DOCUMENT RESUME

ED 355 735

EC 301 992

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TITLE	"People Want the Same Things We All Do": The Story of the Area Agency in Dover, New Hampshire.
INSTITUTION	Syracuse Univ., NY. Center on Human Policy.
SPONS AGENCY	National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
PUB DATE	Aug 92
CONTRACT	H133B00003-90
NOTE	56p.
PUB TYPE	Reports - Descriptive (141)
EDRS PRICE	MF01/PC03 Plus Postage.
DESCRIPTORS	Advocacy; *Agency Role; Case Studies; Costs; Deinstitutionalization (of Disabled); *Developmental Disabilities; Group Homes; *Human Services; *Independent Living; Personal Autonomy; Program Development; *Program Implementation; Quality of Life
IDENTIFIERS	*New Hampshire (Strafford County)

ABSTRACT

This report describes the mission and programs of Developmental Services of Strafford County, Incorporated, one of 12 area agencies serving people with developmental disabilities in New Hampshire. The report specifically examines the agency's activities in the area of supportive living. It highlights the lives of four people, describes the two primary themes of developing community relationships and supporting what people want, discusses issues related to choice and self-advocacy, and provides an overview of issues in organizing to provide supportive living. Changes in the agency's agenda from that of placing formerly institutionalized persons in group homes to dismantling group homes and placing people in apartments and houses are traced. Four case studies describe the individuals' relationships, events, activities, and places important in their lives. The section on organizing to provide support focuses on staff selection and staff roles; the role of roommates and neighbors; case management and day programs; costs; and relationship with state agencies. (JDD)

"PEOPLE WANT THE SAME THINGS WE ALL DO": THE STORY OF THE AREA AGENCY IN DOVER, NEW HAMPSHIRE

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Julie Ann Racino

August 1992

This report is based on a qualitative research site visit conducted on October 22-24, 1991 to document good practices, issues and dilemmas. The preparation of this report was supported by the U.S. Department of Education and Rehabilitation Services, National Institute on Disability and Rehabilitation Research (NIDRR), under Cooperative Agreement H133B00003-90 awarded to the Center on Human Policy, School of Education, Syracuse University. The opinions expressed herein are solely those of the author and do not necessarily reflect the position of the U.S. Department of Education; therefore, no official endorsement should be inferred.

The author thanks Don Trites, Brian Blodgett, Ray Blodgett, Norman Tanner, Kim Frederix, Lynda McAtee, Bev Baker, Deirdre Watson, Robin Carlson, Sue Scott, David Ouelette, Sue Berube, Marjie Rhodes, Alan Blood and Linda Coggeshall for sharing their time and insights.

INTRODUCTION

> We share a similar vision: people belong in the community--[to] live, work, play, get married, have children--and our role is to provide the support for people to do the things they want to do. It is taken for granted that they want the same things that we do.

> Everybody is really clear about why we are here. We are here for the people we are supporting to help them get valued lives. We are here to help people achieve the same things we want out of life. And to help communities understand that these people aren't different just because they may look different or talk differently.

These words of staff members describe the mission and purpose of Developmental Services of Strafford County, Inc., one of twelve area agencies in the strongly Republican state of New Hampshire. Founded in 1982 when virtually no community services existed in the state for people with developmental disabilities, the agency currently supports 180 people in a variety of ways in the region's communities. It is the primary developmental disabilities services and case management provider in this county.

This agency was nominated as a good example in New Hampshire of "supportive living," and this case study will concentrate primarily on this area. After highlighting the lives of four people, the study briefly describes the two primary themes of community relationships and places and supporting what people want. It also discusses issues related to choice, and ends with an overview of mechanistic issues in organizing to provide support.

Developmental Services for Strafford County, Inc. (DSSC) is located in southern New Hampshire about thirty minutes from the Atlantic Ocean and one hour fromBoston, in a county of over 100,000 people. Financially depressed, the county has three major cities--Dover, Rochester and Somersworth, and also includes the University of New Hampshire, which is located in the neighboring town of Durham.

A Brief Agency History

In 1982, DSSC first developed day supports for people with developmental disabilities who were living at home with their families. This was followed in August 1983 by the opening of their first group home. Five people, four from the state institution at Laconia and one from New Hampshire Hospital, were the first residents. From the beginning, Developmental Services of Strafford County, Inc., served people with severe disabilities, which retrospectively was considered by staff members to be "one of the good decisions." The last group home was opened by the agency in 1987. In 1988, there were four group homes, each with five people, except for one with three people.

Several long-time staff members describe two major periods in the development of the agency[1]--the years "before and after David."[2] David Traine is the Executive

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[1] All personal names used in this report are pseudonyms, as are the places marked by an asterisk.

[2] An unpublished, confidential report on this agency was completed as part of the Center on Human Policy's earlier organizational research studies (Biklen, 1989).

Director who moved from Georgia to New England five years ago and took this job role to "see if decent things could happen through services." Many of the people in the disability field whom he knows come from a school of thought that makes prominent the roles of local communities and highlights the potential negative impact of services and service systems.

In the period before his arrival, the agency was very "behaviorally oriented." Direct service staff members spent time on paperwork, described by staff as keeping records as often as every fifteen minutes of what people with disabilities did. Direct service staff did not see or talk with any of the executive directors who ran the agency during that time, and were even discouraged from talking with staff members in other group homes. The Executive Director described the philosophy of the agency when he arrived this way:

> The whole thrust was power and control...If you don't trust the staff; if you don't empower them to make decisions that count, and if you don't allow them to make mistakes..., you won't get the kind of organization over time that feels free to empower the people you are there to provide supports to.

The second major period occurred when David arrived in his new role. As described by one staff member he was a "breath of fresh air." As she explained,

> I have regular, everyday conversations with David. He's real good at talking with people and helping get the big picture. He's been good at listening and pulling it all together.

Several staff members said David helped them to know what their jobs were for--to help people experience a better quality of life. Despite many years in the disability field, prior to his coming, staff said they did not have a clear purpose or understanding of their roles. David believes "value-based training" was fundamental to this change. Many staff attended PASS (Program Analysis of Service Systems) and PASSING (Program Analysis of Service Systems' Implementation of Normalization Goals), which are based on the principles of normalization as promulgated by Wolf Wolfensberger. Consultants with a strong commitment to community life for people with disabilities, such as Jack Yates, also came into the region. As David explained, the staff came to learn that this agency's agenda was to support the "same kind of valuable things in the lives of people with disabilities--friends, family, home, work--as all of us want."

In 1987-88, the people in the agency started planning for the changes that would be made to achieve the agency's agenda. Within six months, the first group home was dismantled, and people with disabilities started moving into apartments and houses.

> The direct care staff got excited. We were working with the most challenged people. People were scared at first, but they saw good things happen with folks. They needed to understand that they wouldn't lose their jobs. Everyone was empowered to be part of the plan.

In 1988, 27 people moved into homes, partially due to the reduction in size of Laconia State School. Since then, there has been a lot of new "development" of residences and day supports, and this is the first year that staff members at the agency can "take a breath." The "big push" to get 35 people out of Laconia back to this region is over, and New Hampshire has become the first state in the United States without a state institution for people with developmental disabilities.

In 1991, of the 60 people supported through the agency's residential services, 55 are living in "their own place." There is still a waiting list, but no money is available for developing new services. David says that the organization is now stopping to reflect and think about its direction and to look at ways to reorganize to better "empower the people closer to the person they are supporting to have more authority and to take some of the bureaucracy out of people's lives."

TEACHERS IN THE COMMUNITY

This section of the case study introduces four people supported by the agency--Ned, Susie, James, and Bob. It briefly describes each person, the context of our interaction during the visit, and some of the relationships, events, activities and places important in their lives. Each person obtains support services from Developmental Services of Strafford Co., Inc., and was selected by the agency for the stories they have to share with others.

