Living Into the Answers

A Review of the Transition to Individualized Supports

For People Served by the Community Services Department of

United Cerebral Palsy Association of Oregon and S.W. Washington

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Acknowledgments

We are grateful for the hospitality, openness, honesty, and spirit of cooperation generously extended to us by the people and families supported by the Community Services Department and by the staff of the Community Services Department, who not only shared their thoughts with us but also acted as our "buddies" to help us find our way through the complex schedules they devised for us. Chrissy van Weel and Lisa Walsh made our logistical arrangements and kept us on track. Bud Thoune showed genuine concern for our personal well-being as well as our observations and ideas. Tara Asai has worked on this review for more than a year with the same energetic competence and quiet class that she has brought to the transition process for the past eight years.

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Introduction

The United Cerebral Palsy Association of Oregon and S.W. Washington (UCP) marked the formal completion of their transition from providing congregate services to offering individual supports for home, work, and community life by inviting our team to review two aspects of the process. They asked us to provide

…an interested outsider's account of the process of their transition in a form that might be useful to other agencies.

…a critical view on the issues that will shape the quality of the supports they offer over the next few years.

Our process was simple. We visited from Sunday, 12 January – Friday, 17 January 1997. From Sunday evening through Thursday noon, we gathered information by meeting some of the people UCP supports and some of the key people in their lives. We also interviewed other people who have an important role in UCP's transition and future. Team members collaborated with UCP senior staff to decide who we would meet and how we would manage our schedules. Team members almost always worked individually, though we had good help from UCP staff or other assistants when we needed orientation to a person's communication system. Each evening and from Thursday noon to Friday noon we met as a team to share our information and our thoughts. We held two meetings with UCP staff and Board members and with others interested in the transition. In these meetings we discussed our conclusions and provided a chance for people to correct or further inform our views.

This report and two brief memos sent separately to the Executive Director and the Director of the Community Services Division are the written record of our work. The extent and richness of what UCP has accomplished means that our learning is much more extensive than what we have written.

Lessons From the Transition Process [*]

UCP's eight year, staged transition process assisted people with disabilities to move from group homes to supported living and from a sheltered workshop into supported employment or community experience. The process also focused staff energy by moving from separate administrative units for residential and vocational services to a unified Community Services Department that functions through three teams

| Community based employment |
| Team based organization |
| Living in your own place |

'87   '90   '93   '96

- Long range planning process begins
- First 5 year plan
- Decision to close Alder St Group Residence

- First person moves in May
- Alder St Group Residence closes in November

- Holgate Group Homes close in June

- Decision to close workshop
- Vocational Services & Home Program merge to form Community Services Department teams

- Workshop closes in June

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[*] This section presents some of the lessons the review team has taken away from the process. It is our construction of what happened, made from what seemed to us to be the important parts of the many different stories we heard about the transition. While the UCP people involved have checked our story, it is not the same story that they would tell. For example, we deduced the six qualities of UCP's leadership from what we heard; UCP's leaders do not talk about themselves as displaying these qualities. This is certainly not a history that describes what people were thinking at the time they were making decisions. For example, we decided to describe the change process as driven by the necessity of dealing with value induced contradictions. We have left it to the people with disabilities involved to tell their personal stories about how they have used UCP's transition to make important changes in their own lives. We don't think our story is any more valuable than the story insiders can tell. In fact, we believe that the personal stories of involved people are far more important than ours . What we do here is tell what we can, that is, what we learned about organizational change by reflecting on what some of the actors in that change shared with us. We have written this in a way that we hope will link UCP's learning to the issues other agencies face as they move into transition.

Through this process…

- 25 people moved from group homes or institutions into homes of their choice . All 45 of the people UCP assists day to day live in their own places.

- 29 people have their own jobs: 2 are employed competitively, 1 is developing a business, and 26 are employed with support.

- 12 people are employed in two UCP operated enclaves

- 11 people are unemployed and seeking work with UCP support.

- 10 people participate in Choices, a program focused on community participation and relationship building.

- 10 people either transferred to other day service agencies or left the developmental disabilities service system.

This process positions UCP to…

…provide good supports to the people who rely on it for assistance at home, at work, and in community life

…offer important lessons to other agencies interested in developing supported living, supported employment, and effective ways to convert their resources from successful congregate programs to flexible, community based structures that allow person centered work

…develop new forms of supports for people and families who have not received intensive services from UCP before.

The people UCP supports, and almost all of their families, believe that the results of the transition process are worth the risks and difficulties of making the changes. As one person put it, "My life is better. I have freedom. I would not go back if someone paid me $100." Community investors in the transition process believe that their money was well spent on projects whose lessons have a high potential to improve services to other people in the community. A number of people in other agencies would agree with the director of another organization, who said, "UCP has gone from a relatively ordinary agency to an agency that has moved to the cutting edge. I've seen their struggle and it's no piece of cake." County and state officials appreciate the systematic, person focused, thoughtful, low key way UCP has gone about making fundamental changes and credit UCP with substantial influence on the state's move toward more person centered services. UCP's national organization recognizes the agency's leadership in converting its services to approaches which embody it's vision of a positive future.

The Formula for Change

The maxim, "There are no easy answers", has become a cliché in discussions of making change in human service agencies. UCP's experience suggests that it may not be completely true. From Bud Thoune's point of view, UCP has followed one formula throughout his tenure as Executive Director:

> *"In every area of our work – our services, our fund raising, our facilities, our community relationships, our community reputation–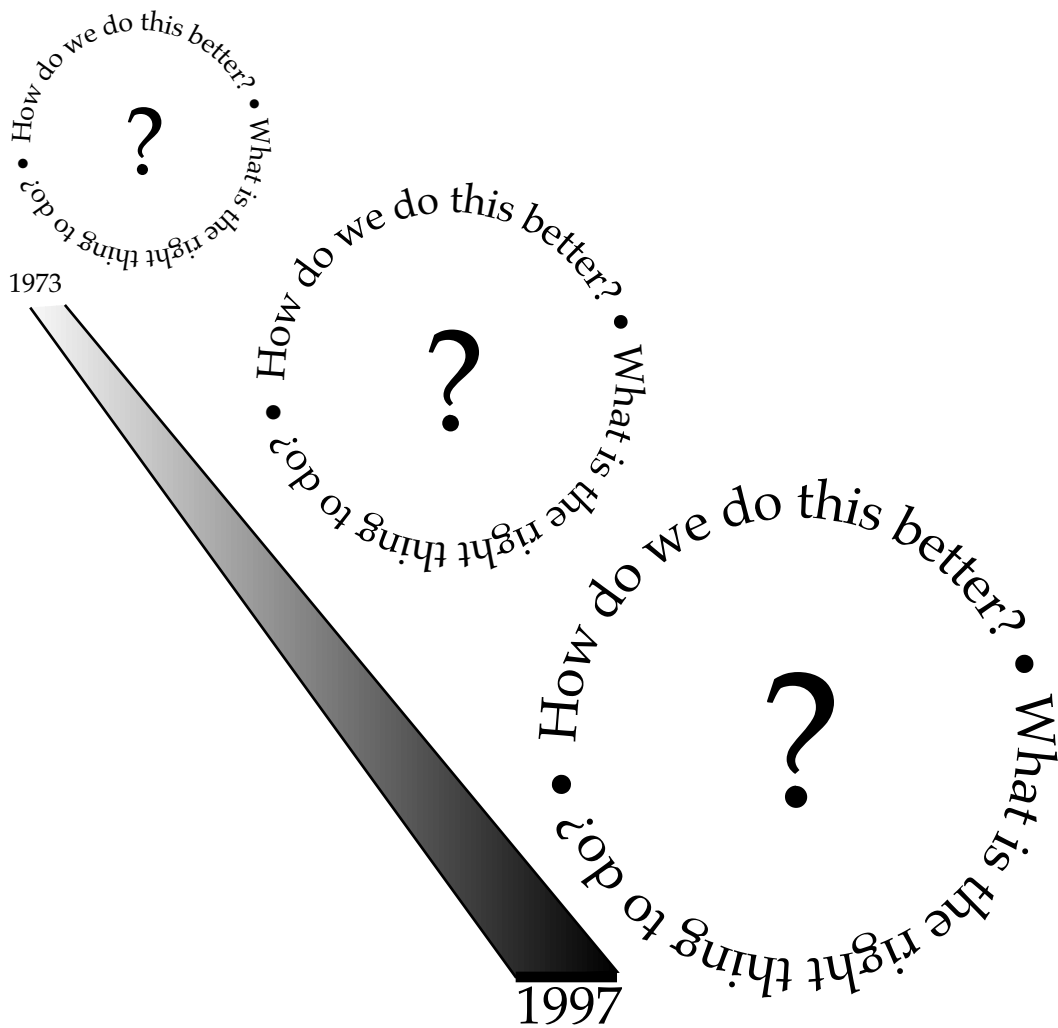 we ask, over and over again, 'How could we do this better?' And, because honest answers to that question cause conflicts with our habits and making progress means taking risks, we test our commitment to the answers to that question by asking 'What is the right thing to do?' At first we asked this question every year at the time we did annual plans for the agency. Then, after we improved our programs and facilities as much as we could within the common paradigm, the questions got too big for a one year plan and we moved to five year, strategic planning. Inside the framework of our mission and our strategic plan, we have plenty of occasions to ask these two questions over and over again."*

How do we do this better? • What is the right thing to do? •

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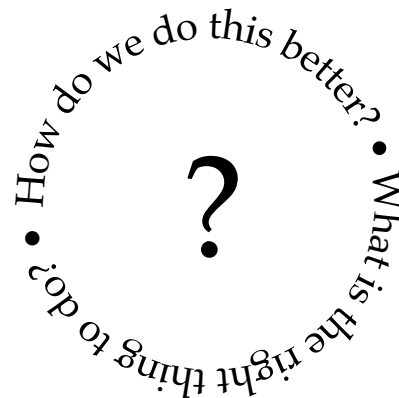
   Looked at in a 25 year time frame, the potential power of this cycle of questions becomes apparent. The discipline consists of asking these questions regularly and rigorously, answering them as fully and honestly as the present level of consciousness permits, putting the answers into practice as much as the ability to attract and align necessary resources will allow, and then raising the questions again. Practiced consistently, this discipline makes the organization able to handle bigger and deeper questions as experience and skill grow. Practiced across the whole agency, including not just services but facilities, fund raising, and agency reputation, this discipline has allowed the agency to build up its capacity to attract the resources it needs for bigger and bigger changes. In the Executive

Director's words, it has "moved us from a pretty laid back culture to a culture of risk taking."

How do we do this better? • What is the right thing to do?

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1973

How do we do this better? • What is the right thing to do?

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How do we do this better? • What is the right thing to do?

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1997

This quotation found on the Executive Director's desk and attributed to Rainer Maria Rilke captures the spirit of this approach to leadership.

Be patient with all that is unresolved in your heart and try to love the questions themselves like locked rooms or books that are written in a foreign tongue. The point is to live everything. Live the questions now. Perhaps you will then gradually, without noticing it, live your way some distant day into the answers.

Quality of leadership as the key to change

Without this spirit, these basic questions could be the formula for years of minor improvements in services that congregate and control people with disabilities The people UCP supports have been spared trivial changes by six essential qualities of the agency's leadership. It is these personal and team qualities more than any strategic secrets or remarkable planning techniques that account for the significant changes UCP has made in the rules that govern human service business as usual.

Respect for people with disabilities

Board and staff leaders hold a deep respect for the humanity and potential of people with disabilities. This respect leads them to keep listening carefully to individual people's hopes, dreams, and aspirations; looking for ways to assist people to realize and expand those dreams; and acting to fit their assistance as closely as possible to what they know of people's preferences and individual needs. Barriers to people's moving forward are there so that UCP can discover ways to help people go around, or go over, or go under, or go through them. Policies and practices that exclude people or put them down or hold them back are wrong and call for change. This attitude of respect is the foundation for the trust that has supported most of the people and families that UCP assists through the risks of significant change.

Living the values

Adopting the language of person centered values is so easy that almost every agency does it. What is hard is living these values every day, under the pressure of difficult situations, in the face of disagreement and disbelief, when switching focus through the flow of dozens of meetings and memos and tasks, while figuring out ways to deal with ever changing system policies that affect the capacity to work in a person centered way. Individual lives are always messier, more conflicted, and more confusing than general statements of principle and policy. So it is easy for people to lose the thread while deciding the right thing to do right now, for this person, with these staff (at least one of whom is nearly always over stretched by competing tasks). There are frequent, tough judgments to be made about the competence of staff to respond effectively to the demands of their jobs. And it is challenging to hold responsibility for safeguarding the duty to keep the person at the center of daily work and organizational decision making.

Change makes people anxious, and big changes make people anxious in big ways. Many good people in positions of authority lose track of their vision and values when others unload the anxiety onto their leader/scapegoat in order to escape the hard parts of the situation. And, when you and

people you care about have worked very hard to accomplish changes, it can be painful to retain the honesty to notice and accept responsibility for the gap between vision and current reality.

In many people's experience, Tara Asai exemplifies the values UCP has embraced. People see her working hard every day on living out every one of the responsibilities these values entail, and most days, people feel her succeeding at it. For many of the people we interviewed, Tara's competency, commitment, and fundamental honesty have underwritten their willingness to support the agency's transition. They see her competency as fueled and guided by a deep and mostly quiet passion for improving the lives of the people with disabilities that UCP supports, people she knows and cares about. Her capacity for work and her ferocity when someone knowingly compromises the rights of one of the people UCP supports can be, in the words of one staff member, "Scary and humbling."

In his reflection on major change in organizations (which is summarized later in this section, Harvard Business School Professor John Kotter identifies the inability of organizational leaders to consistently model the values underlying the change, day by day, across settings and throughout time, as the single most important cause of failure. Tara has only recently seen his paper, but she has lived his advice at UCP for the past 12 years.

Respect for people's diverse talents

One key aspect of the Executive Director's leadership arises from his interest in discovering people's particular sets of skills and talents and helping them find ways to develop themselves by contributing all that they have to give. This calls on his ability to orchestrate the variety of capacities available to UCP in ways that provide people with satisfying opportunities to work together. This executive talent contributes to the transition process in important ways…

…it offers a common perspective on the people UCP assists, the staff, the board, and service system and community leaders: everyone has an important and distinctive contribution and everyone will be well served by an opportunity to make that contribution.

…it entails the expectation that people will work hard to develop their skills and talents under changing conditions.

