



# **The Transition to Supported Living**

## **Realizing the Moment and Moving On**

Report of an Evaluation of Supported Living Services at

Jay Nolan Community Services

13–17 June 1995

### **Team Members**

Wade Hitzing

Connie Saverino

Martha Leary

Mary Ellen Sousa

John O'Brien (Team leader & report writer)

This evaluation was invited by the board and staff of Jay Nolan Community Services (JNCS) as part of their commitment to offer high quality supports to the people and families who rely on them. Team members share a commitment to the values and service practices JNCS has embraced, and balance experience in specialist service to people with autism with experience in developing and delivering supported living services.\*

Three team members have previously been involved with the JNCS. Connie Saverino co-led the 1992 agency evaluation and recently led a retreat for the agency board. John O'Brien has been an occasional consultant since 1993, and Wade Hitzing has visited once.

The team focused on learning from 16 people, 15 of whom receive 24 hour support from JNCS. These people were selected by JNCS's managers to allow team members to visit people in a cross section of situations. We met each person, visited their homes and usually the places where they spend the day, interviewed family members and other members of their circles of support, talked with some present and past staff members, and often attended a circle meeting. In addition, we met with the administrative team, the community living committee, and the board.

We conducted open ended interviews with each of the people and groups we saw. Our questions focused on perceptions of people's present and future situations and concerns about the quality of the support JNCS offers. Mainly, this report assesses what people told us. As we worked, we kept in mind a set of questions and hypotheses generated by the JNCS administrative team. (See Appendix.) In particular, those of us with a special interest in autism considered the possibilities for improvement in the way JNCS staff assist people with communication and behavioral difficulties.

This report represents the team's reflections on the information we gathered. We presented our observations and conclusions in two feedback meetings, which were attended by some of the people JNCS serves, family members and friends, board members, and staff. This report incorporates corrections and comments made at those meetings.

**Readers should qualify everything in this report:** It is based on information reported to the team as of the time of their visit. It is no more accurate than our ability to understand what people told us and showed us during relatively brief contacts. We used no standard measurements and made very limited observations of support staff at work, apart from our meetings and interviews with them. We had limited time and varying ability to accommodate the individual communication strategies of the people with autism we visited, so our report is based more on the perspectives of people who communicate more conventionally than it is on information provided directly by people with autism. We visited only about one in four of the people to whom JNCS provides supported living services. We only considered day services only from the point of view of the people we met, and we did not assess JNCS family support services at all. It will be as important for readers to note and discuss the ways in which they see things differently as it is for them to accept the team's perspective.

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\* Anne Donnellan and Martin Trout were also recruited for the team but, for health reasons, each was unable to participate. In addition to allowing us to learn from visiting six more of the people JNCS supports, their involvement would have improved the team's balance by involving two more people who are new to JNCS; including the perspective of a person who has received residential services and is a member of a Regional Center Board; and adding the insight of a person with rich experience in creating deeper practical understanding of the humanity and potential of people with autism.

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Our thanks to everyone who offered us their hospitality and generously shared their experiences and ideas with us. Because of your openness and candor, each of us who had the privilege of visiting you has learned important lessons about the challenges and the possibilities of supported living.

## **Realizing the moment and moving on**

Our title echos the tension signaled by the title of the evaluation report JNCS commissioned three years ago. The 1992 evaluation team expressed the depth of their concern for the well being of the people JNCS supports, and their sense of the agency's possibilities, in their choice of the title, "A moment in time: An agency in crisis." In their opinion, the part of the agency that gave the most concern, and showed the most promise for change, was its residential service.

In its residential service component, JNCS has largely resolved the crisis of mistrust and divisiveness that threatened the quality of its support to people with autism three years ago. There are still conflicts and difficulties, of course, but now there are ways to approach them that most people trust. People with autism, family members, board members, and staff have come together to realize the possibility of that difficult moment by transforming the agency from a group home operator to a provider of individualized supported living.

This transition is nearly complete. By January 1996, JNCS will focus all of its residential service resources on supporting people in their own homes. To the best of our knowledge, no other agency has made so complete a change from group living to supported living, for so many people who have complex needs for support and highly involved parents, in so short a time.\*

In itself, this achievement would have little significance unless, as a result, the people with autism and the families involved have better lives, and staff have working conditions in which they can better use their abilities in order to provide relevant support. The resolution of yesterday's crisis only creates the conditions within which the next challenges will appear; it does not signal the end of the journey, but a change in the terrain. The hard, fast climb to establish people in their own homes is nearly over. Now there are new opportunities and new problems.

## **Benefits and unrealized opportunities for people with autism**

No one described the changes they have made as easy, but no one we talked to wants JNCS to go back to operating group homes. Nearly everyone identified significant benefits

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\* Many other supported living agencies are larger, but they either serve a substantial proportion of much more able people, or they have grown more gradually, or they have grown by adding new people. The point here is not to award a trophy, but to describe the context for many of the problems JNCS faces now.

in the present situation, and everyone believes that JNCS is only beginning to learn how to make the most of these benefits. Some family members identify important shortfalls between what they were told supported living would be like and what they see happening. Understandably, the sense that “JNCS isn’t delivering what they promised” is stronger in families that accepted supported living from JNCS only when JNCS decided to close their son’s or daughter’s group home; given that the alternative was to seek services from another agency, than it is among families who initiated the exploration of supported living themselves.

### *Benefits*

These are the benefits for people with autism that the people we interviewed have noted since people have had support to move into their own homes.

- People live with significantly less violence. Not only has the violence created by grouping people decreased (violence initiated or triggered by other people with autism in a living group, or by staff trying to cope with violent behavior in a group situation), but there has also been a notable decrease in the number of times people injure themselves or “blow” (as many people at JNCS call violent episodes).
- Expenditures on repairing property damage have decreased significantly.
- A growing number of people have increasingly more personalized...
  - ...homes and home lives
  - ...schedules
  - ...matches to the staff who assist them
- People initiate more, at least in terms of choosing activities and influencing routines.
- Most people seem, to people who know them well, to be happier to be living as they are now than they were living as a member of a group. And, when there are important mismatches between what is offered and what a person needs and wants, there have been honest –if not effective– efforts by JNCS to come closer to offering what the person needs or wants. For example, there have been efforts make changes in the number and identity of roommates and in people’s locations as things don’t work out or as people’s preferences become more clear.
- At least three people with autism see themselves as welcome and valued members of another person’s circle of support, to the mutual benefit of all four people.

- People with autism have shown unexpected resilience and adaptability as they have experienced the ups and downs of establishing new homes. Either transitions have been smoother than many family members and staff feared they would be, or people with autism have mastered bumpy transitions and difficult situations. This is especially notable because some of the people who have responded well to major changes continue to find it unusually difficult to adapt to much smaller variations in their daily routines and rhythms.

In sum, the people we met seem to be on their way toward establishing a stronger base from which to pursue their own lives.

### *Unrealized opportunities*

There remain significant unrealized opportunities for people with autism. Naming these issues unrealized opportunities is not an exercise in euphemism. Only one cost to people with autism was mentioned as such: some parents are concerned that people with autism may not have as much contact with the people they used to live with in a group home as they might like.

Otherwise, with a very few exceptions which team members identified to JNCS staff and board members before their visit ended, the people we interviewed did not speak of problems created by moving into supported living. This is at least partly because we lacked the time or ability to interview the people with autism we met in depth and detail. We had no difficulty hearing of the costs born by family members and staff, so with time and skill we would probably have learned more about costs of the change from the point of view of the people most affected.

But mostly, people are looking forward, with high expectations.

- There is considerable variation in the extent to which people's homes and schedules and interactions reflect their own identity, interests, and strengths. This ranges from...  
 ...situations which seem like (or indeed are, former) group homes, to  
 ...places that seem to represent parents' idea of a suitable service for a person with autism more than they seem like the person's home, to  
 ...situations that seem to be arranged more around support people than around the person (sometimes this results from parental effort to help the person establish a home that looks more appropriate to their age than it might if their parents took charge of the decor and the routine ), to

...places that seem to fit the person, but have great potential to much better accommodate the adaptations and positive modes of expression unique to each person with autism

- The benefits of more personalized living arrangements make the inadequacies of available day services more glaring and more galling. Some people with autism are clear about wanting a job, or a much better job. Others endure what is available, often with surprisingly good humor. Everyone could have a day time that far better reflects their identity and capabilities.
- The presence of some staff people who respect and like the people they are assisting, and the potential for better response to expressions of individual preference, create a good context for much more intensive and imaginative exploration of each person with autism's preferred methods of participation and communication.
- More people with autism will benefit from having, and being, mentors for other people with autism.
- There are still miles and miles to go before many people with autism participate as members of community associations rather than as observers, consumers, or spectators; and before people with autism enjoy many friendships outside the circle of family members and some staff.