Ned

Ned, according to one of his staff, is an enthusiastic, "warm and wonderful guy with very substantial physical handicaps." A person who enjoys people, he is 47 years old, a slight 70 to 80 lbs, and is reportedly becoming a "fixture" in downtown Dover. As one of the agency's staff, Sally, describes him,

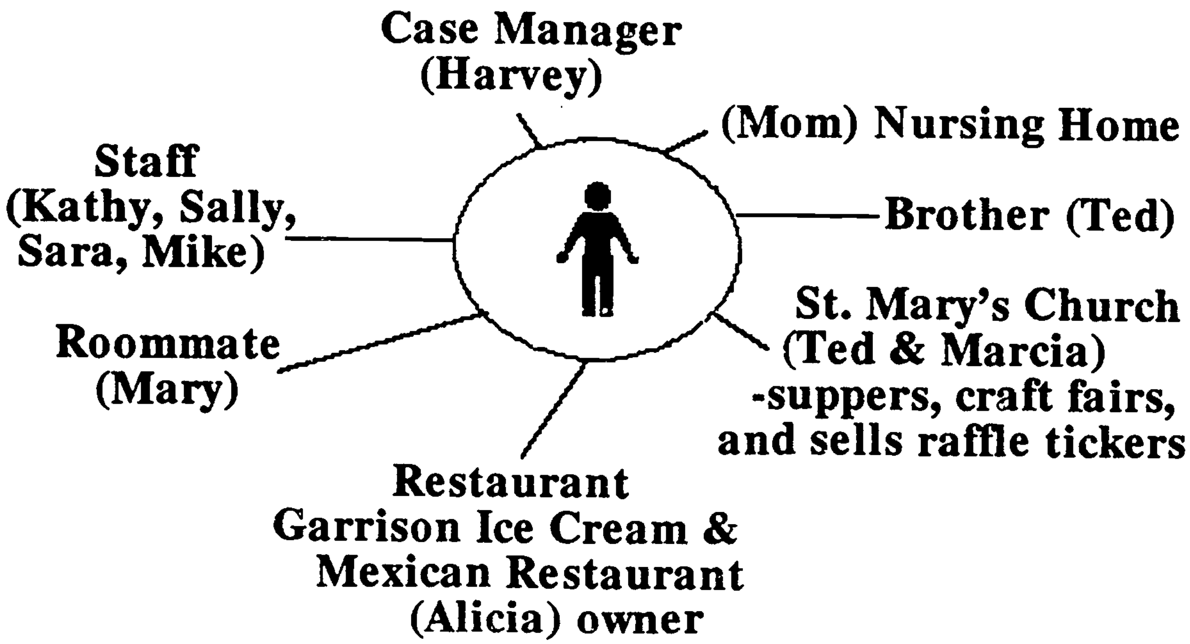
> [Ned] has CP and his muscles are very tight, not a lot of cooking ability, real social; [we] think he is very intelligent. He follows movies, baseball. He knows what the score is. We were told he is a Yankees fan. He gets excited when he knows they are ahead. He is a basic meat and potatoes man, not too into quiche.

Ned is also described by another staff member as basically a happy man, fairly limited in ability, who can make choices and is learning that he can make himself happier, and doesn't have to completely depend on the staff. As she says, "He is choosing what to eat, wear and stuff and he never did that before."

Ned spends time in the community, shopping, going to lunch, and to the laundromat. He is a member of a church, where he also participates in activities such as bingo and raffle ticket sales. There, he has gotten to know two people, whom he has invited over to his house for dinner. The staff tell stories about how other people miss him at church when his schedule changes. Ned also goes to the movie theater on Main Street, has vacationed with one of his staff, and distributes payroll at the agency office. Figure 1 briefly sketches some of the people who are part of Ned's life.

Ned's brother, a retired postman who lives in Milton, pops in to visit when he is near Ned's place, which Ned shares with his roommate Mary. Ned has a niece who lives down the road and is just starting to get involved in his life. His mother, whom we visited at a local nursing home, is diagnosed as having Alzheimers and enjoys

FIGURE 1
Ned's Circle



visiting with her son. Ned stops by to see her every other week, traveling in his accessible van with one of the staff; they have gone out to lunch together, and she has visited his new place.

<u>Ned's "Services" History</u>

Ned lived in Milton, New Hampshire, with his parents and his two brothers until his father died 20 years ago. He never had a chance to go to school when he was young, but would stay home all day. When his father died, he moved to Laconia where he lived until he moved to Dover in 1990, and started with Developmental Services of Strafford Co., Inc.

At Laconia, Ned was very scheduled and there were people around him all the time. Every two hours regardless, he was to lie on the bed and get changed. According to one of his staff, who has known him since the move, "he took a long time to transition, three months." Another staff member explained that the initial adjustment took place within a week.

> We did the best we could to get him used to it before he came, but he was scared. I worked with lots of different people, and everybody was scared. Ned was scared of us and we were scared of him. It wasn't a very long adjustment period. I can say that Ned was happy within the week. He had pretty much figured out that he was safe and it was going to be okay.

The Mexican Restaurant

I had the pleasure of sharing dinner with him and Sara, one of his staff, at a Mexican restaurant he frequents during the week. As we came into the downtown restaurant, Alicia, who works there, welcomes us with a warm hello, greeting Ned by name. She stops by now and again throughout our meal of burritos and fajitas to chat. Sara uses a quiet blender to chop Ned's food and drapes a classy scarf around his neck, which she changes several times in the course of the meal. She talks with both of us, nonchalantly lifting the spoon for Ned to eat and gently wiping his mouth. As we talk, Ned sometimes raises his fingers for yes or no. As a young family comes into the restaurant, Ned turns and says hello, a greeting the man and woman return.

We all order ice cream, Ned's favorite, to top off the meal. Ned loves ice cream, starting this habit when he lived at home with his parents. We then walk the short distance to his apartment in downtown Dover, with Sara pushing his wheelchair.

It is hard for an outsider to know how Ned feels about his new place and the people in his life. From the beginning, though, agency staff tried to figure out what he wanted, including involving him in interviews. Ned would be there, and staff would try to see his reactions to potential staff and their reactions to him. For Ned, there has been little "staff turnover," with the same staff people being able to get to know him over the course of the year. They also share a common vision for his life. As one staff member explained, "Everybody has the same basic philosophy of what is good for Ned, that he should live a normal life and do the same things that everyone else does and be involved and well connected."

Susie

Susie introduced me at her kitchen table to the delights of raspberry tea. Later, sitting on her bed upstairs, her cherished cat, Missy, beside us, Susie proudly shared some of her photographs, and a newspaper article with a picture of her and Missy.

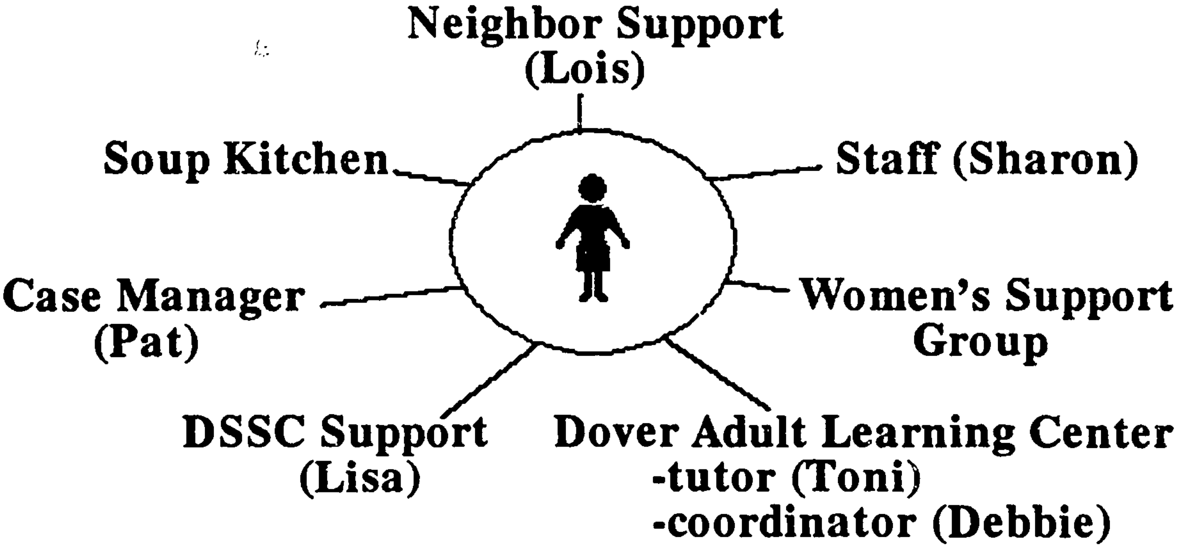
Susie, who is in her late 20s, was described by one of the staff as a "real neat person" and "well loved." She is one of eight children, and loves people and animals. Susie is viewed by several staff members as being "very capable" and has held many jobs. She has not been interested in working recently, but has a lot of other involvements, including cooking and participating in a woman's group. For the last three years, she has also attended night school to work toward her diploma.

