Settling Down				
Creating Effective Personal Supports for People Who Rely on the Residential Support Program of Centennial Developmental Services				
	Report Prepared by	У		
John O'Brien and Connie Lyle O'Brien				
Based on a Program Evaluation Conducted 12 to 17 February 1989 by				
· Joan Bergman	Gail Jacob	Connie Lyle O'Brien		
Jan Nisbet	John O'Brien	Steve Schain		
Jeff Strully	Bob Williams	Joe Wykowski		
		-		
58 W	ponsive Systems Ass fillowick Drive • Lithonia 987-9785			

Tree of

L

Terretere

-Prime

.

. .

Contents

Program Transformation		
A New Design Stabilization	1 2	
Achievements		
Settling Down		
It's what people want	7	
The program's challenge	8	
Learning is the way	8	
Team coordinator's primary task	9	
Leadership for Development	10	
Past understanding won't work for the future	10	
A new understanding of leadership	12	
Role of program managers	13	
An Agenda for Settling Down		
Move Everyone Into Community Homes		
Remember People's Vulnerability		
Confronting isolation & lack of power	17	
Stronger ties with families	18	
Acknowledging staff relationships	18	
People with close relationships to a roommate	20	
Supporting people who have no allies	20	

Better response to people's disabilities 22		
More skilled assistance	22	
Deeper understanding of choice	25	
Attention to the principle of normalization	27	
Maintaining the spirit	29	
Face Constraints in New Ways		
Modify program beliefs	28	
Constraints arising from local conditions	29	
Constraints arising from the state system	30	
Constraints arising within CDSI	31	
Organize for greater accountability to the person		
Clarify the job of primary staff	33	
Clarify the connector's contribution	36	
Manage emotional pressures	37	

Abbreviations

CDSI	<u>Centennial Developmental Services, Inc.</u> , the community centered board certified by the Colorado Division of Developmental Disabilities to develop and coordinate services to people with developmental disabilities in Weld County. CDSI also provides services and has three service components relevant to this report: Case Management, Adult Services (which operates day pro- grams) and the Residential Support Program
	grams), and the Residential Support Program.
DOL	

- PCA <u>Personal Care Alternatives</u>, a funding program administered by the Colorado Division of Developmental Disabilities under a Medicaid waiver.
- RSP <u>Residential Support Program</u>, the component of CDSI that assists people with developmental disabilities who need help to establish and maintain their homes. The focus of this report.

Acknowledgements

Our team had the rare privilege of learning from innovators. We were met with hospitality, willingness to share, and interest in what we discovered as visitors. We are grateful to...

- ... the people assisted by the Residential Support Program who allowed us to visit them and shared time, meals, and their experiences with us
- ... staff who participated with openness and goodwill in what must have seemed an endless series of visits, rides, meetings and interviews
- ... Jay Klein, DeLayne Hinton, and Janelle Enns, who have successfully led the Residential Support Program through the first critical phase of innovation and have the courage and foresight to open their work to the scrutiny of their peers
- ... Diana Ferguson who worried about logistics so we didn't have to
- ... John Wooster and the Centennial Developmental Services management team for arranging and assisting in our work;
- ... Rocky Mountain Resource and Training Institute for a grant of funds which partially supported the team's work
- ... the writing of this report was partially supported through a subcontract from The Center on Human Policy, Syracuse University for the Research & Training Center on Community Living.*

We appreciate the people of Centennial for their generosity with the lessons of their experience. They have agreed to offer this report to others who share their commitment to supporting people with disabilities as they take a valued place in community life.

* The Research & Training Center on Community Living is supported through a cooperative agreement (H133B80048) between the National Institute on Disability & Rehabilitation Research and the University of Minnisota Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily represent the official position of NIDDR.

Program Transformation



Phase 1: A New Design

• While we hope this way of describing the changes will seem accurate and helpful to people involved, we are responsible for the punctuation of events into phases and for the interpretations.

" Syracuse University's Center on Human Policy documented this phase of RSP's development as one of its series of case studies on programs offering examples of good practice. See Pam Walker (1988). Integrating Philosophy and Practice: A Case Study of the Residential Support Program, Weld County, Colorado. Syracuse: Center on Human Policy. In the summer of 1985, the Residential Support Program of Centennial Developmental Services, Inc. began a process of transforming the way people with developmental disabilities live in Weld County, Colorado. To clarify the developmental work crucial to RSP's continuing role in this transformation, we identify two phases of significant change: redesign and stabilization.* The outcomes of these first phases frame the agenda program development. Changes began dramatically with a rapid, highly visable reorientation of the program. Less dramatic, stabilizing influences have accumulated since the redesign.

People with developmental disabilities moved from living in group homes to a variety of living arrangements throughout their community. They have grown from isolation toward community membership. Staff roles changed from providing group home clients with programming to assisting people living in their neighborhoods and community. Staff relationships shifted from supervising groups to supporting individuals. The program mission changed from operating residential programs to supporting people in their own homes, increasing people's ability to manage their own situations independently, and increasing people's interdependence with others who offer companionship and friendship without pay.**

This change —described by one staff member as "turning everything inside out"— generated high levels of energy.

- → A strong vision, clearly linked to the interests of the people RSP supports, animated the effort.
- → The vision grew in validity as many people with developmental disabilities grew rapidly in response to new relationships with staff, new expectations, and new surroundings.
- → Staff and the people they support got used to making rapid adaptions as new kinds of problems arose.
- → There were external threats from skeptical staff in other parts of CDSI, from some family members, and from funders and

regulators uncertain about how to fit the new design into their schemes.

- → People from other places were (and are) excited to hear about and come see the changes.
- Many people developed the kind of closeness that comes from pitching in together to create positive outcomes in uncertain circumstances.

Jay Klein's charismatic leadership style fit the demands of rapid change. Staff people reflecting on this period describe his ability to communicate a positive vision, his capacity to generate commitment, and his problem solving skill as central to their success. "He brought us along," said one staff member, "he always knows what to do next and how to get the best from everyone."

Phase 2: Stabilization



Significant changes continue for many of the people RSP assists. But the program as a whole has grown more stable as the effects of a number of less visible organizational changes accumulate.

- The program has moved from several funding sources to near total reliance on funds designated for Personal Care Alternatives (PCA) under a Medicaid waiver administered by the Colorado Department of Developmental Disabilities. State use of the PCA waiver has grown rapidly. CDS use of these funds has increased RSP income significantly, and much of the increase is reflected in staff salaries. However, requirements, and regulations and increased paper accountability are catching up to early adopters like RSP, limiting the flexibility available when the PCA program was small and new.
- As part of negotiations for better funding, RSP accepted the Division of Developmental Disabilities condition that RSP take responsibility for deinstitutionalizing a group of people with significant needs. This meant working fast to provide for people who were little known to RSP staff.
- RSP removed a number of people who had been receiving minimal support from its rolls.
- The program was restructured. Staff were organized into

Settling Down 2

two teams, with team leaders and the program director forming the RSP management team. Overall, staff salaries increased. An intermediate level of supervision was eliminated and some staff assumed specialist, non-supervisory responsibilities for additional pay. Two staff (known as "connectors") were assigned responsibility to assist a small group of people to make friends and join community associations.

