

CHANGING THE SYSTEM: ONE PERSON AT A TIME

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Novel, conception-shifting anomalies, Kuhn points out, always emerge against resistance. The new world-view always challenges the established order of a field in which people are deeply psychologically invested.

(Schwartz, D, *Crossing the River - Creating a Conceptual Revolution in Community & Disability*, Brookline Books: 1992, p. 93, paraphrasing Thomas Kuhn, *The Structure of Scientific Revolutions* (1962)).

Strategic planning involves strategic thinking. Thought should precede action. Without strategic thinking, however, planning is disguised as strategic when it actually is incremental or linear.

Strategic thinking involves a leap of faith. It begins with the notion of not what is but what can be. To continue building on paradigms or existing structures only furthers what is. There is a certain comfort in this approach as misleading as it is.

This is manifested in organizations that announce a breakthrough that they believe is innovative. Often what has occurred is that an individual in an organization will be exposed to an idea that is new to him/her (not necessarily new to the world) and because this idea is so new, it provides a challenge to the individual organization to try something new, different and bold. As a result, energy, effort and planning takes place around this new idea.

There is one thing wrong with this approach. This model is often inward looking rather than outward looking. It assumes the old theory of the universe in which the sun revolves around the earth rather than the other way around. As a result, the ideas that generated the new planning are not new to the outside world. So while the organization or individual is spending endless amounts of time putting thought into action, by the time the idea is implemented, it is already old, passé and in many cases, not current practice.

A perfect example of this can be seen in what is currently occurring in our field related to both residential and employment services. I am still amazed in my travels around the country at how many times, I'll meet with an organization that is getting ready to develop its first group home, or hear staff members state that they are beginning to "do supported employment". Because these concepts are new to them, these organizations use a linear approach to planning which is an extension of their current system rather than seeing the need for a wholesale restructuring of their services.

How does this manifest itself? Many times the organization sets up parallel delivery systems. It doesn't change any of the old services that it is doing, but at the same time tries out the new things. As a result, if it is currently running a large residential facility, it continues to operate the facility, staff it and run it as before. It then begins this "new approach" as a side-by-side part of its organization. It tries to utilize a different approach but many of the same rules, regulations and philosophies that guided its development of its previous residential facilities (which might have been as

long as twenty plus years ago) are utilized in the development of a group home or what it perceives to be supported living.

With employment services, it is often the same situation. Organizations that begin to do supported employment sometimes continue to run sheltered workshops, possibly even expanding them at the same time that they are trying supported employment. Some of the same staff that worked in the sheltered workshop are now deemed to be job coaches within the same atmosphere, milieu and organizational structure.

In my experience, this can work well for a while. However, reality will eventually set in until one day the organization wakes up to realize that what it has done is to create a parallel universe. It is trying to run two systems side-by-side that are often separate but unequal.

Unfortunately, the organization is not alone in noticing this. Staff, people with disabilities, and outsiders also note these two parallel systems. It often leads to confusing and chaotic outcomes because the implementation of the dual system was done under the basis of "organizational planning", rather than strategic thinking. Then later, it is shocked to find that others have criticized its approach as being "more of the same".

Strategic thinking involves "thinking outside the box". It forces an organization to stop, think and ask this question, "How would the universe be different if we acted or thought differently?"

The example I use has to do with an organization that currently has a large building - either residential or vocational. I often pose this scenario: Suppose during a time when no individuals were in your building, the building was destroyed. You no longer have any building, any structure, or facility from which to operate. However, you have been fortunate that you have been able to retain your funding and now have a distinct choice: do you rebuild what you had previously or do you start from scratch and literally start over? If the organization tells me that it would not rebuild what it has, then it needs to tear down that building figuratively and start over.

Sometimes organizations are precluded from doing strategic thinking because of buildings, budgets and, sometimes because of the egos that are involved in the process. I have seen situations in which there is an executive director and/or board that started an agency has been around a long time. They are very much invested in what has been developed during a time when they were younger, more energetic and full of vision.

In subsequent years, the cumulative effects of an often absurd service system, cutbacks in funding, demanding changes and staff shortages have taken their toll.

As a result of this situation, organizations practice "incremental" thinking rather than strategic thinking. They believe, "we can start small," "we don't have to look at our overall system," "we'll essentially give everybody what they want", and we will be able to continue along our current path.

