CRUCIAL TIMES

Editorial

Jane Sherwin

We learn from our personal engagement with others about the extent of our capacities and incapacities, our forgiveness and our lack of it, our generosity and our selfishness, our ability to live life in a way that gladdens our hearts. *(George Durner)*

Recent editions of **CRUcial Times** have carried articles that have helped readers to consider the real meaning of a word we are all familiar with – Community. In this edition we want to go further by asking, among other things, what is a vital community? We want to try to describe what a vital community looks like, with all its members playing a vital part in its life.

One view of a vital community is one in which there is a rich mosaic of life that is an interconnectedness between people, places and interests. Coming together with others provides social and material exchanges that give meaning to life – we learn about ourselves and about each other, and we find both joy and uniqueness in the ordinary and the everyday. A vital community has a life-giving nature. In this kind of community people find more in common with each other than they do differences in each other. In contrast, barren communities are those where there are few interconnections and where it is easy for particular people to be perceived as the 'other'. In barren communities material and hedonistic values dominate, narrow views of attractiveness and worth are sanctioned, and the definition of a good neighbour is one who doesn't talk to other neighbours.

Vital communities evoke an awareness of one another and a sense of involvement, and there is a strong sense of crafting both the present and the future of the place and its people. This kind of community is characterized by relationships between people – people brought together over a back fence or over a common interest, through familiarity, and through a sense of connection. But what part do people with disability play in the vitality of their communities?

A significant achievement of the past twenty years has been an increased acceptance of the belief that people with disabilities belong to their local communities, enjoying relationships and interests, and their own homes. Yet the hold that people with disabilities have on community life is still tenuous: governments, service systems and local neighbourhoods can all act as gatekeepers to community life for those who are always at risk of being rejected or marginalised, with eviction notices easily served on the basis of disability, behaviour, or multiple needs. People who are isolated through a lack of relationships with other ordinary members of their community are the most vulnerable to this kind of eviction.

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. .

While we might celebrate the fact that there are more people with disabilities present in communities today, they are strangely absent too – absent from the heart of vital communities – present yet absent. Imagine a life that is characterised by unfamiliarity, insecurity, loneliness and dispossession. Such experiences do not contribute to a vital community, yet they are the common experiences of people with disability.

Social history shows that the rise of institutions, professionalism and human services have all contributed to depleting our communities, through the removal of people with disabilities from their families and social networks, reducing the opportunity for communities to embrace members with a disability. Today, human service workers often act as an interface between people with disabilities and the community, and for this reason their role can be vital to whether or not a marginalised person is merely present in the community or a real part of it. The situation of being present-yet-absent most commonly occurs whenever services see community inclusion merely as outings or programs, and marginalised people will always remain on the periphery of their community whenever services create separate groups, places, or activities for people with a disability.

At the heart of vital communities are our own hearts and minds

On the other hand, there are many things that support services can do to increase the likelihood of people with disabilities playing a vital part of vital communities, and many of the articles in this edition of **CRUcial Times** provide insights, ideas and inspiration on these issues. But at the heart of vital communities are our own hearts and minds.

WHY COMMUNITIES NEED PEOPLE WITH DISABILITIES

Roz Cooper from Cooran on the Sunshine Coast shares her depth of understanding about the nature of true communities. She says divisive attitudes cannot exist within a context of a true community because true community can only exist when room is made for the differences and limitations of everyone.

In my heart and around our home, my son does not have a disability. When he steps outside the door he becomes disabled. In the context of community his differences are disabling and become life-defining characteristics. An excluding social overlay is imposed upon him where he becomes challenging, has high support needs, requires specialised care and has various other labels applied to describe his differences. He is viewed and related to only in terms of his perceived disability. Rarely if ever is his courage honoured or his true purpose acknowledged. Rarely if ever does society, whose systems presume to know so much about where he belongs and what is good for him, admit that it needs people like my son. Society remains unaware that it does not know this important information.

