



Home

Home is a central part of your community. At CRU we often speak of belonging to our community, and the ideas of building community and intentional communities, and the L'Arche community is an example of this. Home conjures many different meanings for each of us, and we all need the freedom to explore and express what that meaning is.

I see my home as one of the communities I have created and belong to. I live with my husband and a friend and we have lived together in this arrangement for over 20 years. For half of that time my husband's father has also lived on the same property in a daddy flat. He's not a granny so we can't really call it a granny flat. We share a meal each Sunday evening and have other family members join us.

Home is my sanctuary and a place of security, both physically and emotionally. It is a place to sleep, to practise my spirituality, to store my personal belongings, somewhere to create and share meals with family and friends. It's a place where I feel love and safety and can also freely express my vulnerabilities.

This may be the same for most of us but not all of us. While I have a real sense that my home is contained within a community, so often we see fragmented variations of this connection for people with disabilities. Without connection with others in community, what keeps people safe?

We have seen most recently that for people with disabilities even an ordinary house can become an institution - a place that becomes their everything, yet is completely outside their control. Services effectively taking over their home, and sending strangers in to provide support.

As a sister, I have recently supported my sister to reclaim her home. She is supported to live in her home, a private rental townhouse, each day and evening. She lived for many years with her best friend and together they shared their lives, as well as morning and evening supports. Her friend moved out recently and it has been an opportunity to reflect on what a home is for my sister and to support her to create that again.

It is the same for her as it is me. A place where she feels safe, can store and enjoy her favourite possessions, and be vulnerable.

She and I are the only people who have a key to her home. She chooses who comes into her home. She does her own shopping, with support, not the other way round. She goes to her bedroom to sleep when she is ready not when the worker's awake shift finishes. These little things that mean so much can be taken away with little thought.

It is our role as supporters to make sure they are not, especially with changing circumstances or unexpected events like COVID-19 which can unintentionally threaten the ordinariness of home.



CRU Board Members 2019-2020

Fletcher Tame	Chair
Josey McMahon	Secretary
Narissa Niesler	Director
Luke O'Sullivan	Director
Gerhard Tromp	Director
Sherryn West	Director

CRU Staff

CEO

Margaret Rodgers

Senior Consultant

Lisa Bridle

Consultants

Lindie Brengman

Catherine Laherty

Danielle Mason

Fiona Moore

Jen Mouritz

Hugh Rose-Miller

Finance Officer

Janene Parsons

Administration Officers

Sonia Brown-Diaz

Kathleen Fleming

Kim Jensen

Mercy Kyosiimye

Kerrie White



Patricia Fratangelo was the Executive Director of Onondaga Community Living in Syracuse, New York until her retirement in 2016. She had worked in the field of developmental disabilities for decades, beginning as a direct care worker. Her book *One Person at a Time: How one agency changed from group to individualised services for people with disabilities* was written with Marjorie Olney and Sue Lehr in 2001. Patricia has written previously for CRUCIAL Times in 2004 on 'Listening Differently'.

This article was first published in *TASH Connections*, vol.32, Issue 9/10, September/October (2006), Pages 7 to 8.

Sharing Lives

"All men are caught in an inescapable network of mutuality, tied in a single garment of destiny. What ever affects one directly affects all indirectly. I can never be what I ought to be until you are what you ought to be, and you can never be what you ought to be until I am what I ought to be."

Martin Luther King

Living and sharing life together is part of what makes each of us whole. Learning from, and taking care of another person through the triumphs and struggles of life is part of what helps to bind us together as we grow in relationships with one another. Life sharing is a term that is arising in our field and it is time to now begin to realise what this can mean for a person with a disability. People with disabilities have typically not had the opportunity to choose their home or lifestyle and often times have been placed into a living arrangement with other people who they do not know, nor do they care to live with. The system has traditionally offered only what was available, with little or no opportunity for another type of arrangement that is out of the norm.

As we begin to listen differently to what people actually want, we find that often times those coming for services do not want what has been normally offered. People are beginning to ask more and more for ordinary and regular lives in partnership with other community members. It is not that the person miraculously needs less support and that the human service system is not necessary, the support just needs to be delivered in a very different manner, more creatively with community citizens in partnership in integral roles with those you are paid to support. It is this combination of supports and services that will enable the person to live more effectively and contently in the long haul.

This necessity of becoming a learner as well as a teacher has enabled the life sharing partners to grow together.

Several years ago I was planning for a man who was not happy with his current life. He was living with a group of people that he called 'sick' and he was supported by 24 hour staffing that he did not like.

As we began to plan with him more deeply, we knew that what we were currently providing for him was not working. We needed to find another way. What we learned from him is that he did much better when he was with typical community people and that he had no desire to live with any person who he deemed to be 'sick'. Because he was so distraught living within the group setting, staff often times needed to intervene, setting him up to be at odds with staff. As we began to walk further down this path of understanding, it was clear that he would need a lot of support but that it needed to be delivered in an entirely different manner. He wanted a more normal and ordinary life. He wanted to share his home and his life with people that he valued and who would value him in return. He wanted to be seen as a regular guy, to live with a regular guy and to do the things that regular guys do. He wanted what each of us wants. He deserved to live a gratifying life co-connected with others who he could share in mutual enjoyment with. We needed to open our minds and our hearts to another way of providing support to him. This led us down a different path as we began to recognise community people that he valued as regular guys who could enter into honest and valued relationships with this man.

