Who Do You See? How Do You Think?
About Supporting People With Developmental Disabilities
In Their Own Homes

A Summary of Presentations by Jeff Strully
On Supported Living*

May 1999

*This paper is one of a series of documents related to "Challenges In Person Centered Planning" written by Beth Mount and Barry Warren through an OMRDD initiative to promote person centered development in New York State. For more information, contact Barry Warren at 518-473-7855.

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In an effort to stimulate creative service development, OMRDD in conjunction with NYCRO, the Downstate Person Centered Planning Network, and voluntary agencies, sponsored five one day presentations by Jeff Strully, who is a national leader of individualized service development in urban environments. Over 500 providers, family members, and people with disabilities attended these presentations. Dr. Strully challenged us to examine our assumptions about the capacity of people with severe disabilities to live in their own homes and communities with support, by telling the story of his daughter and the agency he directs that provides supported living for 90 adults with autism.

This paper provides a summary of the lectures, quotes, overheads, references and challenges provided by Dr. Strully as a result of the following presentations:

May 14th:	A Network and Training Session "Community Building is for Everyone" 75 Morton Street, New York, NY Coordinator: Denise Pensky
May 17th:	A Workshop for Providers 75 Morton Street, New York, NY Coordinator: Tom Noonan
May 18th:	A Workshop and Discussion for Families Borough Hall, 209 Joralemon Street, Brooklyn, NY Coordinator: Vaulda Kendall-Browne
May 19th:	A Workshop for Providers and Families Sponsored by the Letchworth DDSO and Westchester ARC, Elmsford, NY Coordinator: Ralph Szur
May 20th:	A Workshop for Providers and Families Sponsored by the Nassau AHRC, Developmental Disabilities Institute, and the Long Island DDSO Coordinator: Nari Bemis-Rothleder

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Overview

Jeff Strully is the Executive Director of Jay Nolan Community Services, a Los Angeles based agency that specializes in personalized services for 800 people with autism and other challenging behaviors. This not-for-profit, family controlled, urban agency provides Family Support, Supported Employment/Personalized Day Supports, and individualized housing through Supported Living. During the past 7 years, this agency has closed thirteen 5-6 person group homes in an effort to provide individualized support for people to live in their own homes. All residents had been identified by the state as needing the highest level of behavioral support.

Using person centered circles of support with high levels of family involvement, the Jay Nolan staff have assisted people in moving into non-certified town houses, condos, trailers, and private homes. Except for twin brothers, all residents are living individually or with non-disabled, paid and not-paid house mates. Almost all have 24 hour staff support.

The transition from group home to supported living was accomplished on a cost-neutral basis, although transition costs were high. In fact, over time, the staff turn-over rate, worker's compensation premium, property destruction cost, and incident report rate all went down.

Customer satisfaction increased a result of living better lives in their own homes. Challenges regarding friendships, careers, and spending money still remain.

Quality assurance is provided through quarterly service coordinator visits, support circle meetings every 4-6 weeks with minutes reflecting issues, bi-weekly visits from the directors of supportive living teams weekly visits from administrative personnel.

Each family carriers their own agenda of important issues and these are reflected in the focus of the circles of support. If no family is involved, the Human Rights committee has hired consumers to act as advocates mentoring consumers.

In addition to being an agency leader with 30 years of experience, Jeff is a parent of 3 adult children with disabilities who reside in their own homes with support. His roles as a director and a parent uniquely quality him to explore family concerns and consumer issues.

This two part report summarizes the highlights of his lectures from his visit to the New York City area in May, 1999.

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Part I: Who Do You See, How Do You Think?
Changing Our Assumptions about Our Daughter, Shawntell

Who is my Daughter? A Capacity View

1. A 27 year old young woman with the dreams and desires of a 27 year old.

2. Went to college at Colorado State University.

3. Owns a car, a black, Honda, Civic.

4. Works in a preschool and is also part owner of the school.

5. Works at the day care center from 1:00-7:00 daily.

6. Looking to buy a home with her current roommate in Malibu (Ideally, next door to Brad Pitt).

7. Has a Hispanic heritage: was an active member of the Spanish Club.

8. Travels extensively to Mexico.

9. Involved in Shalom Zone, a local association involved in community projects.

10. Has a large circle of friends. Two friends in particular have made life long commitments to Shawn.

11. Likes to go to parties and stay out until 2:00 am!

"This is a young woman with endless possibilities of a desirable future. The texture of her journey includes beautiful shades of color, robust, exciting, and multifaceted dimensions that are forever changing and unfolding."

