

Change is in the Air: Beyond Programs – A Parable

Revised and edited from an original work by Michael McCarthy

No Power can take away the yearning for self-determination, because it is a part of human nature. – Paul TP Wong

In the beginning, there were placements, and lo we were happy for placements were not mandated for adults who happened to experience severe disabilities, and so, we said, this is good. And placements multiplied and filled our communities.

And then, we said, let us call these persons "clients" and make programs, which focus on serving their needs. And "clients" were defined and labeled, and grouped according to their labels and assigned to programs based on their labels.

And the professionals created services for each label, and state agencies developed unit costs for each service. And programs prospered and multiplied, and we said, this is very good. And many of the professionals began to earn a fine living in the rendering of service to their "clients." And programs multiplied, and we said, this is very, very good.

And as programs continued to multiply, a cry arose: "Let us evaluate our programs to see how good they really are." And program evaluation systems, state regulations, quality assurance committees, compliance plans, and other program measures were created. And they multiplied and filled volumes.

And in those times, a prophet arose who was also a "client", and said to us:

- "I don't want to be a "client," I want to be a person.
- I don't want a label, I want a name.
- I don't want services, I want support and help.
- I don't want a residential placement. I want a home.
- I don't want a day program. I want work that is meaningful and productive.
- I don't want to be "programmed" my whole life; I don't want to be controlled. I want freedom.
- I want to learn to do the things that I like, and to go places I want, when I want.
- I want to have fun and to enjoy life.
- I want to have friends.
- I want to love and be loved.
- I want a family.
- I want to contribute.
- I want to live where I want and with whom I want.
- I want the same opportunities as all of you.
- I want to be happy
- I want freedom."

And there was a long silence.

And lo, we realized that we must look beyond our programs, our regulations and our labels. But we were deeply troubled, and asked: "What have we done? How can we do what the Prophet asks? Would not each person need their own unique program and system of support based on his own individual measure of its quality?"

And the prophet replied: "Even as you say, so should it be done - just as you have done for yourselves."