We purposely mention relationship building last in this list. It's importance as an accomplishment cannot be overstated, and the agency's current leadership is in no danger of understating it. But at JNCS the importance of relationship building could overshadow some real and immediate improvements that can be made in the accommodations and supports people with autism experience, "Why should we worry about the way the lighting is in the house when the person has no friends."

Overlooking better accommodation to people's disabilities would be shortsighted. Improvement in accommodations to people's autism are desirable in their own right, but they also allow better and more widely shared knowledge of the capacities, interests, and dreams of each person. Confidence in such knowledge is fundamental to building relationships that bridge the gulf between people with autism and the many non-disabled people who are victims of stereotypes about people with autism.

It is also important to put relationship building in time perspective: building relationships is the sustained work of years, more like planting coffee trees than like making a cup of instant. One form of sustenance for this journey is taking pleasure in what has emerged from the relationships that already exist, particularly in renewed and strengthened family

relationships and in the friendships that some staff people have formed with people with autism.

### **Benefits and costs to families**

These are the benefits and costs for families that the people we interviewed have noted since people moved into their own homes. Because the benefits for families are often closely associated with the costs, this section is organized as a sort of balance sheet.

#### *Benefits to families*

Many family members see people they love experiencing a way of life that, while far from perfect, goes beyond their expectations and even beyond their dreams.

#### *Costs to families*

Some parents feel deeply about how much their son's and daughters have missed because their own expectations have been too low. For some, these feelings are compounded by the recent discovery of their son's or daughter's ability to express themselves through facilitated communication.

While they can see benefits, some parents are still very unsure that their sons and daughters can trust the people they rely on for assistance from day to day.

At its extreme, lack of confidence in the process of hiring and supervision of in home support staff leads parents to invest substantial energy in checking on, and complaining about, staff performance. This creates a vicious circle: close surveillance leads to staff resentment which contributes to poor performance and motivates closer surveillance.

Some parent have been delighted by those staff and roommates who accept, like, and want to share everyday life with their sons and daughters. Some of these relationships seem to be emerging as committed friendships in which pay for work is only one aspect of the relationship.

Many parents enjoy the opportunity to invest time, energy, imagination, and money in ways that directly effect the life of their son or daughter.

Some of these same parents have had to deal with staff and roommates who seem to have counterfeited friendship with a person they assist, apparently in order to escape from some of the requirements of their job.

Some circles have had to deal with the consequences of staff and roommates overestimating...

... their ability ("I can manage." "Don't be overprotective, let us be ourselves.")

...the endurance of their commitment to a person ("I care deeply and will always be there.")

Not every parent is equally able to invest time, energy and money.

Some families feel a new and not entirely welcome demand from a service that agreed to take their son or daughter, and a service system that is supposed to provide placements. They are concerned that...

...their son or daughter may experience unequal treatment because they cannot invest as much as other families do

...the service system may be seducing families into allowing it to cut costs through family contributions

Parents who are board members now have to balance commitments to JNCS as a whole with the ongoing demands of their own circle.

Some brothers and sisters are finding new and satisfying ways to be involved in the life of a sibling with autism.

Circles offer parents a mechanism for direct decision making about the services their son's and daughters receive.

Families report lots of staff activity to deal with the problems and dissatisfactions that families identify.

Families are no longer placing their trust in the illusion that an agency alone can ever be an acceptable substitute for close and loving relationships.

Some people don't have brothers and sisters; some parents feel that is inappropriate to expect involvement from brothers and sisters, or that a brother or sister has already done more than enough.

Making decisions in ways that engage and sustain staff commitment and creative effort is difficult.

There is more direct responsibility. Parents can no longer complain about the agency management in the same way as they could before they had the option to be active in managing their son or daughter's support system..

The division of roles and responsibilities between staff and family members have become much less clear.

This activity doesn't necessarily bring satisfactory results.

Parents continue to face the question, "What will happen to my child when I die?"

## Benefits and costs to staff

These are the benefits and costs for staff that the people we interviewed have noted since people moved into their own homes.

### *Benefits to staff*

Some staff experience a strong collaboration with parents and family members who value them and their relationship with the person with autism.

Many staff report that the ability to concentrate on one person at a time has led to important gains in their ability to understand what a person wants; and some staff say that their ability to communicate with a person has increased across a range of topics and situations.

Many staff spend far less time and energy dealing with difficult behavior.

Some staff experience close, even loving, relationships with a person they support.

### *Costs to staff*

Some staff have felt ignored, or even abused, by family members who treat them like incompetent servants or potential criminals.

There is greater potential for conflict with others who understand a person differently. This is particularly difficult when the conflict is with a parent who does not seem open to negotiating the difference in understanding about what a person is communicating or how a person best communicates.

Some staff have experienced uncomfortable responses to this closeness from parents. Some of these staff interpret the parent's reaction as feeling threatened by the staff member.

Some staff who don't feel particularly close to a person they support wonder if they are less valuable to JNCS because they are only doing their job (even if they believe they are doing their job well).

Some staff feel a pressure to promise more commitment than they actually feel

Staff have greater autonomy and can focus their energy on things that really matter to a person.

Some staff feel that they have to take up the slack for other staff who abuse this autonomy and don't do their work.

Some staff report discomfort at having to confront their peers about poor performance or non-performance.

Some staff feel that they have had excellent opportunities for training and advancement.

Some staff feel that these opportunities are unfairly distributed and they have been left out.

### **Re-constituting circles**

Circles have been an important part of the development of supported living in at least two ways: they have provided a forum for decisions about individual supported living arrangements and they have given people a way to contain the anxiety and uncertainty of the change. The requirements of moving have set the circle's agenda. Where should the person live... with whom... with what assistance... how should the place be furnished and decorated? In the period just after the move problems –sometimes big problems– of establishing a household and a support system, and sharing good news about the effects of the move, paced the circle's meetings. These practical issues provided the context for sharing and organizing knowledge about the person's preferences and capabilities and needs and the resources available to the person.

#### *A new constitution*

Once a person has moved and things are reasonably stable, the circle needs to re-constitute itself. Its members need to agree on a new constitution by discussing and coming to agreement on these questions:

- What is the purpose of the circle? What contributions does the circle want to make to the life of the person with autism?
- Who is the focus of the circle? This is not as silly a question as it may first appear. Sometimes the actual focus people in a circle are the person's parents in their role as key decision makers and resource people for their son or daughter. If this is so, it should be clear.

- Who belongs to the circle and what are the obligations of membership? The process of moving brought people into the circle as issues arose (for example, Jeff, the Executive Director, and Harvey, the Board President, have participated in many circles). Are all of those people circle members; do they want to be active contributors? Does the circle want to have a “reserve list” –people who don’t want to be active unless a particular need arises? Are all of the staff involved with the person circle members? If not, who will link the circle’s work with them? Are there other people to invite into the circle?
- How does the person with autism participate in the circle?
- If the person has a conservator, how does the conservator see the role of the circle in assisting them with their legal responsibility of making decisions in the person’s interest?
- What groundrules does the circle want to adopt, and what skills do its members want to develop, in order to build honest communication, creative problem solving, and the capacity to understand and negotiate conflicts?

In considering these questions, circles should first take time to carefully answer two questions,

- Now that the person lives in his or her own home, what is most important to work on now in order improve the person’s life?
- What are our markers and measures that the person is experiencing a good quality of life? What signs will show us that there is a problem we must attend to?

The circle’s answers to these questions will provide a foundation for the circle’s renewed constitution, so in answering them it is important to think beyond just keeping the person from harm. The skills in personal futures planning and group planning (PATH ) that JNCS has invested in developing should prove helpful to circles in this work.

It will be important for each circle to ask, “How can we adapt the way the circle meets and works to accommodate the person’s strongest ways of participating and communicating?”

### *The politics of circles*

Some people spoke to us negatively of “politics” in circles. But politics doesn’t have to be a negative term. In an important way circle meetings are political meetings: they bring people together who have different points of view and different interests and provide a forum for them to discover common ground and organize shared action. The politics of circles only turn destructive if members are dishonest or manipulative.

One way to make circle politics healthier is to surface important disagreements among circle members. Discussions around a renewed personal futures plan provide a good context for mapping such disagreements. We heard seven common kinds of disagreements as we listened to circle members:

- Disagreements about people's vulnerabilities. For example, some people believe that imprecision in administering prescribed medication has severe consequences for a person and others believe that occasional variations in timing or dosage make relatively little difference.
- Disagreements about what staff activities must be performed ("non-negotiables") and what staff practices are optional, depending on circumstances and individual preferences.. For example, some people believe that systematic effort to assist the person to develop friendships is a necessary part of the job; others see this as much less important or even a waste of time because the person with autism is disinterested in friendships.
- Disagreements about a person's strong preferences. For example, some people believe that work matters very much to a person; others believe that the person would rather not work and that the desire is being imposed on the person.
- Disagreements about preferred and reliable methods of communication. Some people believe that a person communicates effectively with facilitated communication; others believe that the person is or was being manipulated by facilitation.
- Disagreements about a person's ability to provide meaningful direction of assistants, regardless of the communication system the person uses.
- Disagreements about how to interpret people's behavior. Some people read a person's difficult behavior as an attempt at manipulation; others read the same behavior as a request for a different sort of relationship.
- Disagreements about how JNCS organizational structure should function: "Who is, or should be, responsible for handling what." (See page 29 for a discussion of this issue).
- Disagreements about the future role of the circle and the future responsibility of parents and family members.