Unfortunately, the world does not work that way. For reasons already mentioned, these situations create cynicism, bifurcated systems and severe financial strain.

So what is the answer? As usual, some of the insights come from outside of our field. During one of my many years in college, I was fortunate to take two semesters of astronomy. During one of the early weeks of class, we were in the planetarium illuminated with an artificial universe overhead. The professor introduced two concepts that have stuck with me since that time: **residual light and first light**.

Using his laser pointer, he highlighted a very bright star in the night sky. He said that if, in an instant, traveling at the speed of light, we could vault from our current position towards that star and reach out to touch it, by the time we reached it, it would be burnt out. He told us that the star had actually burned out long ago and it was the residual light of the star that was shining to the earth.

He then continued his lecture by pointing his laser pointer to what appeared to be a dark hole in space. Using the same example, he said that if vaulted from our position towards what appeared to be a dark spot that by the time we reached that spot, we would bump into a star. He said that this star was being born but that its light had not yet reached the earth. He used this example to explain first light.

Too often in our field, I have seen that we have built our castles and systems on, what I believe, is really residual light, a burnt out star. We ask, "Why would we do anything different?" when we look at the waiting lists that exist for our sheltered workshops, the lack of openings in our group homes and the huge number of individuals who are currently unserved.

Our service system has clearly been built on the notion of the here and now. We look at families whose parents used to be 40, 50 and 60 years old with sons and daughters 20, 30 and 40. Now those family members are 60, 70 and 80 and their children are 40, 50 and 60. Those who are not already in the service system are now coming forward and asking us to develop services. This is a generation whose dream was to have their son or daughter, even if he or she would not live at home, live in a group home and go to the sheltered workshop. Because there is such an influx of these individuals at this time, it begs the fact that this demand is residual light. In the next five to fifteen years, these parents will pass. When they do, much of the demand for the current service system will pass as well.

What this approach clearly misses are two emerging groups that are clearly first light. These groups are parents of younger children and people with disabilities themselves.

It is becoming increasingly commonplace for me, in my talks to parents, to be in a situation where I am talking to parents of children or mixed ages: youngsters and adults. While no group is a monolith, there is a clear distinction in the dreams for these two groups.

As previously mentioned, many parents of adults with disabilities often either want an extension of the current service system or a slight modification. It is also striking how different is the view that parents of young children have. In a recent discussion, I had the parent of a young daughter with disabilities tell me this:

If the parents in the current system like the way it is, that's just fine. I will tell you that my daughter is not going to live in a group home, nor

is she going to work in a sheltered workshop. I expect that she will have a job and, if not, that she will figure out a way to earn income. If she doesn't live at our house, she will live somewhere close by and I will help her either rent a place or she will own her own home.

This is a parent whose daughter was one of the individuals who are members of the first generation of people who have graduated under Public Law 94-142. **This group just thinks differently.** If we do not recognize that this group comprises our future customers, then we will have no one to blame but ourselves when we end up with vacant beds in group homes and empty slots in sheltered workshops.

It is amazing to me how little strategic thinking goes on in our field. I usually recognize this when I talk to people outside of our business. When I look at the changes that have occurred in our world in the last five years, and then I compare them to the changes that have occurred in our business, we pale in comparison. Almost nothing in the world of business is the same as it was last year. In our field, some agencies haven't changed in twenty years.

Too often, the excuse that is given is that "change comes slowly", "this is what people want", or "we have to take it slow to bring everyone along".

The second group that is clearly indicative of first light is made up of people with disabilities themselves. There are a slowly emerging but growing number of individuals who want something different than we are currently providing.

We were able to get by with our current service system before people with disabilities were exposed to the community, demanded to express their own choices and employed a different way of thinking. Without using strategic thinking, we will continuously be blindsided by this group and it will eventually catch up with us.

The way in which we will know whether or not we are practicing strategic thinking is when self-determination truly takes hold. Many organizations claim that they provide quality services, do quality service evaluation and say, "Our people like it here". This obviously begs the rhetorical question, "What do your people know?"

With the advent of the Medicaid Waiver and self-determination, the universe has changed. I have seen on more than one occasion that when person-centered planning is coupled with the development of an individual budget, people finally have the power to make decisions that influence the lives of those around them and not just change their own.

