
STILL WAITING FOR MORE AGENCIES TO CLIMB ON BOARD

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. Jeff and his wife Cindy are also parents of three adults with developmental disabilities and mental health needs who require assistance and support to live valued lives in the community.



A HISTORY OF TRADITIONAL PROGRAMS

There are amazing examples throughout the world of individualised and personalised supports assisting people with developmental disabilities as well as other disabilities to lead valued, exciting lives in the community. Belonging Matters is one such example!

“Can the outcomes people want really happen in a cost-neutral manner? Ultimately, the question is can traditional providers change? The simple answer is yes!”

However the truth is that the majority of people with disabilities currently count on moderate to large size agencies to provide for their support. The vast majority of these providers support people in very traditional ways. This includes group homes of four to six people; day programs with a facility based approach and programs where people may go out into the community for an outing; there are many providers especially in the United

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States that provide assistance to people in large numbers such as eight people in a group

home or 16 people or more in a facility based program.

In 1993, Jay Nolan Community Services, a moderate size provider in Los Angeles, California, undertook a twenty-one year journey to transform the way it provides services and runs its business model. The

question was, can an organisation change the way they are doing business? Can the outcomes people want really happen in a cost-neutral manner? Ultimately, the question is can traditional providers change? The simple answer is yes! The more complex answer is yes, but it is hard work, a difficult journey, not perfect, etc. However, it is the best thing our agency ever did.

In 1993, JNCS administered thirteen group homes for people with autism. Each group home had between four and six people with disabilities and two or three staff. Today, JNCS supports 97

people living in 96 homes of their own. The vast majority of the people we support need

twenty-four hour support seven days per week. A smaller portion of the people require walk in support. Walk in support takes place when the direct support worker drops in once a day or three times per week to provide assistance to the individual.

During this time period, JNCS

administered three day behavior programs for people with autism. A day behavior program was made up of 40-50 people with autism in a building. The majority time, people were engaged in "make shift" work, arts and crafts, educational activities and occasional outings.

WHAT NEEDS TO OCCUR FOR TRANSFORMATION TO HAPPEN?

For transformation to take place several things have to happen. The first is developing and holding a clear vision of the future. This must take place.

Secondly, you need to involve all parties. This includes families, people who are supported by the service, direct support workers, outside entities, etc. This takes place through individual and group meetings; focal groups, training sessions, visits to entities already doing the same work, sharing information, etc.

Thirdly, all transformation should take place one person at a time. There are no simple answers or solutions. You need to move forward one person at a time. This is the only way you can create true individualisation.

Fourthly, you need to shut the rear door! You can't take people out of

the facility and at the same time replace them. If you do this, you will always have programs and group homes i.e. a net of zero! You need to

take the bold position to close the back door!

Fifth, provide good leadership. Most leaders want to play it safe. They don't have the courage to draw a line in the sand, take the

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backlash etc that might be involved with transformation and closing programs and group homes.

Lastly record the story. Pull together all of the outcomes both positive as well as negative about the change. What took place; what was learned from the change; what outcomes happened both directly and indirectly. For example, if an individual stopped running away one outcome might be not calling the police to help search for him/her twice a week. There are many other steps in the change process and if you are interested in receiving a power point presentation please let me know.

WHAT JAY NOLAN SERVICES LOOKS LIKE TODAY

As I shared earlier, 97 people are living in their own places. Some of the homes, apartments, condo's, etc, are owned by the individual with a disability or the family; most of the time they are rented by the individual with a disability. The organisation, JNCS, does not have any control of the housing. We are only involved with the support. Most of the people with disabilities require/desire twenty-four hour

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support. JNCS uses a housemate model to address this issue. A housemate is a support person (without a disability) who may be paid

and/or receive a stipend/reduced rent to live and support another person.

that a group situation would be better. But I said that I don't think we need to put Jim

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in a group home. We really needed to figure out how to provide him with personalised support.

So, what are some of the outcomes that have been achieved in the past twenty years? There has been a reduction of psychotropic medication; a reduction of special incident reports; a reduction of aggressive behavior or self-destructive behavior; people have increased control of their lives, happiness and increased knowledge and learning and many other growth areas. Jim's story below provides an example of just one individual's life and the significant changes that have occurred for him.

His first year was a disaster. Jim put 32 staff in hospital - broken bones, dislocations, contusions and concussion. He caused \$60,000 worth of damage in his first year. Ripping out the toilet was impressive but ripping out the plumbing behind the toilet really got my attention! He kicked in 123 windshields. It was a disaster. We just couldn't get it right around Jim.

