

CRUCIAL TIMES

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

Issue No. 17 March, 2000
Ph: (07) 3870 1022 Fax: (07) 3371 3842
Email: cru@uq.net.au

EDITORIAL

When the social history of our times is written, there is every chance that historians will comment on this era as one in which great progress was made in the development of community services for people with disabilities. We clearly live in an era when the vast majority of people in the disability field have turned their energies to supporting people with disabilities to live in the community.

The era might also be characterised as one in which community living was equated with community services; a time in which formal human services were expanded in response to every human need. As an example, when a particular need of people with disabilities is identified, inevitably it is concluded that a new service is needed. Thus we are rapidly expanding services for almost all domains of life. However, in spite of the fact that many more people with disabilities are in the community and have more opportunities to participate in various aspects of community life than previously, we know that many people experience great isolation and loneliness. Friendship and freely given relationships have remained elusive and out of the reach of many people with disabilities.

Experience has taught us that human services can't meet many human needs such as the need for love and acceptance, or the need for deep and meaningful relationships. We also know that the majority of people in the community are not in relationships with people who have disabilities, and most people in the community expect that human services will look after people with disabilities. If we are to progress true

community-living for people with disabilities, then we need to grapple with the issue of freely given relationship and friendship. In this edition of **CRUCIAL Times** writers explore some of the things we are learning about friendship and relationship formation.

Mike Duggan challenges readers to not back away from this issue, and to face squarely our shared humanity and needs. He also alludes to the cycle of dependence on formal services that happens when people don't have friends or social networks. *Jayne Clapton* explores friendship, its forms and its capacity to promote wellbeing in all of us. She argues that friendship is not only important to all of us, but that it also provides a framework for promoting an ethically decent community. In this way, friendships and the quality of our relationships, both in our private lives and in the public domain, impact on the world in which we live and help to shape it. Both of these writers challenge us to think about social integration and community living as being about all of us, and not just a matter of service technology.

The personal stories in this edition show us that relationships can come about in different ways. They also remind us to be hopeful and believe that relationship and friendships are possible for people with disabilities.

Bruce Harris and *Penny Watson* share the joys and learnings of their relationship. They met with the help of a mutual friend. Certainly their story is a testament to the possibility of mutual support and affection that can exist when disability barriers are crossed. ►

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.

Joan Hailstone shares her joy in seeing her daughter grow and blossom. She reflects on the importance of the unfolding growth of her daughter's life and how this supports and allows her daughter to reach out and explore relationships with other people.

Julie Walder writes some personal reflections as a parent and as someone who has been concerned about disability issues for a long time. She also writes about her work in community development and the importance of developing community structures that allow people with disabilities and other people to be together in public places and activities.

Janet Millward and *Ric Thompson* contribute as service providers. Both write about the inherent limitations of services in crafting relationships for people, and both urge service providers to

have a high consciousness about the importance of relationships. "Not giving up" is a clear message and Janet stresses the importance of nurturing small beginnings.

All of these offerings help us to focus on the importance of friendship and relationships in people's lives. They confront the place that services play and help define their roles and limitations in supporting relationships. These writers urge us to discard the established notions of what it means to live in the community and to continue to push for a better understanding. They take us back to some basic questions about who we are and what it means to be human, and how we develop friendships and communities which nurture, sustain and promote a better community for all of us.

Anne Cross

CONTENTS

Editorial.....	1
From the President's desk.....	3
Friendship – A way to more ethical communities.....	4
The role and limitations of services in developing relationships.....	5
Bruce and Penny.....	6
Including people with disabilities in the community-what can Councils do?.....	8
Building a community for all people.....	10
Life's wonderful fruits and foliage.....	11

CRU Committee members 1998/99

<i>Mike Duggan</i>	<i>President</i>
<i>Alf Lizzio</i>	<i>Vice President</i>
<i>Margaret Donovan</i>	<i>Secretary</i>
<i>Janet Millward</i>	<i>Treasurer</i>
<i>Patti Dietz</i>	
<i>Elaine Stephenson</i>	

CRU Staff

<i>Anne Cross</i>	<i>Director</i>
<i>Pam Collins</i>	<i>Resource Consultant</i>
<i>Jane Sherwin</i>	<i>Consultant & Educ prog Co-ord</i>
<i>Beverley Funnell</i>	<i>Consultant</i>
<i>Kelli Haynes</i>	<i>Workshop Presenter</i>
<i>Sandy Grant</i>	<i>Admin Officer</i>

CRU recently farewelled Silke Collisson and Lake. They made great contributions to CRU and will be missed. We wish them all the best.

