AUTHENTIC TRANSFORMATION OR JUST ANOTHER PROGRAM?

by Pat Fratangelo

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Pat Fratangelo is the CEO of Onondaga Community Living (OCL) in New York. In 1991 OCL took the initiative to authentically transform its services from traditional group based day programs and group homes to personalised supports which assist each person with an intellectual disability to live in their own home, find a job or pursue their interests in the community. OCL now provides supports that are uniquely tailored and relevant to each person's needs and desires in the community. In this paper Pat describes some of the key learnings that have stemmed from their journey to create change that really mattered to people.

Many organisations these days are often being pushed by their governments to "transform" their services. Governments come up with regulations, program types and terminology to follow. Person Centered Plans, personalised services, valued outcomes, choice and many other catchy phrases are now a set of buzz words. Agencies say that each person has a person centered plan and now label their planning process as such. Agencies say that people want, and are happy with the services they are in. New people now get to choose between two different vacancies that are available. These outcomes become terminology for a plan and may have nothing of true value or even understanding to the person. And all of this gets further reduced to the acronyms of PCP, VO and on and on.

SO THE BIG QUESTION IS, WHAT IS TRUE AGENCY TRANSFORMATION?

I met with an organisation the other day at a mixer and the staff had all mastered the new terminology and were very excited. They were very proud about telling me about their person centered work and that each person has a person centered plan. They discussed the right funding streams and were very proud of their new found knowledge, but when we really began talking about what services they offer, it became apparent that they were an agency which delivered traditional day supports and group homes. Words or true change?

I have also met with an organisation that told me that the board decided to close one of the group homes and they were moving people out to apartments. Board decision or decision of the people?

I met a third organisation that said they were waiting for someone to be referred that wanted a personalised service. They went on to tell me that all the people currently served in the day programs and group homes were happy with what they had. Therefore they were waiting to find a new person that did not opt for some program they already had. Are people truly happy or just not offered other choices or opportunities?

Has an agency truly transformed or have they just changed their terminology? Are they really offering choice or just protecting the programs they have already developed? Are they picking up on a new program without understanding the implications? These are hard dilemmas that each agency needs to tackle.

SILOS OF CHOICE OR AUTHENTIC CHOICE

It is often hard to think beyond the program types that have operated for years. It is also hard for agencies not to go after funding for a new program when it becomes available. It is always awkward when a person referred to you does not fit the program type that you are offering and needs a different level of support. These are agency decisions that need to be made regularly. When we think of program type, we are generally thinking of the masses, not individual need.

When meeting with a group of Commissioners for New York (NY) State Government in the past, we talked about this very issue. But as they contemplated the dilemma of focusing on a person versus a program, a light went off when one person stated - *'But if we looked at personal needs, they may not fit into the "silos" we have established!"*

That simple realisation is the beginning of making potential transformation. For example, you can go to McDonalds and get their quarter pounder cheese burger meal that is a stamped copy of everyone else's or you can go to the local café and get the cheese burger on a wheat roll with mushrooms, avocado, swiss cheese and roasted red peppers. McDonalds, being the silo, could not give you what you asked for. And if you only know a silo service, you may not know that other possibilities exist.

Organisational change begins when people work together to assess beyond what the preconceived silos, services and programs are.

IMPLICATIONS OF ASSESSMENT

At another meeting with the NY State Commissioners, who are charged with changing the NY state system of supports, the whole issue of assessments came up. Every department in NY State has an assessment that they were very proud of. The assessment tool examines the person's fit into the system

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of services that has been developed. Most assessments assess a person for eligibility in an already established program, based on staffing and budgets constraints. With this said, this means that if you are assessed to not fit the service in the system, you may not get the support. But, once again, when this group was challenged, an awareness slowly began to occur. *"If we assess a person's needs, then our program may not fit their needs, and we might need to change what we do."*

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LEARNING TO ASK QUESTIONS DIFFERENTLY

Over many years the system has provided programs and service types based on a particular diagnosis or grouping. People have become familiar with what services and supports the system has to offer. The system has taught the clientele well! In fact, when I have spoken to new people that have been referred, they would often tell me that their son or daughter needs a certain "program". It is easy as a provider to fall back into the trap

of assuming we are meeting the needs of a person or family if we provide the "program" that is requested. We can be lured into thinking that this is the person's choice when the reality is they simply may not know what is possible.

