
CRUCIAL TIMES

Community Resource Unit Inc.
Suite 5B, 19 Lang Parade
Auchenflower Brisbane Q 4066

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Ph: (07) 3870 1022 Fax: (07) 3371 3842
Email: cru@cru.org.au

CRU invites and encourages you to attend the conference 'Gathering the Wisdom' in Brisbane on 10, 11 & 12 April this year. The conference will focus on the community living movement – on the ideas and actions that have been taking place since the early 1970s, but which have slowed in momentum in recent years.

editorial

Across time and across issues, dissatisfaction about the way things are has led people to imagine better things, to find like-minded others, and to find alternative ways of doing things. In the lives of people with disabilities and families, there is increasing dissatisfaction with progress in terms of people achieving ordinary lives, in homes of their choosing, in customary lifestyles, regular education, employment and recreation.

The community living movement has fought against notions of the non-humanness and the other-ness of people with disabilities. We have fought hard against beliefs that people with disabilities are sick, and that they need to be fixed. There has been a long struggle against the entrenched belief that professionals always know the answers, that people with disabilities need to be with 'their own kind' and cannot have lives like other people in the general community.

Did the community living movement miss the mark? Were we fighting so hard for the closure of institutions that we failed to see that a dominance by services in people's lives would not be as enabling as we had hoped? Were we sleeping while market and business paradigms overtook the government and community sectors? Did we stand by while our government and service system began an enduring love affair with the idea that people with disabilities and

families are mere commodities? Where was our astonishment as they became wedded to content-free management, to assessments, models, regulations, and to a set menu of service types?

Did we fail to see that what was actually happening was a situation where communities, and the individuals in them, were becoming *managed*? Consultations and opportunities for influencing the course of the future have become forums for sanctioning those things that have already been decided by those with the power. Mechanisms that could be expected to allow greater levels of authority by individuals in their own lives, such as individualised funding and individual planning processes, have instead become the tools of standardisation. The impact of all this on individuals and families is that there is an increasing sense of powerlessness, and a sense of frustration that the future holds more of the same. The service system grinds ever onwards, growing at a rapid rate, becoming increasingly more complex, and more powerful than the ordinary citizens who just want a decent life, and help to get it. The service system works in ways that have become an exercise of power and control in the name of supporting people to live in the community.

Communities cannot thrive under mechanisms that impose restrictions and limited ideas. 'Managing community' could be contrasted with

CRU's MISSION STATEMENT

- To challenge ideas and practices which limit the lives of people with disabilities.
- To inspire and encourage individuals and organisations to pursue better lives for people with disabilities.

policies and strategies that encourage ideas, nurture individuals, families and collectives to have high levels of control over their own lives, and allow supports and services to be truly helpful.

A movement for change, such as the community living movement, consists of a network of relationships, ideas about what is important, and sets of actions. These actions do not need to be in the realm of public rallies, although they could be, but they also include actions which lead to enduring and positive change.

We need consciousness-raising of the kind we have seen in the peace movement, the women's movement, and the environment and indigenous movements. While many people in the disability sector have been engaged in working towards 'good lives' and good ways of supporting people, their ideas and language have been co-opted by government and the service system and used in ways that show low levels of consciousness about what is really needed to support people well.

The community living movement needs investment in ethical leadership, and stronger network relationships. We need to create opportunities for fostering different ways of doing things. We need energy, sophistication, social unrest, and political determination. It may be that what we are now pursuing has moved beyond the ideas underpinning 'the community living movement'. It may be that the movement is still evolving, and that we are yet to name what is now being pursued.