“CELEBRATING 30 YEARS OF CITIZEN ADVOCACY”

Friday 20th–Sunday 22nd October, 2000-03-10
Omaha, Nebraska

The Conference offers an opportunity for people from all parts of the world to gather together – people who work in isolation, well-connected people, people looking for leadership development, people who are paid, and people who volunteer, reflective thinkers, and creative thinkers. They will come together over three days to celebrate Citizen Advocacy and to discuss the diversity of world views.

For more information phone:
Julie Clarke 03.422 94064
or
Heather Hindle 02.9369 2411

Citizen Advocacy is an intentional strategy for developing relationships between people who are vulnerable and interested members of the community.

FROM THE PRESIDENT'S DESK

Mike Duggan

Friendship is a fundamental need for all people. As social beings, we all need other people, and although we need the friendship of others, the paradox is that we are often afraid of exposing our vulnerability by letting others get close to us.

I'd like to quote the following words from GROW, which is a World Community Mental Health movement. GROW publishes a small brochure called "Friendship is the special key to Mental Health!" and it carries these words:

The love of friends requires something more than ordinary adult love. Friendship is a love of intimate sharing between mature equals.

To basic adult love, friendship adds a common philosophy of life and support and mutual leadership for life as a whole. You can love certain people whom you do not like, but a friend is one whom you like and admire, and in whose company you are profoundly at home.

The word "friend" is used for three levels of relationship: friends for play or leisure; friends for work and advantage; and friends for living.

Many readers will be aware of the term "Circle of Friends". This concept refers to occasions when a group of people comes together around an individual who has a disability, usually for the purpose of achieving specific tasks or goals. The concept is instrumental, task-oriented, and often necessary in achieving certain tasks for many people with disabilities and their families. These gatherings often act as stepping-stones on the journey from congregational living to the goal of having one's own home in the community. While a Circle of Friends is task-oriented, some of these "friends for work or advantage" may become "friends for living".

I would like to consider some of the following elements of friendship and how essential they are to our wellbeing, particularly for those of us who carry the label of having a disability.

Intimacy and affection. We all need intimacy and affection and these come from having close and sincere friends: people we are close to; people we can talk to about our deepest feelings. It is quite typical for a person to have only a few such

intimate friendships among their wider group of friends and acquaintances. It has been said that the more severe a person's disability, the less likely the person is to experience intimacy and affection, but *all* people have the capacity to make friends.

Companionship. At some times more than others we all need the companionship of others. We need a range of friends so that we can choose those we would like to be with on certain occasions, or for certain activities.

Feeling valued. We all need to feel that we are valued, and having true friends really helps in this process. This is not to say that we become reliant on others for our feelings of self-worth but we need friends to know the small, insignificant things about us – the things that make us uniquely individual.

If people with disabilities have few friends or have poorly developed social networks, this could mean that we are then more reliant on human services to meet our needs. The less we are recipients of human services, the more non-*special* we are. By having friends, the wondrous possibility of living an active, normal life and of being part of the community is ultimately enhanced.

Actively forming meaningful and reciprocal relationships needs to be nurtured and encouraged in ways that help overcome barriers to the formation of friendships between people who have been labelled as disabled and people who have not. Some of the barriers that hinder such relationship formation are low-expectations, limited opportunities, and inadequate supports. If expectations are low and opportunities are few, then support is needed.

