

To: Participants
From: John O'Brien
Subject: Meeting Summary

Disturbing the Force

This memo summarizes a meeting held at Lynda Kahn's invitation on the afternoon of 11 April 2001. Our discussion focused on identifying long-term issues critical to the development of Rhode Island's DD system. We hold leadership positions in advocacy and self-advocacy groups, service provider organizations, and the Division of Developmental Disabilities, but each of us represented our own point of view rather than representing organizations. We didn't try to resolve differences in points of view and, though there were many areas of general agreement, not everyone will agree with every point made in the summary. We will each make use of this summary in ways that make sense to us. The summary itself is written for our use rather than for others to read; people who didn't participate will probably need more explanation than this memo provides.

Each of us answered this question: **"What issue we face today, more than any other, will define our system's capacity to support good quality lives for people with disabilities, their families, and the people who assist them in 2010."** In selecting an issue we were invited to...

- ...keep our vision for people with developmental disabilities clearly in mind rather than being driven by our worries
- ...consider the whole system, rather than just the part of greatest personal concern
- ...think long-term rather than just about what is currently urgent
- ...look for issues that can develop the most leverage to improve the system rather than focusing only on what we already know to do and what we already have support for

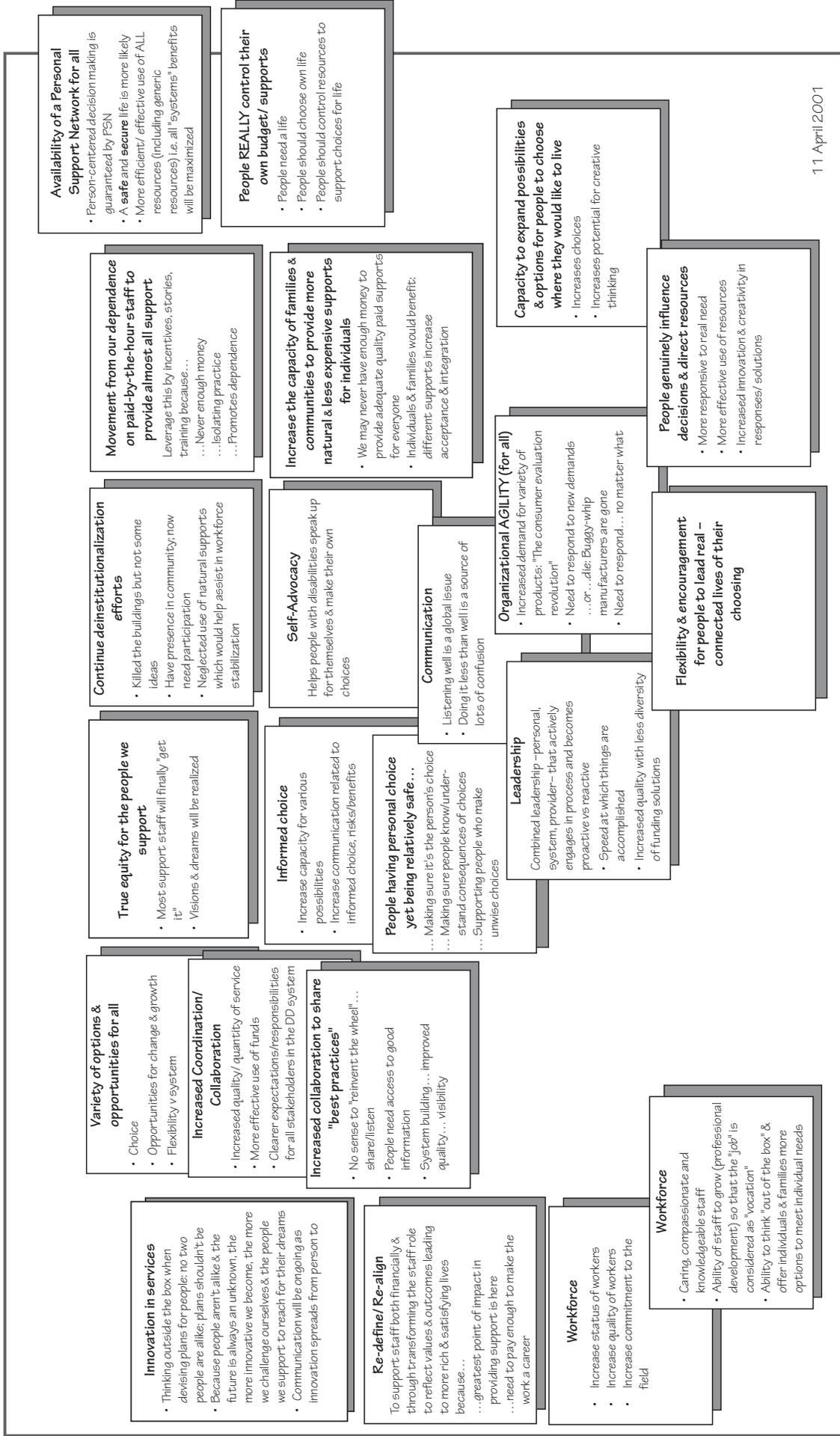
We put our answers on a large chart, selecting a position that reflects the relationship we saw between our issue and issues others identified. The next page reproduces the chart, maintaining our own words and the positions we choose to display them.

