

STORIES

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PLANNING: A ROSE BY ANY OTHER NAME

by Phylinda Clark, Connie Saverino

Although Hazel and Dick are neighbors, they barely know each other. Their apartments are a block apart. Age, race, culture, and personalities would suggest that they were different. At first glance they would appear to be a study in contrasts. We met them in much the same way, in similar places - Skilled Nursing Facilities (SNFs). Although they came because of different circumstances, both were placed in SNF as a result of having no one to fight for them.

Over the years, Hazel and Dick have learned a great deal about fighting for themselves. We often wonder what is most important about these two; what they learned or what they have taught? They have taught us about the elusive and unpredictable qualities of person-centered planning. Dick and Hazel are into reality, and their reality has taught us that planning is really hard work. Sometimes it pays off, even when the planning doesn't go as well as we'd hope. It can be textbook, picture-perfect and be worthless.

Dick, age 44, had been in the geriatric skilled nursing home for over 22 years. Planning for Dick met with obstacles. He had friends, fellow patients that he would miss. Plans to continue relationships were met with refusal by staff. Dick would be able to visit them, but they could not visit him. The staff concentrated on readiness skills that Dick had yet to master; they tried getting rid of his guilt, but Dick was a kind and sensitive guy who didn't want to hurt anyone. His actual planning and mapping meeting turned into a three-ringed circus by SNF staff. The social worker looked at the drawings on butcher-paper from felt-tipped markers, and said "this is a very nice guy". In a video, that was taken during a party, she's seen patting Dick's friend on the back to reassure him "no one is coming to rip you away". It was difficult to elicit cooperation, even with the most basic preparations for Dick's move. The

process of finding a roommate and finding a place went quickly, perhaps too quickly. When the "match" between Dick and his first roommate didn't materialize; and the apartment's bathroom wasn't made more accessible to wheelchairs, Dick remained optimistic. Soon we were back to the drawing board, but instead of finding a roommate - two roommates materialized, that are now Dick's closest friends. We located another apartment that was large, roomy, and with only minor alterations to the width of the bathroom door, it became accessible to wheelchairs. To look at, Dick's busy life - filled with friends, hobbies, and outside activities— one would not know that the initial planning for this long awaited move to the community fell through. It all went the way we hoped it would.

Hazel too was anxious to move from a skilled nursing facility. After her mother's death, her supports had slowly fizzled away. We provided support for Hazel for a year, while she lived in a facility. This put us in a position to become acquainted with her, and evaluate what her needs would be once she placed in her own apartment. The recruitment of finding a roommate hit every road block imaginable in spite of picture-perfect planning. When one was found, within days it would fall through, these things would happen even before an apartment search was underway. Cindy came, a roommate for Hazel; the road began to look smooth. We made acquisitions for an electric wheelchair to improve Hazel's mobility. It didn't fit. Hazel didn't want to start over, she was exasperated with the process. Cindy and Hazel got along famously. Hazel was getting out of the apartment, got involved in her church, she took classes in the local recreation center for seniors, and was on the advisory committee at the agency.

Over the next few months events began to occur that gave concern about longevity of this living arrangement. Cindy began to complain of back pain. Hazel's care grew more demanding as her health began to deteriorate. Cindy became engaged; planning gone awry! We were committed to Hazel, so we pieced things together. Cindy transferred to

another job within the agency but lived with Hazel until a roommate could be found. This process was lengthy. Hazel was specific about her personal needs and the qualifications and characteristics her roommate must possess. During all this Hazel's health got worse; she had to be hospitalized. Because she was now had to be placed on a catheter and a oxygen tank, a home nurse was assigned to come in weekly. Still supports were not in place. We continued to have regular, daytime support during the week, but sleep over support was rotated. There was no one to share expenses with Hazel, now that she had no roommate. The agency had to pay the rent. Hazel made a living will, in it she stipulated that no life support, even the ventilator that the doctor had recommended, was to be used. Meeting and planning sessions took a grim turn. Since Hazel was adamant about remaining in her own place, we were committed to helping. Her struggles continue, a fair hearing for additional needs is pending. Never have we planned so much. Planning, listening, and making commitments are all good, but doesn't guarantee anything.

What we do know about planning with people around their own unique capacities and needs is that nothing that makes sense will ever happen. It is elusive and unpredictable because it reflects the hopes and needs of real people; people like Hazel and Dick.

ROCK BOTTOM AND IN THE CORNER

by Andre Shaw, Sacramento Vocational Services

Jake was born with Cerebral Palsy (CP). The CP, however, was only one strike in a life that almost struck out. He had enough money set aside to take care of him for the rest of his life. He had other plans. He was an angry man with a hankering for a rough crowd; a biker crowd. Even though in a wheelchair, he rode a motorcycle (with the assistance of his "friends"). After his recovery from a crash, Jake rented a house. He was "taken care of by the same "friends". "Taking care" of Jake consisted of pumping him full of drugs, stealing his money, and neglecting to feed or dress him. When Jake was rescued by the State, he was found in the corner of the house with no clothes on, and flat broke. With the help of his county conservator, he was able to slowly piece together his shattered life.

After seven years of strict supervision and little control of his life, Jake and his conservator agreed it was time to take another big step forward. He chose and began to receive Supported Living Services, the heart of which is person-centered planning. This gave him the opportunity to begin making choices in a monitored environment. His long-termed goal was to become un-conserved and independent. With the help of his circle of support, in the context of developing a Personal Futures Plan, he talked about his problem with drugs and his bad choice of friends. He talked about his desire to exhibit his artwork. Also, he would like to tutor other disabled adults on how to use communication devices and electric wheelchairs.

He has thought about living in his own apartment; he knows the exact apartment complex he wants to live in, and who he wants to be his roommate. Jake is now seeking help in collecting furniture and utensils. His plans are to attend the community college. In his Individual Support

Plan (a vision-based planning tool), he has made clear the need for adaptations to aid him in his apartment. Jake also knows that if he blows it, the opportunity to live on his own and gain independence, may not come around for a long time.

Jake has a long way to go, but he has begun the journey. With the supports available to him and backed by the belief of his friends, it will be a journey that Jake will accomplish.