My son, like others who are similarly labelled, has a highly valuable social role. He is a catalyst for communities to become real. Without people with disabilities 'community life' and 'community spirit' are ideals that can never be achieved and therefore community itself cannot exist. While some people remain excluded, the word 'community' will only ever mean a place on the map. There can be no certainty that going to a particular community will be a human or cultural experience. People with disabilities highlight the exclusivity of communities. Their unacknowledged role is that of reflecting to society and individual communities the fear and prejudice that keeps people separate. Attitudes that are divisive cannot exist within a context of a true community. A community cannot afford alienation of its members. Community can only exist when room is made for the differences, faults and limitations of everyone. A community lives and breathes when it enacts principles of mutual respect, understanding and acceptance.

To stand for inclusive communities means desiring social environments in which all people are included. Communities need people with disabilities because they give us cause to set a new social agenda. Without conscious action on the part of society to embrace all people, communities remain localities starved of their own potential to become a collective of human beings working and celebrating together. When efforts are made to connect people with disabilities into the heart of their community,

opportunities emerge for new and simpler responses to life's needs. Natural relationships begin to form that liberate people with disabilities from the model of service delivery which does not reflect their real needs. Inclusion must occur before full community life can be actualised. Inclusion is not achieved through services or programs that exist on the fringes of communities to provide temporary access to community facilities and activities – they are expensive and deprive the community of resources. Initiatives that weave people with disabilities into the fabric of community life enable a greater sharing of human and financial resources. Such initiatives require that roles and expectations change, that planning is person-centered in community, and that resource expenditure is guided by principles that enrich individual and community life. Inclusive community life is a recognition that people with disabilities are regular people whose needs can be met from within the community.

An openness to recognise each other's needs and a willingness to work together to meet life's needs, are all practices that engage the spirit of community. This spirit becomes apathetic when people with disabilities are subjected to systems designed to make up for their deficits, whenever they are viewed as needy, burdensome or requiring care that can only be delivered by someone who is an expert or trained for that purpose. Bureaucratic reshaping of lives, segregated services, and funding strategies that combine complex formulas, rigid eligibility criteria and intrusive application processes, all contribute to the distancing of people with disabilities from community life. They reinforce the notion of special-ness that has been used to justify exclusion and has resulted in planning and excessive spending to create a way of life governed by managerialism, competitiveness and waiting-lists. They numb the community spirit, giving it a false

A community lives and breathes when it enacts principles of mutual respect, understanding and acceptance

sense of security and miss important opportunities.

The pervasive unawareness of the social worth of people who have disabilities can be shifted; new ways forward will become apparent when communities experience their capacity to consider and respond to the needs of all its members. The impetus and skills for making this shift are already present within the community and within people who have disabilities, their families and allies; oppressive forces of isolation, stigma, and ignorance have generated groups who strongly engage values and practices that build strength and cohesion based on values that oppose these forces. Communities that aspire to be real need innovation, communication, determination and cooperation; characteristics that often become a way of life for people who have to deal with injustice. Real communities will eventuate when such skills and resources can be diverted away from the bureaucracy and into a redefinition and renewal of communities.

People with disabilities represent many other people who exist on the fringes of society that challenge communities. Challenge can cause conflict. Conflict results in change. Change is what people with disabilities inspire. Whether we think that the developments which have taken place over the last twenty years are favourable or not, there is no question that at some levels, society has adopted a different response to the lives of people with disabilities. The effectiveness and benefits of changing attitudes are diminished by the persistent perception that people with disabilities are needy. When society realises the gains that come from enacting values of citizenship and inclusion of all people it will discover the integral and necessary role that people with disabilities have played in the evolution of our civilization.

Bill Webb who has a background in human service worker training, says that in order for people with disabilities to feel that they are an important part of their local communities, support services need to be clear about what is helpful and what is unhelpful in their efforts.

A REAL COMMUNITY: ACCEPT NOT SUBSTITUTES

Perhaps the greatest challenge for the disability sector is to define what 'community' is and, as the advertisement says, to accept no substitutes. Generally speaking, disability services and support workers take a 'place' view of community, with the consequence that 'community' is either a house in the suburbs, a seat in the local coffee shop, or a trip to the park. But this definition of community does not include any notion of the experience of social interaction.