In reflecting on the whole set of issues, we noticed many common or complementary issues. There are more differences in emphasis than conflicts on the substance of how our system needs to develop. There are important differences about how to make necessary changes, but it seems that we are all on the same (long) page.

We spent the remaining time exploring how the issues we identified connect one another and looking for areas of possible conflict.

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What issue do we face today that, more than any other, will define the RIDD system's capacity to support good quality lives for people with disabilities, their families, & the people who assist them in 2010?



Points of leverage

More and more people with developmental disabilities and their families demonstrate the variety of ways that they can lead satisfying lives, connected to others and contributing to their communities. We want to continue to support these people as their opportunities and needs change while increasing the numbers who experience the benefits and challenges of a real, connected life.

People's lives are more satisfying when they have genuine influence on their life circumstances. Practical experience shows that such influence grows when people have...

- ... a well organized group of personal allies, strongly committed to discovering and actively promoting their interests
- ... connections to advocacy and resource groups that can provide reliable information and encouragement and give people and their families the opportunity to work with and for others
- ... a way to consider their gifts and needs for assistance that results in plans for creating opportunities and developing the assistance necessary to pursue a life of their choosing
- ... personalized supports provided by competent people who find meaning in assisting people to participate actively in their communities

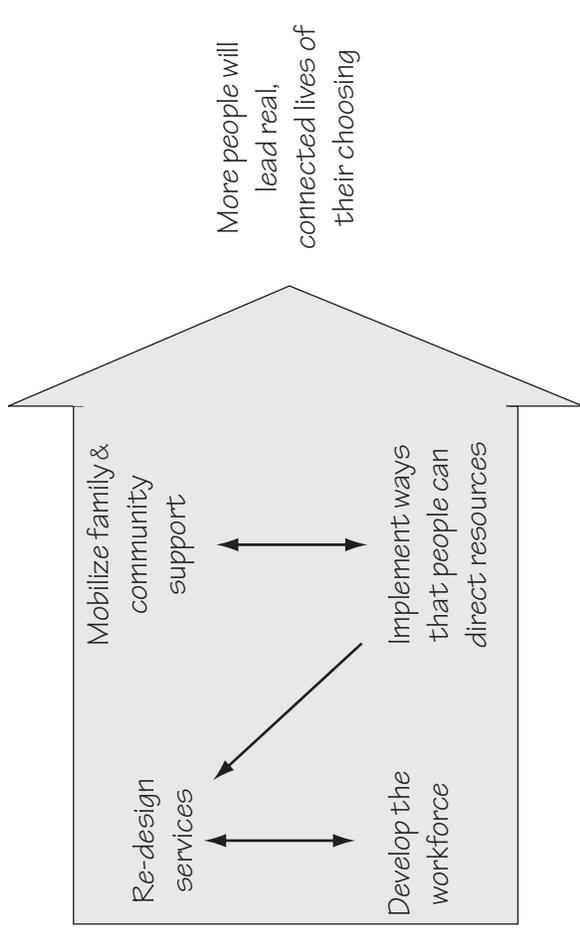
... sufficient control to get and hold the attention of the service professionals and provider organizations they rely on when they set or re-set their goals, when decisions affecting them are made, and when they identify problems that need work

We identified four connected points of leverage that will offer more people the conditions to influence the services they need in order to participate in community life: mobilizing family and community support; re-designing services and service agencies to increase their flexibility in responding to continually changing expectations; developing

a committed and competent workforce who defines their role as aligning themselves with people's hopes and expectations for a good life; and implementing ways that people can direct resources to exercise greater control of the services they count on.