As I have said on other occasions, I often wonder if pride, perfection-ism, arrogance, and the inability to listen, could be even greater obstacles to friendship formation than impaired speech, impaired mobility, intellectual disability, or emotional instability. ■

FRIENDSHIP – A WAY TO MORE ETHICAL COMMUNITIES

Jayne Clapton lectures in Disability Studies at Griffith University. In this article Jayne makes an important connection between friendship and the type of society in which we live

‘Where we are in the world’ can be influenced by many considerations. The space that we occupy by ourselves, and with others, can be affected by relationships that are either voluntary or involuntary, private or public, fulfilling or oppressive. How does *friendship*, then, as one particular type of relationship, promote experiences of goodness, or challenge experiences of harm, in the communities in which we live? By undertaking such an exploration, we are not only engaging in ethical reflection, but, in fact, we are considering the possibility that *friendship* is an important concept by which to envision more ethical communities.

While *friendship* can be experienced within the public arena to enhance citizenship and respect, *friendship* within the private or domestic arena enhances notions of acceptance, and is nurturing. As a significant relationship between two or more persons, *friendship* embraces care, affection, intimacy, closeness, companionship and trust. *Friendship* is intentional and voluntary; it is a relationship of choice, whereby each participant makes discriminatory decisions based on the desire to be in a particular relationship with one person and not another. Such decisions may be prompted by the sharing of common experiences, expressions, thoughts, values or goals; or for other reasons of attraction that are not easily identified by, or apparent to, those outside of the *friendship*. Therefore, expressions of mutuality, respect, and faithfulness are important and necessary components of friendship. In such a relationship, interdependence is experienced between the parties, rejecting negative evaluations or processes of devaluing between participants. Also rejected are negative patterns of power within relationships, represented by such aspects as paternalism, competitiveness, exploitation, and authoritarianism.

Friendship, then, is an informal type of relationship that can span different time periods from short-term to long-term, and is enriched by deeper and more enduring commitment. Significantly, *friendship*, expressed in the private arena, has the capacity to transcend or subvert traditional orderings of exclusion that some people experience in the public arena. *Friendship* is a relationship that is not necessarily bound by roles, conventions or

categorisations that typically dominate other types of relationships within these public contexts (although this is not to deny that *friendship* can be a part of such contexts).

Although *friendship* is a type of relationship that implicitly promotes wellbeing for its participants, it is not without challenges. Because of the nature of *friendship*, it is subject to constraints such as the lack of opportunities to access friends, a lack of shared understandings of the significance of the relationship, or restrictions placed upon commitments of purpose and time. The voluntary nature of *friendship* embraces freedom that can not only enrich commitment, but also accommodate the choice to sever the relationship. *Friendship* suffers greatly when betrayal is experienced, but it can also be profoundly forgiving and understanding.

*Within the intimacy of friendship,
the privilege of
‘moral witnessing’ occurs.*

Whilst some people ignore the role of *friendship* as an ethically significant relationship, others highlight its moral worth because of its ability to promote moral excellence. Within the intimacy of *friendship*, the privilege of ‘moral witnessing’ occurs. By sharing another’s stories and lived experience of his or her world, participants in a friendship share joys and celebrate goodness. In a similar way, each is well-placed to witness and respond to another’s experiences of harm, suffering, vulnerability, oppression or abuse. Such responses can be made at both personal and structural levels through support, advocacy, resistance and change.

Caring and just relationships that consider the wellbeing of another are not only integral to the sustenance of *friendship* but also represent an important framework by which to promote a more ethically decent community. Therefore, the significance of close friendships is not only that they are at the heart of where we are in the world, but, indeed, they continually impact upon the type of world we live in. ■

THE ROLE AND LIMITATIONS OF SERVICES IN DEVELOPING RELATIONSHIPS

We asked Janet Millward how service providers might overcome some of the obstacles that inhibit the development of reciprocal relationships. Janet says that part of the answer lies in nurturing small beginnings and a willingness to take risks.

