IMPLEMENTING PERSON-CENTERED PLANNING

Voices of Experience

EDITED BY

Volume II

JOHN O'BRIEN & CONNIE LYLE O'BRIEN

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John O'Brien & Connie Lyle O'Brien
Editors

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Contents

Previously Published in *A Little Book About Person-Centered Planning*

The Power in Vulnerability

Judith Snow places person-centered planning in the context of interdependence and community.

> *When I am in relationship with other individuals and if these others are networked with each other and especially if these others are different from each other, the possibility exists for all of us to have a rich life, drawing on each other's gifts. Differences in each other's physical and cognitive functioning, our interests, history and experience, our possibilities, our possessions and resources only add to the mix of possibilities that increase our total capacity.*

Learning to Listen

John O'Brien and Connie Lyle O'Brien reflect on listening, the foundation skill for person-centered planning.

> *People come to life when they make contact with someone who works actively and faithfully to understand what they want to say. When people communicate in unusual ways, or when they have been rendered invisible by an environment that discounts the worth of their communication, the effects of listening can be profoundly energizing.*

Person-Centered Planning Has Arrived… or Has it?

Connie Lyle O'Brien, John O'Brien, and Beth Mount identify issues that arise as service systems mandate person-centered planning.

> *We believe that implementations of person-centered planning will be disappointing if people rigorously apply a procedure without sufficient regard for the context of relationships and agreements necessary for it to thrive.*

Think Before You Plan

Michael Smull defines issues for facilitators to consider before agreeing to plan.

> *Be sure to think before you plan. Thinking about a few issues before you get started can help you achieve a better outcome, prevent problems, avoid unnecessary struggle, and save you from public embarrassment. {Plans are} ordinary, day to day efforts to*

> *understand how someone wants to live and what we are going to do about it. The overriding principle is that a plan is not an outcome, the life that the person wants is the outcome. The only acceptable reason to plan is to help someone move toward the life they desire.*

The Politics of Person-Centered Planning

John O'Brien and Connie Lyle O'Brien situate person-centered planning in terms of enduring conflicts that arise at the intersection of individual and family life, community, and human service policy and practice.

> *Person-centered planning belongs to the politics of community and disability. It is not a way to avoid conflict; it is one way to seek real and enduring conflicts in collaboration with people with disabilities who want to consider a change in their lives.*

Revisiting Choice

Michael Smull identifies common abuses and misunderstandings of "choice" in the lives of people with disabilities and provides guidance on dealing with situations when it seems impossible to honor a person's choice, finding balance between choice and safety, creating the kind of opportunities that increase capacity to honor people's preferences about how they want to live, and increasing people's control over their lives.

> *What opportunities we provide, hold back, encourage people to find or protect people from depends as much on our values as they do on the preferences and capacities of the people we support. We need to listen to ourselves when we say that someone is not ready or that they should be able to do something simply because it is their choice. Our values influence and often control what we support. We need to talk about what our values are so that we understand the basis on which we are making decisions. We need to remember that the opportunities that are made available depend on the values of those with control.*

Positive Ritual and Quality of Life

Michael Smull raises consciousness about the routines and rituals that structure our days and embody our relationships.

> *As we look at supporting people in their communities we need to remember that much of the richness of community comes from the relationships that we have and the ritu-*

> *als that celebrate and build those relationships… In our rapidly changing, mobile, and fragmented society, positive rituals deserve attention for all of us regardless of the presence of disability. For people who need substantial support to get through life, developing positive rituals should be a priority.*

More Than a Meeting

Beth Mount identifies the benefits and limitations of person-centered planning, identifies ten conditions associated with positive changes in people's lives and outlines the framework for person-centered development projects.

> *People interested in the future of person-centered planning must look past the lure of the quick fix toward the long journey of learning to do things differently on personal, community, and organizational levels. The resources of the system can be used to support safe havens where people can learn the art of person-centered development. The continuing challenge is to create environments which nurture the concern, commitment, and caring that engenders true relationships.*

The Quest for Community Membership

John O'Brien and Connie Lyle O'Brien use the image of a quest to explore the relationship between person-centered planning and community building.

> *How can person-centered planning contribute to building communities competent to include people with developmental disabilities as contributing members? Failure to actively and thoughtfully engage this tough question unnecessarily limits the effectiveness of the growing variety of approaches to person-centered planning.*

After the Plan

Michael Smull outlines a learning process for closing the gap between how people want to live and how their services are supporting them to live.

> *Whenever people are empowered a dynamic situation is created. The process of listening and then acting on what has been heard is an ongoing cycle. What people want today will be different from what they want tomorrow. The process is lifelong and interactive. The only thing worse than never listening is only listening once.*

Participation Through Support Circles

Judith Snow moves outside the confines of a disability focus to describe the steps to circle building.

> *Circles empower circle members because they are unpredictable. Energized by multiple, complex relationships they often become magnets of synergy, taking advantage of lucky accidents –opportunities that cannot be predicted or bureaucratically managed into existence. This living essence of circles drives out the deadening spirit of disability thinking.*

A Circle Check-Up

John O'Brien and Jeff Strully offer a list of questions that support circle members can use to assess their contribution to supporting people.

> *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 the day-to-day behavior of the people who provide assistance.*

The Ethics of MAPS and PATH

Jack Pearpoint and Marsha Forest define dangers and safeguards in the use of person-centered planning and provide a checklist for good facilitation.