If we...

Then...



Leadership is crucial

There is a great deal to be proud of in our system, and many forces converge to keep things stable as they are. So improvement will require “disturbing the force.” This is the work of thoughtful champions who work to understand and to help others to understand the reasons for change. Leadership is not the sole responsibility of people in positions of authority. Everyone – providers, families, people with disabilities, system managers – needs to proactively look for ways to improve their personal and organizational agility if our system is to avoid the fate of the buggy-whip manufacturers. They failed to notice changes in their

world and changes in demand. They tried to hold on to what had worked in the past. They tried to avoid responding to new expectations and new standards for evaluation of their offerings. They died out.

Elements of leadership

Communication lies at the heart of the leadership we need to exercise. There are many points of view, many anxieties, many opportunities for misunderstanding and hard feelings. This makes listening well and encouraging others to join in even more important than articulating our point of view and directing other's efforts as we exercise leadership. Poor communication generates a confusion in which opportunities for constructive action get lost.

Building up connections among people is necessary if our system is to get better at developing services that respond to people's choices. Connections can be made around sharing examples of "best practice" and around sharing questions that trouble the process of improvement. Deliberate focus on what's working for people is especially important because our society as a whole seems far more focused on news about bad performance than about holding up what is effective and good. Information will spread more widely as we invest in strengthening local advocacy efforts to compliment our already effective state-wide organizations.

Leadership includes identifying both how far our system has come and how far we have to go. De-institutionalization is complete only in the sense that the buildings are gone. Some the ideas that supported segregation and control still influence too many people's everyday lives. People are present in our communities, but there is a great deal of room for development of people's participation in and contribution to community life. Rather than face the challenge of enlisting natural supports, we have too often wrapped people completely in paid staff.

Leadership means expecting creativity in challenging the too small boxes we construct that are so easy to mistake for the limits of reality.

Drivers of change

We agreed that two of the drivers of past changes probably won't energize the efforts we need to make now.

Major public scandal is unlikely -and, the larger system's response to scandal would probably move us more in the direction of centralized bureaucratic controls than toward putting greater control in the hands of people with developmental disabilities and their families

It may well be possible to keep up with demand for services. Initiatives like the proposed 5 year Plan may respond to increasing costs of operations, and even allow incremental improvement in staff wages. However, a big increase in the rate of growth of public money specifically directed towards people with developmental disabilities is unlikely. This means that the DD system can't buy change with large amounts of extra funds. People and organizations will have to choose changes because these changes diversify the resource base (through such strategies as Home of Your Own), or because they will lead to more sustainable efforts, or because they represent a better use of existing funds. To start doing new things on more than a pilot basis, the system may have to stop doing other things that still have some benefits.

In our discussion, there were two points of view on what will energize desirable changes. One point of view would have us amplify what is already "bubbling-up", as more and more people take increasing charge of their lives. The other point of view calls for the next "BIG DEFINING THING" (or BDT), which would be re-designing the system to put control of service expenditures firmly in the hands of people with developmental disabilities by giving them authority over individualized budgets.

This differences came up most clearly in our discussion of people directing resources, so they will be summarized in detail there. However, there are two more general questions worth further consideration.

- What would need to be true about our system to make it reasonable to think that significant change will happen without some BDT, whether it is control of individual funds or not? Some read history to say that there are few if any examples of systems with power training themselves into relinquishing that power. Without generating a shift in the balance of control, significant change will be hindered.
- Without a BDT to motivate people, what are the chances that most of the system will focus on anxiety about scarcities and shortfalls? Or, put another way, what would improve the chances that examples of people with developmental disabilities leading much better lives and examples of the good practices that support them could become as powerful a mobilizer of change as a BDT?

