

Running Head: THE ETHICS OF PERSON-CENTERED PLANNING

NUMBERS AND FACES
THE ETHICS OF PERSON-CENTERED PLANNING

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The Kingdom of Number is all boundaries
Which may be beautiful and must be true;
To ask if it is big or small proclaims one
The sort of lover who should stick to
faces...

– W. H. Auden

The Contradiction Between Service Values and Service Capacity

Person-centered planning challenges the ethics of its practitioners because it creates a context for the kind of listening that invites engagement in another person's life. Borrowing the terms of the first line from Auden's "Numbers and Faces" (1991, p. 623), ethical challenges arise as listening puts a human face on a contradiction between a service's espoused values and its actual performance. Listening reveals personal interests that fit a system's stated commitment to values of individualization, self-determination, and inclusion but attempts at action reveal that the system's capacity to respond adequately lags. These ethical challenges take the form of a decision about whether a contradiction is big enough to call for personal action or small enough for the practitioner to pass by without active concern. The ethical challenge deepens with recognition of the power difference between the practitioner and the person to whom she listens. The person with a developmental disability has very little chance of favorably resolving the contradiction without mobilized allies who will act with him. The practitioner can easily walk away from the situation on completion of the meeting and its related paperwork.

In the context of planning with a person whose challenging behaviors have barred him from moving into a community home (Holburn & Vietze, 2002), noting that Hal likes soft music and dislikes noisy situations and being around lots of people puts a face on commitment to

individualized supports. Is it big or small to discover that his living area “is loud, open, austere... yelling and running is(sic) common... appears chaotic with staff looking exhausted, exasperated... dorm-like bedroom shared with two other people, one hits Hal frequently; no obvious personal possessions.” (p __ [in this volume]) Those involved in person-centered planning for Hal treated his living arrangements as big enough to call for immediate action. Short term changes hugely improved his institutional living conditions and he later moved into a home whose features and routines were designed around what works for Hal.

In the context of a process designed to discover people’s lifestyle preferences (Dumas, DeLaGarza, Seay, & Becker, 2002; Becker, Dumas, Houser, & Seay, 2000), listening to Scott, a 52 year old man with limited support needs, identify the goal of moving from his parent’s house into his own apartment puts a face on an agency’s commitment to enhance self-determination. Is it big or small that after a year he still waits for his service coordinator to act with no idea of why nothing has happened toward his move? Listening to Johnny, a formerly institutionalized 35 year old man, whose pride in his apartment makes having a vacuum cleaner to keep his place clean highly desirable to him puts a face on an agency’s commitment to assist people to live in ways that make sense to them. Is it big or small that getting a vacuum cleaner took nine months and keeping a supply of replacement bags apparently proved more than the agency could manage? Listening to Helen, a 42 year old woman with infrequent support needs, identify a love for animals and a strong preference for working in a pet store puts a face on an agency’s commitment to serve people in a person-centered way. Is it big or small that she was placed in a janitorial job at the provider agency that agreed to assist her to work with animals? These agencies choose to participate in a nationally funded demonstration of self-determination, but the responsible service coordinators apparently decided that these were small things. It was not

worth collaborating with the people involved to find creative ways to assist with work in a pet store, or assure a functioning vacuum cleaner, or orchestrate a move from the parental home.

In the context of a process designed to support people moving out of congregate facilities to specify what was important to them in the move and use their preferences to guide their selection of a group home (Davis & Faw, 2002), it puts faces on the intention to empower people to learn that more than 60% of the people moving wanted a job with pay. Is it big or small to discover that only one of the available placements said that paid community jobs were open to residents and that nearly half of the available facilities said that even segregated work for pay was out of the question? Helping people get work for pay was apparently outside the scope of the change of placement that the preference assessment served, as was the choice of any living option other than traditional supervised group living. These system-imposed boundaries define some things that were big for people as small and thus irrelevant.

