

CONNECTING PEOPLE TO VALUED COMMUNITY LIVES CONNECTING PEOPLE TO VALUED COMMUNITY LIVES CONNECTING PEOPLE TO VALUED COMMUNITY LIVES

BELONGING MATTERS

*Transforming Lives
and Services*

THINKING ABOUT ...



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BELONGING MATTERS BELIEVES THAT ALL PEOPLE SHOULD HAVE THE OPPORTUNITY TO PURSUE A UNIQUE LIFESTYLE THAT IS PERSONALLY MEANINGFUL, RELEVANT AND TYPICALLY INTERTWINED IN THE COMMUNITY.

CHANGING LIVES, YES WE CAN!

by Mary Kealy

Mary Kealy has just retired as CEO of Brothers of Charity, Clare, in the West of Ireland. During the past ten years she led a radical change in how support is provided to people. The agency's focus changed from supporting people in segregated group settings to supporting each individual to pursue opportunities and supports enabling them to live a 'real life in a real place' - embedded in community and meaningful relationships.

This paper is an edited version of Mary's key note address at the 2013 *Belonging Matters' "One Person at a Time Conference: What Could Be"*, in Melbourne



I began my career as an Occupational Therapist in 1976 with the Brothers of Charity (BOC) Services in the West of Ireland and remained with the organisation until my recent retirement. For the latter 14 years I was employed as the Chief Executive with the Services in Co Clare.

Having experienced frequent childhood illness at a time when conservative bed treatment was the norm, my early years, until I was about 10 years of age, were spent mainly in bed with little or no schooling but lots of time to dream about someday having 'an ordinary life'. Therefore when I came to work with people with an Intellectual Disability at the BOC, I immediately felt a special bond with the individuals who were supported there. They slept in dormitories in a large house and spent their days working on the farm or in a sheltered workshop. They did not receive any money for their work. It seemed strange to me at the time that they lived in such unusual circumstances. Unfortunately over time I regarded it as ordinary.

When I reflect on how things were in 1976, it becomes clear that we have moved on in many ways during this time. The extensive developments I have seen have been beneficial and welcome and it is significant that people with a disability are increasingly seen as distinct persons endowed with

many gifts and talents, capable of making many contributions to community and are now increasingly afforded their rightful place to belong in everyday places in their communities.

My first role in the services was to care for 12 adults who had the greatest level of disability in the services at the time, in a small room in the basement of the residential house. One long table, thirteen chairs, a kettle, cups and a radio. That was it! There was little money, no telephone, computers, internet, library or supervision. All we all had to draw on were our own resources to pass the time. I found a piano accordion along with a couple of other instruments and we started a band. Quite a few people in the group were very musical and we put on a few shows. I wanted to make a difference to their lives although I really had no idea how.

As time went on, people moved to live in houses on the campus, then on to community group homes while they spent their days in sheltered work places and training centres.

When I was appointed Chief Executive to the Clare Services in 1999, I was told how fortunate I was to take over a service that was 'a green field site' with no institutions and was completely integrated with the community. I was in for a shock!

The first thing I did in my new role was to get

to know everyone and find out if they wanted me to do anything to make life better. Almost without exception I was told by people that they were lonely, often didn't like the people they lived with, sometimes didn't get on with their staff, had no privacy, couldn't stand the noise in the group home or workshop, were bored and most people wanted friends and a real job with real money. The services in Clare at the time supported individuals to live in approximately 20 group homes (approx 5 in each) and around 110 people were working in sheltered workshops manufacturing special clothing, altar breads, growing plants and participating in arts and crafts. The maximum earnings of a small number of people was 10 euro per week while many had no earnings at all.

The reality on the ground was that those being supported did not have good lives and the service had many, many institutions. Meanwhile there was pressure from families and others for similar services to be provided in other areas of Clare, in particular Shannon and East Clare.