DOING IT ON HER OWN

by Nikki Seid, Sacramento Vocational Services

Joanne was living in a skilled nursing facility and was miserable with the living conditions. She felt she had no freedom and little control of her life. Her friends couldn't visit whenever they wanted; they were even asked to leave a few times. Joanne realized that there had to be a better way to live. Her parents wanted to keep her in the nursing home because they knew she would get the care she needed. They may have felt that they were helping her, but they actually were holding her back and making her very unhappy.

Joanne was introduced to Community Supported Living Arrangements (CSLA) and it seemed like a way out. She knew that this was the solution to her misery. She was on the CSLA list and hoped her number would come up soon. Her parents were totally against the idea, and threatened to take her to court to become her conservators. It was hard but Joanne had to go against her own parent's wishes and think of herself first.

Joanne realized that she could get her own apartment, and began thinking about what she needed to do. She talked to friends about roommates and aides; she found them to be a great deal of support. When she began looking for apartments, her parents realized that she was serious. They decided that they were not going to stand in the way of her happiness, and began to support Joanne. The pieces of Joanne's life were now starting to pull together.

Things got so bad with her living arrangements, Joanne decided she would not wait for CSLA. She and her roommate found an apartment and began setting up a thorough system to make the move successful. Her parents even helped to furnish the apartment. They were very impressed with how well planned things were. Joanne knew that one mistake would turn her parents against the whole idea.

Now, Joanne lives in her own apartment. She has hired three aides, and gets support from her roommate. She made some difficult decisions in order to take control of her life. She is now very confident and also proud of her accomplishments. Joanne attends the local community college and wants to share her success story with preschoolers. A person is not limited because of their physical disabilities, and anything can be accomplished if you try hard enough.

MATT KNOWS

by Scott Donant

I first met Matt a little over two years ago. It was at a Interdisciplinary Team meeting, at the Intermediate Care Facility (ICF) that he was living in. He stayed to himself. Matt didn't care about what was going on in the meeting or who I was. He just wanted to spend some time with his dad. After about five minutes of sitting in the meeting, he got up and left. He was the smart one.

The Recreational Therapist did not know what to do, Matt was not interested in playing any games; the Speech Therapist did not know what to do, he did not want to communicate; nor did the ICF staff, because he kept trying to escape. It took about ten minutes before I realized what they meant by "he went for walks whenever he wanted to". The ICF board described Matt as stubborn, lazy, bull-headed, and wanting to do only what he wanted to do. Matt thought of these as pretty admirable qualities.

During the next two years, I heard stories about Matt escaping. One time, he took the lock off the gate, went out of it, and then re-locked it. The staff's concern was that he had left but I was amazed at how creative Matt was. What else was Matt capable of and not showing us?

Matt perceived me as being the person that got him out of ICF meetings. Whenever I arrived, Matt would immediately grab me by the hand and drag me out the front door. If I had to talk to someone else, it would have to get postponed. Once we got outside the door, he would never be specific about what he wanted to do; but it was clear that he didn't want to be there. When our time had ended, Matt didn't want to get out of the car. It seemed as if I had to drag him back inside. The ICF staff often commented that it was obvious I was important to Matt. I was the only person, outside his family, that he was excited to see.

Through the use of person-centered planning, Matt has a completely different life. He did not verbally indicate what his desires were, but to his circle of support, it was clearly obvious what Matt did not want. Instead of trying to plug Matt into available services that were not always appropriate, we started to look for services for what we thought he wanted. Sometimes we were right, but if not, Matt would let us know.

Things are different for Matt now. Matt is living in his own home, he rents with two other people. When he first moved in, staff was concerned that he might leave without letting someone know. We considered putting alarms and bells on the doors, but later decided not to. In the last nine months, Matt has not left his house without taking someone else with him. It appears that he likes where he lives. He no longer pulls me out the door; he pulls me over the threshold of his new home. Unfortunately for me, Matt does not think I am special anymore, there are many people in his life that are special to him now.

MAKING MY OWN DECISIONS

by Orange Redmond

Living at United Cerebral Palsy, 105th Street, wasn't as easy or fun as it is now. I couldn't make any choices, about the food I ate, the places I would go, or how late I stayed up. I didn't have my own money, to pay rent or spend the way I wanted to.

Now, through Supported Living Program, I am involved in planning my own future. I have the freedom to my own decisions about my life. My friends and I have the freedom to do what we want. My life is better because I'm independent and in control of my life.

CHAIRS ARE OVERRATED

by Diane Turnball, Sacramento Vocational Services

Karen has been living in her own apartment for three months now. Prior to that time, she had lived in a Skilled Nursing Facility for approximately 15 years. While she was there she lost contact with her family, became more isolated, and consequently, began to exhibit more "behavior problems". Because Karen communicates mainly through eye contact and moaning, it was difficult for staff at the nursing facility to take the time necessary to figure out what she needed. As a result, she began to slap herself and scream when she needed something. This was clearly "inappropriate behavior", and the people at the nursing facility felt they could no longer serve her. Fortunately, through an innovative independent living program, Karen was given the opportunity to move into her own apartment, with a 24-hour support staff.

Now, Karen always has someone to "talk" to when she needs them and take care of her personal care needs as they happen. She is slowly becoming confident in her support people, and the care they gave her. Karen is much more successful at communicating her needs; through eye contact and positive response. As part of living in her own apartment, her staff conducts a house meeting twice a week. The first couple of weeks, they tried to sit around the table for meetings, but Karen chose not to participate, choosing to retire to her room.

The third week of the house meeting, the staff tried something new. They all sat around on the floor and talked about how things were going. Karen loved the idea that they were all sitting together on the floor. The staff *talked* to Karen, and she enjoyed being the center of attention.

At her first Circle Meeting, in her new apartment, Karen's sister came to take part in the planning process. They had not seen each other in eight years. Cindy, Karen' sister, said she could not bring herself to visit Karen

in the nursing home (because Karen was so unhappy there). It was a beautiful reunion, Karen smiled from ear to ear. Once all the members of the meeting were together, they all sat in the floor of the living room. Karen greeted each person, and the meeting started. It went a little long for Karen and she left to spend more time in her room listening to music. But, the important thing was that she did join the group, and felt like a part of it. Her staff anticipates that the more comfortable she gets with the support gatherings, the more likely she will be to participate in the planning process.