…it stimulates administrative creativity in the revision of organizational structures and processes by setting a frame for managerial problem solving: "The management's job is to orchestrate all of these diverse skills and talents so that as many people as possible have the best opportunities we can create to contribute all they have to give." This is often difficult and sometimes can't be managed. Bud compares himself to the

vaudeville performer whose act is keeping many plates spinning on sticks and notes that "sometimes a plate falls off."

…it allows executive leadership that is both strong and in the background: satisfaction comes from seeing others develop; setting the conditions for other's contributions requires discernment of people's skills and talents; the willingness to insist that people recognize the demands of changing circumstances; and the capacity to tolerate the discomfort of taking risks and the pain of some people turning away from the challenge of developing their skills. This form of servant leadership seems deeply satisfying to Bud and has kept him at work in the same changing place for more than 20 years.

…it provides an internal guidance mechanism: when others are skeptical or oppose development, the right thing to do will be the thing that expands opportunities for contribution.

A clear sense of priority, rooted in respect for people with disabilities, focuses this concern for diverse gifts. UCP's purpose is to assist people with disabilities to find opportunities to develop and contribute. Other people's differing gifts are essential to this purpose but cannot compete with it. So when some staff people didn't want to discover new ways to develop and contribute when people moved into their own homes, UCP passed the point where it could accommodate their interest in caring for people in small groups. There is regret that so many people chose not to change the context for their contribution, and there is a continuing willingness to question what else might have helped more staff to make the transition, but there is clarity that the agency observed the right priority in putting the changing requirements of the people it supports first.

Sticking with it

Key board and senior staff members have stayed together and provided continuity through the nearly ten years the agency has been in transition. This continuity allowed the time to lay a foundation for each phase of change. People and family members uncertain about the wisdom of change have the opportunity to get to know the senior people responsible. There is time to build up the network of relationships and the history of personal credibility in the community and in the service system that make formal requests and plans easier to negotiate.

Willingness to lay foundations

Many agencies adopt supported living or supported employment as an additional service when and to the extent that the system that sponsors them is able to pay for it. Under these conditions, existing group homes and day programs endure, especially when they are run successfully and attract continuing business. In the few examples of large agency conversion that
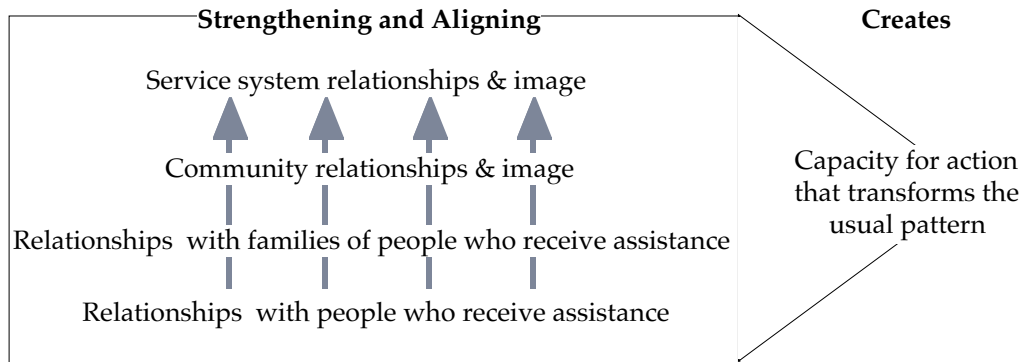
the team knows, there have typically been major upheavals in staff and board either as a prelude to the change or during the process . UCP is an exception to this pattern in three ways.

First, the goal and the accomplishment was transformation. That is, UCP has stopped providing two kinds of service while they were in demand and operating successfully and developed fundamentally different kinds of assistance for the people they were supporting in the old models. They did this without a break in service to people. One board member contrasted this change with changes in manufacturing methods, "It's as if we completely changed both the products and the processes for making them without ever shutting down the line."

Second, UCP moved in response to its understanding of what the people it supports wanted. This led the agency to move early into supported living, before it was clear to most other people in the system that this was an affordable or appropriate type of support for people with substantial disabilities. It also led them to the leading edge of the curve of supported employment for people whose disabilities are substantial enough to make many people doubt that it is possible to develop individual jobs at competitive wages for them.

Third, except for a significant turn over of direct service workers, UCP as an agency, has retained about 90% of the people and families it supports, most of the senior staff, and the board as active contributors throughout the transformation. They have made fundamental change without organizational disintegration.

In large part, this remarkable success results from the agency's willingness and ability to lay the foundations for change by systematically strengthening and aligning its relationships with its stakeholders: the people it assists, their families, the Portland community, and the developmental disabilities service system. In this approach, the sequencing matters. A person centered way to listen to and plan with people with disabilities provides the reason for change and specifies the direction and requirements for change. Engaging family members as early and as extensively as they are willing to be involved strengthens the process. Investments by the Portland community, both through contributions to the agency's overall development initiatives and through targeted investment in the transition process, not only strengthens credibility but also provides the funds necessary to pursue change with some independence from the DD system's agenda and resources. Over time, these alignments strengthen each other.

| **Strengthening and Aligning** | **Creates** |

Service system relationships & image

↑   ↑   ↑   ↑

Community relationships & image

Capacity for action that transforms the usual pattern

Relationships with families of people who receive assistance

Relationships with people who receive assistance

In each of the negotiations and problem solving activities that strengthen and align support for UCP's transformation, the same leadership theme recurs in the form of the fundamental questions, "How can we do this better?" and "What's the right thing to do for the people we support?" Because people have differing experiences and differing ways of under-standing, this negotiation often concerns the paradigm* that applies to understanding the situation and the principles that should govern decision making. So it is important for those who lead change to think very carefully about the essential messages they want to communicate and to plan the way communication will take place. Clarity, consistency, and persistence of message proved important over and over again.

Once people have invested the time necessary to develop a common way to understand and have agreed on the values they want to serve, they can move quickly when an opportunity arises. The Board and senior staff invested time in creating a five year plan that called on UCP to develop the capacity to support people in their own homes. This discussion of para-digms and principles laid the groundwork for a tough decision to move out of the Alder Street Group Home before a balloon payment came due. This decision accelerated the change process in a way that both challenged and strengthened the people UCP supports and the staff involved. As one of the first people to move put it, "It wasn't too certain how the move would come out. But once the first few of us got into our own places, UCP couldn't turn back until everything changed."

Aligning and strengthening support involves senior staff in a continual dialogue with community investors and DD system managers. People outside the agency describe what works about UCP's approach to them this way…

…"Wants to involve you directly with the people they support; they know

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*UCP leaders use the idea of paradigm shifts to refer to the nature of the change they are making and we will follow their usage. As they typically use the phrase, a paradigm shift is a basic change in perception of the way people with disabilities should be assisted.

that the people themselves are the best communicators of the importance of what they want to do."

… "Shows up when groups of people are working on making positive changes and joins in to make a contribution. "

… "Speaks out clearly when they don't agree about a policy or a direction the system is going without acting self righteous or superior."

…"Will openly take risks to find ways to do what they think is right and keeps other people informed."

… "Always keeps bringing the discussion back to what is right for the people they support."

… "Lives up to its agreements."

…"Will share it's expertise and what it has learned from things that didn't work with anybody who wants to learn from them."

…"Highlights the linkages between what they are doing and other issues on the community agenda."

… "Is honest about what hasn't worked the way they planned."

… "Provides plenty of information about what is happening along the way."

UCP may not have always lived up to the high standard set by these comments with all of it's stakeholders. But it is clear that senior staff have consistently, over years, built a foundation of honest, respectful, and mutually satisfactory relationships with almost all of the people they need to work with to accomplish the transformation of their services.[*]

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* The team met one person who strongly believes that UCP has neglected its basic responsibility to support all people with cerebral palsy and abandoned any meaningful response to the concerns of people with cerebral palsy who do not use their supported employment and supported living services even though UCP raises funds in the name of all people with cerebral palsy. Others we talked to do not feel this way themselves, but said they knew other people who did. The person we met says that UCP staff have treated her and other people she knows badly. This important conflict may be an unfortunate consequence of the clarity and focus of the agency's work during the transition period and of the overall shortage of service funds, especially for people whose eligibility for DD services is uncertain. Whether it also involves people outside the transition effort being treated in disrespectful ways by UCP staff, we have insufficient information to tell. Disagreement over priorities seems very likely, as does justified disappointment and anger at the lack of resources to provide desired help. It would, however, be an almost singular exception to what we heard from others if people felt they were treated disrespectfully by UCP senior staff or board members.

Ability to attract and use outside help

UCP has made extensive use of external consultation throughout its transition.* Senior staff have been unusually careful in selecting who UCP will listen to. They have found their consultants through their personal networks, seeking recommendations from people they already know and trust and then taking time to get a feel for the way a consultant will fit their agency. They are also unusually willing to seek guidance and practical help from consultants once experience confirms their judgment about a person's fit with the agency's values and way of working.

Alan Bergman, of UCP's national staff, helped the board and the senior staff lay the foundation for the transition process by building a sense of urgency about major change. He also linked Jay Klein to the transition process. Both Alan and Jay helped state and county managers to see the positive possibilities in supporting the transition process.

Jay Klein continues to play a key role in UCP's development. By building strong relationships with people throughout the agency, Jay has helped them remember and clarify the values that provide direction and meaning to the transition. He has been closely involved in practical problem solving on a range of issues from concerns around individual people to the agency's overall strategy and design. Early in the process, he provided training on supported living that involved other agencies and contributed to the growth of supported living in Oregon.

Consultants have made four kinds of contributions to UCP's transition.

- **Confidence.** In shifting to supported living and supported employment, UCP positioned itself as the adopter of innovations that had been tested in other states. People drew energy and confidence from the stories and visions of people with substantial disabilities in other states who live with individualized support in their own places and work at good jobs. Even though the essence of these ways of assisting people is innovation at the individual level, this position – "We only want to do here what is already working in other places."– contained anxiety and encouraged larger, more fundamentally challenging answers when the questions of how to do better and what is right arose. As an agency UCP did move close to the leading edge of innovation in two ways:

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* A few of the people we interviewed were critical of UCP's expenditures on external consultants. Several people said they thought that UCP could have gotten the help it needed within the state at much less cost. Others questioned the cost of our review. As one person put it, "I don't know why they have to spend all this money flying people in for this gold plated evaluation when they could get better information by just asking the people they support to tell them how to improve."

– In choosing to transform the whole agency rather than simply bolting on additional programs.

– In restructuring to assign responsibility for 24 hour assistance to single teams.

• **Competence**. UCP has invested in extensive in-house training on values and philosophy, team building skills, vocational development and systematic instruction, person centered planning, and creative problem solving. A number of staff are now able to lead training activities in these areas.

• **Clarity.** Sustaining fundamental change through the years calls for making regular times to reflect, renew, and clarify commitment to the vision, values, and principles underlying the thousands of day to day activities required by changing the way support is provided while continuing to support people.

• **Clout.** Especially in the early stages of implementing the first five year plan, UCP called on consultants with a national perspective to help them make the case for change with county and state mangers who had important questions about the move from group living to supported living for people with significant needs for assistance.

Consultant	Contribution
Jay Klein	Supported Living & Organization Development
Melinda Mast	Supported Employment: Voactional Profiles, Job Development, Employment Facilitation
Michael Callahan	Supported Employment & Systematic Instruction
OTAC: Ron Spoesltra, Sherrie Anderson, & Debra McLean	Personal Futures Planning, PATH, & Job Development
Sue Bert	Personal Futures Planning & Job Development

Dealing with contradictions

Implementing a transition to individualized supports from operating congregate services that people and their families rely on for day to day security builds a contradiction into the heart of the process. Individualized supports must be planned and implemented one person at a time and the daily routines, staffing, and budgets of services to groups are based on the presence of a set number of people.

This contradiction baffles many agencies and drives them into a strategy that is too simple to resolve it. They simply add individualized supports while maintaining congregate services. Under this approach, individual supports are developed when additional funds are available. If these supports are offered to people already served as one of a group, the developmental disabilities service system either increases the congregate service's budget to cover the cost of the smaller grouping or supplies a new person to take the place of the person who leaves. This approach has some appeal: the developmental disabilities service system is responsible for most of the financial risk; people who are uncertain about a change can take their time deciding whether or when to move on; family members or guardians who are concerned about the change need not deal with a conflict; other service providers who have achieved satisfactory routines based on the way the congregate service has worked need not be disturbed; and staff who prefer to work with groups of people with developmental disabilities can continue their careers.

Once UCP's leadership shifted their paradigm for understanding what the people the agency assists need from UCP, this simple and appealing strategy failed the test of the second basic question. It is simply not the right thing to do. If what people need from UCP is individual support which makes creative and flexible use of available resources to allow them to live in places of their choice with people of their choice and have good opportunities for employment and community participation, then it would be unacceptable to maintain congregate services any longer than is absolutely necessary. This position creates a second contradiction within the first: The reason for the change is to better honor individual choice, but not everybody is equally interested in choosing individualized supports.

One way to think about UCP's creation of these contradictions and its development of positive ways to manage them is to visualize the situation like this.
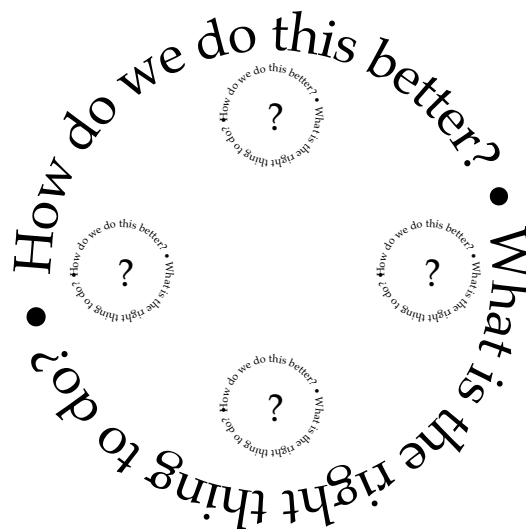
New understanding of what some of the people UCP assists became possible when the agency's leadership shifted its perspective from a paradigm of services to a paradigm of support and learned about practical ways that supported living was developing. This understanding shaped the answers to the big circle of questions about where the agency should aim over five years. The answer to the big circle questions, shaped by what some of the leaders among the people UCP assists said was right for them, both opens up new possibilities and closes off old solutions. The aim is to reshape the organization so that authority and responsibility for raising and answering these basic questions shifts from the agency level to the individual level (represented by the four little circles inside the big one; drawing the ninety little circles necessary to show each person UCP supports would have made the diagram too busy to read). The first problem to solve is the problem of transition.

UCP dealt with the contradiction created by the necessity of organizational transition with a combination of seven approaches.

