

DOCUMENT RESUME

ED 402 728

EC 305 260

AUTHOR Hulgin, Kathleen M.
 TITLE Jay Nolan Community Services: The Advantages and Dilemmas of Converting Quickly from Group Homes to Supported Living Services.
 INSTITUTION Syracuse Univ., NY. Center on Human Policy.
 SPONS AGENCY National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
 PUB DATE Sep 96
 CONTRACT H133D50037
 NOTE 26p.
 PUB TYPE Reports - Descriptive (141)

EDRS PRICE MF01/PC02 Plus Postage.
 DESCRIPTORS Attendants; *Autism; Behavior Disorders; Case Studies; *Change Strategies; Delivery Systems; *Developmental Disabilities; Family Involvement; *Group Homes; *Independent Living; Normalization (Disabilities); Personal Autonomy; Program Development; Quality of Life; Residential Programs
 IDENTIFIERS California; *Supported Housing

ABSTRACT

This report describes the experiences of one California's nonprofit agency which evolved, in less than 3 years, from supporting 65 people with autism and other challenging behaviors in 13 group homes to supporting 57 people who live in their own homes. The report describes the program's initial focus on providing integrated services in the group homes and providing community living services for individuals desiring them, and then the eventual decision to close all the group homes. Opportunities and strategies which contributed to this rapid transition are briefly summarized, noting the agency tradition of parental involvement, willingness to consider many alternatives for individuals, and utilization of diverse sources of funding. Current efforts in the evolutionary process are explained, including implementation of "circles of support" (in which the individual, family, and staff meet regularly and share decision-making); rearranged staff responsibilities (with emphasis on matching living assistants with clients); and continuous formal and informal staff development activities. Two case studies of individuals who live independently but receive support 24 hours a day, 7 days a week are presented to illustrate the positive effects of the change on the lives of individuals. (DB)

 * Reproductions supplied by EDRS are the best that can be made *
 * from the original document. *

ED 402 728

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION
CENTER (ERIC)

This document has been reproduced as received from the person or organization originating it.

Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

**JAY NOLAN COMMUNITY SERVICES:
THE ADVANTAGES AND DILEMMAS
OF CONVERTING QUICKLY
FROM GROUP HOMES TO
SUPPORTED LIVING SERVICES**

**Center
on
Human Policy**

**JAY NOLAN COMMUNITY SERVICES:
THE ADVANTAGES AND DILEMMAS
OF CONVERTING QUICKLY
FROM GROUP HOMES TO
SUPPORTED LIVING SERVICES**

**JAY NOLAN COMMUNITY SERVICES:
THE ADVANTAGES AND DILEMMAS OF CONVERTING QUICKLY
FROM GROUP HOMES TO SUPPORTED LIVING SERVICES**

by

**Kathleen M. Hulin
Center on Human Policy
School of Education
Syracuse University
805 South Crouse Avenue
Syracuse, NY 13244-2280**

September, 1996

Preparation of this report was supported by the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education for the National Resource Center on Community Integration through Contract No. H133D50037 awarded to the Center on Human Policy at Syracuse University. The opinions expressed herein are solely those of the authors and no endorsement by the U.S. Department of Education should be inferred.



INTRODUCTION

Jay Nolan Community Services (JNCS) is a non-profit organization that provides a range of services to people with autism and other developmental disabilities in Los Angeles, California. Since January, 1993, this agency has made remarkable changes in the way that it provides residential services. It has moved from operating group homes to supporting people to live in their own homes. This report is based on a visit to JNCS in November of 1995.

JNCS was formed by parent members of the Autism Society of Los Angeles in 1975. This history is important in understanding the agency's growth. JNCS was developed as an alternative to institutionalization for people with challenging behavior. It is driven by parents who have been actively involved in advocacy, legislation, and service development on local and national levels. They are aggressively interested in providing quality services for their sons and daughters.

Over the years, JNCS developed residential, vocational and family support services. It is the agency's residential services that have undergone much change and are the focus of this report.

By 1992, JNCS provided residential services to 65 people in 13 group homes. The process of shifting away from this service approach began when most members agreed that these individuals were not receiving responsive services. In fact, several of the homes were considered dangerous places to be for residents and staff, many of whom were getting injured regularly. Furthermore, there were growing tensions between administrators, staff, board members, and family members about who was responsible for this.

