly to the person to provide quality life for them. I know in our case, our son is enjoying a life that is so near to being like his other brothers and sisters that it is worth whatever effort it takes.

Some of us are asking, "Are we making people's lives too good? What are the neighbors going to say about how we're helping people to live?" If we get worried about that, we'll forget to get right back into what we are doing, and to do it well enough in each case so that when the neighbors look at it, they'll say, "This is the right thing to do; this is what we should be all about."

There is no single answer that we could come to consensus on that will suit every situation. That is part of the fun of it! Each day you walk into a new set of challenges and it can not get old and boring. So there's no final answer on what's good enough, but we can always strive, each time, to do it better for the next person. We can look at each person's life, and ask "What would it take for him to live well in our community?" Then try to provide exactly that. Not try to find a recipe, just do it each time, for each person.

"I know of no other way to support people that provides more dignity and more rights or the possibility of blending people back into the communities which they come from and which they deserve to live in."

Myrna Bartlett –

"We need to share all the good things that happen and acknowledge and talk about the things that don't work. It's not someone's fault…. We all have some responsibility. It's just something that is not working right now and we need to find another way to take care of it."

It's interesting to get together with a group of people who have a similar desire to see people be happy whether they have disabilities or not.

I've gained a lot of strength here. There are many people here with concrete things to say about community and about how systems, and parents, and people with disabilities can work together to have ordinary lives. As our expectations shift, we're all going to have to be flexible and move with that; enjoy the movement. I really like that.

It is hard to ask for help, because when you ask for help –for yourself or for your son or daughter– you make yourself very vulnerable. But it is so important to share both ways, so that people can help each other.

It is important for people to know –whether you are a parent or not a parent– that it doesn't help to have someone telling you that you don't know what you are doing or that you are not feeling what you are feeling..

I think parents are really tired and I think that people trying to help parents don't want to hear that. Because they don't know how to help sometimes. That's OK. If you don't know how, just say, "I don't know how."

It is so important for people who want to help to be honest, to tell parents or a person with a disability, "I can't do that." or "I can't do that right now", instead of promising and then never calling back. And if a parent is asking for something, or a person with a disability is asking for something, that doesn't make sense to you, just be honest and say that. So don't show pity or try to dodge issues, just be honest. Honesty liberates people's ability to take action.

I trust the person who will say to me, "I don't think that is what Tim would want to do, but I think that is what you want to do." And I know then, that is someone I can trust when I'm not here to help Tim make those hard decisions. I don't trust because this person necessarily has the right answer, but because someone would care enough to say honestly what they believe. Not many people find it easy to tell me not to do something, or to tell me that I'm wrong, but it is comforting to me when people say, "You kind of stepped over the border this time, you might want to think about this a little bit more."

Honesty and listening works both ways. I was hearing a lot of people who have worked hard to provide supported living opportunities. They too were saying "We're tired. We feel really responsible for people's lives." When I heard people say that, I was puzzled by it, but it's important that we share these feelings of tiredness and responsibility and work together on them.

I didn't say anything while staff people were talking about their sense of total responsibility

because I realized, "My God, it's hard for those people, too." And maybe when I go home I'll be nicer to the service providers. But I also thought, "If it's that damn hard, why didn't you say something?"

To be honest and to share the things that hurt is so hard, it has come from a real commitment people make to one another. But out of that honesty comes lots of celebrations, and lots of shared actions that give the energy to just keep going.

"When something comes up, we sit down and think, 'This is the issue. This is Tim. What is it that we want out of this situation? How could we help it?' Working together this way there has not been anything we have been unable to accomplish."

I don't know exactly how to grapple with our shared tiredness. I do know that in our community, it has been most helpful to identify what we can't do alone and finding someone else to help with that. Over time, this admitting what we can't do and looking for help has built up a coalition: hardly ever do people with disabilities get help with one of their issues without their families, their circles, and people who work for a variety of agencies coming together.

