

From Institutions to Individuals: On Becoming Person-Centred

Susan Stanfield

When we hear the word *institution* in the context of community living, we think of the daunting, prison-like structures where people with disabilities were warehoused through much of the last century. The very term “community living” denotes a position against such structures and the exclusionary attitudes that led to their creation. But institutions aren’t just a physical thing. The word also applies to organizations (as in a banking institution, or educational institution), and to social customs (the institution of marriage). To be “institutional” is to be structured, formalized, bound by a set of established principles or rules. A *system* can be institutional, through its policies and practices, without any physical manifestation of what we commonly think of as an institution.

The service delivery system for people with developmental disabilities is in many ways an institutional system. It’s structured, formalized, bound by rules...and while we’re starting to move toward more individualized options, many of the existing services still operate within an institutional framework. The overwhelming majority of funding is allocated to agencies that deliver services to groups of people in the form of programs – residential programs, day programs, supported work programs. The stated mandate of such programs is to help people become more independent and more included in the community, but the assumption that a *program* is the means to that end represents an institutional way of thinking; a way of thinking that lingers with us from a past we’re still working to overcome. We closed the big institutions, but, in some cases, replaced them with new structures that are every bit as rigid and inflexible.

We’re just now starting to realize the limitations of some of our program models. They’re expensive to operate, difficult to change, constrained by bureaucracies and hierarchies that often place more value on the input of professionals and program supervisors than that of individuals and families – even to the point of sustaining a particular model past the point when it ceases to be relevant. How does an agency that only runs congregated group activity programs respond to a new generation of youth who don’t want day programs?

Over the past decade, service providers have begun downsizing their large facility-based programs, in what feels like a case of déjà vu for anyone who was part of the institutional downsizing projects. But it’s important to keep in mind that size alone isn’t the issue: to change the appearance but not the fundamental approach to supporting people will only perpetuate the institutional system. The shift away from large group settings to smaller, more normalized environments is a positive one, for sure – but this shift must be accompanied by a whole new approach, one that genuinely supports (rather than directs) individuals and

families, that builds flexible supports around individuals instead of forcing them to fit into pre-defined *placements*.

Toward a person-centred approach

In recent years, the term *person-centred* has made its way into human services vernacular. The term was popularized by Psychologist Carl Rogers in the 1950s to describe a therapeutic approach that recognized the patient's innate motivation to develop his or her potential to the fullest extent possible. According to Rogers, the role of the therapist was to create an environment where his patients felt safe and supported to explore their potential; it was not the therapist's job to solve people's problems or dictate a course of action. Rogers' approach was "non-directive" – meaning the therapist was there to nurture the person's natural curiosity and desire for self actualization, not to *fix* people. Fundamental to his approach was the belief that people have the capacity to solve their own problems, given appropriate support, and that *relationships* are key to our personal growth and development.

It's a pretty simple idea, really. Unfortunately, we have a tendency in our field to take simple ideas and make them complicated – to institutionalize them. By definition, person-centredness is about individuals; it's not about systems and structures. It doesn't lend itself to standardization. It's not a bureaucratic exercise we go through once a year as part of a mandated planning meeting. We must take care not to institutionalize this idea, to turn it into another task that gets added to the endless "to do" list (*replace the furnace filter....tally the petty cash...do the person-centred planning...*).

It's easy for organizations to claim they're being person-centred, but the evidence doesn't always bear out the claim. Taking groups of people on outings of the staff's choosing in a 12-passenger van is not person-centred. Renting a bigger space so the day program can accommodate more people is not person-centred. Replacing swimming with arts and crafts because the new staff doesn't know how to swim (but loves doing arts and crafts) is not person-centred. Hiring staff without the input of those they'll be supporting is not person-centred. Providing everyone's support from 9-3, Monday through Friday, because that's when the program operates, is not person-centred.