These disagreements are based on real uncertainties or real differences in perspective; no outside judge or expert can provide a final or objective answer. The circle's obligation is to be clear about the important disagreements they have and explicit about the ways in which they will negotiate these differences. It is not necessary to make an idol of consistency: some disagreements might be resolved by accepting that "when he is with me, this is what

happens; when he is with you, that is what happens.” Other issues will require negotiation (“How can we discover a way to proceed that will satisfy all of our interests?”) or the willing acceptance of authority (“We do it this way because this is the way his mother wants it.”) If these disagreements remain unspoken, or if circle members don’t accept a common way of dealing with differences, the differences will poison and paralyze the circle.

### *How you know when your circle isn’t round*

Before a circle considers what matters most for the person and what it’s constitution will be, the circle should take time to review its own functioning. Based on our interviews, we constructed this checklist of potential problems in the functioning of circles:

- ✓ Circle members see the circle as belonging to someone else: “We have these meetings because they are important to \_\_\_\_\_” Staff say, “parents”. Parents say, “staff.” Anybody says, “We have them because Jeff says we have to.”
- ✓ Important decisions about a person’s life happen without the circle’s participation, for example: a circle member says “It’s not like we work together or anything” when explaining why someone who is not a circle member is creating a vocational profile for the person the circle supports.
- ✓ The circle turns to a pyramid with a parent at the top. Parents review the details of staff performance. Parents feel, “We are expected to do what JNCS supervisors are paid to do.” Staff feel, “The parent wants to use me to control every detail of the person’s life.”
- ✓ The circle turns to a pyramid with no one at the top. Staff try to get parents to act like supervisors or representatives of their agenda to JNCS administrators.
- ✓ The circle spends time on activities that would be much more efficiently done in other ways, for example: paying the person’s bills, explaining JNCS policies, reviewing the details of staff schedules when there is no major issue at stake.
- ✓ Circle meetings focus mostly on “How things were done” rather than on “What we have learned” and “What it is important for the person for us to do.”
- ✓ A parent feels, “I am the only advocate for my daughter or son.”
- ✓ Staff people are disengaged during the meeting and feel frustrated or angry after the meeting.

- ✓ The circle gets stuck in polarization: its “staff against parents” or “circle members against support staff” or “administrative team members against support staff”, or “outsider parents against insiders on the board.”
- ✓ Some circle members treat other circle members in a disrespectful way but the issue is never raised and people do not make amends for the offense.
- ✓ Conversations about circle problems happen outside the circle, in pairs or other groups, and do not result in changes in the way the circle works.
- ✓ The only thing that gets a circle unstuck is when a person in authority (often Jeff) shows up and assumes responsibility for dealing with the problem, perhaps by delegating action to a staff person.

Because circles deal with difficult issues and because their work is organizing action on important issues, all circles will lose their roundness from time to time. This issue is whether the circle has the strength to notice that it is stuck and find a way to get unstuck that makes the circle stronger.

#### *JNCS role in making circles stronger*

JNCS can do several things that will make circles stronger:

- Invest in training and supervision in facilitation, creative problem solving, conflict negotiation, and personal futures planning for anyone who wants to learn. Assure that each circle has more than one member interested in improving their skills.
- Identify and share the variety of ways members of different circles have of listening to a person and making decisions about the person’s priorities and preferences. Approaches may include: stories about shared experiences, observations on the way a person responded during a private discussion, rituals that have meaning to the person or in a particular relationship, responses to photographs or drawings, and unconventional methods the person has invented in order to communicate.
- Make facilitators who are not members of a circle available for personal futures planning, PATH, or circle reviews. Facilitators can be members of other circles: staff, family members, others who are interested and willing to get training and supervision.
- Make consultation available to circles that are deeply stuck (what some people call “The Circle Doctor”). The emotional work involved can sometimes overwhelm even capable people. Consultants focus on process rather than having an organizational authority role or a stake in the outcomes of a circle’s decisions.

- Find ways to make information about routine JNCS business available to circle members without taking up circle meeting time.
- Much confusion and conflict comes from lack of clarity about the responsibility of circles, parents, and JNCS supervisors. Ask each circle to go through a systematic process of identifying responsibility for key tasks. One way to do this is sketched below.
- JNCS can gather and share its experience with circles: benefits, disappointments, what has worked, what has not worked as expected, guidelines from experience. *The circle cookbook* might be a nice title.

This process of re-constituting circles should be carried out systematically, for each circle. It should raise a number of important questions whose answers have implications for JNCS as a whole:

- Is it acceptable for a person JNCS supports to have no circle, either around the person or around the person's parents? If so, how will the planning, decision making, and safeguarding functions of the circle happen for the person?
- Is it acceptable for a person to have a circle when the person's parents do not participate; if the person's conservator does not participate? If so, how will JNCS respond to conflicts between the person's circle and the person's parent/conservator?
- Is it acceptable to have a circle in which the person with autism does not participate?
- Do staff participate as circle members as an expected part of their job responsibilities or can they choose not to be members of a person's circle? Can a circle exclude a staff member?

### **Re-considering autism**

One of the most exciting possibilities we noted was the opportunity that has emerged from more individualized supports for a far deeper understanding of people with autism. Deepening understanding depends on making the most of the possibilities of supported living to create better accommodations to each person's autism. More exact accommodations will allow a better understanding of the person's identity and interests. Better understanding will guide the development of new opportunities. The person's responses to new opportunities and better accommodations will refine the accommodations available to the person.

To organize this discussion, we will oversimplify JNCS's history by dividing it into three periods:

- I. people with **AUTISM**
- II. **PEOPLE** with autism (the transition period)
- III. people with autism (a possible future)

JNCS has always put people first, but in its first period (people with **AUTISM**), the agency organized its residential services around the treatment of autism by positive behavioral means. This emphasis was strengthened by the unintended consequences of grouping people with autism together in small residential facilities and group based day activities. In the second period (**PEOPLE** with autism), the transformation from group living to supported living, the emphasis has been on the rights and needs that people with autism share in common with non-disabled people. This emphasis has been strengthened by the emergence of many of the hoped for results of assuming that, like most other people, people with autism will be most comfortable in a home of their own with companions and supports of their choosing. One sign of this emphasis recurred in many interviews with support staff who emphasized the ways in which the people they assist are “just like anybody else.”

*Positive shared beliefs about people with autism*

This history gives many of the staff associated with JNCS a firm foundation of commonly shared beliefs:

- People with autism have the same right as anybody else to live their own lives in their own place and to make a positive contribution to life through work or some other means.
- People with autism should be accepted by other people. Rejection is ignorant. Discrimination is wrong.
- The people with autism that JNCS supports are adults with the same rights to self-determination as any other adult.
- The behavior of people with autism communicates important messages about their satisfactions and desires.
- People with autism are persons, with inherent dignity and value, who are fully capable of natural and satisfying relationships.

Staff have also found practical ways to assist people through their daily routines, to “read” at least some of the preferences of people whose verbal communication is unreliable, and to deal with episodes of difficult behavior. Throughout JNCS’s history, a number of staff have become skilled at positive, non-violent responses to crisis. In general, these ways of

coping seem to work even better when people are in their own homes than they did when people lived in group homes.

### *A decision point*

It does not diminish these achievements to suggest that even more is possible. Each circle, and JNCS as an agency, is at a decision point: “Will we continue a pattern that works well enough much of the time or will we search for a better understanding of autism as a part of this person’s identity?”

In considering this decision, circle members may want to imagine what things will be like if they continue to make adjustments within their current level of understanding of autism in the person’s life. While the individual particulars are most important in this discussion, it is our general impression that if present patterns continue...

... people’s lives will generally be OK. There will continue to be crises, but staff will continue to refine their abilities as crisis managers. There will be ups and downs, but overall people will have a safe and decent homelife, and a good chance at more satisfying ways to spend their days.

... as circles and JNCS become progressively better at recruiting and retaining good staff some, perhaps even most, people will be matched with staff that respect, like, and sometimes even come to love them.

### AND

...the person with autism will continue to do the greatest share of adapting to the limits of other people’s abilities to understand and respond to them. They will have to put up with what people can understand from simple words and behavior patterns.

...people around the person will be satisfied with positive, but marginal accomplishments. Staff might stop with celebrating a person with considerable musical talent for holding down a simple part time job instead of moving on to seek more challenging and interesting opportunities with the person.