In response to these growing tensions, the agency invited a group of outsiders, people with experience in innovative services, to conduct an evaluation of JNCS. This evaluation was a pivotal point in the agency's growth. It provided a clear and harsh criticism of the agency's services, particularly the residential program, but also made enthusiastic and specific recommendations for change.

CREATING A FOUNDATION FOR GROWTH:

GETTING PEOPLE THEIR OWN HOMES

As a first step toward change, JNCS recruited as its Executive Director a member of the evaluation team, Jeff Strully, who was particularly passionate about setting a new direction for the agency. The agency was attracted not only to his passion, but also to his experience. He has children who have disabilities and has been very innovative in developing integrated services and opportunities for them. Jeff also has many years of experience in working to create integrated services within the broader system. When he came to JNCS he had a strong vision of developing integrated services for the people living in the group homes.

Initially, Jeff provided the opportunity for members of the agency who were interested to learn about community living. The agency hosted discussions with outside consultants and sponsored members to attend training workshops and visit other innovative agencies. Jeff also personally worked to develop the opportunity for several individuals to live in their own homes. As interest in this alternative approach began to build, a significant number of people began moving out of the group homes.

Though the initial approach was to support people who were interested, there came a point when the agency made a decision to provide only supported living services. Furthermore, it established December, 1995 as a deadline by which it would no longer operate group homes. This decision was based on the following considerations.

1. Many people still living in the group homes were in crisis. Several parents and staff explained that things were so bad, they believed something needed to change.

2. An increasing number of agency members saw that the lives of people improved significantly with the opportunity to live in their own home. They began to view supported living not only as a good option, but as a preferable alternative to the group home approach.

3. Supporting people in their own homes required new practices and ways of organizing that conflicted with existing practices. For example, the agency began by having group home managers maintain a supervisory role with people's assistants when they moved from a particular home. Over time, however, it was decided that it would be more effective to assign supervisory responsibilities based on relationships and geographic location of people's homes. To provide effective support, it would be necessary to rearrange roles and responsibilities.

4. Lastly, as people moved, it became too costly to continue to operate the group homes with fewer people living in them.

By September, 1995, all of the group homes were closed and people were living in homes that either their parents had purchased or that they leased. Several opportunities and strategies contributed to the agency's success in such quick change.

1. Agency decision makers were given the opportunity to learn from other agencies that were successful in developing supported living services. The JNCS board, which consisted mostly of parents of people receiving services, was personally committed to providing the best services available. A number of members believed in the concept of supported living and viewed it as "state of the art," but needed to know more about its implementation. One strategy was to invite an administrator from an innovative agency in the area to assist in developing services for the first few individuals who moved.

2. Jeff cultured the commitment and skills of a small team of administrative staff who personally took responsibility for developing new living situations with people and their families. One member of this team described how they often worked 80 hours a week during the transition period. She recalled, "It was really, really hard work, but it was so rewarding that even though we were totally wiped out, we felt the urgency to keep doing it...The thing that was the hardest and that took the most time but was totally worth it was meeting with people one person at a time. Jeff and I would go to every family's living room or to a coffee house or restaurant and meet with people and it would usually be about 3 or 4 meetings until people's fears and myths about supported living were demystified."

3. Early in the planning process, the agency began to clarify the issue of where decision making power should lie. Though the concept of supported living is grounded in the principle of supporting the choice of individuals, JNCS viewed this principle as a complicated one. First of all, many of the people the agency supports have not had the opportunity to know what they want in their lives and to complicate matters, many do not communicate their needs clearly. Second, JNCS has a history of strong parent involvement. As Jeff

explained, "Because of the heavy family involvement, people are not going to stand up, not right away at least, and say, 'Mom and Dad, I don't want to hear you anymore, it's my life'...not only would we be hurting the family, we'd be hurting the person, by trying to get them to draw this line, saying it's my decision now." The agency moved forward with the stand that supporting individuals also meant supporting their families.

Recognizing that it would take a lot of time to determine the preferences of individuals themselves, the preferences of family members were often used to guide the moving process. For example, many families wanted their son or daughter to live in a house rather than an apartment. Though apartments might have been a better choice for some people because of cost or other factors, some parents were concerned about higher crime rates in apartment situations and potential complications of "sharing walls" with others. One administrator recalled, "We did whatever it took for them to feel safe and to nullify their fears."