Things may not ever be perfect for Karen. She still gets frustrated when her staff don't understand her, and at times resorts to her old behavior. What's different is that the people consider her preferences, in facilitating her success in her new apartment and her new life. As a result, Karen is more confident and much happier.

"IT'S JUST LIKE CHRISTMAS": MAKING DREAMS COME TRUE THROUGH PERSON-CENTERED PLANNING

Christine Dixon, Mary Ellen Sousa & Deborah Tweit-Hull

Author's Note:

The following story was written for several reasons. Perhaps most importantly, we feel it's critical to take time out to celebrate the "victories" that touch all of us. Secondly, our collective struggles create a need to try to make sense out of the sometimes frustrating maze known as "the system." (In other words, writing this story was therapeutic for the authors!) Thirdly, we believe that sharing stories with others helps us to better understand and continue the work, which enables all of us to fulfill the basic dream of a real home. One final, but important note: Chris is clearly the "star" of this story. True we have formed a partnership and friendship, but without Chris' shared courage and sense of justice, we would still be at the proverbial "Square One." We're still learning, as writers, how to capture Chris' thoughts on paper using her exact words. We struggle with the reality that people who use labor-intensive communication systems learn quickly to speak very succinctly to facilitate conversations. This same skill, however, can make it difficult for the reader to follow the story.

With all of that said, we dedicate this piece to all the dreamers who are willing to do whatever it takes to make those dreams come true.

The Journey Begins

When we met for the first time, forty-six year old Chris was lying in a bed at a local hospital. Too weak to use her communication board, she gazed up to indicate "yes" and down for "no". She appeared frail, having lost more than twenty pounds from her normally petite frame. Extended hospitalization is difficult for anyone, but it becomes even more so when

one has significant cerebral palsy and relies on alternate forms of communication that hospital staff frequently misunderstand.

Approaching her one-month "anniversary" of being admitted via the hospital emergency room, Chris had already endured numerous invasive and frightening medical procedures and a discharge date was nowhere in sight.

We learned that Chris had lived with her family until she was forty-four years old. Following her father's passing and mother's subsequent health problems, Chris had no other choice but to move to a group home to obtain the support she needed.

Chris' understanding of the realities of her situation didn't help her "adjust" to group home living. She expressed this frustration, as well as her continuing grief over loss of her father, through her behavior.

Prior to her sudden hospitalization, Chris had spoken to Tom, her case manager/social worker, about her unhappiness; she wanted to move from the group home. But Chris was scared to make a change and fear of the unknown ran high. She lost her temper frequently and became frustrated easily. Chris and Tom worked out a plan. With Chris' permission, Tom referred her for Regional Center's CSLA "supported living" services. Bureaucracy being slow by definition, months elapsed. Then, Chris was hospitalized. Finally, we were "officially" invited to the hospital to meet Chris.

"Who is this Mary Ellen, anyway?!?" Chris thought to herself.

Our young agency, Creative Support Alternatives, assists people who have disabilities to live in homes of their choosing, secure employment, and establish a valued presence in their neighborhoods and communities.

Pretty basic stuff, really. Definitely not rocket science, as they say. But for people with disabilities and their families who have been surrounded—and sometimes consumed—by "special" services and programs, what we

do can sound somewhat unorthodox. And sometimes scary. So, as we met Chris for that very first time, we were struck by her quiet and gutsy determination.

"I thought I would go back to the group home, anyway. I did not think it would happen. But I was wrong."

We relied on a type of "Twenty Questions" to communicate, with Chris using her eye gaze to respond to yes/no questions. Tom was in the hospital room along with Chris' mother, brother, group home worker, the Regional Center nurse consultant, and of course, Chris. Due to a hospital-acquired infection, Chris was in isolation and we were all required to wear surgical gowns and masks.

Meeting us, two strangers with faces hidden by hospital garb, Chris was assertive despite her obvious pain and discomfort. She wanted to move out of the group home and she wanted our help to do it. (We couldn't help but feel honored. Chris had, in one short meeting, impressed the hell out of us. This was one persistent individual). And the irony didn't escape us; because of a newly implanted gastrostomy tube, Chris couldn't return to the group home even if she had **wanted** to...the home wasn't "licensed" to provide the type of assistance that Chris now required. Yet, she could move to her own (unlicensed) place!

Making Plans

We have learned that "Person-Centered Planning" doesn't—and shouldn't—look the same twice. More than just a different type of meeting, person-centered planning is a continually evolving process because that's what constitutes **life**. In other words, when the process is over, so is life. We know it to be a process of building trust, communication, commitment, and relationships. Person-centered planning represents opportunities to plan together, tackle challenges

head-on, celebrate triumphs, and re-group when necessary. Person-centered planning puts the individual in control, and others supporting versus supplanting that control. On that first day with Chris, we embarked on the journey together.

Over the next month, we visited with Chris at the hospital three or four times each week. We thought of ourselves as "running interference" between Chris and the hospital staff. At every opportunity, we modeled what we were learning about how to communicate with Chris. We explained her yes/no response. We tried to protect her from the day-to-day, unintentional insults that often characterize hospital life. We participated in physical therapy sessions. We assured the nurses that Chris was very much interested in communicating with them. And Chris continued to amaze us with her determined approach to regain what she had lost because of her illness.

We began to piece together a sort of composite picture of what Chris thought she wanted in her new living situation: one or two female housemates, a San Diego location, nearby stores and services and bus line access. We learned a lot about each other. We learned that there is absolutely no replacement for spending time together. Chris shared her fears with us:

"I did not know where I was going to live. I was scared".

Our continuing reliance on Twenty Questions sometimes proved frustrating. We felt uncomfortable knowing Chris' yes/no eye gaze response limited her only to choices we presented to her. She was restricted by our ability to creatively—and consistently—think of the "right" questions to ask. We continued to talk with Tom and Chris' family, asking questions about Chris' preference, experiences, important relationships, anything we could think of. We met with the group home service provider. She seemed genuinely interested in Chris.