And yet all of these things happen in the current service system. We're so used to doing things a certain way that we often don't notice the extent to which our structures are limiting people until someone from outside the system points it out. A new support worker asks, "*Why don't I meet Charlie at his house at 9:00 and go straight from there to his volunteer job?*" and we suddenly realize we've been making Charlie come all the way across town to our program site just to meet up with a staff person, turn around, and go back across town to his volunteer job. Or in another example, a group of participants who might be capable of taking

transit use the program's passenger van, because it's there. Or a young woman who may only need a few hours of support has staff with her 24 hours a day, because that's how the group home is staffed. A kind of "regression to the mean" occurs, where the diversity of individual strengths and capabilities becomes increasingly uniform – no-one's needs are entirely satisfied, but everyone is somewhat satisfied. We settle for the lowest common denominator, for passive participation over active engagement: watching movies, listening to music, being taken on van outings, having meals prepared and served by staff. At best, this one-size-fits-all approach keeps people entertained and cared for; at worst, it instills in them a sense of learned helplessness. The person's pre-supposed need for constant staff support becomes a self fulfilling prophecy.

So, what does it mean to be person-centred? For starters, it means checking our impulse to jump in and take charge of people's lives. It means resisting the temptation to group people on the basis of disability. Perhaps most importantly, it means involving the right people in decision-making – families, friends, significant others – and not presuming that we have all the answers. It's not enough to invite families to a meeting, present them with a plan we've come up with, and ask them after the fact if they have anything else to contribute. Being person-centred requires that we get to know the person and those closest to them at a whole different level from what we're used to, and that we actively encourage and support their involvement in the planning process:

- ***Who is in the person's life?*** Who helps the person make decisions, who do they enjoy spending time with? What role do family members have? Are there siblings, grandparents, family friends who might like to be more involved? It's important to get clear on who is part of the person's existing and potential network, so we can support the *network*, not just the individual. We can't (and shouldn't) do everything ourselves.
- ***How and where does the person like to spend their time?*** What are the *natural supports* (the people and resources that are available to everyone) that might be tapped in some of those environments?
- ***What, specifically, does the person need support with?*** Think in terms of targeted support, as opposed to coverage. "*How many hours of staffing do you need?*" leads to one kind of discussion; "*What are your goals, and how can we support you to achieve them?*" leads to a whole other discussion.
- ***Who might provide the needed support?*** We sometimes assume that whatever support someone needs, our staff will provide it. A good rule of thumb is to ask ourselves, if we needed support with the same activity, who would we turn to? Look *first* at natural supports you might access or enlist. If the person needs transportation to work, is there a co-worker they might car-pool with?

Starting with these questions can lead to a whole different plan than we're likely to come up with on our own. But the plan is just the beginning. Being person-centred doesn't end with a good plan. It's a way of *being* in our relationship to those we support. It's a journey we take together, as equals. It requires tremendous organizational support, a genuine letting go of some of our power and control.

The chart below examines some of the differences between a *program* approach and a *person-centred* approach:

<i>In a program...</i>	<i>In a person-centred service...</i>
Decision making is driven by staff and professionals	Decision making is driven by the individual and his/her support network
Planning occurs as a singular event, according to a prescribed format	Planning is ongoing and individualized
The person's goals are defined within the context of the program	The person's goals are defined within the context of a holistic plan
Specialized supports are the first response to meeting individual needs	Generic supports are the first response
Staff take the place of natural supports	Staff augment natural supports
There is a pre-set schedule of activities that people take part in (or don't)	Individuals develop their own personal schedule based on their goals
Staffing is provided at pre-set times according to a fixed schedule	Staffing is provided flexibly
Focus on participation	Focus on increased independence
Focus on group needs	Focus on individual needs
Staff skills determine the selection of activities	Preferred activities inform the selection of staff with appropriate skills
Support is tied to the program – the person can't take their support with them if they leave the program	Services are portable – the person can take their support and change service providers if they so choose

A tale of two approaches

To illustrate how these two approaches might play out in someone's life, consider the case of "Anne":

Anne, a 21-year old woman with a developmental disability, is seeking community support services. She is described as being friendly, outgoing, and having a variety of interests, especially classical music and spending time with children. Her parents are concerned that Anne spends too much of her time at home and, since finishing high school, has lost touch with her social group. She has no close friends.