Relationships are at the heart of a person's quality of life and wellbeing. A person in a house in the community who has no meaningful relationships in life is not truly living in the community. As service providers, one of our basic goals should be to strive to ensure that people experience a variety of relationships. Achieving this goal can be very challenging. Every day, services that are trying to encourage the development of relationships for people with disabilities, face challenges that could be described in the following ways.

The professionalisation of the human service industry has meant that many professional people come in and out of a person's life without ever getting to know that person. They provide quick-fix remedies but never really get to the heart of matters. Due to the implementation of award conditions, staff work to rigid contracts, and anything outside of these contracts means additional costs for the service that cannot be sustained within service agreement budgets.

Many people with disabilities who do not live close to public transport face the relatively high costs of travelling to and from activities or family events. Many people also share their support-hours with another service recipient or co-tenant. This means that someone wanting to attend an activity must do so either with their co-tenant or at a time when their co-tenant is out, rather than at a time of their own choice. As individualised community support hours are usually provided on weekdays between the hours of nine to five, this also limits the opportunities that are available to a person.

Staff turnover within organisations impacts on the way a service is provided. For example, staff members who have worked with a particular person for a period of time have significant knowledge of that person and the ways in which the person's networks have been built up. New staff members are not always able to pick-up on

those support networks because they don't have a good understanding of the person.

Role-conflict often exists for staff members between the role of "friend" and the role of "support worker". For example, when staff members suggest inviting a service recipient to their own home, the question to be asked is: What is the purpose of the invitation? Some staff members have a genuine interest in a person and will sustain their relationship with that person even after leaving the service agency. Others may introduce a person into their own personal network of friends, but when they leave the agency these relationships no longer exist, and the person with the disability is left isolated and grieving.

While many service recipients are supported to attend TAFE and other courses, unfortunately we still find that particular courses are set up especially for people with a disability. When the main purpose is to provide opportunities to meet others from the general community with similar interests, this type of class arrangement restricts a person's ability to meet a variety of people from the community.

Despite the obstacles that have been described, people with disabilities are able to establish genuine, interest-based relationships, and the following example is a good illustration of how this might be done. The name "Joe" is used although that is not the real name of the person.

Three years ago Joe was given support to leave the institution where he had been living. Very little thought went into planning who might live with Joe or where he would live, and it would be fair to say that Joe himself had little or no choice in these matters. He was allocated public housing situated in a cul-de-sac. After six months it was clear to everyone involved in Joe's life that the arrangement was not working. Neighbours were complaining, Joe's behaviour was deteriorating, his co-tenants were at risk of physical abuse and

their families were demanding that Joe be removed from the house.

While many people questioned whether Joe could continue to live in the community at all, we believed that he could if he had the right kind of support. Many hours were spent with Joe looking for a suitable house and one was eventually found. While it is located in a housing estate, Joe is not “living on top of his neighbours”, and his own needs for space are accommodated. Joe’s house has a pleasant outlook and is close to public transport.

A support worker, who had worked with Joe through the worst times, moved with Joe to his new home and supported him through the transition period. A genuine friendship developed between them. This support worker no longer works for the service agency but, instead, has chosen to be a friend to Joe. Joe often spends time at this friend’s house, and occasionally a weekend.

Joe has been in his own home for fifteen months, and in that time has made friends with his neighbours. This has been a big achievement for someone who finds it difficult to keep positive relationships. Joe’s family now has more involvement with him and he is learning how to act appropriately with friends and family. Joe has meaningful relationships in his life and I am sure that, over time, he will build more.

How did this change happen in Joe’s life? The service saw its most important role as that of

supporting Joe to develop relationships. Broadly speaking, the service takes on three roles in this area: visioning new possibilities; exploring opportunities; and a facilitating role.

The service spent time planning with Joe, identifying his needs and interests and supporting the natural process of communication with his new neighbours. Joe held a house-warming party, inviting family, neighbours, staff members and many others. Following this event he was encouraged to talk to his neighbours, invite them for coffee and so on. Once the service had identified that a possible friendship was developing, it encouraged the relationship by providing supports to the neighbour when required, and provided resources for Joe to attend outings, ensuring that they happened with the least stress for Joe. We also identified those areas where Joe needed skill development in appropriate social interaction, and staff members acted as role models to support his learning in these areas.