This edition of CRUcial Times brings into sharper consciousness the critical importance of true community living, and the importance of being engaged in a broad, social movement to make this possible for all people with disabilities. The CRU Conference, 'Gathering the Wisdom' will be an opportunity to hear others illuminate these important matters of our time, and of the future. We look forward to your company. ✻

Jane Sherwin



CONTENTS

Editorial	1
A Matter of Life and Death	3
Leadership and Change	4
Actions for Change	6
Being Accepted and Valued	8
The Unravelings	9
The Search for Meaning	10
"Who am I to Impose my Values?"	11

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A MATTER OF LIFE AND DEATH

Kathy Buckler works for change from a range of roles: parent, educator and organisational change consultant. The imperative for change can come from many sources such as a passion for social justice or a vision of a better life. In the Buckler family, there was an even more compelling reason.

When my daughter, Belinda, was nineteen she had a chance meeting with a friend from primary school. That meeting triggered some lifelong changes for Belinda. Hearing from the friend about boyfriends, TAFE classes, nightclubs, and other social activities ultimately led to a hunger strike by Belinda, which lasted for six weeks. The hunger strike was a desperate but clear expression of Belinda's dissatisfaction with her own life. Not eating was the only mechanism that she had for making known her deep dissatisfaction, and it took only two days for me to really start looking at what her message was.

Prior to her hunger strike, Belinda's day ran to a tight schedule, mainly due to my work and the other needs in our family. For example, it was always clear to me that Belinda did not appreciate the need for her to be out of bed early each morning. This was always hard for a person who doesn't *do* mornings. During the early stages of the hunger strike, medical specialists were extremely dubious about my assertions that Belinda was actually controlling her food intake in a purposeful way. I heard them express opinions about people with significant intellectual impairments being unable to make high-level decisions, or of even having the ability to understand the consequences of decisions. However, after a month, these opinions changed to ones where Belinda's intelligence was no longer the issue, and the focus became one of finding solutions that would stop the hunger strike being the sole focus of every day.

The hunger strike ultimately ended when I said to Belinda that I would have to 'let her go': whether to death, through her self imposed starvation; or by doing everything I could to fast-track arrangements for her to move into a home of her own, where she could begin to develop her own lifestyle. I was in great pain and distress when I said this to her. Nothing prepared me for the shock of later hearing that she had eaten lunch after I left the house. This

event, and the six weeks prior to it, reinforced my awe of my daughter's will, and her strong drive to determine her own life. She had even been prepared to die for it.

Within one year, and in time for her twenty-first birthday, Belinda was living in her own home. On her first day there, the full impact of her move didn't seem to register until her father and I said we were leaving to go back home. Apparently, her squeals of happiness lasted for three hours. She appeared to quickly settle into having a team of three people supporting her each day, and this kind of support has continued. Belinda has been supported by people whose ages range from late-teens to fifty-plus, and has been supported by young men as well as young women. She has also been involved in the extended families of some of her supporters and friends, many of whom I do not know.

Belinda has now been in her own home for nine years. She has changed and matured during that time. As Belinda's thirtieth birthday approaches, I know that there have been trials as well as good times in those years, yet Belinda now expresses a serenity and peace that I could never have imagined. This does not mean that I am complacent – far from it. I have learned along the way that whenever things seem to have settled down, an event will occur that will propel all of us to another level of change where we will need to make further improvements in Belinda's life.

Throughout the past nine years, my role and that of Belinda's father has been to strongly support her staff, and to commit to implementing a self-managed team, which includes Belinda in all decision making.

This team has become one that is also self-determining in many ways, with staff members making day-to-day decisions, as well as assisting Belinda with her longer-term goals. They manage Belinda's

Leadership and Change

Lesley Chenoweth has worked as a change consultant, social worker and academic to further the interests of people with disabilities and families, and to encourage personalised, responsive services that support them. In this article, she points out that there are several aspects to leadership that are particularly important for change efforts.

household finances, and interact with personnel at Public Trust, who have responsibility for Belinda's funds. During the past year, Belinda and her staff have recruited new support workers and conducted the orientation process without the direct involvement of her father, a Human Resource Consultant, or myself. The staff have been scrupulous about who they want to see supporting Belinda. Belinda's father and I are now seeing our roles, as well as that of the Human Resource Consultant (who is employed for ten hours per month to oversee support staff and rosters), diminishing as time goes on.