- As RSP has changed, tension has grown within CDSI between RSP and Adult Services and Case Management. RSP staff have become increasingly frustrated with the work opportunities available to the people they support. And, as RSP staff have taken more responsibility for individual planning and assisting people with using other community opportunities and services, conflicts with the role and function of case managers increase. RSP staff tend to view these conflicts as evidence of lack of commitment by other CDSI employees. Case Managers and Adult Service workers tend to view RSP staff as elitist and unwilling to cooperate because they claim to possess superior values. So far, CDSI's management group has been unable to deal constructively with these tensions, which involve not just priorities but fundamental debate about CDSI's mission and service designs. This leaves the organization polarized, RSP staff isolated within it, and most of the people RSP supports without adequate work opportunities. Chronic tension stabilizes RSP by maintaining unresolved problems and providing staff in all three programs with people to blame for the problems.
- RSP changed its practice of staff setting their own schedules based on their judgments of people's needs. Some staff didn't offer assistance at the time and in the amounts necessary. Some staff felt overburdened by the combination of support activities and increasing paperwork and meetings. In response, RSP adopted uniform scheduling rules for staff. These rules provide clear, formal expectations about the amount of time staff spend in contact with the people RSP supports and allows scheduled time for paperwork, meetings, and other responsibilities. Despite the formal quota, many staff say they spend substantial unscheduled time with people. Sometimes this is because of emergencies, but often people meet after working hours out of friendship.

- Jay Klein spends an increasing amount of his time on external activities. Some relate to influencing CDSI and the state Division of Developmental Disabilities to insure that RSP will have the funds and flexibility to continue. Others arise from communicating RSP's vision and experiences to people in other states. Many staff see these activities as important to RSP's mission, but they regret the loss of Jay's direct engagement with their work.
- The staff has almost doubled in size and there has been a modest staff turnover (not more than 20% a year in the past 2.5 years). So an increasing number of staff did not form their sense of RSP's mission by working through the phase one changes. Instead they rely on RSP's process of orientation and staff support to understand their mission and the people they support.

These stabilizing forces increase the proportion of people with substantial support needs and the proportion of staff and people with disabilities who don't know one another very well. They also make RSP more formal and increase the bureaucratic content of staff work. Divisions of responsibility for tasks have become more explicit. This increases concern for the boundaries of people's roles and leaves some staff with a sense that their opportunities for growth and promotion are limited because others have responsibility for the most valued tasks. The program director seems at times to be more distant, less accessible, and more of a manager and a go-between with outside bureaucracies than an engaged member of the staff group. Teams become both the place for increasing amounts of organizational work and the place where the feelings that have animated the changes can be recollected.

Settling Down 4

Achievements

In three and a half years, changes in RSP have assisted significant changes for the people who rely on it.

- Many people live in nice places with people they choose to live with.
- Three people hold mortgages on their own homes and about half the people rent their own places in their own names.
- There are significant signs of a sense of ownership, even among the people who don't hold their own lease. Many people are proud of their homes and their furnishings. Most people seem to feel good about the privacy and personal space they have. Many people seem comfortable in their homes and in their neighborhoods.
- An increasing number of people have made new friends in the community and have become members of various community associations and participants in a wide variety of community settings.
- People make more choices and many have more control over their daily lives.
- Many people have a growing number of others who know them, are attentive to their capacities, are willing to identify with them, and are concerned for their future.
- Several people have painful personal histories which have resulted in behavior that is challenging to understand and deal with. Most staff respond to most of these people with constructive effort to understand them and reduce the circumstances that contribute to their difficulties.
- A number of people have strong friendships with staff members, and often also have good relationships with staff member's families and friends.
- ✤ A number of people have benefitted from creative everyday problem solving by staff.
- A number of people have benefitted from staff who have been tenacious in seeking benefits, information, services, and opportunities for them.

These achievements result from the joint effort of the people RSP supports and RSP staff. Given opportunity and committed support, people who were judged to "need" life long services in congregate settings have clearly demonstrated how poorly their interests and abilities were understood. Five characteristics of RSP seem to account for the extent of change in people's situations:

- → The successful redesign of the program focuses most available resources on supporting individual people in their choice of homes. (Poverty, the lack of functionally accessible housing, and deficiencies in local arrangements for personal care attendants severely constrain the range of most people's choices. But, unlike typical residential programs, RSP does not constrain people's choice of homes by its design.)
- → A vision of communities that include all people in positive ways animates RSP. Most staff clearly and strongly believe that community life and community participation are everyone's right, regardless of the severity of a person's disability.
- → RSP maintains open organizational boundaries. The program director has sought advice and assistance for himself and the rest of the staff from a number of people identified with missions consistent with RSP's. And RSP welcomes people who want to see their work at first hand.
- → RSP staff have a sense of themselves as a cohesive team pioneering important new approaches in hostile territory.
- Staff people combine personal commitment with practical knowledge. Unencumbered by clinical perspectives and professional procedures, many staff want to do "whatever it takes" to support people.

Settling Down

In response to a question about her future, one person RSP assists said,

"I've got a nice place now; so for a while I'll just be settling down."

This makes a good headline for the developmental work we identify as essential to RSP's future effectiveness.

Settling down is less exciting than making a big move. It involves developing routines to support a good quality of day-today life. People and places become familiar. Changes come less frequently and usually in smaller increments. Awareness of novelty quiets. It takes some extra effort to identify potential problems before they get too big and to recognize opportunities before they pass by.

Settling down doesn't mean sitting back. Everyday and every week, a bit of work done maintains order; undone it invites disarray. Order gives some leisure to fix the place up and to cultivate personal interests.

Settling down doesn't mean staying in alone. Maintaining safety and comfort makes a stable base to go out from and a welcome place to return. Being settled makes offering hospitality more graceful.

Settling down makes a good theme for the next phase of RSP's development for two closely related reasons.

First, RSP follows a vision of the commonplace. What staff and the people they assist work so hard to attain and maintain is ordinary: a home of one's own and a place in the everyday life of one's community. It takes effort because people who require substantial extra assistance due to disability face pervasive devaluation through inaccurate perceptions and unjust treatment masked by paternalism and professionalism. Despite obstacles, many of the people RSP supports are becoming established; many have begun to find their place; none are secure without assistants who remain committed to learning better how to support them day in day out.

settle down , to become established after wandering or movement or restlessness. -Concise Oxford Dictionary

It's what people want

Settling Down 7

The program's challenge

Second, the people who constitute RSP face the challenges of settling down as an organization. This is a dangerous metaphor: it may sound like we are joining the chorus of skeptics who say, "Grow up, you can't make this vision real." But we mean to say the opposite. The challenge of settling down as an organization is to develop the leadership to make RSP's vision real day-to-day.