Is It Fair to Hold Person-centered Planners Responsible?

Practitioners of person-centered planning don't cause contradictions between service values and service capacities, they encounter these contradictions in the lives and futures of the people they choose to plan with. They did not cause and cannot single-handedly dissolve the current service realities that inhibit people moving toward the lives they want. In services where producing person-centered plans for everyone has become a required activity, they themselves may experience a contradiction between a value that attracts them --that they discover and honor people's preferences-- and the pressures of their own work.

It is not fair to blame practitioners of person-centered planning for contradictions between service values and service capacities. It is not fair for service managers to mindlessly assign accountability for person-centered outcomes to practitioners of person-centered planning without

themselves accepting responsibility for necessary changes in their organization's structure and culture. But what is at stake is not blame or organizational accountability but personal responsibility. Practitioners of person-centered planning who accept responsibility for living in the tension between service values and service capacity support the development of more competent services. Those who shy away from living with the tension become part of the barrier separating people with developmental disabilities from inclusion and self-determination.

Person-centered planning contributes to developing service capacity when its practitioners mobilize people to do the hard, sustained, creative work necessary for a service organization to live up to its commitments to human development, inclusion, and self-determination. People are mobilized when they take responsibility for the tension between what they want –to actively and competently support Helen to work in a pet store– and their current reality –a service that places people in jobs it already has rather than developing jobs around people's interests. Those who can hold the tension between what they value and what they are currently doing are more likely to find creative ways to resolve it than people who walk away from the tension by scaling down what they want to match what they can do – we met our goal when we placed Helen in a job that we already had. (To learn more about this perspective on organizational change, see Senge, 1990, Chapter 9 and visit the Society for Organizational Learning webpage, www.sol.org)

Practitioners who blame themselves for the contradictions that person-centered planning reveals between espoused values and current performance are auditioning for martyrdom. Practitioners who want to mobilize action to resolve a contradiction begin by accepting responsibility for that contradiction as it affects the life of the person they plan with. Living up to that responsibility does not mean a single-handed, heroic effort to give the person whatever he wants, it means enlisting as many people as possible, beginning with the person himself and

those who know and care about him, and supporting them to work together for positive change.

The group work that is particular to person-centered planning, the work which ethical practitioners hold responsibility to skillfully facilitate, comprises four tasks and upholds an animating spirit. The first task is to align a person and her allies around a common understanding of what is desirable for the person now and for the future. The second task is to generate creative actions that will, immediately and over time, realize more of what is desirable for the person. The third task is to support the person and her allies to negotiate for the accommodations, technology aids, services, supports, and funds required to realize more of what is desirable for her. The fourth task is to sustain focus on the person by supporting the person and her allies to deepen their understanding of what is desirable and adapt their actions by reflecting on what they are doing. The spirit that animates effective person centered planning calls on people to resist low expectations and social discrimination by imagining alternative ways that the person can express her particular capacities in the life of her community.

How much a practitioner of person centered planning contributes to developing an organization's capacity to offer support consistent with its values depends on his skill in guiding people through the person-centered planning process. But skill counts for less than a decision that what matters to the focus person matters enough to him to accept responsibility for the contradictions between service values and service capacity that hold a person back.

There is one constructive way to decline responsibility for service contradictions. That is to discover a way that the person can realize at least some aspects of a desirable future outside of services. For example, person-centered planning allowed some people with developmental disabilities and their families to find jobs or leisure connections that fit their interests through their own social networks (Lyle O'Brien, Mount, O'Brien, & Rosen, 2002).