> *Good facilitators hold questions with people, then wait, and listen to the silence. The tension in this silence creates a safe space for people to fill with their deep yearnings and simple unspoken needs, the real stuff of life. As facilitators we open an inviting space for the focus person and insure that their ideas and wishes are heard. Then the hard work begins.*

Telling New Stories

John O'Brien and Beth Mount differentiate person-centered planning from planning that serves systems by contrasting two different sorts of stories about people's lives and the role of service providers with them.

> *Burton Blatt said, "Some stories enhance life; others degrade it. So we must be careful about the stories we tell, about the ways that we define ourselves and other people."*

Finding a Way Toward Everyday Lives: The Contribution of Person-Centered Planning.

John O'Brien and Herb Lovett identify what different approaches to person-centered planning have in common, discuss the ways person-centered planning influences change, consider its limitations, and define some of the controversies among practitioners.

> *Person-centered planning can invite, align, and direct shared efforts to create positive community roles for people with disabilities. It allows people to exercise their practical wisdom to work for more inclusive, more just communities… The future of person-centered planning depends on the willingness and ability of its practitioners to improve through critical reflection on the effects of their work in the lives of people with disabilities and their families.*

A Guide to Personal Futures Planning

John O'Brien considers the role planning plays in improving the lives of people with substantial disabilities, defines five essential accomplishments of human services as a perspective on service quality, and outlines a very early version of the procedure for personal futures planning.

> *None of us creates our lives alone. We each create better quality life experiences with the other people who form our social network. And usually we are resources to each other without much formal planning. Like all of us, people with severe disabilities develop in relationship. But because they rely on other people's co-operation to an unusual extent, and because human services often play a larger than ordinary role in their lives, people with severe disabilities count on other's planning and organizing skills.*

Authors

Betty Boomer is the Associate Executive Director for the Waterloo and Wellington-Dufferin Branches of the Canadian Mental Health Association. With a background in psychiatric nursing, Betty has worked for many years in clinical and community mental health settings and does training for the Collective for Community Action on a variety of topics related to mental health. E-mail: boomerb@cmhawrb.on.ca.

MaryJo Alimena Caruso is from Pittsburgh, PA, where she lives with her husband and three children, Griffin, Mackenzie and Connor. Her role as a facilitator of person-centered plans began in 1990 and since then she has added on the hats of trainer, mentor and writer. She enjoys the opportunity to help others think about how values influence our work and ways to apply person-centered thinking and tools to a variety of situations.

Patricia Fratangelo is Executive Director of Onondaga Community Living, where she has worked since 1990. She has worked in the field of developmental disabilities for 22 years, beginning as a direct care worker. She remains a close friend with several people with disabilities that she previously worked for, vacationing and spending holidays with them. She lives in Trumansburg, NY, with her husband, John King. Onondaga Community Living. 518 James Street, Suite 110 Syracuse, New York 13203 E-mail: patfrat@aol.com.

Rob Greig is National Director of Implementation for Valuing People –the English national strategy for learning disability. Previously he was Director of Organisational Development at the Institute of Applied Health and Social Policy at King's College London. Earlier experience included managing learning disability services in both the health and social care field. E-mail: Rob.D.Greig@doh.gsi.gov.uk.

Steve Holburn I am a Research Scientist at the New York State Institute for Basic Research. I spent much of my career trying to help people with intellectual disabilities and serious behavior problems, but my impact was often blunted if the person lived a poor lifestyle in a bad environment. I was struck by person-centered planning because it sought to change such conditions and bring about better lifestyles. It offered a sensible starting point. However, I have been equally struck by how difficult it is to *do* person-centered planning and how few attempts have been made to empirically demonstrate its effectiveness. Many professionals are eager to dismiss person-centered planning as a fad or a panacea. For these reasons, I and my colleagues have been trying to find ways to (a) assess and implement person-centered planning faithfully, and (b) measure its effects over the long term. While some may see a contradiction in applying "science" to a "counter-science" approach such as person-centered planning, I believe the blending will contribute to the survival and evolution of this approach. E-mail: holbursc@infi.net.

John Jones is the Chief Executive Officer of the Waterloo Regional Branch and the Wellington-Dufferin Branch of the Canadian Mental Health Association. John has over twenty-five years of experience as a funder, administrator, and consultant with boards, staff, people supported, and volunteers of human service organizations. E-mail: jonesj@cmhawrb.on.ca.

Susannah Joyce is the Director of Realizations Training & Resources. She works internationally with people who have disabilities, families, and service organizations on person-centered planning, circles and friendships, positive approaches to challenging behavior, leadership, and systems change. Visit her website at www.realizationstraining.com.E-mail: susannahjoyce@sprint.ca.

Jo Krippenstapel offers consultation and training focused on enhancing quality lives for individuals, more responsive organizations, and richer community life. She provides support to individuals with disabilities, families, and staff to create teams of people who learn and take action together. Jo lives in Cincinnati, OH. She can be reached by E-mail: Jokripp@cs.com.

Sandy Landis lives and works in rural Perry County, OH, where she is involved in projects designed to increase community capacity and improve the quality of day to day experience for local citizens.

Kathy Lee is a native of Meadville, PA, where she lives with her roommate Connie and their 2 dogs and 3 cats. She has been actively involved in thinking, planning, teaching and writing about person-centered planning and circles of support since 1991. Kathy travels about occasionally and talks to others about the importance of community for everyone.