Susie has started to get to know and connect with some people in the community. As her support person, Lisa, described Susie's last birthday,

> (At) a local store...the woman knows her very well...they will always call if they are concerned about her. They love Susie to visit and hang out in the store. On her birthday they gave her presents and sent her to the beauty shop next door and the beauty shop gave her a free haircut and a little gift basket.

Susie goes to the local soup kitchen on a regular basis to meet her network of friends there. She also knows and shares meals with a large number of people who are involved with the mental health system and other "folks" supported by this agency. Her ex-roommate, Melissa, still visits and stops by for coffee. Everyone in the agency knows Susie, and the staff believe she can call on them to come to meetings and advocate for her. Figure 2 is a sketch of the key people in Susie's life today ("Susie's circle") as drawn by one of the agency staff.

FIGURE 2
Susie's Circle



Susie is on a very tight budget. She gets $405 a month in SSI, an additional $84 in food stamps, and a biweekly check of $13.50 for personal needs and spending money. Her cat food and litter needs to come out of the $13.50, which leaves very little left for other enjoyment.

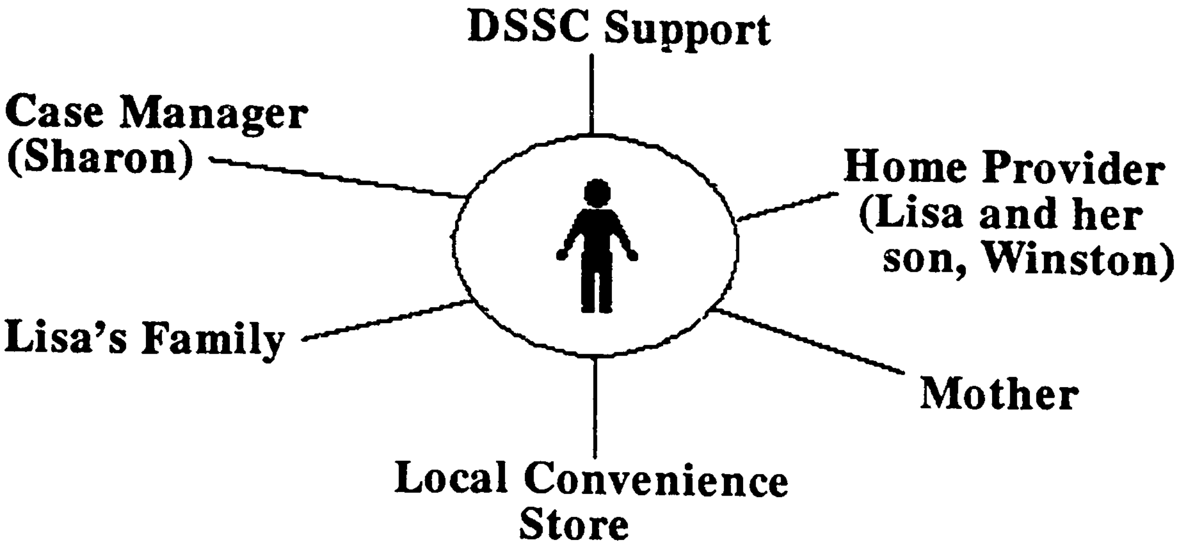
Her Personal "Services" History

Susie carries with her a powerful history of a rocky family life, experiences with seizures and hospital stays, and a series of diagnoses from schizophrenic to psychotic to borderline personality. Susie became "hooked up with the system" when she was 16 years old and her parents dropped her off at the local mental health center. She lived in a group home and was also "under" a mental health facility. She came in contact with Developmental Services of Strafford County, Inc., when a lawsuit was filed to get her out of the mental health facility. She has been in and out of state hospitals for brief stays, never beyond a couple of months at a time. How the organization and its staff have tried to support Susie will be described later in the case study.

James

I had lunch at a family restaurant with James, who is supported by the agency, Lisa, one of the people he lives with, and Rosie, one of the four assistant residential directors. On the way to the restaurant, Rosie told me that James, who is in his 40s or 50s, "is really kind of neat, very tall; he kind of reminds me of Abraham Lincoln, kind of grey hair, distinguished looking." James has lived with Lisa and her son, Winston, in Milton a small, tourist bedroom community about a 45-minute drive from the ocean, for about two years. Figure 3 illustrates briefly the people in James' life as sketched by one of the agency's staff.

FIGURE 3
James' Circle



James is intently interested in the weather, loves the ocean and the environment. He was in his first hurricane in 1954 and became intrigued with the weather when a big tree fell down near the family's home. His mother bought him weather gauges when he was younger which he still uses today. We talked about Hurricane Bob that had recently hit the East coast, including this area, and about ocean surfing, which they saw on their trip to California and I watched recently on the Atlantic.

Both Lisa and James like to travel, and find each other to be good travel companions. They have made one trip to Florida and Alabama, where they saw the white sand beaches of the Gulf of Mexico. On another six week trip, they visited California, including a stop in the Mohabi Desert and at the casinos in Nevada. We all shared our dislike of the sharp, hairpin turns along the California coast. On both trips, they were able to stay with Lisa's relatives.

James' "Services" History

James's brother called Developmental Services about three years ago when James was in a general hospital after a stay in a psychiatric one. Previous to this, he had been living with his 85 year old mother who could not care for him anymore. James, who is 6'2", could at times be scary to his mother, a small, very petite woman. As the director explained how the agency responded,

> First thing we did was set James up in a staffed apartment. He was not happy and he hated it. He didn't like staff in and out of his life; and he didn't like his roommate very much;...and he was unhappy that he couldn't live with his mother anymore, that disturbed him a lot. So he lived in that situation for a year and a half, and progressively got worse mental health wise. He was just miserable; and subsequently, because of that, he seemed to act in very strange ways, do very dangerous things and would scare people.

James ended up moving in and out of the state hospital, and even spent the most of one summer there. While he was at the state hospital, people at the agency, who stayed in close touch with James throughout these periods, realized James wasn't living the life he wanted and a staffed apartment with people coming in and out was not a good idea. So the agency launched a big search for "providers, people who would invite him into their home." The agency looked for people who would be very clear about what his needs were and what issues he had, but who would also be willing to live with him and help him get better. He then moved in with a family, but that situation also did not work out. According to the director, the family was much more stressed by him than they would let on. "James wasn't happy; they really liked to tell him what to do and treated him very childlike."

James and Lisa met when she worked as support staff in his apartment. Lisa had resigned from the agency to move to Alabama. Coincidentally, at the time of James' last crisis, she called the agency and said she decided not to stay in Alabama and was looking for work. James and she always got along well, so he moved into her home. As the director explained, "It looks remarkably like what life sharing would be like if there wasn't any money. It is not a tremendously costly thing. Her tie to James is absolutely clear. They are very much like brother and sister." James echoes this sentiment when he says to me the best thing about Milton is Lisa.

James, who has been diagnosed as schizophrenic, has now been out of the hospital for a year and a half, without any even brief stays. Both he and Lisa are proud of that accomplishment. While he still hears voices and may be concerned about being poisoned, he feels safer and more able to handle things. As one staff member said, "He is so much happier it seems he is more able to control his fears and not be ruled by them." Before I left, James told me that he wants to see people out of mental hospitals, explaining that people get forgotten in there.

Bob and His Father Roger

I first met Bob at Frisbee Memorial Hospital, where he does volunteer work delivering the mail, a job he also used to do at Laconia State School. We then shared a lunch of cold cuts, salad and brownies at his small house in Rochester with Bonnie, one of his staff, and Roger, his father.

Bob, who has a rare degenerative condition of the nervous system called San Fillippo's Syndrome, lived at home with his family until he was eleven. As his father describes, the parents' decision for his "enrollment" in Laconia,

> The professionals, quote, unquote at that time said you've got to do something because if something happens to you, he is going there anyway...So with our backs against the wall, we took him up there. That was a day neither one of us ever recovered from. It was without question the worst day of our lives. And my father died a few years later and his funeral was a church picnic compared to taking Bob up there. It was just a horrible experience and it took quite awhile to get over it so we could even talk about it.

