

# Networking through Life's Transitions: Looking to Relationships First, and Systems Second

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A transition can be thought of as any period of significant change in our lives, where we move from one place to another, one state of being to another, or make crucial decisions about our future. Do I take a year off after high school and work, or go straight to college? Should I rent my own apartment, or move in with a friend? Do I take that job offer, or not? Starting school, moving from elementary to high school, graduating, moving away from home, starting our first job, starting a new relationship, growing older: life is a series of transitions.

In the words of Benjamin Franklin, "When you're finished changing, you're finished."

Any period of transition in our lives can bring with it excitement, fear, anticipation, anxiety. For people with disabilities, there may be the added stress of bureaucratic changes to deal with – funding issues, moving from one service stream to another, having one's "case" transferred from a particular office or government department to another. The special education assistant you've had by your side all through high school is replaced by community support workers at your new day program. Transitions can be a scary thing for anyone, but most of us don't also have to deal with service providers and social workers as we move from one stage of life to the next.

## **Networking**

Networking is an idea that's been around for decades in the business community. Contrary to popular belief, it's not about self promotion or manipulating others into giving you what you want. Any successful entrepreneur will tell you that networking is about building reciprocal (mutually beneficial) relationships.

As community living moves away from congregated to more individualized models of support, from *integration* to *citizenship*, networking becomes an important consideration. Not just in the usual sense of agencies networking with other agencies, but individuals building their own personal support networks. In a person-centred service, planning doesn't follow a formulaic process as it does in some of our traditional program models. It becomes more fluid and relational, more about tapping opportunities and deciding who to enlist to help us move from here to there, than about securing the next "placement." These kinds of decisions are best made by individuals and those closest to them, not by service providers. That's not to say people don't need services. But we do need to rethink some of our assumptions about how those services get delivered.

In terms of ongoing support, the person's network also plays an important safeguarding role. It's relatively simple for an agency to keep an eye on thirty people when they're all in one place; if they're in thirty different places, the task of ensuring a consistent quality of service requires a different kind of discernment and accountability. Families, friends, neighbours and community members become our eyes and ears in the community.

### ***Five good reasons for looking to relationships first, and systems second***

1. To be sure we have the right people at the table:

Before we start asking *what* we can do for the person and *how* we might do it, we first need to ask *who* to invite into these conversations. Our tendency is to focus inward on our own teams of staff and professionals, instead of focusing outward on the larger team (or community) around the person. Sometimes we don't even know who's out there, because no-one thinks to ask.

2. To empower the person:

The traditional service system assigns individuals and families to a passive role as service recipients, with professionals and bureaucrats as the ones in charge. The assumed power and control of so-called experts perpetuates a paternalistic attitude toward people with disabilities as being incapable of governing their own lives. For individuals to achieve full citizenship and equality, the balance of power needs to shift.

3. To clarify our role:

*"Are we friends?"* is a question that comes up often for staff working in this field. This could be the subject for a whole other paper, but for our purposes here, suffice to say, *"maybe."* We have seen genuine friendships develop between staff and individuals they support, friendships that continue long after the staff moves out of a paid position. However we cannot count on this happening, and even when it does, it should not replace natural relationships. As often as we see genuine relationships that enrich people's lives, we also see a kind of possessiveness where staff start to believe the person doesn't need other relationships (*"we're the only family they need"*) or make judgements about other relationships (*"John's parents treat him like a child"; "If Sarah was a real friend, she'd call more often."*). Staff shouldn't be debating whether to respect the input of families, or whether a person's choice of friends is appropriate. True, relationships may need some facilitation – but that's where we need to focus our energy, not on second guessing the validity of those relationships.

4. To tap a wider range of opportunities:

Human service agencies have a particular kind of expertise. Families, friends, neighbours and community members have a much broader range of skills, perspectives and connections to draw on. If Brian wants to plant a vegetable garden, maybe his next door neighbour knows more about how to do this than his key support worker. Maybe his neighbour is looking for a way to connect with Brian, but isn't sure how to get involved. This could be a win-win opportunity for both of them – but only if someone thinks to tap it.

5. Relationships keep people safe:

During periods of change, when we're at our most vulnerable, our family and friends are there to comfort and guide us. Not that service providers and staff can't provide comfort and guidance – but we have multiple, often competing, interests to satisfy. Even the best services cannot take the place of family and friends whose primary concern is the well-being of the individual.

***We all know how to do this***

Imagine you get a call from an old friend saying he's moving back to town and looking for a basement suite to rent, and you happen to know someone with a basement suite they want to rent out. Or your nephew needs volunteer hours for school credit, and your next door neighbour who coaches youth soccer is looking for a volunteer assistant.

You'd be happy to put them in touch with each other, wouldn't you? You'd give your friend the number of the person with the vacant suite. You'd introduce your nephew to your neighbour. These are everyday examples of networking. We all know how to do this, and in fact we do it all the time in our own lives, and the response is almost always positive. People want to help.