Because we've built up our relationships, it doesn't take a week to set this kind of action up. It can be done in an hour. Someone from Community Mental Health, someone from the ARC, someone from the circle, get together and work together. No one is really totally responsible; there is a shared responsibility.

Getting a group of people together that can surround the person, whether you call it a circle or whatever else you want, is a really helpful way to go about trying to ask and answer the questions with the person and with the family.

For a long time Ed and I did not do that with Tim. We didn't look for a circle and we didn't include him directly in our planning. Because Tim has health problems, we always thought Tim would die before we did. Rebecca had been following me around for a long time, saying, "But when is Tim going to move?" and I said, "Shut up." Then we both had some health issues, and Tim got healthier.

So I stopped telling Rebecca to shut up and we got the circle together to share our concern, and it was helpful. We thought about a house or an apartment and how people would come through the house and do the laundry, and check on Tim, and someone would live there with him, he'd have paid support, people would live there while they are doing their job. Then the neighbors put the house up for sale, so we thought. "That will be good, it's on our block. He can't cross the street. So we might as well." But up to this point we had not involved Tim in these discussions. So Rebecca said, "When are you going to include Tim in this discussion?" We keep learning.

Forming a circle and including Tim were not things I could just do for myself. I felt like I was putting Tim out on the street. I needed help to find new ways to understand.

"Honesty liberates people's ability to take action."

We know that we need to share all the good things that happen and acknowledge and talk about the things that don't work. It's not someone's fault. It's not Mom's fault, it's not Tim's fault, it's not the system's fault. We all have some responsibility. It's just something that is not working right now and we need to find another way to take care of it.

When something comes up, we sit down and think, "This is the issue. This is Tim. What is it that we want out of this situation? How could we help it? "Doing it this way, together, there has not been anything we have been unable to accomplish.

Since the time Tim moved, he has developed some additional health problems. But he did not have to come home with his diabetes. He did not have to come home when he had a pulse rate of 186. We worked it out together.

One of the parents here said that she had lowered her expectations over time, and all she really wants is for her son to be happy and have supports to pursue his happiness. I'm trying to figure out, what else is there? If you can be supported in your life and you can be happy, then that's really all there is. But that is not simple to accomplish.

"I don't know exactly how to grapple with our shared tiredness. I do know that in our community, it has been most helpful to identify what we can't do alone and finding someone else to help with that."

Interest groups met to explore six issues in depth.

Sustaining commitment over time

We have to learn how to develop an organizational culture that supports commitments over time. A supportive, nurturing, caring working situation is all of a piece: we can't expect respect, regard or sharing power from staff unless these qualities are present in the whole organization. That has implications for how problem-solving happens and how decisions get made.

In a culture that supports commitment…

- People are able to have different kinds of conversations: both celebrations and occasions for reflection around values. Writing personal journals or stories are ways for staff to share, to think about their own lives, to think about their experience, to get to know one another in different ways, and to reflect.
- Each situation needs an answer and the organization produces them in a timely way. But people are also free to worry out loud, question, and puzzle over things; people are not punished for honesty.
- Individual differences in commitment are recognized and respected. Support for others cannot be everyone's whole life. It can't be that the only people who can do the work are those with a whole life's calling or people who are missionary zealots. It can't be all or nothing. There are useful roles in between. There have to be a variety of stories about different types of involvement. Finding people's capacities to do different kinds of thing is a necessary contribution of leadership.
- Family commitment is invited, respected, and sustained over time. It is not just assumed or taken for granted.
- Leaders intentionally look at where people are overall. People meet, not just in formal groups, but also informally, to talk about focus, commitments, and boundaries, especially when a person needs a lot of support and is vulnerable without that support.
- There is an active recognition that people are key. Leaders ask and act on the answers to these questions: What happens to the critical mass of people who uphold organizational values when a key person leaves? What happens when a person who holds a key commitment to a person leaves?
- Commitment over time matters, but so does focus. It can help to stop and ask, "If we only had two years, what would the focus be?"
- People, both staff and the people and families they support, reflect on what initially brought them into the work they are doing or into the life circumstances they are in. It's not just commitment to a particular person, or looking for better things for oneself that motivates. Commitment to issues of social justice also motivates and sustains people. There are a variety of ways

that people can link their own lives to helping other people pursue better lives.