The major problem is that when a 'place' concept of community is used, those who are marginalised in society are unlikely to be presented with opportunities to make new friends, to have new experiences, or to pick up new skills. The person in the street does not have opportunities for engaging with a person who is marginalised, or opportunities for seeing that person as someone with strengths and vulnerabilities, joys and hopes, particular interests, and all the other things that go with being human. In this context the person with the disability always remains 'the other': the one who is sitting at another table, sitting in an empty park or living with four other people in a group-house down the street. That person is always in the presence of a support worker who is believed to have a mysterious combination of cleverness and a capacity for caring which is not to be found in ordinary members of the community.

This sense of 'otherness' or 'strange difference' is actually promoted by many so-called community activities. For example, the general public often has the strange experience of hearing about people with disability in community awareness campaigns or when hearing someone talk about people with disability as part of community development work. But these activities rarely lead to ordinary members of the community getting to meet a person with a disability in a real situation.

Someone has coined the term 'community tourism,' which is another way of saying that people with disabilities visit many places but actually belong in very few of them, reinforcing the thought that people with disability frequently play the role of spectator in the life of their community. A definition of community that does not stipulate, as an absolutely necessity, some form of friendship or relationship outcome should be called what many support workers already call it – 'an outing'. If that is the case, then people with disabilities will have to rely on paid-relationships as a substitute for friendships because we cannot expect that bridges to real relationships will be built when the only interactions that take place in the community are over bank-desks, in the corners of fast-food chains, in dark theatres, or at the end-lane of bowling alleys. If this is all that 'community' is about, then in most cases we have found it. □

If, on the other hand, we know what we are really aiming at in our support of people who are marginalised, we are far more likely to achieve our aims. Real relationships and authentic community participation do not happen

by magic for those whose lives have been marked by stigma, marginalisation, segregated schooling, or whose range of relationships is limited to those who are paid to be present in their lives. Achieving authentic relationships and true participation in the community for people who are marginalised will require creative work from the disability sector and this work will need support in terms of training, funding, and peer mentoring. This work will also need a different method of working.

I believe the method that is presently used (based on the simple concept of community-as-place) has inherent problems. Firstly, the notion of community participation for adults with disability is somehow confused with notions of recreation. With this approach, recreation can become an end in itself, because if people go on an outing and genuinely have a good time, it is difficult to convince support workers that they need to consider other options. If any one of us in the general community mixed with only four or five people (and often, not by choice but because we shared a group-house) or only ever went out with the same people, I believe we would be keen to meet new people.

I also believe that the methods that are presently used to try to bring about more authentic connections between people with disability and other members of the community are unhelpful for reasons that include the following.

For various reasons agencies seem unable to retain support workers with the result that many worthwhile community efforts come to an abrupt end. When support workers are transient, then ordinary members of community groups, who may have a developing involvement with a particular person, have the experience of never knowing if that person will ever come to their group again, or if so, who the support worker will be.

There are often competing agendas in community organisations. The most common agenda is that support workers need to take out a bus-load of people so that everybody gets out once a week, and so that house workers won't need to be rostered. This is one the worst possible methods that can be used if relationship outcomes are genuinely sought through community activities.

Another flawed method is that of relying on a community directory of clubs, pubs and everything else in the world, most of which are never visited. If the support work starts from the interest-base of the person who is being supported, only a few places and a few people are needed for connecting the person to others in that person's community. This saves the effort of mapping the world.

Support leading to true community involvement is seen as the 'cream', which we are not able to afford, but we are willing to spend lots of money on many different kinds of therapies, which may actually contribute to an outcome of loneliness, lack of purpose or roles for a person with a disability. Instead, therapies need to be harnessed, and used to foster community outcomes for the person who is receiving those interventions.

In order to go beyond these unhelpful methods it is important to recognise that workers are needed who are right for the job and who are supported to do the job well. For a number of reasons, some people with disabilities will find it harder to form friendships, and some workers will be more suited to this kind of support work than others. Some workers may need more training, supervision and nurturing. It is important that success comes as early as possible to build hope and belief. Long periods of struggle, failure to achieve, and a mystification about 'community efforts' can make it difficult for some services to really engage in this kind of work.