Mobilizing family and community support

Encourage contribution

The reasons to mobilize family and community support as a necessary part of a person's arrangements for assistance do not come from a sense that professionals or service providers perform poorly (though strong support from family and allies provides a safeguard in case a person does suffer from professional or provider malfeasance). The most important reasons to organize family and community supports are at least these four:

- When they are able to remain involved, family members and committed allies provide an irreplaceable safeguard for the well being of vulnerable people
- For many people with developmental disabilities, family members and committed allies provide a powerful source of energy, encour-

agement, information, knowledge, and wisdom which strengthens the person's ability to make choices and discover and act on a vision for a better life

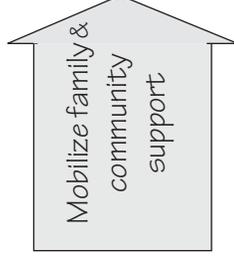
- Families and communities can diversify and extend the resources available to a person with a developmental disability

Encourage continuing family & community contributions to support people in services

Continue to strengthen self-advocacy

Invest in educating staff, public, families & people themselves about how to honor people's value, dignity, & equality

Create Personal Support Networks



- Families and committed allies can be a source of innovation as they work to personalize the supports a person needs

Family and community contributions can bring difficulties as well as benefits: there may be increased conflict between staff and involved family members over what makes sense for a person; some families and community sources lose their ability to make a contribution that a person has come to count on; and a few families face a variety of problems that can make it difficult for them to play a constructive role or even make them a cause of abuse.

Looking for contributions from family could induce a big disturbance in the force. Many families expect that, once they have done as much as they can, the system is responsible for taking over. Some may say that the expectation of family contribution is unfair.

Create Personal Support Networks

Personal Support Networks are a systematic approach to assisting parents and family members to face the question “What will happen to my child when I am gone?” The approach combines building a support network, with estate planning, person-centered planning, service brokerage, and a systematic and least restrictive approach to substitute decision making. It develops outside the system and maintains its independence, seeking its funding from membership and private sector grants. (See www.plan.ca)

Personal Support Networks will grow gradually but steadily in RI: a handful in the next year or so, a few dozen by 2004, and then, as competence grows and the word spreads, a steep growth curve through 2010.

Personal Support Networks may not directly benefit people who have been cut-off from their families or people whose families choose not to invest in this form of insurance for the future. However, they will be an important force to shape the systems direction.

Educate for true equality

While most people would say they held no prejudice against people with disabilities, many hold and act on unexamined beliefs that assign people with developmental disabilities to a second-class citizenship.

Many children still attend segregated schools. Many adults are commonly believed to be unable to contribute to ordinary workplaces. Some staff, and even some family members, lobby for funds in terms that present people with developmental disabilities as a burden or a tragedy. Many unthinkingly assume that anyone without a disability label can take over decision making because “they’ need supervision and ‘we’ know best.” Some staff still talk about “my clients” and “our

people” as if staff owned the people they assist, and many would accuse anyone who called them on it of “political correctness.”

These low expectations and negative beliefs can even infect people with developmental disabilities themselves. Too many people with developmental disabilities don’t see themselves as having gifts to bring to their communities or to have the right to make choices. Too many people with developmental disabilities have no effective voice in the way they receive services or the way their communities overcome barriers to access and participation.

People with developmental disabilities and family members are powerfully effective educators. They educate by the way they live their lives. They educate by making presentations and developing publications and videos that express their beliefs while they strengthen the voices of the people who make them.

A structure for creating educational experiences and materials can transform things that hurt into positive action. For example, people who found the negative portrayal of people with developmental disabilities in testimony to the legislature are already sketching the outline for a video with the working title “You don’t own me. A guide for lobbying.”

Investing in people with developmental disabilities and family members as educators offers important leverage for a stronger, more effective system.

Strengthen self-advocacy

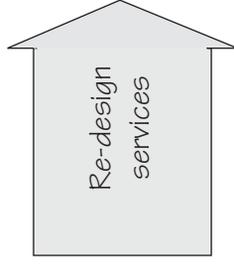
For many people with developmental disabilities participation in self-advocacy is a key to greater control over their lives and the satisfaction of joining others to make positive changes. When people have a strong and growing organization they can resist the beliefs and barriers that would otherwise make their lives smaller.

As it grows stronger, self-advocacy faces at least three challenges:

- Developing more local groups throughout the state
- Getting even better at getting useful, understandable information to people with developmental disabilities and their families about what is possible for people with disabilities and how the system works
- Finding more ways to involve people whose disabilities make it hard for them to participate in self-advocacy as it is now

Re-design services

Service providing organizations face big problems. The most immediate problem is finding a sufficient number of capable workers and making sure they have jobs that they want to stay with. As urgent as the problem of the workforce is, we think it would be a mistake to put off work of re-designing services for two	Increase variety of alternatives to paid-by-the-hour, agency-employed staff Organizations expect flexibility & creativity from themselves & other parts of the system & community	Expand the number of people who can choose where and with whom they would like to live
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changes that will offer them and the people who work with them a chance to be at their best.