Central focus

The transition process was the agency's central focus throughout the eight years it took. The agency also offers advocacy services and family support services, but though they have done important work for large numbers of people, they have been a lower priority for organizational resources than the transition process.

Phased transition

The transition process moved in phases, first from one group home to the next in residential services, and then to the day program. Because residential supports are more complex and expensive than day services, this complicated the first phase. However…

… the change focused on a small number of people; UCP staff knew them and already assisted them successfully with their day to day needs for personal assistance.

… for some people who lived in the group homes, the issue of daily assistance is literally a matter of life and death; this imparted a clear sense of urgency and gravity: poor plans or good plans sloppily implemented would hurt people.

… because the vocational department of UCP also supported many of the people involved during the day, there were fewer negotiations with other providers to manage.

… most families who were involved in people's lives believed that UCP was a responsible agency and felt positive about the residential staff's knowledge and ability; this provided an initial foundation for discussing

the risks and uncertainty that came with the move to a person's own place.

… the experience and learning senior staff gained from the process of successfully replacing the group homes with individual supports increased their skill in managing transition and their conviction that closing group based services is the right thing to do. …

Once people demonstrated the benefits of living in their own place with individualized support, the transition process gained great momentum.

However, though each specific step was well planned, the whole process didn't follow an eight year blueprint. Instead, UCP followed the people it supports, developing next steps out of the problems and possibilities that arose from the step before. Jay Klein, who has maintained contact throughout the process describes the process like this:

> *For me, the most significant lesson about the change was that it was only as a step was completed that Bud, Tara, hence the board, could begin to believe in the possibility of the next step. Therefore, while Alder Street was being closed and for some time after, this was the only goal. Tara and Bud could not imagine or think that it was possible to transition all of their existing residential services. When their residential services all began focusing on individuals, Tara was in constant conflict with the day service. At that time, no one believed or thought that the workshop would close. The reorganization that made the workshop closure possible came about some time after all the residential services were individualized, partly because the resulting dissonance with the day service was so great.*

Deadlines

Deadlines set the tempo of transition. Deadlines allowed a reasonable amount of time for individual decision making but sent a clear message about overall direction and communicated : the group home *is* closing; the workshop *is* closing. That it happens is no longer negotiable; how it will happen for each person depends on the individual person centered planning process. The deadline for closing the workshop was not absolute; a careful review of progress postponed the closing by a year, and even now a small group of people who have not yet found jobs return to the building where the workshop was for a daily program focused on job finding.

Alternatives

People (and their guardians) had the choice of transferring to an agency that provides congregate services, or one that provides individualized supports in a way that suits them better than those offered by UCP. Two people moved into other living arrangements during the residential transi-

	Investments	
Residential Transition		**$110,000**
UCP of Oregon & S.W. Washington	Jan 89 / Jul 91	80,000
Multnomah County DD Programs	Jan 89	30,000
Vocational Transition		**$322,000**
UCP of Oregon & S.W. Washington	Feb 93	102,500
Cerebral Palsy Foundation	May 93	100,000
Clark Foundation	Mar 95	500
First Interstate Bank Foundation	Jul 94	2,000
Jackson Foundation	Jan 95	2,500
Roy & Eva Jarman Corporation	Apr 95	500
Meyer Memorial Trust	Feb 94	50,000
M J Murdock Memorial Trust	Dec 94	40,000
Mark & Cindy Nizic	May 94	500
Oregon Community Foundation	Nov 94	5,000
Oregon VR/DD Council	Apr 94	5,000
Swigert Foundation	Jun 94	5,000
Roe Tucker Charitable Trust	Jan 95	3,500
UCPA's Inc. (National UCP)	Mar 94	5,000

tion (one to a group home and one to a foster home). About one in eight of the people in the sheltered workshop exercised this option and either transferred to another day service provider or left the service system.

Investment in buffers for change

The demands of transition were buffered by using money raised outside the developmental disabilities service system's service funding to pay for training, consultation and additional staff time during the transition period. Besides community contributors to UCP's and the Cerebral Palsy Foundation's general fundraising efforts, fourteen investors committed $149,500 to the transition process over seven years. UCP does not use such "soft" money to pay for people's ongoing supports; so these funds were only used to make the transition smoother for the people UCP supports.

Commitment of personal credibility

UCP senior staff members, who had positive relationships with most people and families, were active in the person centered planning process and sometimes dealt with uncertainty about the risks involved by making a personal commitment to stand by people and deal with whatever problems that arose.

Organization to focus energy

Before replacing the sheltered workshop, the agency re-organized into teams responsible for managing people's assistance on a 24 hour basis. All staff involved in assisting people are accountable to the Community Services Director, who has been instrumental in the transition process since its beginning. Within this stable overall structure, there has been considerable experimentation with the way tasks are allocated and the ways in which organizational support functions like staff training and recruitment are performed. Each team has also had the chance to develop its own traditions and approaches within the wider culture of the Community Services Department. This structure seems to allow for considerable flexibility and opportunity for staff engagement within common values, goals, and guidelines.

Links to the literature

> Organizational change is a hot topic both in the field of management and in the human services. Among the many discussions of change, two seem to UCP's senior staff to reflect the lessons that they have learned.

> John Kotter [*] summarizes his inquiry into why so many efforts to transform organizations fail by turning the eight reasons he identified as accounting for failure into an eight stage process for creating major change.

The Eight–Stage Process of Creating Major Change

1. Establishing a sense of urgency

- Examining the market and competitive realities
- Identifying and discussing crises, potential crises, or major opportunities

2. Creating the guiding coalition

- Putting together a group with enough power to lead the change
- Getting the group to work together like a team

3. Developing a vision and strategy

- Creating a vision to help direct the change effort
- Developing strategies for achieving that vision

4 Communicating the change vision

- Using every vehicle possible to constantly communicate the new vision and strategies
- Having the guiding coalition role model the behavior expected of employees

5 Empowering broad-based action

- Getting rid of obstacles
- Changing systems or structures that undermine the change vision
- Encouraging risk taking and nontraditional ideas, activities and actions

6. Generating short-term wins

- Planning for visible improvements in performance, or "wins"
- Creating those wins
- Visibly recognizing and rewarding people who made the wins possible

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[*] John Kotter (1996). *Leading Change*. Boston, MA: Harvard Business School Press, p. 21. This book is an expansion of John Kotter (1995). Why transformation efforts fail. *Harvard Business Review, 61*.

7. Consolidating gains and producing more change

- Using increased credibility to change all systems, structures, and policies that don't fit together and don't fit the transformation vision
- Hiring, promoting, and developing people who can implement the change vision
- Reinvigorating the process with new projects, themes, and change agents

8. Anchoring new approaches in the culture

- Creating better performance through customer –and productivity–oriented behavior, more and better leadership, and more effective management
- Articulating the connections between new behaviors and organizational success
- Developing means to ensure leadership development and succession

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Stephen Murphy and Patricia Rogan [*] identify these lessons learned from their review of the literature and their study of four conversions of sheltered workshops into services supporting individualized work. Introducing their outline of lessons, which they richly document in their case studies and helpfully expand into implications for practice, they soberly note, "Change within most traditional human service agencies has come slowly or minimally, or it has not come at all." (p.180).

Essential Ingredients for Conversion

- Build support for change from within the agency.
- Define clearly the values that drive the agency's vision and mission.
- Ensure that internal leadership provides support, encouragement, and guidance throughout the process of change.
- Plan to act, and act on plans.
- Consider the use of outside consultants to plan for and guide change.
- Invest heavily in staff development and support.
- Strive for a flat organization with most staff providing direct services.
- Change the agency's image to match its values, vision, and mission.
- Define, demonstrate, and celebrate large as well as small successes.
- Pursue creative, alternative funding options.
- Involve key stakeholders from the beginning.
- Unload sunk costs.
- Terminate facility admissions and backfilling as soon as possible.
- Do not wait for everything to be in place before beginning the process of change.

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[*] Stephen Murphy and Patrica Rogan (1995). *Closing the shop: Conversion from sheltered to integrated work*. Baltimore, MD: Paul Brookes Publishers, p. 180.

When UCP's leaders read these discussions they have three reactions. First, they feel a sense of connection and a kind of relief that others have experienced some of the same issues that they have and that many of the problems UCP has faced are common to major change efforts. Second, they are glad to find a vocabulary and a process outline that gives them some more words to explain to others what they have done. And, third, they sense that these lists, and the helpful books that they summarize, seem more useful as a way to discuss where they have been than they will likely be as a road map for the journey. The real process will always be more confusing and take more time. The real people involved will always find their own ways to get stuck and to get lost. The real problems will always be just different enough to make even the best description of how to do it frustrating. The good advice will always prove hardest to follow exactly at the point of implementation.

What is true for those two accounts of major change from the literature is true of this account of transition as well. UCP's experience can inspire other people to undertake the journey, provide helpful guidance, and warn of potential pit falls. But each organization needs to find its own way to accomplish the tasks of transformation **with its own people.**

In their own words: Community Services Department Commitments

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UCP Mission

To positively affect the quality of life for person's with cerebral palsy and their families.

Community Services Department Values

1 Dignity in every aspect of life.

2. Individuals be directly involved in all decisions that affect their lives.

3. Services that foremost respect the desires of the individual.

4. Opportunities to develop relationships and networks to support their life's choices.

5. Services which are the least intrusive as possible.

6. Services that focus on abilities and assume people are "ready".

7. Services that encourage individual growth to experience new opportunities throughout their lives.

8. No "less than minimum wage" jobs unless it excludes someone from participating in employment.

9. No "less than 20 hours per week" jobs unless it excludes someone from participating in employment.

With UCP the game is simple.

We work hard,

play fair,

cut the edge,

&

chase dreams.

Let's play!

Community Services Goals

1. Strengthen the Community Services Team, promote independence, improve and increase cross training.

2. Assist and encourage people we support to spend time with people who are not paid to be in their lives.

3 Focus energy on assisting people who spend time in the workshop to secure jobs.

4. Support Roommates, Personal Assistants, and On-call people to be contributing and valued team members.

5. Develop deeper relationships with individuals and community organizations in order to facilitate, build bridges, and introduce people who receive our support to others.

Guidelines for the Community Services Teams

1. Welcome differences of opinion and style as being important contributions.

2. Communicate clearly, honestly, in positive ways and to the appropriate person or group

3. Mutual support and respect across teams/individuals.

4. Utilize everyone's individual strengths to solve problems.

5. Recognize that the growth and happiness of staff and people who receive support are interconnected.

6. Take care of yourself so that you can in turn take care of your team and people who receive support.

7. Enhance and share individual team resources and strengths.

8. HAVE FUN!

9. Provide people who receive our support with the education and knowledge needed to set goals and make decisions.

10. Allow people who receive our support and staff to make mistakes

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*The mission is from the 1996 Annual Report. The Community Services Department materials are dated October 1996.

The Fourth Phase

The third phase of the transition project ended with a community celebration of the closing of the Sheltered Workshop on 27 September 1996. This event marked a milestone in UCP's history, formally closing the transition project and opening the way for the board and executive staff to develop new strategies for improving the quality of life for people with disabilities. Several important opportunities have surfaced for consideration, with many people strongly interested in the agency strengthening supports to the families of children with cerebral palsy or developing a greater capacity to organize people with disabilities and their families to work for change through advocacy and community education.[*]

The formal completion of the transition project doesn't finish the work of the Community Services Department. In fact, in one sense, even more difficult tasks lie ahead as ninety people figure out how they want to continue to live their lives with the personalized assistance of UCP staff. Reflecting on one of the metaphors for change embedded in the word, "transition", a team member observed. "Transition is a painful stage in the birth process. Soon after doing all the work of transition, you have a baby. Then you get a little rest. Then raising the baby takes over. You'd be mistaken if you thought your job was done when you struggle through transition."

Organizational transition has finished. Individual lives continue.

By design, UCP's organizational transition process has happened through ninety individual transition processes. People with disabilities have moved into new roles as employees, as directors of their personal assistance, as householders, and as members and participants in community associations and activities. The organizational change had two related points: to remove the major barriers UCP itself posed to these personal transitions by its practice of service by grouping people apart from community life; and, to focus the Community Services Department's whole energy on assisting people to lead full and dignified lives in relationships, homes, and jobs of their own. Organizational transition has an endpoint, which UCP nearly reached when the workshop closed. Each person's process of living the sort of life that makes sense to them does not have an endpoint. Some people have moved farther along their path to their own relationships, their own job, their own opportunities for contribution, and their own home, while others are closer to the beginning of this journey. Wherever a person may be on their path, it does not end until they have chosen how they want to spend their last days.

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[*] We prepared a separate report, *Options for the future,* for the Executive Director. This memo summarizes the opportunities, hopes, and expectations for UCP as a whole that people told us about while we were gathering information on the Community Services Department's transition.

Strengths can become a barrier

Reflection on what the people we met know about the current state of people's individual transitions identifies an agenda for the fourth phase of the transition, which is outlined below. But one of the major strengths the Community Services Department has developed through the time of organizational transition will hinder response to the issues raised in individual lives.

Through the transition process, support coordinators became capable of dealing with much of the planning and action necessary to respond to people's choices and needs, and were identified as the responsible people for assuring that personal assistance systems worked. Teams have become the place that individual problems and opportunities and action plans are discussed, defined, decided, and followed up. This provides clear accountability and the necessary structure for self-management. It is also a structure that can easily become overloaded.

Jeff Strully, one of the review team members, has extensive experience with creating and, more importantly, with sustaining personalized support systems. He observed that support coordinators and teams were very busy dealing with issues for many people that will, over time, be much more effectively dealt with by circles formed around each person.

The role of the support coordinator and the team makes sense as a way to solve some of the problems of organizational transition. Movement needs more coordination when people remain reliant on group services. Many of the steps in helping someone try a first competitive job or set up house for the first time can be done more efficiently when support coordinators learn the ropes and then do what is needed. Many people were isolated and many people's families were distant or worried; asking them to form a circle and accept responsibility for something they didn't understand or even really agree with might have made the process too hard.

However well the pattern of individual support coordinator–team responsibility might have met requirements of organizational transition, it becomes a bigger source of friction on personal transitions with each week that passes.

- Support coordinators and teams grow more overloaded as problems and possibilities accumulate across the thirty or so people a team and its support coordinators serve. The adaptive practice of team members helping each other out in many practical ways by filling in for one another and sometimes filling in for missing roommates or personal assistants adds to the overload as it gets important jobs done.

- Because their first priority must be holding together the practical assistance essential to people's safety, and because sickness, turn-over, and life demands virtually guarantee that a week without rescuing at least one support system will be a memorable one, it is easy for teams to get so good at managing routine emergencies that some of the threads get dropped in the lives of the people whose situations are currently more stable.