Meeting this challenge means recognizing that stabilizing forces already strongly influence daily performance in ways that threaten RSP staff's capacity to realize their vision. When statements about vision substitute for daily action informed by vision, program staff either live in a dream or in cynical detachment. The people RSP supports don't need cynicism and they don't need staff who live in a dream. They need concentrated, continuing effort by staff to discover and live their dreams with them.

Learning is the way

Learning from and with the people who rely on RSP through everyday problem solving is both the way to better serve people's interests and the way to meet the program's challenge. Learning to implement RSP's vision means continuously improving effectiveness in four dimensions of the relationship between staff and each person they support:

- ✓ Getting better at listening to the person about what works in daily life. Finding ways to look at and evaluate situations from the person's point of view.
- ✓ Offering the routine assistance the person needs to maintain a dignified, secure, and comfortable home life.
- Discovering the person's interests and sense of a positive long term future.
- ✓ Allying with the person to make opportunities to move toward a desirable personal future.

This ongoing learning organizes staff time and defines program structure and procedures. Without learning from action and reflection with real people in everyday situations, RSP risks becoming frozen by hunting for new structures and new procedures and new fads in reaction to problems. The process of learning, and the proper relationship with new ideas from outside, can be depicted simply:



Learning begins from engagement in action with the people RSP supports. It proceeds when those involved take time out...

- ... to look again at some aspect of what has happened
- ... to think about how to deepen understanding of the person in relation to the community and how to improve the effectiveness of their efforts to make positive changes
- ... perhaps to get some new ideas from others
 - ... to plan the next steps

and then to act again with people on what they have discovered.

The Role of Program Managers

Such learning cycles, repeated many times, will increase RSP's realization of its vision if and only if the vision guides those decisions that shape the process of action and reflection. The primary task of RSP's team leaders is to insure that RSP's vision is alive as they assist staff to learn from their everyday experience. New staff and staff with performance problems particularly need explicit guidance in relating RSP's vision to their day-to-day work.

Leadership for Development

Settling down to realize RSP's vision day-by-day requires a different understanding of leadership than the understanding of leadership that shaped the first phase of RSP's change. Rapid, dramatic change formed the sense that leadership rests in one person who inspires commitment to extraordinary cooperative performance, wins and protects necessary resources by virtue of compelling values, and guides the organization from superior insight, knowledge, skill, and energy. This is a popular understanding of leadership and reflects how RSP staff describe the way Jay Klein vigorously applied his personal gifts in initiating and managing the first phase of change.

This understanding of leadership blocks the development of RSP's capacity. It reinforces the expectation that one exceptional person will always have to provide the necessary leadership. This makes it hard for many people to see themselves as capable of leadership and increases anxiety that the leader's departure would destroy the effort. This understanding of leadership also encourages people to accumulate disappointments about the performance of their leader when things don't seem to be going right ("He's the reason for the success; he must be letting us down somehow.") Finally, this understanding limits the way people understand the next steps, because it makes it hard to see that what made things work in the past had at least as much to do with conditions of the initial change situation as with the leader's personality. But conditions have changed.



Past understanding won't work for the future

Settling Down 10

	Initial change phase	Now
Staff numbers	Small (9)	Doubled (20 plus people paid by purchase of service)
<u>Goals</u>	Ambitious but clear (move a group of people from group homes to their own homes)	More complex because more individualized and based on better personal knowledge and higher expectations
<u>Timescales</u>	Short term	Longer (lifelong assistance for many people & more goals that will take a long time for people to achieve)
<u>Problems</u>	Challenging but novel and an- swerable (find housing; help people solve the problems of moving in)	While some problems with clear answers remain, more often the problems with the most potential benefit are complex, challenging, and sometimes ambiguous
<u>Barriers</u>	Barriers mostly "out there"; external "enemies" a source of energy	Though many external bar- riers exist, a growing number arise from RSP itself, e.g. consequences of decisions, limits on ability to understand, problem solve, advocate
<u>Rewards</u>	Quickly visible; RSP staff contribution clear & primary	Slower in coming; more the product of person & friends & community members with RSP staff assistance
RSP position in larger systems	Innovator of whom no one has previously expected much beyond ordinary residential programming	For other program components of CDSI: revenue source; irritant to be isolated; For state system: one vendor in PCA program; For service reformers in many places; model demonstration of important future directions

A new understanding of leadership

The shift suggested by this list of changes can't be managed by hoping that a single leader will recover the power to make things work smoothly again. This shift calls for a new understanding of leadership as a shared responsibility. In this understanding,*

leadership means mobilizing people's resources to make progress on the difficult problems arising from making vision real

Many of the problems of making RSP's vision real, day-to-day are difficult because:

- People who control necessary parts of the solution often don't share the same definition of the problem. For example, a person with a disability may define the problem as getting a job and a vocational provider may define the same problem as developing basic prerequisite skills. Problems are difficult when definitions must be negotiated among people with different understandings.
- Many problems come mixed up in each other. They don't yield to the common sense advice to break a complicated problem down into small, manageable problems. For example, RSP increases limited funds by taking a management fee from a housing agency. But this fee requires that CDS lease and sub-let property, thus limiting RSP's accomplishment of its mission to support people in homes of their own. Problems are difficult when their solutions are tightly linked to other important problems.
- RSP's work pushes the edges of the field. Very few people have been where RSP is going; so there are fewer and fewer ready made solutions to borrow as time goes on. Problems are difficult when responses must be invented rather than simply selected from a menu of proven solutions.
- Many times RSP staff must respond to situations that stimulate strong emotions. Strong emotions create pressure to avoid the situation. Problems are difficult when people understandably feel a pressure to avoid them.

Understood this way, anyone contributes to the program leadership when performing the activities that enable people to face and deal with difficult problems. Leadership does not flow from organizational role or personal charisma but from willing-

^{*} To read about this way of thinking about leadership, see Heifetz, R.A. & Sinder, R.M. (1988). Political leadership: Managing the public's problem solving. In R.B. Reich, ed. *The power of public ideas*. Cambridge, MA:Ballinger.

ness to engage self and others in the daily learning necessary to provide better assistance to the people who rely on RSP.

Of course, RSP needs a variety of administrative tasks done. These necessary tasks, and the authority to perform them, go with the team leaders' and program director's jobs. They are responsible for preparing, negotiating, and implementing the program plans and budgets; making sure that required paperwork gets done; and managing relationships with external service agencies. Some parts of these administrative tasks may be delegated and other staff may provide advice or participate in decisions, but program managers remain accountable.

