

Is 'good' enough?

Not just a good organisation but a great one

by Jeff Strully

Jeff Strully has been the Executive Director of Jay Nolan Community Services (JNCS) in Los Angeles since 1993. JNCS has worked hard to transform itself from a traditional congregate care human service agency (i.e. group homes and day programs) to one that supports people in individualised and personalised ways in a cost neutral fashion. JNCS has demonstrated that it is possible for people with high support needs to live in their own homes with an array of supports, work in paid integrated employment, attend school, volunteer and be active participants in the community.

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Being asked to write an article about our organization's journey from group home living to supporting people in personalized and individualized approaches seemed "no big deal" because I have spoken about this issue for years. However I found it was a difficult assignment and one that forced me to think and reflect.

As I begin my 18th year as the Chief Executive Officer of Jay Nolan Community Services, I find myself reflecting on what has been achieved and what remains not yet accomplished. Let me state from the onset that this change is important, can be done, even when things fall apart or get complex it was a journey that we have never looked back on. We never questioned whether we should do it — we did question ourselves and still question ourselves on how we could do this better.

I have come to learn that this is not "our" journey, but the journey of 97 people. We are honored to be on that journey with them. But, it is their journey. That is my way of saying that people with disabilities, family members, allies, supporters, co-workers, neighbours, friends, relationships and paid staff all have to work together. Good things happen not because of one person but because people work together, struggle together, figure this stuff out together, weather bad times together, etc. There are no easy answers or simple short-cuts. Having a good life is hard work!

Looking back

Jay Nolan Community Services was founded in 1976 by the Autism Society of Los Angeles. The organization started out as a social recreation program, but soon received some money to open its first group home then another. Then they opened up a day program in the garage of one of the group homes. Between 1976 and 1992, the agency grew to 13 group homes, 3 day behavior management programs, a small supported employment program and a family support program.

In 1992, there was a crisis within the agency. The Autism Society of Los Angeles, which remained in control of JNCS through the governance process of appointing board members for JNCS, was very troubled and had replaced the board of directors of JNCS. The "new" board then terminated the previous Executive Director; this caused a split within the organization literally down the middle. Finally, the organization was in fiscal crisis.

The Board of JNCS received a donation from one of its members to conduct an external evaluation and determine what should be done.

I was leaving for Australia in 1992 when I got a phone call from a dear friend, Jay Klein. Jay informed me that this father in Los Angeles was calling him and that they wanted to conduct some sort of evaluation. Jay was not in a position to

perform the evaluation and suggested myself as not only a member of the team, but as the coordinator. I spoke to Dr. Lapin, Founder and Board President, about Jay Nolan Community Services and told him I would love to be involved but I could not do this until I returned from my trip in July.

When I returned from Australia, I started to think about the evaluation. There were a number of very well known and respected people who were already on board as team members such as Dr. Lou Brown, Dr. Ian Pumpian, Dr. Rob Horner, Connie Saverino and Claudia Bolton Forrest. In July, 1992, two separate teams came to visit JNCS. This resulted in a written report entitled “A Moment in Time”.

This written report indicated that while everyone cared about the people — people’s lives were not very good. People lived in group homes that were dangerous, people were hurt, people hurt others, people spent their days in very traditional segregated centers or walking around in malls, zoos, parks, etc. Wasting time, wasting lives was the general feeling.

The group homes had four, five or six people with autism and almost an equal number of staff. The staff ratios were 1:3 and sometimes higher to 1:2 and in a few cases 1:1. Turn over was high; violence was high; parent satisfaction was low, workers compensation was extremely high; our funders were not pleased; our consumers were not happy, life was miserable for everyone. To be honest, there was at least one group home that things were better, but this was the exception not the rule.

In 1993, I started my tenure as the Chief Executive Officer with two goals. The first was to try and move the organization toward personalized and individualized approaches to supporting people in valued lifestyles and secondly, the organization had to break even. We had to remain a fiscally viable organization.

What was achieved?

Over the next three years, thirteen group homes closed and sixty four people moved into their own homes. At the same time, three day behavior programs also closed, which were replaced with people doing things in the community. Finally, some of our family support programs also closed and were replaced by more individualized approaches.

Initially, people were living in their own homes/apartments/trailers/condos, etc. with mainly with paid staff coupled with a housemate model. The

housemate was a non-disabled person who would live with the disabled person so that the disabled person could live in their own home. While people with disabilities and their families controlled who was chosen to be staff, how the house was organized, who did what, when and how the move from house to home took longer to happen.

To be honest, some of our folks who moved into their own places made it their homes immediately. It was their place. Others, it felt like mom and dad had fixed it up; in other situations, it felt more like the staff’s place then the person’s place. However, the journey started. The same is true for the relationship between the person we are supporting and their circle of support. In some cases, the individual really took leadership immediately and people came together and worked to first identify and then move forward with the person’s dreams. In other situations, it felt like a staff meeting and in other situations it felt like the parents informing everyone of what needed to be done. Again, the journey just started.

When people moved out initially, concepts such as community connections, relationships, choices, control, power, etc. were all evolving concepts that fell all over some sort of continuum. Some people and circles bought in quickly and others did not.

2010 — Where are we today?

As of February, 2010, JNCS supports 97 people in 96 different homes of their own. Of the 97 people, 89 receive 24-hour support and the remainder receives “walk — in support” ranging from just a few hours per day/week. Most people who require support are receiving support from paid staff.

However, there are people who receive support from neighbors, church members, co-workers, friends and other relationships.