So why don't we do this on behalf of those we support, or better still, teach them how to tap their own networks? It seems like such an obvious source of support, and so natural to us in our own lives, but for some reason it runs contrary to many of our long standing practices in social services. We're so conditioned to think in terms of a system response, we sometimes miss the forest for the trees. John wants to get a job in construction, but our work experience placements are all in food services or janitorial settings. Little do we know that John's cousin owns a construction company, and would gladly help us figure out how to support John to achieve his goal. But we don't know about John's cousin, and he doesn't know about us, because no-one has made that connection. We don't even think to ask John, "do you know anyone who works in construction?" – we just dive right in to service provider mode.

When you or I are in some sort of transition, we turn to our family and friends, our “network,” for support. Perhaps we have a peer group going through the same transition, and we support each other. If we need help filling out college applications or applying for a student loan, likely there’s someone in our network – an older sibling, or a family friend – who has been through the process already and can give us some pointers. Many of us found our first jobs through personal contacts (and in fact, research shows that at least 80% of jobs are found this way), and not through traditional job-search strategies or employment programs.

We figure things out, with the help of people we know and trust. We muddle through some transitions, sail through others, but ultimately we gain a sense of accomplishment and personal growth through successive life changes. Even when things don’t go according to plan, we can usually glean some valuable learning from the experience that will help inform our decision-making when the next transition comes (which it surely will).

Sometimes we don’t even have a plan. Just because one stage is ending doesn’t mean the next one falls into place seamlessly. There may be a period of exploration, we may retreat temporarily to the comfort of an earlier stage (the thirty year old who goes back to live with his parents between jobs), while we figure out what to do next. Or we may stumble into something quite unexpectedly that ends up changing our lives. My involvement in the field of community living started with a volunteer position in a Saturday recreation program for youth with autism at my local community centre, while I was still in high school. One thing led to another, and thirty years later, here I am. It wasn’t a methodical step by step plan, but more a process of discovery, of seizing opportunities and connections. Likewise, my living situation evolved through a series of trials and errors. I tried living on my own, with various roommates, a brief stint in residence at UBC, then back on my own again. Altogether I moved seven times in the six years following my graduation from high school. Each experience taught me something new, and over time I discovered the kind of living arrangement I’m most comfortable in, and what qualities are most important to me in a roommate.

My experiences were not unusual; most of my friends went through similar periods of adjustment on their respective journeys into adulthood.

By contrast, the participants in our Saturday recreation program had a very different journey. Where I was trying out different housing options, figuring out what kind of work I wanted to do, what field of study to pursue at university, they were being “transitioned” from high school directly into the adult service system of group homes and sheltered workshops. My future was wide open, the possibilities virtually unlimited. Theirs was being mapped out for them by social workers whose job it was to find them “placements” in special programs – placements which were presumed to be permanent. It didn’t occur to anyone

back then to ask why this was the case. It's just how things were done. Specialized services were the rule, not the exception.

***If all you have is a hammer, everything looks like a nail***

There is a kind of deferral to professionals that happens when someone is part of the service delivery system, an assumption that typical life transitions require a specialist response, and that the service system will manage these transitions.

Think about this for a moment. It's one thing for a social worker to transfer a file from one office to another, or for a service provider to gather information from a family so as to begin providing services to their loved one. It's another thing for these professionals to assume responsibility for the decision-making about what the person's life will look like, decisions that we wouldn't dream of allowing someone else to make for us. Someone wants to move out of their group home into their own apartment, or quit the job they've been doing for two years and look for a new job. But their choice is constrained by the available program options, and the often arbitrary requirements of those programs; then of course there's the issue of waitlists and funding. Bureaucracy dictates the choices we can offer people. Or we make assumptions about their potential, and don't even offer them a choice. We decide that Jane needs to master certain housekeeping skills before being "ready" to move into her own apartment.

I think back to the unkempt state of my first apartment, and count my blessings that no-one thought to assess my readiness for independent living.

The question shouldn't be whether we think Jane is ready to live in her own apartment, but how we might support Jane and her network to achieve that goal. If you or I wanted to move, we wouldn't need to ask for permission or prove ourselves ready.

There is, of course, the question of whether people are making informed choices, and where our responsibility lies with regard to facilitating responsible decision making. However, if this is a concern, then it becomes even more crucial that the person have trusted allies outside the service system who can explain things in a way the person understands and help them make a decision, or if necessary make it on their behalf. There's an inherent conflict of interest in agency staff and professionals making decisions for people, or accepting their acquiescence to decisions they doesn't fully understand, in the name of individual choice. Someone's unquestioning compliance with our program rules should not be construed as informed consent.

Administratively, it's a lot of work to set up a new resource. It takes time and energy, contracts need to be drawn up, budgets negotiated. For the sake of expediency, transition planning often amounts to little more than moving people

from one vacancy to another within the system, when the optimal solution might lie somewhere else entirely. Moving someone from group home A to group home B does little to expand their network or build community. But if the only housing option your agency provides is group homes, then this becomes the default response when someone requests a move.

### ***What if there's nobody in the person's life?***

What about people who have no identified family or friends? Who do they turn to?