At first Bob lived in an old farmhouse run by the institution with other boys his age. Within the year, the institution closed the place and Bob was moved back on the grounds to one of the large, overcrowded institutional wards. As his father continued,

> You could not even walk between the beds. It was just terrible. These kids who had the freedom of a large home were like caged animals. It was horrible. And we told them that this was a move strictly for convenience and the kids were not considered in anyway...and they knew it...We stood this for a few weeks, these horrible, crowded conditions on grounds, and we brought him home one time and couldn't bring him back. He was now 12.

Bob then stayed at home until he was 18, attending the Big Lake Training Center*. He then again went to the institution where he lived for 17 years. As Roger explained, while the institution had "grown in humanities" during that time, Bob still was abused and became more institutionalized. As Roger continued:

> He took a lot of abuse up there as did some of the others who would not defend themselves. Bob was kicked in the testicles so much that he was herniated from it and that had to be repaired surgically after a few years, and they would find him unconscious...It is a pit or a jungle, you learn the laws of survival...a moving target was less likely to get hurt. He just kept moving all the time and vocalizing.

His parents continued to visit him and take him out. From time to time they would look for alternatives, but it either was not what they expected or they couldn't afford it. As Roger explained, "We came to feel a certain sense of security there; it was a state operated institution so as long as the state was functioning, why there'd be a place for our children."

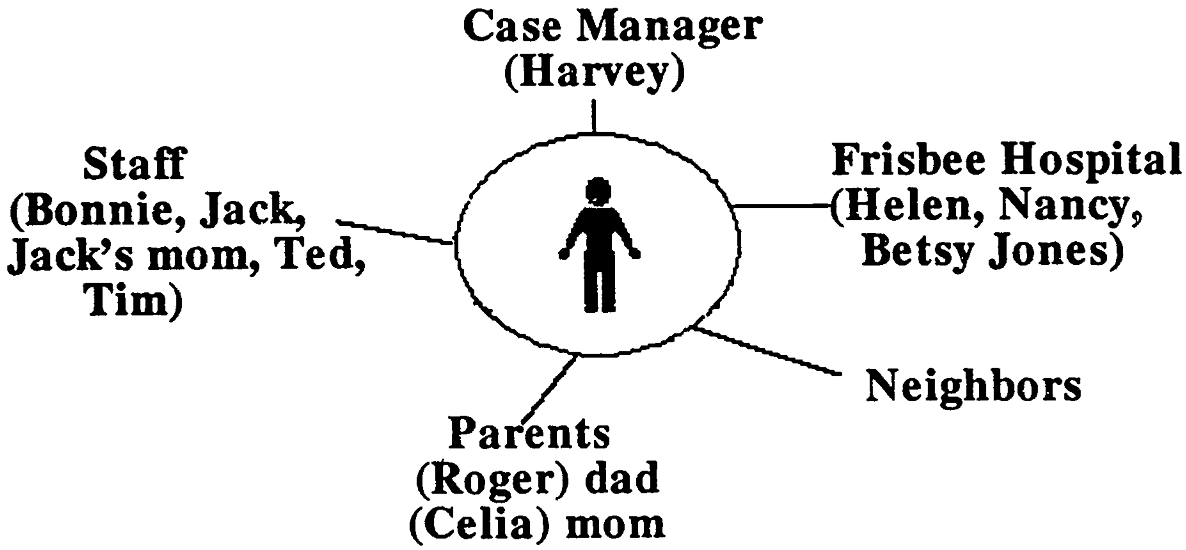
Bob was one of the last people to leave Laconia before it closed, and Roger, as a leader of the institutional parent group, opposed the move for a long time. As the institution dwindled in size, Roger said he realized the writing on the wall. Region 9, Developmental Services of Strafford Co., Inc., was the designated area agency in the region where Roger lived with his wife, Ethyl. When he met with David, Region 9's director, Roger said he was promised "great things" for Bob in the community. Yet, Roger was reluctant to have him leave Laconia because "We (his parents) had been promised great things many times, but nothing ever happened, so we took it with a grain of salt."

Bob now lives in his own house with staff support in a residential neighborhood in the same community as his parents. As Roger explained,

> They (the agency) have done everything they said they would do, and if we can find anything to ask for, which isn't much, they are right on it. They are a super group of people, and we are fortunate to have people like we have caring for him...It is just something we would never have dreamed of happening. A few years ago we just couldn't have imagined Bob in this situation, but thank goodness it happened...(Bob) is living like you and I live or anybody else, in a home, and he has recreation and activities and cleanliness. He is not beat up or kicked everyday. It is a normal form of the way..a human being should live and he is able to experience that now, when there was a long time he couldn't.

Today, Bob has gone ice fishing and to a game at the University of New Hampshire. He and Bonnie walk around the neighborhood each day and have met some of the neighbors, who also came to a cookout on Bob's birthday. Figure 4 briefly sketches some of the people in Bob's life. Three times a week Bob goes to a nearby ball field to walk around the track. He likes all kinds of food and now feels comfortable enough to take a cookie off his own kitchen counter and eat it without fear of retribution or punishment. Bonnie shared her view of how life has changed since Bob moved from Laconia:

FIGURE 4
Bob's Circle



> As time went by, Bob became relaxed with us and the habits he brought from Laconia stopped or were suppressed to being at the house. Out in the public, he became a very pleasant person to be with. That's when we started to take him out more often to see what Bob liked. We went to parks and shopping and once he got to the point where he was very comfortable in public, (her supervisor) suggested a volunteer position. That's when he went up to the hospital. He seems to really enjoy that. The people up there love him and it is just another part of their family. My family really loves Bob. I bring my kids to work. They love to be over with him. He is very happy with them.

COMMUNITY PLACES AND RELATIONSHIPS

This agency strives to expand the network of community places and relationships in the lives of the people it supports. This can include getting to know neighbors, maintaining and re-establishing ties with family members, and meeting and knowing community people, such as store owners, customers, and others. As Rosie explained,

> Our biggest step is to help people build relationships with people who are not paid...Some people don't even have family. And even that is something that most people take for granted, even having someone to spend Christmas with.

Initially, the main focus of the agency was on the physical presence and participation of people in community life. In the past several years, it is no longer unusual for someone using a wheelchair to be on the streets, to be seen in the restaurants or in the stores. Also, people are developing different social roles, ways in which they are viewed by others as members or active participants with assistance from the agency. For example, people might be a regular in a cafe. Now, David says the main question is one of personal relationships. As a guide to staff members, he asks them to think about "Who calls on Saturday night?"

Supporting Connections: Staff Roles

Staff members use a range of strategies to help support the connections of people in the community. Ned had lived in the institution for most of his life, so he had few connections in the community. When he moved into his neighborhood, Sally described the first thing that the workers did to help him connect with the neighbors:

> ...we had a party...Not a lot of neighbors came, but their kids came. I think what happened is they went home and talked about Ned. And they came over and visited a lot, especially in the summertime. We made cookies and stuff in the evenings. And I think their kids would just talk and when we went out for a walk, they'd say, "so this is who you met?"

Ned's roommate, Melissa, was new to the area, and as she was trying to get to know people and her surroundings, Ned would go with her. Being an outgoing guy, he would greet people as he saw them on the street. Sally, one of the agency staff, described how this occurred:

> Ned would be out and about so I guess that is how he met people. You can't help but notice Ned when you are walking by on the sidewalk and he is calling hi to you; you are drawn to him and you talk with him.

His support staff would also create other opportunities where they and Ned could both contribute to his neighborhood and meet and become involved in activities with neighbors. They viewed this as helping to establish Ned's and their place, in a positive sense, as a part of the area.

> Besides the party, we had a clean up Second Street, and sent out flyers. Not a lot of people came and joined us for donuts or anything, but you could see that people got out and started cleaning their lawns and stuff. We were very visible and we talked to people and Ned talked to people. It was nice, gave a positive atmosphere.

