Conversations on Citizenship & Person-Centered Work

EDITED BY

Volume III

John O'Brien & Carol Blessing

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Conversations on
Citizenship & Person-Centered Work

with

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Jack Pearpoint • Mike Green

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Contents

Thanks **8**

Carol Blessing
Citizen-Centered Leadership 9

John O'Brien
Some common threads 19

Beth Mount **23**
What is citizenship? 23
What keeps people with disabilities from full citizenship? 23
What is community? 24
What inspires you? 24
What drew you into this work? 25
What makes a positive difference in the lives of people in services? 25
What is leadership? 26
What does it mean to be person-centered? 26
Why is courage important in person-centered work? 26
How did Personal Futures Planning begin? 27
What were your intentions in developing Personal Futures Planning? 27
How do participants in Personal Futures Planning connect to their community? 29
What role does art play in your work? 29

Diana Whitney **33**
What is Appreciative Inquiry? 33
Where did Appreciative Inquiry come from? 36
Tell us about Appreciative Inquiry as a methodology. 37
What are the core principles of Appreciative Inquiry? 39
What has Appreciative Inquiry taught you about leadership? 41
What strategies implement Appreciative Leadership? 43

Michael Smull **45**
What inspires you? 45
What drew you into your work? 45

What are the origins of Essential Lifestyle Planning? 45
Is person-centered planning just for people with developmental disabilities? 47
Are there circumstances in which you shouldn't do a plan? 47
How did the person-centered thinking skills develop? 47
How do person-centered thinking skills contribute to change in organizations and systems? 49
Please describe the person-centered thinking skills. 51
How do you respond to people who say that person-centered skills are too costly to implement? 53
How can we track development in the service system? 54

Denise Bissonnette **57**
What is citizenship? 59
What has kept people with disabilities from citizenship? 60
What is leadership? 60
What inspires you? 61
How can people make a positive difference? 61
What is community? 62
How does somebody actually build community? 62
What does work mean to you? 62
What impact has the ADA had? 63
What differences do you see between traditional job placement and true job development? 63
Why would an employer create or carve a position? 65
What do we need to keep in mind in order to keep true partnerships with employers? 66
What support is important for the person who wants to work? 67
How do you support people to develop those skills? 67
Can you give us a feel for the *Cultivating True Livelihood* curriculum? 69
What does it take to sustain us in this work? 71

Jack Pearpoint 75
What have been some of the important influences on your work? 75
What does it mean to be person-centered? 76
What does person-centered planning have to do with people's disabilities? 76
Tell us about your early involvement with person-centered approaches. 76
What was your first approach to person-centered planning? 77
How does exclusion affect person-centered planning? 78
How do you know person-centered planning is working? 79
Are there times when person-centered planning does not work? 79
What are the risks of person-centered planning? 79
What is MAPS? 80
What is PATH and how is it different from MAPS? 81
What's important in preparing for MAPS or PATH? 83
How do you choose between MAPS and PATH? 83
How do you address the concern that person-centered planning takes too long and costs too much? 84
How do we build community? 84

Mike Green 87
Where did Asset Based Community Development (ABCD) come from? 87
Your work is in community organizing, what interests you about person-centered work? 88
What does citizenship mean to you? 88
Isn't citizenship for people with disabilities a right and not an option? 89
How does ABCD compliment person-centered practices? 89
How does ABCD increase people's potential to experience citizenship? 91
What assets should we be looking for in a community? 92
What contribution does asset mapping make? 92
What is a capacity inventory? 94
Tell us about social networks. 95

Say more about associational life. 95
What does it take to make connections between people with disabilities and community associations? 96
How can organizations become a real resource to their communities? 96

Connie Ferrell **99**
How does our society view people with disabilities? 99
What does it mean to belong to a community? 100
How do staff make a positive difference? 100
How do you see leadership? 100
What is supported employment? 101
What are the principles of effective supported employment? 102
How is a person-centered approach to people with disabilities different from other approaches? 103
How do you see the difference between person-centered planning and person-centeredness? 105
What do we have to give up in order to move to person-centered work? 106
What is the Framework for Planning? 107

John O'Brien **109**
What is disability? 109
Why citizenship important for people with disabilities? 110
What keeps people with disabilities from being full citizens with access to valued community roles? 111
How does all this matter to person-centered work? 113
What is leadership? 114
What place does courage have in social innovation? 115
How has innovation in service provision affected person-centered work? 117
How can we minimize stereotypes and biases against people with disabilities? 118
What is discrimination? 119
How does poverty affect person-centered work? 120
What is the principle of normalization? 120
How did the principle of normalization influence the development of person-centered planning? 122

How do you judge the effectiveness of person-centered work? 123
What is the purpose of person-centered work? 126
What's the difference between person-centered work and typical service practice? 127
Are there people for whom person-centered planning doesn't work? 129
What conditions increase the effectiveness of person-centered work? 130

Index **135**

Learning More **137**

Implementing Person-Centered Planning: Voices of Experience 137
A Little Book About Person-Centered Planning 141

Images by Beth Mount

Make Your Mark 31
Learn the Neighborhood 32
Celebrate Relationships 56
Raise Expectations 74
Celebrate Community 86
Listen With Heart 98
Build Alliances 134

Connie Ferrell

How does our society view people with disabilities?