Joe is just one person with whom we work. There are many more people who are in need of meaningful relationships. How do we make it easier for such relationships to develop, given all the limitations? Part of the answer lies in the willingness of a service to take risks and allow things to happen, and to nurture small beginnings in the hope that some relationships will flourish. ■

BRUCE & PENNY

Bruce Harris and Penny Watson tell of a friendship that they both value highly. It’s a friendship marked by support for each other over the past ten years.

Bruce and Penny have been friends for about ten years. When they were introduced, Bruce was living in a residential centre with about seventy other people, and Penny lived in a house down the road with her two daughters. They met through a mutual friend who worked for the organisation running the centre. Penny mentioned to her friend that it seemed strange she didn’t know anyone from the institution – after all, they were neighbours.

The friend, on reflection, thought Bruce and Penny might both benefit from knowing each other. Bruce is a fighter with a strong sense of justice who often makes a stand, and at times this had landed him in trouble with staff at the centre, to the point where the mutual friend felt he could be at risk. Having an outside connection would be a safeguard. She thought Bruce and Penny might get on well (both liked music, both had red hair), despite the fact that Bruce was into

football and Penny couldn't tell League from Aussie Rules or Soccer to save her life.

So they met. Bruce, being a tolerant soul, took Penny's football illiteracy in his stride. They found they had deeper common ground - a love of life and of human efforts and foibles; a strong belief in the importance of family and children; a need to each have a home that was both practical and comfortable. Bruce had lived in institutions since the age of thirteen and was very keen to move into a home of his own. Over the first four years of the friendship, a lot of get-togethers were in Bruce's room at the centre, which was full of the necessities for a future life in the community - from a fridge to pot-plants and fuse-wire.

Those years were full of hope but also frustration. The steps that were needed before Bruce's dream could come true seemed infinite, and some of the barriers appeared insurmountable. Part of the friendship revolved around this dream, and sometimes Penny would help Bruce fight a battle in some small way by writing a letter or going along to a meeting. At other times they did more regular things such as going shopping, or having coffee or a beer together.

In those first years, Penny was greatly in need of friendship. Her marriage had ended, leaving her with two young children to support. She was working hard, was emotionally fragile, and had lost a lot of her former support network. Bruce also had limited social contact outside the centre; it's not easy to meet people when you're in a restricted setting and have trouble getting around, particularly if your speech isn't easily understood. Mostly Penny would visit at night or on weekends, with daughters in tow. They too got to know and love Bruce, and he them. Often Penny's younger daughter, Katie, would fall asleep on Bruce's bed while they talked.

Finally, Bruce's new home was ready. Penny went to the centre to watch with Bruce as the moving-van drove off. The only shadow clouding a day of triumph was that Bruce was moving to the far side of Brisbane. Over the next couple of years Penny and Bruce had contact

less frequently - a few phone calls, a couple of visits from Penny and her family on their way to the Sunshine Coast for holidays. Community living had its ups and downs for Bruce, and Penny's busy life continued unabated. Then Bruce decided to move closer to the city. Although still almost an hour's drive from Penny's place, it was a lot closer than before and they started connecting more frequently.

How do Bruce and Penny see their friendship? From Penny's point of view, Bruce is one of her oldest friends, and a vital part of the network she has rebuilt over the past ten years. From Bruce's point of view, finding friends has not been easy. One downside of community living for Bruce is that he is often alone and Penny's friendship is particularly valuable in that context. Penny and Bruce can turn to each other when things are hard as well as in the good times. They still occasionally work together on problems that crop up in Bruce's life, however Penny is very clear that her relationship with Bruce is that of a friend, not of an advocate. They keep in touch by phone a couple of times a week and get together every month or so.