There are many easier though less constructive ways to resign from the effort to make a necessary change. Bandura and Barbaranelli (1996) inventory mechanisms through which people disengage from moral responsibility. Thoughtful practitioners of person-centered planning will check themselves regularly for these five symptoms of ethical disengagement: 1) disregarding consequences, for example, “I have completed person-centered plans for my whole caseload but I have not had time to find out what the outcomes have been.” 2) advantageous comparison to worse practice, for example, “Not much has happened for people, but the person-centered planning meetings we have now are much better than the IPP meetings we used to have.” 3) displacement of responsibility, for example, “The administration gave me a workload that makes it impossible for me to build relationships with the people I’m supposed to make plans for; what can you do?” 4) diffusion of responsibility, for example, “I did my part, I facilitated the planning meeting and mailed out the minutes. Implementation isn’t in my job description.” 5) attribution of blame, for example, “Those parents make unrealistic demands, who would ever want to hire their daughter?”

Listening well enough to see a person’s desires as reasonable and legitimate creates ethical conflicts when a service lacks the capacity to support the person to pursue those desires. It’s understandable that mechanisms for disengagement will show up in people’s thinking. Doing the work of person-centered planning requires noticing these maneuvers for what they are, a signal that something ethically important is at stake and at risk of being ignored, and then reaching out to find support to re-focus with the person in order to imagine and take a hopeful next step. Such steps will only show themselves when practitioner’s of person centered planning decide to work to discover them.

The Uses and Limits of Numbers

Numbers, the products of well designed studies or the tracks of a carefully designed schedule, however beautiful and true, offer only limited guidance to a practitioner of person centered planning trying to decide whether something is big enough to demand action or small enough to excuse absence. There is no adequate moral equation waiting for numerical inputs. The ethical decisions that determine whether person-centered planning keeps moving or stops are better understood in these terms,

Much contemporary moral philosophy...has given such a narrow focus to morality that some critical connections are incomprehensible in its terms. This moral philosophy has tended to focus on what is right to do rather than on what it is good to be, on defining the content of obligation rather than the nature of good life; and has no conceptual place left for a notion of the good as the object of our love or allegiance or as the privileged focus of attention or will. (Taylor, 1989, p. 3)

Given current social and political reality, practitioners of person-centered planning will do well to decide on the kind of people it will be good for them to desire to be, and the kind of relationships they want to create, and the nature of the good they wish to attend to if they want inclusive communities where people with disabilities are free to exercise their human rights.

That numbers do not help much with these ethical decisions does not make them unimportant. For those who choose to be influenced by them, numbers can indicate more or less fruitful ways to assist people. For example, Mank, Cioffi, and Yovanoff, (2000) report that people with severe disabilities in supported employment have higher levels of wages and greater workplace integration when they experience typical employment conditions with the minimum necessary accommodation and assistance than they do when a supported employment program

routinely creates special conditions in their hiring, job training, and workplace routine. This is an important finding to those who choose to respond to people's desire for a particular real job. It is less salient to those who decide that the desire for a particular real job is a small thing and ignorable. When the culture of a service supports their use, numbers can structure support routines to assure people the active support they require to engage the opportunities of everyday life, as Felce, Jones, and Lowe (2002) demonstrate. However, depending on the values that a service culture serves, numbers can also structure routines that promote staff behaviors with less desirable consequences, as Rea, Martin, and Wright (2002) describe in their account of the service pattern that they have worked successfully to shift. In the culture of habilitation, data collection and systematic scheduling and a token economy created a setting in which "individuals were denied control over many aspects of their lives, and there was little regard for their values, preferences, and desires." When people have the desire and skill to use them, numbers can steer an intervention toward an important improvement in a person's life, as Holburn and Vietze (2002) describe in their account of assisting Hal to stop hitting his mother. Numbers can also steer interventions that have little relevance to durable and meaningful life changes. Carr, et al.'s summary (1999) of their review of a database of 109 published studies of positive behavioral support includes this finding.