WHO DO YOU SEE? HOW DO YOU THINK?

WHO IS MY DAUGHTER? A DEFICIENCY VIEW

1. She is a young person with severe, profound mental retardation.

2. She has a chronological age of 22 months, and an IQ of 13.

3. She has vision and hearing problems.

4. She has cerebral palsy, and walks with a toddler gait.

5. She learned to walk at 10 years of age.

6. She is not toilet trained, nor is she schedule trained.

7. She does not use words to speak, nor does she sign, use Bliss, or any other reliable communication system.

8. She has serious seizures, and can therefore be hospitalized quickly based on her seizure activity. She had 127 seizures during the first several years of her life.

9. She has been on many experimental drugs and therefore has experienced many unexpected side effects including a compromised immune system--she can become critically ill in a matter of hours.

10. She doesn't chew her food and can therefore choke easily.

11. At times she has self-stimulatory behavior such as biting her hands, and bruising herself.

13. According to some professionals, she needs to be in a licensed medical facility with medically trained professionals.

"If this is how I see my daughter, then the color of her journey is dimmer, and has many more shades of gray. There seem to be many fewer possibilities and options for this daughter. "

WHO DO YOU SEE? HOW DO YOU THINK?

Changing Our Assumptions about Shawntell

"If I can't look into my daughter's eyes and see strength and capacity, then her options are few. As parents (and professionals) we have to see capacity, talent, and possibilities. We have to see and be excited about their futures."

About 20 years ago we realized that Shawn was not broken and did not need to be fixed. She didn't have to learn more skills and increase her competence to have a good life. She did not have to earn the American dream. She did not have to get better.

We wanted Shawntell to grow up in a loving home, go to a neighborhood school, have friends, have jobs and careers, to have fun, to leave home at age 18, to play, to have a relationship with God, to travel, to have intimate relationships. To have common and ordinary experiences.

Unfortunately, these ordinary experiences are not common in the lives of people with severe disabilities. We wanted to change the pattern for Shawn, and by doing so, change the way we think about and support the lives of all people with disabilities.

These are the assumptions we made then and live by:

About Friendship

I don't want Shawn to be abused, neglected, or exploited. I don't want her growing up lonely. What she needs are friends. People who are going to be in her life for the long haul, looking out for her best interests.

Because I care about her friends, I want their lives to be richer because of knowing her. They should never go through life without the honor and privilege of knowing my daughter.

I trust that Shawn's two best friends mean what they say about looking out for her as long as they live. This commitment does not solve all of our problems, but it helps.

The real test of friendship is who is there when no one else is. When things are dark and falling apart, who can you count on? Shaun has friends who will be there for the good times and the bad.

I'll take friends over skill development in a micro second. The issue that I think is critical is friendship.

About Community

Shawn has to be in the middle of things in order to be part of the community.

Shawn adds to the strength of community. The absence of my daughter weakens community for everyone.

> She is as much of a teacher as she is a learner.
> She is as much of a giver as she is a taker.
> Her presence in community strengthens all of us.

Location in housing is everything. You have to be in the middle of things.

About Learning

We treat Shawntell as if she understands everyone and everything. We expect everyone in her life to treat her with this degree of respect and expectation as well.

She knows that the best way to learn is experiential, not in classrooms and lectures, but through experience that is interactive.

About Support

As a parent, I learned to let go. I learned I cannot protect her from life.

Shawn will always need support, 24 hours a day, 7 days a week for the rest of her life, but the support does not always need to be paid for.

If you are not around Shawn a lot, you probably do not really know what she is saying. Therefore, the people who spend the most time with her have the most authority to represent her interests.

Congregation does not work. Groupings of 4,6,8, or more people of any type creates barriers to real integration. One person with a disability is not likely to overwhelm the environment. Several people with disabilities will.

About Planning and Meetings

Planning is critical but most traditional meetings are really boring and useless.

We believe in circles of support--a group of friends who meet every 4/6 weeks to sit and talk. We ask: "Is life good enough? What went right? What went wrong? What can we do about it? What would make things better?

We never have a meeting without people of Shawntells's age. They help us understand what life is like for her at whatever age she is at the time. They help us understand what really matters. Her friends keep her parents honest about whether she is living her own dream, or that of her parents.

