

The Art and Soul of Person-Centered Planning

Beth Mount

Tyesast and I look together for photos and objects to tell the story of the things she loves. We made a collage out of the pictures to express her interests. We also made a basket to put in items that represent her interests and hopes for the future. Since Tyesast does not speak, working with images and objects really helps her communicate. She expresses her interests by pointing and clapping her hands. Her accomplishments over the past two years have been wonderful. We just put a beautiful flower in the basket to represent how she has grown from a seed into a flower!

—Louisa Henderson

I am in the process of creating a wimple with Tzvi and his family. In Judaism, a wimple is made from the blanket one was wrapped in as a baby and used during a Bar-Mitzvah ceremony. On it is your life story and things that are most important to you. It is similar to quilting in many ways. After the ceremony, it becomes the covering for the Torah. Tzvi never has had a Bar-Mitzvah, so we will be making this for him in lieu of having the actual ceremony. We chose that as the concept (a theater term used to describe the metaphor for the main idea of the play) for his futures plan because it is the time when we are welcomed in to the community of adult Jews and recognized as an independent person with a life of our own. It is re-birth in many ways. Tzvi was rejected from his own community for an extended period of time, so we thought the symbolism of the event and the wimple was an important way to describe the themes in his life.

—Josh Skolnick

These service workers provide far more than practical assistance. By participating in artistic creation with Tyesast and Tzvi and the others who know and care about them, Louisa and Josh join the body work of helping someone through the day and the mind work of coordinating activities to the soul work of claiming and celebrating

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each person's human identity and belonging. Their shared creations are beautiful and ordinary. They depend less on formal artistic training than on the pleasure of using everyday crafts in a sacred way to arrange pictures, to collect meaningful objects, to sew a garment rich in symbol.

The simple act of attention to images and objects that tell the story of what Tyesast loves, and their thoughtful collection into a collage and a basket of wonderful things, embodies respect for her interests and helps communicate her identity to people who spend time with her. Resonance with a culturally familiar path of initiation into adult independence as a responsible community member—in which signs of important life events from infancy forward enrobe first the initiated person and then the community's Holy Scripture—gives power and direction to Tzvi's claim on belonging to a community that has not previously known quite how to welcome him as a grown man.

This art grows from and nourishes and transforms relationships. Obvious differences—in status, or ability, or language, or culture, or material wealth or race, or any combination of these—shape relationships among people with disabilities and their families and the people who assist them. How these differences affect the quality of everyone's experience depends, in part, on achieving a living sense of what connects us, differences and all. Part of what connects us is working together toward a jointly meaningful goal. Part of what connects us is our participation in life's ordinary mysteries, the mysteries of life's journey: birth, growth, coming into adulthood, work, relationship, belonging, grief, suffering, and death. Each people, tribe, and family provides resources for encountering these mysteries, and these resources differentiate the ways that we understand and cope with them.

One powerful modern strategy for encountering these mysteries is to reduce them to problems to be solved through the application of expertise. This strategy has many benefits. Among other good things, it makes childbirth safer, instruction more systematic, the pursuit of economic success more rational, and many diseases less threatening. It provides some people with disabilities the means to move about, to learn useful skills, and to communicate. One effect of this strategy is to leave most questions of meaning up to people as private individuals. Access to good health technology means that death comes to many of us later than it otherwise might have, but

we must still find a way to face death's uncertainties and those who survive us must still find their way through grief. And, despite the presence of many experts who fill the self-help shelves and the talk shows with advice, relationships remain more wonderful and more maddening than reason can handle.

I am convinced that deep change in the lives of people with substantial disabilities depends on soul work. Soul work does not replace skilled help or good management or political organizing, but it is essential to energizing, directing and sustaining efforts to assure people their place in community life.

A direct support worker who understands her two years of engagement in a person's life as the unfolding of a seed into a beautiful flower has different possibilities for action than a worker who sees her job only in terms of doing the prescribed chores. She can become excited about figuring out how other's can share the beauty and pleasure of Tyesast's interests. She can be alert to the unfolding of new blooms because she knows there has never been a flower quite like Tyesast before. A facilitator who chooses the concept of growth into manhood in community has inspiration to search for the unique combination of opportunities, accommodations, and assistance that will allow Tzvi to enact valued adult roles. The root's of this concept in tradition will carry sustaining energy when others resist or falter in their support of Tzvi's journey into manhood.

I am increasingly interested in how art can serve as a bridge across the differences that segregate people with disabilities and expose them to control by others. Sharing in the creation of artifacts that express what is meaningful honors the ordinary mysteries of human life. Honoring the ordinary mysteries encountered along life's path opens the possibility of mutuality.

Mutuality offers people moments of rest from the strictures of the power-over/under-power positions assigned by staff and client roles. Judith Snow (1998), whose survival depends on the competence and reliability of her personal assistance and whose vocation includes discovering ways to understand people who do not speak, writes of the importance of opening this space in our relationships:

Sustained vibrant relationship demands that the person with a handicap be viewed with a different vision and listened to with a different ear. Foremost of the alternative possibilities is to see and hear the person as a welcome

fellow traveler. We must see our shared life journey as one of transforming human suffering by creating the supportive relationships we all need to sustain life and of celebrating together life's joys, victories and surprises (p. 12.).