Unfortunately, we're still in a place where for the most part, we see disability before we see a person, and so we bring a lot of prejudice and myth into what we see in a person. Many people have moved on from thinking "Those people make us uncomfortable, let's keep them out of sight" to "They can be here, but we shouldn't really expect much from them." I don't think these beliefs usually comes from an intention to harm, but sometimes the result is harmful.

It's harmful when people with disabilities don't have the opportunities and obligations of citizenship. I think that's because people, including some people with disabilities themselves, think that they don't have anything to contribute so we don't expect people with disabilities to have roles and responsibilities that encourage their contribution.

People with disabilities have made real progress, but we have to be careful of complacency in our expectations. If we sit back and talk about how much better things are, we lose the itch, the urge, the pressure that comes from saying, "This is better, but it's not true citizenship. It's not true inclusion yet."

We can see this plainly in the area of employment. More than two-thirds of people with disabilities are unemployed. This doesn't change until we expect that people will work and figure out what it takes for that to happen. As my friend Joe Marrone says, "To withhold the expectation of employment for people with disabilities is to deny them citizenship."

When we see people with disabilities only as needing others to take care of them, we rob them of something that is important at the very core of who we are: to feel needed, to feel wanted, to contribute.

What does it mean to belong to a community?

If you truly belong, you have these experiences:

- Being missed when you're not there.
- Having your gifts recognized and received.
- Knowing that your contribution is valued.
- Being in a position to welcome someone else into the community because you know that you are a part of that community.

How do staff make a positive difference in the lives of people with disabilities?

First, get rid of all of the myths about people with disabilities. Get rid of notions about how I'm supposed to act and be if I'm in this job role. Instead, be with the person. Really value getting to know the person and building a relationship. I don't think you can do much of value with and for a person if you don't take the time and invest the energy and the heart into getting to know them. Not just at the beginning, but more and more throughout the relationship. Trust comes from wanting to know someone, spending the time, taking the energy, creating the focus to truly get to know who they are and then in valuing who they are and being led by the person in how you would support them forward.

How do you see leadership?

I don't think leadership has to do with your job description, your ranking in an agency, or whether you have high profile in your community. I think anyone can be a good leader.

The people I look to for leadership have a vision and walk their talk. They are really clear in their own mind about who they are, where they're trying to go, and what they believe in. Because of that clarity, they lead other people. The best influence that a leader can have on me is to share their vision by living it versus talking about it. Every day, every minute, leaders demonstrate what they believe in.

When we think of ourselves as not being powerful enough to make change, we are really dead wrong, regardless of who we are. Every single one of us has an orbit of influence. Every day we influence things in a positive or negative way for people with disabilities, either intentionally or unintentionally.

Our power comes from intentional decisions about our own attitudes and behaviors. So it's important to think about basic questions:

- What is the change I'd like to see in our society?
- What's the change I'd like to see in potential employers for individuals with disabilities?

When we want to see something in others but we model something different, there's a disconnect. So how can I be what it is that I'd like to see.

What is supported employment?

I've been involved in supported employment delivery since 1981. From the beginning to this moment, supported employment is all about being still, being with an individual who has a disability and is trying to go to work, learning from them what's getting in the way, using creativity, problem solving, resources, to create a support structure specifically designed with that person to get those barriers out of the way.

Supported employment looks so different from person to person. I have certain expertise and knowledge of resources that I bring to the table, but the person is the expert on their life circumstances. So I have to come with a feeling of learning and a willingness to be guided by the person. Together we craft a plan for moving ahead into employment and how support is going to look.

For one person I may be right on that job, right alongside them for some period of time. For another, we may meet at the corner drugstore at the breaks. For another, some coaching and confidence building will get them out there and do for themselves what they need to do.

There are lots of rules and regulations that define supported employment as a funding source, but at its heart it is working with one person at a time and together making and following a totally customized plan to support that individual into employment.

The beauty of supported employment is that every situation is different and requires creativity. We can ask what it takes for this person to get and keep a job and then, as long as we stay within ethical and legal limits, we create whatever it takes.