All these changes in Belinda's life have also been life altering for me. I know in my heart that Belinda has been, and will no doubt continue to be, a major catalyst in my life. I also know that Belinda has needed my energy, belief, passion and commitment to make the necessary changes. I think it is true that the most important changes that occur in people's lives are the ones that are the hardest won – and that is certainly the case for Belinda. As the anthropologist, Margaret Mead, might have said on Belinda's behalf: *Never doubt that a small group of thoughtful committed citizens can change the world. Indeed, it is the only thing that ever has.* I hope that this will continue to be the case for Belinda and for those people who are at present in Belinda's life, and for those who will continually come into her life in the future. ✕

Leaders who presume that key values issues have already been resolved may often find that this is not so, particularly as these are tested by events. Equally, a field that is too assured in its assumptions and dogma is already imperiled by the complacency, habits, and lack of mindfulness that these bring. A much better ethic for a human service field that wishes to stay at the cutting-edge would be for its leaders to embrace the familiar saying "comfort the afflicted and afflict the comfortable".

Michael Kendrick

Many of our efforts in achieving good lives for people with disabilities mean that we must deal with change: we have to initiate it, point it in the right direction, survive it, sustain it and, importantly, safeguard it. Change efforts require having enough critical mass of stamina for a long haul even though individual people may need to withdraw for a while to restore energy or attend to pressing personal or family issues. And there are times when a proposed change would have negative implications for people, families or communities. How many change initiatives have been promoted as innovative but a closer analysis has revealed major flaws that would have led to negative or even harmful consequences for vulnerable people? Under these circumstances we need the capacity for discerning flaws and for resisting harmful change. Central to all change efforts, however, is leadership.

One of the leadership challenges is to recognise the different forms that leadership may take. Change efforts need different kinds of leadership that can address the complexities of systems and community. For example, large-scale change occurs over a range of different situations, systems and contexts.

In contrast, some leaders never work in the public arena; they work invisibly, quietly making a difference in the lives of families and vulnerable people. Other leaders make incremental changes over long periods of time. Some leaders work to develop new knowledge or theory that will make a difference, and others work to make opportunities available for innovators. ➤

Most of us carry assumptions about what 'leadership' is. Leadership has become such a gripping subject that it has frightened off many people. Richard Louv, a writer for the San Diego *Tribune*, and author of many books on community life in America, claims that too many of us think that being a leader is a job for someone else; that only celebrities qualify for the position; or that "leaders somehow appear magically – summoned by fate, endowed with charisma, and usually good hair". In many organisations leadership is seen as somehow the same as management. Although good managers need to be good leaders, I would argue that the vast majority of leaders are not managers.

Joseph Rost, an expert on leadership theory, explains that most ideas about leadership reflect the values and assumptions of the industrial model of organising, which dominated the twentieth century. He says that the ideas have been "management oriented, personalistic in focusing only on the leader, goal-achievement-dominated, self-interested and individualistic in outlook, male-oriented [and we would add to that: mostly white], utilitarian and materialistic in ethical perspective, rationalistic, technocratic, linear, quantitative and scientific in language and methodology".

Rost goes on to say that the values and assumptions that leadership needs to reflect upon are "collaboration, common good, global concern, diversity and pluralism in structures and participation, client orientation, civic virtues, freedom of expression in all organizations, critical dialogue, qualitative language and methodologies, substantive justice, and consensus-oriented policy-making process". I think that this describes a more hopeful standpoint. Social movements such as those that strive for a better and fairer world need collaborative and transformative types of leadership. Our understanding of the world is changing rapidly, so searching for alternative approaches to the study of leadership may be in order.

Leadership is often situation specific and this is so for the disability movement. Some people possess great leadership qualities but they haven't been placed in a situation where these qualities can come to the fore. Specific situations can bring out qualities

and different situations require different kinds of capacities, skills and attributes. In a movement for change, there are many situations across different contexts and time, each calling for its own kind of leadership.