I recall one mother from East Clare phoning me. She said "My daughter is 11 years of age and in 7 years she will need a group home and day centre here. I responded "People here are not happy with what we have been providing. We want to do things differently, but right now I have no idea what that will look like." I promised to get back to her.

THE START OF A NEW BEGINNING

Sometimes the greatest challenge is to actually

begin! We held a conference for all the people we supported and we asked them to tell us what they wanted us to do and how we could

"Sometimes the greatest challenge is to actually begin!"

support them to enjoy the good things in life. We committed to write down and publish their wish list and this would then become our mandate. It is interesting to note that the first request from those we supported was "We want you to accept we do not want to live in Group Homes". This was long before the notion of individualised supports had reached Ireland.

A VISION TO GUIDE US

From this we developed our vision which we undertook to hold in our hearts and in our minds and would inform our every action.

'Love and respect for all towards a full and valued life'

By love I mean relationships but we realised that while we personally couldn't take on the task of loving everyone, it was beholden to us to begin to support people to form relationships and to be far more connected with their family. Our duty was to never again take people away from where they were loved.

Respect is to look again at the person. If you break down the word respect, 're' means again, 'spect' means to look. Sadly, in congregated

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settings we develop strong perceptions of people, often unconsciously, and see disability first, last and always. We now made a commitment to look again and really discover the unique person and their gifts and talents.

We had been clearly told that people were not experiencing a full and valued life in 'serviceland' and so we had to step out into the community and begin to work intentionally to support people to live in a 'real place'.

ROBUST RECRUITMENT

At this point on our journey we acknowledged that many staff had a medical background and that we were not necessarily the best people to get out there and make things happen in community. So rather than follow the route we had previously taken in other geographical

"She had never really wanted her daughter to attend a workshop or live in a group home but she never dreamt it could be otherwise."

areas, which was to build a day centre and a couple of group homes and then inform people on the waiting list for that region that they 'had a place', we would try something different.

We placed advertisements in the local newspapers in East Clare and Shannon that we were looking to employ highly motivated, 'can do', people who had a proven track record in developing community capacity who would support local people to find work and participate in everything local. We said no experience was necessary in working with people with Intellectual Disability. We found

"Yes, when you get outside the four walls of service and you begin to work in real places, you will see the little miracles."

two fabulous people, Martina and Richard who in turn said they would not have usually applied for a job in Disability Services but the advertisement had caught their eye.

Both local communities responded with

enthusiasm and invited us to share offices, resources etc. Things just took off in both areas and we began to find one thing leading to another.

The parent who had originally phoned me, called again to thank me for keeping my promise and said this was exactly what she wished for her daughter. She had never really wanted her daughter to attend a workshop or live in a group home but she never dreamt it could be otherwise. She then offered to assist us as she was on the board of the local community development group whose brief was 'to improve the lives of people locally'. We

were now immersed in the community we had longed for with no special buildings, no special

signs, no special transport etc.

It was only later when I met Michael Kendrick and we began to tell him our story, he reflected "Yes, when you get outside the four walls of service and you begin to work in real places, you will see the little miracles". That is what was happening!

SHARING STORIES

Joe and Brian had attended the large workshop in Ennis (capital town of Co Clare). The local co-op in Scarriff (East Clare) were looking for someone to run a coffee shop at reasonable rent. Joe and Brian decided to give

it a go. They both had part time jobs by now and could job share the coffee shop. They lived

with their families close by.

In the meantime Professor Kelly Johnson from Australia was working with Trinity College for 18 months and offered assist people with intellectual disability in Clare to do inclusive

research on matters that were important to them. Joe and Brian told Kelley they would love to research the coffee shop, to find out how local people felt about it and of its benefits to the community. Kelley supported them to do this and as a result 'Brian and Joe's Coffee Shop' was published. It has since served to be a remarkable record of the business from its early days. As in Brian's words he describes how in the beginning it was not that easy. He said "We started off with a cash box. Then with help I got a grant to buy a till that was easy to use. I found it hard to manage the till and stuff like that. Lots of things I hadn't done before.