It may help to look at the challenge of re-design in a global perspective. All over the world, from the Berlin wall to the rise of entrepreneurs in China, systems based on centralized, hierarchical controls are breaking down. The time when it was possible to settle most conflicts with a single, decisive contest is passing. Now, more and more people expect to have a say. The units for getting important things done are getting smaller and smaller, and there is a growing demand for customization. No sooner does a producer catch up to expectations than those expectations change.

We shouldn't expect to be immune from these trends just because we work with people with developmental disabilities. In fact, if we can figure out how to keep up with the complexity that these trends introduce, we will get better at fulfilling our mission because we will be organized to figure out how to find out what people really want from us and how to assist them to get it.

More people in their own homes

People with developmental disabilities have demonstrated over and over again that choosing where and with whom you want to live and then getting the support you need to live safely and comfortably leads to more satisfaction -and to more problems and risks that build skills and maturity as people handle them with support. We think that many people who are now placed in groups that someone else created would grow from the opportunity to make the move to a home of their own. Some of us think that this is the next stage in the process of deinstitutionalization, and that the change will involve facing some of the same concerns and fears now that we successfully mastered then.

People and their families have already figured out a variety of ways that a person with a developmental disability can be a homeowner.

Many people will choose to rent or perhaps to live with families. But more people want the chance to aim for a mortgage of their own.

Personalize supports

The most effective supports are those that have the best fit to a person's changing goals and needs. A good fit can't be achieved by placing a person in a pre-defined program and then trying to make few small alterations. A good fit comes from negotiating creatively with people or guardians who have a plan and a good idea of what they want.

There will always be compromises based on shortages of money, or lack of knowledge or skill at doing something a person wants. But if these compromises are negotiated with people and their families, rather than decided up-front by the way a program happens to be structured there is a better chance of a creative solution. And, when compromises come, everyone can own them rather than feeling victimized.

Negotiating supports one person at a time may threaten some professionals or service providers who want to stay in control. So we will have to support and challenge one another to get over the "we know best and our way is the only way" habit.

Create alternatives

Some people misunderstand personalized services. They think it always has to mean paid-by-the-hour staff working one-to-one. There are many other ways for people to get the assistance they need to be safe and take reasonable risks besides having their lives completely structured by staff.

We need to learn more about these alternatives, spread the word about what the benefits and problems are, and get to work on increas-

ing the variety of ways people can use service money to assist them in living well.

Seeking alternatives gives us a chance to explore the possibilities for recruiting community support. What looks like a "workforce problem" from the point of view of an agency searching for family support staff might also be seen as similar to finding a trustworthy baby sitter. This latter understanding might lead people to think about suitable people they already know and to invent co-ops through which people might barter support.

Support responsibility for contribution

Another misunderstanding of personalized services assumes that people with developmental disabilities should be protected from responsibility. While we know that there are some tasks that people can't handle without help, we think that there is room in many people's lives for them to take more responsibility for looking after some of their own needs.

Much more important, though, we believe that people with disabilities have important contributions to make to the well being of other people and their communities. Some of these contributions are economic, and more and more people need the rewards and responsibilities of meeting the expectation of working for pay in their community. Some of these gifts are social, emotional, artistic and spiritual.

The reason for services is not to fix broken people or to watch over defective people. It is to assist people to discover how they can contribute and to develop opportunities for contribution.

Expect flexibility and creativity

It is easy to get caught inside a box of our own making. In this box, we can't see ways to do what we want to do with people because these

walls, among others are too close to give us room to grow: “this is how we have always done it” and “what will medicaid think” and ‘they’ll get mad” and “there is no way to afford it”.

There are tough problems. Some important resources are scarce, now. Some people won’t help, yet. Some rules won’t bend, yet. But problems get tougher, scarcity cramps more, help is farther away, and rules are more imprisoning when people and organizations let themselves and each other off the hook for finding as many ways as can be of being flexible and creative. Service organizations have to be accountable for creativity in customizing supports, not just for staying out of trouble.