Forty-six percent of those people whom we support who have a housemate, have been in that person’s life living with them for more then eight years now! This has shown us that people without disabilities and people with autism can develop long-term lasting relationships. It also shows us that there are people out there who want to be involved; that people with histories of violence and property destruction can, with assistance and over time, change things in their lives and within themselves. Then such things do not happen, or happen with significantly less intensity, duration and frequency.

People we support live with significantly less violence in their lives, they have more control and

power in their own hands, they live with the ability to influence how they live their lives and what is worth spending time doing.

In a recent evaluation, we learned the following:

- Better roommate matching...
 - Better matches in personalities
 - People spending time together
 - Feels like roommate's home too
 - People are sharing lives not just staffing a home
- People are living their lives like other people....
 - When you walk into their homes, they're doing what other people do
 - They look comfortable in their homes
 - They know they belong there
 - Their homes look like other people's homes
- People are a part of their neighborhoods and communities...
 - Working, going to school, volunteering
 - Need to keep focusing on this in circles
 - Need to include specific plans to continue to expand valued social roles and community connections
- People have better care from and relationships with their doctors...
 - We're getting better at advocating for good care
 - We're doing a better job of documenting health issues (San Jose)
 - We're helping them change doctors
 - We're using regional centres to help us get better health resources

At the same time, we have learned there remains a lot of hard work. Our most recent evaluation showed the following:

- We wish people had more relationships other than staff and family. We need to....
 - Raise low expectations some circles have
 - Share success stories
 - Provide training and support for staff
 - Help circles focus on valued social roles

- Challenge what some people are doing; raise the bar higher
- Recognize the efforts of the staff who are making a difference in this area
- We wish people were doing their own thing and having their own schedules not just going along with staff's preferences and choices. We need to....
 - Help circles increase awareness of this issue
 - Challenge circles to think differently about how activities are selected and scheduled
 - Provide training and support for staff
 - Keep better track of what is happening in people's lives
 - Recognize the efforts of the staff who are making a difference in this area
- We wish more people were employed in real jobs with adequate wages. We need to ...
 - Provide more training and support on how to help people get and keep jobs
 - Have an agency plan for employment support
 - Support an agency wide shift in culture toward the idea that work is what adults do.
 - Help individuals, families and staff see benefits of working and solve problems that keep them from working
 - Assure supports are in place around managing benefits while working
- We're worried about circles where the family controls a lot of the person's life and we're not clear what will happen when they're gone.
 - We need help to figure out a way to approach this with families, maybe from the Board
 - We need to make this a part of the person's plan to assure smooth transition
 - We need to enlist the regional center in helping with this
 - Perhaps we could bring in an outside person to do a training on planning for when you're gone
- We're worried about the amount of stress and tension our CSS's are under.
 - They often are the ones who have to deliver

- bad news and difficult decisions
- They don't get the respect and recognition they deserve
- We need to recognize their contributions and support them in their roles
- We need to think about how information is passed down to circles and help with this
- We wish we could come back more fully to our vision and values and be less caught up in politics and bureaucratic complications. We need to:
 - Be able to spend more time on person centered issues
 - Find ways to support each other within the agency
 - Pay more attention to morale issues
 - Create more opportunities for people to talk about their work and solve problems together
 - Do more circle building for the agency's senior management staff; focus on creating a supportive environment to work in
 - Position the agency for the future, not letting ourselves get bogged down in current crises
- We need to recommit to concentrated efforts to assist people to improve their quality of life. We need to:
 - Re-energize the quality indicators approach
 - Use more visual ways to tell the story of people's quality of life (scrap books or posters with pictures of good stuff happening)
 - Find more ways to recognize staff's efforts to improve quality of life for the people they support.
- We need to find better ways to help individuals advocate for themselves and for changes in the system.
 - Continue to address self-advocacy with each individual
 - Support individuals and their families to get involved in systems' issues that affect their services
 - Provide training and information to people on larger issues

Some very good things have happened for lots of people. Better things need to happen for everyone. We have failed some people not because of the lack of trying or effort, but because we can not fix everything — we don't understand completely — we are in the dark about why someone does something — this is a reality we all live with.

What is needed to make this happen?

Person-centered work which includes person-centered planning, person-centered support, correct and appropriate matching of staff and housemates, listening, circles of support, standing with people both during the easy as well as the difficult times are all part and parcel of what it takes to make it work. Then trying to sustain these efforts over time as people change, their needs change, conditions change, economic and health related crisis takes place, etc.

But most of all, it takes WILL. You need to have the will to keep going each and every day. Some days are wonderful and things work out perfectly and sometimes no matter what you do it just don't work out. The best you can do is get up tomorrow, think about what went right or wrong and then figure out what you are going to do today to make it better.

Final thoughts

Just having an individual budget and control of the purse strings is not the answer; just having a person-centered plan is not the answer; just having kind and good employees is not the answer; just having a circle of support is not the answer; and the list goes on and on. However, when all of these and many other things come together such as people working together, people learning from each other, listening carefully, when people are open to new ideas, trying things and not blaming others etc. it is possible that people with disabilities get the chance to have valued, good lives in the community. Many people are experiencing this both in Australia and the United States and many more could.

Government can be a leader or they can be an obstacle. It depends. But the truth is, so can providers, parents, communities, technology, etc. It all depends. In his book *Good to Great*, Jim Collins writes "Good is the enemy of great." As a provider of services, we want to become a great not just a good organization. We are headed in the right direction and have made many positive strides, but we are not there yet. The journey is not over — as Yogi Berra said "It ain't over till it's over!"