JIM'S STORY

I first met Bob and Jean Riley in 1992. Their son, Jim, was in a state institution in California. He had been placed there by our agency in the past and the State of California would not release him. Jim lived in the institution with two staff guarding him, 24 hours a day, seven days a week because of his high level of aggression. When I met Bob and Jean they had just won a lawsuit to have Jim move into the community. We talked about Jim and I said, "Well, I think it would be a great idea if

However in 2005, Jim's life looked quite different. Jim had not been involved in any major incident in five years. He now has two part-time jobs. He has a girlfriend. He talks at national conferences. I believe if you met Jim you wouldn't walk away saying there is a dangerous person.

What did we learn from Jim? We learnt that you have to walk with people through difficult times. People are not new clothing that you try on and if they don't fit you give them back. We said we would support Jim and so we had to stick by Jim. I didn't want staff hurt, \$60,000 worth of property destroyed, visits from the police every single day or 22 incident reports.

"We had to struggle with the question of how do we help Jim to stop having the hurt in his life and how does he find peace, how do we find peace, how do Mum and Dad not have cardiac arrests every time the phone rings?"

But we had to walk with Jim. We had to deepen our understanding of who Jim was. We had to truly understand that a lot of, if not all

Jim moved into his own place and got a job and made friends." Bob and Jean said, "Oh Jeff, do you have any idea who our son is?" They thought there were too many challenges and

behaviour is a way of communicating un-met needs. If Jim was upset, then we were failing to meet his needs. I wish Jim could have said "Jeff, excuse me, if you would give me this, life

would be perfect and I will be in harmony.” But the fact of the matter is Jim didn’t. He didn’t have a reliable communication system in 1993 and 1994. But we had to walk with him until we figured all of this out. What that meant in practice was that the people closest to Jim had to make decisions.

My role was not Executive

Director. My

role was just one member of Jim’s Circle. We had to struggle with the question of how do we help Jim to stop having the hurt in his life and how does he find peace, how do we find peace, how do Mum and Dad not have cardiac arrests every time the phone rings?

Knowing the questions is as important as knowing the answers. All of us in Jim’s Circle of Support needed to know how best to support him. It was about asking the right questions. What is going to make Jim happy? What’s he going to do? Who are the right people? What are the issues? Are there health issues? Hundreds and hundreds of issues that needed solutions. The people closest to Jim had to be the people making decisions.

We also discovered we needed the “right people” with Jim. We all know relationships matter. It does matter who is with Jim. For example, Jim cares about me but I can be the worst person

for Jim. I have a loud voice and it’s squeaky!

It’s like Jim says “Five minutes with you, that’s about all I can endure!”

WHY ARE WE STILL WAITING FOR AUTHENTIC TRANSFORMATION?

So, why has this not taken place in other organisations if the results are so positive? This is a complex answer. There are some

fine examples of change taking place in organisations but very few in comparison to the number of organisations that have remained stagnant or have just added a new service to the array of more traditional services.

“The people closest to Jim had to be the people making decisions. ”

I would argue that the following contribute to the stagnation of services

- Lack of vision and leadership by the Executive Director, senior management team and Board of Directors.
- Lack of leadership by governmental entities that do not push the issue of individualisation and personalisation in an authentic manner.
- Lack of advocacy by families and consumers who continue to accept or even like traditional ways.
- Citizens who just don’t know, care or are aware.
- Low expectations for people with disabilities.
- The belief that people with disabilities should be with their own kind (other people with disabilities)

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- Professionals know best.
- An attitude of “let’s hide these people away so that we in the community do not have to deal with them, see them, interact with them, know about this, etc”.
- The belief that programs and group homes are cheaper.

ECONOMIC RATIONALITIES

Interestingly, and on the surface the belief that programs and group homes are cheaper would sound plausible. However, it is not true! At JNCS we have in fact found it is less expensive to do individualisation and personalisation (THE RIGHT THING). It has reduced our staff turn-over, worker's compensation costs, health care costs, use of medications, police attendance and property destruction!

Using an economic reason to create change appears to be a valid reason to create authentic transformation but the more interesting question is what type of society or community do we want to live in? Do we want to hide our older citizens in nursing homes and retirement villages? Do we want to protect the neuro-typical citizen from experiencing people of diversity? I think not. The bottom line is simple. Why should providers do this? Because belonging matters!

Strully, J. (2010) Is Good Enough? Not Just a Good Organisation a Great One. In Thinking About More Than Accommodation. Issue 3. Feb 2010. Belonging Matters: Melbourne.

FOR MORE INFORMATION

Visit: www.jaynolan.org

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Read: The following resources which are available in the Belonging Matters' Online Bookshop www.belongingmatters.org

Strully, J. (2005). One Person at a Time: How One Large Agency Strived to Convert its Traditional Service Delivery to Personalised Supports. In One Person at a Time: Sharing Stories & Insights from the Search to Create Better Lives. Belonging Matters: Melbourne

Strully, J. (2006). Challenges of Organisational Change & Authentic Choice. In One Person at a Time: Sharing MORE Stories & Insights from the Search to Create Better Lives. Belonging Matters: Melbourne