Develop the workforce

Developing the workforce reaches well beyond dealing with the growing shortage of capable workers. It is a matter of understanding what is necessary in addition to fair pay, decent benefits, and a chance to see responsibilities and earnings grow with time and growth in skill.

We must recognize that we are competing for more than people’s time on the job. We are competing for people’s hearts and people’s interest in creative problem solving in service to their community. If we can’t lift up the meaning in the work, we will miss a key leverage point in strengthening our service.

Improve status and pay

This issue has been so much on our minds and at the focus of our work that we had little to say about it in this meeting. Its importance is obvious to us.

Consider the work a vocation

It’s worth thinking about where the status in the work comes from.

Status comes from having a job that demands real and continuing learning to do well. More must be learned than can be covered in required courses on first aid and record keeping and universal precautions. Staff need to learn about how to deal with difficult human problems, like helping a

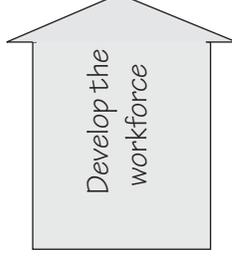
person and her family sort through a conflict over what risks are reasonable or striving to discover the best thing to do for someone who hurts himself or learning to build a bridge that a person can cross out of loneliness into participation in her community. Staff need to learn how their own beliefs and behavior affect other people’s lives. They need to learn to notice their own prejudices around disability and the ways that they slip into controlling others or avoiding real engagement with them. They need to learn to notice when straightforward solutions –like exploring people’s immediate neighborhood for people to meet and things to do– gets buried in professionalism –like hunting through the paper for “outings” to drive a group of “residents” on. This means investing real money and talent to match the expectation that people will be learners.

Improve status, pay & benefits

Consider the work a vocation: recruit & build commitment through investment in professional development

Promote storytelling in many media about the results & rewards of respectful partnerships between people with disabilities and staff

Confront efforts to build support for staff by putting people down: “them” as “burden” or “danger” or “our’s - (staff possessions) with education on equality



Status comes from translating general principle, like promoting choice, into the particular circumstances of a real person's day. The work is not simply a matter of being able to say words like "self-determination". It is being able to use every sense to figure out how this person can take greater responsibility for her life, today.

Status comes from assisting socially excluded and devaluated people to overcome the injustices of segregation and low expectations. It comes from walking with people through their troubles and toward their goals.

Don't "go negative" on people with disabilities

Inability to pay a competitive wage and shortfalls in meeting personnel costs like health insurance or workers comp puts organizations under strain. It's easy to slip into trying to build up the case for better pay by tearing down people with disabilities.

It tears people down when they are portrayed as a burden whose caregivers deserve sympathy, or as teetering on the edge of life because their need for specialized medical care is so great, or as taking special, saintly people to put up with them, or as themselves creating hazardous duty for the people who work with them.

The grains of truth in these negative messages are much better understood in the context of what our work really means. People who lack a sufficient amount of the right assistance can be difficult to be around, or endangered by inadequate or incompetent attention to their particular needs. And, there are a very small number people for whom we have not yet identified what the right kind of assistance is. But the real story is that in spite of difficulties, most people with developmental disabilities are interesting and rewarding people to be with. Assisting them can be hard, skilled work that requires thoughtful people who can listen and join in solving serious problems but it does not call for saints

or martial artists, or keepers, or couch potatoes with a high tolerance for boredom.

Negative messages will backfire. If we don't communicate the rewards of supporting people as they develop and claim the rights and responsibilities of citizenship, those with a gift for sharing the struggles of life with others will not know that the work can satisfy the desires of their hearts. They won't apply. Instead, people with a taste for low demand looking after others who are less than themselves will drift in and out of our jobs and the lives of the people who count on us.

Promote storytelling

Learning, renewal, and celebration all flow from capturing moments from the journeys that people with developmental disabilities and their families take in the company of staff who enter a respectful partnership with them.

We need to invest in creating settings for people to exchange and reflect on the meaning and the lessons in such stories. We need to find the people with a gift for telling stories of respectful partnerships. We need to capture them in as many media as our imagination will allow. We need to spread these stories far and wide. They will be an important part of attracting and encouraging people with a gift for the work.

Implement ways that more people can direct resources

It was in the discussion of this leverage point that disagreement emerged.