It is important for us to understand that leadership itself needs to be developed. Most people will be familiar with the famous story about Rosa Parks, an African American woman who refused to give up her seat at the front of a bus to a white man. This story is often used as an example of the power of one brave act of leadership, which set off bus boycotts and the

civil rights movement in America in the 1950s. Most people assume that, in a moment of indignant resistance, Rosa sat at the front of the bus, which was reserved for whites. What is less well known is that Rosa

was not acting on a whim. She had been involved in social justice activities since high school and had spent twelve years leading the local chapter of a national organisation, and just before her bus sit-down she had attended a ten-day session at a training school for leaders in civil rights. Rosa was not a spontaneous leader; she spent long years preparing for the 'fabled moment'. She had been working at the grass roots and was involved in deliberate leadership development over a long period of time.

For those who have been involved in social movements, there is an acute awareness that efforts for change take a long time, and most of the theory and research on change would argue that slow deliberate change is the most sustainable. This is also true for leadership development in change movements; it takes time. While leadership development opportunities are prolific in the business sector, for example, in the disability sector they are patchy at best. (CRU is one organisation that has provided opportunities for leadership development for at least a decade. The most impactful of these are the formal strategic programs for leadership development that they conduct. These efforts and others like them need to be supported if we are to sustain a movement for positive change into the future.) ➤

in people or groups where leadership is called for,

Actions for Change

Nowdays change is so rapid that it sometimes seems we need to be working for stability rather than for more change. As the world becomes more complex and turbulent, efforts for change become more difficult to implement. Followers are more resistant and perhaps less optimistic, and so this too will call for different kinds of leadership, and we will need to time our change efforts to the situation at hand.

The following are some principles that I have gleaned from other leaders I have been privileged to follow, from reading, from teaching others, and from my own modest efforts at leadership.

- Put people first. At the heart of our movement are people with disabilities and families. It is their lives that are ultimately affected by any efforts we make.
- Make sure the values underpinning the change are ones you agree with. Ask: will this work towards a better life for people with disabilities and families?
- Be flexible in approaches and strategy. We will face a range of situations, some of which are new and unknown. We need to be open to different approaches and try another way if needed. Leadership needs creativity and innovation.
- Sustain optimism even when things are bad. This is key in a movement such as ours. We have faced tough times with despair and it is hard to dust off and keep going. Leadership can help sustain optimism.
- Balance caution with optimism. This is related to the previous point. We need to carefully consider what we do before we act.
- Lead by example. It is no good expecting others to do what we are not prepared to do ourselves.
- Work with others. When we need collaborative leadership, we need many others around us.

Striving to create more inclusive communities will always involve a call for change, and leadership will always play a vital role in bringing about such change.



Brian Martin is chair of the board of *Illawarra Citizen Advocacy* and has been involved with social movements for several decades. In this article he says that individual action, small group actions, and large social movement all play a role in creating a better future – different actions are needed at different times, when change is sought.

Chris has a wonderful life: she has friends, satisfying work, good health, a nice home and an enthusiasm for learning. Her significant intellectual disability does not seem to make much of a difference because of support from friends, employer, health workers and others. That's the way that society might operate — but unfortunately seldom does. In the real world, Chris is more likely to be living in a group home or an institution, lack any meaningful work, to have few or no friends, to be repeatedly let down by 'the system', and to be excluded from the general community.

What can be done to move towards a more inclusive society? The first step is individual action: service workers who care can develop their skills to bring about better results for Chris. Neighbours and others who know about Chris can take the initiative to meet her and to make her part of the community. This happens occasionally, but not often enough. Citizen Advocacy programs are needed because there is not enough spontaneous advocacy by family and friends. As society becomes ever more fragmented, greater efforts are needed to create community bonds.