Penny and Bruce say they've learned some important things about friendship over the past ten years. They say it's important to keep in contact regularly. However they have found that even though they don't actually see each other often, they can stay in contact through other avenues of communication. The fact that they've known each other for so long helps here. They have also learned to include other people in their communication network. Because Penny can't easily understand Bruce's speech, it's hard for him to raise new topics of conversation, particularly over the phone, so sometimes he passes information to Penny through a third person who is aware of what's happening.

Bruce and Penny have been an important part of each other's lives and have shared many good times together. They have met quite a few of each other's friends and family too, and feel they have a richer circle of friends and acquaintances as a result of sharing these connections as part of their own friendship. ■

***“Penny and Bruce
can turn to each
other when things
are hard as well as
in the good times.”***

INCLUDING PEOPLE WITH DISABILITIES IN THE COMMUNITY

- What can Local Councils do?

Julie Walder is Community Services Manager with Townsville City Council. She sees community development work as being like a jigsaw that has many pieces, all of which have to be in place to make a picture of inclusion.

In the last edition of **CRUCIAL** Times, Graham Schlecht posed the question, *Full Integration: Myth or Reality?* I believe that community living is not a myth, however, it is clearly not yet a reality. It is a goal, something to work towards, a piece of work that may never be finished because we will always see that things could still be better.

Graham Schlecht's reminder of the days when the Commonwealth Government was promoting the Disability Services Act of 1986 had a personal resonance for me. My beautiful daughter, Anna, passed away three years later. Although surrounded by a loving family, Anna had few opportunities outside her home and family. She did not attend school until age twelve because the professionals believed that she would not benefit. We did not expect or hope that her future would be very bright. I see now that we were wrong, and that there could have been a future for her. I am still in touch with some of those who Anna had known at Special School. A couple of years ago I was privileged to attend a twenty-first birthday party for Cassie, one of Anna's former schoolmates. What a wonderful night! Cassie's life is rich and interesting, and she has many friends. I am not suggesting that this has been achieved easily, or that life is uncomplicated for Cassie and her family; I know very well that it is not. But it is infinitely better than it was in 1986, and this is true for many people.

There have been many facets of reaching where we are today, and these aspects will continue to be important if we are to make community living a reality. It is a bit like a jigsaw that has many pieces, all of which have to be in place to make a picture of inclusion. For example, we all know determined and visionary parents who have moved mountains. People with disabilities have advocated for themselves. Good legislation, supported by elected representatives with vision, is critical. Bureaucrats who are prepared to go the extra step to get resources for people are also

critical. Individualised funding that is not just to get people through the day, but to support their community participation, work and leisure, is another part of the picture.

Even with all of these pieces of the jigsaw in place, there is still something missing. None of the above will complete a picture of inclusion unless there is a wider community that has the capacity, the willingness, the interest and energy to welcome people with disabilities. It is in this area that Local Government has a particular role.

When we talk about the inclusion of people with disabilities within the community, the cry is often heard: *what community?* or *how can there be community inclusion if there is no community in which to include people?* "Community" is not a single entity, instead, there are a multitude of communities. They may be neighbourhoods, cultural groups, or interest groups. Communities are created when people connect with one another by sharing experiences and interests. Of course, the existence of community does not guarantee inclusion, but without a strong and healthy community there will be no inclusion.

Many people today are concerned at a perceived loss of community, and it is not only people with disabilities who experience loneliness. A public inquiry in Western Australia in 1990 found that "loss of community" was one of the greatest concerns of the people surveyed. In the Townsville region in 1998, a survey of a wide range of community agencies identified 'loneliness and isolation' as major problems facing clients of community services.

Jim Ife explains the problem in this way: *"Instead of having a responsibility to meet the needs of one's neighbours, the responsibility of the citizen is to pay taxes so that somebody else (usually a professional 'expert') can be employed to do the job. Direct responsibility for human services thus moves from the citizen to a team of experts employed by the state, leaving*

the citizen free to pursue her/his private ends unencumbered by the needs of others (except in terms of financial obligation)."

Community building involves strengthening social interactions, bringing people together, and helping them to communicate with each other in ways that lead to genuine dialogue and understanding. Local governments have an important role in community and cultural development because they recognise that people-issues are mainstream to Local Government, and for decades now, Councils have been involved in shaping and building community.