...possibilities for community participation and friendship will be constrained.

A circle that wants to search further will commit itself to moving into period three, where there is an equal emphasis on both terms, people with autism, and neither term claims a bold face.

### *A way to search for a better understanding of autism*

The possibility of taking this step seems to us to rest on having thoroughly mastered the lessons of the past. Namely, that without adequate support, social systems under stress will over-emphasize autism as a justification for segregation and control. The stress will not go away. The difficult side of autism will not go away. So circles who want to search for a more helpful understanding of autism will have to hold a clear focus on the dignity and worth of each person with autism and maintain strong mutual support among circle members.

The base for learning about autism in the person's life is incorporating another belief into the common foundation described above. That is, autism is a unique way of being which is acceptable and which calls for creative efforts to facilitate the person's participation and communication. Saying that autism is acceptable means that it is not necessary to "fix it." Identifying it as a unique way of being draws attention to the ways in which a person who is "like us" in important ways is at the same time "different from us" in important ways. Noting that it calls for creative effort to learn how to facilitate recognizes the importance of a careful search for effective ways to join and enhance the effectiveness of a person's ways of accommodating autism.

This stance opens up room to question and explore. The people who know and understand a person well enough to get by can stop to wonder, "What more could we know of this person, what more could this person do and contribute, if we were better able to facilitate his or her participation?" The purpose of this wondering and creative problem solving is to add the imagination and abilities of a facilitator to the imagination and unique abilities of a person with autism with the result that the person with autism's participation, contribution, and satisfactions are multiplied.

In this sense, facilitation is much more than just typing with assistance. Facilitated communication is one type of facilitation, but there are many others that can be invented in collaboration with people with autism.

### *Learning the lesson of experience with facilitated communication*

However, before JNCS embarks on a search for a better understanding of autism in people's lives, it needs to openly discuss and learn the lessons of the agency's experience with facilitated communication. Such a discussion will explore important questions like...  
...what level of investment in training and supervision is required from people who wish to practice a particular approach and from JNCS as an agency?

- ...how can circles, and JNCS as an agency, reduce the chances that an effective form of facilitation will be lost when one particular person leaves?
- ...how can circles, and other parents and experienced people, support people to assimilate changes in their understanding of a person with autism's identity and capabilities? It is our impression that some people jump quickly to a changed point of view and others find significant change unbelievable and discredit it. Neither person is assimilating a new understanding. The same circle—even the same marriage—could include people with either style of response.
- ...how can circles, and JNCS as an agency, deal effectively and responsibly with conflicts that surface between sincere people who draw different conclusions about a person with autism's preferences or communication?
- ...under what conditions is it legitimate for a staff person to refuse to offer a form of accommodation, facilitation, or assistance that others believe benefits a person with autism?
- ...under what conditions is it fair and reasonable for a parent or conservator to refuse a person with autism access to a form of assistance that other concerned people believe is of genuine benefit? How can circles effectively deal with the consequences of such basic disagreements?
- ...how can circles, and JNCS as an agency, deal effectively with the controversies that sweep the field when new methods challenge old positions and when wishful thinking can drive out thoughtful inquiry?
- ...how will circles, and JNCS as an agency, evaluate experience with a particular approach and share what works and what does not work with other circles?

Without careful consideration of these questions, circles and JNCS are vulnerable to either lurching from one fad to the next or of depriving people with autism of access to important assistance.

### *Better support for participation and communication*

Once the lessons of JNCS experience with facilitated communication are digested, there is much to learn alongside people with autism. A detailed description of the possibilities is beyond the scope of our team's work, but we can indicate some possibilities and some challenges.

The search for better methods of facilitating participation and communication depend on noticing, and creatively modifying, the extent to which our relationships depend on

conventional signs: words, either written or spoken; conventional “body language” and facial expressions; and environmental arrangements that are so commonplace that we do not even notice them. One way of understanding autism is to recognize that people with autism have unique ways responding to these conventions. Staff who “read” only two or three emotional states in a person with autism (“He’s OK.” “He’s happy/sad.” “She’s going to blow.”) may well be stuck in conventional signs.

Getting unstuck means noticing the ways particular people relate to different dimensions of their environment. This leads to questions like these,

- What pace and tempo of activity or conversation does the person find easiest to join?  
How does the person deal with a pace that is uncomfortable because it is too slow or too fast?
- What medium does the person find best to express different kinds of messages: music? drawing? dance?
- What kind of lighting and furniture arrangement does the person find best to support their participation in a meeting?

In approaching these opportunities, it is important to consider ways to go far beyond the expectable limits of individualization. For example, presently lighting, furnishing, decorating, texturing, and sound damping in the places we visited reflect a common sense of a nice, “normal” home. Each of these physical dimensions offers a chance for collaboration with each person with autism (and, as necessary, negotiation with his or her housemates) to move from nice and “normal” to a nice home adapted in particular detail to the strengths, preferences, and comfort of a valued person with autism. A particular person may find up-lighting more comfortable than down-lighting, or find harder or softer or higher or lower or more or less furniture and decorations accommodating. The issue here goes beyond simple preference; the issue is continual improvement in the level of accommodation people with autism experience in their own homes. As people’s homes are more accommodating, they can live more comfortably and present themselves more completely.

This important work is likely to feel strange to at least some staff people. It may seem “unnatural” or “Not normal” because it involves challenging conventional codes for communication. It may also feel weird because it involves breaking one’s set idea about who a person is. What was stable about a person becomes different. A staff person who felt comfortable and competent has to notice ways to improve. This example illustrates:

An evaluation team member spent some time with a person with autism and discovered that drawing was a preferred method of communication for her. She later met the person again because the person was accompanying a staff member she was scheduled to interview. As the interview began, the person with autism took a pad from a backpack and began to draw. The staff person said that the person with autism would keep herself occupied by drawing while the team member and the staff member talked. Toward the end of the interview, the staff member noticed that the evaluation team member had no watch and teased her about being out of step with the fast paced life of LA. During this exchange, the team member glanced at the page the person with autism was drawing on and noticed that she had drawn a clock. The team member acknowledged this by saying and writing “You have drawn a clock face.” The person with autism then drew a clock with a face on it.

In this brief interaction, the staff person saw drawing as an activity that would occupy the person with autism; the staff person was a participant in a two person conversation. The team member, because she had formed an impression about how the person with autism preferred to communicate, saw the drawing as part of the interaction; she was part of a three person conversation. In order to better facilitate participation, staff will need to join people with autism looking at their interactions in new ways.

### **The Transformation of JNCS Residential Services**

In a field rich with management jargon, the word transformation is too easily used. Some people apply it enthusiastically to stirring new statements of mission and trendier organization charts. Often, they seem to imply that transformation should solve all problems and result in a utopian situation. When we call what has happened in JNCS’s residential services since 1992 a transformation, we mean it as the dictionary does, “a dramatic and fundamental change in character”. And we don’t think that anyone would describe the results as utopian; though almost all of the people we met believe that the hard work and anxiety has been worth it, and that the problems JNCS faces now are vastly better problems than those that confronted the agency three years ago.

The problems and possibilities created by this transformation frame all of the specific issues JNCS must deal with now. We will sketch our understanding of the way the change has happened as a backdrop for understanding the agency's challenges.

The 1992 evaluation confirmed the JNCS board's view that its residential services were in crisis. The evaluation report argued that there were fundamental problems, not just in the way current group homes functioned, but in the way that the group homes would ever be capable of functioning. The board decided to make reforming residential services the agency's first priority because JNCS is responsible to more than 90% of those people for 24 hours of every day.