Individual action is vital, but it often runs up against bureaucratic barriers. The next step is fighting the system. A recent example is one where three citizen advocates made a complaint about the institution where their protégés lived. This led to a formal investigation, and for plans to close the institution. This sort of action happens occasionally, but again, not often enough. Also, it has limits: some systems have the capacity for internal reform, but others are highly resistant to change. People in top positions in many systems often put a higher priority on internal control than on addressing problems. ➤

When a service worker reports a colleague for abuse of clients, or reports the misuse of an organisation's money, that person is likely to suffer harassment, ostracism, threats or even dismissal on trumped-up charges. Blowing the whistle is seldom an effective way to bring about change. Action by individuals and small groups is absolutely vital, but to really make a difference this action needs to be tied to a wider programme of change. When enough people have a vision of an alternative society, and are willing to work towards achieving it, this is called a social movement. Familiar examples would be the feminist movement, the peace movement, and the environmental movement.

Social movements typically have a relatively small number of hard-working core members, a larger group of supporters who may provide financial assistance or join occasional activities, and an even larger group of passive sympathisers. All these layers are necessary for a movement to be effective. A growing movement mobilises sympathisers to become supporters, and for supporters to become activists.

Some movements are reactionary: their goals are oriented to the past, such as a call for a white Australia. Other movements draw their inspiration from imagined futures that go beyond the present or past. A movement for full development and inclusion of all people, regardless of ability, is one such future-directed movement. Some movements, such as the labour movement, are composed primarily of those who stand to benefit from the movement's success. (Note that the labour movement should be distinguished from the Labor Party, just as the green movement is broader than the Green Party. It is quite possible to be in a movement but not in a political party.)

There is a long history of movements that act on behalf of others. For example, the anti-slavery movement was largely made up of free people; and many peace activists are not those who are at personal risk in wars. These

sorts of movements are built on altruism rather than on self-interest. To maximise support for people with disabilities, a movement needs people without disabilities.

A movement helps to harness energy and mobilise participation. Actions can take many forms, from rallies to lobbying, and from door-to-door canvassing to casual conversations. Successful movements will eventually change people's ways of looking at the world. For example, environmentalism has now become taken for granted to the extent that polluting businesses tout their allegedly 'green' policies as a way of promoting themselves in the community.

However, movements are not guaranteed to succeed. The peace movement has a long history of peaks and troughs, with periods of mass mobilisation and then years of relative inaction. One of the dangers to social movements is the bureaucratisation of activism: activists obtain jobs and become part of the system, operating through inside channels and discouraging popular protest.

It's not possible to manufacture a social movement out of nothing, but nonetheless the movement model has much to offer. The first element is a vision of a desirable future – something that will inspire participants. Next is the willingness of a small core of individuals to put in significant amounts of energy promoting the ideal behind the movement. Finally, it is vital to develop a strategy, namely a plausible road between the current reality and the desired future. It might involve reaching out to new potential allies, taking direct action, or producing educational materials. Astute activists will learn from trial and error, all the while keeping an ear to the ground for social trends.

Individual action, small group actions, and large social movement — all can play a role in creating a better future. ❖

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Being Accepted and Valued

Francis Vicary describes herself as someone who is totally reliant on others for eating, dressing and bathing, yet lives in an unmodified unit, by herself, and does not have or want 'twenty-four hour care'. In her early life, Francis was involved in individual action for change, and has more recently been engaged in collective action through membership of various disability groups, including Queensland Disability Network.

What, you might ask, is a 'good life'? The word 'good' is so over-used that it sometimes seems that good could even be bad. For example, imagine that you have a daughter with a disability and, for reasons of hygiene, she never gets to feel dirt or mud, or make a mess. She would be a very hygienic child, but she would never have felt that squelch of mud through her toes or the tickling, sprinkling of rain on her face, or smelt that soft, sweet smell of rain. My parents let me play with mud and even swim in dirty rivers with my sisters. And on washing days, I'd be lowered into the blue-water of our twin-tub machine. I remember this with pleasure. I would be hot and dirty and Mum would lower me into the ever-so-soft, cool, blue water. This is why 'good' is such a contested word. But if this article is not to further muddy the waters, I will explain what I think a 'good life' is.