It's not just individual circumstances that matter. Knowing and connecting with informal community resources is important too. Getting to work is a real problem when there is no public transportation and people don't drive. I was training supported employment staff in rural northern Indiana, where many Amish people live. When I asked about transportation problems, I was surprised when staff said they didn't have any transportation problems and I asked them if they limited their work to people who could drive. "No," they said, "we use Amish haulers." I had never heard of an Amish hauler, but it turns out that Amish people don't drive cars and in this area they have organized an informal network of people whom they can pay for a car ride when they need one. Connecting people into this network capitalizes on what's already there in the community. These resources may not be anything you can look up in a service directory, but if you go beyond the obvious when you learn about people's communities they are very often there.

What are the principles of effective supported employment?

First, follow a zero reject philosophy. The only criterion for being supported into employment is that you want to go to work.

Second, do a rapid job search. The longer the time people are engaged in assessments and preparatory activities, the lower their odds of getting to work.

Third, keep it person-centered. The person drives the plan and the process.

Fourth, include all those who play a part in the person's success in the process.

Fifth, develop one job for one person. Research shows that the individual placement model of supported employment is linked to decreased unemployment, higher wages, more hours worked, greater inclusion in community, and a decrease in mental health symptoms.

Sixth, continue the support that the person requires for as long as the person needs it. There is no time limit on the availability of support.

These principles serve an important purpose of supported employment: to create integrated workplaces, places that give everyone more experience of diversity, more opportunities to interact in ways that change attitudes about people with disabilities, and more chances for people with disabilities to contribute and earn.

How is a person-centered approach to people with disabilities different from other approaches?

I'd like to compare traditional services with a person-centered approach and insert a kind of hybrid that has unfortunately developed as service providers try to make the shift from traditional services to person-centered supports.

Traditional services are based on identifying people's needs for training and intervention. The focus is on the things a person doesn't do well, their deficits. Services are based on fitting the person into the program a provider offers that will do the best job of addressing the person's deficit areas and fixing what's wrong.

The problem with the traditional approach is that it doesn't take the individual into consideration. The programs available are the context for what people think about and do, not the life the person wants to lead. We all have things we don't do well, but in some cases we're not particularly interested in changing them. The traditional approach doesn't ask whether a person has any interest in developing the skills that would remediate particular "deficiencies". It doesn't ask what will move the person toward the life they want to lead.

The traditional approach assumes that the person will fit into one of the available program models. So the person is placed in the available program box that comes the closest to fitting needs. This hides an important sign that the traditional approach doesn't work: it takes people an incredibly long time to graduate out of those program boxes that are supposed to fix them and move them on.

Many people let us know behaviorally that the traditional approach doesn't work for them. Some people can handle being

placed. Even though they may have square edges, they can tolerate being put into a round hole that they really don't comfortably fit. Other people aren't as flexible or forgiving and tell us that what we are doing isn't working, sometimes very dramatically with difficult behavior and sometimes by withdrawing. But the traditional approach makes these messages hard to understand; they are heard as symptoms of more deficits to fix in the person and not as demands to change the approach to better fit the way the person wants to live.

A person-centered approach is the opposite of the traditional approach. We look at the person and where they're trying to go with their lives. We ask,

- What are your talents and gifts?
- What skills and knowledge do you care about developing?
- What is a meaningful life from your perspective?
- If you could close your eyes and think about having a life that you'd really love to have five years from now, what would it look like?
  - Where would you be living?
  - What would you be doing?
  - Who would you be hanging out with?

Then coming backwards and asking:

- What's keeping that from happening?
- What do you have going for you?
- Why does this make sense in relationships to the who you are?
- What are the barriers?

Once we've explored those questions, we try to figure out how the person's natural support system, together with the human service system's resources, can help the person along their own life's path. We start from program amnesia. We forget the boxes of pre-voc or workshop and work on crafting something customized to fit each unique individual.

Then there's the third model, a hybrid of the first two, the customer-driven approach. It's sort of the Burger King idea: you can have it your way, but don't go crazy on us. We don't just put

you in a program box based on our assessment of your deficiencies. You don't have to move through a continuum of placements to get to a job or a place to live. We consider your preferences. But it's not like the world is yours, we have a menu. We have a limited number of options and some flexibility, so we can modify what we have a bit. But we can't forget about our programs and customize supports to match you.

I don't want to put the customer driven approach down. It's better than the traditional approach. However, it will get in the way of moving to a person-centered approach if an organization stops there and thinks they've arrived. To keep developing, call the customer-driven approach what it is, be clear about the dramatic differences between a customer-driven approach and a person-centered approach, and develop strategies to keep moving on toward person-centeredness.

Traditional Approach	Customer Driven Approach	Person-Centered Approach
Analyze person's deficits, define needs and make a plan to fix what's wrong	Ask person to identify the needs they want to work on	Start with the person's ideals and value system
Fit person into best currently available service program	Make program options more flexible to allow for some choice	Customize supports and maximize community engagement

How do you see the difference between person-centered planning and person-centeredness?