Debra McLean. I am a practitioner of employment and person-centered planning processes since 1988. I have lived and worked in Oregon since 1979. I have provided consultation and training to families, individuals and agencies on those topics, both locally and nationally. I owe a huge debt to those families and individuals who allowed me to learn from them how to successfully enter the world of work. I work at Oregon Technical Assistance Corporation. E-mail: dmclean@otac.org.

Karen Green McGowan is a clinical nurse consultant with 38 years of experience in developmental disabilities. She specializes in teaching clinicians and service providers to work with those persons perceived as medically fragile and difficult to serve because of major movement disorders and other health obstacles. She has been appointed to several court oversight panels, and currently monitors services to persons in Massachusetts nursing homes who are also identified as having developmental disabilities. She has developed a number of publications on health issues for persons with disabilities, including an electronic instrument to identify health risk. For more information, see her website at www.mcgowanconsultants.com.

Beth Mount. For the past 25 years I have been searching for new ways to discover, affirm, and describe the beauty and strength in the lives of people with disabilities, their families, and the people who support them. During the past twelve years, I have been involved with person-centered planning and community building in New York City. Living in New York City has given me the opportunity to deepen my understanding of the universal themes in the spirituality and artwork of world cultures. As another way to help tell people's stories, I work on my fabric art while my son does his homework. Visit www.capacityworks.com.

Connie Lyle O'Brien and **John O'Brien** work together to learn about building more just and inclusive communities from people with disabilities, their families, and their allies. They use what they learn to advise people with disabilities and their families, advocacy groups, service providers, and governments and to spread the news among people interested in change by writing and through workshops. They work in partnership with a group of friends from 12 countries. They are affiliated with the Center on Human Policy at Syracuse University and the Marsha Forest Center for Inclusion, Family, and Community. Connie's E-mail: connielyleobrien@mac.com John's E-mail: rsa315@cs.com.

Anne O'Bryan has twenty years of experience in developing, managing, and improving services for individuals with learning difficulties in the United States and Europe. She is currently providing support and technical assistance to individuals, their families, employers and support services. Anne lives near Bath in England and can be reached by E-mail: anneobryan@compuserve.com.

Jack Pealer. Some of his friends once called Jack an "Ohiopatriot". He has spent the last 32 years in Ohio trying to help people with disabilities find or make "home" for themselves. E-mail: jackjr158@earthlink.net.

David Pitonyak can be reached at Imagine, 3694 Mt. Tabor Road, Blacksburg, VA 24060 For additional information, log onto David's web site: www.dimagine.com.

Pete Ritchie works for Scottish Human Services Trust (SHS). SHS is a non-government organization working with others to build more inclusive communities and more responsive services. SHS offers encouragement, training and consultancy to people and organizations who are learning about person-centered planning. You can contact SHS at www.shstrust.org.uk or at 1a Washington Court, Edinburgh, EH11 2HA and reach Pete directly at pritchie@shstrust.org.uk.

Mary Romer. To paraphrase the lyrics from John Lennon's song, "Imagine," some say Mary is a dreamer and she is glad she is not the only one. She is exceedingly grateful to have grown up in a family that promoted her ability to dream, both for herself and for people labeled with a disability. For the past 29 years, she has worked along with people with disabilities, their families, and people who provide services striving to give life to the dreams people hold. E-mail:mromer@seanet.com.

Fredda Rosen and her colleagues at Job Path in New York City support people with developmental disabilities in their efforts to make choices about their lives. Job Path, which was established in 1978, strives to be a reflective organization where staff carefully listens to people and thoughtfully considers the implications of their work.

Martin Routledge is the Valuing Support Team Regional Advisor for the North West of England. Martin's work over the past few years has been in service management and development. Prior to joining the VPST he was co-ordinator of the North West Training and Development Team, which is funded to work with self advocates, families and service agencies in the region to promote the full inclusion of people with learning disabilities. Martin can be contacted at Martin.Routledge@doh.gsi.gov.uk.

Helen Sanderson works part-time for the North West Training and Development Team. She has a Masters in Quality Assurance in Health and Social Care, and has recently completed her Ph.D. in person-centred planning with people with profound learning disabilities. Helen is the primary author of the book *People, Plans and Possibilities* and has written extensively on person centred planning. Helen is an essential lifestyle planning mentor trainer, and much of her work is around the practice and development of person centred planning processes and systems. Helen lives in Manchester with her partner Andy, and three daughters, Ellie, Laura and Kate. E-mail: helen.sanderson@nwtdt.com.

Sally Sehmsdorf lives in Seattle with her husband Art Gomez and her children Johann and Kayta. She works for the Center for Community Support, a project of TASH, under Mary Romer's leadership. For the past seven years, she has had the privilege of sharing life and dreams with many people with disabilities and their families. E-mail: salliese@attbi.com.

Mayer Shevin has worked at various times as a professor of special education, a psychologist at a large state institution, and a teacher in the areas of positive approaches to behavior change, advocacy, and communication development. He directed the "Home-made Futures Project," developing person-centered planning resources in North Dakota. He is an associate of the Facilitated Communication Institute at Syracuse University, where he edits their newsletter, the Facilitated Communication Digest. In his private practice as a trainer and consultant he supports individuals seeking to progress toward their personal goals despite challenging behaviors and communication impairments, their families, and the agencies that support these individuals.