The three program managers have five administrative responsibilities that offer daily opportunities to contribute leadership:

- In hiring, orienting, training, and evaluating new employees
- In assisting staff to develop, implement, and review individual plans and schedules
- In reviewing the quality of support people receive and insuring people's safety
- In supervising staff as they develop responses to crises and ways to deal with barriers to implementing individual plans
- In managing the program's investments in innovation (presently the investment of two full time staff in the role of "connectors")

The program managers can lead as they exercise these responsibilities through the daily administrative routines of meetings, appointments, and supervisory conferences. They do so when they take responsibility for...

...RSP's vision, by interpreting situations in terms of the vision and encouraging others to do so (for example, by asking an individual planning group "Can we come up with a way to offer toileting assistance that contributes more to the person's sense of control and dignity?")

...the learning process by asking people to take time to stop, look back at what has been happening, think about it, and plan some action; and then following up to insure that actions that get planned get triedin action

Settling Down 13

...RSP's learning themes by insuring that each staff member, and each team, continuously improve their ability to look at situations from the point of view of the person they assist, to offer needed routine assistance effectively, to understand personal futures, and to ally with people to create opportunities

...linking people to other resources among RSP staff and to outside resource people

Leadership happens through these administrative processes because of who Janelle, DeLayne, and Jay are as people in the organization, not because of their role as managers. This means that they need to be in regular personal contact with the people RSP assists, working for themselves on RSP's learning agenda. Staff are responsible for making decisions about the assistance they provide, and managers shouldn't be interfering, second guessing, or getting pushed into acting as answer people. But, to contribute leadership, managers need to be personally engaged in the lives of the people staff are assisting. There is no alternative to sustained, day-to-day, personal involvement.

An Agenda for Settling Down

The risk is to try to simplify life when, 1) life is never simple;

2) life certainly isn't simple when you have a disability

-Bob Williams

RSP has moved rapidly toward the state of the art in providing residential support. But, as one team member observed, "The state of the art is still a very long way from what's desirable for people." This agenda suggests several difficult problems which we believe define RSP's next phase of development. The quality of engagement with this agenda will define the character of RSP, the capacity of its staff, and the life chances of the people who rely on it for assistance.

Deepening Understanding of RSP's Mission The Agenda for Development			
Direct focus on the people	Focus on RSP's organiza-		
RSP supports	tional capacities		
Move everyone into homes in the community	Face constraints in new ways.		
Remember people's vulnera-	Organize for greater accounta-		
bility	bility to each person		

Ironically, many of the problems RSP now faces reflect the strengths that have led to its current accomplishments. Resolving these problems means facing the darker side of RSP's strengths and developing complementary capacities.

Settling Down 15

Move Everyone Into Community Homes

For a few people, the first phase of change had not happened at the time of our visit.* RSP placed them in congregate, virtually institutional settings where they have remained for months.

Although not in homes in their community, these people have clearly benefitted from RSP's assistance:

- They have expanding opportunities for community involvement
- They have help to get necessary equipment
- They have people to monitor and try (sometimes unsuccessfully) to make the medicalized attendant care system they must rely on more accountable and responsive
- They have people who are concerned about them and their future.

But they don't yet have a dignified, secure, comfortable home.

Remember People's Vulnerability

The people RSP assists are both capable and vulnerable. They can live successfully in their own homes, make friends, take part in the life of their community, and express choices. They risk having a lack of allies and getting inadequate assistance with the individual consequences of disability.

RSP has developed a service design that builds on people's capacities. Instead of using people's need for assistance to justify congregate living, RSP takes responsibility for offering necessary assistance to people in their own homes and neighborhoods. Celebrating and supporting people's desires and abilities gives life to RSP's work. But the work cannot be sustained without remembering people's vulnerabilities.

* By August 1989, five of the six people in one of these settings have moved. The sixth person chooses to remain unless a friend decides to move with him.

Settling Down 16

Confronting isolation & lack of power

Without competent allies, the people RSP supports cannot achieve or maintain good lives. And strong alliances don't usually come easily...

- ... the socially devalued status of people with disabilities makes it difficult for many people to identify with their personal interests and aspirations
- ... the enduring, even life long, nature of some of people's difficulties frustrates the desire for quick and final answers
- ... the relentless unresponsiveness of many of the systems people rely on discourages initiative

Many RSP staff work hard and effectively at helping people to develop and maintain a variety of positive social relationships. As a result, many of the people RSP supports benefit from a growing number of companions and acquaintances. Many have also become members of community associations and regulars in less formal community settings like restaurants, stores, and taverns. Staff call this vital work "making connections."

Making connections doesn't necessary develop the kind of friendships that give people competent allies, though it is worthwhile for many other reasons. RSP staff provide crucial assistance when they increase and celebrate the variety of people's connections. But they can't let talk about "connections" -a necessary term in their jargon- obscure plain words like friendship. It's good to have someone to share a meal or an activity with, but that person might not be a strong ally.

Each person needs RSP to ask a basic question and deal with the consequences of the answer:

Who stands with this person over time, and, when necessary, fights to defend or promote this person's best interests?

Stronger ties with families

Some people's family members are their strongest allies. RSP staff have worked to maintain and reestablish family relationships for some people who had lost contact. In consequence, staff face difficult problems when family members have unduly negative expectations of their relative's abilities or seem to lack respect for their relative's clear choices. Learning more about how extend people's family membership and renew relatives' sense of capacity and hope provides one key to confronting people's lack of allies. Another key lies in creating ways to negotiate differences between people with disabilities and family members. When differences become hard to resolve -or when RSP staff feel afraid to confront them- it might help to recruit someone outside RSP who can structure ways to resolve conflicts.

Acknowledging staff relationships

Several staff people identify some of the people RSP supports as friends and include them in their personal life outside of work. Staff share their homes with people. A number of staff have sustained good relationships with people for years. Sometimes these good relationships mean that an RSP staff member has a strong personal commitment, perhaps the only strong personal commitment in a person's life. This is both good and confusing:

- Friendships have a different emotional and practical rhythm than formal staff relationships do. Friendships unfold by choice. As time goes by, friends become more deeply involved and move away from one another; they enjoy one another more and can disappoint and anger one another. It can be hard to know what a staff person owes someone RSP assists as part of the job and what is given out of friendship and therefore depends on the staff person's individual, moment to moment choice.
- Boundaries between work and home life blur. Spouses and children may sometimes feel that their partner or parent is always working.
- Those staff people who have deep and genuine relationships with people can find organizational processes confusing.
 - Organizational decision making is can be complicated when someone speaks both as a friend and a team coordinator, a team member, or a member of another team.

Settling Down 18

- Limits on assistance which might seem organizationally necessary may seem intolerable to impose on a friend.
- When should the opinion of a friend have greater weight in discussion?
- What effects do friendships have on the allocation of program resources?
- Being a staff member doesn't immunize a friend or an ally from error, any more than being a parent or a best friend from school days does. But a person who relies on someone who is both a provider of necessary services and a friend faces a very difficult situation when that person fails to act in their best interest.
- Because of their history of segregation, some people have nobody but a staff person who cares at all. This can inflate the importance of the staff person's commitment beyond the depth of the relationship either person feels.
- Friendship with the people RSP serves may become an organizational norm. Staff may feel in the bind of being obliged to be friends and thus presume a deeper relationship than actual time together or mutual inclination would support.
- Friendships with staff members are currently devalued from two opposing sides of the human services field. Many professionals believe that friendship violates the objective conditions necessary to perform properly. And some human service critics suggest that friendship is impossible in the context of a paid service relationship. This may leave some staff uneasy with their positive feelings.