If we understand what it is that we are trying to do, and have thought clearly about how to do it then the remaining question is: Are we as a sector really willing to do what it takes and to accept no substitute for a community that is relationship based?

The Contribution Of Service Workers
In Getting The Relationship "Right"
Between People With Disabilities And Their Communities

__Michael Kendrick__ is a regular contributor to CRUcial Times. *In this article he sets out some important ways in which the small efforts of ordinary members of the community can be encouraged by direct support workers, who have a role at the interface between the local community and some of its vulnerable members.*

It is not always obvious to us that our personal efforts in our communities make all that much difference on any given day. Nevertheless when we step back and view it over a longer period of time there are often signs that give encouragement. This is the case with what may seem the rather 'ordinary' efforts of everyday service workers in helping people with disabilities to be more fully a part of their communities and to fully enjoy it. The very simplicity of these contributions often masks their potential profundity and importance. That is why it is important to give them the recognition they deserve. What follows are some examples of how such contributions are made.

__Help people meet people.__ Loneliness and isolation can be terrible burdens and it is always a welcome change to meet and spend time with others. However, meeting new people is not always easy, and even a small amount of thoughtful assistance can go a long way towards making the process an easier one. It is also true that the more a person gets experience with doing this, the more relaxed and natural it can become. Many a service worker has found a way to be helpful in bringing people together.

__Keep community encounters comfortable.__ Underneath the surface of our lives within community there are many fears, doubts, anxieties and apprehensions that can inhibit the ways in which people simply 'are' with each other. For example, many people with disabilities encounter a certain discomfort in those who are not sure how to act, or who are uneasy being in the presence of people whose appearance or disability is a difficulty for them. It is interesting that despite the fact things may start this way, people can quite quickly shed such fears and inhibitions as they come to realize that people are just people. Anyone who helps build feelings of comfort between others is making a useful contribution and often this may be a contribution that support staff can make.

__Help people see the potential of people with disabilities.__ It is a common problem that most people underestimate the capacities of people with disabilities to play a larger role in community life. This is not easily overcome but it will eventually yield to the efforts of people with disabilities, their staff and other supporters to open people's minds and to change their ways. Since these changes often come in small increments it may not always seem like a 'breakthrough', but looking back it can be seen that indeed it was one. Often it is just be a matter of persevering until we get a chance to show people what is really possible when someone is given a chance and thoughtful support. Many support workers would do well to be recognized as potential 'mind changers' and 'opportunity makers'.

__Help non-disabled people to see their own potential in relation to people with disabilities.__ It may not be clear to many non-disabled people that they have a contribution to make that would be welcomed and appreciated. Some people may be bound up with their own misleading stereotypes about themselves and thus not act in ways that would be helpful, but many people are simply unsure of themselves and may benefit from a bit of expanded vision and steady encouragement to explore the kinds of roles and contributions they can make to benefit people with disabilities. Their contributions could spill into any conceivable role in life that they could either personally play, or

support being played by people with disabilities. These roles could include friend, neighbour, employer, club member, colleague, spouse, business partner, mentor, ally or many other roles. There is no 'automatic' role; people must discover what comes naturally and what is most welcome and needed. In this regard, they might well be aided by a supportive and encouraging service worker.

Help people to develop and live important values. We are all familiar with values and attitudes that would benefit people with disabilities. Often we discover that we need to re-learn and re-apply these. It is an ongoing struggle to develop and live our values with a measure of integrity, yet these values are well worth the effort in terms of the way they can make life-changing differences. That is why it is important to not lose sight of values such as respect, open-mindedness, fairness and honesty. It cannot be assumed that people always understand the connection between their values and how others are eventually perceived and treated. Nevertheless, this awareness can be stimulated and nurtured, as can be the realization that their values and resultant attitudes matter. Many service workers often provide good role models to others in regard to these, particularly when they have to struggle hard themselves to behave honourably.

Help people to stay involved with and connected to people with disabilities. Being part of a community is not just a matter of meeting people in a community, it is much more a matter of continuing to be part of a community and staying connected to its life and people. This embedding of people in community life is a process that builds one day upon another, and dividends will be paid by maintaining focus and effort. This may be made a lot easier if service workers understand and commit themselves to the continuity of relationships and community presence. When they do so, the natural facilitative process is helped along thereby ensuring that people with disabilities are more deeply an ongoing part of the life of their community.