Money and the working of it was hard. Print on the till was too small. I contacted the service man

in Ennis myself, and he came out. He printed up bigger stickers. In Joe's words "Writing the cheques was hard because I'd never done it before. I got people in the shop to spell out the words for me... We went to Galway to meet a man from Costa Rica who grows his own coffee. He told us about fair trade, and he showed us some of his coffee. After we met him, we decided to sell "fair trade". Eventually they also begun fund raising nights, musical nights and general interest talks.



So you begin to see what came out of two men

setting up a business. Eventually, at different times both Jo and Brian quit the coffee shop to pursue interesting full time careers and find homes of their own.



"We have fallen out of belonging. To be, we need to be home. When a place to belong is assured, then the adventure of growth can begin with great promise."

John O'Donohue



To quote John O'Donohue, the late writer from Co Clare, "We have fallen out of belonging. To be, we need to be home. When a place to belong is assured, then the adventure of growth can begin with great promise". This was certainly starting to happen for the people we supported.

CHANGING THE WAY WE DID BUSINESS

People's lives were becoming rich, interesting and often exciting in community settings. But

back at the traditional service settings not a lot had changed.

the last person leaves.

“At the time of my retiring, just 2 group homes remained open and they were gradually closing. The large workshop in Ennis also closed when the last person there found a job.”

Over time Michael connected us with those mentioned above and many others. I would like to pay tribute to Michael and all the people who

It was around 2005 that I met Michael Kendrick. He was speaking at a conference in Limerick. At the end of the presentation he said “there are a lot of areas around the world where really good things are happening. If anyone is interested, I can let you know where”. So I went up to him afterwards and he suggested I send him an email.

helped us on the way, because we learned from everyone. It’s a tough journey, stepping into the unknown, so we begged, borrowed and stole every idea we could find to help us from leaders who had been innovative in a valued way. We knew if we waited to figure it out ourselves, we just wouldn’t. Pat Fratangelo says “We never get there”, and that’s true. But definitely you can take short cuts by finding out from others who’ve travelled this road before you.

Several months later Mary Rowan, our Training and Development Manager and I met with Michael while he was in Dublin. We explained we were struggling with what to do next. He advised us to work with ‘one person at a time’ and he mentioned people like Pat Fratangelo, Jeff Strully and so on who had faced similar challenges and had managed to transform

We had a number of staff and family exchanges with organisations internationally which really fast tracked our learning. For instance when we wanted to learn about recruiting ‘housemates’ to share people’s homes to encourage

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affordability and meaningful sharing relationships we organised an exchange with

their agencies to support each person to have ‘a good life’. He also mentioned people like Janet Klees and Deb Rouget. I remember we stood in Grafton Street afterwards and we looked at each other and said “Just imagine, no group homes in the future”. That’s how innocent we were but at last we had begun to fulfil our mandate from the people we supported - “Accept we do not want to live in Group Homes”.

Pat Fratangelo in Syracuse. Brian (home sharing expert) came to Clare for 6 weeks and meanwhile one of our Managers went to Syracuse to learn how to work in this new direction under the mentorship of Pat. We have many examples of this kind.

DRAWING A LINE IN THE SAND

And so, with the strategy of ‘one person at a time’, things also began changing and created momentum for the many others who had lived quite institutionalised lives from an early age. However, we continued to ‘admit’ new people into existing respite, day and residential services which we began to realise

At the time of my retiring, just 2 group homes remained open and they were gradually closing. The large workshop in Ennis also closed when the last person there found a job. Michael had advised us, nothing closes until

was damaging and traumatic for them. We decided at a management meeting one day to ‘Draw a line in the Sand’ and made a decision from there to not bring anyone else into a congregated,

segregated setting. Easier said than done! We faced a difficult time for a while. For example our funders withdrew funding for two brothers who were sharing a home together because they had not gone to live in a group setting! It required much courage at this time but eventually as the evidence began to show that people’s lives were getting better the funders came around. Our funders then began referring people to us who were residing in mental health institutions or in units with high security. While initially they wanted us to ‘find a bed for a person immediately’, we explained that we had to get to know a person really well first and gradually support them to find

a ‘home of their own’ which they then could move into. The funder’s reluctance to do this was

overcome as they saw over time that not one person was ever readmitted to these long stay services again.