What we call a 'good life' might be totally unattractive to many other people; and what they might term a good life might not appeal to us at all. Some people's ideas of a good life may even vary greatly from so-called societal norms, but how boring life would be if we were all the same. Each individual has an equal right to pursue his or her idea of a good life. But what if people need help to choose a good life for themselves? If this is so, we need an outline to assist us in defining a good life.

A good life is living in a community where you are accepted and valued. To achieve this, every person needs to be given choice and freedom. Often people with disabilities are accompanied by workers and this can act as a barrier to real community engagement. In contrast to this, during the writing of this article, I had to go out to do the shopping, post mail, see the real estate agent and do some other things. The women at the grocery shop asked how I

was and where I'd been because they had genuinely noticed that I hadn't been around for a few days. The real estate agents were pleased to see me and know me as a good tenant who attends to business. The people at the post office found the parcel I wanted to post in my backpack, got a parcel-pack, wrote the address, noticed that I'd bought a CD, and discussed *R.E.M.* They see me as an independent person. Because they know me, all these people ask where I have been and what I have been doing. Observant acquaintances like these can be the best protection for people who might be vulnerable. But we also know that service providers can inhibit this type of engagement. There should always be a careful assessment about the form of the supports that are offered to a person. If supports are necessary, workers need to be instructed to become 'invisible' so that the person that they are supporting is the one who is given the focus.

A good life for anybody includes a secure place to live, where we can be surrounded by the things and people that we like: a place to enjoy good food, and maybe wine, with friends who like us for who we are. Sometimes friends may even have started out as paid support workers; often the friendship continues long after the person ceases to be a paid worker. Friends from work, play or any part of life, are the ones who stick with us even when life is not so good. The major qualities of a good life are acceptance and inclusion. These qualities are almost always gained through reciprocal relationships. For any of us, the more inclusive and accepting we are, the more favourably we will be received into the community.

A good life also includes change and variances: the opportunity to change direction, place and acquaintances if something is not right. This is highly integral to creating and maintaining a good life. While opportunities for change are taken for granted by most members of the general community they are ignored or negated in the lives of people with disabilities.

In summary, it could be said that a good life does not include the same things for everyone. But a good life does include acceptance, inclusion, and having friends and places where we can feel comfortable and relaxed. It also includes having the opportunity to gain the wisdom and power for making change if things are not working well. ✦

THE UNRAVELLING

The beauty of the beast is there.
But to uncover the reality of that beauty is something that is rare.
For people to understand and accept others totally
Has been a hidden crime of age.
The awakening of people to differences is still evolving.
To see new faces eager and aglow,
But knowing it is yet to come is heartbreaking and burdensome.
But they will know!
In drops of coloured pain,
I feel the emptiness of people,
Drained in time, but stifled with emotions.
The hidden truths of wandering minds,
Explode on stained and shattered pallets.
Revealing tortured creations that have held broken bodies –
To give a peace that reality to combination of futures yet to be perceived.
If only we could see beyond our souls,
Have chosen this unsettled life in remorse.
I have seen the cruelty of others and am blinded by my own needs.
My eyes will open to a new earth, and shame those beside me,
Who do not meld with the totality of being –
To be outside to drift through the silence of our minds.
Pulling threads of gilded moments to be at one.

“To be free is unique”
The soul can not be tied to our lives, it is immortal.
It wanders with the lights in mists our minds seek,
But still it reaches for the path to freedom.
The pitch of depth, is shallow to some.
You feel the closeness of those walls of life,
Spiralling up and out into the lights.
The lights of angels, that have filtered through the web of old souls.
Weathered and worn as they will be,
Bringing the pinnacles to molten fractures.
That plunges into a green darkness, that has been.
I want to escape to freedom.
To see the earth beneath me.
To feel the passages of night.
To reach and touch the edges of the distant stars.
To glow in shed rays of moon.
To smell the distant odours.
To feel the touch of equality and love.
Only that is enough.