Recognize and appreciate the contributions people make. A day hardly goes by where an ordinary person does not behave in a way that is helpful and welcome. Often, such actions would continue, strengthen and become more natural if they were noticed, appreciated and reinforced. Such recognition can help to move conduct that is tentative or impulsive into something deeper and more enduring if it is applauded and affirmed, however discreetly. Sometimes just letting people know that they are on the right track can help keep them there, particularly if it becomes clear to them that their action is welcome and needed. Service workers often play a critically supportive role in noticing small gestures by ordinary members of the community and in encouraging them to continue and flourish.

Help people struggle for a sense of what a better community would be. If we cannot imagine better, we often fail to achieve what is possible and practical, because of our limited sense of what is possible. Even when we can see the potential of individuals we might still miss seeing what the role of an 'enabling' or 'better' community would look like. Thus it is very important for all of us to play some part in both imagining a better community and creating small examples of it. Though it may surprise some people, this often begins not with grand schemes of community change but rather in the small examples of 'better' that can be created in opportune pockets in our communities. Consequently, these imaginative efforts at community improvement often involve everyday service workers who have a sense of mission and the resolve to make progress.

In our everyday efforts in our communities, it is important for us to remember that it is always the few that precede the many, the small that beget the large, and the obscure that humble the famous. It is important that service workers not become persuaded that their efforts do not matter, as we would all be the poorer for their absence. It is better that we see these contributions for the importance they hold, and encourage service workers in their efforts to get the relationship between communities and people with disabilities to be 'right'.

WHAT IS A 'VITAL' COMMUNITY?

*We asked **Michelle Clark** to describe a 'vital' community and she provides some interesting insights into the relationship between place, roles and a belief in one another. Michelle lives in the Townsville community.*

A vital community is a place where everybody is welcome. In understanding what a vital community is we need to understand what it means to welcome and be welcomed.

At the heart of vital communities is a sense of belonging. A sense of belonging goes hand-in-hand with a sense of place. A sense of belonging enables people to share a place, and brings about feelings of ownership and identity with that particular place. For example, a person might say: "I am part of the motor boat club community" or "We go to the Heritage bar every Monday evening to listen to the live band, people are so friendly there."

When we are part of a vital community there is a sense of ownership, a sense of place, and a sense of belonging to that place. Sharing a place and belonging to a community eventuates in interactions within that community. A sense of belonging comes from having a particular role to play within the community, and to have a role means to participate. To participate, we have to feel confident in our role in the community. And to feel confident, other people in the community have to believe we have the skill to fulfil our role.

Vital communities not only own and share a place, they also own and share problems, and part of the ownership is finding solutions. A vital community is about human beings sharing responsibility for each other. A vital community is about reciprocity, belonging, participation and responsibility. A vital community constitutes the idea of a sense of belonging, and a belief in ourselves and in others.

SUPPORT WORK IS A MEANS NOT THE END

*As the coordinator of a service **Kris Lumsden** sees support work as a means to an end, and provides some helpful examples of challenges to doing this work creatively and sensitively. Most importantly, says Kris, the spirit of spontaneity, enthusiasm, personality and variety needs to be kept alive by support services.*

Many factors arise when seeking to support, through good service practice, the development of relationships and roles in the community for people with disabilities. The biggest challenge for all involved is to remember that the support work is a means to an end, not an end in itself.

By its very nature, a formal service can create a barrier in that the number of support hours that is offered to a person is sometimes seen as the sole objective rather than as a tool for creating something that is meaningful. A person may be considered well supported when having increased hours of support, the belief being that this will increase the likelihood of something occurring, but *more* is not always *better*. However, for some people increased support hours can assist in building skills and self-confidence, which are important stepping-stones for further growth in connections with others in the community, and some of this personal growth can be clearly linked to the efforts and focus of a paid worker.