Michael Smull plays a key role in developing and disseminating Essential Lifestyle Planning. To contact him and read much more of his work visit www.allenshea.com/friends.html.

Jeff Strully I am the Executive Director of Jay Nolan Community Services. I have held this position for the past ten years. I have been involved with people with developmental disabilities for over 32 years in a variety of capacities and environments. My wife and I are the parents of three adults with developmental disabilities. Visit the JNCS website at www.jaynolan.org.

Marsha Threlkeld has been creating plans and working on behalf of people with disabilities for 17 years. She is also a choreographer and has performed with individuals with disabilities at The Kennedy Center. Marsha gets bored, looks for new ways to entertain herself, and likes to be recognized and appreciated for work well done. She assumes everyone else does too. Marsha works at Washington Initiative for Supported Employment in Seattle. Visit the Initiative's web site at www.theinitiative.ws.

David and Faye Wetherow share their lives with an adopted daughter who has complex mobility and communication challenges. They have long been involved in innovative service development, teaching, facilitating and community-building. You can reach their website at www.communityworks.info.

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The Challenges of Person-Centered Work

How Two Agencies Embraced Change

Patricia L. Fratangelo and Jeffrey L. Strully

> *So many large community services are really just institutions broken up and scattered around. No amount of good will, regulation, or monitoring can ever make either a large institution or its smaller community analogs a home. I often despair that these so-called community services will never change as they work under the misperception they are just fine as they are.* (Lovett, 1996, p.29)

For more than 60 years, well-intentioned family members and professionals have established community organizations to serve people with developmental disabilities. The desire to provide good services and the requirements of state agencies, who have played an increasing role in paying for services, have led most agencies to implement local services based on models developed elsewhere. While these models vary with time and place, they embody a common pattern, which we will define in order to describe the baseline conditions from which our two agencies have transformed.

Until very recently, program models for residential and day services have been disability-specific and group-based. First, an agency implements a program model by acquiring property, then it hires supervisors and staff people, then it chooses people, who may be strangers with little in common except a label, to fill the number of available slots. While program developers thought about how many people would live in a home, its floor-plan and furnishings, and its staffing patterns, they usually paid less attention to the ways routines and rhythms would be shaped to match each particular resident's life (Smull, 1999).

The decision to support people as a group, dictates much of a household's organization. Dinner will be at five o'clock for the household, even though for the first 33 years of one person's life dinner was always at six-thirty. Because everyone can't bathe at the same time, one person is assigned to bathe at eight in the evening instead of showering in the morning after breakfast. A person shares a room with a stranger, although before moving she had her own room.

The worker responsible for scheduling may not experience these events as significant, but the person placed in the group –away from family and familiar routines, living with people they may not like– experience these efficiency measures differently. Shortly after the residents move in, problems develop. One person starts to throw food when required to eat dinner at five o'clock. Another person angrily yells at staff who prompt her to take an evening bath. A third person hits his roommate for touching his prized possessions. As problems multiply and increase in intensity, staff tighten rules, get help to implement behavior plans, and call for medication to control "mental health problems". Eventually, a person who lives under this group regime either loses their individual spirit and succumbs to the setting's demands or fights even harder for what is important to them. Those who keep their spirit and decide to resist are often defined as disruptive or disordered and, if available control strategies fail, referred to a more restrictive setting.

Staff and managers are more likely to see the individual people as being or creating problems than they are to question the design of their program. This all too familiar scenario blocks the changes necessary to deliver person-centered supports: Programs created for groups become the machinery which keeps an organization thriving. Effort goes into keeping that machine properly lubricated so that it will run efficiently (Schwartz, 1997). The people using the service are the nuts and bolts necessary to keep the machine running smoothly. When a person becomes unmanageable, the machine's efficiency is reduced. That person can be discarded in favor of a new person, with the hope that the new person will function properly and get the program machine back into proper working order.

Too much effort in the developmental disabilities' field goes into trying to fix the wrong problems. Until an organization questions the way its programs are designed, staff and managers and boards will waste energy looking for the perfection that will make their group-based program work like a Swiss Watch. They will spend countless hours and dollars hunting for the perfect group match and mix, the perfect person-centered planning technique, the perfect behavior plan, the perfect job description, the perfect staff training and motivation package. This futile search for the perfect program machine will continue until leaders find the insight and the courage to get people throughout the organization to ask two questions and take the answers seriously as a demand for real change in the way we offer services:

- Why do we usually see it as the person's problem if they cannot conform to the program that we set up?
- Why don't we understand these situations as our program's inability to do what people need and then re-create our supports from the ground up, starting from individual people we know or get to know?

Our two agencies –Onondaga Community Living (OCL) in Syracuse, New York (Pat) and Jay Nolan Community Services (JNCS) in the San Fernando Valley of Los Angeles, California (Jeff)– have worked for twelve and ten years to learn the lessons that come from understanding and changing the limits imposed on people with developmental disabilities by group-based programs. We strive to center our organization's work more on the people we support, rather than the systems that we operate. We focus on learning to listen to behavioral problems with a different ear (Lovett, 1996). We struggle to align our efforts with people with disabilities and family members, not with today's most popular version of state of the art group-based service models.