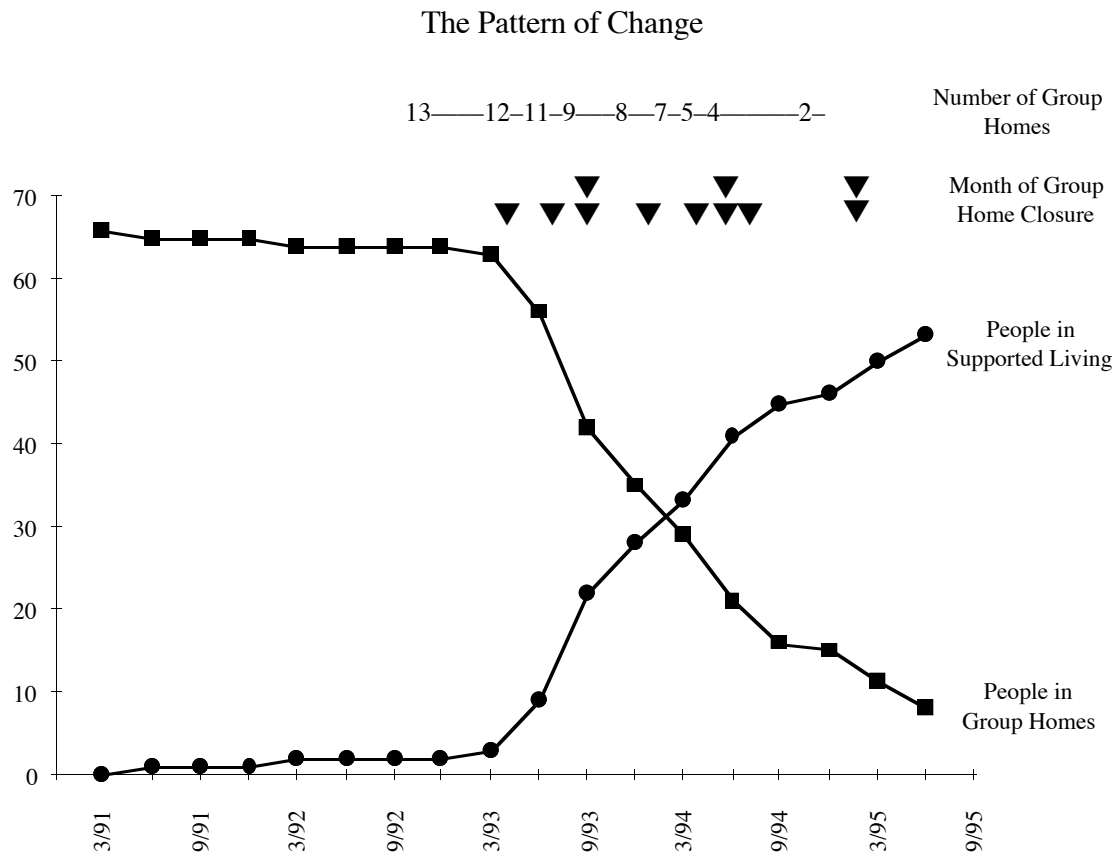
The board had a sense of direction. Most board members agreed that conditions in the group homes were unacceptable; many agreed that these unacceptable conditions were created by the design of the group homes and the climate of mistrust and mutual blaming in the agency rather than primarily by bad staff who could be replaced by good staff; and some believed that people with autism should, if possible, live in their own homes. But many fundamental questions remained about what living in one's own home could mean, and how it could be done for people with very substantial needs for assistance. There were two local pioneers in supported living to learn from, but most people regarded them as much more able than the people JNCS served in its group homes.

With the involvement of key staff, the board recruited the co-author of the evaluation report as its executive director, specifically because of his deep and outspoken commitment to the inclusion of people with disabilities in all aspects of community life and his experience in developing supports around one person at a time. In close collaboration with him, a few board members carefully re-examined their basic assumptions about their son's and daughter's futures and described the kinds of supports necessary to pursue these futures with safety and dignity. This process clearly established three principles for the change:

1. Supported living is developed one person at a time,
2. Through the deliberations and activities of a circle of support,
3. Under the final control of parents (or other family members).

The first small group of people with autism and their families, who tried supported living with courage and ingenuity, demonstrated that the practical problems of supporting people with autism in their own homes could be solved, although sometimes with difficulty; that

there were tangible benefits to the people involved; and that the regional center would support JNCS in solving them.



Once begun, the shift to supported living developed momentum. After 9 months of stability before the change began, the number of people supported in their own homes more than doubled in six months, more than doubled again in the following three months, and doubled again in the following year. By December 1995, JNCS will provide all of its residential assistance to people who live in their own homes.\*

The number of people and families who wanted supported living grew as more people had the opportunity to form circles of support and develop personal plans.

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\* All families were offered assistance in seeking other arrangements. Six families (about 10% of the total number JNCS provided residential services to as of 1/93) have chosen group living arrangements for their sons or daughters. Two families now receive services from another agency, and five people will remain at Parkwood, the group home in which they have lived together for some time. From late 1995, Parkwood will be operated independently of JNCS by the current manager, who will become its proprietor.

JNCS invested substantially in training events, which not only clarified values and provided information but also offered a forum for family members and staff to express their uncertainties and fears and explore their concerns. A growing number of family members and staff concluded that supported living offered people with autism better support than would ever be possible in group homes.

The agency invested substantially in developing new staff leadership to replace key people who moved on to pursue other opportunities. Other staff who did not agree with the new direction saw that the change was for real and left. The North Los Angeles Regional Center devised an effective method of contracting for the way JNCS provides supported living.

Begun with the notion of learning from a few families who chose the option, demand from families increased faster than expected. As this demand was met, financial considerations became an accelerator. Housing assistance became available sooner, and for a larger number of people than anticipated, but with a “use it or lose it” deadline. As people moved out, group homes were no longer financially viable, because the board decided not to increase the number of people JNCS offers residential support, at least until it is sure that the people already served have good quality support, and because the terms of JNCS’s contract called for the change to be cost neutral. Faced with a choice between seeking services elsewhere and developing a supported living arrangement through JNCS, many families who had not previously chosen supported living consented to their son’s or daughter’s move into supported living.

After people moved out of group homes, JNCS sold the buildings.

### **Continuity through change**

While the scope of change draws attention to what is different about today, there are fundamental continuities in JNCS as an organization that are as important to the transformation we are describing as any of the change strategies its leadership has deployed. The sister of one of the people that JNCS supports describes the agency culture this way,

“Jay Nolan has always been a war zone where people fight about the best ways to support people with autism. That can be pretty hard on people, but it’s the reason a lot of good things have happened for my brother.”

This tradition of fighting for, and over, the best ways to support people with autism probably provided JNCS with the matrix necessary for the rapid and fundamental change it has made in moving from group homes to supported living.

Several continuing features of JNCS seem fundamental to the change.

- JNCS was founded on a commitment to provide excellent service to people rejected by other services because of the severity of their disability. This commitment has held firm throughout the change: no one has been excluded by JNCS because of the extent of their disability.\*
- JNCS is controlled by its board, a core group of whom...
  - ...are parents who embody a ferocious concern for the well being of their sons and daughters with autism
  - ...have, from the time their sons and daughters were small children, been motivated by a powerful drive to insure that people with autism benefit from the best possible services
  - ...have a long personal history with JNCS, and with its sponsoring organization, the Autism Society of Los Angeles
  - ...have strong ties to state and national autism networks and a great interest in discovering and implementing state of the art services
  - ...are powerful, highly competent people accustomed to investing a great deal of effort in JNCS
  - ...initiated the agency change process well before the 1992 evaluation and remained actively involved throughout it
  - ...were themselves among the first families to actively explore supported living

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\* Though we did not interview them, it is possible that families who have chosen to leave JNCS could see this differently. Their judgment of the extent of their son's or daughter's disability and consequent service requirements for treatment or supervision or companionship might have led them to decide that he or she is too disabled to benefit from supported living. Our point here is that JNCS did not make eligibility judgments: readiness or apparent ability was not an issue for JNCS; developing appropriate and sufficient supports for each person was JNCS's goal.

...have developed a way of interacting with one another, with staff, and with regional center representatives that, at its mildest extreme, could be described as assertive and vigorous

...are likely to distrust professionals and officials of the service system because they have seldom found welcome, understanding, or competent treatment of their sons and daughters among them

...strongly believe that, because of the vulnerability of people with autism and their unique needs, parents should be in control of the services their son's and daughters receive

- JNCS has hired executive directors who are entrepreneurial and provided its directors with considerable latitude and support to innovate. These relationships have not always ended happily –a pattern which we hope will not repeat itself in the future.
- JNCS is assertive in its relationship with the Regional Centers that purchase its services. The agency positions itself as an innovator that knows best how to serve people that other vendors are frightened of and incompetent to serve.

These continuities underwrite the transformation of residential services. They represent great organizational strengths. Strengths, of course, cast shadows; shadows define important, and easily neglected, developmental work. For example,

- Without a cohesive and highly involved core group, the kind of change JNCS has made would not have happened. But people outside the core can feel closed out, frustrated, and powerless. If they withdraw into passivity or into complaining about “a few families who run things for their own benefit,” much energy is lost. If they can find a welcome for their initiative –as those working to establish the voice of people with autism on the JNCS board persist in trying to do– the agency will grow even stronger.
- As an organization, JNCS has great energy because of its high emotion. Without extraordinary energy, many people would still be stuck in group homes. High emotion attracts and stimulates commitment and motivates long hours of intense activity. This can become a trap when enthusiasm leads to overfocus on activities instead of strategies, escalating stress, consequent poor judgment, and the crash of good people who cannot sustain the pace.
- The principle that parents should be in control of services has energized and legitimized the change. The increasing emergence of people with autism as choice makers in their

own right, with lives of their own, not only creates the potential for family level conflict, it challenges one of the foundation beliefs in the organization's culture.\* A positive future seems to lie in the most difficult direction possible: shared and mutually limited control. This probably involves developing a way for parents to define boundaries for their control that both protect their son's or daughter's vulnerabilities and allow ample room for other people to come into his or her life and for new paths to emerge from their initiatives.