Charmaine Clark is an activist, writer and poet. In the early 1990s Charmaine demonstrated that even with significant disabilities, it was possible for her to live in her own home with the support of friends and paid service. She continues to fight to have what other people take for granted – living in her own home and having control in her own life. This poem is from Charmaine’s recent book of poetry, ‘Pieces of my mind’.

THE SEARCH FOR MEANING

David Barnes, who works with young people, helping them to find their spirituality, shares his own search for meaning. He found that 'giving' brings meaning to life. The community living movement is underpinned by the belief that people with disabilities, like all of us, are givers as well as receivers.

When I was a kid I had dreams. I wanted to be superman, then Elvis Presley. As I grew older I wanted to be a sporting star. At the age of fifteen, after a near death experience, I had new heroes. They were Mother Teresa, Gandhi and Martin Luther King Jnr. These heroes were people who seemed to have an understanding of something important in life. Then, in less than what seemed a heartbeat, I was twenty-five. I seemed to simply go through the motions of life. Complacency seemed to be laying its foundations around my life and soul.

It is claimed that life on earth has existed for about five billion years, and humans live for about eighty years or less. I couldn't get these thoughts out of my mind: *These are our few precious moments; what are we meant to do with them? How do we find purpose in life?* With these burning questions, I set out for India, to ask them of a woman in Calcutta. She was the only one of my three heroes still living – Mother Teresa.

Dreams do come true and I met Mother Teresa. The immediacy of her presence filled the air yet she seemed so small. Her face was deeply wrinkled, as though suffering and understanding had been etched there. The meeting was, for me, the culmination of a life of dreaming and searching. I now had my chance to find out how she found happiness and meaning in life. With Mother Teresa seated beside me on a simple timber bench, I began: 'What are we here on earth for? What are the most important things in life? What would give it meaning?'

After some time, and as though she knew how deeply I was searching, Mother Teresa gave me a matter-of-fact look, and with a heavy accent, said: 'To have peace and happiness, you have to give.' It was as if the sun had appeared from behind a cloud. I knew these were the words. Mother Teresa continued. Although I was very tired, my head and chest were pounding, demanding me to listen. And then she said, 'You must have silence.' Silence? It was almost too easy. It was so accessible and universal. Joy filtered into me. In a few simple words, Mother had paraphrased the common themes of the great spiritual thinkers and doers – silence and giving.

While in Calcutta I worked as a volunteer with Mother Teresa's Missionaries of Charity Sisters and Brothers. I worked at a refuge for street kids and for people who were severely disabled, many of whom had been abandoned. I went to the countryside with the Sisters, taking food and medical supplies. I also spent time at a Leprosarium. Finally, I began working at Khaligat, a home for dying and destitute people. Mother Teresa established Khaligat after she stumbled over a dying woman on a street. Mother carried her to a hospital but they refused to accept the woman as a patient and, on the way to another hospital, the woman died in her arms.

Inside the walls of Khaligat was like walking into another world – a world full of all the worst suffering. The Sisters, aprons around their saris, selflessly went about their work, tending to wounds, comforting people, bathing them, feeding them. How did they do it? How could I find such meaning, purpose, peace and happiness? One day, as I stood in my dirty apron, I glanced through a curtain and saw

the dead body of someone being carried in from the street. Instantly I was aware of my own mortality. My mind jolted back to my world. I pondered that in Australia at that very moment

it was Friday evening. It would have been happy-hour at the city bars of Sydney and many of my friends would be there.

But Calcutta was a long way from Sydney and my work at Khaligat was harsh and tiring. My learning curve was steep. I had to learn by doing. I soon realised that the only protocol here, was to love. As I worked on, I found my feet and could feel myself coming alive. The awareness of silence and giving was not my journey's end but just the beginning. All the great ones in history, including Gandhi, Martin Luther King Jnr, Buddha, many philosophers and prophets, were givers. They served others. My great learning from those that I knew, or had read about, was that they all gave of themselves in some way. They also had periods of silence – going off alone for quiet time, to contemplate. I realised that silence fills us up. It costs nothing to be still. Silence helps us to be responsible for our own world. Silence restores us spiritually, and allows us to keep giving – to give to others, and to give to ourselves. ✦

“Who am I to impose my values?”