BEING CLEAR ABOUT OUR VALUES AND PRINCIPLES

Michael Kendrick recommended that we undertake training in Social Role Valorization (SRV) and had given us an introduction to this when he ran a number of Optimal Individual Service Design Courses (OISD). Janet Klees

who had co-presented with Michael during an OISD recommended that we needed to have

“By using the toolkit of SRV we became clear on our values and paid attention to bending over backwards to support each person to enjoy a real life in a real place in a valued way.”

SRV around the kitchen table. In other words that through supporting people to attain and maintain valued social roles they would begin to have access to the good things in life. By using the toolkit of SRV we became clear on our values and paid attention to bending over backwards to support each person to enjoy a real life in a real place in a valued way. We designed a training programme for everyone who was to become involved with us, including families so that people were clear about our values i.e. no one was to be supported in a congregated setting. This training became mandatory for all staff.

“So as families became more involved with their loved one’s life, the quality of people’s lives improved significantly, and the impossible became probable.”

DEVELOPING OUR THINKING AROUND FAMILIES

As the importance of relationships was a core value, we needed to respect the natural authority of families and to also encourage their leadership in each of their family member’s lives.

I travelled to Australia as part of the International Leadership Exchange Event in 2009 and Michael again through his mentorship, arranged for me to meet Deb

Rouget and to visit Mamre in Brisbane so that I could begin to understand how we would go about introducing a Family Leadership Series.

me that dramatic change is often possible and that supporting each individual in a valued personal way will pay dividends.

“His gentle eyes were always in love with the unseen.”

John O’Donohue

Remember, the ordinary is the most precious thing in life. It is challenging

Deb introduced me to many family members. I remember saying to her one day “you know Deb, we have been inviting groups of families in for training for years but they hardly ever turn up, or if they do, they don’t come again. I’ve just realised we have been doing the same thing to families that we have been doing to the people we have been supporting. Now I see it is one family at a time.” Deb said “yes, now you are getting there!”

I then spent 2 days in Mamre, a family led organisation and saw that we needed to learn the nuts and bolts of Family Leadership from them. We then arranged for Martina to have a work placement at Mamre for four months. On her return we were fortunate enough to get funding to run our first family leadership programme.

We learnt about the importance of engaging and encouraging the leadership of families - when you love someone, you always bend over backwards to ensure they have the best possible life. So as families became more involved with their loved one’s life, the quality of people’s lives improved significantly, and the impossible became probable.

BEING IN LOVE WITH THE UNSEEN

The opportunities now being afforded to people to develop lifestyles that are immensely more satisfying than what had come before are a credit to the many people I have encountered and worked with in my career. These include families, staff, community, statutory and voluntary agencies and exemplary leaders and service providers both in Ireland and internationally. This has shown

to hold on to this. We must take a paradigm step from providing “services” to people to become “of service” to each person. That is the meaning of true leadership.

To finish with John O’Donohue who paid tribute to his father in his book ‘Benedictus’ “His gentle eyes were always in love with the unseen”.

We too must fall in love with the unseen to give us the courage to make a new beginning.

FOR MORE INFORMATION

Email: Mary Kealy marykealy28@gmail.com

Watch: Mary Kealy’s full presentation “Changing Lives – Yes We Can”; “Workshop or Community”? and “A Vision for 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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