Each of the staff also has learned a way of talking about and presenting people's participation. For example, Sara uses language such as "we (Ned and I) were talking the other day" and "It was that way, wasn't it, Ned?" that includes and presents people as active participants. The images they create are of people similar to others, involved in similar activities, with similar issues and concerns. They are concerned about questions such as "How do you introduce people?" As Sally talked about the neighbors, she said:

> One of his neighbor's is Ned's age. They don't hang out and talk a whole lot, but they visit a little on the street corner. "Hi, how are you doing? What do you think?" We got this new trash business where we have to pay for our bags, so they had a little discussion about that last week. Neighborly type of things, not real close friends.

From the beginning, in the interviewing process, agency interviewers looked at how the prospective staff member talked with people with disabilities, such as Ned. While no one would ever say, "don't talk like that," staff said they learn the way to talk with people, partially by being paired with another staff member early on.

Staff members are encouraged to develop their own unique relationship with each person and to find activities that they can do together on an ongoing basis. Theresa, for example, will go to church regularly with Ned, while another person will accompany him to visit his mother. This offers some continuity in their own relationships with people, and builds on their specific interests and talents. As David said, "We all have different connections in our own communities and through those different connections you know different people and have new ideas."

Connecting is viewed as a process, where there will be both good and bad experiences. People need to spend time with each other, see how each other interacts, and how comfortable they are in the world. One staff member explained that the workers have to remind themselves that building connections takes time. As she said,

> As service people we think that connections will happen quickly. We need to step back and see where people are coming from. Ned is more connected than me and I have lived here for six years.

Learning to Value Each Other's Contributions

Support staff, like Dan, who arranged for Bob's hospital job, also help other people in the community to understand the importance of rapport and connections, of knowing and being known, instead of focusing solely on skills. They try to convey a sense of the varied contributions people make besides standard concepts based on productivity and performance. For example, Helen, the volunteer coordinator at the community hospital, learned to measure success in this way:

> I don't measure Bob's success by his ability to distinguish between names and departments. I don't feel that is what he is here for. I know very little about Bob's clinical background and I don't think that is really my concern. My concern is what he is going to do while he is here that builds his self esteem and makes him feel that he has some worth and value and that people recognize him, and that he establishes a rapport with people and in the morning, he wakes up knowing I have...a job.

Bob does work that someone else would need to do if he did not perform those functions. However, people here value other contributions besides productivity and also appreciate being part of something outside of their own narrow interest.

Dan explained that when Bob used words like hello, it really had an effect on people at the hospital, who had come to appreciate what that meant given who Bob is. As Dan said, while originally some people at the hospital were wary of Bob or "felt sorry," now "everyone knows who he is, what he does, and he has a wonderful rapport with everyone." As Barbara from the personnel department said, she now knows him and enjoys him and would genuinely miss him if he was not there.

Knowing What It Means to Live Together

People with disabilities and their staff play a role in educating others about what it means to live together. Through the example of their lives, professionals and agency staff are learning about the possibilities that they had never previously envisioned. For example, David told me about a conference in Maine where one of the people from that state who had visited Ned stood up from the audience and said,

> I went and visited a man by the name of Ned in Dover, New Hampshire, and I can tell you that there is nobody in the state of Maine who is as disabled as Ned. And he is out in the community in his own apartment, with a roommate, with staff, and we went to the restaurant and people knew who he was, and that doesn't happen here.

This is an example of a person-by-person approach to change, with a key role played by people with disabilities themselves. This type of leadership on the part of people with disabilities often happens in partnership or alliance with others, such as this speaker, with support workers, or community members such as Helen, who share a vision of what coexistence means and are trying in their own ways to create this in their lives and those of others. As Helen explained, her vision of what she hopes to accomplish by her support of Bob,

> My hope is that the 500 plus people who work at the hospital who...had an opportunity to see what Bob does here, has allowed them to carry that along with them outside the hospital. It has forced them to think and hopefully...people will be more responsive, more accepting and more receptive.

Roger, who has the capacity to recognize the importance of this large vision and what it means to his son and others who have repeatedly faced negative societal experiences, responded with strength and graciousness to her efforts. He said:

> I think that is a lesson you taught within the building; to learn to associate and be a part of the lives of those with handicaps. Apparently, the people who have been here before have never been exposed to that segment of society. So now you have taught them a lesson of coexistence. That is very good.

"SUPPORTING" WHAT IT IS PEOPLE WANT

The assumption by informants in this agency is that, in a general sense, people with disabilities want the same things that everyone does. Yet, while staff members strive for "individuality, not groupness or stereotypes," they also recognize that "we are all one people." In other words, that people share a commonness with each other that is more fundamental than surface differences such as disability labels.

Getting to Know and Trust Each Other

A premium is placed on getting to know people and listening to what it is people want. One way this is done is by involving people with disabilities and their parents in the interviewing process. Roger, for example, said he appreciated the courtesy of being involved in the last interview. In Susie's interviews, she asked questions like: "What are you going to do for me? Are you going to help me with banking? Are you going to have lunch with me? Are you going to help me with my cat food? I want to know."

The agency workers also have a reputation for listening to what it is parents want for their child and to their own personal sense of security and comfort. As Roger recounted about his first meeting with Developmental Services of Strafford Co., Inc.,

> The first day we met...they said what do you want for Bob?...we told them things that any parent would be concerned about. We didn't want him in an abusive situation. We wanted him to receive the care he should receive, the medical care, the dental care, just the things that any parent would expect for their child...So Bonnie and Lynn (another staff member) found this place and we came to look at it...I think we all make some bad decisions in life, but this wasn't one of mine. And so they have been really supportive and very cooperative.

People at the agency seem aware that learning what people want is based on the building of trust and rapport. They do not assume that people with disabilities or parents should automatically trust them, but that it is a process of becoming comfortable with each other, and of overcoming past negative experiences with the service systems. As Roger explained, it took a long time to believe that people at the agency would keep their word.

> For the first few months, we just kept waiting for the next client to move in and the next one. We figured there would be two, three or four, but that hasn't happened and then we begin to relax a little bit...then we learned that there are others in Region 9 (the agency's catchment area) with their own private residences.

People with disabilities also need to feel safe and assured that the negative experiences they have had in the past will not be repeated in the new situation or relationship. Moving into the community, like any major change, especially to the unknown, can create a lot of stress and tension. As Roger continued in describing his son's transition to the region:

> When he (Bob) came out of the institution, (he still did) the constant on guard thing he learned so many years, never being able to relax...He has had to learn a whole new lifestyle. We have pictures of the day he came here and the look on his face was just horror...He didn't know what was happening.

Often it was "the little things" that helped to build trust between people and the agency workers. For example, Roger saw a rocking chair he thought would be perfect for Bob's new house. He called and was astonished when agency staff said they would buy the chair. Another time, the staff spontaneously called to see if Bob's parents would like to come over to supper because there was extra food. They came and had dinner with their son "like anyone would," but it was something that for them had not happened in 17 years.

In order to "support" people, the expectation is that staff will accept people for "who they are." This means that while still keeping high expectations about people's capacities to grow and change, that they are accepted holistically, with their disability as part of them. For example, one staff member said in referring to a staff person who did not work out, "We all have to understand that (Bob's incontinence) is part of him."

James, too, has "not stopped being James," and his concerns and fears are part of who he is today.

Supporting People: Susie and the Agency Responses

Supporting people also means that the agency needs to be flexible and make changes in concert with the changes in people's lives. David describes his vision of what the role of an agency should be and where the locus of responsibility for change should lie. His underlying assumption is that the nature of human lives involves change and that service systems must adapt to and not direct these changes. As he explained:

> People's lives change and a service system that makes sense is not determining what the change will be as much as trying to help people grow so that when they change or the circumstances change, the nature of the supports can change too.

Sometimes, what the agency needs to do to respond to what people want in their lives is relatively straightforward, though most agencies are not organized to do even these simple changes. For example, Susie, at various times, wanted to live in a different place or with another roommate. Like all of us, she changed what she wanted based on her experiences, opportunities and life circumstances. In some organizations, Susie would be given the message that she could only choose once and then would need to stick by that decision. In contrast, this agency assisted her to make different decisions, even though it was cumbersome in the system to do so. As one of the agency staff described, When Susie came in contact with Developmental Services, she said she wanted to live in downtown Dover. The agency staff recruited a roommate, and did the bulk of the apartment hunting together with her. The first apartment they found was on the third floor. When an apartment opened on the first floor, Susie and her roommate wanted to move; the agency took the time to recertify the downstairs one so they could do so. Later, Susie and her roommate decided to recruit a third roommate, a woman they knew. Then Susie wanted her own apartment (with 10 hours a week of paid services).