- Commitment moves beyond just individually standing beside someone over time. It also means figuring out ways to invite other people in to the person's life.

Recognizing, valuing, and sustaining, family commitment

We explored a simple picture: the person is in the middle with family and friends closest to the person, and services workers in a supporting role. Service workers nurture and support close relationships, but certainly they do not supplant them. The role of services and supports is to grow the inner circle.

It is important for families to be seen as valued partners. In discussion we immediately went to those families who either do not want to be or, for whatever reason have not been able to be, particularly nurturing or caring. We noticed this and shifted our focus to describing what practices would create an environment where families feel that they are valued partners.

There is no sense in severing relationships that people already have. Many people say that the most important things in their lives are their families, their friends, and where they live. In order to focus on the person we will pay attention to their families and friends and do what we can to nurture these relationships.

Some ways service workers can grow relationships include…

- Identify the ways that families can be essential resources. Many families can open doors to community. We need to value that and ask families to play a role in helping us with that.
- Enthusiastically offer families opportunities to be involved in all aspects of their son's or daughter's or brother's or sister's life. Do this sensitively and continually even when the family appears to be opposing or resisting more independence or something else service workers value.
- Recruit family to participate and contribute as much as they can to positive changes without making judgments that put families into situations where they stop listening.
- Help families get all available information about new possibilities. Let families see things. That's hard because families have been approached time after time with the latest new idea and supported living can seem to be just the latest fad.
- Take care so that supported living is not just seen as one more new idea. This problem is compounded by the difference between supported living and so many other services. It is hard to describe supported living clearly and vividly enough so that it really

comes alive as a possibility for the family.

- Involve family members with more experience of supported living in bringing the message to other families and helping other families sort out their thoughts and issues about supported living.
- Involve family members who aren't sure supported living makes sense for their family member in helping another family to achieve supported living.
- Life does not begin with supported living; lots needs to happen before it's time for a person to move out so that the idea of a person having a place of their own will just be a natural thing in their lives. If children grow up with other children and teenagers hang with other teens, and young folks are doing things together, then the idea that people will move out and live on their own will seem like "That's what everybody does and that's what I want for my son or daughter and what she or he expects for themself." The expectation should be that a person is included from birth. There is a close relationship between family support and supported living. The mission of family support is to support families so that they can build positive visions of their son's and daughter's lives both now and in the future.
- Help families re-frame or develop positive interpretations of things that have previously been framed in more negative ways.
- Recognize the fact that the loneliness, isolation and rejection experienced by a person is also experienced by the person's family. These things have a tremendous impact on families, not just on the person with a disability. There are pressures from very early on that tend to isolate families and push them in on themselves.
- Assist families to open up earlier in the life of a child to include other people, to invite other people into their lives, and to provide assistance when families cannot do that.
- Set up opportunities early on for collaboration, so that families can have experience of having someone else help them achieve something that they identify as important, even if in a small way. With experience, they can see how partnership can grow.
- Help families create spaces where families can just enjoy children and have fun; where everything does not have to be focused on the disability, or changing policy, or on working for change. In these settings a family can get a sense of the wonderful individual who is a part of their family.

If people are developing relationships all the time that they are growing toward adulthood, and families see their experience of having relationships, people will be much less dependent only on their family. It will be much more natural that there is a network of people who can help them create the kind of life that they want and it won't seem as scary as it does when it's always been just the person and their family, and they are the major people trying to move ahead. If people are develop-

ing relationships all long, they will be much less dependent on their family. It won't seem as scary if there are people there all along.