Consumers... judge interventions in terms of their practicality and relevance and are concerned with how well intervention plans mesh with the realities of the complex social systems in which the consumers must function. The database [i.e. the 109 studies], more concerned with issues of rigor and demonstrations of experimental control, generally failed to focus on larger consumer goals. (p. 83)

Hal's story exemplifies a search for the relevance Carr, et al. report missing. Hal mattered

as a person to each of the members of a core team of five people who accompanied him on his four year journey from institutional to community life. They engaged more than fifty people in one or more of the 34 formal person-centered planning meetings they held to construct, remember, and revise a common understanding of Hal as a whole person and to make decisions in light of this understanding. They made the most of Hal's position as one of the last Willowbrook class members to move from an institution to push a huge service system ill equipped for individualized supports to new levels of flexibility. They learned with Hal by spending time doing new things alongside him -beginning with a risky walk around the block-- and by offering him new opportunities --much better living conditions, stable connections to staff he liked, a routine that made sense in terms of Hal, and support to experience his community. They used their personal contacts with system administrators and service providers to enroll them in moving toward their vision of a desirable future for Hal. They made hard decisions, balancing the immediate availability of services that did not fit their shared understanding of Hal as a whole person against the time it took to develop better fitting alternatives. Over and over, through difficulties and uncertainties, they continued to demonstrate fidelity to Hal. In this context, they deployed a systematic behavioral intervention which not only decreased Hal's hitting his mother but also shifted his mother and father's expectations of and for him. In this context, they did person-centered planning.

Wagner (2002) might read Hal's story as an easily understood example of the systematic application of scientifically established laws of behavior. Environmental changes expose Hal to fewer aversive events and provide him with ready access to reinforcers; thus his challenging behavior decreases. Person-centered planning provides an effective way to identify the aversive events and reinforcers. I would offer an alternative reading. People with the ability and

willingness to act with him found a new way to see Hal's face. Then they faithfully and persistently challenged what was taken-for-granted about Hal and his relationship to the system that serves him until the settings and relationships that hold Hal were transformed. They stuck with a commitment to change things that other people had defined as impossible to change. Person-centered planning provided them with one way to focus and guide their efforts. Both of these readings risk reductionism. They are both a bit like saying that *War and Peace* proves the folly of invading a big country during a difficult winter. They each may be true as far as they go, but they offer too thin an account to motivate and guide wise and positive action.

Resisting the temptation to oversimplification forms the foundation of understanding how person-centered planning contributes to better lives. Hal's father's assessment, "Person-centered planning is the Liquid Plumber of DD.," summarizes a complex experience. The meetings, the graphic profiles, the vision statements that are easiest to identify and replicate as person-centered planning would not have freed the service system's many clogs without all of the other elements of the story.

As part of an ongoing program of research to test the effects of person centered planning on outcomes, Holburn, Jacobson, Vietze, and Sersen (2000) have developed a useful instrument that enumerates 12 process factors believed to be associated with positive outcomes in person-centered planning and provides a way to count their presence or absence. It is instructive to map Hal's story onto this instrument. However, such little magic as there may be in person-centered planning is in people's relationships. Not even a carefully defined list captures the vitality of people working together from commitment to a particular person to resolve the contradictions between a system's espoused values and its capacities. Process scales are more like a handbook of rhetorical devices than they are like Burton Blatt's "Family Secrets" Presidential Address to

the 100th anniversary convention of the American Association on Mental Deficiency. This powerful speech (Blatt, 1977) can be analyzed in terms of its rhetorical turns, but the analysis cannot capture the passion of its delivery or the waves and ripples of its impact. As important as counting may be, there is no adequate way to understand human action without story.

Story as a Way of Knowing and Organizing

Bruner (1986) identifies two distinct cognitive resources, complementary but not reducible to each other, each with its own contribution to make to human knowing. The scientific mode of knowing proceeds logically to make empirical discoveries guided by reasoned hypotheses. The narrative mode of knowing seeks to disclose meaning in experience by creating and interpreting stories that trace the course of human purposes.