Being ‘abandoned to choice’ is one of the perversions of community living. In this article, John Armstrong encourages more helpful responses towards those who are vulnerable. John is an associate of CRU and is well known for his teaching and advocacy work.

Patrick is a man who spent most of his life living with eighty other men in a privately run institution. He had a small corner of a large room that was shared with seven other men. His days were a rigid routine of waking, cleaning, eating, sleeping and endless hours of sitting. There were few decisions for him to make because his life was so regimented and so Patrick’s capacity to make decisions grew extremely weak. Once, however, Patrick took a walk out of the facility – just down the road – but well out of sight of everyone else. The police were called and when Patrick was found and returned to the institution, his family decided that he should never be permitted to leave again. Even yearly visits to his mother were no longer permitted.

After twenty-five years, the institution underwent a change of direction and Patrick was one of the first to be chosen to live in a group home. Things would be different there, he was told, and this began to frighten him a little. Patrick moved into a house in the suburbs with four other men, but something else was different – Patrick was now given the chance to make many decisions for himself, even in areas that he had never before experienced. The staff said that he was an adult, and could do anything he wished. But this presented a dilemma for Patrick; he didn’t know what there was to choose from, except for the limited range of things that he had always known. For example, Patrick always had his evening meal at four-thirty and then changed into his pyjamas, watched television and retired at six pm. The staff said: “This is your decision, Patrick.” The staff discussed how they might support Patrick to do new things, but each of them kept coming up against the notion: *Who am I to impose my values on him?* They found it difficult to get beyond this notion, to questions about what is typical or valued by people in the general community, and for using that as a guideline when thinking about what might be of help to Patrick.

One of Patrick’s housemates was a man named Thomas. Thomas had no trouble getting out and exploring the world. He would walk straight up to people in the street, asking them their names, and enquiring if they would be his friends. Thomas also noticed women and girls for the first time. He was often transfixed by a woman when he was out, staring at her in a prolonged manner. Staff would try

to redirect Thomas towards something else but this was never quite as interesting to Thomas as a lovely woman who caught his attention. Workers were reluctant to impose what they called ‘their own values’ on Thomas, so like Patrick, he never learnt how to get the most out of the freedom that life in the community might have brought him.

Freedom brings the potential to learn new things; to discover preferences, desires and wants, as well as opportunities for discovering good decision-making. Freedom is the proving ground of autonomy, where mastery in self-control and social interactions may be developed. So how might the richness of community life be experienced by people in situations like those of Patrick and Thomas, without violating their autonomy? How are people like Patrick and Thomas able learn what is appropriate and what is not? Is it to be through punishment, or by exposing them only to the consequences of their actions, even when those consequences are potentially harmful to the person? A much more helpful response is to give people ordinary, typical and direct encouragement and feedback about some of the things they are choosing to do. This helps a person to develop actions that are more likely to enable successful choices, acceptance in the community, and personal growth. Personal growth comes by placing certain restraints on the self, and this in turn corresponds to the responsibilities that go with the exercise of our rights. Personal freedom is tied to responsibility and obligation.

The kind of community living that many of us seek for people like Patrick and Thomas comes about not only through learning to enjoy the freedom that community life can offer but also through learning about the reciprocal interactions that we have towards one another in the community. People who have been deprived of opportunities to exercise freedom of choice will benefit from gentle, caring and relevant feedback and support so that they can modify their actions and come to enjoy one of the most precious features of community life – acceptance. For those of us who are engaged in the support of people with disabilities, there is a need to deal with some of the unhelpful notions that we hold – notions that can limit sensible actions and common sense. People who have been deprived of opportunities to develop and learn in the context of everyday lives deserve the chance to learn and grow or they may continue to suffer lives of marginalisation, destitution or even imprisonment. ☒

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