Person-centered planning is certainly a part of person-centeredness, but it's not all that we're talking about. A lot of agencies have moved to person-centered planning and confuse that with embracing person-centeredness. That's not enough: person-centered planning without person-centered work is empty.

Good person-centered planning usually makes good things happen in the room where the plan gets made. We bring the players together, we start with positive attributes, we come up with a plan based on individual interests and abilities.

But if it's business is as usual as far as what we actually do with a person on a day-to-day basis, then how a person spends their time and where they're putting their precious efforts remains basically the same. We've create an expectation that things are going be different and they really aren't.

Person-centeredness is about really being with the person, visiting where they're trying to go with their lives, and truly committing yourself. It means developing the ability to pull together a team of people that reaches beyond our current programs and agencies. It means making our resources so flexible that we really can practice program amnesia and fit our support closely to the direction that each person wants their life to go.

What do we have to give up in order to move to person-centered work?

We get stuck sometimes because person-centered work is more about asking the right questions than giving the right answers. I think many of us who have been in this business for a long time were brought up to believe that we have a professional responsibility to come up with the answers and solve any problems that come up. It's part of the traditional assumption that services exist to fix the person and people can misunderstand being person-centered as taking full responsibility for delivering whatever the person wants.

We're really talking about a complete realignment of our professional role in the lives of people with disabilities. So as long as we hold on to the idea that we staff have total responsibility to make what the plan says happen, for fixing you or making your life work exactly the way you want it to work, we're going to create a menu of choices that's still very limited. Holding complete responsibility for fixing inevitably puts us in control of people's lives.

We need to make the shift to thinking of ourselves as listener, question asker, idea creator, facilitator, bridge builder. Our role is to help each person clarify their answers to these questions:

- What is it that I want in my life and from my life?
- Who are the right people to help me move towards your life goal?
- How can service resources help?

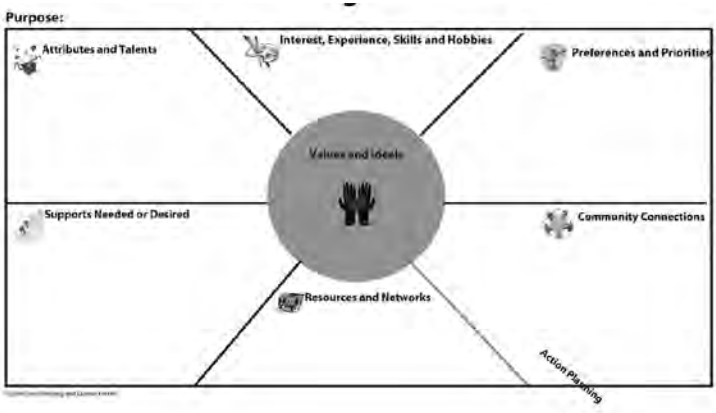
What is the Framework for Planning?

Carol Blessing and I were asked to provide training and facilitate a person-centered planning process with a man who was at risk of losing employment services because it appeared to the team that he wasn't motivated because he hadn't kept any of the several jobs that they had found for him.

Because we wanted to fully involve him in his planning process, we invited him to attend the training and then consult with us on what would suit him best. He said that planning should begin with an understanding of a person's core values and keep those values central to everything else. Based on his insight, we came up with A Framework for Planning as a container for information that comes from exploration and discovery.

The Framework guides an inquiry process for a purpose that's important to the person, for example "to find a direction for employment." It has eight sections, seven to focus the process of gather-

A Framework for Planning



ing information and an action plan that synthesizes what's been discovered. The sections fit together to define a positive profile of the person and how they're trying to move ahead in their life.

Three sections create an insider-view of who this person is, their abilities, interests, experiences and skills and their preferences and priorities related to the plan's purpose. Three sections identify the connections, networks, resources and supports the person can draw on or needs to develop. Energy grows when people begin to move outside what the service system can do and identify where in the world a person could be involved and included, belong and contribute.

As information begins to fill these six sections, the facilitator listens for and helps those involved in the process identify common themes that can be distilled into a statement of the person's core value. A core value is more than a person's next goal. It's a part of their identity that stays pretty similar throughout life. Once identified, this core value becomes the compass that guides everything from that point forward in planning and offering support. Actions that flow from a person's core value are likely to work.

A dream without an action plan is nothing but a frustration; so the eighth step identifies next steps that people take responsibility for doing. A good action plan pulls together all the information that has been shared and faces the person with a choice about what they are most interested in pursuing and what they are going to do next.

The Framework is structured to support a creative process that's based on listening comprehensively and organizing information in a way that leads to action that respects a person's core value and connects them more strongly to the world. It's not a list of specific questions that magically produce results. It's a reminder of what's worth inquiring about, a record of what matters to a person, and a guide for creatively turning information into action.*

* For more information on *The Framework for Planning* and to order materials, e-mail Integrated Services at Cferrell_connie@yahoo.com