She offered lots of practical information about Chris' routines, mealtime support techniques, and the difficulties Chris had with group home "adjustment." (To us, these "adjustment" difficulties served to further confirm her tenacity and sense of self).

Getting Down to Specifics

Together, we devised a housemate flyer: "I'm looking for a person who would like to: share a home (San Diego area, exact location flexible); make a friend (I'm 47, female, enjoy meeting people and going places); earn some money (I use a wheelchair and communication system—I need some help at home and other places, pay negotiable!) Interested? Call Creative Support Alternatives at _____ and they'll connect us!"

Chris chose bright red paper. We began putting the flyers up in several neighborhoods that met Chris' qualifications. Sometimes, we were forced to make what we called "educated guesses." For example, growing up in Chula Vista, Chris was unfamiliar with most of San Diego, yet because she was hospitalized we couldn't tour neighborhoods together. We talked to her about specific neighborhoods, looked at maps, shared insights...and listened. We put an ad in the Reader, a San Diego newspaper with a somewhat "alternative" slant. (The Reader ads also utilized a voice-mail message system, enabling us to explain beyond the actual print ad what Chris was looking for).

We also placed an ad in the San Diego Union-Tribune. The ad read: San Diego Area: Lkg. for F. to jointly rent apt./house, I use a wheelchair, nd. some assistance, pay negotiable. Lv msg. at _____. (The high cost of the ad forced us to be succinct!)

One day, while talking with Chris in her hospital room, she kept glancing at the shelf near her bed. After a few attempts, we understood: she wanted to try to use her communication board again. With her health improving, Chris had the strength to use her board. With a pen as her

"pointer", she slowly spelled out words. After nearly two months of "Twenty Questions", Chris excitedly talked □ via the communication board—for 1 ½ hours! Following the conversation, we said good-bye to an exhausted, but satisfied, Chris. Our spirits soared.

"It was great!! I could express myself!"

Chris' doctor let all of us know she was getting better. The physical therapists continued to help her gain strength and exercise her weakened arms and legs. We pushed the nurses to re-introduce foods to Chris. The doctor's orders said she could begin to try eating again, but the nurses were afraid that Chris would choke easily because of her strong tongue thrust. And their fast-paced schedules didn't allow much time for assisting Chris with eating. We began bringing in yogurt, ice-cream, anything Chris wanted to try (provided it was fattening—she had twenty pounds to gain!) We too were somewhat nervous about helping Chris to eat. Still, we made a point of letting the hospital staff see how we assisted Chris. We shared what we learned and dubbed it "subversive in-service training" for the staff.

Chris' sense of humor and wit increasingly came through via her communication board. The "Discharge Planner" informed us of the hospital's plans to transfer Chris to a county-run rehabilitation hospital (an old geriatric facility, really).

We gently tried to break the news to Chris. We feared that the transfer and additional weeks or months of institutional life would cause Chris' depression to return. After listening to us ramble on for several minutes, Chris used her communication board to interrupt. She had heard the Discharge Planner talking to some of her nurses. "It's a dump!," she said with a smile. So much for breaking it to her gently. (We learned that Chris had a friend who had lived at the facility for 23 years and she was quite familiar with it).

"I thought I might have to stay there. I thought they might keep me there."

Being There

Chris' fierce independence continued to unfold. In her group home, this strength came to be viewed as a behavior problem. In fact, Chris' Individual Program Plan (IPP) contained the following goal:

Chris will communicate her needs appropriately without tantrums by reducing tantrums to one or fewer per month.

Medication had been prescribed by a psychiatrist to decrease her anger and frustration. Everyone knew, however, that the medication merely addressed the symptoms, which Chris' real needs (i.e., a longing for control over her life and living situation) went unfulfilled.

On the day that Chris was transferred to the county facility, we met her at the door as she was taken out of the ambulance and wheeled in. We had promised her that we would be there.

"I was scared. I was glad you were there."

Our mission was clear: make sure the facility staff understood that Chris was there for physical therapy and rehabilitation purposes—in other words, this was a **short-term** admission. It was incredibly important to Chris that this be understood. Within moments, facility staff were taking charge, physically examining Chris, talking about her as if she didn't understand them, asking simultaneous questions without yet learning how she communicated. We had the sense of watching a movie and not being a part of what was happening. We tried to stay close to Chris, answering questions, assuring the staff that Chris was *only* going to be with them for a little while.

Chris' mom and a long-time family friend arrived to visit. We used the opportunity to chat, adding their comments and insights to the ever-

evolving picture of Chris. Facility staff kept coming in and out of the room, asking questions, signing forms. We found ourselves answering the same questions repeatedly. When it was finally time to go, everyone was exhausted. We were frustrated and tired. This was going to be more difficult than we thought.

On the third day after Chris' admission to the facility, we stopped by near dinnertime. A nurse's aide told me Chris would have to eat in her room because "the way she eats upsets the other patients." We flipped...and firmly told the aide that, "Chris eats the best way she can and if anybody has a problem with that, then *they* could eat in *their* room." We stayed through dinner, and it was never mentioned again.

Housemates and Houses

Weeks passed as we helped to screen potential housemates responding to Chris' flyers and ads. If the person calling sounded like she met the criteria set forth by Chris, we arranged to meet her. Generally, we would meet at a coffeehouse or restaurant. During these initial conversations, we shared things we had learned about Chris, what she was interested in, and the types of assistance she needed.

We listened—often between the lines—to learn everything we could about the potential housemate.

We avoided meeting in offices or other "official"-looking places, striving for relaxed and informal conversations. If, at the end of the conversation, the prospective housemate expressed a continuing interest and we felt comfortable with pursuing it further, we helped to set up a meeting with Chris.

Chris' health continued to improve. She made friends with the physical therapists and worked hard to regain her strength. It was tough and demanding work for her. She also resumed her employment program.

While we had mixed feelings about this because of the segregated nature of the program, we knew that the Chris' spirits would be lifted by seeing her old friends. We also knew that the agency was in the process of converting its service delivery to integrated, community employment.