Dealing constructively with the fact that some people have no one but a staff member as their ally begins with open acknowledgement of the fact, followed by discussion of the effects of the relationship on the way the RSP works to assist the person involved. Recognizing these relationships as both a source of strength and a source of strain will make it easier to notice and deal with opportunities and problems as they arise. Each person with a staff friend has the opportunity to build on that good relationship to deepen their relationships with others. People with close relationships to a roommate

A few roommates have such close relationships that they present themselves as couples. As many staff know from personal experience, couple relationships offer the possibility of intense emotional and practical support as well as the possibility of stifling dependency and great emotional pain.

Couples have a strong boundary around them. Staff sometimes decide not to respect that boundary. For example, they require one member of a couple to perform domestic tasks both she and her partner prefer that he do for the two of them. Staff's reason -that the person should be independent in these tasks- might be sound. But the situation needs careful consideration.

Many people feel safer and stronger as one of a couple. Witness the difficulty most people have leaving relationships, even when they are very trying. These important relationships become more complex when the members of the couple need substantial daily assistance from staff who may not agree that the couple's choice of one another is a wise one. And the complexity is compounded when parents disapprove of the relationship and expect staff to see it as a problem.

Couple relationships challenge RSP to improve staff ability to look at situations from the point of view of the people they serve. Careful listening to both people and careful thought should go into deciding how to best to support each couple and each of the people in a couple.

Supporting people who have no allies

Some people have no one to stand with them and be their ally through their lives. RSP can't manufacture friends and allies, but staff can take some action to confront the situation:

- It's critical to acknowledge the person's situation. Staff should fight the pressure to avoid the reality of a person's isolation by assuming that roommates are necessarily friends, or that companions will necessarily be allies, or that people who agree to join a person's circle will necessarily take the time to get to know and care about the person.
- Someone with no allies requires special attention from program managers to insure the effectiveness of the assistance they rely on. Program managers don't need to be

Settling Down 20

"surrogate friends," they simply need to insure that effective help is responsibly provided by people who are working everyday to understand situations from the point of view of the people they assist.

- It is easy to lose the history of an isolated person unless someone systematically assists the person's ability to remember or communicate the past. Efforts to recover and remember a persons history are important in themselves and sometimes lead to renewed contacts with important people from the person's past.
- In difficult times, and when people are difficult to like, staff need to think carefully about how to live up to their mission with an isolated person. An isolated person who is hospitalized or at risk of going to jail needs extra effort to contribute to protection.
- There is much more to learn about inviting and nurturing committed friendships with those a person meets by becoming better connected to community people and activities.
 - Where do we look for connections for someone who is isolated? Who might be likely to have the competence and desire to get to know this person?
 - Some people begin a lasting commitment to a person with a disability when they respond to an emergency situation or a clear need for practical help. How do we offer people the chance to be involved when someone faces a crisis or when they need help moving or finding a job?
 - How can we be sensitive to the roles the isolated person has the opportunity to take in new places. For example, being a regular customer in a cafe leads easily to recognition and possibly to companionship. But it may not lead toward closer friendship or someone to count on. What roles might make a person's unique gifts evident?
 - How can we assist a person who is isolated to take action on their own behalf to bring people closer? For instance, how can we insure that someone who has difficulty has an effective communication system?
 - How can we encourage someone who is friendly to an isolated person to make a commitment to that person's future? In doing so, do we need to help the potential ally understand the person's situation? How do we do that

without taking over the relationship?

- How do we deal with the discomfort we may feel from taking an unusual social role, that of match maker or go between? How do we manage the strange feeling that we are purposely doing something that typically happens spontaneously?
- How do we keep from confusing activities (like circle building or personal futures planning) with what we want for people: friends who are allies?
- How do we deal with our own impatience and fear for isolated people so that we allow the time it takes for many relationships to develop?

Better response to people's disabilities

Professional domination arising from negative stereotypes and resulting in low expectations and fixation on deficiencies hurts each of the people RSP assists. RSP's focus on supporting each person to have a home builds the program on each person's capacities, challenges both staff and the people they support with high expectations, and offers each person who is effectively supported a valued social role.

This program focus offers a positive context to understand the practical consequences of each person's disability.

More skilled assistance

* We identified specific situations in discussion during our visit. A team member with relevant expertise was scheduled to return soon after our visit for consultation around specific people with severe physical disabilities. We believe that some of the people RSP assists would benefit from more skilled help with mobility, communication, and the management of everyday physical health. Indeed, we see some risks if RSP does not improve assistance to several people.* Others would gain from systematic opportunities to learn relevant skills. Still other people, who struggle with difficult emotional and behavioral challenges, need all the staff who work with them to maintain consistently high levels of skill in listening and responding to their situations.

Some of RSP's strengths become barriers to offering more skilled assistance when they lead to denial of the reality of disability as one part among many of people's daily experience.

• Rejection of the notion of training for readiness, and the

Settling Down 22

remarkable changes that many people have made after changes in opportunities, keeps staff from developing the skills they will need to teach those people who could improve their situation as a result of systematic instruction.

- Trust in the abilities of ordinary citizens, and criticism of professionalism, results in inadequate attention to orienting new staff and training staff in useful skills drawn from professional repertoires.
- To only focus on people's capacities can lead to inaccurate descriptions of the daily challenges people must live with. Inaccurate descriptions lead to incomplete plans and ineffective responses.
- Understanding the stigmatizing effects of negative stereotypes leads some staff to feel that descriptions of a particular person's very difficult or socially unacceptable behavior are unhelpful. But some people's appearance or behavior contributes to their negative reputation.

Of course, the next step is not to give up these strengths but to complement them. People should have opportunities without waiting to be ready *and* some people will benefit from systematic instruction. Ordinary people have much to give *but* some ordinary people apply pop psychological theories to people who struggle with life-long wounds. Many professionals have served people poorly *and* some professionals have useful skills to transfer to RSP staff.

To increase RSP's skill in helping people:

- Each person needs the opportunity, and the assistance necessary, to make a clear statement to staff assigned to help about the practical, everyday consequences of disability as the person experiences it. This statement includes the person's individual preferences about how assistance is offered. Some people will express their preferences in words, others through staff memory of their positive and negative responses to different approaches.
- ⇒ Each person RSP hires or compensates to assist a person can be oriented by the primary staff person. If the person wants to orient his or her own assistant, the primary person should help as necessary. The way new assistants or roommates are oriented can be reviewed in detail by the team

leaders to insure that orientation is accurate, complete, and positive.