Dealing with isolation in a positive way:

Many individuals are isolated and that isolation hurts the person and others who are close to them. Sometimes what that hurt means is that we stop trying to counteract the isolation, because of the rejection people have already experienced. If the person with a disability experiences rejection, their family experiences a similar, though maybe not as direct a rejection. As a result of this, family members can have smaller expectations or hopes for the kinds of experiences that people can have.

We want to be happy with a first step: one good experience, and then another good experience, and then another good experience. We don't want to set ourselves up with the expectation that people will suddenly make a life-long friend who is always going to be there.

One struggle concerns the questions, "What can we ask people to do?" and "What is it that we really can't ask people to do?" and "How do we ask people?" It's really difficult to deal with those questions.

People who receive support and their friends are dependent on current support people for helping to maintain the relationship, or at least making those relationships comfortable. People are very vulnerable. Even if a person has a friend, if the support staff changes, the situation changes, and those previous relationships can be lost.

We realized that isolation is an issue for many of us in North America. A lot of us, whether disabled or not, are not really well-connected: not to our families, or to our physical neighborhood, or to any type of community of people who have made a commitment to each other, even if that commitment is just to be good neighbors. Perhaps we need to think about some practical steps that we can each take to change some of those dynamics in our own lives. We could look out our window and say, "This is my neighborhood. This is where I live. This is where I belong." We might smile at our neighbors when we see them out on the street, organize potlucks, and talk to people over the fence. We might really take some of those small steps and, over the long run, these small things might add up. We could also show our willingness to be on the receiving end of some of those very small efforts at mutual support.

Expanding choices and dealing with conflict

Issues around choice and conflict are just hard. That's the way it will be, and we can learn more about it as we go on.

There are extreme situations: a person has lost custody of a child, and now is going to have another child; a person has very severe health issues and is not following doctors advice. But those little things that don't go away can really hang people up. If a person very capable of cleaning house doesn't, if the person would call a human rights advocate if forced to clean the house, what should we do? Call an advocate or pay for a housekeeper?

We can't let people get sick, but on the other hand, what do we do when someone we know could really learn to do something, but chooses not to? At what point do we interfere, especially when we are being paid with public money to provide support? What about people who chose to watch TV and sleep in, rather than to do anything that fits the American idea of what's productive?

The answers come by getting deeper into each particular situation and using creative imagination. A person with epilepsy who didn't take medication, wasn't interested in going to the grocery store, and really became quite ill. Instead of the state taking over completely and the person not living in the community, they used a type of limited guardianship just around the groceries — grocery guardianship, instead of taking guardianship over person's complete life.

We all need to work around the issue of consensus. When we don't achieve consensus, we negotiate, which means someone wins and someone loses or we simply stuff the question down altogether. The real art of consensus is arriving at a point when no one will say "I told you so." if something goes wrong.

Circles, teams, and organizations need a keeper of the important questions so that there is an on-going process that creates new and different choices. You don't stuff it, you don't win or lose on it, but you keep raising it and coming up with your next best support.

We thought about the reasons why some choices that seem bad to us might make sense to a person.

- There can be an issue of having power or control when you've never had it before.
- People have not seen gifts of reciprocity.
- Loneliness can lead to some choices that aren't so good.
- Lack of experience.

Ideas for finding and nurturing people to do the work

We have two sets of ideas: one about finding people, and one about nurturing and molding people once they get in.