Tom continued to be a helpful and supportive guide. He shared information on resources, advocated for services for Chris, and encouraged all of us by recognizing and reinforcing the progress being made. In turn, we made an extra effort to let Tom know just how much we appreciated him. His presence helped to personalize a large bureaucracy and make it more "user-friendly." We spent a lot of time together with Chris: going out to eat, supporting her involvement in the annual Self-Advocacy Conference, visiting with her family, meeting potential housemates, talking with the staff who worked at her employment program. Spending time together helped us to build a solid foundation for what we hoped would become a long-term relationship with Chris.

We tried to avoid an "us/them" attitude with the facility. Several people at the facility had, in fact, become quite supportive of Chris and her plans to move. Still, others there pushed the limits of our patience by their adherence to facility procedures and policies that made no sense for Chris. We forged ahead anyway, with Chris' sense of humor getting us over the rough spots.

After a number of meetings and conversations, Chris selected a housemate. Unfortunately, the housemate's family personal problems necessitated her backing out several weeks after the decision had been made. While we fretted over this setback, Chris had this to say,

"It's a part of life...it's OK."

We smiled at her philosophical approach and resumed conversations with potential housemates. We were learning a lot from Chris.

Two weeks later, Chris was introduced to another woman who captured her interest. She was a few years older than Chris, with her own business and an Old English Sheepdog. We talked at length about our approach: helping Chris to establish a living situation and housemate relationship based on equality and mutual interest, while identifying her support needs/schedules, what the housemate would like to do in terms of support, available compensation, etc. Simultaneously, we tried to keep the facility staff informed of our progress.

While a seemingly simple task, we were overwhelmed by the facility's inability to comprehend our efforts. We marveled at the collective ineffectiveness of having *too many* professionals. It appeared that they operated in total isolation from one another, even though they all worked at the same facility. The result was a frustrating web of rules and procedures, phone calls and requirements, none of which seemed to have any relevance to Chris or her plans.

In spite of those difficulties, we dove into the time consuming task of identifying an affordable apartment or house that met the requirements set forth by Chris and the prospective housemate. It became apparent that the prospective housemate was a busy woman, with more time commitments than we had initially believed. Still, we thought it would simply be necessary to involve additional supports to accommodate Chris' needs at home.

We used the Union-Tribune and Reader again, this time for available housing. We also tapped into personal connections and put the word out about what we were searching for. We realized one of the most difficult "requirements" was finding a landlord that would allow a friendly and personable Old English Sheepdog!

Finally, we located two strong housing possibilities. We arranged for Chris to see them and called the new housemate so that she might do the same. We were devastated when she informed us that her current living

situation had become unbearable. The previous night, she had made hurried plans and was moving in with a family she had met. The arrangement was cheap and relatively permanent. Chris had just lost housemate #2 and hadn't even moved yet! We wondered how long this was going to take.

"I wondered if it would work out. I thought I still might have to go back to the group home."

We re-grouped again and tried to keep our spirits up. We continued spending time with Chris and kept her family and staff from her employment program updated. They, in turn, encouraged us. They also provided much-needed emotional support for Chris during moments of self-doubt.

There were days when Chris seriously questioned her ability to make it "on her own." We thought it was a healthy and positive sign that Chris was sharing her fears, rather than turning them inward and becoming depressed or angry. We tried to be supportive, sharing our own stories of transitions: changing jobs, leaving home for the first time, moving cross-country.

Unfortunately, Chris later realized that she had made a mistake when she shared her fears with the facility's social worker. Rather than provide emotional support (as one would do for a friend who was questioning her ability to succeed in a new situation) the social worker told Chris that perhaps she really *wasn't* ready to be on her own.

The facility social worker had neither experience with, nor understanding of, supported living. She told other facility staff that Chris was not sure she wanted to move and, therefore, in need of "counseling".

We were furious with the facility social worker's response to Chris. We reasoned that if Chris didn't have what we considered to be very natural concerns over her impending move, we would have wondered if she fully

understood what we were trying to do. And, once again, Tom stepped in with a rational approach. He talked to Chris. He talked to a "neutral person" Chris trusted at her employment program. He asked questions and listened thoughtfully between the lines. And finally, he let us know that he felt confident Chris wanted to move into her own place and needed support to *believe* she could do it.

"I was sure. But I could not go back. I had to go on."

Meeting Mickey

While Chris wondered if she could really make it on her own, we wondered how long it would take to get things in place. We continued the housemate search, this time also looking under ads placed in the "roommates" section, rather than placing an ad. We thought it was somewhat of a long-shot: finding a person who wanted a housemate, who might also like to provide some assistance/support **and** had a reasonably accessible apartment or house.

We left messages with five different people who had placed ads. Of those five, we talked with a woman named Mickey. She sounded interesting and we liked her ad: "Clairmont Area, off I-5, near beach. Quiet college student seeks non-transient housemate. 2BR, 2BA. Laundry, Pool, Call _____."

After a brief phone conversation, we arranged to meet at her apartment. The irony of our "connecting" made us all feel fate was at work. Mickey was living in the same apartment complex where another woman we knew lived. That woman, who utilized the supported living services of another local agency, also had cerebral palsy and used an Epson communicator. Further, we had looked at the same apartment complex two weeks earlier—actually, the apartment right next door to Mickey's—as a possibility for Chris and prospective housemate #2.

The apartment was conveniently located near stores, banks, the bus line, a bowling alley, and even a nightclub called the "Volcano Club" (complete with two life-size dinosaurs perched on the roof!). Chris also had a long-time family friend whose name was, you guessed it, "Mikki." If it wasn't fate at work, perhaps it was at least a good sign! We liked Mickey and thought she met a lot of Chris' preferences.

We met with Chris again and arranged a time to meet with Mickey. We shared what we had learned about Mickey, the apartment, and the neighborhood. Chris anticipated the meeting with reserved excitement.

Several days later, we arrived at Mickey's apartment. She was friendly, a serious student pursuing a new career in animal health. She had a colorful past and her dry sense of humor reminded us of Chris. We talked about what Chris was looking for, as well as what Mickey hoped to find. As the conversation headed towards an end, we suggested that both women think it over and we'd touch base the following day. Mickey said that wasn't necessary from her point of view, she wanted to live with Chris! (Secretly, we were ecstatic. We liked her and thought she'd be a great housemate). Still, we sensed hesitation in Chris.