As you begin to move away for relying on preconceived notions and predetermined

needs. By building around what the person already has or looks forward to having, you are bringing in family, friends and neighborhood connections that are meaningful, life enhancing and will ultimately make your job as a service provider easier and much more cost effective.

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programs or answers, you can begin to open your conversation to more typical questions. For example:

- *What connections with people, places and situations does the person already have, or want to have?*

- *Where are those connections and who are they with?*

- *What social and community connections does the person have or would like to have?*

- *What neighborhood makes sense?*

- *What does the person look forward to doing or having?*

CHALLENGING OURSELVES BEYOND LIMITED CHOICE

Many agencies provide a rationale for programs as they feel that people like their support and that the program type works. But the real question is what did the person have the opportunity to choose from? Is choice really when option A or B is offered? Some may say yes, but life has many more choices than people with disabilities are typically offered. We as professionals, fall into the trap of thinking we offer choice and that people are happy, when in fact they know nothing else. Our job with transformation is to open our

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- *What support does the person have now and where is additional support needed?*

- *What has not worked in a person's life? What should we never do?*

- *What are the person's vulnerable areas? What are we afraid of? What do we need to protect?*

- *What is the plan on what the person wants to learn.*

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eyes so that we can help others to see beyond what they are used to and have been given or offered in the past. The test will be when people begin to choose supports in life that goes beyond what you have to offer and you then challenge yourself to make it happen.

As I think through our early stages of agency transformation, as we began to ask questions differently, new stories emerged and it was the people who we support that taught us how to change and readapt our system of support to meet their personal needs. It was an exciting

time as we each challenged ourselves out of the comfort of agency service to shared support with the community.

TO FILL OR NOT TO FILL? MOVING BEYOND VACANCY MANAGEMENT

A huge consideration with agency transformation is what to do about vacancies in the service when, for example one person moves out of a group home into a place of their own. From our experience, it is one of the toughest decisions an agency needs to make.

When people at our agency worked with us to design a different support that would enable each person to leave the group home, we were forced to deal with vacancies. It was a very difficult decision as there were other people who could have moved in. But the bigger question was - Do our vacancies really meet what people want and need?

This was a decision that tore through our agency as the Board and staff were divided. Many felt that there was merit in keeping the program and filling the vacancies. Others felt that the program could never meet each of the needs of people within it and needed so it should be closed.

We brought consultants in to brainstorm these issues and to try and resolve them. We utilised consultants with sound ethical values, as this was, in fact, an ethical dilemma. We were set up to run a system of programs and this was now being challenged, due to our new knowledge and success with individuals who asked for personalised supports and services. A decision was made to individualise all supports and rid ourselves of the group arrangement. A decision which had supporters and opponents. As a result we lost both staff and Board members who felt the decision was wrong. However, the people left were people who

steadfastly believed that we needed to commit to personalised supports and no longer have predetermined programs available. We gained clarity of vision, purpose and momentum.

MOVING FROM AGENCY CONTROL TO OWNERSHIP

Another dilemma was ownership. Were the

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new homes to be the agency's property or people's homes? A decision was made to separate housing from services and keep each home in the name of each person who would have legal responsibility for it. People now signed leases, had mortgages, or houses in trust for them, not the agency. Each person now had their own budget for both housing and staff support. Each person also had social and vocational lives in the community of their choice in the neighborhood, not in an agency program.

The mindset moved from agency control and property, to enabling the person to have power and control over his or her life with a Circle of Support who could help them attain it.