These commitments enable us to walk down a different path with each person we support, seeing the many problems we experience along the way through a set of lenses that show us how we can better adapt and adjust to better match each person's changing situation. These commitments demand that we design services one person at a time, a practice that has taken us into new territory for our agencies and for the systems that pay for and regulate us. Group-based residences and day programs are a thing of the past for our agencies, but the search for effective ways to sustain person-centered work goes on.

Our agencies support people with varying needs, but most of our work serves people who challenge the system in multiple ways. Earlier in their lives, many were abused, neglected and exploited. We see these people as spirited individuals who worked hard to fight against services that did not work for them. They were not always successful. Many have suffered the brunt of behavioral plans, behavior controlling medications, and, often, multiple moves from placement to placement –all to serve the system's interest in gaining control of them without changing its ways. We are determined to change this pattern in the lives of the people with developmental disabilities who trust us to support them.

Our approach is simple to state: we focus on individual people and figure out what each person wants and needs to have a good life, and then we arrange organizational resources to support each person in a way that works for them. Creating the organizational capacity to do this simple thing calls for much more than small changes. It has taken organizational and personal transformation.

After briefly describing the changes in our organizations, we will each tell the story of how change happened for one of the people we support. Each of these people has taught us a lot, but neither one is "typical" of the people we serve. Our purpose has been to work one person at a time, so fully describing what has happened would take many stories, one for each person.

The agencies then and now

Onondaga Community Living (OCL)

In 1990, OCL supported people through traditional group living arrangements that were designed around disability. The homes were structured and staffed according to state of the art ideas about what constituted a good group home. The people we served and their staff lived through many variations of the group-based services pattern that we described above.

Though there were problems, group home staff worked hard to deal with them and, for a time, most people thought that the group homes offered people the best possible support, given the extent of their disabilities.

As new people were referred, OCL began to spend more time getting to know people as individuals and personalizing services for new people. Each new person supported by OCL moved into their own home with a support structure that enables the person to live effectively. Some new people lacked skills in cooking, personal care, and budgeting, and some had behavioral or medical problems. Many required 24-hour support. Staff and families of people in the group homes began to notice that some of the new people had more needs for support than some of the group home residents. This realization raised a new question.

> *If OCL can develop personalized arrangements for new people coming in, why can't we do the same for people we already know who live in a group home?*

Taking this question seriously began to spread a change in mindset throughout the organization. People began to question the assumption that a person had to have a particular set of skills to live in their own home. It became clear that all a person needs is a desire to live the life that can be theirs if personalized supports are available. Once people at OCL learned to recognize this desire and work with the person to develop proper supports, the transformation was on. People in the existing group homes got the option of more personalized living arrangements and the numbers who chose to move into their own homes steadily grew.*

Today, OCL serves about 75 people with a combination of supports that may include residential, supported employment, day support and service coordination. Which services a person gets from OCL depends on what each individual requires.

Ocl supports 38 people to live in homes that are personalized for their unique situations. Many of these people need 24-hour support and several also require personal care. No one must live with another person with a disability, though some people choose to do so. A large percentage of people now share their lives and homes with ordinary community members instead of people with similar labels. These life-sharing living arrangements are based on the personal interests of those involved. Sometimes a person or a family member recruits a housemate; sometimes the person and family look to OCL to assist in recruiting a suitable housemate and ensuring a good match.

About 35 people a year receive personalized vocational supports from OCL. Depending on a person's interests and needs, he or she can work competitively or volunteer in the community. Ocl does not have a congregate vocational site, but rather supports people in many ordinary community places.

Jay Nolan Community Services (JNCS)

Founded and governed by the families of people with autism, most of whom had no community alternative to institutionalizing their sons and daughters, JNCS has been committed since its founding to never terminating service to a person because of that person's behavioral challenges. The family members who govern JNCS have a long standing desire to assure that their agency's services reflect the state of the art.

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* For more about the changes at OCL, see Fratangelo, 1994; Fratangelo, Olney, & Lehr, 2002; Olney, M., Fratangelo, P. & Lehr, S. (2000); O'Brien, 1996; Warren et al, 1999.

In 1992, JNCS served 65 people with autism in 13 group homes, 140 people in three "day behavior management programs," and offered an array of segregated and congregate recreation, respite, and family support programs.

The agency was in fiscal crisis. Morale was low and tension was high among staff, management, and the Board. People lived out most of the pattern of problems generated by group-based programs (except exclusion from the agency). These problems were particularly intense because so many people experienced major communication impairments and behavior that was injurious to themselves or others or damaging to property.

A comprehensive review of JNCS by a team of nationally recognized experts brought these chronic difficulties into focus and catalyzed a process of organizational transformation led by an alliance between Board members and Jeff, a review team member whom the Board recruited to lead the agency.

Within three years, JNCS closed all 13 group homes and moved people to their own homes, one person at a time. Responsibility for designing, overseeing and modifying personalized supports rests with each person's circle of support.*

All three "day behavior management programs" closed and the people involved now receive personalized day supports, including supported employment.

Most segregated family support activities have also been redesigned to support people to participate in community settings.

These changes were based on trying to understand who people were, listening to each person, helping people find their own dreams and then walking with people to achieve their dreams.

Today JNCS offers three types of support –supported living, personalized day support and supported employment, and family support– to a total of 650 people throughout Los Angeles County and surrounding counties including Santa Clara County.