- Under stress, the JNCS board is most likely to fight. Its best moments have come when there is an opponent whose defeat brings benefits to people with autism. Probably its worst moments have come when fighting becomes primarily an expression of frustration and turns inward.

These great strengths remain essential resources for JNCS's future. But some of the work that needs doing will challenge those strengths. For example, one of the important reasons that some people embraced the change was to increase opportunities for people with autism to enjoy committed friendships and individually meaningful participation in community life. This won't happen unless family members and JNCS staff join people with autism in a way that enables them to all become community builders. This work is slower, less exciting, and less activity driven than changing the form and structure of the agency is. It is frustrating, collaborative work with a different style than the kind of advocacy the agency is used to doing. While it takes courage to confront unthinking prejudice in a way that makes strangers into associates and friends, there is really no one to fight whose defeat will do people with autism any good. Many other people in autism networks and associations don't see the point of focusing on relationships, and most of the people to learn from about this work live and work with people whose disabilities are different from autism. Expertise has to be grown at home; it can't be easily or reliably imported.

While we are confident that the people of JNCS can develop the complementary strengths necessary to do this work, we think it will be struggle of a different kind than the agency has grown up on.

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\* This conflict is compounded when a staff member speaks on a person's behalf, based on the claim of a close relationship or a particular ability to assist a person to communicate

## **Implications of the change process\***

Five aspects of the change process will powerfully affect the way JNCS realizes the opportunities that come at the end of the shift from group homes to supported living: circles have been an effective transitional mechanism; the executive director and the president of the board have contained much of the anxiety generated by the change process; there is a new kind of contract with the North Los Angeles Regional Center; there is a new type of organizational structure with new roles and relationships; and, the group of people JNCS serves is becoming more and more differentiated.

### *Circles have been a transitional mechanism*

Fundamental change engages people and organizations with great uncertainty and creates political opposition. Assigning responsibility for planning and decision making to a separate circle of support for each person with autism has proven a very effective way to deal with uncertainty and opposition. This structure for change...

- Divides an unwieldy mass of uncertainty, opposition, and confusion into sixty or so separate packets of uncertainty and confusion, each held by a circle that include the family members and staff most closely involved.
- Provides many distinct forums in which staff and family members can enact the principles that...
  - ...supported living is planned and implemented one person at a time and
  - ...parents are the decision makers.
- Makes manageable sized problems and assigns their solution to people who know, or can get to know, the person involved. Instead of trying to solve the problem of where to get more than a hundred personal assistants, the problem is how to get three or four assistants to match the particular hours and tasks one person requires. Instead of locating fifty units of housing, the problem is how to use available resources and contacts to find a suitable, safe and decent place for one person to live.

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\* Although this section presents observations and recommendations that reflect team consensus, its framework comes from the writer's reflection on his experience with JNCS as he reviewed his notes from the evaluation. A visitor less interested in organizational analysis would probably notice much different aspects of the changes, and this approach probably does not represent the perspective on organizations that the other team members would adopt.

- Reduces the need to make and rely on general policies. Parents place varying weights on such diverse things as the balance of risk and control in trying new experiences, the standard of housekeeping, and the way a person's money is managed. Making individual circles responsible for decision making provides a way to take account of differing preferences.
- Gives the people most involved direct responsibility to set the limit of risk they feel able to deal with safely.
- Redirects and scales down opposition: "Don't ask what's good for 64 families, ask what's good for your family, and then we'll work to see if we can make that happen." If the JNCS board had faced a vote on a master plan to move more than 50 people from group homes into supported living in just under 30 months, opposition would have been easily mobilized. Leaving the choice of group living open (initially within JNCS; later by transferring to another provider), and giving parents the choice of the best available option, limited the effects of opposition.
- Allows more rapid learning. Circles can make the most of the opportunities they see without always having to wait for larger chunks of the agency to get ready for change. This allows different kinds of solutions to emerge and gives people the chance to see what others have done and how they have done it.

Circles have served the change process well. As we will discuss below, we think they will only contribute to a positive future if they are re-constituted.

*Authority figures have been holders of anxiety*

Fundamental change generates great anxiety. An organization that lacks an effective way to contain that anxiety will not change and risks being wrecked in the attempt. JNCS has relied on its executive director and board president to contain much of the anxiety over change. It is not the roles that the organization has used, but the men: not the executive director, but Jeff; not the president, but Harvey. In an odd sense, JNCS as an organization has treated them the way Gotham City treats its superheroes.

Both men seem important to many of the parents and staff touched by the change in ways that go well beyond their ability to articulate a vision and engage in skillful problem solving. Many people seem to identify the change with them and depend on them for its success. Sometimes this has made them the target of anger and blame ("Why did you do this to us?") but often they have been a source of reassurance. Their presence at circle meetings and their availability to hear out people's uncertainties seems like an important

reassurance for many people. Even the few people we interviewed who are deeply dissatisfied with the present situation, express dependence on Jeff or Harvey for a successful resolution of their situation (remember that dependence can be expressed as frustrated anger that someone who a group assumes could fix things isn't fixing them) .

Holding anxiety is a very good use for authority, though a profoundly demanding one when changes are major. Both men seem suited to it. They each have near manic levels of energy, which for years they have channeled with singular focus into making positive change for people with disabilities. They are both fathers of people with significant disabilities who are deeply engaged with them. Their personal presence makes them stand out in an organization filled with vivid personalities. They are open with their emotions, quick to confess their personal foibles, willing to own up publicly to errors, and ready to assume responsibility for dealing with problems. Both are courageous in confronting their opponents and in openly expressing their own convictions, concerns, and fears. Neither holds back from demanding significant changes from systems and significant effort from colleagues. They have developed a strong working/personal relationship. If one wrote a screenplay of this change story, Harvey would be the JNCS and Los Angeles insider and Jeff, the outsider, expert in the ways of circle making, supported living, and community building.

This description is not meant to minimize the effort, imagination, and courage that many other people with autism, parents, and staff have invested in the change, or to present Jeff and Harvey as candidates for a Nobel Prize. It is to identify one of the parts that they have played in the drama of change. A part that people involved can't afford to keep them playing.

Anyone who thinks about it for a moment recognizes that neither Jeff nor Harvey cannot be an active part of every circle. But some of the people we interviewed spoke as though they were apologizing for Jeff when they identified things that were left undone by the circle or by JNCS staff. We heard, repeatedly, from family members, staff, and some people with autism, "Jeff works so hard and is so overstretched." This is true, but beside the point. If circles are to grow stronger, as some now are, their members must assume increasing responsibility for defining and dealing with problems without depending on the fantasy that the agency's visible leaders can deal with the uncertainties and conflicts that arise. If staff members are to develop their own competencies and their own relationships with people's parents, as some now are, they must assume increasing responsibility for developing their skills and their relationships and dealing with their own concerns about lack of skill or lack of credibility with people's parents.

Reducing the dependency that helped the agency through a time of transformation is also important because individualizing supports means that people's life paths will diverge more and more with time. Jeff's practical experience with setting up individualized supports, which provided sound guidance in helping people establish themselves in their own places, becomes less and less relevant as people face opportunities and problems that arise from living their own lives in their own homes.

Facing the reality of people's possibilities and their vulnerability will challenge each circle. Some people may feel angry or depressed because they feel abandoned by the people "who got us into this." Some people may feel anxious because "without Jeff we lack the skills and judgment we need." The issue is not to abandon people to flounder, but to be thoughtful about how to help them develop their own collective strength by building a stronger circle.

Jeff's and Harvey's honesty in admitting mistakes ("confess early and often" might be their motto), and their willingness to accept responsibility for problem solving makes it easier for circles to shift the circle's work to them. They need to walk a tightrope with each circle and each staff person between rescuing people from the problems they need in order to develop their own strength and abandoning people. This problem mirrors a fundamental dilemma in supporting a person with autism; Harvey and Jeff have an opportunity to model effective learning about this complex and emotional issue in the way they deal with circles and staff.

#### *A new relationship with the Regional Center*

The North LA Regional Center has been an active partner in the transformation. In collaboration with JNCS, the Regional Center has developed ways to support individualization of supports by adopting a new vendor category that allows maximum flexibility, by assuring accountability through satisfaction surveys and review of the plans and records of accomplishment kept by circles, and by contracting with JNCS for case management services for those families and individuals who agreed to have Community Living Coordinators become their case managers. In return, JNCS agreed to make the transition to support services cost neutral for the whole program and to develop a fair and useful way to demonstrate accountability.

JNCS has diversified the financial base available to the people it supports by helping them to make the most of IHSS-In-Home-Support from Los Angeles County; available housing benefits, including HUD section 8 funds; money available through the Department of

Rehabilitation, exploring income safeguards through seeking the approval of PASS plans, and making the best possible use of family resources and organizational fund raising capacity. However, every person JNCS assists still relies on Regional Center funding for the day to day support necessary to make good use of other resources and opportunities.