Our person-centered planning formats and techniques are meaningless unless they help us open the door to a space of mutuality where we discover transforming images, and commit to action inspired by deep listening and concern. This is particularly important for people immersed by prejudice and social devaluation in what educator Paulo Freire (1994) has exposed as a “culture of silence”. In this state of imposed silence, not only do people lack words and images for the oppressive states that limit them, but they also lack awareness of their own sources of life potential, and the conditions that encourage the emergence of that potential.

The culture of silence is locked in place by a system that offers necessary assistance in a way that disregards relationships and denies human mystery in a blind frenzy to reduce people's lives to problems-to-be-solved under expert tutelage. Such a system encourages definition of people's lives in terms of their potential to generate billable hours of service. Such a system reduces person-centered planning to specification of the terms of clienthood. Such a system squeezes the life out of people in the name of efficient service.

The role of art and soul is to bring life in. The keys that open the box of silence that entombs so many people with disabilities are three: deep listening that leads to discovery of words that name the structures that enforce silent passivity and images that express a powerful vision of contribution. These keys can wake-up the imagination and commitment and voice of small circles of people and guide their action to shape a community that recognizes and receives the gifts that they bring.

Sometimes, deeper listening means respectful attention to the possibilities for social action in what is obvious on the surface. Douglas's devotion to coffee is apparent in the excitement with which he talks about it as well as the enthusiasm he brings to finding, preparing, and sharing a cup. As part of the process of gathering knowledge of Douglas's interests, Nathan Hernandez, a direct support worker, wrote this verse:

I like coffee. Yes I do.

I like coffee. How about you?

I like the taste and I like the smell.

I like the stories that the commercials tell.

When I drink coffee, it just quenches my thirst.

That's why I put coffee always first.

The way sugar and cream just mix together,

Makes me wanna drink coffee forever.

When I don't have sugar or I don't have cream.

That'll be okay cause I'll always have my dream.

Honoring the obvious allowed Douglas and his supporters to generate his own business as a vendor of “Stardust Coffee.” The poem invites Douglas's customers into his dream. Along with his coffee cup, it goes everywhere with him.

Sometimes, deeper listening means searching together and collecting clues from which a meaningful image emerges and asks for action. Gathering to share these clues, going out to look for more possibilities, returning to share again builds a rhythm of interest that calls for a powerful image. Color coding bits of information—green for what seems to bring life and meaning to this person and red for what seems to frustrate or block—reveals patterns that point toward well-springs of possibility. Inviting and recording graphic images honors visions and dreams.

The essential capacity in person-centered planning is the ability to listen for, invite, and express images of personal identity and possibility that will energize, guide, and sustain action that transforms the relationship between people with disabilities and their community. This capacity grows with practice. Having assembled photos and objects that are signs of Tyesast's passions, Louisa has opened a way to listen more deeply. Having conceived Tzvi's garment, Josh has opened a way to invite new energies. Having written the verse about the place of coffee in Douglas's life, Nathan has opened a way to keep the dream in view.

This essential capacity also grows with exposure to images and ideas that express the human potentials for transformation. The rest of this chapter comprises a small gallery of images and ideas. See color versions of these images on this book's web page (inclusion.com).

References

Freire, P. (1994). *Pedagogy of hope*. New York: Continuum.

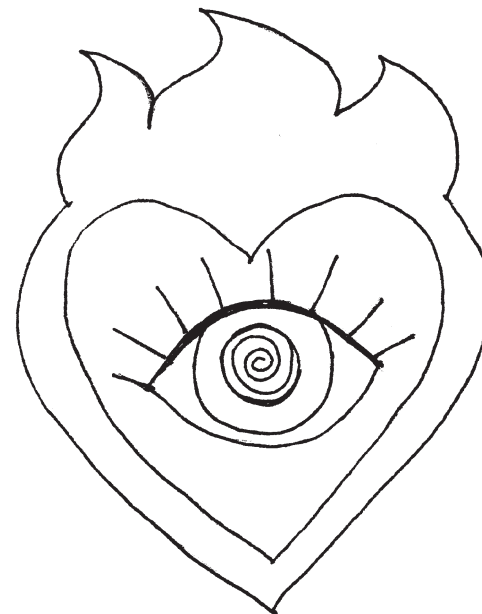
Snow, J. (1998). The power of vulnerability. In *A little book about person-centered planning*. Toronto: Inclusion Press.



The spiral, an ancient symbol of the soul's journey, reminds us that working together for change means sharing a universal journey. We enter that place of wandering, exploration, discovery, and struggle that nurtures the life force in us all. The spiral indicates the path we walk together toward the justice for which our soul's yearn.

Meaning is important for the health, well-being and wholeness of individuals and communities. The presence of symbols in a community, as well as the living out of a belief in these symbols, is a measurement of the health and energies present in the community. Indeed, to live without symbols is to experience existence far short of our unlimited capacity as human beings. Thus every rebirth of the life and purpose of a people is accompanied by the revitalization of that people's symbols.