Sometimes instead of paid services, people share parts of their own lives and homes, thus getting to know each other in new ways. In this agency, it is common for staff members to look to their own networks and personal resources, including in times of crises. This is possible because people with disabilities share activities with staff members and staying at another's home in a crisis is not contrived but can evolve out of the relationship. For example, once when Susie was evicted from her apartment, she stayed at a staff member's home. As Rachael, the staff member, describes,

> She lived with me for a month, and I got to know her very well in that month. It kind of was nice, and you don't know people until you live with them. So it really worked well. She liked living with us, but she hated Rochester which was a town away. She decided that she definitely wanted to move back to Dover,

but initially there was no money to move her with, so we needed to wait until next month's check.

During a major crisis in a person's life, no one may know exactly what "to do" and sometimes both personal and agency responses will not seem to be up to the challenge. Recently, Susie went through such a crisis where things were going along okay and then "her life just started falling apart." The emergency services were constantly at her house; she would call when the "demons hit" and "the voices" would become more and more intense. There were not adequate paid resources in the community, and people in her life were at a loss of what "to do." As Lisa described:

> Midnight to eight...these were Susie's times. She would wake up and hear voices and pace. And her old neighbors in her apartment used to think that she had a crowd of people over and complain there was a party and literally call the police and it would be Susie all by herself.

Even though no one wanted to see her in the hospital, Susie and the agency were getting little help from the local mental health agency, and they believed Lisa needed help that they could not provide. As Lisa continued,

> I was getting calls from them to come and get her. She was at the hospital a block from her house. They (mental health workers) were there, but they wouldn't transport her home. I live a town away. I would go get in my car and go get her at the hospital and bring her home.

Finally, Susie went to a local hospital in Portsmouth, which the agency workers felt had a good mental health unit, where she stayed for 45 days. The agency "lost money" during this time, while different medications were tried and the agency tried to change their thinking about Susie and the supports she might want. Susie did not have 24 hour support services available to her prior to her admission, though money finally came through three days before she was to move back to Dover. Given the circumstances, a lot of the decisions were made by the support person about finding the place and the "paid neighbor" who was the niece of someone who worked for the agency and "happened to come along." As Lisa describes this process of deciding on this living arrangement:

> Susie's complaint always was that she was lonely. She had a lot of outside people and people did visit her...but it wasn't enough. But Susie couldn't handle a roommate per se living with her...so this way the neighbor has her space and Susie has hers. We have an intercom between the apartments and when Lois is on duty, the intercom is on. And it reaches all over the apartment, so she can wake Lois (the "paid neighbor") up in the middle of the night if she needs to, but knowing she is there, she hasn't needed to.

Susie and Lois, who is 19, also spend time together "when (Lois) per se doesn't need to be there." She might run down and have a cup of tea with her. Susie has also met her next door neighbor and at night Susie walks their dogs with them. Susie also still has some of the same support staff as she did before, though "her whole program has changed."

Making Mistakes

In this organization, there is a recognition that mistakes inevitably can and do happen, and that each person develops his or her own unique relationships. Everyone needs to go through a process of getting to know each other, including each staff member and the person he or she supports. As a staff member described,

> I've known Susie for two and a half years. They (the support staff) have only known her for a month and a half...Susie is not supposed to drink, so she went to this table and took a drink...I can't step in. These are issues between them. You have your typical data and people can read it and get a picture of what happened in the past. But you can't predict what will happen in the future...I think anything is trial and error as long as they are not devalued or hurt and they are helping her to be accepted in the community.

Of course, this learning process is particularly hard on people with disabilities who often repeat this process over again as staff come and go in their lives. There is also a tension between realizing mistakes happen to all of us and acknowledging that the situation may not be working out well for people. For staff and administrators, this means always going back to the questions "Who is it I work for?" and "Why is it I am here?" As one staff member explained, "I am here for Ned...I know that Ned is happy that I am helping him lead a better quality of life."

When the situation isn't working out for Ned or any other person the agency supports then "no matter how much you like that roommate or that staff person, you got to say it is not working. You've got to be true to the person we are supporting."

This means learning how to listen better to what it is people want, and to respond to this. As one staff member said,

> I think we are getting a little better at that. We haven't always been so in tune, especially if it is somebody we don't know very well, we are not in tune with their needs and don't always hear what they are saying about what they want.

This remains as a critical challenge.

When Staff Disagree and Values Differ

As in any organization, people do disagree with each other. This is expected since everyone has their own styles, opinions and personal values. However, people try to remember whose life is central and whose values really matter. As one staff member explained,

> We are all different people and have different ways of doing things and different ideas of what is best.....the most important part is that we really listen to what the people we are providing support to want. And that's very key to providing support to anybody because if we ignore what they really want and what they are telling us that they want, then we are doing nothing but trying to make them like us, like our values. It is a matter of really hashing it over, including thinking foremost of what the person really wants.

Sometimes figuring out what to do is a real challenge to staff, especially when decisions by the person do not seem very responsible or against the moral values and beliefs of the staff member. While they are not recommending a laissez faire, do whatever you want approach, they try to step back and see how to maintain their relationship under these difficult circumstances. As one staff member said:

> We need to step back and realize that we are not their parents...we need to be careful not to force our opinion...because we may alienate her...(and) she may not want to come back and say,"Hey can you help me out again?".

PERSONAL CHOICE, SELF-ADVOCACY AND FAMILIES

This agency is a strong supporter of both families ("parents are real important to us") and people with disabilities. A number of adults with disabilities have been assisted to reconnect with family members with whom they have lost contact for many years. Yet, most of the agency services are oriented toward adults, and many of these adults do not have parental ties. The agency does work closely with the region's family support council, which consists primarily of parents who have young children.

Parents and Their Children

Since the establishment of the family support councils and the success of families in passing family support legislation in New Hampshire, some people in the state are viewing families as the central element of the service system. David, who represents what appears to be a minority position in the state, explains that it is important to distinguish the views of parents from those of adults with disabilities. As he explains:

> We've got to be clear that the person we'll provide support to is the person with a disability. While 95% of the time, the family's interest and the person with a

> disability's interest may be exactly the same, sometimes they are not going to be and that is exactly the issue...At some point in time, I am not here to represent the interest of the family (parents).

As one example, presented by another staff member, a parent and their adult child might disagree about whether their child should come to the funeral of a relative. While the staff try to encourage people to talk their differences out together, and also try to give information, such as the possible effect of attending on their relationship with their parent, ultimately, "if the person wants to do it, they will get support to do so." In the same vein, the agency staff will also support people to maintain ties with their parents, even if they do not view that in the person's best interest. As one staff member explained, "It is not our job to dissuade family...but it can be difficult at times."

Personal Choice and Self-Advocacy

The agency staff make clear distinctions between personal choice and self-advocacy. Personal choice occurs as part of the "natural course of living," and is part and parcel of every aspect of a person's life. In thinking about personal choice, one issue that commonly occurs is how people who have never been exposed to many options can "make choices." As David describes through an analogy, people need to have experiences in order to make choices. He recounts the following:

> I'll invite you over to my house tonight and you can have the choice between Ethiopian and Peruvian food. Well, what kind of choice is that? If you don't know what Ethiopian or Peruvian food is, you have no choice at all. And a lot of people we are working with by virtue of their institutionalization or their

> experience in the community don't have any idea what their choices really are. So part of what we do is help them see and experience some stuff with the world so they can actually tell they like this better...that's just basic, that's fundamental.

Another aspect of personal choice in relationship to the "system" is how staff can help people better articulate their choices and to pay closer attention to what people want. This is a difficult challenge, and people hope that avenues such as assisted communication will help this process.

In contrast to personal choice, the self-advocacy movement is defined as "people collectively standing up and expressing a point of view." Self-advocacy is seen as directly related to the lack of power that people with disabilities hold in society, and as a way of entering into the "public fray" and political issue involved in people's lives. This holds the possibility that people with disabilities can be hurt in the process, and the director is concerned about naively sending people into situations where they have no real power. As he explains,

> We are not kidding anybody in a lot of places by saying that people have power. People (with mental retardation) do not have power...And when someone else decides to use their power, they will steamroll them fast..