While the partnership with the Regional Center is a promising achievement, both JNCS and the Regional Center need to work to broaden and strengthen their partnership. This necessary work is difficult because history gives each partner reasons to distrust the other and because some of JNCS's leadership may have positions on the proper role, structure, and priorities for the Developmental Services System as a whole that conflict with the positions of Regional Center leaders.

Three considerations are important in maintaining and strengthening this important partnership.

- Broaden relationships between Regional Center Board and senior staff members and JNCS's leadership. This will mean: increasing personal contact; maintaining clarity about areas of collaboration and areas in which there are different positions between the two agencies; and keeping in mind the differences between individual positions and agency positions.
- Assure that the Regional Center's leadership knows what people with autism and their families are achieving with JNCS support and the Regional Center's assistance. And make sure that the Regional Center gets due acknowledgment. This will mean avoiding the reflex to fight with the Regional Center unless there is an issue important enough to fight over that cannot otherwise be negotiated.
- Upholding JNCS's side of its agreements with the Regional Center.

In upholding its agreements, JNCS staff need to think through the question of accountability. Paperwork holds negative associations for almost everyone we talked to: at best it seems a low priority annoyance, at worst a sign of unnecessary bureaucratic control of people with autism. While it may be understandable that detailed plans and documentation (apart from billing) have had low priority during the time of transition, making this a habit could have unfortunate consequences.

- Poor documentation could generate a negative cycle of conflict over compliance and resistance to compliance, this will use up time and good will.
- JNCS poor performance would justify a claim that the agency doesn't take the interests of its partners seriously. If experience shows that compliance interferes with the quality

of people's lives or that the Regional Center's interests in accountability can be met with less cost or greater effectiveness, this should be the subject of open negotiation. In this negotiation, it is important to begin by considering the need for accountability as the Regional Center understands it; not just as JNCS defines it.

- JNCS would be wasting effort creating a pretend, paper agency unrelated to its real work. This might undermine some staff people's sense of the agency's concern for honesty and integrity.
- Greater clarity about plans, accomplishments, necessary activities, and what people have learned about what matters to a person with autism could well be a benefit to the person over time. While we did not focus on paperwork, we did review the person centered plans and circle minutes for a few of the people JNCS supports. This limited review suggests that there is very great potential for improvement in the clarity and usefulness with which these important occasions are documented.

The basic question we suggest JNCS staff attend to around this issue is, "What opportunities does compliance with our agreements offer us to improve our support to people?" Avoiding mindless paperwork may be reasonable. Failing to clearly record and track agreements that people have made with a person with autism is a disservice; failing to express what people have learned about people's interests, identities, and what works and doesn't work to assist them is a disservice; failing to create a way to track how plans have progressed and changed is a disservice.

#### *A new organizational structure emerges, fuzzily*

In the transition from group homes to supported living, JNCS's organizational structure has become either more straightforward and person-focused or more complex and unwieldy, depending on point of view. Family members and staff who are active in well functioning circles see the agency as focused and effective, with minimal drag from formalities. They speak in terms of people, unfettered by job descriptions, taking responsibility for dealing with problems as they arise, and backed up by "rings" of support. Other's see JNCS as burdened with excess layers of supervisors whose roles and accountabilities are confused and confusing; it just isn't clear who is responsible for what. From their point of view, JNCS has gone from a simple structure, with a single accountable home manager who supervises staff and reports to a central office, to a complex hierarchy, in which multiple levels may all be involved in making the most basic everyday decisions. Based on their attempts to trace the chain of command, they identify five levels of management (primary staff, community living coordinators, resource

coordinators, the residential service director, and the administrative team) between support staff and the executive director. To them, this seems like a nightmare of irresponsibility and wasted time and money. In turn, those who enjoy a more team based approach are tempted to dismiss those who complain about lack of organizational clarity as supporting an “old paradigm” of regimented control.

What is at stake is a tension between, on the one hand, generating the variety of different arrangements that match differing individual circumstances and, on the other hand, assuring that the staff who support a person organize their attention and effort and follow through in terms of what matters most for the person.

Two principles may help in dealing with this tension.

First, JNCS owes it to the people it supports to set clear expectations around situations in which people are particularly vulnerable. Given the great differences between people, these expectations need to be defined and communicated in terms of what is most important to each individual. However, JNCS should consider adopting agency wide expectations around at least two issues where people in supported living are especially vulnerable: unacceptable behavior control methods and the means of accounting for people’s money. These agency wide expectations would hold unless a person (or a person’s conservator) agreed with the person’s circle that staff should behave otherwise for reasons specific to the person.

Second, the structure of support around each individual should be clear to all of the people who are necessary to assure that person’s well being. Everyone involved in a person’s circle should be able to say clearly who is responsible for each matter of importance to supporting the person, with high confidence that others in the circle will agree with their assignment of responsibility. This is very different from everyone being able to answer a more abstract question like, “What is the role of the resource coordinator in JNCS?” There may be no general answer to this kind of question in an organization that provides individually tailored support. In changing situations, responsibilities will probably shift as new opportunities and new problems arise. But members of each circle must be definite and confident in describing each person’s particular contribution to a better life for the person with autism at the center of each circle. It may be very desirable to have a variety of answers which depend on individual circumstances; confusion is undesirable. “What exactly does the resource coordinator assigned to Reggie, do for Reggie, and what do we do if this isn’t getting done?” can legitimately have a different answer from the question “What exactly does the resource coordinator assigned to Val, do for Val, and what do we

do if this isn't getting done." It is unacceptably dangerous for Reggie and Val, and for people close to them, not to have clear and specific answers to these individual questions.

Perhaps responsibility charting, a technique developed to clarify decision making in situations where there are multiple authorities, could help each circle assure that they have a common understanding of necessary tasks and responsibilities, a way to identify and negotiate conflicts, and a simple way to orient newcomers. The technique uses a simple matrix: necessary actions and decisions make the rows and all circle members' names (including of course the name of the person with autism) and the circle as a whole make the columns. At each intersection of task and person, describe the level of responsibility, such as, "does", "facilitates", "assists", "backs up", "decides", "checks", "approves", "no responsibility", etc.

Four important questions will come into focus as these charts are made by a circle:

- What exactly are the tasks that are most important to the person's support? This is worth considerable discussion and circle members should avoid the false efficiency of using a checklist. Tasks should be identified in terms of what matters to each particular person. In negotiating the description of these tasks, and in assigning priority among them, the method of distinguishing between "non-negotiables" and "highly desirables" used in essential lifestyle planning\* may be useful.
- What can the person with autism do for him or her self, given adequate environmental accommodation? And, when should another person facilitate the person with autism rather than deciding or doing for them? (The answers to these questions will grow more interesting as JNCS explores accommodation and facilitation.)
- What is the role of the circle? The circle is a forum for planning, problem solving, and negotiating conflicts. It is worth considering, on an individual basis, which issues should be decided by the circle and which should be checked and decided by the person, by the person's parent, or by the JNCS staff or supervisors. Are there any decisions the circle cannot review and negotiate? These will either be matters the person's conservator decides it is in the person's best interests to withhold from the circle or matters to do with JNCS compliance to agency policies or labor laws.

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\* See M. Smull and S. Burke Harrison (1992). *Supporting people with severe reputations in the community*. Alexandria, VA: NASDDPD.

- What is the role of JNCS staff as supervisors, distinct from their role as assistants in performing important tasks, or as planners and problem solvers? In what areas does the person with autism count on the community living coordinator or the resource coordinator to exercise authority with support staff?

In dealing with these questions it is important for circle members to understand one another's priorities and signals. A parent who views the accurate and timely completion of a medication log as an important signal of quality should feel that their signal is understood. Staff who treat this statement of a quality indicator as foolish or backward or unimportant escalate a power struggle. If other circle members or staff disagree, there should be a mutual commitment to discuss and negotiate them. A staff person who is concerned about the way a parent deals with a person's check book should feel that their signal is understood. A parent who treats this expression of concern for a person's autonomy as irresponsible or inappropriate escalates a power struggle. If there is a disagreement, there should be a mutual commitment to discuss and negotiate it. The goal of negotiation should be a creative resolution that everyone can live with, though with deference to the preferences of involved family members.

Beyond clarifying the structure of responsibility for each person's individual supports, the most immediate organizational issue concerns the way JNCS will develop day time supports for people in supported living. The present organization structure makes sense in terms of JNCS's past: separate programs with distinct groupings with separate managers based on separate funding streams. However, each of these conditions has changed for people in supported living. Now the focus is on individualized supports, what is the rationale for having people be clients of a separate day program operated by another division of JNCS? Circles have assumed responsibility for overall planning, what is the rationale for a separate process for constructing a vocational profile or for limited participation by day staff in circles? Community living coordinators supervise the staff who provide most of a person's support, what is the rationale for involving another supervisory structure for 35 or fewer hours of a person's week? As of 1 September, day supports are funded under the same regional center vendor code as other support services are, what is the rationale for accounting the person's participation in two distinct programs?