- Many of these dropped threads concern the unfamiliar possibilities of helping people improve their quality of life through better jobs, better opportunities for friendship and community membership, and better suited homes. Exploring these issues will take busy support coordinators into new and unfamiliar territory, where they may have to develop new knowledge, new relationships, and new skills. Conscientious support coordinators can feel disappointed or even guilty about their continuing inability to assist people in these important new areas. In a sense, the support coordinators typically function at the survival level, even if some of the people they support want and need to deal with issues that reach well beyond survival. In these circumstances, teams can collude in the defensive function of denial: the team is simply too busy for its members to notice that vital issues go un-addressed, and, when team members do notice the distance between what is happening and what is desirable, the demands of helping people survive provide a ready justification for the gap, a justification which is accurate as far as it goes. Not all of these issues concern efforts to make things better. In at least one situation, it seems as if the team may be so busy patching up chronic defects in day to day assistance that they fail to notice and follow through on obvious major questions about improving the person's life.

- Given that people's support coordinators change pretty frequently, people's stories can get lost as their new support coordinators focus on learning only what they need to know to deal with breakdowns of people's supports.

- Most insidiously, responsible support coordinators and teams leave limited room for family members and friends to contribute to the person's life. The admirable capacity that support coordinators and senior staff have for getting to work on problems and taking responsibility for offering help can disconnect those who care about people from working actively on important issues. Dealing with people's anxiety and uncertainty about change by saying, "UCP staff will take care of it." and then following through, supports the transition but weakens the capacity for longer term change.

Obviously the way out of this dilemma is for support coordinators to find

ways to share responsibility. The solution is not for support coordinators to practice being irresponsible or to abdicate their crucial role in people's lives. The solution lies in the direction of support coordinators and teams acknowledging their limitations in a way that makes room for more shared responsibility. If support coordinators do a good job of helping all the people they assist to establish and maintain a personal assistance system adequate to help the person manage a decent life at home and at work and in their community, they will make an essential contribution. And, experience so far shows, support coordinators who do this vital task well will have only limited energy to bring to helping the person make hard decisions or take steps in the direction of making life better.

The single most important step

While this report offers a number of observations and suggestions, we believe that the single most important step that UCP can take now is to **assure that each person has the support of a circle** of allies, committed to the person and authorized by the person and by UCP to assist the person to manage and modify their system of assistance in terms of his or her personal preferences about how to pursue a life that makes sense. The function of the circle is to articulate the vital few issues that are most important to the person as circumstances change and decisions have to be made and to keep energy focused on them day to day to day.

As we understand them, circles of support have many different configurations and take many different approaches. They are not the product of a technique or a procedure. They usually have meetings of various shapes and kinds, however they are not meetings but practical ways for people to share some of their lives and talents. They result when people with disabilities realize the strength that comes through interdependence with people who are personally committed to respect and support them in discovering and maintaining their place in community life, in defining and solving the problems that arise as life changes, and in creatively managing all of the service system resources that can lend necessary assistance.

Such circles are working groups, not remote dispensers of advice or detached critics of service performance. Their task is to hold the many dilemmas and tensions and problems and conflicts that arise day by day in designing, operating and re-designing an effective support system for a changing life. Because members provide good help, the person will count on circle members when important decisions have to be made around critical issues like hiring and firing assistants, finding and changing roommates, figuring out the puzzles of finding and keeping jobs and pursuing careers.

There is nothing romantic about circles. People can have as much trouble meeting, dealing with tensions and disagreements, and making and following through on commitments to action as any other human group does. Calling a group a circle does not endow it with any special insight or creativity. There is a built in tension between many people's understandable desire to get on with their lives without interference or intrusion and the fact of people's interdependence. Despite all this, most people who belong to functioning circles –whether disabled people or family members or community members or staff– find the results worth the work and the trouble, especially if they compare what happens to the results when a person with a disability is alone and vulnerable to control by circumstances.

Can people with substantial disabilities have good lives without a circle? Of course they can have good lives without something self-consciously designated as a circle. But can anyone, disabled or not, live a good life alone, without allies whose relationship results in shared feeling, thinking, and acting? And, in the face of the confusion, challenge, and suffering that life brings, can anyone, disabled or not, live a good life alone, without allies who sometime offer the kind of listening or practical help or guidance or confrontation that embodies care? We believe that the people UCP supports will benefit from help to call together and organize their allies, in whatever fashion that happens and whatever it may be called. We'll keep calling these alliances circles, at least until particular people tell us what they call the people who support them ("my familia", "my team", "my posse", and "the mob" are among the particular names we have heard recently).

Support coordinators need to form the kind of alliance with people that earns them a place in the circle. Friends with disabilities will usually be an important part of the circle. Family members and some other friends are a vital part of the circle. Some staff will join the circle because they feel and show the kind of personal concern that goes beyond their duty to work in a respectful and friendly way. Some former staff will stick with the circle, perhaps joining when they quit the person's employ and move on with their lives. At least at first, many people's circles will include few if any people they did not meet through their family or through UCP. Some people may have no family members able to join. And having a circle with missing members will be far better than leaving the person and the support coordinator to decide and manage alone, with only the team and senior UCP staff for back up.

Many people with disabilities will be challenged by the prospect of interdependence as the context for decision making, as will many families and guardians. The negative experiences of enforced dependence or isolation will often be sufficient explanation for their uncertainty. Most staff will be challenged by taking direction from their place in or in relation to a circle.

The habit of being in charge of the level of engagement with the people they support, and the reflex of assuming control will often be sufficient explanation for this. Whatever the source of the challenges, we recommend getting over them with the same spirit that most people with disabilities and UCP staff show in dealing with the challenges of establishing their own homes and their own jobs.

This is not the place to map out the path the Community Services Department should take in developing support circles for the ninety people who continue to navigate the transitions of their individual lives with UCP's assistance. There is some relevant experience to learn from, and UCP has demonstrated an exemplary ability to learn and invent approaches that work for the real people involved.

The best way to begin inventing the necessary circles is to establish a clear way to know when a person lacks a good enough circle. There are two tests for the negative. First, whenever the support coordinator feels major responsibility for making things happen for the person, the person doesn't have a good enough circle and the support coordinator is in danger of undermining the formation of such a circle by taking away its most vital functions. Second, whenever the service coordinator sees the UCP team as the primary source of ideas and support when a person faces difficulties or wants to take a major new step, the person doesn't have a good enough circle and the team is in danger of colluding with the service coordinator in avoiding raising the hard question: "Who cares about this person enough to help them with this issue?"

(See *Of warriors and bubble bath* page 39.)

There is at least one person UCP supports who is ready to be a partner in this learning. She already has a support circle; and her current support arrangements are past due for re-designing.

The agenda

Unfinished business

The transition from the sheltered workshop is incomplete for eight people who have not yet found their first job.

UCP set itself a high standard for the work supports it offers: individual jobs, for no less than minimum wage, for no less than 20 hours a week. They qualify the wage and time commitments if a person would be excluded from employment if UCP dropped its support because a job does not meet them. This diagram shows the results when the jobs that all employed people supported by UCP had in December 1996 are tested against these three criteria.
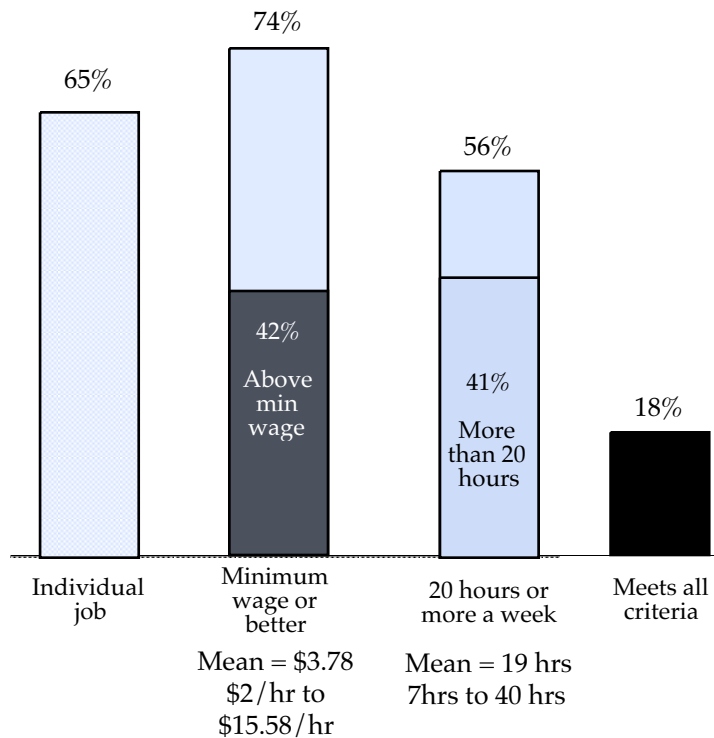
Twelve people are employed in one of two enclaves. The eight people employed in one enclave work 25 hours a week for $2.00 an hour; the four people employed in the second enclave work 30 hours a week for $4.75 an hour. Over all, enclaves raise the average hours worked and depress the average wage. In individual supported employment, people work an average of 15 hours and earn an average of $5.53. The person who works the most hours is employed individually but earns $2.83 an hour.

Section 4, *Better Jobs*, discusses the issues around work supports (see page 47).

Despite many observer's pessimism, a significant number of people have moved into jobs of their own. The next step for them involves considering not just a job but a person's career.

Greater continuity

High staff turnover interacts with the lack of organized support circles to threaten four human continuities that make a vital difference to people's quality of life: continuity of knowledge of the person's story; continuity of personal projects; continuity of systems of communication; and continuity in the performance of necessary tasks.

Learning from difficult situations

Almost everyone feels satisfied with the transition, but there have been a small number of conflicts that have been very difficult to live with and resolve. UCP needs to develop ways to identify difficult situations, explore them productively, and get whatever help may be necessary to learn a way through them.

Deeper understanding of the work

UCP staff play a very important role in people's lives. Done well, the work of organizing and providing support engages people in dilemmas that call for deeper understanding of the nature of the work and the principles that guide it. We believe that a lack of appreciation for the social reality of significant disability may tempt some staff to be satisfied with too simple an understanding of choice and self-direction as operating principles.

Expanding opportunities at home

A number of people have opportunities to have better homes and better support at home.

- The *Home of Your Own* project offers access to the money for people with low incomes to buy a house.

- At least one person UCP supports may be able to move into her parental home if her brothers and sisters can join with her in figuring out a reasonable arrangement.

- A number of people will benefit from continuing effort to reconnect them with their family and extended family.

- Families will benefit from the opportunity to talk through their understanding of the transition to date and to consider how they want to support their family member's future. Thorough and systematic discussions about estate planning, and sometimes about successor guardianship or effective alternatives to legal guardianship are fundamental to securing some aspects of a person's future. Despite their importance, these discussions can be difficult to get started.

- There is room to expand the variety of ways roommate arrangements are made if people and their circles will explore different ways people can live together. Paid roommates are one option, but some people might exchange some support for somewhat reduced rent, and others might enjoy living with someone as any other roommate does with a fair sharing of costs.

- The process of recruiting personal assistants and providing people with the support they need to make good hiring decisions, provide good training and supervision, and deal with performance problems requires continual improvement forever more. There is much to learn from regular, thorough, and systematic reflection on what seems to work and why and what doesn't seem to work and why. The process of managing problems can make a person think she is too busy to take time out for learning, especially if the situation came out badly. So reflection time needs to be scheduled, skillfully facilitated, carefully recorded, and jealously guarded.

- As people's needs change, the cost of their supports may increase. When people officially become old, responsibility for administering their personal assistance funds changes from one part of the county system to another. This calls for establishing new relationships and learning to influence new system staff.

People need the support of a circle to make the most of these opportunities.

Of Warriors and Bubble Bath
A warrior for rights and independence

Rosella's courageous spirit, powerful will, and keen intelligence distinguish her as a leader among people with disabilities, especially people who have survived institutionalization. Her sense of humor and gift for vivid phrases communicate her sharp insights into difficult issues. Her anger at injustice fuels her advocacy for all people with disabilities, especially people who are institutionalized. Her willingness to make herself the guinea pig (as she calls herself) in experiments that have a chance to increase freedom and dignity for disabled people have blazed new trails in employment, supported living, and civic participation. Today she is a state employed advocate for people moving from the institution where she used to be a resident, she lives in her own apartment, she serves as a valued member of the Developmental Disabilities Council, and she counts many strong and influential people as friends and members of her circle of support. No one who truly hears her voice will forget her, whether or not they agree with her. She is, and sees herself, as a living example of the independence that too many people still don't believe possible for people with substantial disabilities.

Rosella gets assistance from an agency that has worked hard to earn it's reputation as a state and national leader in supporting people with substantial disabilities to live their own lives in responsive and effective ways.

It would be easy to think that the match between a person who has risked her life to demonstrate that people with disabilities can live in their own homes free of staff control and an agency that has risked its stability and reputation for the same purposes would be nearly perfect. But that isn't so, at least not right now. Now, Rosella and some members of her circle criticize UCP as unresponsive to her real needs and wishes. And UCP staff see this criticism as puzzling and maybe unfair, primarily because they believe that they have been careful to exactly follow Rosella's instructions about how she wants them to assist her, and also because UCP is funded to assist her for only a few hours a week. UCP seems to Rosella to be untrustworthy; Rosella seems to UCP to be unreasonable.

Rosella is willing, once more, to risk exploring new territory –to choose again to make herself the guinea pig in order to teach about what is possible for people with disabilities. If UCP will partner with her and her circle, she can make another important contribution to improving the support available to people with disabilities. And she will probably have better assistance for herself. If she can help UCP staff learn to play a more effective role in her life, UCP will have a chance to work on some issues that matter for every-

one they support. Because people with disabilities and service providers throughout the state pay respectful attention to Rosella and to UCP, others will benefit from the lessons they learn together.

The opportunities

Supported living means avoiding the institutional idea that "one size fits all", but only a few people can comfortably wear the same size all their lives. There are at least five signs that Rosella, her circle, her supervisors at work, and UCP need to work together to redesign her arrangements for assistance…

- Twice in the past year Rosella has had to spend time in a nursing home recovering from an injury. Changes in the health care system mean that people spend less time in hospital beds, so everybody has to face the question of what sort of help is available while they recover, and single people have to think particularly hard about who they can count on to provide practical assistance. Twice, Rosella went from needing a few hours of assistance a week to needing a lot of assistance, and her regular support system couldn't keep up with her need. She ended up paying a lot for 24 hour service in a nursing home and, even if it made sense for her to spend some time in the nursing home, she stayed longer than she would need to if better help were available at home.