For some of the contributors to this volume, perhaps because they define disability from a clinical perspective that suits their role in responding to difficult and dangerous behavior, person-centered planning seems to be an instrument for scientific knowing and a fit object for scientific study. This legitimate way of knowing forms questions like, “Does offering people scheduled access to the preferred activities identified through person-centered planning decrease the incidence of problem behaviors?” (Klatt, et al. , 2002) as a way to contribute evidence to the question that interests the editors, “Does person-centered planning work?” These interesting questions classify person-centered planning as form of clinical assessment or intervention and look for ways to isolate and test its effectiveness.

This structured and analytic form of inquiry sets aside some potentially important questions. Carl, one of the subjects of Klatt et al.’s study, likes to vacuum his room but offering him access to these activities actually increases problem behaviors. Does this empirical finding mean that Carl should not be allowed to vacuum his room? No, this finding leads from science to story. As

it turns out, Carl gets frustrated when he has difficulty operating the vacuum cleaner and when his teacher signals him to stop. This indicates a need to review and revise the functional analysis of Carl's difficult behavior.

The report of the story of Carl and his vacuum stops here, but its incompleteness begs for some resolution and so I speculatively provide it: stopping to make sense of the fact that Carl hits or attempts property destruction more when he is doing something he prefers may open the way for systematic instruction in using the vacuum cleaner and negotiation about how Carl can judge the task finished. I supply this happy ending based on my positive inclinations toward an agency that gathers annually in a person's favorite restaurant to celebrate his accomplishments and acknowledge his strengths before considering the possibilities generated by an assessment intriguingly entitled "And Here's What I Want." I also like the metaphor they have chosen to describe the way they hold the commitments to action made at this meeting. They call them "promises", which is a great idea to guide their organizational efforts to be accountable to the people they support.

For me, and some other practitioners and students of person-centered planning, it is best understood as an expression of the narrative mode. It is about composing and enacting good stories. These stories are not fictions, if invited we could visit Hal at home (Holburn & Vietze, 2002). These stories are not "happily ever after", it is reasonable to think that Hal's life since establishing a stable community home will have its ups and downs. But Hal's living in the home he does, matched as it is to him, had to be imagined as a story before it could be lived as a reality. The very idea of a scientific instrument which would predict the particular features that would make Hal comfortable and secure at home is as silly as the notion of a meter to measure his happiness.

Theorists of narrative (Tracy, 1986) draw attention to two features of stories like Hal's, they are acts of resistance which are constructed through an interpretive process. The system that serves Hal had no way to pay for a person to assist him to explore and participate in his community, but it happened because his person-centered planning team decided to resist the assumption that their system could not adapt to Hal. Based on Hal's experience, the person-centered planning process imagined and then negotiated a way to pay for a community bridge builder, selected by Hal's parents and paid through a voucher that his parents signed. Imagination can involve borrowing. The idea of community-bridge builders did not originate with Hal's person-centered planning team, what the team imagined was that their enormous and complex system would create a way to make this highly individualized support available to Hal in a way that his parents could control. Hal's experience with the community bridge builder gave his parents another reason to revise their assumption that there was no way that Hal could be safe on the streets of their community, which raised their expectations for Hal.

Like all good practitioners of person-centered planning, Hal's team worked through many turns of an interpretive circle. Their thinking moved from a best attempt to express their understanding of Hal as a whole person to important and actionable specifics of his life and back again. Their vision of Hal as a participating member of his community, broad and somewhat tentative at first, provided a sufficient context to imagine and create a way for him to experience his community. Their shared understanding of his responses to community life led them back to a richer, better grounded picture of Hal as a whole person which in turn allowed them a better understanding of the specifics of his life. Those team members who moved together through many turns of the interpretive circle built a common understanding strong enough to make them "the Liquid Plumber of DD."

Realizing a Desirable Future

It is possible to listen appreciatively to a person's story and think creatively about a desirable future with no other resource than a bit of quiet time. When services structure that person's life, the design and quality of the services determine how difficult it will be to move toward the desirable future revealed by careful listening, creative thinking, and courageous action.