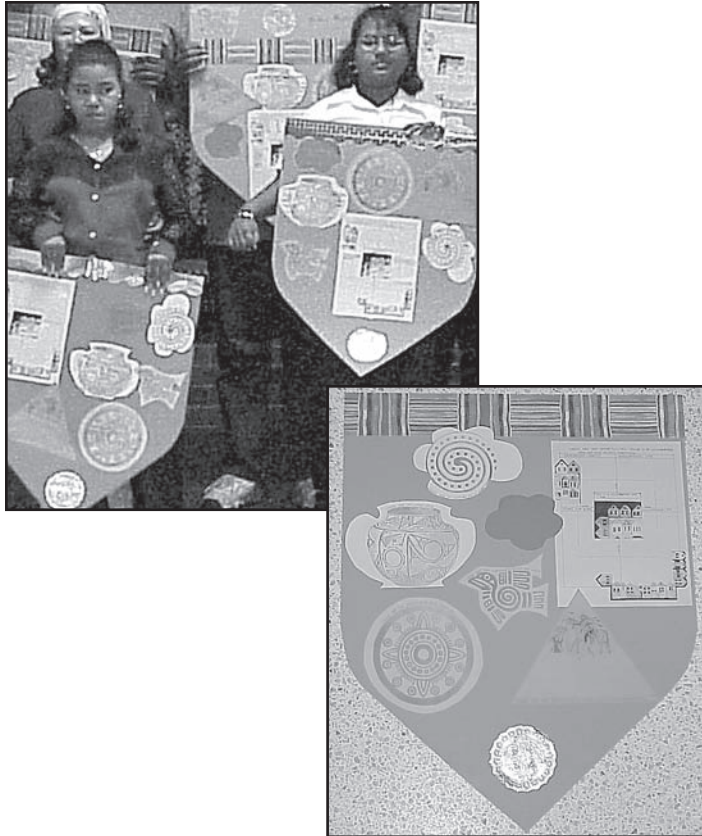
– The Sacred Tree: Reflections on Native American Spirituality



Through person-centered planning we work together to reclaim the inherent potential of each person and establish their belonging and connection to community life. When we honor the soul work in person-centered planning we open the eyes of the heart. This allows us to feelingly see the yearnings, dreams, possibilities, and capacities in people. When we share the images that we see with the eyes of the heart, our voices change. We are no longer talking heads but whole people giving voice to ourselves.

Let us look at our children and families in our community, not as blurred objects in the landscape, or by their possible usefulness to us; but to see them with imagination, with the “eyes of the heart” with faith in their possibilities... It is a great loss when we look at people from a financial or business point of view and neglect the life side.

–Mamie Hillman



It is important to give form and color to what we see when we look with the eye of the heart. These shields, created by young adults moving from school into adult life, are emblazoned with icons that they have selected to communicate the visions they have come to as they have explored their unique interest and gifts and the opportunities for contribution their neighborhoods and their city offers. Each shield carries visible signs of the young person's identity and serves as a way to stay awake to the possibilities they have discovered and as a guide for telling their story.



The hand print is a sign of the power that arises within us when we act on the urge to make our unique mark on the world by making contributions that reflect our gifts to the world. Hand prints have been found on rocks, icaves, and walls around the world. They transmit the spiritual power of people who made their mark on the world through all of humanity's generations.

Each person bears a uniqueness that asks to be lived and that is already present before it can be lived. You and I and every single person is born with a defining image. We each embody our own idea, and this image does not tolerate too much straying. The heart has it's reasons. This means that each child is a gifted child, filled with data of all sorts, gifts peculiar to that child which show themselves in peculiar ways.

—James Hillman



The Build a New World Quilt grew from the stories of five young people and their families whose bold efforts to seek their dreams have inspired and encouraged others to overcome segregation and seek their rightful place as contributing citizens of New York City.

For as long as we've been around as humans, as wandering bands of nomads or cave dwellers, we have sat together and shared experiences. We've painted images on rock walls, recounted dreams and vision, told stories of the day, and generally felt comforted to be in the world together. When the world became fearsome, we came together. When the world called us to explore its edges, we journeyed together. Whatever we did, we did it together.

—Margaret Wheatley



Enactment, engagement, creation, rehearsal –each of these ways of doing exercise our imagination when they are fed by a desire to realize what we have seen with the eye of the heart. This spirit bird, an icon from Mexico, reminds us to open ourselves to inspiration.

Of course, not all stories are successful. How can we discern whether one telling of events is any a better or more worthy than another? A story must be judged according to whether it makes sense. And “making sense” must here be understood in its most direct meaning: to make sense is to enliven the senses. A story that makes sense is one that stirs the senses from their slumber, one that opens the eyes and the ears to their real surroundings, turning the tongue to the actual tastes in the air and sending chills of recognition along the surface of the skin. To make sense is to release the body from the constraints imposed by outworn ways of speaking, and hence to renew and rejuvenate one's felt awareness of the world. It is to make the senses wake up to where they are.

—David Abram