While some people from this agency are involved in the state's self-advocacy efforts (which is sometimes confused with citizen advocacy), there is also a women's group that has met and evolved over time. Group members have developed a basis for friendship and closeness, and are moving toward dealing with broader issues that generally fall under self-advocacy.

WAYS OF ORGANIZING TO PROVIDE SUPPORT

This agency is in the process of examining ways to reorganize their resources--people, services, finances--to figure out how to determine and to provide the support that people want or to assist people to develop the connections or relationships where such support will occur. As the director explained this organizational process,

> 80% of things are routine, so it gets people fired up...Some of it is..figuring out how to use the talents of the people you've got...We don't want the talents of people squandered or (for people) not to feel they are appreciated and their potential untapped.

Their agency change processes often involves staff groups coming together to figure out better who they are and what they have to offer. This extends to all parts of the organization, with even areas such as the transportation providers developing their own mission statement.

Staff

The director describes the staff in this agency as good people, who are no different than people in other parts of the country. He believes a lot of problems exist today in services because people do not know where they are going and how to go about accomplishing it. He explains,

> They (the staff) are regular folks...They are in Butte, Montana, Keakuk, Iowa, they are everywhere. We have to find them, good people who work hard, care

> about people, like what they are doing. You know the service systems stink, but that's because...people do not know where they are going, what to do or how to organize.

In selecting staff, emphasis is placed on a clear commitment to a core set of values about people with disabilities and about acceptable ways of being with each other, whether people with or without disabilities. What is considered to be most valuable in the lives of the staff--friends, family, work, home and so on--is also considered to be most valuable, too, for people with disabilities. Staff are challenged to think about issues such as the meaningful and productive use of people's time; how choice and good leisure time is defined by individual people; where the person spends their time; what kinds of interests the person really has; how staff can help people get their own home; and how staff can help people become connected with friends and develop a range of relationships.

Decision Making and Problem Solving

Unlike some organizations where support staff are expected simply to implement the decisions of others above them, this agency is striving, though not always successfully, to respect and support the decisions of those who work most closely with people. As one assistant residential director said,

> We all have to realize that the people who do direct care have a harder job and you have to listen to what they are saying about people because they are in the trenches. And you also have to be willing to get your hands dirty.

Staff members are encouraged to problem solve and make decisions, using "directors" and others as consultants and resource people. In fact, the agency is looking at changing titles to better reflect these functions (e.g., director to consultant). All staff are involved in areas such as the agency's budget. David strongly believes that if people throughout the organization understand how money works, then people can see what they can do in one area to translate into other supports for people. This also gives the flexibility for individual staff to decide at their level what somebody needs on Tuesday instead of on Wednesday. The intent is to create an atmosphere where staff have space to use their creativity, and respond flexibly and spontaneously.

Personal Commitment and Networks

In this agency, personal commitment is fostered between people, and it is not uncommon for support staff to share holidays or vacations with the people they support. As Lisa said,

> Christmas and Thanksgiving have always been lonely days for a lot of these people because they don't have family to go to...Some people in the community have people over and hopefully that will increase as the years go by.

People celebrate together, especially birthdays, which are a personal holiday that is often neglected in the lives of the people supported by the agency. For example, when one man did not know his birthday and the information was irretrievable, he chose a date to create a past that he could carry into the future.

People are also encouraged to use their own personal networks to locate staff, roommates, and others who might become involved in people's lives. As in all relationships, some of the best ones "happen" or are "flukes." James, for example, regularly spends some weekends with a man named Gary, who is in his twenties and lives in Portsmouth. He loves the jam sessions Gary holds at his house, and is very impressed with Gary's talent. The weekends away gives Lisa private time with her son, Winston. Rosie heard about Gary through a couple who supports a woman connected with the agency. As the assistant residential director described:

> Matt knew Gary and he wrote me a letter saying I have a friend who is interested in working with this agency. He is one of the kindest men I have ever met...I called and talked with him for awhile, and gosh he is...(Gary) is very soft spoken and laid back and that is exactly what James needs. James has his own opinions; he is an intelligent man. And he doesn't enjoy being pressured into doing things that he doesn't want to do.

Valuing Staff

As an organization, a group with a social history of their own, attention is also paid to what it is staff need and want. People within the organization try to support one another. Recently, Lisa was stressed out about custody of her son. She asked Rosie if the agency could find somebody that could hang out with James for four or five days while she worked this through. Rosie said,

> Oh yeah, I'll help you. I have no ideas. Let me talk with James and see if he wants to come and have supper with me and my daughters. And I talk with James and he said sure and spent the night with me for a few nights. And in the meantime I tried to find someone else who could. Not everyone I am directly involved with would I invite to my home because I don't have a

> relationship that friendly or comfortable with everybody. But James is somebody I see, or we have lunch, we have dinner together,...so he has been to my home and he has had meals with me, and he's been comfortable and gets a kick out of my kids.

This is much more the norm at DSSC than the exception. As one might expect, the kinds of staff issues that are arising in the agency grow out of this level of commitment and responsiveness to each other. There are times when support staff care about other people and may not take good care of themselves in the process ("overcommitment"); or where they may be afraid that people in the community might let the person down and hurt her or him ("overprotection"). Also in trying to support another person's connections, the individual staff person may not feel as valued or acknowledged for who they are. In other words, in trying to be "nonintrusive," staff, many of whom are women, may be left out and their contribution ignored. While a complex issue, little consideration is given to what this message conveys to others. For example, sometimes Bonnie, who goes with Bob to his volunteer job, feels that people say hi to Bob, but not to her. As the volunteer coordinator concluded,

> Maybe that is something we need to be a bit more attuned to is Bonnie's recognition and Bonnie's presence with Bob...She is really an important person in all this...We couldn't do it without her.

There are no easy solutions to this, but more exploration is necessary between the extremes of staff taking over and being invisible.

Roommates, Neighbors, Staff and Their Roles

This agency is beginning to examine issues such as the roles and relationships of neighbors and roommates who may also be paid in some way by the agency. As one staff member explained, the relationships workers are trying to promote is different from that of staff:

> It is...very hard too because we need to try...not (to) make them staff people. Relationships are entirely different. We are trying to support a more normal relationship than a paid relationship, even though in reality, they are giving a service and they are getting something in exchange, but it is not quite the same. So the way that we support that is quite different. We try to encourage, not govern as we would staff, not regulate, not as much agency involvement.

In looking for roommates or neighbors, the agency workers particularly are wary of people who simply might want to do this for a "free apartment." As one staff member described about finding a neighbor for Susie,

> I think you are looking for someone who is going to give the time that is needed...I did a background check just like I was interviewing a staff person... I think it was harder to do that one than the staff person 'cause you really had to feel she would be there for her. It is a lot different. It really is because they can walk away easy, easier than leaving a job.

"Paid" roommates (people who share the same apartment or house) and "paid" neighbors (who may live in an adjoining flat) generally receive room and board for providing some kind of support to the individual with a disability. A written roommate agreement is drawn up which is unique for each situation. For example, Ned's roommate, "sleeps over" seven nights a week and also gets free rent, food and a stipend of $300 a month. She must be available from 10:00 pm until 8:30 am, and has responsibilities in the evening and nighttime, such as getting Ned out in case of a fire or responding to other emergencies. The agency, however, is trying to promote a shared housing arrangement. Michelle, who is also a student, is involved in Ned's life and goes out to lunch with him. She's "considered part of the whole house," brings her friends over, and shares the place with her pets, a bird and a goldfish.

Yet, the agency also has strong expectations and does hold control over many situations, such as asking Michelle not to keep one of her animals. While informal, the agency workers do meet individually with people to see "if they are doing what they are supposed to do." If they are not or do not get along well with the person, they will be asked to leave. As one staff member explained, "We can say leave if it is not working out...It really needs to be that way so the folks we support also get what they need." People continue to struggle with the tension in these roles, which at the time of this visit more resembled staff than those of typical roommates or neighbors.