- Based on a review of what works, what doesn't work, and what is uncertain for every person it serves, each team can implement a plan for skill development linked to meeting specific day-to-day needs. We imagine that some staff will want opportunities to learn more about how to teach systematically; others will want support in listening and responding to people who experience great emotional pain; others will want to know more about insuring that people get and use equipment and adaptions that will improve their control and competence.
- Each person who assists or lives with a person RSP supports can have regular conversations to review what's working and what needs improvement in the provision of day-to-day assistance. People who are new can have very frequent conversations with the person who has primary responsibility or the team coordinator; so can people who are involved with a person in crisis.
- When a person is unable to train and supervise assistants, staff can help the person to do so. Staff who are more skilled in providing specialized assistance can take assigned responsibility to teach others. Teaching can be direct and hands-on, with the teacher responsible for certifying competence based on repeated direct observation.
- The changing situation of people whose health is declining be regularly and carefully reviewed.

⇒ Involved staff can work to understand people's health

problems.

To improve and communicate understanding of what works to assist people, staff can develop a record of what people have achieved and what types of assistance worked to support achievements.

Deeper understanding of choice

Service programs frequently deny personal choice. Other's refusal to attend to daily expressions of choice dispirits people and encourages rebellion or withdrawal. In opposition to this common practice, RSP makes choice a major theme in its relationship with the people it assists.

Reflection on choice reveals critical opportunities for deeper understanding of the people RSP serves.

- Poverty and by the impoverishing effects of the policies under which they receive essential assistance restrict most people's choices severely.
- A history of negative and painful experiences impairs some people's ability to choose.
- Restricted experience of the rewards of many common life experiences limits some people's choices.
- Disabilities in understanding the nature of situations constricts some choices for some people.

None of these constraints on personal choice justify imposing blanket restrictions or withholding the opportunities people deserve. But they do point to important issues for RSP staff to consider.

- Choice is not a reason for a person to live in an unsafe place.
- Choice is not a reason for a person to live in filth.
- Choice is not a reason for a person to smell bad.
- Choice is not a reason for a person to inflict self-harm.

Respecting choice cannot mean avoiding personal engagement when a vulnerable person who is incompetent to some degree acts detrimentally. In these circumstances, RSP staff need to look for ways to understand their role in the situation that will lead to a stronger alliance with the person involved and thus increase their ability to influence the person.

We do not suggest engagement in influencing the person because it always works but because we see it as the most respectful posture staff can take.

To better understand issues related to choice:

- Each team can list the ways in which team members currently restricts people's choices. In making the list, pay attention to...
 - ...any areas in which a team member feels involved in a power struggle with a person the team assists
 - ...approaches that seem to work to influence people and which of these seem respectful
 - ...people over whom the team exercise a great deal of control either by what team members do or by what team members do not do
 - ...crisis or emergency situations to see how decision making happens and what effects there are on personal choice
- Each team can describe all the situations that worry any team member because the person seems unsafe or because the person seems to significantly jeopardize quality of life. In discussing these situations...
 - ...acknowledge but rule out of the discussion statements that explain the situation away by promoting the idea that "it's none of our business because its the person's choice"
 - ...acknowledge and rule out statements that leave team members powerless by saying that the person is "unmotivated" to do any different
 - ...acknowledge and rule out statements that justify disengagement by suggesting that "taking the natural consequences" will teach the person
- When the team identifies a situation in which a person is unsafe, members can look for alternative ways to influence the situation positively. Consider the possible contributions staff may be making to the undesirable situation as well as

Settling Down 26

options for forming a stronger alliance with the person.

Attention to the principle of normalization

The principle of normalization holds important lessons for RSP staff, especially newer staff.

- Careful study of the likely long term effects of congregation of socially devalued people would lead RSP staff to reconsider the desirability of locating housing for people in congregate facilities for elders or an apartment complex which houses a large proportion of socially stigmatized people.
- Consideration of the importance of actively and consistently promoting age and culturally valued personal appearance as a facilitator of good relationships would lead some staff to increase their efforts to help people present themselves positively.

These and other normalization related issues may seem to some staff to be trivial or in competition with personal choice or in themselves devaluing of people with disabilities. If this is so, it is all the more reason to make them the subject of discussion and debate.

Maintaining the spirit

People with disabilities are vulnerable in subtle ways. The notion of people with disabilities as the object of control through the programming of all interactions pervades the field. We are concerned that RSP staff could loose the spirit of their mission to the pressure to program.

For example, when number of relationships becomes a way of keeping score, those people with few connections are at risk of being diagnosed as deficient and in need of a relationship building program as a remedy. Because space in the official relationship building program is limited, people go on a sort of internal waiting list for the service necessary to overcome their problem.

The problem in this example is not with careful work to help people meet other people. The problem lies in understanding the person as the object of professional work and treating the person as a client whose treatment consists of doses of friendship rather than does of medicine. The challenge for RSP is continual renewal. Renewal grows from daily experience with people and enlivens staff commitment to identify with the people they serve and to offer assistance because of their alliance with them.

Face Constraints in New Ways

RSP changed by taking fast action despite constraints and counting on it's adaptability and position as an innovator to deal with problems arising from changes. This high risk tactic worked to achieve program redesign. However, the constraints on RSP's future development call for different approaches which offer the opportunity for greater collaboration, community development, and broader involvement of people with disabilities in the political life of their community and state.*

Modify program beliefs

Dealing better with these constraints begins with RSP staff acknowledging the reality of constraints and their continuing negative effects on RSP's ability to realize it's mission. Recognizing the stabilizing forces that influence the program strains two program norms that have been important in the RSP's development until now. The program has changed because...

...RSP staff act on the belief, "We do whatever it takes to support people in their own homes." This key attitude expresses an essential commitment. But it needs to grow stronger through the explicit recognition that sometimes whatever we can do isn't enough to overcome a constraint. This doesn't justify denial of responsibility, or reducing effort. It just means taking responsibility to become more strategic in dealing with constraints.

...RSP staff have taken strength from their conviction that, "We are the best. We know the people we support better than anyone else. We are consistently consistent in our values." RSP staff's talent and commitment show in significant changes in the lives of the people they support. But commitment needs to deepen even further to move beyond competition to recognition and nurturance of commitment and ability in some other service workers.

* The opportunities we identify shouldn't be read as recommendations but as possibilities to explore. Each opportunity has associated costs and risks that need discussion and more opportunities will be apparent to people familiar with the local situation.

We suggest that RSP's director model changing these norms by talking more openly about about RSP's missteps as well its achievements and by seeking advice on some situations from his local and state service colleagues.