- Several people who care deeply about Rosella are concerned that she isn't as safe as she should be. They recognize and honor the risks she chooses to take so that she can live her own way, but they want Rosella to have a much more effective back-up system.

- Rosella occasionally and unpredictably needs prompt, practical help in dealing with everyday problems. The UCP emergency system doesn't work very well for this because these calls aren't emergencies even though they are very important. Using the emergency number frustrates Rosella because she thinks it reasonable to expect exactly the help she needs from UCP at the time when she needs it, but UCP staff question her defining these situations as an emergency. She thinks this is unreasonable because she usually gets by with very few hours of help compared to most of the other people UCP supports. She points out that many of these situations involve problems that could happen to anyone – like running out of gas– and that they don't happen very often. She also says that she knows exactly what she wants her helper to do when she calls for help and she does not need, want, or appreciate UCP staff questioning her requests or doing more than she asks. She gave an example, "If you couldn't get somewhere you needed to be, you might ask your secretary, or your wife, or your friend to call and tell the person

you'll be late. You wouldn't like it if they said, 'Why don't you do it yourself.' or started on some kind of investigation of the situation. They would just help you out and make the call." UCP staff may not think of themselves as like Rosella's secretary or car assistance provider, but if that is true, that is the point: Rosella has a different picture of how UCP needs to help her through the week than UCP has. Maybe she needs a secretary; maybe she needs an AAA membership. There are probably a hundred ways to meet the need, but clearly, Rosella requires a kind of help that is designed more specifically to fit her circumstances.[*]

- Rosella's supervisor at work, who has firsthand experience of making a personal assistance system work, thinks that Rosella would be even more effective in her job if she had more and better personal assistance. For example, her transportation arrangements are unreliable and her appearance sometimes suggests that she needs more careful help while she is getting bathed and dressed. Moreover, he believes that Rosella lacks practical help with making available funding sources work better for her and he wonders how strongly she is connected to the network of people with physical disabilities who help each other make the system work for them.

- Some of Rosella's friends have good ideas about changes that would improve her quality of life, including: a better strategy for maximizing her income; help with career planning so that when Fairview closes she will be ready for her next job; a nicer and more convenient place to live; and a chance to enjoy more of life's simple pleasures. Rosella may not agree that these are good ideas, but they seem to be worth investigating and arguing about.

UCP and the other people UCP supports and teaches will also benefit if Rosella and her circle work with them to improve Rosella's supports. Her situation involves many of the key issues this review identifies as critical to improving the quality of UCP's work. These issues include…

- Helping people establish circles of support and aligning UCP's work with the contributions circle members make to a person. Rosella has a circle that includes talented and influential people who know her well and care for her deeply. However, it is not clear how Rosella's circle members understand what it means to be part of her circle of support, what contributions Rosella can count on from circle members, and how the circle relates to UCP staff and Rosella's other assistants. So much around the circle remains undefined and unspoken that there is lots of room for

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[*] Options in Community Living in Madison, WI has an approach to this kind of need that might be worth thinking about: for a small retainer someone carries a pager for a particular person and responds to that person's calls for assistance in a timely way for an agreed fee.

misunderstanding, frustration, and even resentment. UCP staff seem to see circle members as more of a potential source of criticism than as Rosella's allies with whom they can join.

- Sticking with people over the long haul and quickly and flexibly adjusting their assistance as the person's needs change.

- Gaining, holding, and passing along a deep understanding of the person's identity, gifts, and preferences and helping the person fight threats to them. Rosella's status is well recognized by UCP staff, but it does not seem to me* that most staff know her very well. The frequent turn over of support coordinators compounds this lack of understanding. For Rosella, it may not be important that UCP staff know much of her story. If members of her circle know her deeply, will remember who she is, and will remind her and others of her story when conflicts and hard times arise, so much the better. But UCP staff do need to know Rosella well enough to carry out their responsibilities to her.

- Developing a powerful understanding of what it means for a person to be in charge of her own life and a willingness to struggle with a person at critical moments. While thoughtful and honest discussion between Rosella, UCP staff, and circle members must clarify this issue, I think that there is good reason to believe that a superficial understanding of choice and self-direction increased the risk to Rosella's safety and increased the pain and inconvenience she suffered as a consequence of both of her injuries. The fact the Rosella fights hard to protect her autonomy means that it is particularly important that the people who care about her fight with her to assure that she take due regard for her own safety and comfort.

The barriers

There are several practical barriers to realizing these opportunities.

- As a participant in the semi-independent living program, Rosella currently doesn't have enough flexibility in funding to pay for the assistance she needs when she needs it.

- Her earnings create complex personal financial management problems.

- It is hard to get the best from Rosella's existing personal assistance system because…

  …it is not clear who is responsible for managing the whole system; the person who provides most of Rosella's personal assistance sees herself as working completely independently from UCP's support coordinator; and UCP's support coordinator isn't clear on what UCP is responsible for coordinating.

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* The "I" in this section is John O'Brien, who interviewed Rosella and some of the members of her circle.

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…if Rosella wants to organize and coordinate her personal assistance system for herself, this needs to be clearer to everyone involved (among other reasons so that Rosella and her circle don't hold UCP accountable for work Rosella chooses to do in their place) and she would probably benefit from some consultation on how to be a more effective manager.

- There doesn't seem to be an effective way for the involved people to get together and make decisions. This lack of a way to meet has pushed people farther apart because there isn't a regular way for people to identify problems and check out different perceptions and points of view. This leads to the different people Rosella counts on having very different stories about what has happened and who needs to do what in order to make improvements.

But these are the simple barriers. Rosella and her circle and UCP staff have a surplus of talent and influence to deal with them. How well they are resolved depends on Rosella's willingness to explore her situation in new ways, her circle member's interest in being not just her friends but also her circle of support, and UCP staff's courage in learning from Rosella. In this work, all will encounter some thornier questions.

Rosella guards her independence as fiercely as she fought to attain it. For so long, most people doubted her ability to make it on her own and she deeply feels the importance of proving that they are fundamentally wrong about her abilities and about the potential other people with disabilities. She may hear a suggestion about changes to where she lives, or how she is assisted as though the person making the suggestion doubts her right to be in charge of her own life. This means that necessary discussions about better management for her support system, or more hours, or different funding will take courage and persistence and creativity. Rosella will have to draw on her courage to keep her mind open to new ways to understand her independence and new ways to organize assistance. The people who want to work on changes with her will need courage to face her quick dismissal of their ideas and her anger in a way that keeps everybody's attention on the goal: Rosella living her life with freedom in a way that others benefit from her gifts. Everyone will need to be persistent and creative in inventing better ways to accommodate her need for different kinds of assistance while honoring her identity as an independent and powerful woman.

One of the most challenging issues in constituting an effective circle of support is dealing with the unfamiliarity of making some dimensions of everyday relationships conscious and purposeful. It can seem "unnatural" to talk about and openly negotiate about how circle members want to involve themselves and how the circle wants to relate to Rosella's personal assistance system. It can seem intrusive for circle members to pursue issues

that Rosella may feel uncomfortable considering. It can seem risky and somehow inappropriate to ask people to make clear commitments to Rosella's future. It is, of course, up to Rosella and her circle members to establish the relationship that they want. There is no circle police that will issue a ticket for failing to be the right kind of circle. Deciding about this calls for weighing the disadvantages of having more people "in your business" and having some people openly acknowledge the limits of what they can offer you against the advantages of having conscious, committed help to figure out hard questions and live through difficult times. Those of us on the review team with experience of other circles can say that there is much more potential than the current arrangements realize.

Rosella is a complex person whose abilities, desires, and possibilities are easy for those who know her to understand and identify with. But her life experiences are very, very different from those of most of the people around her. Those of us who have not lived through institutionalization can barely imagine its effects on a person's inner world, no matter how different life now seems from life then in the outside world. And few people with years of institutional life behind them have traveled nearly as far on the freedom road as Rosella has. One way to glimpse the meaning of this difference is to listen more deeply when Rosella seems to be contradicting herself. An example, Rosella can read but usually prefers that others assist her with reading. I have no idea why this is, but I think that there is more to learn about her, and about how life goes for people with disabilities, by inquiring about this in a quiet moment and respectfully exploring it with her than from complying with the request while superficially judging it as a tactic which manipulates people to keep her company and contradicts her claims of independence.

Another example. Rosella is angry with UCP because she had to go to the nursing home (especially the second time) and she says she doesn't want any different arrangements for assistance. I have only a glimmer of an idea why this is. When I asked, Rosella told me she is afraid that if she asks for more hours of support what she has will be taken away from her. Given her own strength and the strength of advocacy around her, this seems unlikely to me, but it also seems very real to her, at least some of the time while she is thinking about the situation. Another guess, Rosella's injuries resulted in her living bits of her nightmare: being alone, afraid, in pain, thirsty because she did not drink so that she would not have to go to the toilet. Then being re-institutionalized, however briefly, no matter how different the nursing home may be from Fairview. These bits of living nightmare can be dismissed by blaming Rosella or minimizing the experience: "She told us to leave her alone." or "The nursing home offers good care and didn't try to keep her any longer than she wanted to stay." Or, those who care about

Rosella can try, with respect and thoughtful concern for the complexity of her life, to understand just a little bit better.

Breaking through

And so, to bubble bath. Rosella and Charlotte and Rosemary and Dan and I sat in the Fairview cafeteria talking about their concerns about UCP's performance for Rosella between interruptions from some residents asking Rosemary who the new superintendent will be and others yelling and throwing furniture while staff watched. Dan said that he thought Rosella didn't have enough hours of personal assistance because he noticed that she comes to work with her hair washed and with freshly washed clothes each day when she stays with one of her friends, but when she comes from home she is often wearing the same clothes and her hair is unkempt. His point was that Rosella likes to look good, but doesn't have the assistance necessary.

I wondered aloud what might keep Rosella from asking her personal assistants to wash her hair every day if that's what she prefers. Then Rosemary got Rosella's permission to tell me about an evening they shared.

Rosella came to visit. Hospitality is a major value for Rosemary and she likes her guests to enjoy themselves. Rosemary thought that since she enjoys candle light and bubble bath, Rosella might too. Rosella needs help bathing, so Rosemary offered to help Rosella with a candle light bubble bath and shampoo.

In the middle of enjoying her first ever such bath, Rosella looked right at Rosemary and asked her very seriously if she minded helping her. Rosemary said that she enjoys making things comfortable and pleasant for any guest in her home and Rosella is no exception, even if she does need a little extra help.

I thought a lot about this small anecdote. It teaches that…

- Friends can offer the gift of new experience in simple ways that matter deeply. And part of being a circle of support is exchanging such gifts thoughtfully and occasionally.
- The attitude of giving a gift is sometimes the key that will open up possibilities that a person might never imagine asking for, much less demanding.
- Uncertainty about whether a need for extra assistance diminishes one's worth can surface suddenly and threaten even a relaxed moment between people who know one another well and care for one another.
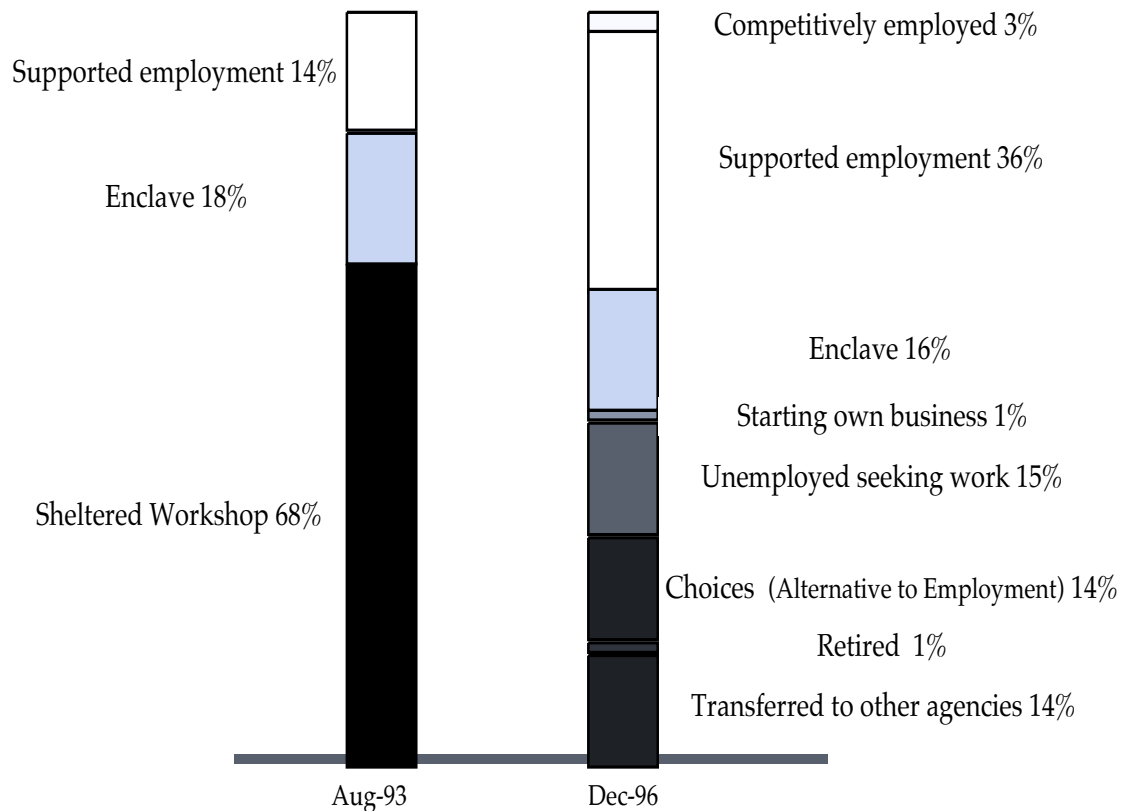- Even warriors enjoy occasional bubble baths.

Better Jobs

Achievements

The sheltered workshop is closed and the agency remains viable and responsive to changing individual needs. Continuing success in building on the foundations laid during the transition not only benefits the individuals involved but contributes the strongest kind of leadership to other agencies: leadership by living example. Well established agencies commonly follow the path of simply adding on additional services as funds for supported employment become available, maintaining their sheltered workshop and activity programs, especially if they are financially viable and satisfy some families and people with disabilities. By avoiding that path, UCP demonstrates its values by choosing to risk not just addition of something new but subtraction of something they believe is less effective. Even those established agencies that see the benefits of individual supported employment commonly take a passive stance, saying that supported employment is the best way while complaining that it is the responsibility of their purchasers to smooth the way for them by funding the costs of transition and removing regulatory obstacles before they can move. By openly negotiating with county and state authorities and by investing money raised from community sources in the transition process, UCP broadened the network of people with a stake in its success and built channels for the dissemination of people's accomplishments while making the change other agencies talk about. County and state officials, community foundation leaders, and a number of consultants with many connections across the country feel a sense of participation in what UCP has supported people to accomplishment and an interest in getting other agencies to follow UCP's lead.

