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@mailbox.uq.edu.au

CRU 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.

EDITORIAL

In this edition, *CRUcial Times* again presents stories and articles which help us to understand many aspects of Community Living. The stories consistently highlight the importance of listening to the person with disability, the importance of families, the importance of relationships and of positive expectations, and the great importance of "the ordinary". In many of the following articles, there is reference to the courage and persistence of people with disabilities whose stories seem to be ones of waiting for others to shake off their prejudices, to break down the stereotypes, and to realise that the ordinary will do just fine!

There is a saying that "you should not spread news if you are uncertain of its truth". A commitment to the ideals of authentic community living can now be supported by mounting evidence gathered from what is being quietly achieved by people with disabilities, their families and friends together with the support of service providers. The stories which we have presented illustrate the widespread changes that have been occurring in expectations and practice during the past decade and these provide cause for celebration and hope.

At the recent CRU Lunch Time seminar, called "Keeping Hope Alive", Beverley Funnell and I spoke about the importance of hope, and of understanding that despair will be inevitable unless we sustain and nourish hope in ourselves. While the nature of hope might best be addressed by theologians and philosophers, it is critical that ordinary people also grapple with what gives meaning to their lives, and to recognise what it is that will sustain them throughout the many struggles in their lives including those associated with achieving community living. CRU trusts that the reflections and stories in this edition will help to sustain your own hope and expectations for people with disabilities.

Many of the stories speak of the importance of families in any pursuit of community living. Not only do families provide the most natural sources of love, care and support, but the stories also demonstrate the advantages which come to people with disabilities when families are empowered and enabled to seek real opportunities for them. The stories are not fairy-tales; all of them are the result of dreams and hard work by people with disabilities, their families and supporters. What is clear is that most people will not have the opportunity to realise their life dreams if their families and supporters don't work with them to achieve a real life.

Service Providers know all too well that it is easier to segregate and congregate, than it is to use resources to strengthen family relationships or to facilitate the building of social networks. They also know that many versions of community living are only pale imitations of authentic community living. However, some of our articles offer examples of service providers trying to recognise, as fundamental to their own work, the aspirations and needs of people with disabilities to belong to family and community life. They provide support in a way which assists people to maintain and develop social networks and they work flexibly in recognition of the unique needs, personality, and situation of each person.

What is clear, is that whenever we see people with disabilities leading dignified, typical lives, this has not happened by accident. It has happened because of the presence of people who believe in the inherent need of the person with a disability to lead a dignified life like other valued people, and the willingness and capacities of service providers and policy makers to arrange their resources to ensure that this is possible. ■

Anne Cross

From the President's Desk

Words and terms can be used so often that they become meaningless. I believe that the terms "inclusion" and "community living" have fallen into this category. When I hear these terms, I often find myself wondering if the speaker knows their meaning. Using such terms can mask what we are truly saying at the same time making listeners believe that we are "speaking the speak".

I would like to offer some thoughts on this issue. I believe that in order for each of us to demonstrate our complete, untiring and persistent embracing of what is really meant by the terms "inclusion" and "community living", we must acknowledge our prejudices and try to gain an understanding of the roots of the prejudice, in order to eradicate it. For me, my religious faith has been important. Recognising that all people are chosen by God, I understand at least intellectually, that this means that we have to be aware of the barriers we erect around ourselves and that we need to make a very conscious effort to go out and reach someone who might be labelled as different. Other people will have varying ways of thinking about and dealing with the acceptance of others, especially those who are labelled as different.

Inclusion does not just mean building a ramp (though in many instances it would help). Inclusion means undergoing a complete paradigm shift to one that is a social justice framework. The four main principles of social justice are participation, self-determination, access to resources and opportunities, and empowerment. Peter Westoboy (a Brisbane social justice activist and author of the book, *Waiting in Line)* stresses that these principles should be driven by compassion and responsibility, and should strive to achieve:

- Equality rather than the passive acceptance of inequality
- Freedom instead of domination or exploitation
- Dignity for all rather than selfishness and individualism
- A sense of the mutual instead of a disregard for community
- Co-operation instead of competition
- The placement of social consideration over the economic
- The will to meet human needs for health, growth and development

If we are personally challenged by any of these thoughts and concepts, this might be a good indicator that we are not simply content to be comfortable with our own set circle of friends, but are prepared to get a little uncomfortable and step outside the circle so that we can join with another person in their journey of life.

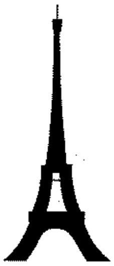
Whilst I would be one of the first to acknowledge that there are many hurdles to overcome before we can even whisper that community living has become a reality for people with disabilities, I believe this is what we must all aim for, all of the time. By not doing our very utmost to uphold such an ideal, and seeing to its implementation in the best possible ways, we are not only betraying people with disabilities, we are actually harming our entire community, because we all belong with, and need, each other. While some are excluded, the whole community is deprived. ■

Cheers, Mike Duggan

A Year in France

Some reflections and learning

KATHRYN TRESTON



In this leading article, the writer shares some helpful reflections about vulnerability, community, and relationship building, based on recent travel experiences.