Community development is a way of facilitating this process, but it is not sufficient to simply bring people together and hope for the best. Developing a sense of being a group, building trust, mutual dependence, and a common sense of purpose are all critical. This process is through a range of ways that bring people together to share interests, passions, and have fun. These activities, events, and programs must be undertaken in a developmental way that maximises participation, is based on principles of social justice, develops skills and confidence, and promotes a sense of place.

There are many examples of community development in the Townsville community. I would like to offer the following example, which is based on a vision of inclusion that is still far from complete.

Around 1970, the Townsville Council commenced school vacation care with "Vac. Care" programs operating from community centres and schools. To this day I do not understand how it worked, but work it did! There was no system of booking ahead, and if extra children turned up on the day (which they invariably did), a few phone calls were made and extra staff (usually young students) were brought in. Miraculously it seemed to flow, children had fun, staff survived and nothing drastic went wrong. Some of the children who attended had disabilities. They were present, but I am not sure how well they were included, given the constraints of the situation.

In the mid-nineties the Commonwealth government developed year-round, integrated after-school and vacation services that were linked to local schools. Recognising that its services were no longer needed, Townsville Council considered that its role in providing vacation care was over. But there was a problem; although children with disabilities were able to attend the new services, and Council's Inclusion Workers were available to give support, many of the children who had been in the Council programs were too old for the primary school based program. It was then that we faced the reality that you cannot include people with disabilities into an aspect of community that doesn't exist; there was simply no holiday program for teenagers in the local community.

Recognising this, the concept of the Summertime programs was developed. It represented a vision for a holiday program that would be age appropriate and attractive to all young people,

and would not be modelled on traditional vacation care. This highly successful program has run for four years, and aims to provide young people with daily choices – they can select to go to a workshop, an event such as 3-on-3

basketball, or use one of the discount vouchers on offer. Most of the activities take place during the day but the program includes night/evening activities such as DanceWorx and Dive In Movies. This year's Summertime program had a total of 2662 attendances at both Council and non-Council run events.

The inclusion of young people with disabilities in these programs is still dependent on other parts of the jigsaw being in place. Although Council is able to provide some support for those who need it, the inclusion of children and young people with disabilities into recreation is still an undeveloped area. And so the task continues – that of bringing the concept of community living closer to a reality - with many people having a responsibility to make sure that their piece of the jigsaw is in place. ■

“Community building involves strengthening social interactions, bringing people together, and helping them to communicate with each other in ways that lead to genuine dialogue”

BUILDING A COMMUNITY FOR ALL PEOPLE

Ric Thompson is Coordinator of a small community agency in Townsville that is committed to the promotion and development of meaningful, reciprocal relationships in the Townsville community and Ric shares some of the learnings of that work.

The issue of securing meaningful, relevant and potent experiences and relationships for people with disabilities has been the theme of much legislation and many mission statements of human service agencies. But when we look around, we see little evidence of people with disabilities actually participating fully in the community or enjoying relationships that are freely given and reciprocal. The serious consequences of this are captured in John McKnight's famous observation of a residential facility which, although staffed full-time and located within an urban city they had failed, after eight years, to link any of the residents into unpaid, reciprocal relationships in the community.

It would appear that, over time, governments as well as human services have locked themselves into responding only to the basic needs of nutrition, accommodation, and safety. They have ignored the critical human needs that are identified by theorists such as Maslow who say that human needs such as social belonging-ness, self esteem, and creativity are essential. Social theorists stress that it is our close personal relationships that are the most valued, yet it appears that human services have failed to see this as a priority in the lives of people with disabilities.

In order for services to promote the development of meaningful, reciprocal relationships, we believe there are three principles that are critical to the success of "building community" around the lives of people with a disability. They are: You have to believe that people with disabilities have a place in community, and the capacity to

contribute to the development of community; You have to believe that community members have the capacity and willingness to welcome people with disabilities and their families; You need to let go.