Constraints arising from local conditions

Functionally accessible housing and transportation are ex-**Constraints** tremely scarce. Congregate housing controls the present housing market for people who need accessible homes. There is no personal assistance option that offers consumers (or their representatives) direct control of hiring, training, supervising, and firing assistants. Medical agency based attendant care dominates local provision of assistance for people with physical disabilities. \Rightarrow These serious community problems offer the opportunity for Opportunity coalition with others similarity disadvantaged: people with physical disabilities, parents of children with physical disabilities, elders, and people concerned about elderly family members. Some of the people RSP assists might want to participate in action to make necessary changes. Changing federal and legal mandates for more accessible housing and transit offer a chance to raise the issue on the local agenda. Weld County lacks effective, independent local advocacy. Constraint No organized group monitors RSP to insure that people move on schedule from temporary placement in congregate settings. No organized group holds CDSI accountable to provide supported employment to the people RSP assists. No advocate recruited and supported independently of CDSI represents the interests of people with severe disabilities and no active family members. **Opportunities** \Rightarrow As the major service provider in the county, CDSI can't set up or operate or fund advocacy efforts without compromising their independence. However, CDSI could raise the issue in the community by clearly stating its inability to offer people the representation they need, by asking community based funders to support independent advocacy efforts, by opening its programs to outside community monitoring,

and perhaps by contributing financially to a local effort to inform people about a variety of advocacy forms.

- ⇒ RSP could broaden its ability to identify and deal with problems by inviting community leaders to act as well informed advisers on key program decisions as well as on the effectiveness of staff response to difficult individual situations. It would be especially valuable for RSP to enlist some people with severe physical disabilities who value community living for all people.
- RSP staff could assist interested people to find out how to organize a local chapter of People First, perhaps beginning with a local presentation by experienced People First organizers. The program's ability to involve community members should make it easy to help people locate a advisers from outside the service system.

Constraints arising from the state system

Constraints

- Funds for personal assistance do not go directly to the people who use the assistance (or their representative).
- The PCA program is increasingly intrusive into people's lives. Many people capable of partial control of their personal finances have lost control of their money through implementation of PCA regulations intended to protect people from financial exploitation. Moreover, CDS collects "room and board" payments from program participants only to return the money to them in rent or mortgage payments.
- As applied to RSP, the rate setting mechanism results in a rate that is likely too low to sustain effective support over time for the RSP group as whole, given the level of support most people will continue to need.
- State level plans to move people out of institutions combine with the lack of other residential providers in Weld County to create a pressure on RSP to grow.

Opportunities

* This creates a dilemma. There is the danger exploiting people with disabilities and distorting friendships with community members to work on service system reform. There is equal danger of patronizing people by assuming disinterest or incapacity to deal with civic issues of personal concern. Drawing this delicate balance in individual situations might be further complicated if CDSI does not explicitly recognize an obligation to promote active citizenship among the people it serves, even if opinions or tactics are incompatible with agency priorities.

Constraints arising within CDSI

Constraint

Opportunities*

* These possibilities are obviously too easy for RSP or other CDSI staff to sabotage for us to offer them with confidence that they would work. We offer them because they seem like good and generous things to try in a situation that has become dysfunctional for the people RSP assists.

- Among the growing number of ordinary citizens who are getting to know and value the people RSP supports, there may be some people who would benefit from knowing about the dilemmas imposed by a state policy of dealing with resource scarcity by maximizing the number of people whose lives are controlled through medical assistance.
- Some of the people RSP assists might want to share their own stories and express their own opinions to decision makers.
- Some of the people RSP assists and some of the people who know them might want to join civic efforts to deal with statewide service issues.
- RSP's program director could look for different ways to join other residential providers who have similar concerns about the effects of the PCA program on their capacity to offer people good support. This might involve building or rebuilding relationships with people who feel competitive with him.
- Many of the people RSP supports want to work in community jobs and could do so if adequate support were available from Adult Services or from employers or co-workers. Most of these people are stuck in the inability of Adult Services to find them jobs and develop the supports they need. Their stuckness is compounded by competitiveness and mutual blaming among staff of different CDSI service programs and by the continuing inability of CDSI's management team to offer leadership in resolving what have become dysfunctional tensions.
- ⇒ RSP staff could experiment with reducing the blame they direct at staff of the CDSI programs that fail to provide appropriate support to the people they care about.
- Because the disadvantages of unemployment weigh heavily on the people RSP assists, avoiding blaming would be very hard to sustain unless CDSI's management exercised strong, visible leadership to identify and negotiate the many issues at stake. The situation has deteriorated to a

point that the management team probably can't resolve the issue within itself. Problem solving meetings between concerned staff and management from Adult Services, Case Management, and RSP are necessary. These meetings should be sustained over time and led by CDSI's executive director until the group has a record of successful collaborative problem solving.

- Some people RSP assists may be able to get and successfully keep jobs with the help of RSP staff, community members, employers, and co-workers. As of the time of our visit, CDSI's policy was to discourage RSP staff from finding and supporting jobs. This policy could be relaxed by RSP's Program Director on an individual basis if an RSP team were satisfied that adequate support were available outside Adult Services without compromising RSP's primary responsibility for residential support.
- RSP could do its part to reduce the perception that RSP staff believe that they alone among CDSI staff know and care for people by inviting individual staff from Adult Service and Case Management offer advice on a regular basis, outside conflict situations. Perhaps people from other programs might be invited, on the basis of their personal abilities, to join RSP's advisory group.

Organize for greater accountability to the person

Sustained, reliable assistance depends on the way RSP staff organize themselves. It takes continuous review to insure that the organization's structure and habits stay accountable to the people RSP assists. Without regular, critical discussion, the structure will dominate the people who rely on it. We think that RSP can grow if staff carefully examine two organizational issues: the job of the primary staff person and the role of the staff assigned as connectors.

RSP assigns a primary staff member to each Clarify the job of person. We think that each person would benefit if one staff primary staff member were accountable for... ... learning to understand the person's present needs, personal history, and future plans ...multiplying the person's power to deal with daily life and to create opportunities for a better personal future ... representing the person's interests in organizational decisions affecting the person's assistance Presently, most primary staff don't understand or do their job this way. Several organizational features fragment and dilute this basic responsibility. ■ In the interest of fairly distributing the workload, staff allocate small blocks of time to a number of people. For example, current schedules assign some staff members to ten people apiece. This fragments contact and makes it hard to see how a newly hired staff member could ever get to know a person well enough to confidently represent the person's interests.

> ■ Large numbers of involved staff also make it difficult for the primary person to actively coordinate the work of those who assist a person. This leaves people who have difficulty supervising their own helpers with no one to understand and represent their interests to the staff they rely on. Instead of

being a person to person negotiation, assistance is coordinated impersonally through scheduling a number of staff to perform particular tasks for the person. Schedules are usually negotiated in team meetings, for the whole group of people the team supports.

■ To provide for job enrichment and extra pay staff have assumed special responsibilities for particular tasks, some of which are closely related to people's support. For example one staff person specializes in managing the paperwork related to personal funds.