We met in our house until she moved into her own home. Now we meet there.

Shawn's life is not perfect. We keep on trying things, asking questions, and changing things when they are not working.

Part II: Changing Organizations: The Story of Jay Nolan Community Services

How do we apply what we are learning from Shawntell to the lives of 800 people served by Jay Nolan?

Jay Nolan Community Services Mission Statement

The mission of Jay Nolan Community Services is to enable individuals with Autism and other disabilities to learn, work, play, and live fulfilling lives as members of the community. Jay Nolan Community Services is committed to providing life long, individualized support services custom-tailored to each person and his or her family's specific needs.

Values and Beliefs that Guide Us

1. We believe that all persons have capacities and gifts.

2. We believe that all persons need a sense of belonging to a community.

3. We believe that all persons contribute to a community.

4. We believe that relationships and trust are equally fundamental for inclusion to happen.

5. We believe that all persons can live in their own homes with the right support.

6. We believe that all persons should be treated with dignity and respect and have the right to privacy.

7. We believe that for all persons, self-advocacy and empowerment should be promoted.

8. We believe that all persons have the right to be free from pain, coercion and cruelty.

9. We believe that all persons have the right to be heard and their ideas acknowledged.

10. We believe that the people we support are entitled to live full and rich lives with dignity and respect as productive and contributing members of our community.

"Our vision is like water.
We act like water when we come up to a problem.
Water doesn't just sit there or study the problem.
Water goes around, under, over, or through the barrier.
However it goes, it just keeps moving.
Water does not take no for an answer.
Water finds a way."

Key Tenants and Values of Supported Living

1. Individual decision-making.
2. Control and power.
3. Good support.
4. No models.
5. Making a house a home.
6. Flexibility.
7. Ordinary lives.

Organizational Culture: GO DO IT!

1. Commitment to values and beliefs.

2. Zero Reject.

   There is no behavior that will get you thrown out of Jay Nolan.
   We are committed to you as long as you choose to be supported by us.

3. Truth telling.

   There is a big difference between living a dream and living in a dream.

4. Commitment to quality.

5. Customer driven services.

   Even if we don't agree with parents, we still support their decisions.
   Therefore, we are always mediating ethical issues.

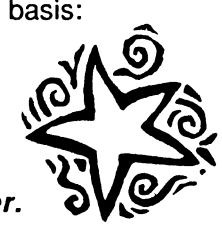
"We created a culture in which no one says "It's not my job." Every single person in the agency is involved in people's lives. If I lose touch with people with disabilities, I'm in trouble.

"There are no magic answers.
There are no simple techniques.
There is a need for commitment.
There is a need to lead from your heart.
There is a need for good support and assistance.
There is a need to listen to people and honor their dreams."

About Circles of Support

People must sit down and talk together every 4 to 6 weeks. You have to keep talking. You have to ask these questions on a regular basis:

Is life good enough?
What went right?
What went wrong?
What can we do about it?
What would make things better.



What is a great day?
What are people doing?
Who are they with?

What is a bad day?
What are people doing?
Who are they with?

A Circle Check-Up. from Inclusion News: 1997-98. By Jeff Strully and John O'Brien

For the past four years, circles of support have been a key element in developing and guiding the supported living program operated by JNCA in Los Angeles. Initially responsible for designing and implementing each individual's move from group home life into their own home, each person's circle now manages the person's support system and makes and implements long term plans. This shift of responsibility from agency to circles moves family members from being monitors of a group home to being directors of a personalized support system. It moves staff from being in charge of a group of clients to participating with circle members in designing and offering the supports and services a person requires to live successfully in their own home and participate in community life in satisfying ways.

Circle members hold responsibility for developing a deep, accurate, and clear account of the person's interests, preferences, and dreams and assuring that this understanding guides day to day staff behavior. People will require a highly organized support system for the rest of their lives.

Circle members hold responsibility for extending continuity through the person's lifetime by clarifying and supporting the commitments necessary to the person's security.

Prejudice, widespread confusion about the nature of autism, and a history of segregated services leave people at great risk of isolation. Circle members hold responsibility for expanding the circle's membership and supporting and challenging the person to expand the network of those who know and care about him or her.

Many barriers stand in the way of pursuing simple things, like living comfortably or having a job; and keeping the supported living program focused on individual needs can call for the most assertive and creative negotiation with the service system that funds and regulates supportive living. Circle members hold responsibility for persistent, creative, problem solving, and vigorous representation of the person's interests.