Via her Epon, Chris said,

"Go for it"

...but then slowly added,

"I'm not sure."

We feared that Chris' self-doubt was returning. But, at the same time, we didn't want to push her into anything. We agreed to talk again with Mickey on the following day. As we drove Chris back to the facility (we always joked that we'd never refer to it as "home"!) we talked about Mickey and the conversation we had just had. We tried to point out important aspects for Chris to think about, such as, compatibility, bus access, the neighborhood.

We dropped Chris off, leaving with a sense of uneasiness. We wondered if Chris would choose Mickey. And if she didn't, would it be because of Mickey, or simply her overall fears of being on her own?

We went to see Chris the following day at the facility. We chatted about a number of things until we couldn't stand it anymore and finally blurted out, "Well??" Chris was not-so-secretly enjoying keeping us in suspense. She then smiled and spelled out the following:

"Let's go for it."

"Are you sure? What *exactly* are you saying?", we asked. Chris' response confirmed that she did, indeed, want to go forward with Mickey. We were excited at the prospect of things moving ahead. To ourselves, we hoped it would all work out for Chris. We were optimistic, but we had been let down twice before.

We proceeded with plans: talking with Mickey and Chris, meeting with Chris' family, relying on Tom for negotiating funding and paperwork details. We joked about Chris' room having a view...of a Tyrannosaurus Rex! We continued to be buoyed by Chris' gusty determination. With the decision finally made and a move-in date set for two weeks away, Chris seemed genuinely happy.

The Final Days

Meanwhile, we learned that the facility had held what they referred to as a team conference. Chris was not invited, nor was Tom or anyone from our supported living agency. Still, the "team" had decided that Chris was not ready to leave and needed to stay at the facility for another month.

Once again, we felt we were watching a movie unfold which we had no control over. We still tried not to adopt an "us/them" attitude, but knew we felt that way in spite of it all. We could hardly believe that they were

making decisions, which greatly affected Chris without her input.

At issue was Chris' weight and gastrostomy tube. We met again with Tom and the nurse consultant from the Regional Center. Their support proved invaluable to Chris, as well as those of us trying to assist her. We reluctantly postponed the move-in for one week.

While we were committed to supporting Chris with or without the gastrostomy tube in place, the facility wanted her to gain more weight. We wanted her to be discharged with the physician's approval versus AMA ("against medical advice"). According to the staff, she had lost two pounds since the supplemental gastrostomy tube feedings were discontinued a week earlier. Chris did her part by eating full meals and snacks three times per day, even when she wasn't really hungry. And we continued planning with Mickey and Chris for the move.

A week passed. Our relationship with the facility social worker and physician became increasingly strained. We resolved to get Chris out of the facility by the targeted date anyway. Simultaneously, we were gathering up Chris' belongings from storage at her mother's house.

Together with Mickey, we helped Chris to set up her new room; we organized the closet and hung pictures on the wall. We looked forward to the Big Move with increasing excitement.

Two days before Chris was to move, we spent nearly five hours on the telephone advocating on her behalf. We were amazed at how many professionals - some who had barely met Chris!—wanted us to "jump through hoops" before officially discharging Chris. We were frustrated because facilities are not designed, sensitive to such issues as the planning and timing involved with a move (e.g., Chris was paying rent and had support people lined up...and waiting).

Finally, the big day arrived. We arrived at the facility. The physician discharged her with the stipulation that Chris be followed up by a to-be-

determined community physician. We had already lined up a home health agency to monitor our support for Chris' gastrostomy tube. We loaded up the car, said good-bye to some of the folks ("residents"), Chris had come to know, filled her prescriptions, and drove away.

We all sighed with relief. It had been a stressful week.

Home Sweet Home

Together with Mickey and Chris, we finished setting up Chris' room. By the time we finished, it was after 10:00 p.m. We helped Chris into bed and pulled the blankets up over her. She was exhausted, but as we said good-night she broke into a huge smile that clearly said, "we did it".

Chris' move was actually the beginning, rather than the end, of the story. We know that every life had many endings and many beginnings. Chris and Mickey have lived together for nearly two months now. They are developing a terrific relationship. Her gastrostomy tube has been removed and the scar has healed. She has gained over ten pounds and, according to her brother, looks healthier than she ever has before.

With our support, Chris has joined a self-advocacy group and is on the steering committee for the annual self advocacy conference. She is attending the monthly Regional Center Board of Directors meetings and has applied for a seat on the Board. Plans for getting a job and taking a community college class are in-the-works. Her relationships with her family members have deepened, along with her new self-confidence. She's meeting her neighbors at the apartment complex and making new friends. Chris has a new life and has taught us many things.

We look forward to continuing the journey together. When asked what it was like to finally have her own place, Chris said, "It's just like Christmas."

Chris

Hello. My name is Chris. I am really happy to be here today. I am going to share some things with you about my living situations. And then, if you like, you can ask me any questions.

I grew up in a home with my mom, dad, my brother Tim and a day-time housekeeper. (A real wholesome Andersons-type family like the one from "Father Knows Best.") After high school Tim moved out on his own. I continued living with my mother and father.

In March of 1989, my mother had a stroke. She continued to live at home but needed assistance with daily living. She lost her speech. (Though, I am happy to say, as time went by, she regained it.)

In October of 1989, my father got ill and passed away. Then I just lived with my mom. Due to my mother's stroke, she needed assistance with living, which made it difficult for her to take care of my needs, too.

I had to leave my home though not by my choice. I was placed into a group home. It was a very uncomfortable situation. I was so used to my lifestyle, with my biological family and my home.

And there I was, living with a houseful of strangers with a whole new set of rules. I was afraid. The way my needs were being met, the expectation of my abilities, my privacy, and the personalities of the people in my home were all different. It was a very rough time. As time passed, I became more accustomed to the routine and adjusted. It was my first taste of being on my own (or so I thought).

Still, I was having a hard time. I was frustrated and very unhappy. I know the people at the group home cared about me. But I felt like I was being worked to death...lots of goals and plans and such. They even had a "class" to teach me how to drink...that made me feel bad. I just wanted a home of my own.