Many staff say that team coordinators make most important decisions regarding the person they are assigned. And a number of decisions are referred routinely to the program director. This pattern of decision making creates a reasonably tall bureaucratic structure in a very small organization. As some staff describe it, people sometimes wait while the team coordinator and the program director decide. They say decisions are sometimes delayed because the program director is so busy. This moves important decisions from those who are more engaged with the person to someone who presently has limited day-to-day contact.

Relatively small staff size and multiple necessary tasks make it hard for program managers to conclude that someone might not be able to be effective as a primary staff person. Indeed, it seems that some newly hired staff have assumed primary responsibility with very little orientation or time to get to know the person.

■ It may be difficult for direct service staff to represent a person's interests to other components of CDSI, which value position and status in negotiations.

PCA program requirements add another layer of complexity to taking responsibility for the person.

Increasing the responsibility of primary staff offers a path to development for RSP.

The fundamental question each team coordinator answers for each primary relationship is:

> What will it take for me to develop confidence that this staff person can assume responsibility to understand this person and represent this person's interests effectively?

- The team coordinator's responsibility is to develop the abilities of each primary staff person. Until sure that the person can do so, she will engage herself more with the person and talk very frequently with the staff member to support the staff member in developing personal identification, understanding, and capacity to solve problems from the person's point of view. Once she decides -in consultation with the person supported and the person's allies- that a staff member can assume primary responsibility, she can decrease direct contact with the person somewhat and hold somewhat less frequent supervisory discussions. Throughout, her role is to develop staff not to substitute for them.
- Team meetings take substantial time and can be regularly evaluated to insure that they work to support primary staff to understand and respond better to people and to coordinate the assistance a person needs from other team members.
- ⇒ Each of the specialist tasks assigned to staff can be evaluated by primary staff and team coordinators by asking...
 - ...has this person's assignment taken something out of the primary staff member's job that needs to be there to effectively serve the person?
 - ...what is the effect of this person's work on the primary staff member's ability to assist?
- Primary staff can contribute to the evaluation of team coordinators and the program director by describing the effects they have had on the primary staff member's ability to understand and represent the person.

Clarifying the connector's contribution RSP invests a bit more than one and and a half full time staff positions in the role of connectors. As the initiative was developed, these two staff have dual responsibilities: 1) to work on behalf of small groups of focus people to develop relationships and memberships; and, 2) to assist the rest of the RSP staff to become skillful in developing and supporting community connections.

As the connectors have learned about their first responsibility, the second aspect of their role — as explorers who improve the capacity of the whole staff — seems to have been lost.

- Connectors do not seem to function in the context of the teams they are linked to. They work more as independent practitioners, developing and implementing their own plans for people separately from the team.
- Connectors seem to make and act on judgements about people's future, sometimes without involving the person with primary responsibility.
- Some staff speak of the connectors as specially gifted people, who are able to do things that they never could.
- Some staff note that the connectors have a well focussed task for a relatively small number of people. They wonder how they can find the time to do the same kind of work on behalf of the people they work with.
- Some staff have helped people develop connections.

If the present pattern of work continues, we worry that a core part of the organization's mission will be cut out of most staff's jobs. People not assigned to connectors will end up waiting for a vacancy on their "caseload" (as more than one staff called the group of focus people). Important opportunities to expand the meaning and contribution of each staff person's job will go unexplored.

To shift the relationship between the connectors and the rest of the staff:

Conduct an internal evaluation of the connector's role including staff, focus people, and some of the people connectors have developed relationships with. Focus this

Settling Down 36

Manage emotional

pressures

evaluation on three questions:

- What have connectors accomplished for focus people, how did they do it, and how could their contribution be improved?
- What effects have connectors had on the community?
- What effects have the coordinators had on the work of the teams and the competence of other RSP staff and how could they improve their work as explorers and communicators?
- ⇒ Based on the internal evaluation, make a plan for the next year of the connectors' work. Decide whether the connector role as such will continue and how it will change.

RSP's work stimulates strong emotions: people's safety and people's future depend on staff decisions; staff have to manage complex human relationships across a variety of organizational boundaries; and many of the problems staff have to deal with don't have clear answers.

RSP needs strong leadership to confront four common ways the organization has learned to avoid the anxiety inherent in it's work:

- Blaming problems on external enemies whose vision and values are believed to be inferior.
- Depending on the program director to be able to almost magically solve problems and dissolve staff conflicts.
- Looking outside RSP and its local relationships as the primary source of ideas and problem solutions.
- Using statements of vision as a kind of stimulant to push staff over difficult situations.

When people blame, leaders will focus attention on RSP responsibility and on finding opportunities for collaboration or for reducing people's dependency on the problem source. When people expect the program director to have the magic fix, leaders will focus on the capacities of the whole RSP group, including both staff and the people they assist. When people reflex-

ively look up to seek the next new idea in service improvement, leaders will direct people's eyes down to the learning cycle and put new ideas from outside into their proper context. When people talk about vision, leaders will encourage specific discussion of how RSP's vision can help define and guide solution of everyday problems.

Settling Down 38

The Team Process

The evaluation team process was initiated by Jay Klein, Director of the Residential Support Program. Jay designed the evaluation collaboratively with CDSI staff and John O'Brien. He recruited team members who complement one another's experience in developing, managing, and assessing innovative vocational and residential service programs. Program staff nominated people they support and obtained their consent for team members to visit and interview them. Staff also developed a list of questions for the evaluation team's consideration

Evaluation team members interviewed more than half of the people the program supports, interviewed some family members, some case managers, some adult service staff, the CDSI executive director, and most residential staff. Open-ended interview questions focused on the person's perception of what is presently working to provide good support, what must be improved, and what the organization's agenda for development should be. Team members gathered information about the relationship between staff and the people they support both in day-to-day life and in work toward desirable personal futures. They also inquired about the way supervisory, team, and agency structure and process affect the quality of support.

Evaluation team members shared impressions and refined the inquiry at meetings during the two and a half days of inquiry. Then the evaluation team met for an extended discussion of their observations. From this discussion, the evaluation team defined issues critical to the continuing development of the program.

The team communicated with program staff and interested others in six ways.

- To insure timely exchange of information and suggestions about specific individual circumstances and to insure a good understanding of the limits and strengths of the team's process and conclusions, Jay Klein observed all of the team's meetings and made extensive notes on the team's perceptions and ideas for improvement.
- One team member with expertise in assisting people with

physical disabilities returned to the program to offer specific consultation.

- Two feedback sessions were held on the final afternoon of the evaluation team's visit. One, presented by Jan Nisbet and attended by a number of interested people, focused on CDSI's project to improve the effectiveness of work supports to several people who are jointly served by case management, adult services, and residential support services. The second, chaired by John O'Brien, involved the evaluation team with residential support staff and the CDSI Executive Director.
- A brief written report on the project to offer work opportunities to some of the people who rely on CDSI for twentyfour hour support is a companion to this one.
- This report presents the team's view of critical developmental work necessary to strengthen the residential support program.