Another organizational issue may develop more slowly. The emphasis on building teams, working collaboratively, and blurring roles makes sense, but it raises an important question: "If people accept responsibility for all manner of different tasks, regardless of job title, what is a fair way to deal with pay?" Is it fair for one support staff person, who does the tasks that a community support worker typically performs, to earn similar wages to

another support staff person who does not do these tasks? If a community support worker has (or develops) several support staff or circle members who perform many tasks that other community support workers do, does she have a fair workload compared to those who have more of the tasks to do themselves? A few support agencies are experimenting with payment based on tasks performed rather than on job role, but others have considered and rejected that option as unfair.

We don't have a position about the conclusions JNCS should reach on these questions, but we do think that these questions should be thoughtfully considered as matters of organizational design rather than through ad hoc responses to specific problems.

*The group of people JNCS serves becomes differentiated*

When JNCS operated group homes, some people's parents were more involved and other's parents were less involved, but the extent of family involvement was not a central factor in the organization of the agency. But the transition from group living to supported living makes family involvement a far more important dimension in JNCS's future design.

While each of the families we met reported some benefits and some costs in the transition to supported living, it may be that the difference between two broad groups of families will grow sharper as the transition period ends. In the first months of the transition period, families split on the issue of whether or not it was desirable and feasible for people with autism to live in their own homes. Now families see the advantages to people with autism living in their own homes with appropriate supports, but they may be dividing on the question of how much direct involvement it is reasonable to expect of family members.

One group will want to decrease their involvement now that the person with autism has successfully moved. They see JNCS managers and staff as primarily responsible for dealing with problems and assuring quality service. Family members are primarily responsible for monitoring and exercising conservatorship. If JNCS wants to hold circle meetings as a way for families to make their wishes known to staff, they will attend them. From their point of view, relieving family members to get on with their own lives, assured that the person with autism is well looked after, is a legitimate part of the mission of JNCS and a basic goal of the developmental services system. They might wish that they could be more involved, but they cannot. For them, the "journey" that JNCS leadership keeps talking about is over when their family members with autism are established in their own homes. Family members in this group want to be able to get off the cutting edge of services to people with autism and get on with other aspects of their own lives.

Another group will see the move as one important step, a step which provides the person with a base from which to build a better future. They see their continuing involvement as essential to this future, both as safeguards for the person's safety and dignity and as allies in creating opportunities and supports that match and develop the person's interests and capacities. Their relationship will continue to change as they remain an important part of the person's life. JNCS staff are important resources, but they can't substitute for family. JNCS's mission is to support family involvement not to supplant it. This means facing hard questions about what and how much they can do with the person with autism, and who they can trust and recruit to continue their role in the person's life when they are unable to be involved, but these questions can best be dealt with from a position of continuing, active involvement. The circle is a fundamental way to guide decision making and to strengthen the ties among the people who matter to the person's future; strengthening the circle and extending its influence is vitally important. For them, the journey goes on.

It is too soon to know whether this division will occur and what its implications are, but the lessons of the transition from group homes to supported living may offer some importance guidance for dealing with this division if and when it emerges. In particular, parents and other family members need forums in which they can explore this highly emotionally charged issue. Respectful listening, courage in sticking with the issue, and mutual support are fundamental. Letting the difference guide the development of different kinds of responses, perhaps even separate from JNCS, could assure that no family feels the risk of abandonment.

One way to engage this difficult issue would be to explore some of the negative stories that many family and staff members tell one another (and us visitors) about JNCS. These stories may be signals of discomfort about the need for further personal involvement. They may also be signals of serious problems that require creative problem solving by circles. And, in some situations, they may sadly be part of a history that the parties cannot forget or let go. Three stories in particular are widely repeated:

*m JNCS isn't careful about hiring people; anyone can get work here and there is no effort to check people's references or criminal records.* Given the frequency with which people tell this story, every circle should give some time to investigating it:

- How do we make sure that we located decent, honest, and capable people to work with the person we support?

- Who in our circle is responsible for background checks and for checking the overall balance of positives and negatives in the match between what matters for the person and the staff person's capacities?
- What safeguards do we establish if someone who might make an important contribution to the person we support also has potential danger signs in his or her history? What supports and extra structure do we provide to the staff person? What extra checks and balances do we provide for the person with autism?
- If we have hired someone who turned out to be untrustworthy, what have we learned about how to identify the problem, get the person away from the person with autism, and decrease that chances of it happening again?
- If a dishonest or neglectful or abusive person recommended friends and we hired them, are we sure that they are doing their jobs honestly and capably.
- How can JNCS as an agency help us with our responsibility to assure that we recruit and retain honest and capable staff members?
- *JNCS doesn't train the staff who work with people.* Given the frequency with which people tell this story, every circle should give some time to investigating it:
  - How do we assist new staff in developing a positive relationship with the person we support?
  - How do we identify what staff need to learn in order to do a competent job with the person we support and how to we make sure they get a fair chance to learn it?
  - How do we check to make sure staff are putting what they learned into practice in a way that benefits the person we support?
  - How can JNCS as an agency help us with our responsibility to assure that staff have adequate opportunities to learn?
- *Turnover at JNCS is incredibly high and hurts people with autism.* Given the frequency with which people tell this story, every circle should give some time to investigating it:
  - What are the facts about turn over of staff for the person we support?
  - What are the negative effects of turn-over and what have we done to reduce the problems they create?
  - Does turn-over offer any positive opportunities and how do we make the most of them?
  - What have we done to identify and deal with the root causes of turn-over?

- How can JNCS as an agency help us with our responsibility to minimize turn over?

A circle that approaches these issues as problems that belong to JNCS may benefit from a chance to discuss their sense of their future responsibility for the well being and safety of the person with autism they support. This reflection will probably be more fruitful if the circle has a facilitator who has not been a member of the circle and who is not one of the administrators the circle may be expecting to handle these problems.

### **A final note**

The most important part of the journey lies ahead. Most of the people JNCS supports have a strong foundation of relationships with family members and staff who have demonstrated their willingness to learn by facing and solving the myriad problems involved in helping them to establish their own homes. Safeguarding what has already been achieved, deepening understanding of one another's capacities and gifts, and extending the network of friendship and support around each person will reward the efforts of the years ahead.

## **Appendix**

### **Evaluation Team Questions and Hypotheses**

1. How do we get better at really listening to people with disabilities and negotiating the delicate balance between people with disabilities and their families and other stakeholders? Where should we stand as an agency when it comes to conservatorship, where the family's desires are in direct opposition to the consumers, and/or contradictory to the values of the organization

Hypotheses: A. When families begin to let go and learn to trust their child and the organization and work collaboratively with their adult child, staff and other stakeholders, people with disabilities will be able to lead more valued lives which more closely mirror the values of inclusion. B.. When staff begin to let go of pre-conceived notions of caretaking and instead assume competence, begin to believe in the organization and its values and work with the circle of support, people with disabilities will be able to lead more valued lives. C. When we begin to listen to people with disabilities we will have a clearer understanding of their wants, needs, desires and aspirations. We will better support them to lead the kind of lives they want to lead, We will see their gifts and capacities. We will gain their trust and credibility. We will show them respect; we will treat them with dignity. We will learn a great deal

2. How do we reintroduce technologies to assist people to better communicate, to help develop competencies and address behavioral issues which interfere with people's abilities to participate?

Hypothesis: When consumers are given the appropriate support, technology and skills, they will be able to author their own lives, will strive to be heard, will develop their competencies, begin to know and believe in their gifts and capacities. This will lead to greater quality of life.

3. How can we increase diversity on the Board of Directors, to include persons who are not involved in JNCS in any capacity, persons who are professionals who have resources and experience outside the field of disability, primary consumers, professions within the field of disability, etc.?

Hypotheses: A diverse group of people (background, experience, expertise) make better more thoughtful) decisions. A diverse Board of Directors will lead us to provide better services, will be less biased, more global and will look beyond personal interests. In

addition, making decisions and policy that aims to provide overall quality support to all stakeholders

4. How can we move circles forward to really embracing, struggling with and living the values of inclusion? How do we create a better structure to have the capacity to truly support nurture and facilitate circles of support? A structure that is collaborative, person centered and circle/team driven?

Hypothesis: A creative, collaborative, team decision making structure such as a circle of support, will lead to less crisis management, greater motivation and involvement of all stakeholders, more effective support structures, better quality assurance and will have the capacity to truly support people to lead valued lives.

Respectfully Submitted,

Laura Broderick

Jenny Lenqyel

Kristin Jostad

Lisa Marhevka