Consistent with the values that drive UCP, the final measure of the transition's success is its outcomes for the people directly involved.

- Almost half the people in the workshop at the beginning of the transition have had one or more individual jobs either competitively or with continuing support. Most people did not see these people as capable of employment and did not believe that employers would employ them at or above minimum wage.

- People hold a variety of different jobs with seventeen different employers. Developing these jobs has provided validation of the effectiveness of vocational profiling and negotiating reasonable accommodation with employers.

- A number of people hold jobs with the potential for support from co-workers and supervisors.

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- There is a back-up available if people become unemployed.
- Wages have improved for people employed in one of the two enclaves.
- News of people's continuing success ripples through the system to add strength to the forces that undermine the practice of congregating people with significant disabilities in workshops or activity programs. As one VR staff member put it, "The fact that these people are working success-fully means that I have to revise my ideas about who can work and who can't work." The sense of breaking new ground for other people with disabilities is a source of satisfaction for several of the people we inter-viewed.

Competitively employed 3%

Supported employment 14%

Supported employment 36%

Enclave 18%

Enclave 16%

Starting own business 1%

Unemployed seeking work 15%

Sheltered Workshop 68%

Choices (Alternative to Employment) 14%

Retired 1%

Transferred to other agencies 14%

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A Platform for Development

The transition provides UCP an organizational platform for developing a distinctive competence in assisting people with their jobs, careers, and periods of unemployment: their whole work life. Developing this competence will exercise the same personal and organizational learning process that has guided the organization all along its journey: asking and asking over again "What is the right thing to do?" and "How can we do this better?" and living into the answers.

While this competence must be shaped primarily by the ways the people involved decide to live out their work lives, we can sketch some characteristics of this competence and identify some of the constraints UCP will need to master in its pursuit.

Competent work life supports will…

Competent supports will **consider work life in the context of a shared understanding of each person's whole life**. There will be occasions for thoughtful discussion of the many ways each person can contribute to the life of the community, not only through paid work or volunteer jobs but also through engagement in issues affecting the whole community; involvement in making changes important to disabled people; membership in associations that reflect personal interests; response to the needs of neighbors and neighborhood; and acceptance of responsibilities to family and friends. Everyone who cares about or assists the person will be alert for clues about ways the person can contribute and opportunities for the person to do so.

This growing understanding of how the person can contribute forms the foundation for understanding jobs and careers. It includes, but goes beyond, the answer to the question, "What job interests you?" While it is critical to avoid forcing people into jobs without appeal for them, it is also important to challenge the limits of what people assume can be. The question that calls for more careful listening and discernment is, "What job provides the best current fit between the person's developing capacity to contribute to community life and the real needs of an employer in our community?" In this understanding, work is not just a way to earn wages, it is one of the major ways that citizens develop their talents and make a meaningful contribution. People and their circles assess critical decisions about such matters as how much work to do for pay, what kinds of work to do, when to look for new work opportunities, how much of a job challenge makes sense now, and how to make best use of available assistance in terms of their personal gifts and calling. Building this kind of understanding with a person increases the chances that there is a good match between the identity and vocation of the person and the challenges of the job.

If this seems too grand a way to think about people's work lives, consider how much energy people with substantial disabilities and their assistants have to expend in order to do a job. If the job or its wages or other benefits have no larger meaning to the person, it is hard to see a good reason for the effort. If contribution to community life seems too big a question, remember that many employers and co-workers report that people have made an important difference to them.

This kind of understanding of the meaning of work for each person will assure that supports will be **career oriented and safeguard people against under-employment**. As people's experience and skills grow, and as their interests develop and change, the demand for better or different jobs will grow. In the short term this demand may have to be balanced with other people's demand for a first job, but balance cannot be achieved by ignoring the need for career development among those already employed.

A strong foundation in the skills and techniques of job development, kept alive through active participation in the growing international network of people and organizations committed to expanding opportunities for employment, assures that work life supports will **justify high expectations by sticking with the people who have the most difficulty with employment**.

Competent work life supports will **maximize the benefits of assistive technology** and stretch the boundaries of adaptive environmental design. Groundbreaking research by UCP's national supported employment projects demonstrates that this is primarily a matter of ingenuity and collaborative problem solving around each individual person-job fit. Access to high cost, high tech devices and controls can be important, but it is secondary to creative team work.

Competent work life supports will **push the limits of co-worker, supervisor, and employer contribution** to each person's success on the job. From before the first job development contact, people and the staff supporting them plan specific strategies to assure that co-workers, supervisors, and employers share as much responsibility as possible with the person for successful job performance. Necessary training and adaptations are performed systematically to allow the job coach to fade from the job site as soon as it is practical. On-going support provides consultation to people on the job as they solve the problems that arise. This approach contributes to flexibility in the allocation of staff time because staff are not tied down to assuring people's day-to-day success at work. This flexibility makes it possible for people to work more hours than job coaches are available and for other people to change jobs.

There is much to learn about providing and paying for personal assistance on the job and considerable advocacy required at every level. Help with meeting personal needs shouldn't be confused with job coaching. A UCP staff person whose main reason for being at the job site is to provide personal assistance should be thought of as a personal assistant, not a job coach. This distinction isn't to downgrade the work but to raise the question of the most efficient way to deal with personal assistance needs and the most appropriate payer for them.

Competent work life supports will **offer an individually planned and delivered approach to un-employment**. Over the length of a person's work life unemployment is an expectable event; it is not a disaster; it is not usually a fruitful occasion for assigning blame. When someone leaves or loses a job there is an opportunity to think through the lessons of the job the person has left and use the information to revise the vocational profile and refine job development and assistance strategies. People are as different in their ways of being un-employed as they are in their ways of being employed. If people face more than a short period of looking for another job, they need to make a plan that makes sense for them about how best to use the time between jobs. Some people may wish to sharpen their skills. Others may choose to invest some time in their general or further education. Others may want to invest time in some community activity of interest. Others may value some time to be at leisure. The balance of these possibilities and the invention of other possibilities can not be imposed by a program that groups people and serves them together simply because they share the condition of unemployment.

Some people have limited control over the supports they receive from residential providers other than UCP. Both employment and unemployment planning are more complex if a residential provider doesn't provide flexible supports. For example, a provider with a group home budget built on the assumption that a person will be in a day program six hours every weekday may find it difficult to find the resources necessary to help a person implement their un-employment plan. It is reasonable for the individual planning process to deal with these facts of a person's life, especially if the person's living arrangements offer real benefits that balance this inflexibility. But clarity matters: if the person needs a place to be from 9:00 to 3:00 in order to accommodate the group home they live in, this deficiency in residential support needs to be dealt with on a person-by-person basis.

Competent work life supports will **join people in vigorously advocating for a fair share of all the work and education related resources they are entitled to**. Because this is a dynamic policy area, UCP will support people with disabilities and staff in active ties to the network of people advocating

for sufficient resources to support all people at work. Vocational Rehabilitation is an important partner in UCP's efforts, and assuring that counselors and administrators make the most of their opportunities to invest in the people UCP supports needs to be a clear and continual focus of work.

Reflecting the unification of staff team responsibility for supports to people's homes and their jobs, UCP will **assure that support for people's work life is a clear priority for all staff**. This means that all UCP staff from the front office to the thrift operators:

- Have a broad perspective on job development and job supports.
- Are as oriented to seeking job leads for people as they are to locating good prospective roommates or assistants.

And everyone who has direct contact with people:

- Stays alert for information about each person's interests and capacities.
- Joins in problem solving to deal with the problems involved in assuring a person's success at work.
- Joins in team problem solving to assure that adequate team resources are allocated to providing and improving the ability to provide job development and job supports even when this means resisting the pull of staff time into holding people's living arrangements together.

Constraints

While individual people in the county and state agencies responsible for assuring that people have access to work are strong and creative supporters, rates, rules, and incentives have not yet caught up with the people UCP supports. Collaborative problem solving and vigorous advocacy to change policies remain essential to the development of UCP's capacity to support people's work lives.

Fewer employers understand the possibilities and benefits of employing people with significant disabilities than would make it easy to do job development. Unfamiliarity and uncertainty –if not prejudice– continue to meet job developer's proposals.

These external barriers are significant, but UCP's ability to continue making progress on dealing with them depends on addressing constraints internal to the Community Services Division.

The transition process infused considerable skills in job development and job coaching. Making the most of this investment means assuring that staff with work related responsibilities have the chance to acquire, maintain, and continually improve their skills. Our observations suggest that some staff may be…

…relying on less effective strategies like building job coach prompts into the job a person has been doing for some time, or having unemployed people perform vocational readiness tasks such as practicing general interviewing skills

…missing opportunities to recruit and organize co-worker, supervisor, and employer contributions to people's job success

…responding to the uncertainties in a job situation by minimizing the risk a person will lose a job at the cost of maintaining their own presence on a job site (sometimes even as a kind of extra, one-to-one supervisor) to provide occasional help and in case anything goes wrong. In one situation, the person's need for help was so episodic that the job coach had time to read a book between the person's need for prompts. More effective practice would balance the risk of job loss against two other risks: the risk of 'building the coach into the job', thus limiting either the hours a person can work or the amount of job support available to other people; and, the risk of doing things that co-workers and supervisors might do given the opportunity and support.

If this slippage in staff skills reflects a pattern rather than an accident of the time and place of our observations, at least two factors contribute to the pattern and stymie UCP's development.

- Turn over of staff, promotions, and rearrangement of staff assignments and responsibilities may have left some responsible people without the training and supervised practice they need to develop their skills in the first place and to sharpen them through practice, reflection, and advanced training. The two days of training on vocational profiling and systematic instruction is only an introduction; it can't be allowed to take the place of a through approach to staff training that includes supervised practice, coaching, and consultation.

- Unifying responsibility for supports to people at home and during the day has clear advantages. But it creates a significant, continuing problem for team leaders: keeping a balance of allocation of time and attention so that problems in supported living and emergencies don't dominate developmental work on people's work lives. When someone faces a health crisis or a roommate quits in the middle of the night, it is hard to preserve space and energy for improving people's work situations. Job coaching then becomes a more marginal activity. And the people who receive 24 hour support from UCP may get disproportionately more assistance than the people who live in other places. One small sign: we noticed lots of reminders for staff to help in recruitment of roommates; we missed similar reminders about job leads.

Resolving this issue means keeping alive the tension that led to the creation of community services teams in the first place: the balance between specialization and keeping focus on people's whole lives. By moving this tension very close to the people it supports, UCP demands that teams be effective in allowing the development of specialized skills.

The transition process concentrated energy and attention on closing the workshop by providing employment or alternatives to employment for everyone. The success of this process needs to allow a reconsideration of both types of group oriented supports UCP continues to offer.

Enclaves provide employment for twelve people, allowing them to work on the premises of a company and earn wages by doing necessary work. People in enclaves remain part of a group that works for UCP, and in a way that seems to mostly separate them from other workers. There are limited opportunities for expanding skills or varying tasks. People and important people in their lives may be satisfied with enclave employment because they don't see an alternative. Over time, it's as necessary to invite the people in enclaves to develop their careers as anyone else. Otherwise, the good will become the enemy of the better.

The VOTE program - which provides activities for people who are unemployed - solved two transition problems. It provides an answer to the deep concern often expressed by families or residential providers, "What if the person loses the job?" and it allowed an official end to the transition project with the formal closure of the workshop. From our point of view the VOTE program has four disadvantages:

- Its day-to-day activities continue to congregate people in the same building and have only a loose and indirect relationship to their getting a job. If these activities led to jobs for people with substantial disabilities, activity centers and sheltered workshops would have worked.

- People in VOTE need to mobilize resources around an individualized job search and job development process. The program's activities don't have the kind of intense, personally based exploration and problem solving that is necessary. Instead of being out hunting for job leads, accompanied by a job developer, they (and perhaps their families and friends) are more passively waiting for a job to be developed.

- At least one person attending VOTE compares it unfavorably to sheltered workshop days because there is no real work and no paycheck.

- The existence of the program covers up conflicts that need to be acknowledged and dealt with openly and creatively. Some of these conflicts must be resolved one person at a time, such as disagreements about whether a person can or should work. Others are systems problems, such as funda-

mental differences in mission and approach between UCP and other residential providers or insufficiency of funds to support each person from the workshop in an individual job.

Dealing with these constraints calls on the Community Services Division's management team to exercise the same farsightedness, courage, and willingness to learn demonstrated by UCP's management team in the transition process.

Action Steps

- Discuss the qualities of a competent work support service we have identified above. Argue with it and revise it until it reflects the Community Services Division's shared beliefs: add what we missed; find better words; delete things you don't agree are important. Then, use the revised description for self-assessment by identifying strengths and areas for improvement on each dimension and assign an over all rating reflecting "How we are doing?" on each dimension. Use this self-assessment to guide division and team planning.

- As part of the focus on organizing the supports around individuals, assure that people thoughtfully consider people's contributions to community life and specify the way the persons work supports those contributions. It is important to consider these questions very carefully for people now employed in enclaves.

- Conduct a peer review of each job coaching situation. Take necessary action to make sure that each job coach …

  … has had adequate opportunities to learn the agency's approach to job coaching through attendance at training sessions, supervised practice, and consultation.

  …has well defined strategies for fading their support through an individually appropriate combination of negotiation for increased support from people at the work site, employment of assistive technology and job adaptation, intensive personalized instruction, and continuing consultation with people at the workplace.

- Conduct a peer review of each job development situation. Take necessary action to assure that job developers have…

  …the skills and supports they need.

  …a clear strategy for implementing each person's vocational profile in a way that maximizes the support they will get from co-workers, supervisors, and employers.

- Arrange "master classes" for job developers and job coaches. This kind of training involves direct observation, coaching, and feedback by a highly skilled practitioner from outside the agency. UCP might swap some time

from its own highly skilled staff for assistance in this area.

- Convene a small team to develop ways to have conversations in each workplace about the possibilities for expanding the contribution that co-workers, supervisors, and employers make to the increased success of people already employed. It is worth inviting the people who are competitively employed without UCP's direct support to consider having such conversations on their jobs too.