So many pages of this book discuss efforts to change the culture, structure, and practices of service organizations that I wonder if its central question, "Does person centered planning work?", might better be re-formed as "Under what conditions can a service honestly test the usefulness of person-centered planning?". The experience reflected here suggests three such conditions.

- **Organizational capacity to accommodate individual control.** The service settings in which people live and spend their days, because they are organized to support groups of people with developmental disabilities, can make it so difficult to individualize supports that testing a person-centered planning team's ideas in action is impossible. McLaughlin, Spinosa, and Marasalis (2002) report the positive effects of a large agency revising its pattern of service to promote staff continuity, decision making by people responsible for the service's responsiveness to the whole person's whole day, flexible transportation arrangements, personal space, and individualized scheduling. This remarkable level of commitment to creating personalized supports, and thus the conditions for person-centered planning to make a real difference, exemplifies management taking responsibility for the contradiction between person-centered values and the actual capacity of their organization. The micro boards studied by Malette (2002) emerged with the support of an agency that has

transformed itself from a provider of residential services to an organizer and supporter of people with developmental disabilities and families who want to both design and manage their own supports. This level of personalization would be very difficult if the government were unwilling to provide sufficient and flexible individualized funding.

- **Organizational capacity to build staff teams able to keep and renew agreements to provide specific assistance.** Even in small settings with stable staffing, simply following through on agreements to support continuing access to important opportunities can be very difficult and reaching toward new opportunities can be even more difficult. Sanderson (2002) identifies the importance of continuing guidance, based on specific information about everyday life, to increasing the capacity of skilled staff to hold their focus. This process, which included the creation and implementation of an Essential Team Plan to complement people's Essential Lifestyle Plans, supports the development of a stronger, more flexible team which is better able to respond to what it learns from person-centered planning .
- **Organizational capacity for learning.** Person-centered planning helps an organization test what it means by saying that its mission is to support inclusion, or self-determination, or quality of life. Passing that test requires some organizations to change their culture, a process that calls for widespread learning about new things to do and new reasons to do them. Rea, Martin, and Wright (2002) describe such an ongoing culture shift in their work to make an institution as responsive as possible to its residents. Person-centered planning provided one element of their strategy for changing from a culture that successfully supported active treatment to a culture that offers residents greater respect and control. Over 10 years, significant changes in the way things were done gave staff new topics of conversation and shaped new and more directly responsible roles for them: meals moved from cafeteria to

living unit; control of transportation and leisure activities shifted to living units; a functioning token economy was replaced by a procedure for negotiating with residents; staff were encouraged to identify themselves as champions for individuals; information on increases in jobs and decreases in use of emergency personal restraints, decreases in restrictive behavior reduction procedures, and behavior management medication let everyone track the effects of the changes. The managers of this setting took responsibility for their organization learning to function in ways that provide a reasonable chance to test the ideas that emerge from person-centered planning.

Responsible practitioners of person-centered planning will assist the people they plan with and their allies to assess these three capacities in the services they use. Where these conditions are present, participation in person-centered planning gives people a chance to shape the development of more effective services while they pursue a desirable future. Where these conditions are absent, the going will be harder and it will be especially important to build a strong person centered planning group. This group will have to find ways to influence the service to increase its capacity to accommodate individual control, keep agreements about specific services, and learn. If negotiations to improve organizational conditions fail, the group will have to search for alternative services of better quality or for other ways to realize a desirable future.