The question of 'what is helpful and what is a barrier?' is not always easy to define. This is especially so when a service recipient is very clear about only wanting to spend time with a particular support worker, thus eliminating other members of the community who may provide more meaningful or long-lasting connections. An example of this occurred when a service recipient who was seen by the support agency as being isolated and needing enhanced communication skills, was offered short-term support to attend a TAFE communication program with a worker. But the service recipient had a different preference for how the support hours were to be used and continually chose to go to the movies, nightclubs, and shopping with the support worker whose company was enjoyed immensely. When the allocation of support hours ran out, the person quite happily went off to the TAFE course alone. In this case, some of the questions we had to ask ourselves were: was the motivation to go to TAFE already present in the person; were we getting in the way rather than assisting; did support for the social activities give the person the confidence that then enabled that person to attend TAFE independently?

Other drawbacks of human services are the formalised elements of the work, such as accurately planned funding, service agreements, and a letter-perfect resonance with mission statements. But part of the thrill of real connections in the community can be lost in the meticulous planning of such things as the need to fit outings into accommodation programs and therapy sessions, and the time and duration of outings. Support agencies need to keep the spirit of spontaneity, enthusiasm, sensitivity, personality, and variety when supporting people in their community. In the case of spontaneity, for example, we need to find ways of making it possible for a person to stay longer than might have been planned when that person is really enjoying a particular outing or activity in their community. This kind of spontaneity is not something that can be achieved through timeframes or other service specifications. I find it disturbing that a support package is supposed to contain 'health, house and 2.2 meaningful community links'. Real life is not as neat as this.

All those who use support services need allies to cheer them on and to celebrate all the things that come into their lives, making it richer and more varied. Real support is about creating opportunities for a person while at the same time striving to inspire that person to want and expect the company of other people in their life in real and enduring ways.

RELATIONSHIP BUILDING IS A WORK-IN-PROGRESS

***Vicki Grinlaubs** co-ordinates a service that supports vulnerable, marginalized people to develop relationships in the local community which Vicki describes as a vibrant, bustling cluster of suburbs in Brisbane. Direct support workers, and those they support, are encouraged to have a strong sense of place.*

Relationship building is a complex task for any of us, but supporting a person who is socially marginalised in making real and lasting links with others in that person's community takes time and thought. Even the most creative, community-focused support worker would be unable to turn this kind of support into a fool-proof recipe with all the right ingredients: the correct levels of 'participation', the exact amount of 'support hours' and the most perfect 'timing' for a connection to be made.

To begin a community-linking process for a person with an intellectual disability who is newly arrived in a well-established community, a service organisation may seek to work within the local community by engaging local residents to explore and re-explore their own community with the new resident. In this method, members of the local community are employed as support workers by the agency to spend time with each newly arrived person while they both enjoy a mutual sense of ownership of the public space that is their local community. The experiences that support workers have while engaged in this work can be very valuable as they can provide vital insights that help in understanding some of the perceptions of people with disability that are commonly held in the community. Their personal reflections should be valued, especially when they bring about change through a willingness to have their own values and beliefs challenged.

For most support workers exploring the local community with a person who has a disability, opportunities will sometimes seem to present themselves. Opportunities arise in the everyday life of the community and the key is to value the small steps that are made in this everyday context. For example, a local café assistant begins to recognise Elsie, will start to say 'hello' each time Elsie comes in, and to engage directly with Elsie, perhaps looking for communication cues from the support worker.

"Isn't there more to linking than this?" I hear you ask. The reality is that I cannot always answer this question. Having a sense of belonging to a community is multi-faceted for all of us. It means knowing what's around and who's around, but it also means being known: by those who serve you coffee, pack your groceries or sell you fruit. Certainly not everybody in the community will highly value these relationships, but they are at least able to take them for granted, something that marginalised people are rarely able to do.

To actively participate in the community may mean joining local groups, engaging in local events or using public space for recreation. I often hear concerns raised that too much time can be spent on outings in parks and nature-reserves where people are not being engaged in activities, but time spent in the local community, absorbing its depth and breadth, is a vital part of feeling ownership of public space, and its importance should not be negated. The way to build relationships is through meeting people, and through engaging with others on common ground.

Ultimately, the facilitation of relationships for a person with a disability is a completely natural process; it begins by relating and happens through doing