Circle members hold responsibility for sticking with the person through crises in order to protect the person's interests.

Myths of Supportive Living

1. Supportive Living is only for **some people**.

   There is not a person you know who cannot live in their own home with appropriate support.

2. Supportive Living means you **live by yourself**.

   You live with whom you want to live with.

3. Supportive Living is for people who do not require **24 hour support**.

   95% of the people we serve require 24 hour support.

4. Supportive Living requires that the **person acquire specific behaviors** or skills before they move into their own home.

   We would wait for hell to freeze over if we waited for everyone to acquire all the skills they need or get their behaviors under instructional control.

5. Supportive Living **costs more** than group living.

   Not true. The issue is how do we put money into things that make sense and how do we use the money we have.

6. People are more **isolated** and lonely in Supportive Living.

   This can be a real problem if we don't work on it. However, people need real lives and not just outings. Supportive Living significantly increases the possibility of living a real life.

7. People are more at **risk of victimization**.

   Look at the data. People are the least likely to be abused when they live in their own home.

8. **Accountability is less** in supportive living.

   It's not less, it is just individualized, and therefore defined by each circle/situation.

9. **People want group living**.

   People may appear to want group living if that is all they have ever known, or if that is all that is ever offered.

10. You **can't find people** to support people.

    You can find great people to support people, particularly when they share a home together. When people are treated with respect, they will stick around.

Outcomes in the Lives of People: Quality of Life

From: Group Homes	To: Supported Living
Lack of privacy	Privacy
Lack of choices	Choices/Empowerment
Integration	Inclusion
Chaos	Consistency
Artificial structure	Real life
Limitations	Services designed around the person
System centered	Person centered
Power over relationships	Power with relationships
Quality assurance	Circle of support
Houses	Homes
System resources	Community resources
Decisions made by organization or teams	Decisions made by the person and his/her circle of support
Systems based	Values based
Assumed incompetence	Assume competence
Treat people	Support people
IPP plans	Personal Futures Plans, MAPS, PATH

"No size fits all.
Everything we do is custom tailored.
We have to build a system so that
we can respond quickly to changing needs. "

Key Issues we have to Overcome

1. Segregation and congregation.
2. Fixing people.
3. Not listening.
4. Low expectations.
5. Taking away control and power.
6. Misuse of medications and misunderstanding of health needs.
7. Not understanding accommodations.
8. Failure to support positive relationships.

"I don't know how to do integration when people are segregated.
We are not filling up people's schedules with activities,
we are creating lives based on people's dreams."

Outcomes Achieved for the Agency

1. Workman's compensation was reduced by $250,000.
2. Staff injuries were reduced by 1/3.
3. Repairs were reduced by $150,000.
4. Turn-over was reduced from 102% to 26%.
5. Financial position of agency from "red to black."
6. Parental Satisfaction increased.
7. Happiness increased.
8. People learned more.
9. Many people developed relationships with people in the community.
10. Incident reports were reduced--there were less incidents of "behavioral problems."
11. New questions are being asked.

"You do this work for two reasons:
Because it is time
and because it is right."

References and Resources

Available from Inclusion press
24 Thorne Crescent
Toronto, Ont. M6H 2S5
416-658-5363

Celebrating the Ordinary: The Emergence of Options in Community Living as a Thoughtful Organization. (1999) John O'Brien, Connie Lyle O'Brien, and Gail Jacob tell the inside story of the Options organization over 20 years.

A Little Book on Person Centered Planning. (1999). Edited by John O'Brien and Connie Lyle O'Brien. A thought provoking and challenging collection of articles by the leaders and designers of the major person centered planning tools. Includes articles by Jeff Strully.

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Supported Living: What's the Difference? (1993). John O'Brien discusses the difference between supported living and the traditional ways of providing residential services, based on discussions among representatives of supported living agencies.

Remembering the Soul of Our Work: Stories by the Staff of Options in Community Living, Madison, Wisconsin (1992). Edited by John O'Brien and Connie Lyle O'Brien who collected 150 stories written between 1987 and 1991 by Options staff who support people with disabilities in their own homes.

More than Just a New Address: Images of Organization for Supported Living Agencies (1991). John O'Brien and Connie Lyle O'Brien discuss the changes agencies most make in moving to a "supported living" approach to community living, and is based on in-depth work with a number of agencies and individuals across the United States.

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