In 1964, Wolfensberger published “Diagnosis diagnosed” in which he described a fallacy so appealing that it continues to entice people sincerely committed to improving the quality of services. In those days, reformers talked of proper diagnosis. More recently, they talked of Individualized Program Planning. Now, the good guys call for person-centered planning. Underneath the important differences between diagnosis, and individual program planning, and person centered planning lurks the same fallacy: getting the plan right is the primary thing in

helping someone have a good life. This fallacy entices because it makes sense. But it only makes sense to the degree that there is a capacity to respond that is at least as complex as the plan's requirements. As Smull and Lakin (2002) note, the thousands of hours of effort required in the late 1990's to produce grade a, inspector-approved individual plans offer people little real improvement over what the subjects of the diagnoses Wolfensberger analyzed 30 years before experienced. What makes the difference to a person who relies on services is what the service itself offers everyday, not what the plan says. If a system offers slots in boxes, there is no need to decorate the interior walls of the boxes with colorful individual vision posters; its planning need not proceed beyond establishing eligibility and waiting list position. If an organization commits itself to the hard work of resolving the contradictions between its espoused values and its actual performance, person-centered planning has an important role to play. Responsible practitioners of person-centered planning won't get trapped in the fallacy of hunting for exactly the right words as if they were a golden key to a better life. They will encourage action for organizational change based on a common understanding of what is desirable for the person they plan with.

The Centrality of Disciplined Imagination

At its best, person-centered planning lets disciplined imagination play in the lives of people who are profoundly vulnerable to the low expectations and prejudices that leave them on the sidelines of community life. It casts people with disabilities and their allies as the authors and enactors of positive stories about themselves as valued contributors to community life. Like any aesthetic activity, study and practice and coaching build on natural ability to improve performance. Different people come alive to different media, so for some the activity will be more like playing basketball, piecing a quilt, composing a picture, or creating a dance than like telling a story. Poor stories are possible, so it is important to seek guidance and good examples.

Some people's ways of communicating leave the important people in their lives unable to hear their views about a life that would make sense for them. Those important others have little choice but to create a story that has a valued and central role for the person whose preferences remain ambiguous and then make adjustments based on what they learn from the person's responses to the real settings and experiences that result from their imagining (see Shafer, 1998 and O'Brien and Lyle O'Brien, 2000 for examples).

I like the idea, old as Aristotle, that the capacity to tell and respond to stories distinguishes zoe, biological life, from bios, human life. Shared narrative –whether communicated in drama or in images or in movement or in reading- is a source of the common understanding that makes possibilities of community and compassion. Story is a foundation for phronesis, the practical wisdom necessary to make decisions that apply generally understood values in particular circumstances and draw a sensible balance among competing goods, like freedom and safety. Story provides a channel for imagination to discover and broadcast the hopeful possibility that alternative realities are possible. (Kearney, 2002). People with developmental disabilities come alive when there is careful attention to their stories. Person-centered planning can provide a social space for appreciating a person's story in a way that leads to meaningful new chapters. A decent community life needs to hear and participate in changing the stories of people who have been mindlessly excluded and controlled because of disability. Person-centered planning can provide a social space for shaping and learning from positive stories of disability in community.

Because the people with developmental disabilities that I know best face a long, tough struggle to claim and hold a valued place in community life, I like the idea that story and image and dance help us to slowly and in our own time find meaning in disappointment, in defeat, in failure, in tragic error, and in suffering and death. The aesthetic side of humanness, largely a

stumbling block to psychology since Dewey (Sarason,1990), expresses and celebrates imagination, which is the capacity to think of things as if they could be otherwise. (Greene, 2001). It is this sort of practical imagination that people trapped in the box of segregation and socially sanctioned deprivation of opportunity need almost as much as they need fresh air. Bringing disciplined imagination into people's lives is the privilege of those practitioners of person-centered planning who decide to heed the call of people's faces and honor their concerns as worthy of attention.