Susan's story (OCL)

Susan started life without a disability, but as an infant she developed a serious infection that left her with a seizure condition and profound cognitive disability. She lived with her parents until she

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*For more about the change process, see Hulgin, 1996; O'Brien, Leary, Hitzing, Savarino, & Sousa 1995. Learn more about jncs at www.jaynolan.org was five. At age five she went to an institution where she lived for twenty-eight years in living units with many other people with challenging behavior. Susan developed a reputation as demanding and self-abusive.

Susan and one other person from the same institution came to live with four other people from our community when OCL opened it's second group home. The Selection Committee had worked hard to match the six people so that they would be compatible, but on day one the problems began as people in the house, including Susan, damaged property or lashed out at one another.

Susan was very jealous and demanding of group home staff attention. She became agitated and angry when staff went out with another resident and she was not included. She often stood at the front door and pounded on the window or wall unit until it was damaged or broken. After replacing many windows, we installed Plexiglas. Staff tried to keep Susan away from the door and tried to sneak out of the house to avoid scenes. Susan also took her frustration out on other residents. She would hit, bite and throw things as people left and again when they returned.

We discovered that the person who moved with Susan from the institution did not like Susan. When the two of them were left at home, they engaged in hitting, hair pulling, biting, and screaming. Sometimes this behavior would spill over and involve residents.

Susan has limited verbal skills and is not easily understood by many people. She could not say, "I want to go out more" or "I do not want to live with so many people" or "I do not want to live with this person." As staff became more reflective and better able to listen to the messages in Susan's behavior, they associated much of Susan's difficult behavior with her not being as busy as she wanted to be. When someone left the house to do something, Susan wanted to be part of whatever was going to happen. But she could not always go out because of the needs of the other members of the household.

We tried medication to control her behavior. The meds may have slowed her down a bit, but it became clear to staff that Susan's behaviors were not going to change until her situation changed. This deeper understanding helped us comprehend our part in the problem. Instead of thinking of Susan as a person, we were trying to fit her into a group that she didn't want to join. The design of the group home was working against us and Susan was not willing to compromise her desire for supports that suited her.

Susan's support needs were complicated: she required 24-hour support, had difficulty communicating and dealing with frustrations, lacked most self-help skills, was unable to do housekeeping or take her own medications, could not cook or budget, and required help with personal care. Our staff vision for Susan had changed, but it still was not clear how to set up a living arrangement where she could be successful.

OCL staff, along with Susan and her family, struggled for months to think out a different method of support. Even though other people were succeeding with personalized support from OCL, Susan's parents doubted OCL's ability to provide the amount and kind of support she would need outside a group home, and so did some of the staff who worked with her day-to-day. Despite their doubts and our uncertainties, we kept trying for an understanding that would support Susan in a better way. Carefully considering family and staff doubts gave us a deeper understanding of the assistance and safeguards Susan needed in her new life.

Persistently pursuing these key questions together helped us arrive at some of the answers and to enlist Susan's family in allowing the change.

- What does Susan's life and history show us?
- What are her preferred personal daily rhythms and routines?
- What people bring out the best in Susan and what people bring out the worst?
- What places bring out the best in Susan and what places bring out the worst?
- What situations bring out the best in Susan and what situations bring out the worst?
- How is Susan vulnerable?
- What safeguards can be put into place to reduce the risk from her many vulnerabilities?

We wanted to discover what made Susan's life most pleasant and minimized her agitation. We wanted to eliminate things that caused her distress. As we re-visited the key questions, we kept coming back to the mismatch between our group-based program and Susan's life: Susan had not chosen the people she lived with and she continued to dislike them as much as they had come to dislike her. The paid people who spent most time with her did not believe in her ability and only saw her inadequacies. We knew it was critical to find people who truly enjoyed Susan.

Susan moved from the group home into her own place in 1996. She lives there with a non-disabled housemate and has back-up support from paid staff. She attends a day service provided by another agency. A personal care aide assists her daily with her morning routine. Susan no longer has to compete for attention because she is the focus of her support. All of the non-disabled people who have been housemates to Susan got to know her either in a paid role or socially before deciding to live with her. They share a normal household and a typical lifestyle of working separately and living together.

Susan is happier and more content than she has ever been. Her problem behaviors have decreased dramatically. Comparison of records for a random month in the group home with those of a month in her new home, show that she is enjoying life with less personal stress. For example, in the group home in June, 1994, Susan hit, bit, banged on and broke windows, or banged on and damaged property 12 times in 30 days. In June, 1998, two years after moving there were only two indications of arguing (no hitting, biting or damaging property). In June, 2000, there were no notable incidents.

Susan teaches us that to effectively support a person whose behaviors threaten us, we have to take time to discern what the person is trying to communicate and to understand the person more deeply. People with this deeper knowledge of the person have both a full awareness of the person's vulnerabilities and a powerful desire to work with the person to create a situation that is truly better. This knowledge underpins the kind of personalized supports that give a person their best chance at true security.

Jim's Story (JNCS)

Jim has taught us a lot these past seven years about person-centered planning and support. Most of all, Jim has taught us to "walk with people" especially during dark and difficult times. Jim has also taught us to listen. Listen not only to the words, but to emotions and feelings. Listen to and honor Jim's concerns. Finally, Jim reminds us of the absolute, critical importance of personal relationships. Sometimes walking with Jim means running very fast to keep up with him and sometimes it means paying attention to the little things that only show up when we slow way down.