In late 1992, my case manager, Tom, referred me for supported living services (CSLA funding). I was scared but wanted to make a change. But in early February 1993, I became very ill and was hospitalized for 2 1/2 months. I lost 25 pounds and a lot of my strength was gone. I couldn't even use my old communication board. After recovering from my illness, I had to be placed in a nursing home because of medical reasons (with another whole set of rules). Again, this was not by choice. I was afraid when I first went there. Again, I became accustomed. Overall the people there were nice. They really took good care of me, but I knew I didn't want to spend my life there. It was a very old place with lots of old people and it made me sad.

Then a very special person came into my life, Mary Ellen. She reassured me that I wouldn't have to spend my life there. She helped me with the opportunity to live in my own apartment with a roommate. I chose the person that I wanted to live with, we made the rules together, I can go wherever I want, whenever I want. (I can use the elevator to get to my apartment on the third floor by myself!) I eat what I want, when I want. I do my own shopping and banking, and I have my privacy when I want it. I enjoy old movie classics on cable. I have fun with my roommate Mickey's pets -- Pinto, Shakespeare, Aldo, and occasionally, "rescued orphans." I should add something here. I've been on my own for nearly six months. I'm starting community college part-time in late January. I went to visit the people at the group home for the first time last month. It was neat to see that they are proud of me. I'm also getting involved in self-advocacy meetings. And I have interviewed for a seat on the San Diego Regional Center's Board of Directors. I have lots of plans and lots to do.

TWO WAYS TO DESCRIBE MARY AND TWO WAYS TO PROVIDE SERVICES FOR MARY

Margaret Kane

The Traditional Way:

Mary is a 34 year old woman with a diagnosis of moderate mental retardation with moderate neurological deficits, depression and congenital hemiatrophy. Mary has a history of a) "behavioral outbursts" (i.e. yelling, screaming, cursing, self abuse, and threats of physical aggression) occurring at a rate of at least once per month; and b) bossing and threatening peers (in the group home and community) occurring at a rate of 5 times per month. The behaviors identified above can lead to AWOL behavior and/or "physically intrusive behavior" (i.e., hitting, scratching (self and others) and throwing objects). Mary also has a history of crying and screaming several times per day and several hours at night. Mary has tantrumming behavior as well (throwing herself on her bed and throwing objects in her room). The tantrumming occurs at least daily. Mary is on both Mellaril and Klonopin.

Mary tends to move from group home to group home either because she can no longer tolerate the staff and peers, or because neither the group home staff or peers can tolerate her. Mary has also moved from sheltered workshop to sheltered workshop, these moves have been generated by both being demitted for "behavioral outbursts" and by moving out of the area.

Key to Mary's success will be concerted effort to reduce her "behavioral outbursts". Mary will benefit from living in a group home with a staffing ration of 1:3 or possibly 1:2, and with the implementation of a behavioral plan designed to reduce her "outbursts".

Mary will also benefit from working at a day program with a similar staffing ratio, and with a behavioral component. Stabilizing Mary's environment will hopefully create more independence for Mary and will eventually expand her options in the future. A service plan will be developed to reflect Mary's needs.

The Person Centered Way:

I am Mary. I can't remember how old I am. I like people and I like to help people. I want to help handicapped children. I want them to feel loved and not be so lonely. I want a volunteer job at Children's Hospital. I want to live in my own apartment. I don't want to live in a group home all of my life. I am not a baby and I feel bad when I am treated like a baby.

I want to go out whenever I want to and I want to sing in the Church Choir. I don't want to work in a workshop because they make too much noise and everyone is always yelling. I sometimes do bad things and say bad things. I don't want to do that. I should be treated like an adult and not like a baby. I need to learn how to take care of myself. I want to learn how to cook. I want to learn how to wash my own clothes.

Key to Mary's wishes is the opportunity to live much more independently than she currently lives. Mary will be assessed for Independent Living and will either receive ILS Training or will be referred to Supported Living. Possibilities for a volunteer position at either a Hospital or a Child Development Program, with natural supports, will be explored and secured. Supported Work possibilities will be explored and secured. Hopefully, as Mary's wish for independence is encouraged and enhanced, Mary will experience a reduction in her frustration level, and she will be less hampered by "doing and saying 'bad things'". A service plan will be developed to reflect Mary's wishes.

LAUREN'S STORY

Susan Ferrell

At age 22, Lauren faced a major life change. She would no longer be eligible to attend the County Office of Education Special Education program at Shasta College. This was a totally integrated, individualized program in which Lauren worked in the cafeteria and in the laundry, took adaptive physical education and cooking classes, rode the public bus to go on shopping outings and ate lunch with her friends in the college cafeteria. These activities sound fairly run-of-the-mill but, given the extent of Lauren's handicaps, it was anything but ordinary for Lauren to be participating in so many "normal" activities.

Lauren was brain damaged at birth. She has a diagnosis of spastic diplegia (cerebral palsy with no functional use of her legs), severe mental retardation (the last formal test she had put her mental quotient at 18 months) and epilepsy, which is totally controlled with medication three times daily. She does not speak except to say, "hi!, all done, and mom". She appears to have the receptive vocabulary of a 2-3 year old. She is not toilet trained, and she needs assistance with all daily living functions. She is in a manual wheelchair which, when motivated, she can move from point A to point B.

Lauren is also a real charmer. She has a wonderful sense of humor and an infectious laugh. She has a strong sense of self-worth, and she likes being in situations where she can be in control. She has learned over the years how to manipulate people and situations to get her way, and she has learned ways of communicating her basic needs to her care providers.

I am Lauren's mother. Her step-father and I saw a lot of positive changes in Lauren in the two years that she participated in the Shasta College program, and we were anxious for her to continue to grow and develop in the new adult day program that she would be attending. We had par-

anticipated in (in fact, initiated) transition planning meetings with staff of the adult day program with the hopes that her new program could replicate to some degree the community-based model that Lauren would be leaving behind.

Unfortunately, after six months of meetings, phone calls, notes, observations, anger, frustration and tears, it was obvious that Lauren had taken, from our perspective, a giant step backward. She was in a center-based program and only got out into the community for short outings two times a week. She had no job assignment, and her days were filled with activities such as current events discussions and bead stringing. The heartbreaking aspect of this to me was knowing that this was all that Lauren's future would hold.