4. With respect to the needs of families to learn more about supported living, the agency provided the opportunity for them to learn from those who had begun the process of supporting their sons and daughters to live in their own homes. For example, several parents wrote short stories in the agency newsletter describing their feelings, successes, and concerns. This approach was more responsive to the needs of many families than formal kinds of learning opportunities.

5. There were some families who did not want their sons or daughters to move into a home of their own. JNCS respected their decisions and even though the agency would no longer operate group homes, these families were supported to choose alternatives. Some of

them chose to seek services through another agency, and a couple of people moved back home with their families. In another situation, several people continue to live together through an arrangement in which the former manager took proprietorship of a group home.

6. There were many staff who did not support the agency's new direction. After the initial period of giving people the opportunity to learn more about the approach, there was the expectation that staff be either "in or out." One administrative team member recalled a particular pressure point. The agency invited an outside consultant to facilitate a team building session during which it became obvious who was on board with the new direction and who was not. Several staff decided to leave following this session. Overall, the agency had a tremendous amount of staff turnover during the transition. New staff are hired based upon their belief in supported living. Though administrators believe in providing extensive opportunities to learn, they are convinced that someone must first be open to the approach.

7. JNCS made an agreement with the state that it would shift to supported living services without asking for increased funding. At the time, the cost of running the group homes was very costly. Jeff believed that it would continue to be costly to support some individuals, but that many people would be more satisfied in homes of their own, have less behavior problems, and therefore need less support. The agency also managed an agreement to receive their funding in a lump sum to allow for more flexibility. In fact, the overall cost of supporting people has decreased over time. The agency, however, does struggle with financial issues that are discussed in a later section of this report.

8. Several sources of funding were made available to facilitate the moving process. The agency was awarded eighteen Section 8 slots through the Department of Housing and

Urban Development that provided affordable rent for some individuals. A couple of other sources helped with initial expenses. The Autism Society of Los Angeles created a \$50,000 pot of money from which people could take no interest loans to cover security deposits and first month's rent in some cases. Individuals could make their own repayment arrangements. In addition, the state provided each person \$500 for necessities such as washing machines and refrigerators.

By September of 1995, the agency supported 57 people to live in homes of their own. Thirty-one people lived in houses that they rent or their parents purchased. Nineteen people rented apartments or condominiums. Forty-five of these individuals receive support 24 hours a day, seven days a week. About half of them have roommates who provide support. These situations are arranged with a combination of Medicaid waiver funding, supported living funding from the state, in home support services funding from the county, and people's Supplemental Security Income benefits.

According to the majority of families and staff see that the lives of people have improved significantly with the opportunity to move into places of their own. Most people are confident that this was a good move. However, there are still a number of people who range from uncomfortable to "angry and bitter" with the way things were done in this conversion process.

There were some things that in hindsight people wish that they would have done differently. For example, Jeff explained he would have closed the group homes one at a time. He was concerned that a number of people were shuffled from one home to another in the closure process.

On the other hand, the decision to move quickly, which was the most difficult part of this shift, for families as well as staff, was one that many people still stand by as a good decision for the reasons stated above. Agency administrators, however, have maintained an awareness of what this quick change meant for most people. Jeff concluded, "I think the reality is maybe only a half a dozen people, at maximum, went into supported living you know with a clear idea of it...Most of the people just followed." Another administrative team member added, "There was a lot of pressure because we changed so quickly that people either had to change or they had to leave. We have a lot of people who feel like they were forced into supported living. And even though they admit things are better, there's still some bitterness..."

Providing the opportunity for people to move into their own homes was the first step in this agency's development of supported living services. Members described it as a necessary foundation for supporting people to live the lives they choose. They no longer live in places that are owned or necessarily controlled by the service system.

MOVING FORWARD

JNCS is now working to develop ways of identifying and responding to the needs and preferences of individuals over the long term. In this effort, it has implemented circles of support, rearranged staff responsibilities, provided continuous opportunities for learning, and worked to gain system support.

Circles of Support

As explained earlier, the individuals JNCS supports are only beginning to explore their preferences and to complicate matters, most do not communicate clearly or directly.