Jim lived in a JNCS group home for many years. Then things got out of control and his medication level became more and more dangerous to him. He was admitted to a state institution on a temporary basis so that physicians there could safely stabilize his medication. Once Jim was in the institution, state and local authorities decided the level of violence Jim exhibited barred him from living in a community setting.

Jim's dad and mom fought state and local authorities in court to win the right for Jim to return to the community, and finally achieved their goal in the fall of 1992. At that time Bob (Jim's dad) came to JNCS and asked that Jim be returned to our agency and be placed in one of our group homes. The JNCS Director said that Jim should indeed come home, but that he should move into his own place with appropriate support rather than into a group home. Though he had doubts, Bob agreed as long as we hired Mike, a long time support person for Jim.

The first year after Jim moved into his own home was a major challenge to everyone. Jim destroyed, broke, or ripped out lots of things. Tens of thousands of dollars went to replace or repair walls, windows, windshields, sinks, appliances, and bathroom plumbing. Jim went through more than 30 different staff people. A number of staff members ended up in the hospital with injuries Jim caused. Other staff were fired for myriad reasons. Mike, the key staff person, hung in with Jim, but he had some significant personal problems of his own, including addiction. Mike made several errors in judgment which placed Jim at risk and had to go. Jim had trouble connecting with staff, and the few times he did connect with a staff person, the staff member left him for one reason or another. People were afraid of Jim or Jim was afraid of them. It was a very, very difficult year for everyone.

At the beginning of the second year, a crisis occurred with Jim's support people. All three staff had to be terminated at once. Because, through all the chaos of the first year, we had managed to learn some more about who Jim was and what he wanted, we were able to use the staffing crisis to find three new support staff whose attitudes seemed more in sync with our deeper understanding of Jim.

These three people turned out to be the right match. Their personalities and their respectful way of listening to and being with Jim were exactly what he needed. Over time, they formed a good working relationship with Jim. It is not credentials or training that made this relationship work, it is who these people are when they are with Jim. The way they relate to one another allowed Jim to get to know and care for them and for them to get to know and care for Jim.

Six years later, these same three people continue to work as Jim's support staff. Property destruction has decreased almost to zero. Injury to staff is almost non-existent. Jim is happy. Jim lives with less violence in his life and in the lives of the people who support him. His parents are happier and under less stress.

Jim uses facilitated communication (Bicklen, Morton, Berrigan, & Swaminathan, 1992) and is almost independent in his typing: support at the shoulder or shirtsleeve is enough for Jim to express his views on life. He communicates with a lots of different people including his mom and dad, his support staff, and several other people.

Jim's circle meetings have become opportunities for good conversation and a chance to think with Jim about the future. Jim has had several jobs and is most interested in returning to school. He has had several dates with a young lady he has known for years and cares about greatly. He and his dad go to happy hour every week. Life is not perfect for Jim, but his life is headed in the right direction. Today we don't spend time with special incident reports, property destruction, and staffing challenges. Now we discuss where Jim wants to go on vacation, or what classes he wants to take in school, or when he is going to see Jenny. These questions are closer to the questions that Jim has always wanted to discuss.

What have we learned?

In both agencies, the transition from group-based services to person-centered supports happened as more and more people adopted new ways of seeing people with disabilities, new ways of thinking about supports, and new ways of acting. We can describe some of the tools that moved our transformation forward:

Tools for transformation

Dreaming of Desirable Futures: People with disabilities as well as their families, friends, allies and supporters deserve to have vibrant, beautiful dreams for their future. Dreams that are bright and multicolored. Dreams about doing things you always wanted to do. Dreams of ordinary and common experiences that allow a person the opportunity to live every day to it's fullest. Dreams that are not only recognized and heard, but shared by people who are willing to work to bring dreams into reality.

Person-centered planning: Person-centered planning is not a one time phenomena but a way to stand with people over time, listening carefully to them, validating their hopes and dreams by taking action with them, and learning to know them more deeply. Our ability to listen this way depends on the relationships we form with one another. Person-centered planning is about walking with a person day in and day out over time as the journey of life unfolds.

Circles of support: A committed group of people have a much better chance of achieving dreams and avoiding nightmares than a lone individual does (Mount, Beeman & Ducharme, 1988). The circle comes together as the person with a disability joins willing family members, friends, co-workers, neighbors, supporters, and allies to support and protect a good life. The circle brings imagination, strength, help, and wisdom to the personal direction a person works to take.

Zero rejection: An agency commits to stand with the person no matter what challenges they have. We work to improve our understanding of who the person is and what the person wants. We adapt support structures to enable the person to live life more fully. (Smull & Burke-Harrison, 1992)

Outcomes

Some of the notable results of our agencies' transformation from group-based programs to personalized supports include these:

- Many people and their families say that people's lives have significantly improved
- People are living with less violence
- Behavioral incidents have decreased significantly
- Medications have often been dramatically reduced
- Staff turn-over has decreased significantly
- Staff injuries have decreased
- Premiums for Worker's Compensation are lower
- Families are happier and more satisfied
- Staff are happier
- People are moving forward with their dreams
- JNCS has increased its net assets from about $200,000 to more than $800,000. OCL went from running a $200,000 deficit to running in the black

Lessons

After more than a decade of doing this work –in a smaller agency and a larger one, in a medium sized community and in one of the most populous areas on the planet– we would list the lessons we have learned like this:

- *All* people can live in their own homes. It is not dependent on skill level. It is dependent on support level. Willing people can develop supports to enable anyone to live effectively in their own home. Sometimes it takes time and trouble (remember Jim's first year).
- Listening to people is essential. Staff must learn how to listen both to words and behavior to discover something about the desires and interests that make a person uniquely themselves. So many professionals think they have heard what the person wants after a brief talk. Such superficial listening leads to placing people in slots. We need to avoid preconceived notions of what people need and take the time to listen with open ears and an open heart while being willing to change our typical service structure to enable new things to happen.
- Behavior is truly a form of communication, though it can be terribly misunderstood. Like Herb Lovett (1996) we must find the will to listen differently to behaviors that confuse or threaten us. A person does not usually bite someone, damage property, or hit themselves or others for no reason. Unless we take the time to understand the deeper, more personal reason behind a particular person's behavior, we may never get to the root of the problem.
- Power and control must rest in the hands of the person and when appropriate his or her circle of support. Decisions must be made at the individual level not at the agency level. Professionals have been tagged as the experts for people with disabilities and for what they need. Our experience shows that professionals need to let down our façade and learn to trust the real experts, the people who come to us for support and those who love them. Together, this partnership will undoubtedly know more about what the individual needs than any one professional can. We need to respect the person and their support circle as we work to develop the services around them.

- Being in the community is not the same as being part of the community. A person can live in a wonderful house on a nice street and have a nice job, but if no one knows them, says hi to them, or wants to be with them, life can be very lonely. We need to ensure that each person is supported in growing numbers of relationships in the communities and activities that are of interest to him or her (Walker, 1999).
- Relationships and friendships are at the heart of the matter. Relationships are the glue that holds communities together. Relationships are the lifeline to happier lives and more satisfying existences (Amado, 1993; Amado, Conklin & Wells 1990). People with disabilities are sometimes less able than others to initiate, develop and maintain relationships on their own. Each person needs thoughtful staff and others in their lives to recognize the importance of personal relationships with other community members. Our role is the on-going work of helping people stay or become connected to people, places and associations where they are citizens, members and friends (McKnight, 1987).
- The people we support can be some of the most wonderful teachers we have ever experienced. Susan and Jim are just two people who taught us how to listen differently, how to stand with a person over time and how to change service systems to meet individual needs.
- Families can start to see their sons and daughters in new and exciting ways or be challenged by this new experience. Both Susan's and Jim's families were hesitant about a more personalized service. Both families knew the challenges their son and daughter presented and neither family had experienced anything but group-based programs. It took many discussions and experiences, over time, for their parents to realize that different support would give Susan and Jim what they needed to thrive.
- Existing systems of accountability, regulation, and funding –which were built for group-based programs– do not prohibit the development of personalized supports. Our agencies use the same funding streams and are accountable to the same regulations as other providers, we just use them differently. Regulations can and do adapt to person-centered work. Under existing regulations, effective power and control can rest with the person with a disability; a home can belong to a person, not an agency; support systems can be tailored around individuals, not the

regulation staff quota for a group residence. We have made this happen through negotiations.

- Managers face new demands that call for significant personal learning. It was simpler when the pattern was simpler: place the person into the open slot. Now managers worry:
  - *Is the right person supporting the right person, in the right way, in the right situation?*
  - *Are we doing what we said we would do?*
- Changes in organizational rules, procedures and policies can encourage the new ways of thinking necessary for personalized support. For example, changing staff roles from skills trainers to community connectors made an important shift in staff attitudes and behavior.
- Changing internal policies away from agency control and toward giving the person effective control of agency resources sets the framework for generating personalized supports.
- Regular retreats, discussions, and opportunities to learn from leaders in the field and discussions with the board, parents and staff provide opportunities to touch more of the realities of people's lives. This opens minds to new possibilities.
- There are no pat answers and it isn't easy to figure out solutions to complex human problems. Sometimes all we can do is to continue to walk with people through dark or dangerous or confusing times. Plans will not always work out; we must expect to have to rethink and refocus. From time to time we will need help to find new ways of approaching problems. The trust that provides the foundation for our work sometimes grows slowly because of past bad experiences with people like us.
- The excitement of moving from a group-based program to a person's own place is the first and almost the easiest step. It is more challenging to maintain excitement about quality on a day to day basis. Person-centered work is only as good as you are today. Some days will bring joy; tomorrow or the day after will bring new issues. That is what life is all about.
- The human service empire changes slowly. People with disabilities continue to be socially devalued, mistreated, and abandoned. But Sue and Jim show that good work can be accomplished if people join together to enable it to happen. We plug ahead and negotiate our way through all the red tape and bureaucratic ten-

sion that threaten to drag us backward into group-based programs.

Working in a person-centered way requires continual flexibility that arises from deep respect for the person. Respect creates the willingness to slow down and listen more deeply so that it becomes possible to discover new ways to understand a person, stepping into their shoes and trying to see life from their perspective. Respect creates the willingness to hold on to a vision for a person. Respect motivates acknowledging and picking up after mistakes. Respect keeps us from blaming a person's disability or difficulties in life and encourages us to acknowledge our responsibility to join in changing structures and practices that keep people from the life they deserve. The respect that founds good support informs our heads, but it has its source in our hearts.

> *There is no such thing as a value-free way of working with others. The challenge is to keep ourselves honest and to consider what values we actually use in our work, not just what values we say we have.* *(Lovett, 1996, p. 30)*

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