The agency is also struggling with the question, "Whose home is it?" The concept of shared households, with varying kinds of relationships between housemates, still seems new. Sometimes, a staff member would say a person with a disability was "living alone" when they actually had a roommate. Also, many roommates are short-term arrangements and resemble boarder situations. "The first choice" of people supported by the agency generally seemed to reflect an agency bias toward two people living in a place, one with and another without disabilities.

Living in a house or an apartment with one other person can have both negative and positive implications. As David shared on the positive side,

> We certainly have seen time and time again as we have moved people out of those congregate settings to their own place that people have just blossomed. You don't need to worry that someone will steal your corn flakes. You can have quiet if you want quiet or yell.

On the other hand, the loneliness that people with mild disabilities have experienced in their apartments may also be another result. Though the agency seeks to support connections, this is still a very small part of most people's day.

There are also some practical questions that the agency is attempting to address. For example, with the Internal Revenue Service (IRS), for purposes of taxes is it stretching the definition of foster care too far to have a lease in the person's name? How does labor view these arrangements? Are support staff considered to be independent contractors? The agency tries to act responsibly by keeping current and obtaining legal opinions, but many of these issues remain unclear or in flux. The agency also tries to be helpful to people and give them the best advice they know how. Ultimately, as in other decisions made by agency directors and boards, they attempt to act in good faith, with a liability policy as the back up if they make a mistake. "Independent contractors," though, may not be afforded the same protections. Further consideration needs to be given to the balance between workers' rights and those of people with disabilities, especially at a time in this country when workers' rights are being eroded.

The Agency Role in "Case Management" and "Day Programs"

In this agency, they are trying to stretch the way in which people think about the "right ways" to approach both "case management," which they provide directly, and "day programs," which has been a particularly difficult area during these hard economic times.

The general rule of integrationists in the disability field has been that: case management should be provided "independent" of the provider organization, and that different organizations should provide residential and day services. In thinking about these areas, David tries to go back to the reasons these rules were created, and instead asks, "What was the goal? What did we intend to do?" Can this be accomplished in other ways?" Specifically, he believes that there are two key goals to consider. First, is one person dominating a person's life in such a way that it works to their detriment? The answer to that, he believes, should be clearly no. Second, is the person's life differentiated between a set of activities so there is some flow to the person's life? He believes it should be. He explains, "My impression is like anything else in the world, there are as many drawbacks as advantages" to independent case management and work/residential separations.

Work

David holds that the decision about whether to work, have a volunteer job, and/or participate in other community activities should be guided by the individual person. Acknowledging that all else being equal, work can increase status, promote contacts with others, enhance one's personal sense of value, and be a source of contribution, he believes we need to keep remembering "whose question is it?" The solution needs to vary based on each individual.

A number of people supported by the agency have little, if any involvement in paid, integrated work. For some people, this is viewed as appropriate.

> James is getting what is called adult day services out of his home...Linda helps him Monday through Friday work on specific objectives...The things James needs to work on are things like relating with people, just being comfortable with people who are new, just saying hi to somebody and not just being real shy and becoming withdrawn...James is starting to feel comfortable with people he doesn't know and say hi. That's a big step, believe it or not.

Other people are experiencing tremendous difficulty in finding and keeping jobs, though they would like to work. As David said, "The economy soured and people lost jobs and businesses failed and other kinds of things. It was miserable. It was very disadvantageous to people." The situation has not tremendously improved, and people have very few options for work or other integrated options during their days.

Agency staff may provide services in home and at work. While consistent with what some people with disabilities might prefer, this is not decided by personal choice, but is agency-determined. This area needs more exploration to assure that this is not done primarily for the convenience of staffing under the rubric of plausible theory.

"Case Management"

In this agency each of the case managers work with about 30 people. David believes that although this agency provides both case management and other services, safeguards are built in so other people can also play some of the roles, such as advocacy, that case managers often do. He explains,

> The issues really seem to be building some sense that we are in this together and we have different roles to play in this...A lot of people can play this role, and somebody needs to be speaking up, unafraid enough to say, we shouldn't be doing this...We crossed the line...And I would like to see a lot of people empowered to do that...it is not just the job of the case manager.

The agency has a number of "safeguards" that help to promote quality and to keep the focus on trying to figure out what it is the person who is being supported wants. These include the philosophy; the training of staff; the openness for anyone to call a meeting or to say that "something is not right"; the welcoming of external consultants and input; the encouragement for neighbors, friends and families to visit; and the intimate knowledge of the region by the state's program specialist.

The agency's philosophy stresses that the person is most important, and an atmosphere is promoted whereby people can check on each other and bring up issues. As one staff member explained, "It is important to remember that it is their lifestyle, not exactly ours. We need to be sensitive, supportive, but not pushy. We are good at asking each other, whose agenda is this?" Anyone can call a meeting no matter what one's role. As another staff member explained, "If anyone has a problem, the door is always open. It is just okay to say things." For example, when people felt that the nursing care for one person was not adequate, several staff called a meeting and said it wasn't fair to the person to have this amount of nursing care.

David is concerned about any movement that would include independent case management in national legislation. His main concern seems to be that this kind of decision cannot be made through national policy. As he describes:

> And part of what I am fearful of...is the wisdom of (this) sort of thinking that there is an answer in national legislation that will tell everybody how to do it...[Through] P.L. 94-142, we created in a lot of places in this country an exclusionary system that gained a tremendous amount of support from what became a set of court decisions that justified professional judgment to set up a continuum from the least to the most restrictive environment. That wasn't what anybody thought; that wasn't what I thought in '78. But, that is what happened and that is what it became. We don't want to do that again with case management and a piece of federal legislation.

Costs

The agency staff feel that they have been creative in keeping costs down, though some individual living situations are expensive. The residential director explained that they compared the costs of what it used to take financially to run the Durham group home five years ago with the costs where people lived now. The agency is spending the same amount of money on the average in the new situations, which are better suited to people, even without inflation being taken into account.

David has been looking at the financial figures and says it is not more costly to provide supports in this way. He continued,

> If we put someone who is costly together with someone who is significantly less (costly), the average cost of the household would drop. Would that be a better arrangement for the person? Probably no. So why would we do that? The average of the two is the same.

In looking at costs, he said it is important to compare the average costs, not simply to look at the expense of a single arrangement. Sometimes the cost of an individual situation may also look more expensive because of how costs have been allocated across cost centers.

While many of the agency's services are funded through the Medicaid home and community-based services waiver, David feels there is a lot of flexibility in the system on how money is spent. There are some problems with cash flow and time spent in documentation, but they survive alright. The area agency has had a tremendous amount of flexibility in being able to move money as the need arose, which David believes is not common in many systems.

In the past, it was easy to justify community costs by comparing to the exorbitant costs for poor quality living in an institution. In the future, David said, as institutions no longer exist, the cost issue will be examined in relationship to other costs in the society.

The State Role

David considers the state support the agency has had as critical in his "day to day reality." This includes an atmosphere in the state where one can speak up if one believes something "is not right." He believes state leaders have made decisions in the context of an overarching set of values about people and that many of the people are "very decent human beings." As David says, "Melvin Long (the state developmental disabilities director) really cares about people and about what is happening....Peter Sharp is an extremely good politician and...somebody needs to be good at that stuff."

Todd Van Nessen, the "Medicaid whiz kid" at the central office, has figured out how to make the fiscal situation work. He also has looked at situations, not just from his job role, but from the point of view of the people. For example, David says when they were "under the gun" to close Laconia, Todd called to see how many of the remaining people could move to this region. When David said they wanted to meet the remaining people, Todd reportedly replied,

> Yeah. That is great. That is something I'd hope someone would say about me if I'd been institutionalized for fifty years, that they'd at least meet me before they make plans.

The most critical person from the agency's vantage point is the field representative, who is the liaison between the area agency and the state office. David says, Mark Earles "is terrific..a major reason for the success here...he knows people; he knows what we are doing..He's a good filter of information, and that filtering is done within a very strong commitment to see to it that we get better at providing supports to people."

CONCLUSION

As one of the younger staff explained, her generation is looking for "frontier" issues that they can "fight for." In many ways, this agency has brought together people who are seeking a new way of being together with others, including with people with disabilities. They are involved in a process of learning what it means to "support what it is people want in their lives" and to "support" people to develop relationships and become a part of community life. As David concluded, while it may not be possible to do great things through services, certainly their experience in Region 9 in New Hampshire shows that decent things can occur in people's lives.

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