References

- Auden, W.H. (1991). *Collected Poems*. New York: Vintage International.
- Bandura, A. and Barbaraneilli, C. (1996). Mechanisms of moral disengagement in the exercise of moral agency. *Journal of Personality and Social Psychology*, 71, 2, 364-374.
- Becker, H., Dumas, S., Houser, A. & Seay, P. (2000). How organizational factors contribute to innovations in service delivery. *Mental Retardation*, 38, 5, 385-394.
- Blatt, B. (1977). *The family papers*. Syracuse, NY: The Center on Human Policy.
- Bruner, J. (1986). *Actual minds, possible worlds*. Cambridge, MA: Harvard University Press.
- Carr, E., Horner, R. & Turnbull, A. (1999) *Positive behavior support for people with developmental disabilities: A research synthesis*. Washington: American Association on Mental Retardation.
- Davis, P. & Faw, G. (2002) Residential preferences in person-centered planning: teaching individuals to identify preferences, assess their availability, and use this knowledge to affect their lives. This volume.
- Dumas, S. DeLaGarza, D, Seay, P. & Becker,H. 2002. "I don't know how they made it happen but they did." Efficacy perceptions of people with developmental disabilities and family

- members in using a person-centered planning process. This volume.
- Felce, D., Jones, E., & Lowe, K. (2002). Active support: Planning daily activities and support for people with severe developmental disabilities. This volume.
- Greene, M. (2001). *Variations on a blue guitar: The Lincoln Center Institute Lectures on Aesthetic Education*. New York: Teachers College Press.
- Holburn, S., Jacobson, J., Vietze, P. and Sersen, E. (2000). Quantifying the process and outcomes of person-centered planning. *American Journal on Mental Retardation*, 105, 5, 402-416.
- Holburn, S. & Vietze, P. (2002). A better life for Hal: Five years of person-centered planning and applied behavior analysis. This volume.
- Kearney, R. (2002) *On stories: Thinking in Action*. London: Routledge.
- Klatt, K., Juracek, D. B., Norman, K.R., McAdam, D., Sherman, J., & Sheldon, J. (2002) Person-centered planning: Assessing preferred activities and problem behavior. This volume.
- Lyle O'Brien, C., Mount, B., O'Brien, J, & Rosen, F. (2002). Pathfinders: Making a way from segregation to community life. In Fisher, D. (Ed.) *Inclusive urban schools: Lessons learned in big city schools*. Baltimore, MD: Paul Brookes.
- McLaughlin, D. M., Spinoso, T., & Marsalis, M. (2002). Comparison of an alternative, person-centered model of support and a more traditional model of residential and day program support. This volume.
- Malette, P. Lifestyle quality and organizational change in a person-centered support paradigm: Jeff, Janet, Stephanie and the micro board project. This volume.
- Mank, D, Cioffi, A., and Yovanoff, P. (2000). Direct support in supported employment and its relation to job typicalness, co-worker involvement, and employment outcomes. *Mental*

Retardation, 38, 6, 506-516.

O'Brien, J. & Lyle O'Brien, C. *Walking toward freedom. One family's journey into self determination*. Syracuse, NY: The Center on Human Policy. <http://www.soeweb.syr.edu>

Rea, J., Martin, C., & Wright, K. (2002). Changing culture in a large intermediate care facility: Moving from facility based programs to supporting persons with mental retardation. This volume.

Sanderson, H. (2002). A plan is not enough: Exploring the development of person-centered teams. This volume.

Sarason, S. 1990. *The challenge of art to psychology*. New Haven, CT: Yale University Press.

Senge, P. (1990) *The fifth discipline: The art and practice of the learning organization*. New York: Doubleday.

Shafer, N. (1998). *Yes, she knows she's there!* Toronto, ON: Inclusion Press.

Smull M. and Lakin, C. Public policy and person centered planning. This volume.

Taylor, C. (1989). *Sources of the self: The making of the modern identity*. Cambridge, MA: Harvard University Press.

Tracy, D. (1986). *The analogical imagination*. New York: Crossroads.

Wagner, G. (2002). Person-centered planning from a behavioral perspective. This volume.

Wolfensberger, W. (1965). Diagnosis diagnosed. *Journal of Mental Subnormality* 11, 62-70.