My first suggestion would be, do some digging. We've been surprised, time and again, at who shows up when we start looking into people's connections. We've discovered grandparents we didn't know about, siblings we were told had no involvement in the person's life, but were just waiting to be invited in or given a role, a cashier at Safeway who became a lifelong friend of one of her customers, thanks to the intentional support of the fellow's key worker. There are former staff, friends from school, church congregations who remember the person from years ago when their family attended the church. And as with our own networks, people are happy to hear from us. We're not looking to burden them with extra work or responsibility; we're inviting them into a relationship.

One of our most poignant moments was realizing that someone we believed to be having imaginary conversations on his cell phone was in fact talking to his long lost father, who he had managed to track down. Having been removed from his family's care as a child, he was afraid he might lose his father again if anyone knew he was talking to him. This young man had been in our services for three years, and we had no idea he even had a father. Somehow, in the process of being "transitioned" from children's services to adult services, this vital piece of information had been lost.

If someone comes to us without an identified network, then it should be a priority for us to help them establish one. In our experience, about half the time when we think there's no-one there, it turns out there are indeed family members or others who would like to be a part of the person's life. We've seen many instances of families having been excluded from their loved one's life by previous service providers, for various reasons – staff complained that the family was difficult to work with, so the agency set limits on their contact; individuals were going through a difficult time and parents were told to keep their distance until things settled down – and as time passed, tragically, some of these relationships simply petered out. We know a grandmother who waited eight years for someone to get back to her after a social worker told her "don't call us, we'll call you when he's ready." The social worker left, her grandson's file was transferred to a different ministry, his service provider changed – and she had no idea where he was until he himself happened to find her years later.

Family and friends are vital to our quality of life. They keep us safe. To paraphrase David Pitonyak, they hold our story. Your grandmother remembers Christmas dinners with you and your cousins; she knows what kind of cookies you like and that you won the egg-and-spoon relay at sports day in grade five. She keeps in touch with your great uncle in Norway, and translates his letters for you when you come to visit her. She can list the names of all ten of your grandfather's siblings and tell you where they all lived, how many children they had, and whose marriages worked out. Imagine losing touch with her over a series of bureaucratic blunders.

We owe it to these families to get crystal clear on who's out there for the person, to ask the right questions and dig for answers. We should not be setting ourselves up as their de-facto decision-makers or surrogate family. This only increases people's vulnerability, and besides, we have no right. Who will hold us to account if the person isn't happy with our services? Who will the doctor turn to for consent if the person needs medical treatment?

Who will hold their story?

A simple strategy for generating discussion about relationships is to make an exhaustive list of everyone the person knows, and all the ways in which they are connected. Look beyond the usual suspects...think about neighbours, extended family, former staff, friends from school, the bus driver who always has a kind word, the waitress at Denny's who serves the person breakfast every Saturday morning. They're not all going to become close friends, but somewhere in that list there's someone looking for more connections in their own life. Probably several people. Pick one person, and start with one thing – exchange email addresses, invite them for coffee. Or think of a new way to approach the people you see on a regular basis, to shift the interaction. Rehearse with the person what they might say ahead of time, practice telling a joke, or make up personalized business cards to give out as a fun way to share contact information. Do something. Take one step in a new direction, and then another.

We've all heard the expression, "do what you love and the money will follow." The same can be said about relationships: "do what you love, and the friendships will follow." Many of us connect with people through a common interest or activity. We belong to the same softball team or book club; we see the same people at the gym every morning. The more that people are engaged in typical activities, the more connections they're going to make. The challenge for staff is to pay attention, to recognize and seize opportunities when they come up – and learn how to get out of the way. Learning to step back, to facilitate rather than direct, is one of the hardest things for staff to do. We want to take care of people, we want to be busy. But our very presence can become a barrier.

Keep in mind, relationships are a personal thing, and highly subjective. My network might consist of a few immediate family members and a couple of close

friends; for someone else, having a large group of friends and going to social functions every weekend is what they're looking for. Think quality, not quantity. We met a young man whose parents were concerned because he spent all his time in the basement playing computer games, or out walking by himself. They wanted to see him have an active social life, with lots of friends. When we talked through what he wanted for himself, it boiled down to having someone to go hiking with once a week who didn't talk too much. One friend, one activity, minimal conversation.

In another example, an agency in a small rural community that we've done some work with supported a woman to get a job in the next town. Instead of going the specialized transportation route, they asked around and found another woman who was driving to the same worksite every day and agreed to give her a ride. They discovered they both enjoyed knitting, so they started getting together on the weekends to knit, and that led to meeting for lunch, and so on.

One thing led to another.

Studies on what constitutes a good quality of life always rank relationships as one of the prime indicators. When we're faced with big decisions or major changes in our lives, our family and friends are the ones we turn to for support. While people with disabilities may need extra support navigating through periods of change, looking for specialist solutions before generic ones is like putting the cart before the horse. Specialized services offer a narrow range of options that too often promote compliance over citizenship. Communities have abundant resources waiting to be tapped, opportunities for people with disabilities to learn about reciprocity, contribution, and leadership. It's through those opportunities, through relationships in community, that they will achieve true citizenship.

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