HOW ORGANISATIONAL TRANSFORMATION CAN IMPACT ON A PERSON'S LIFE

I need to share a story with you about Michael who was referred to us as a "challenge". Michael was repeatedly thrown out of group programs due to violent behavior. He was put into the local institution which also failed. He then went to a Forensic Center in another community. He spent his days in a locked ward in an institution with no hope of a better life. He was restrained, medicated and his rights were taken away.

As we were closing the first group home, the

area Director of Disabilities was one person who wanted the program kept open. He wanted vacancies for people coming out of the institution. As an agency we could have filled the vacancies as people moved out and we would have been paid significantly for this but we had learnt that people did not like living in a group. So why would we look for another person or set of people to put into a system that we no longer saw as beneficial to people? Organisational transformation brings many challenges. Which way you go strengthens the organisation one way or another, with past securities and limitations or new endeavors.

The Director of Disabilities referred Michael to our agency, a man who challenged the system,

One of his circle members found Michael a job at a grocery store where she had a connection. This logically informed us which neighborhood he would reside in. An apartment was found

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broke the law, was known to be dangerous and the only way the system saw to support him was in a locked ward. We offered to provide Michael with personalised support.

After much listening and planning we learnt about Michael's reactions to systems that did not work for him. We developed a list of things to never do and a list of what brought out the best in him. We spent a lot of time looking at what made him fail and how to put in effective safeguards. There was no sense

within walking distance of his job. We looked for two sturdy men to share Michael's home. He moved in with these two housemates and also had staff support. We met weekly to talk about life, irritations and successes.

That was 1992. In 2014 Michael still lives in the neighborhood where he works. He has celebrated 20 years of employment at the grocery store. He has also celebrated over 20 years of sharing his home and life with Richard, a friend and unpaid housemate.

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repeating history. Michael wanted to come back to his home community. He wanted to be successful. We needed to find a way to support him to be the successful man he wanted to be. We needed to be successful if he were to be successful.

We have decreased staffing from two full time live in people, to one unpaid housemate with 15 hours of staff support. Michael has not been arrested, no longer is fighting a system or seen as a threat to the community or a "behavioral problem" to the system. He is known by his

neighbors, has a social life, works out, loves the NY Yankees and plays some pool. He is accepted as a true employee and co-worker at the grocery store. He is happy and well-connected and no longer a ward of institutional care!

those who come to them for support and can withstand the challenges of change.

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TRANSFORMATION REQUIRES DRAWING A LINE IN THE SAND

An organisation will often hit some hard ethical and programmatic dilemmas as it begins to learn about different or more successful ways of providing supports. You will hit numerous dilemmas which require drawing lines in the sand to see where your ethics and values truly lie. The system will challenge you. People's behaviors will challenge you. Families will challenge you. The list goes on and on. Although many of these bumps in the road are difficult, they are important steps as an organisation moves ahead. Any one decision can make or break what you stand for.

These dilemmas are challenging and will work to further embed the philosophy that an organisation chooses to work within. If you move towards true organisational transformation, your original philosophies about service delivery will be challenged again and again and ultimately will change.

It is not so much the words, it is the values behind the service and what you believe is possible that creates authentic transformation. Transformation occurs when people are listened to, see greater possibilities and their lives change. Transformation is not for the faint of heart, but it is for those who are willing to challenge themselves for the betterment of

FOR MORE INFORMATION

Visit: Onondga Community Living's web site: www.oclinc.org

Email: Pat Fratangelo: patfrat@oclinc.org

Read: Various papers on OCL's web site

One Person at a Time: How One Agency Changed from Group to Individualized Services for People with Disabilities. Patricia Fratangelo, Marjorie Olney, Sue Lehr

Watch: Pat Fratangelo's presentations "Home is Where the Heart Is" and "What Does it take to Create Organisational Change" by becoming a member of Belonging Matters or purchase the DVDs in the Belonging Matters' online shop.

Go to www.belongingmatters.org

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