Approach # 1) ABC Community Services: A program approach

ABC Community Services has a vacancy in its "Friendship Centre" day program, which operates out of its head office. The intake worker feels this program would be a good fit for Anne, so she signs her up and arranges for Anne to be picked up by HandyDart at home each morning. At the centre, Anne takes part in various activities: arts and crafts, exercise class, cooking, karaoke, dancing. On Wednesdays the group goes to an adapted aquatics program at the local pool, and on Fridays they meet up with participants from another day program. Weather permitting, they have a barbecue at the park, but on rainy days they all watch movies at the centre. At her annual planning meeting a year later, Anne says she enjoys the day program but would like to find a part-time job. The program manager tells her the agency's supported employment program doesn't have any vacancies right now but they'll put Anne on the waitlist, and in the meantime they'll request a vocational assessment.

Three years later, Anne is still at the centre. The vocational assessment indicated that Anne needed to learn some pre-employment skills before she'd be ready for the supported employment program, but unfortunately the day program doesn't have enough staff to support her to learn these skills. Anne's parents are still concerned about her social isolation. They feel she is showing signs of depression, and are also concerned that she has picked up some ritualistic behaviors from another participant at the day program. The manager suggests they put in a referral for a behavioral assessment.

Five years later, Anne is still at the Friendship Centre. Her parents are worried about what will become of her when they're no longer able to care for their daughter. ABC Community Services agrees to put her on the waitlist for one of their group homes.

Approach # 2) XYZ Community Services: A person-centred approach

XYZ Community Services spends time getting to know Anne and her family. They ask what kind of a life Anne envisions for herself, what she likes to do, what interests she'd like to develop, who she'd like to spend time with. They learn that Anne has a cousin, Marie, who she used to be very close to. Marie is married now, with two young children, and Anne doesn't get to see her very often because she lives about 50 miles away in another town. They talk about other people who used to be part of Anne's life, and make a list of people Anne would like to follow up with. A support worker helps Anne set up an email account and get in touch with some of her friends from high school through a social networking site. Anne reconnects with her cousin Marie, who is delighted to hear from her. Marie sends Anne some pictures of her children and invites Anne to come visit them sometime. In keeping with Anne's interest in music, her support worker arranges for her to sit in on a symphony rehearsal at the big concert hall downtown, which Anne loves; they go back again, and again, and eventually Anne begins volunteering at the symphony as a greeter.

At a team meeting a year later, Anne talks about the new friends she's made and how she's learned to take the bus independently to her volunteer job at the symphony. She's been to visit her cousin a few times and got tickets for Marie and the kids to a special children's concert at the symphony, which they all enjoyed very much.

Three years later, Anne is working two evenings a week in the gift shop at the symphony. Her volunteer job as a greeter has been expanded to include helping with school tours, where she gets to interact with groups of children. She and Marie get together about once a month, and correspond regularly via email.

Five years later, Anne is living in an apartment with a roommate. She's looking forward to hosting Christmas dinner at her place this year.

ABC Community Services gave Anne a program. XYZ Community Services gave her a good life.

Which would you rather have?

The time is now

Person-centred approaches aren't just the latest trend in social services. They're a natural next step in the evolution of the community living movement. If the goal is to see all people enjoy full citizenship and equality, then we need to recognize

the limitations of the current service system. When we group people together on the basis of disability, when we build programs and then populate them with people who fit a certain set of criteria, we perpetuate an institutional way of thinking. Not all people will *fit*. Others will refuse to comply with our rules, and may even be asked to leave. Those who comply will likely stay for a very long time – a lifetime, perhaps.

Spending one's entire adult life in a day program, with no other options from which to make an informed choice, is not full citizenship.

It's time we embrace a new way of thinking about the people who come to us for services, to stop seeing them as *clients in a service delivery system*, and instead see them as *individuals in community*.

Let's put institutional thinking behind us, once and for all.

Susan Stanfield is a co-founder and Director of Spectrum Society for Community Living in Vancouver, B.C., and co-author of 101 Ways to Make Friends: Ideas and Conversation Starters for People with Disabilities and Their Supporters.

susan@spectrumsociety.org
www.spectrumsociety.org
www.101friends.ca