This was not a transition program or a temporary assignment that was a "filler" before the next exciting opportunity came along. This was the only program in town for low functioning adults, so it appeared that Lauren's future would be a succession of useless strings of beads and non-verbal discussion groups.

It was about this time that I met Ann Turnbull of the Beach Center for Families and Disabilities at the University of Kansas. She spoke at a conference that I attended about how she and her husband and a group that she called an Action Group had turned her autistic son's life around or, in her words, because of the Action Group her son "got a life". In so many ways her son's story paralleled that of Lauren's that when I left the conference I was determined that Lauren too could "get a life" in the community doing meaningful activities.

Within three weeks Lauren's first Action Group meeting was held. There weren't a lot of people, but they were the people who knew Lauren best and could help with planning her future. Those attending included the Director of the County School's program at Shasta College and an aide from that program who had worked with Lauren during her two years at

the College, her Regional Center Service Coordinator who would be instrumental in getting Regional Center funding for this program, a past teach of Lauren's, and a close family friend. Over the past year and a half as Lauren's horizons have expanded, other people have joined her Action Group, but generally the core group has remained consistent.

The Group met every other week for the first two months. Each meeting had a formal agenda, and members left each session with an assignment. In two months, we mapped out what a day program could be for Lauren, got Regional Center approval for funding (I am vendored as a family day care provider), hired staff, and on January 21, 1993, began Lauren's adventure.

What types of things can someone with Lauren's limitations do? She does mobility practice at the mall with the seniors and others who use the mall for exercise before it opens in the morning. Her attendant does not push her but does offer verbal prompts. Initially, she would sit just inside the doorway and complain; now she cruises the mall saying hi to her new friends there and sometimes taking a break with them at the donut shop if she can push herself that far!

She attends Shasta College for adaptive physical education twice a week. She tried adaptive art, but was bored and gave that up before the semester was out. She attends a handicapped horseback riding program in another town. She loves music, so she now takes a private music lesson once a week with a young gal who teaches fiddle.

I must have spoken to ten different music teachers before I came across Tricia, who has never worked with anyone with a handicap before but was willing to give it a try. She has been teaching Lauren basic rhythm (clapping and using a tambourine) and also encouraging her to sing, which she enjoys doing (she now sings "alllll done!"). Once a week Lauren goes bowling with a friend who is also in a wheelchair. They use a ramp to get the ball down the lane, and Lauren has actually broken 100! Todd,

her bowling friend, recently turned 30 and Lauren received the first birthday party invitation in her life for his big 3-0 celebration.

Lauren also shops for all of her own personal items and special food items from the grocery store. Lauren's generally good disposition would often turn sour and she would very loudly tantrum when she went in the grocery store. Now she generally enjoys her short jaunts in the store. She has to carry the items to the check out stand, give the clerk her money and carry the bag to the van. It was wonderful when I went to the store after work one day and was told by the check-out clerk how much improvement he had seen in Lauren's behavior when she's in the store!

Lauren also has a few jobs in the community. At the college, she had learned to hand towels for folding to a co-worker. I approached a local exercise club and even though I was not a member and I didn't know the owner, he was willing to have Lauren do the same thing with the towels that they wash and dry for their clients. Sometimes Lauren has to be removed for a short time-out when she doesn't want to do the job but since it is a job, she must go back in and finish. She is generally there for 15 minutes twice a week, which is about the limit of Lauren's tolerance for that type of activity.

Another job that a member of her Action Group found for Lauren was being an aide in a pre-school class at the YMCA. Lauren went for music and story time (her favorite) and she would do things like hold up a felt board in her lap for the class to see while the teacher attached items depicting the story. The 3 and 4 year olds were told about Lauren by a member of her Action Group who visited the class before Lauren started attending. Although some of the children were a little uncertain about this strange visitor in a wheelchair when she first started attending, she soon became a favorite of the children and they each wanted to be the one that got to sit next to Lauren! I think Lauren wasn't the only one learning something from her being in that classroom! Unfortunately, the

class had to move to a non-wheelchair accessible room, so that assignment came to an end. However, she has been assured of a volunteer slot at a new integrated day care center that will be operated by the Easter Seal Society when it opens in about a month's time.

Lauren's program lasts 6-1/2 hours a day, and they are days that are full of normal activities. At home Lauren is learning to use a duster to wipe her dresser in her room and to operate an adaptive switch to use the blender to make her orange juice. She participates in putting her laundry in the washer and hands it to her attendant for folding. She stirs the pot when they make simple food items like Jell-O or pudding.

I feel I can confidently say that Lauren has a rich and fulfilling life. I do not want to underestimate the work that it takes to keep this type of program operating. One of the major problems in doing our own program has been keeping both attendants (one works three days a week and the other, two). One has been with us since before we started the day program; she was Lauren's after school attendant since 1990. We have had six people in the other slot, however, which has been trying for Lauren as well as her father and me. The current new person seems to be working out great, so we're keeping our fingers crossed!! The other major problem has been back-up on days when an attendant can't make it. It generally falls to her father or me to stay home from work on those occasions. I also now have to handle payroll for the attendants and deal with all of the reporting requirements that go along with being an employer. And finally, there are the constant schedule changes and the challenge involved in finding activities that Lauren can participate in and find meaningful. This however, is one problem that her father and I don't have to deal with alone; her Action Group is there to share that responsibility. Although they do not meet as often as at the beginning of the program, they do come together to help brain storm new activities for Lauren to try. We also, as a group, write her Individual Service Plan and semi-annual reports that I have to submit to the Regional Center. Clearly

this group is instrumental in keeping her program current and adaptable to Lauren's changing needs.

There is no question that, even with all of the negatives that I outlined above, I feel the program is well worth doing. I could not imagine Lauren back at a center with little contact with the "outside world". Lauren has taken on a new air of independence at home which is wonderful to see. Her temper tantrums are much less frequent, and I can take her into a public setting without worrying about how she will behave.

I hope someday I'll be able to turn Lauren's program over to a professional organization that is committed to full inclusion for all people, even those with severe mental retardation. Until that day, we will keep plugging along, doing our own thing, seeing to it that Lauren's life is a good life.