Historically, families and agency staff and administrators have been the decision makers for people, often not in a cooperative way. The agency is now working to support individuals and the people who know them best, including their families, and assistants to meet on a regular basis and develop a process of shared decision making. This process, referred to as a "circle of support," has been helpful as well as problematic in the following ways.

1. The emphasis of the circles of support is on regular meetings to share information and work out differences. These meetings are the place where decisions are supposed to be made. In many cases, however, there is not full participation at the meetings. Some assistants choose not to participate. Some people's families do not want so much responsibility in their lives. Most importantly, many individuals themselves do not want to attend meetings and do not want them held in their homes. In most cases, people are getting to know and responding to the person's needs and interests through their personal relationships. As one assistant explained, "I understand Shawn now because we're friends." Several staff explained how they have become good at reading people's behavior. One staff person concluded, "...ultimately they are the decision maker because many let you know through their behavior." The circles provide an opportunity for people to share what they are learning about the person through their experiences.

2. Circles of support provide a way to share responsibility for failing to meet a person's needs and working to make things better. Supported living does not involve a specified way of doing things. Especially in the beginning stages of supporting an individual, it involves much uncertainty. Often people do not yet know what they want, and their supporters are learning to listen more effectively. One of the major reasons JNCS

implemented circles of support was to develop a sense of shared responsibility for dealing with uncertainty and the failures that can be expected from that. Jeff explained:

...everyone needs to shoulder the burden of decision making. When something goes wrong there's no one person to blame....Every once in a while families say, what do you think and I'll say I have this opinion, but this is not the decision and I need you to be part of the decision, because if I make the choice and something goes wrong, then it's my fault. But if we all make this decision and this choice, and something goes wrong, everybody can carry the burden of making that choice or making a mistake, and it really is the only way you can do this supported living thing.

Though in the past, staff may have been hesitant to relate difficulties to parents, they are developing a new sense of honesty and willingness to get problems out in the open.

According to one administrator, "No matter how awful something is, we'll all rush to contact people immediately." They are more confident that everyone is expected to be in this together.

3. In some cases, circles have provided a strong sense of stability in people's lives, and this has settled some families' fears about supported living. One administrator explained that through experiencing difficulty or crisis, families have learned that there is a group of committed people there. For example, if a staff person leaves, things do not fall apart.

4. In some circles, the process of meeting regularly and building trust has provided an opportunity to discuss and think through some complicated issues. Some people are beginning to express interest in things that make the people close to them uncomfortable.

For example, one man wants to go to topless bars. Another woman has decided she would like to have a relationship with a man. A staff person who lives with this woman said, "She's not sure what that means for her and neither are we." Rather than simply reacting to her, members of her circle are spending time talking about the possibilities.

5. The fact that circle meetings are routine has made it difficult in some cases for members to pay attention to the bigger issues in people's lives. The challenge ahead is to assist people in developing a social life. One administrator expressed the need to push people to "dream" again. For example, one man's parents expressed the desire to see their son have his own friends and a better job but are frustrated because staff do not have that vision yet.

In the effort to support individuals and this new decision making process, JNCS developed new roles and responsibilities for staff.

Redefining Staff Responsibilities

During the first two years of this change, administrative staff were given the freedom to continuously reorganize in ways that made sense. The staff roles that worked with the group home model did not make sense with this new approach. They were expected and given the flexibility to figure out a new way of arranging their responsibilities to support people. According to one administrator, "...it was a different way of doing services and...Jeff gave us the opportunity to try things out and fail, try things out and fail, and I think that was really valuable."

For example, they spent a lot of time figuring out how to organize the responsibilities of supervising and providing resources to the staff who directly support individuals. At first, the group home manager positions were converted to community living coordinator (CLC)

positions. The idea was to have the managers maintain responsibility for supervising the assistants of people who used to live in a particular group home. This did not work well for a few of reasons. First, people often moved a great distance, geographically, from one another. In some cases, the CLCs were travelling 45 miles between people's homes. Second, staff were becoming more aware of the importance of matching people based on relationships. In some cases, there were staff who really wanted to take on this role with an individual and their assistants because they liked and cared about them. Finally, some people needed more attention than a CLC who was typically responsible for six situations could provide. Now, the responsibilities of CLCs are arranged with consideration of location, relationships, and the level of support people need. Several CLCs have responsibility for coordinating the services of only one individual, while others are responsible for five or six.