The more we see those with disabilities as dissimilar from those in society, the farther away their service and lifestyle will be from that of the general population.

What this man was teaching us was that there are many unique ways of providing services. He was pushing us towards a new path for how services could be delivered, helping us to realise our weakness; the facilitation of connections of the people we serve with typical community members in honest and productive relationships based upon each of their personal interests and aspirations. We were also caught up in delivering only what we had available and not necessarily what someone needed. He was helping us to fully realise the deep fundamental needs that were being neglected in the service delivery of the past, the profound importance of honest and fulfilling relationships between people. Our new focus was how to support a person to join in partnership with members from his or her community in honest and valuing ways.

The first of the essential tenets that we all must believe in, is that every person we support has an inner spirit core, although it may have never been recognised previously, it lies within. It is the task of each of us to discover what that inner core is all about and where that contribution may lie, even if it is not readily apparent. If we are successful with this then we will see the beauty of each person, allowing us to assist them in finding others who can enjoy that exquisiteness while working to nurture and enhance the magnificence that the person shares.

As we continued down the path of learning more about this man, we found many interests that he had while growing up, that were now lost with

his life within the system. We also realised more and more the importance of many of these experiences for this man. He truly valued working men and saw himself as a working man, not a client of the system. Although people say he cannot read, he could identify all construction trucks by company names. We knew he would not succeed in another traditionally staffed arrangement, so we looked to the community to find a man out there who could share this man's love of work and construction. Our goal was to look for a man who could enter into a potential life sharing role, sharing this man's dreams, his home and his life in a meaningful way. Such a man was found and they have been sharing their lives together now for over 12 years.

As I look back on the many people who have entered into the life sharing role with a person with a disability, I have found that they originally saw themselves as a teacher. Various people have entered into this role believing that they could give something to a person. They could teach, they could support, and they could model. But as they take on the role of a true life sharing companion, living life day to day alongside of someone (who was at first seen to be the person in need) they begin to realise that as a life sharing companion they are also being taught. They are being taught about their own humanity and their own humility; their personal failings and inhibitions, their capacities and weaknesses. As people grow in this role as a sharer of life and all that comes with it, they begin to realise the depth of the experience that they entered into. This necessity of becoming a learner as well as a teacher has enabled the life sharing partners to grow together. I have spoken with many of the community people, who have entered into life sharing roles with someone with a disability, and it seems when they meet with this awareness then life becomes more settled. The inner development of both people is now the work, as together they continue to share their lives with one another. No one is the burden to the other. I have seen this deep personal attachment; mutual growth and awareness go on between people for years upon years as they surmount the triumphs and struggles that each new day gives to them.

"The healthy social life is found when in the mirror of each human soul the whole community finds its reflection and when in the community the strength of each one is living."

Rudolf Steiner

A critical tenet to enable those with and without disabilities to share life and enter into honest and caring relationships with one another is that the service system must allow the creation of conditions that permit such meaningful and important relationships to unfold. The more we see those with disabilities as dissimilar from those in society, the farther away their service and lifestyle will be from that of the general population. It is when we begin to understand fundamentally the needs of all people to be in valued, honest and ordinary relationships with others that the possibility of community members sharing life in straightforward and personally rewarding ways will occur. We must give up the mindset of the service system being all knowledgeable and the inimitable protector over people who are deemed to be different. We need to listen more carefully to those who come

She realises now that her perceived role as this woman's protector and teacher has changed, as she learns more and more each day with the person she thought could not teach her in return

to us for support and we need to support them in becoming involved in valued and honoured roles with others. We need to support the development of ordinary relationships between those with and without disabilities. We need to recognise the growing relationships for what they are, friends and companions and not lump them into a human service category. If we can begin to do this, we will begin to experience the wonder and excitement of people who are choosing to share their lives with one another in some very honest and real ways.

I was talking with a woman who is the non disabled housemate to someone that we support. She lives there freely as a companion and friend and is not in any paid or volunteer role. These two women have lived together over the last few years. Her housemate had been institutionalised and always supported through the system in very traditional services. Although her housemate is classified as severely intellectually disabled, this woman has come to know her as a very intelligent peer. They have a wonderful home and work together to share the responsibilities of not only their home but also their interdependent lives. As I was on the phone with her the other day, I realised that her role had shifted from teacher to learner. She tells me of the times they share in the gardening that they do and how much they both enjoy it. She also shared with me the times that they have had in growing together through times of struggle. She realises now that her perceived role as this woman's protector and teacher has changed, as she learns more and more each day with the person she thought could not teach her in return. As she has gotten to know her life sharing partner more fully she has learned much about her own self along the way. She remarked that she felt she was a part of such a wonderful arrangement, that her housemate was

Sharing a life with someone you value and respect should not be by chance or luck, it should be the norm.

such a lovely person and that she felt so fortunate to have been brought together.

Stories like these should not be the exception. We had a state official come to visit us recently and she met these two particular women. When this state official came back to talk with me she said, 'She is a very lucky woman.' Sharing a life with someone you value and respect should not be by chance or luck, it should be the norm. Just because you have a disability does not mean that you do not aspire to all the ordinary lifestyles and experiences that each of us take for granted. How did we get so far from normal and ordinary lives and relationships for people with disabilities?

We need to look at the changing role of the human service system as we begin to facilitate and support more honest and valued roles between the people we are paid to support and common community citizens. It is all very possible, we just need to change our mindsets and our hearts, and find the inner core of each person that we support.



Jo and Justin answered the question themselves of who would share Jo's home.