On one side were advocates of re-centering the DD system's expenditures by giving people or their guardians responsibility for controlling expenditures from their individual budgets –the next **BIG DEFINING THING** (BDT). They hold that a bold move is timely. They suggest putting people or their guardians in control of their allocated service funds

and thus de-centering the system from a focus on the behavior of a few agencies to the decisions of hundreds of empowered purchasers.

Even better capacity to plan with people & share resources & information

On the other hand, some of us felt, the existing system gives people genuine opportunities to have a choice about which agencies assist them and to negotiate about the assistance they get.

People and families can find convenient ways to exert about as much self-management as they want. Many, perhaps even most, people and families are satisfied enough with their current arrangements to stick with them. And many interesting ways to arrange supports and live a satisfying life are bubbling-up. This variety reminds us that there are many ways to live a meaningful life, and control of the expenditure of funds is not a necessary condition to experience them.

Time didn't allow most of us to have a say on this important difference. But there was wide agreement on the leverage in substantially increasing the numbers of people who have genuine influence on decisions about goals and methods and a meaningful way to direct the resources allocated to their assistance. There was also agreement on

two of three strategies for increasing people's control of their life circumstances.

Improve resources for personal planning

There is substantial experience with assisting people and families to clarify their goals in light of high expectations, to identify what matters most about personal assistance, and to problem solve around developing opportunities and arranging necessary assistance.

More people need to learn how to assist people in planning and this should include a growing number of interested people with developmental disabilities and family members. Those involved in planning need continuing support to develop their skills and, even more important, to consider the possibilities in the many puzzling and difficult issues that they encounter.

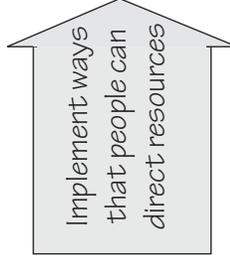
We need to grow an even stronger set of networks of resource people who can offer ideas, information, encouragement, and practical help. People's chances for real influence grow stronger the more these networks reach into their own neighborhoods.

Strengthen support for choice

Many of us see strong links between a person or family influencing or determining the supports a person gets and the ways a person exercised choice and deals with risk in other areas of life.

Many family members have good reason to be concerned about the consequences of poor choices. They want to see evidence that people have good information about what the choice is and what the possible outcomes of different choices could be. They note that some people's choices may reflect staff preferences rather than their own desire and they would like to see ways to increase confidence that the person is choosing, especially when communication is difficult or dependency on

Individual Budgets with expenditure controlled by person or guardian, at least as a strong option



Develop ways for people to learn about their responsibilities for resources & insure against poor decisions

staff is high. They are aware that much can be at risk in significant choices and they want to know how risks are anticipated and what safeguards are available when choices go bad.

Some service providers have experienced some family members who listen poorly to the person they support, hold low expectations of their abilities to cope with difficulties, and micro-manage people's lives and the minute details of a person's assistance. They too are concerned about the responsibility of interpreting the interests and desires of people whose communication is difficult or who depend almost completely on others.

We see a clear link between choice and responsibility. We would like to discover more effective ways to help people and families to understand and fulfill their responsibilities as users of public funds.

We would like to assure that the responsibilities people assume when they use public money to buy necessary assistance make sense in people's real lives and not just in the world of medicaid and social assistance.

Personal control of individual budgets

This strategy needs more discussion.

As a prelude to the next round of that discussion, it may be worth identifying some of the assumptions that surfaced in the discussion of personal control of individual budgets that we did have.

- Most people with developmental disabilities and their families and guardians have no interest in controlling the expenditure of funds. They are concerned with the services they get, not with the details of their purchase.
- In fact, many people would experience the offer to manage expenditure through an individual budget as a disruptive imposition which would add to their stress. Most families count on the system to look out for the best interests of their sons and daughters and would feel overwhelmed, or at least burdened, by greater responsibility.
- Individual budgets would firmly shift power directly to people with developmental disabilities or their guardians.
- Many, if not most, people would (come to) welcome the opportunity to control an individual budget and would make smart and satisfying decisions about how to spend their money.

These mirroring and opposite assumptions seem worth investigating. Experience with individual control of funds in Rhode Island and in the growing number of demonstration sites elsewhere offers the chance to gather some evidence to check them. Creating forums that would involve a much larger number of people with disabilities and families in the discussion would also be a useful prelude to deciding on whether to develop a strong option for individual control of funds or not.