What does it say, if an agency believes that it provides quality services but the individual who now has control of his/her budget chooses something other than the agency-offered services? Recently, I saw an example of an agency that provided a wide array of services: sheltered employment, supported employment, transportation, residential facilities and supported living.

An individual with a disability had a person-centered plan and developed a budget. Having control of his budget, the individual decided that he no longer wanted to ride the agency's vehicles and wanted somebody other than the agency's supported employment job coach to provide him with support. At the meeting, the agency representatives looked like "deer in the headlights". They were stunned to find out that

now that the individual truly understood that he had a choice, some of the choices no longer involved them. Despite the fact that the individual liked his residential program and wanted to stay with that piece of it, the agency simply could not accept the fact that he didn't want a full service menu anymore, he wanted a la carte.

Agencies that develop strategic thinking and get behind a vision of what this means will be ready to embrace the future. Those that do not will perish.

So how does one practice strategic thinking? Strategic thinking really involves the utilization of three different concepts: values, vision, and mission. These can best be described as the following:

- Our values describe what we believe
- Our vision describes what we want
- Our mission states what we do to get there.

In order for strategic thinking to lead to strategic planning, the first and most important step is stating clearly what we believe. Two examples of this will help illustrate the point. I have recently worked with two different organizations that have two different visions of what they believe. The first organization stated: "We value all people and believe that they should reach their highest potential with the supports needed to do so." The second organization stated, "We believe it is the right of every person to live, work and play in the community". While these statements may not appear to be significantly different, further illustration of what services were developed or are in existence might again help to underscore the difference.

The first organization had a vision that resulted from the stated values that led to the development of a dual system. They continue to operate a large residential facility and, at the same time, run group homes and a few independent apartments. The second organization closed its residential facility and everyone it serves now lives in small settings in the community. Each ended up fulfilling its mission by creating services and supports that embraced its particular values and vision.

If an organization's values, vision and mission allow it to do anything it wants, it is basically worthless. There needs to be a clear, definitive, unique statement of values with a corresponding vision that challenges the organization to have a clear mission statement. Often these discussions are clouded in phrases involving "choice", "something for everyone", "respecting the needs of many", "not wanting to take sides," etc.

If these statements go unchallenged and organizations ultimately are able to state values in fuzzy terms and attempt to be all things to all people, they will fail. With budget cutbacks, evolving technologies and changing times, what previously was accepted is now being severely challenged.

In a recent discussion, I laid out a framework regarding the use of the word, "all". I mentioned that following the Preamble, the Declaration of Independence states: ". . . All men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness."

I found it interesting that our founding fathers did not just say that some were created equal, but rather “all” were. In addition, we are guaranteed life and liberty as outcomes but only the pursuit of happiness as a process.

I am reminded of statements that I have previously made and been challenged about regarding the use of the word, “all”. I might have said something like, “I believe that all individuals should be given the opportunity for integrated work”, “I believe that all children have a right to be educated in an inclusive environment with typical peers”, or, “all people with disabilities can live in the community with proper supports”. Often the challenges come back to me in the form of questions, “Do you really believe that everyone is going to get and keep a job?” “Do you really believe that all children are going to make it in regular schools?” “Do you really believe that everyone is going to succeed in the community?”

People are often startled when I give them the answer, “No, I don’t believe everyone is going to make it.” Then, in some cases, playing a game of “gotcha”, the person will say, “See, I told you, not everyone is going to make it.” My response is simple, “I don’t believe that everyone is going to make it. I just don’t know who is and who isn’t.” If we state upfront that a person is not capable of working, then he/she won’t be. If we state that this child is not going to make it in a regular classroom, he/she probably won’t. If we state that this person cannot live in the community, he/she probably won’t either.

There will always be people who make it and who don’t in our society. Strategic thinking involves the development of a concept of values, vision and mission that allows for maximum success and yet realizes the human condition. What is the worst thing that will happen if we use the word, “all,” in strategic thinking - that some won’t make it? That some will take longer? That people will not always like what we offer?

This reminds me of the discussion about the good old days. The only thing I am finding truer and truer the longer I am involved in this field is the use of the word, “old”. I’m not sure how good those days were. **We must challenge the notion that just because we’ve done something for a long time, it’s the right thing to continue to do.**

The greatest legacy that we can leave as a result of our work or involvement is not necessarily seen in our lifetime. If we have planted seeds, offered opportunities and set the stage, then we have contributed to life worth living. People with disabilities deserve no less.