JNCS has also come to think differently about the role of people who provide direct support. Overwhelmingly, assistants who have had success attributed it to the fact that they have a positive relationship with the person. Several assistants who support people whose behavior has improved considerably made comments such as, "It's all about our relationship." The chances of finding assistants who are compatible is increased by the fact that they are selected by an individual's circle. The reality for many people, however, is that it is very difficult to find assistants who work out well. In fact, several people have had an incredible number of changes in their assistants. One man had over 20 different assistants in the first year he lived in his own place. Now he has had the same assistants for almost two years. Jeff reported that this is a common experience, "Some relationships fall apart quickly and you start over again and then something solid emerges." He concluded that in the most

stable situations, assistants have included the people they support in their own circle of family and friends. In one situation, an assistant's sisters are also interested in providing support to the person.

On an administrative level, staff were given the opportunity to identify their roles and responsibilities based on their particular strengths and interests. For example, some people provide training because they are good at it, and others have taken responsibility for paperwork and finances.

The responsibilities of agency members have evolved through this process of change. Administrators believe they have a good structure in place now.

Providing Opportunities to Learn

JNCS is working to provide continuous opportunities to learn and to more actively engage members at all levels of the agency in the development of supported living services. It is viewed as an approach that is not simply adopted because it requires a change in thinking for most members. Creating new living situations and a new organizational structure were only the foundation for new thinking.

One strategy that administrative staff have used to keep members grounded in this new direction is to refer back to the agency's mission statement which includes a list of principles and beliefs. One administrator explained that members are expected to practice these principles in their work.

Another strategy is to provide opportunities to learn from each others' experiences. Staff members have been especially receptive to the idea of sharing their successes with members from other programs operated by JNCS. Once a month, staff from the vocational,

family support, and supported living programs get together for what they call the "all star salad bar" where they "celebrate" their successes and share ideas. This has been beneficial to all, but it is hoped to be especially helpful in influencing the vocational program.

During the three year transition to supported living, not much attention was given to the vocational program. It was simply too much to work on at once. Over time, however, members of the supported living program are increasingly anxious to improve the way people spend their days.

Another way in which staff from the vocational program are being influenced is through their participation in circle meetings. One staff person said his membership in an individual's circle has provided a good way to identify the person's interests.

In addition to these opportunities, JNCS has developed a mentorship project. It is based on the belief that typical one shot training is not an effective way to learn about supported living. Recently, an administrator led a session to assist a group of seventeen staff to learn about person-centered planning. She described it with excitement, "There's now seventeen people who know this stuff and are feverish about it. It's about passion and there's seventeen more people who are passionate. That's what this change is about." These staff will receive ongoing support to implement what they have learned.

One concern that a couple of administrators expressed is that the agency's learning must be grounded in the understanding of people's histories. They have seen what people's lives were like when they lived in the group homes versus how they are now. The reality is almost all of them have had significant changes in their behavior. One administrator explained, "It's amazing the difference in people, in people's violence basically. I mean it's

amazing the difference in people and there's a number of us around this table who have known these people, 6, 7, 8 years and have seen.. a difference of more than night and day." They believe that understanding this difference is critical in understanding the supported living approach and are working to record people's stories before it is lost.

Another concern administrators expressed is the need to get more of the agency stakeholders involved in learning including board members, families, and people with disabilities.

Gaining Support from the System

In addition to gaining the support of agency stakeholders, JNCS is working to build a more cooperative relationship with the larger system. The President of JNCS's board concluded, "We have to impact the system or we'll lose." Though supported living services have proved to be more cost effective than the group homes were, the agency continues to be spending more than it receives in funding. A major challenge to this agency is the fact that it supports so many people with intensive needs. As in most states, supported living funds in California are not adequate for people who need 24 hour support.

JNCS sees its responsibility is to push the system to recognize the difference this approach makes for people. It is working to have state level decision makers visit and get to know people personally.

THE DIFFERENCE IN PEOPLE'S LIVES

The following brief descriptions illustrate the changes that JNCS staff and families report have occurred in the lives of two individuals.