We have also learnt some important things along the way. Some of these include learning that human services cannot manufacture reciprocal relationships; all they can do is assist in the linking of people to opportunities and experiences that may lead to the development of meaningful relationships. This is not to say that human services do not have a role, but they must heighten their consciousness of this important need, and allocate time and resources.

Working in this way, we have also learned that the capacity to contribute to community life is made possible when we identify, acknowledge and promote individual gifts, talents and contributions. The community may offer a number of opportunities, but in seeking those that might result in reciprocal relationships we

must look for the *best* opportunities. When seeking support for people within community clubs or in other experiences we must seek out the *best* person to assist with this linking.

One of the most important things that we have learned is that it is essential to know when support is required and when to let go. We have learned that one of the greatest barriers to the development of reciprocal relationships is the failure to let go so that people in the community can accept a responsibility that was once theirs. ■

"It is our close personal relationships that are the most valued, yet it appears that human services have failed to see this as a priority in the lives of people with disabilities."

LIFE'S WONDERFUL FRUITS & FOLIAGE

Joan Hailstone

It is almost five years since my daughter, Susan, with the assistance of family, friends, and a small community-based service moved out of our family home to establish a home and a lifestyle of her own. When I look back on the changes in Susan's life during those years, I realise I'm glad that some things *haven't* changed during that time. For example, one of the major driving forces in establishing Susan in a home of her own was the hope of a better life for her. Several years ago a friend gave me this small quotation: "*For hope grew around me like the twining vine, and fruits and foliage, not my own, seemed mine*". I keep it to remind me of how necessary it is to be with people who are hopeful. Susan, and all those who assisted in her move, were hopeful people and remain so.

Maybe the "fruits and foliage" of Susan's life could only appear when hopes became intentions, and when there was a framework to support the "growing vine" of her lifestyle. As part of that framework, I have gained some understanding of the complexities of encouraging, supporting, and planning for a better life for my most vulnerable daughter. Probably for the first time in her adult life she is beginning to be herself, and I am learning to appreciate the differences in her. It worries me that, when supporting vulnerable people (particularly those with an intellectual disability) to be part of their local community, many people talk of "strategies" and make pronouncements about "desirable outcomes". However desirable for the planners those outcomes may be, I cannot, and feel strongly that it should not, see my daughter's life with such a degree of predictability. As one of Susan's most committed friends has said, "we need to remain committed to a process that assists her to develop the decent life that is unique to her". Increasingly, I see this process as being like a growing, twisting vine that has a journey of its own.

As well as staying hopeful, another thing that hasn't changed in Susan's life is her persistence in struggling for a life of her own. In spite of

anxiety and confusion at times, she persists. I think I can say with some certainty that she wouldn't want it any other way because Susan's life as an adult, living in the family home, was very predictable. Her commitment to her own home and lifestyle continues, as does her joy of living and sharing it with others, especially the friend with whom she has lived for the past three years.

I cannot underestimate the role of the hopeful young women who have been persistent in their roles of lifestyle support workers. Over the years, they have developed active, creative roles that seek and facilitate opportunities for the "vine" to grow around Susan. Without this outreach role there would be far fewer opportunities for Susan to have and maintain an active social life.

I believe that just as service providers cannot provide a lifestyle of their choosing and call it Susan's, neither can her family, friends or allies. They are all part of the framework that supports the growth, but the fruits and foliage are intrinsically part of Susan. Her outreach to others and their individual responses may bloom for a time as reciprocal relationships, and while some of these relationships will fade away and others may last, each of them is a part of Susan's personal journey. All of these relationships are welcomed by Susan and all have contributed to her life in some way. I do not know many of these people and that is a good way for it to be. I only need to know from observing Susan's responses that she gives and receives many of the personal attributes that we all seek in the gifts of friendship and fellowship.

When I finish reading to Susan what I have written here, I expect to get one of her famous looks - you know, the one that daughters have especially for mothers who talk about them and their lives. And she will say, "Go home and feed the dog" which is her not-so-subtle way of saying, "Go back to your own house, I'm doing OK."