- Figure out who is linking UCP to the various local, state, and national networks of people interested in work for people with substantial disabilities. Be sure that these links are active and involve the people actually doing work support, the people with disabilities UCP supports, and their co-workers and employers.

- Consider ways that employers who already experience the benefits of employing people with disabilities can extend the reach of job development efforts. What would it take to make them more effective and enthusiastic salespeople for supported employment?

- Re-do the transition process within the division in order to move VOTE from a congregate program to a capacity to provide a variety of individualized supports for periods of un-employment. This mini-transition project would be managed by a small project team with the responsibility to attract necessary resources, develop and implement a plan aimed at a specified closure date for VOTE. The UCP management team should negotiate the terms of the plan (especially the proposed closure date) and then act primarily as coaches. Such a project would build leadership around work life.

Turn Over and Continuity

The problem as given

People inside and outside UCP identify staff turn over as a problem more often than they identify any other issue. They see turn over both as a problem in itself and, more frequently, as a major barrier to dealing effectively with other important issues such as assisting people to expand their social relationships or pursue new jobs. People familiar with human services know the pervasiveness of turn over and the elusiveness of solutions. Obviously it links to chronically low wages for demanding work in a low unemployment local economy where a growing proportion of employees expect to make frequent job shifts. So UCP's problem seems neither unique nor easy to solve.

UCP deals with difficult environmental conditions by making the most of them.* It has created a very attractive place for well educated and caring young people to invest some time doing good, hard work by making a real difference in other's lives before they move on to careers and family lives. A number of former staff left to pursue professional training in human services and some have moved into leadership positions in other agencies. For many staff, including some experienced service workers, UCP offers a good landing place for newcomers to Portland and the Northwest. Direct engagement with people who have clear practical needs and the opportunity to promote disabled people's rights in a leading and well respected and sometimes controversial agency mobilize staff member's considerable energy and talent. One team member provided a good image, "It's kind of like the Peace Corps used to be. You do 'the hardest job you'll ever love' for a couple of years. Then you get on with your life."

The results are mostly positive. Without exception, people UCP serves and people outside the agency describe UCP staff as professional, hard working, bright, committed, capable, and young. They almost always quality occasional criticisms of staff performance with reference to the staff's youth and enthusiastic inexperience. Only two problems were voiced, the first by everyone, the second by a few.

These bright, dedicated, capable young people keep leaving. Some family members apologized because they couldn't remember the name of the support coordinator currently involved, and a number of people have trouble remembering the succession of support coordinators who have

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* While the turn over of people's roommates and personal care assistants is also an issue this discussion centers on support coordinators and team leaders, Many of the same considerations apply to the people who provide direct, day to day assistance, but we focus on full time UCP employees.

worked with them or their family member. Most people identify Tara as the fixed point in a rapidly changing universe of staff.

A few people wonder if UCP offers its staff adequate support for staff development –not access to training, but mentoring, guidance, and supervision as staff grow in their ability to make good judgments and positive contributions in what can be very difficult circumstances. Given adequate support, staff grow in ability to understand and respond thoughtfully to people who are suffering hard times: facing life defining problems with health, or emotional balance, or aging, or mortality with which staff might lack personal experience. Given guidance, staff develop a broader repertoire of approaches to people who are working out personal issues about such matters as relationships to their family, or their career plans, or their place in civic life, or the expression of their sexuality: issues which often resonate with what staff are dealing with in their own lives. One person put this concern vividly, though in a way that might lead staff to dismiss it as an expression of overprotection of the people they support or underappreciation of their abilities, "I worry a little whether there are enough grown-ups at UCP: especially because people seem to get promoted to team leadership so quickly, and Tara has so much to do." It would be a serious mistake to brush this concern off without careful discussion..

Trying different ways to understand the problem

Asking naive questions sometimes helps find new ways to approach intractable problems. Two such questions arose for the team:

- Why is turn-over a problem?
- Are their any ways in which UCP helps create this problem or makes it worse?

What's the problem? Take 1

Turn over seems to create two kinds of costs: costs to the people UCP assists and costs to UCP as an organization. Take 1 looks at the situation from the point of view of the people UCP assists and turns the problem inside out. Take 2 considers ways to minimize costs to UCP as an employer.

From the point of view of the people UCP assists, the real problem is not staff turn over, but continuity of essential supports. At least four continuities make the vital difference between danger and safety and between merely surviving and having a fuller life...

… **Continuity of knowledge** of who I am, what my life has been like, what matters to me and what I'm indifferent to. Someone who experiences this continuity can say, "Some people I trust know me, each in their own ways."

…**Continuity of personal projects.** The promise of personalized supports is that each person is free to discover and pursue relationships, memberships, and activities that matter to them. A person who needs assistance to pursue a line of interest in their life can find themselves having to start over every time a key assistant leaves. Someone who experiences this continuity can say, "I can keep up the pursuit of what matters to me, even when my assistants change."

…**Continuity of systems of communication is** vital to many of the people UCP assists because other people are challenged to understand their signals. Every way that a person expresses themself is precious. When someone depends on devices, signs, familiar listening, or any other methods, anything the people who assist them don't know about how they communicate reduces the level of communication with them. Someone who experiences this continuity can say, "The people I count on for assistance know how best to understand me and how to help others to understand me."

…**Continuity in performance** in necessary tasks. People need a variety of kinds of physical help, and experience shows what a person finds works best and most comfortably to provide it for them.

– People benefit from a variety of devices, from wheel chairs and lifts to communication devices and adapted computers. Assistants need to know how to use each device to its best advantage, how to perform routine maintenance, and how to troubleshoot common problems.

– People count on UCP staff for help with the paperwork associated with increasing their incomes, tenure in their homes, getting and keeping their jobs, their health, and paying for their personal assistance systems.

– Some people need assistance with maintaining important relationships: making calls, sending cards, having people over for dinner or to spend the night.

Someone who experiences this continuity can say, "The different people who assist me know what they are doing and so I usually feel safe and comfortable and able to reach out to other people."

   Continuity doesn't mean that people, especially staff, don't go away. It means that important understandings and skills don't get lost and that important threads don't get dropped when they do.

   There are at least three possible sources of continuity: staff and written records, people themselves; and the person with a circle of support. Of these, the weakest position is to simply rely on staff and routine agency processes to pass along the necessary knowledge, plans, and skills. The strongest position is to rely on the strength and redundancy that comes from

a person who is supported by a circle of committed people. This suggests several possibilities for minimizing the discontinuity created by staff turnover.

- Each person UCP supports gets encouragement and help to form and maintain a circle of support, beginning with the people who are the most isolated. This help might come from UCP staff, from other disabled people, or from other experienced people.

- Each person UCP supports gets a chance to think carefully about how they want to supervise and train new staff, including new support coordinators, and help in becoming a better communicator of what staff need to do to perform satisfactorily. This help might come from UCP staff, from other disabled people, or from other experienced people. It can, of course, include asking another person to perform some or most all of the instruction and interpretation for new staff.

- Staff who develop a friendship with the people UCP support's join the person's circle of support and, when they leave their job, they are encouraged to maintain their membership in the circle. Some people in other places have found that former staff who have accepted the responsibility of circle membership can make first rate instructors for new assistants.

- Each person will be able to count on UCP to maintain a clear, straightforward, up to date written description of all of the assistance they need, including the exact help they require from PCA's and support coordinators to pursue their life projects and maintain their personal connections. This description will be available to the person and the person's circle as an aid to hiring and orientation for support coordinators and assistants. As well, each team will review these statements over again, in detail, with new support coordinators, who will check with the person and the person's circle for any necessary revisions.

- Staff will strive to stay clear among themselves and be clear to others that they are far more likely to be passing through a person's life than settling down to stay. Understanding this fact will promote...

  ...urgency in learning what is necessary to the performance of their work from the person, those who know the person well, and those who have served the person well in the past. They haven't long to make their contribution.

  ...humility in their expectations that a person will trust them to share their story and their personal lives and restraint in deciding that they know what is going on with someone whom they haven't had time to get to know.

  ...willingness to respect and seek guidance from the person and those who know the person well: this respect includes willingness to inquire

and negotiate carefully around conflicts between themselves and the person and their circle rather than to assume a position of superiority based on their understanding of agency values or their own personal experience.

Of course, staff who stick with people make a major contribution, even if they are the weakest source of continuity. So efforts to recruit and retain good people remain well worth exploring.

What's the problem? Take 2

It costs UCP as an organization significant time and money to recruit and train new people, and a discouraging number of people seem to leave just about the time they become comfortable with the work Moreover, the demand on teams to fill in while positions are vacant adds to job stress and can make it hard to focus energy on life issues that rise above helping people hold together their status quo. And, because staff turn over is obvious and widespread throughout the field, it can serve as a kind of excuse for not finding better ways to help people move farther and faster on their personal journeys. Accounting these costs more carefully opens up several possible approaches.

- If working at UCP is going to be a bit like being in the Peace Corps (or the modern Army), does it make sense to explicitly negotiate for a time limited commitment of at least two years, given satisfactory performance? A practical answer to this question requires the help of skillful people, committed to community life for people with disabilities, and expert in the intricacies of labor law.

- If the notion of time specific enlistment makes sense, are their ways to…

  …make a personal plan with each new staff member that clarifies how two years work at UCP fits into their life and defines what UCP will invest in them and what skills and knowledge they can expect to gain from working with UCP throughout the term of their "enlistment"

  …think of incentives for re-enlistment by encouraging staff to clearly define "What it would take for me to stay another year or two" and developing a process to negotiate such propositions. Donors might be interested in providing targeted funds (or perhaps other incentives) that would keep skilled staff at work

- How many ways are there to accelerate new staff member's learning to do the work. For example...

  …How many tasks can be defined and supported by protocols, manuals, and other job aids and how can UCP's computers provide better support to these routine tasks? Exploring ways to automate as many

routine tasks as possible and developing some of the uncertain potential of the world wide web as a way to say current with information on say, social security related issues, might be a way for UCP to join other Oregon providers or UCP national in attracting grant support for a project that some staff might find rewarding in itself.

…How can some of the knowledge that experienced support coordinators gain be decoded and made more rapidly available to new staff? These are matters that can't be reduced to procedures, such as helping people build support circles; supporting people in their work life; supporting roommate and PCA relationships or helping people to end them; or setting and maintaining personal priorities on issues that are essential to better lives for the people they support.

…How can the agency get the best and quickest return on its investments in person centered planning, vocational profiling, and systematic instruction? It may be that there are ways to train people sooner more thoroughly, and quicker. UCP will create these new ways to learn when everyone takes seriously how fast the clock is ticking on each new hire. Perhaps these will involve more one-to-one instruction, more explicit and focused periods, or shared training with people from other agencies.

...Can the processes for individual supervision and consultation be improved and new employees linked to them more strongly and more quickly.

…How can the people UCP supports and their families play a much more active role in training support coordinators, not only in the practical aspects of their jobs, but by purposely and deeply immersing them in what it means to be a disabled person in a society which makes them marginal to the world where most staff grew up and live.

• How can team objectives and team performance focus on promoting longevity? This might involve...

…making time to reflect, as a team, on the personal and social meaning of their work.

…supporting team mates to search for ways to renew themselves when the thread of meaning gets lost.

…quarterly or six monthly cycles of identifying whichever of the chronic stressors in the work is hassling team members most and inventing new ways to deal with them. While hassles like having to do overnights to fill in when a support system breaks down, or responding to beeper calls, or filling in for sick teammates probably can't be eliminated, team creativity might reduce their effects at least enough to provide some sense of satisfaction and control.

How does UCP contribute to the problem

Higher wages reduce turn over. Opportunities for promotion reduce turnover. Changing work force dynamics probably accelerate turnover, though this is harder to analyze because models for understanding these dynamics remain underdeveloped. UCP can and should continue to work hard to attract the resources to pay people fair wages for their work, but the continuing fiscal crisis imposed on services to people with disabilities makes progress slow and difficult. UCP can *and* should offer people chances to expand their skills and figure out more ways to reward people's development of new competencies, but the size and flatness of the organization work against offering people very many promotion opportunities. And young, talented people are more likely to see the kind of work UCP does as a transition than as a career.

Given the magnitude of these forces, identifying any contributors to staff turn over that UCP can control is like discovering gold. One way to look for less obvious handles on turn over is to ask "What are we doing that makes the problem worse?" and then to see what it would take to make a change. There are at least four candidates for UCP to investigate further: the effects of reassigning people among support coordinators; the apparent homogeneity of UCP employees; the need to learn from staff whose leaving seems related to difficulties in living up to agency values; and taking the possibility of deep relationships seriously.

Some of the people UCP supports experience even more staff turn over than can be accounted for by staff leaving their jobs. Someone's leaving often results in a reallocation of people among support coordinators, thus increasing the tempo of the dance of staff through people's lives. While some of this sort of change is probably necessary and even can be desirable, there are at least three things to consider:

- Do teams ever experience "bumping" as changes in one support coordinator's assignment creates changes in another's assignments which in turn results in still more movement? If so, can teams invent ways to decrease this?

- To what extent do teams move people among support coordinators as a way to share responsibility for a person or family that staff find difficult to work with? Anyone can discover a bad match, and it often makes sense to find a better one. But it seems as if some people may experience a kind of "staff churning" because they or their families are especially hard to work with. If a team can identify any examples of this kind of turn over, they have the opportunity to look for:

  …better ways to understand and assist the person

…hiring specifications specific to the kind of person who can work well with someone others have found difficult

…alternatives to avoidance as a way to deal with conflicts between staff and a person or a family.

- How can the people UCP assists have more influence on support coordinator movement?

The apparent similarity of UCP's staff in age, education, current family circumstances, and background suggests that it might be worth purposely recruiting some people who are different on these dimensions. It could be challenging to incorporate older people with less formal education and more family ties into UCP's work force, but greater diversity might bring greater strength.

The experience of the transition period included an unexpected outcome: none of the staff who worked in the group homes and none of the staff who worked in the workshop successfully made the transition to providing new kinds of support, at least not for very long. This happening was disappointing and difficult to understand One reasonable way to make sense of it is to attribute people's leaving to their inability to live up to UCP's values. This lesson of history could be over generalized however, leading managers to define performance problems and conflicts with agency leadership as problems with the staff member's values. The departure of someone who doesn't seem to have what it takes to live out UCP's values may seem like a relief rather than an occasion for reflection and learning. Of course, some people may not have what it takes. But the departure of people whose values seem mismatched raises three questions:

- What are the lessons in this situation for the hiring and orientation process?

- How can teams and UCP's senior staff become even more effective at confronting differences in values in ways that promote positive change?

- When do conflicts that might have other substance (such as a sense that the agency has unrealistically high expectations of how hard staff will work) get redefined as values problems?