Shawn

Shawn is a 27 year old man who was one of first to move out of a group home. At the time of this visit, he had been living in his own place, a ranch home which he rents, for three years. He enjoys music and his walls are decorated with posters of some of the musicians he likes.

Shawn receives support 24 hours a day, seven days a week. Jon, who provides most of this assistance has been supporting Shawn for 1 1/2 years. Louie, who used to work at the group home where Shawn lived, has been supporting him for over 6 years.

Louie was originally skeptical of the prospect of Shawn moving to live in own place. He described his time with Shawn at the group home as non-stop crisis management. Shawn was frequently aggressive and staff restrained him sometimes a couple of times a day. There reached a point when the agency was planning a police intervention for Shawn's behavior and his parents were afraid he would be kicked out of the agency.

In retrospect, Shawn's father explained, "It got so bad, something had to be done, thank god." All of the people who knew Shawn then and now believe this move was the best thing for him. He still has problems but they are much less frequent and his assistants have developed a good understanding of what makes him frustrated. For example, Shawn is described as very particular. He likes certain things in certain spots and as Louie explained, "It's easier to accommodate Shawn now. It's much more difficult when trying to

accommodate four other people." Jon said he might have been "scared away" if he had known Shawn when he lived at the group home. He added, "When you get to know Shawn it's fun. He has bad days, but it's nothing. I understand why he gets mad because we're friends now."

Shawn has begun to develop interests and a few relationships. For example, people know him at the local supermarket and the Japanese diner where he and Jon go for brunch each Sunday. In fact, the waiter knows how Shawn likes his food and prepares it, without him having to ask. He is just getting to know his neighbors and is particularly friendly with one who recently invited Shawn to go to the beach. Shawn and his parents were most excited about his attending a Jethro Tull concert recently with his two brothers.

Shawn works as a security guard at a medical building three hours a day, five days a week. One of his assistants accompanies him and provides whatever support he needs to do his job each day. Afterwards they often enjoy going to the local Common Grounds coffee shop where Shawn has come to know the manager.

As the people in Shawn's life are getting to know him better, he is more satisfied and has fewer problems. His parents, Jon, Louie, and Don, the community living coordinator make up Shawn's circle of support. They meet regularly, but Shawn has only begun to participate. His parents attributed this to the fact that his experience with meetings has been negative and that in the beginning even circle meetings were too focused on the negative.

Shawn's mother described how this circle has grown over time, mostly in terms of people becoming more comfortable with each other. She explained, "In the beginning deep things didn't get addressed. Some things were just difficult to bring up. I think we didn't

want to hurt each other's feelings." Now there is trust that everyone has good intentions and they are discussing more difficult issues.

Shawn's parents have changed the way they think about what he needs. For a long time, they assumed, "Jay Nolan can fix my kid and I can go to my grave OK." Now they are more actively involved and excited about Shawn's future. He father concluded, "It is more involving with Shawn this way, so much more meaningful... The bottom line is that Shawn smiles a lot."

Jim

Jim is also a 27 year old man. He is a soft spoken man who communicates with limited words and phrases and with some people, he types. He has spent many years living in institutions, including a state hospital where he lived from 9 to 14 years old. Then he moved to a group home operated by Jay Nolan where over the years he had many problems and was put on a great deal of medication to control his behavior. When his parents insisted that he be taken off the medication, he was admitted to a developmental center for this process, but ended up there for over three years.

Much of this time was spent in legal proceedings through which Jim won the right to leave the developmental center and to receive services through JNCS. Part of the condition was that Jim have three staff with him during the day. JNCS made an agreement to do this provided they got the same level of funding it took to serve him at the developmental center.

While Jim was in the developmental center, JNCS had begun to develop supported living opportunities. Jim's parents had concerns that this approach would not work with him

because he needed so much support. Through the opportunity to speak with other parents and Jeff, however, they decided to support Jim to get his own place in May, 1993.

The first several months in his own place were very difficult. Jim continued to break windows which has been a long time problem and did have up to three staff providing support at a time. JNCS did not approach this as a situation in which Jim had to prove himself as it might have in the past. Rather, the emphasis was on developing more effective support. Jeff took the stance that, "The return of Jim to the state hospital is not an option."