In terms of **finding people**, we have not marketed ourselves well. We've used, a lot of standard techniques like advertising in the newspaper, looking around, and asking people. Some additional possibilities:

- Imitate H & R Block. They came into our town and started looking for people to come to work there. It wasn't very long before they offered a seminar about their technique that people payed to go to. That gives them a way to get to know people and to select people who will make the biggest contribution. This is one example of trying a different way of looking at recruiting. We have important skills to teach. Marketing the skills we can teach would give us a new way to bring people into contact with our work.
- Recruit close by. Once people have decided on a place they want to live, look around the neighborhood, "One of the best providers who works for one person is someone in her trailer park." Sometimes people within hollering distance can become very helpful.
- Tap people's personal networks, including staff networks. Who do we know? What organizations do we belong to that bring us personal contacts? Word of mouth remains the most powerful tactic.
- Look for people who want to build community. For example, find out who wants to join a housing co-op and offer them an opportunity for involvement with people with disabilities.
- Recruit in colleges. There are pros and cons to working with college students. Offering credit may get people's interest; then students can learn what the work really is. At the very least people get a lot of important ideas. College students may be on the edge and be willing to put up with some things other people are not.

Nurturing people

- Make building community an expectation for everyone in the organization. The goal is to expand community for everyone.
- Staff are often involved in other organizations in the community. People with disabilities need to also be involved in these. Even if it didn't work last year, this year it might click. Don't give up.
- People have to get together and talk. We have to make the time to do this, even though wage and hour laws could be a barrier. People can get together to eat pizza and then talk about supporting people
- Orientation. We need to give people lots of information up front so they will know what they are getting into and we'll know who we are talking to. Interviewing for an hour is not a good way of finding people to work in supported living.

- What data are we asking people to collect? Are we asking people to record important things and are we giving it back to them? The information we ask people to collect tells a lot about who we are as an organization.
- Encourage and expect personal development and support for each other. Expect people to share stories and information with everyone in the organization. Leaders need to model what we want and continually shape management practices that make the philosophy of the organization come to life.

Waiting lists as source of creativity

"Your number is 676, and we're now serving #4." Our image is of a Soviet deli where there are hundreds of people in line to buy two sausages.

We can build relationships through which people can tell their stories about waiting. Culture a sense of respect for people's patience, because those are important stories.

The extent of what people are waiting for varies extensively. Some things are very small, but we often don't even know exactly what people are waiting for, we just know that they are on a waiting list. And we exacerbate the situation by making people stand in line.

Maybe if we go out and find out who these people are and exactly what they think they might need, instead of making them come beg or for things to become a crisis, we might find that what people actually want is smaller than what the list says people need.

We are not very good at thinking beyond the deli counter. When we run out of things we just order some more. We are not good at thinking of potential solutions that exist beyond our traditional menus and rescues, systemic structures and paid professional resources. As we explore, we need to develop processes without guaranteed outcomes. These processes are ingrained in our desire to know how things are going wrong. Rather than looking for solutions to things and ways to be successful, we need to look for ways of knowing when we are going wrong.

We don't spend enough time helping people learn to assess their own resources, to figure out who they are, and what their capacities are, and what they can draw on. We need to go for coalitions with other people who are also waiting. Housing is a big issue for a lot of people. It's a community problem, it's not a disability agenda. Failure to work in coalition is a lost opportunity to connect to, influence and create community.

Disability issues should be presented in terms of other community issues. We can form mutual relationships to bring other people into the soul of the work. We can bring people

into the idea of personal assistance. We start by asking ourselves, "How do we find and form those relationships?"

We can advise and assist people who are waiting to begin work with other people to figure out how things can be done, and how to directly involve the key players. We need to bring more people in to help figure out the solutions.

We need to make it clear to parents and other family members that they are capable, active partners. We can do this by adopting a learning posture in relationship to families: how do you do it? This means accepting uncertainty as a feature of learning new ways to support people rather than using uncertainty as an excuse not to try things with people.

We need to make clear what's possible, what people are capable of accomplishing if they commit to working together. We can create opportunities to bring others in by inviting them to meet people in community situations

We can nurture a shift in a fundamental assignments of care-giving roles in order to expand responsibility beyond "the women".

We can break down territorial boundaries that keep us from working with other agencies that might help us to support people.