Staff people can't presume friendship with those they assist. And staff need to exercise caution to avoid taking center stage in people's lives. But experience teaches that some people do transcend the staff relationship and find a stronger basis for being in people's lives. This can be a source of conflicts and problems, but it is also a possible resource to people. It may be helpful for staff to explore the occasional call to deeper and longer lasting relationships, and the possibilities and problems this creates in a retreat setting, with the assistance of someone who has thought the matter though.

Learning from Difficult Situations

In any sustained effort, people will experience conflicts. When that effort involves life supports for vulnerable people, the stakes in the conflict go up. When there are major changes in the ways people receive essential assistance and the mental models for understanding the purpose and process of that assistance, the odds of deep conflict increase. So there is no way that UCP can expect that every situation will be handled without generating conflict. The management team's responsibility is to make sure that there are effective ways to identify conflicts as early as possible and deal with them as openly and creatively as can be. Beyond this, making time to reflect on conflict situations and consider the lessons they can teach contributes to leadership development. Well tended conflicts will build shared understanding –at least of what specifically it is that divides the parties– and often stimulate creative problem solving.

UCP leaders and staff have faced and dealt effectively with their full share of conflicts in the transition process. To simplify, visualize most relationships between UCP and the people and families it supports something like this:

| agreement | disagreement | agreement | BIG disagreement | agreement | disagreement |
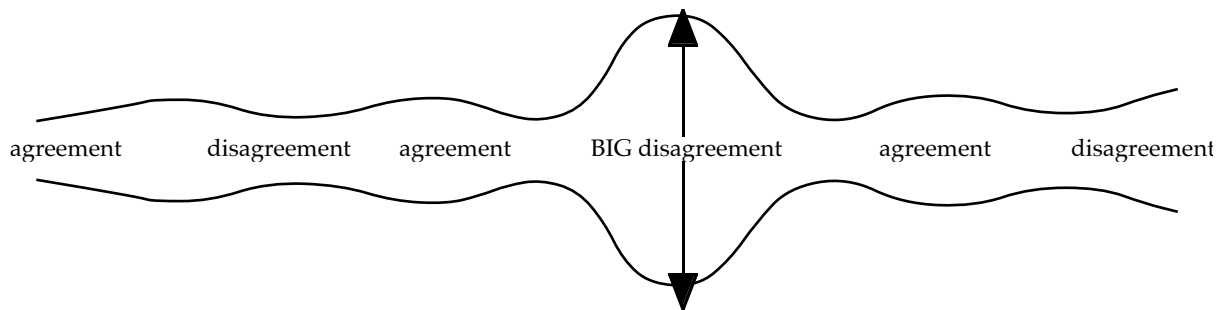
Most of the time the people involved are pretty close to agreement. On occasions when conflict threatens to drive people apart, there is an effective process for exploring what is going on, figuring out what people want from the situation, helping people decide what they can live with and what has to change to keep them engaged, and doing some active and creative problem solving. Over time, working together on agreed solutions will draw people back together, sometimes closer than ever. The manager's responsibility is to be sure of two things: 1) that people who have to collaborate in order for the person's life to go well feel the pull of the person's need for collaboration when conflict or fear of conflict threatens to pull them apart; and 2) that all parties to the conflict have access to an adequate process for dealing with the conflict.

Sometimes situations develop in a different way. UCP asked us to meet two people where misunderstanding seems to have grown up with time. In general terms, this seems to be what has happened.
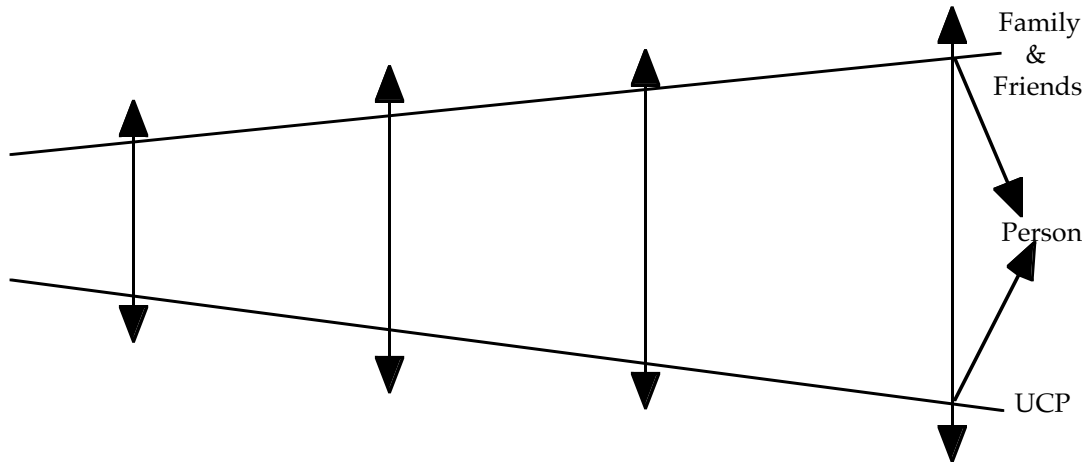
UCP and the person, and the person's family and friends have different pictures of what is going on and what makes sense for the person. This not only leads to disagreement, but to increasing misunderstanding. As time goes by, this kind of conflict can escape containment. So, instead of people getting a better understanding of each other, UCP's story, the person's story, and the family's story grow farther apart. Incidents feed the conflict based on the interpretation each places on the other's behavior. Sometimes people look back and trace the history of the conflict in a way that amplifies it; "We never said…" "Yes you did, I wrote it down…" At the extreme, things can get polarized and frozen, and the person gets caught in the middle. Because both UCP and family and friends matter to the person, the person may see things one way when they are with family and another way when they are with UCP staff. This compounds the misunderstanding because the person's messages aren't always consistent.

One of the signs that a situation has gotten stuck in this way is that outside listeners (say a senior staff member or a case manager) will have a problem in getting the story straight. Concerned people's accounts of what is going on are so different that they cannot be reconciled and this tempts the listener to deal with the dissonance by figuring out which party is wrong, or bad or crazy. Another sign is a feeling that the person needs to choose between people they still care about, "The family is intrusive and irrational. The person would be better off if the family let go and got out of the person's life.". A third sign is that problems in day to day life don't get identified, explored, and worked on because people avoid each other or

spend their time together blaming or trying to avoid being blamed. People feel and act powerless. They know something is wrong, but they can't get a clear handle on exactly what's wrong and what to do about it.

The first step out of this trap is to stop and reflect on what it might be like from the person's point of view to have so many people on the sidelines telling conflicting stories about them while bad things continue to happen.

Because misunderstanding has grown up and hardened, these are tough situations in which to learn about drawing people closer together. People may have fundamental differences about whether supported living or community employment is the right thing to aim for. They may have a much different sense of the person's abilities. They may have very different pictures of what UCP's role is in the person's life. They may have become suspicious of the other's motives. They might not like each other. And continuing misunderstanding makes it hard to explore these differences with one another. But hard or not, such exploration is what is called for.

The issue for exploration is not who is wrong but what might be done to stop this pattern of increasing distance and to get the person out of the middle. The middle may be a very hard place to be; it may also offer the person some influence over both UCP and their family. But any power this being trapped may offer has a high price.

If, after reflection and exploration misunderstanding continues, there is a second question for reflection, "When we get locked into a conflict to the extent that our own well intentioned actions seem to keep making things worse, who do we turn to for help in re-building a working relationship and how do we decide we need help?" Sometimes a person's case manager can be an effective mediator. Sometimes the case manager may not have the time, or skill, or strength to help people extricate themselves. Good mediators and arbitrators are a valuable resource. UCP should use the very few occasions when misunderstanding seems to be winning to seek out such people and enlist their help.

Going Deeper: Spirit and Choice*

So far, this report has examined the transition from the point of view of UCP as an organization and described some of the effects of that transition from the point of view of the people and families UCP supports. Community Services Department staff have mostly appeared as people for us to assign tasks. But their work involves more than performing tasks in the outside world; their work engages their spirit.

The reason for the transition is the creation of new opportunities for people with disabilities; so consideration of their experiences guides the journey. But there is more opportunity and far greater complexity to this journey than simply accounting its outcomes in terms of hours worked or wages earned or goals met, no matter how imaginative and person centered those goals may be. The opportunity for staff people to develop themselves mirrors the opportunities for people with disabilities.

It is a kind of dance, played out over weeks and months. As staff stretch and risk letting go of the assumptions, roles, and relationships that define their comfort zone, people with disabilities have more room, better support, and more precise assistance to stretch for themselves. This happens because in this work, development means cultivating the ability and willingness to listen more imaginatively, understand more deeply, feel more compassion-ately, and act more courageously. As people with disabilities risk discover-ing and voicing and acting to embody their preferences, interests, and concerns, staff feel more energy and clearer direction in their contribution. Who goes first depends: sometimes a person with a disability reaches out and invites the staff person to join in; sometimes the staff person reaches out to the person with a disability.

For people who need a lot of physical assistance, this dance is the subtle side of ordinary busy-ness around earthy realities: getting in and out of bed, getting washed, getting dressed, eating and figuring out who will help with these tasks and when and how. Because the necessary tasks are routine and often involve close physical contact, it is easy for the subtle side to disap-pear into tedium. This dance happens while figuring out what to do about a balky and often discourteous transit system, the roommate who seems to be having a hard time, and the many demands of living on a very low income. Solving these daily problems is urgent and often overwhelms more quiet conversations.

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*This section has been shaped both by my experience with UCP and by a week of intense conversations with Gail Jacob, which happened as part of our collaboration in writing about Options in Community Living, just two weeks after my visit to UCP. I acknowledge that this increases the risk that the discussion will stray from reflecting exactly what our team saw and heard and thought in Portland. –JOB.

One of the people UCP supports appreciates the importance of both the material and the subtle side of this daily routine. She said,

> *If I could, I would give each staff person a gift. I would give them the gift of feeling what it is like for me to get up in the morning and get ready for the day. They know it from their side; they know what its like to do the work of helping me shower and get dressed. But I want them to feel the work it takes to get the help. It takes a lot of energy from you and you can tell, by the person's touch, whether they care anything about your day or not. When you matter to the person helping you, this work is not so tiring.*

It is hard to be mindful while doing routine tasks, many of which lie outside the usual boundaries of privacy. It is hard to be mindful while dealing with routine emergencies. It is hard to be mindful when someone is facing a difficult time and has nobody besides you to count on. It is hard to be mindful when people are mad at you. It is hard to be mindful when people are sending confusing messages or defeating themselves. It is hard to be mindful when you are human.

But it is important.

Only a tiny bit of the conversation that encourages exploration, risk, and focus on personal contribution goes on in meetings. What someone can say when asked for their ideas about a desirable future grows from many small interactions. As with any humans, these interactions build a relationship as one person dares to share a concern or a desire; dares to ask the other "What do you think about…?"; dares to confront an issue between them.

What brings awe into these relationships would be easier to describe if we were a culture that credited the notion that people are, in one aspect, spirit and that a person's spirit can be stolen away from them by forces we can feel if we attend but can't see.*

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*If this idea seems too weird or primitive to even consider, it might help to read *Naming the powers*, by Christian scripture scholar Walter Wink. He makes the argument that our ethics needs an awareness of the presence and power of competing spiritual forces. If that seems too religious, read management scientist Ian Mitroff's book, *Corporate Tragedies*, in which he argues that business managers have to be aware of and responsible for the activities of what he calls "archetypal forces." If it's still too weird, just pretend for a few paragraphs.

Many of the experiences that go with significant disability threaten a person's spirit. The chances of being rejected, being isolated, being controlled, being neglected, being abused –all a part of ordinary life– increase dramatically with disability, especially when a person is institutionalized.

That people with disabilities survive years of such assaults is remarkable. The resiliency and courage with which most people have taken on UCP's transition will be a genuine source of inspiration for anyone who takes the time to meditate on it.

That people with disabilities can lose their spirit is understandable. Some of the signs: tolerating intolerable treatment from roommates or assistants; being stuck in violent or hurtful responses to people who live with you or assist you; not having any sense that you have a contribution to make to others; not having any way to express what matters to you, even to yourself; withdrawal (not quietness or even shyness) from human contact.

People whose spirit has been stolen have work of their own to do but lack the will to do it. One way through this paralysis of will comes when a person feels the presence of allies who are, in a sense, willing to wrestle for the recovery of a person's spirit.

Wrestling for people's spirit means doing simple things that take courage, clarity, and compassion. Things like…

…speaking up "out of turn" to protect a person's rights when some authoritative bureaucratic process threatens to ignore who the person is.

…sitting quietly and thoughtfully with a person who is having a hard time.

…arguing respectfully but vigorously and skillfully when someone seems about to do something that seems to you to be a big mistake.

…listening carefully and imaginatively to catch and confirm any clues about a person's identity and contribution no matter how softly or how violently the message may come.

…naming the social forces that oppress a person and helping the person figure out how to resist as effectively as possible.

…crafting invitations that bring a person to new experiences.

…standing up for the person's responsibility to discern, develop, and contribute what the person can uniquely bring to the world.

UCP has an admirably clear commitment to respecting people's choices. Some of the clarity of this commitment comes from revulsion at the opposite possibility: taking impersonal control of people's lives and mindlessly coercing them to follow routines "for their own good".

In a strange way, UCP staff may be too clear about choice. Choice may be so obvious a value that they have too few problems with it. Too few problems means that people do not struggle to figure out what choice means in the context of the real lives people live and the real histories that have shaped them.

Superficial respect for choice can put staff in unthinking collusion with exploitative roommates or "friends". Superficial respect for choice can put staff on the side of the forces that oppress people with disabilities by mindlessly conspiring with idleness, segregation, and fear of failure. Superficial respect for choice can cause staff to overlook the opportunity to stand up for a person's spirit, as when a person's choice represents acquiescence to feeling stuck in a bad situation without good options. Superficial respect for choice can muffle staff perceptions of how people are living and how people desire to live.

As with many human issues, the power –and the confusion– lies not in the opposites but in the "and". Respect for choice is fundamental and so are the oppressive social forces that rob people of the spirit to live more fully. A complete response is not a matter of finding an abstract middle ground. It is a matter of building relationships in which people can be honest and fight hard when they need to. There is no way to respect choice without mindful personal engagement with the person and willingness to stand up beside the person against the forces that want to squash the life out of them.

UCP staff have the opportunity to learn their way into this deeper set of questions as they accompany the people they assist through their lives. To be good companions, they must be mindful and willing to move away from comfortable slogans, even if they are wonderful slogans about "choice and self determination".