During the first year, Jim had over 20 different assistants. His father believes staff changes and the lack of a good match for his son were a large part of his problems. He recalled problems with staff, "Most of whom were unable to accept Jim as a person and to communicate with him as a friend. Some attempted to control Jim, some viewed their job as babysitting, and others thought they had all the answers."

Things have improved significantly over the past year. He rents a small house. The biggest difference seems to have come through finding the right match in people to provide assistance. At the time of this visit, Jim still received 24 hour support but only needs one staff at a time. He has had the same three assistants for over a year. Jose and Raphael work Monday through Friday and alternate responsibility for sleeping at Jim's house. They have been friends since high school. David stays with Jim from Friday night through Sunday. According to Jim's father, he still has "occasional problems but at a level previously thought unattainable."

Jim has a job with JNCS delivering mail to the central office two days a week. He is learning to do his own shopping and banking and the tellers know him by name. For fun he

likes to bowl and ride his bike in the park near his house. Staff have invited Jim to parties with their friends. Most recently, Jim had attended a party with Kurt Miller, his CLC and stayed out until 4:00 in the morning. Everyone agree that this is a great opportunity which Jim really enjoys. Staff's friends treat him like anyone else. Jim's parents, however, think this is not the same as having his own friends. This is one of their dreams for the future.

Jim's circle is not as active as Shawn's. His parents are sometimes frustrated that not all of the staff are active participants in meetings. Their ideas about how Jim's life could be improved have become more clear over time. They would like to see him involved in more meaningful activities, particularly in terms of work. They also explained that Jim had a housemate at one point and has expressed that he would like another. His parents are enthusiastic about this idea because they thought Jim's place was "more of a home" when he had a housemate. They recall being invited over and offered a drink. This was a highlight for them.

Jim's father concluded that these are relatively minor concerns, given their history. Now that they see how good things can be, however, they have a sense of making up for lost time.

CONCLUSION

JNCS has accomplished a great deal in a short amount of time. The experience of this agency makes clear several lessons that have emerged from implementing a supported living approach.

1. The majority of staff and families believe that people with challenging behavior improve when given the opportunity to live in their own homes and to have positive relationships. It has been easier to respond to people's needs within the context of personal relationships and when they are not competing with the needs of several other individuals and the rules and pressures related to operating a facility.

2. It is possible to support people who have a lot of needs to live in their own homes with existing resources, but this requires loosening up and rearranging resources.

3. Supported living is not just about supporting people with disabilities but facilitating supportive relationships with the people in their lives, particularly with their families.

The process by which JNCS shifted to supported living services should be considered within the context of this agency. As agencies are making the shift from facility controlled services to supporting people to live in the community, they are doing so at different speeds and in different ways. The strategies that JNCS used were related to the agency's circumstances and characteristics. As described earlier, the decisions to convert its services quickly and to implement circles of support seem to have made good sense in this particular agency.

In moving quickly the agency avoided the many pressures and compromises that come from operating two conflicting approaches at a time. This decision also presents certain

challenges for the future. Though people are obviously more satisfied in their own homes, their living situations were arranged without a clear idea of their particular preferences. The challenge will be not only to assist people to identify their preferences but, to support those that may be different from their parents' or staff's. Furthermore, circle of support is a strategy that may or may not be effective as a decision making and planning process for an individual.

In reflecting upon the changes in people's lives, Jeff attributes the agency's success to the fact that members have been willing to look critically at their work. He stated, "We did not let ourselves think that things were better in people's lives than they were." JNCS recently hosted another external evaluation of its work (O'Brien, 1995). One of the conclusions members came away with is that while people's behaviors have decreased considerably and their lives are improved, that is not enough. The challenge they pose now is "How do we make things good?"

REFERENCE

O'Brien, J. (1995). Realizing the moment and moving on: Report of an evaluation of supported living services at Jay Nolan Community Services. Lithonia, GA: Responsive Systems Associates.



U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement (OERI)
Educational Resources Information Center (ERIC)



NOTICE

REPRODUCTION BASIS

This document is covered by a signed "Reproduction Release (Blanket)" form (on file within the ERIC system), encompassing all or classes of documents from its source organization and, therefore, does not require a "Specific Document" Release form.

This document is Federally-funded, or carries its own permission to reproduce, or is otherwise in the public domain and, therefore, may be reproduced by ERIC without a signed Reproduction Release form (either "Specific Document" or "Blanket").