I cannot say that I have planned a great many things in my life as I like the element of spontaneity. One thing I had always planned however, was to have the enjoyment of living in another country, for at least a year, where I could experience the four distinct seasons, and a different language, as well as different patterns of living from those I am used to. Last year that opportunity came when I departed for France to live in a small farming village for twelve months. I left in a haze of anticipation and excitement.

This was to be my year off. My plan was to walk the countryside, stroll to market each day, cook tasty dishes from French recipes, read lots of books, undertake creative activities, sleep as much as I wanted, and occasionally sneak a pastry from the local patisserie. These activities, combined with getting to know the villagers, and gaining an understanding of village life, seemed to promise a very good year. Most of all, I wanted to slow down the pace of life, and to learn to savour each moment of the experience.

It was a very good year, but I have to say that some of the main experiences came in unexpected ways and became valuable lessons for me.

When we arrived in the village where we were to live, winter was almost at an end. The landscape was quite grim, but beautiful in its own way. Four weeks after our arrival, spring arrived and I was awe-struck. Never had I seen such a change of season. I remember writing letters to friends and family raving about the beauty, variety and colour. The whole atmosphere of the village changed too. Outdoor furniture appeared in every garden. Children played in the streets. Cyclists whizzed past our window. Geraniums appeared in window boxes everywhere. What had seemed a sleepy little village was suddenly quite different.

With a surge of creativity I painted, decorated our house, and planted a garden. I scoured second-hand shops and flea markets, finding treasures. The season seemed to bring an incredible energy. The villagers themselves were welcoming and friendly, smiling and making attempts at conversation with: "Bonjour, Madame. Ca va?" I heard that greeting many times because French social etiquette dictates a welcome to every person as they are met in a new day. I thought it a lovely feature of French culture.

> *"I felt isolated and lonely as it became apparent that it would be enormously difficult for people to get to know me."*

I enjoyed all of these things for three months, then life took on some new patterns for me. The friendly "Bonjour Madame" became an embarrassment because I did not have the language to continue in conversation. I was humiliated because I could not communicate. I did not have the words to ask for my most simple needs and I sensed other people's hesitation in approaching me because they, too, were embarrassed that they were not understood by me. I felt foolish when I misinterpreted people's wishes, and frustrated when I was misunderstood.

I became anxious because everything seemed so "different" and therefore problematic.

I felt vulnerable when I realised it would be extremely difficult for me to get help if I ever needed it, and on one occasion, I had to rely on someone who was almost a stranger to interpret for me when I consulted a doctor. I felt isolated and lonely as it became apparent that it would be enormously difficult for people to get to know me.

This was a bleak period in my year. I was living in a beautiful environment and yet I felt so out of harmony with it. I managed to lift myself out of the depths, and began to look differently at the village and its people, and to identify some key people with whom I needed to start connecting in a strategic way.

> *"I realised that it was the simple things which were making a difference."*

One was a twelve-year-old girl, called Maria, who visited our neighbours several times a week and who seemed totally intrigued by "les Australiens". Maria was very keen to learn English, so reciprocal language lessons became the order of the day. As I watered my garden, Maria and I would chatter and we taught each other much. If I needed help to translate a recipe or instruction, she would do that, and if she couldn't, then she would seek help from someone else and then there would be three people struggling to understand language. We would laugh and mime without feeling self-conscious. I cooked jam and felt brave enough to share it with my neighbours. They reciprocated by giving me home-made pate.

We planted a vegetable garden in a communal area of the village. This provided another opportunity to meet people and to have a chat about the growth of the vegetables and to receive endless advice about gardening techniques. I realised that it was the simple things which were making a difference.

One day the owner of the local grocery store waved excitedly at me with a French/English dictionary. The fact that she had acquired the dictionary to be kept in the store for our use indicated that she, too, wanted to communicate with me.

Many of our own friends came to visit us during that year in France, and those who had children helped enormously. Every day for three weeks, a young girl who lived nearby came to play with our visitors. This meant contact with her mother, her grandmother and her father, and we had invitations to her home. As she accompanied us around the village, we became more and more accepted.

Another key contact in the village was a retired farmer who walked through the village each evening, stopping to chat with every person he saw. He was the village news-carrier. The most important key person for us was an Englishwoman in the village who came to teach us French each Tuesday. We used this lesson-time to ask the hundreds of questions we had, and the one criterion of the sessions was that we must speak French only.

I did do all of the things I had planned during my year in France. Some of the experiences were deep and very enlightening. It became very clear to me that similarities and commonalities are the things to concentrate on when building relationships, not the differences. I know there are some strong lessons in these experiences for all of us about the importance of connecting with each other through simple or ordinary experiences, and about how isolating and vulnerable we are when we are not able to communicate with others. ■

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WHAT KEEPS A PERSON SAFE?

By Sarah Nolan

Keeping ourselves safe in the world takes a combination of strengths, abilities, knowledge, resources, and numerous people who are interested in our welfare. It takes personal resilience, built up over years, which comes from feeling accepted and loved. This starts even before birth, through being welcomed into a family and growing up in that family. "Trying out" who we will become in life needs good role-models, and many opportunities and experiences which include a good education, the development of social skills and relationships, and financial security. It also involves feeling at ease in our local community. Most importantly, it relies on being happy with who we are, and having a sound belief that there are people around us who hold us in positive regard and are interested in our well-being.

For many people with disabilities these "building-blocks of life" are simply not there. Once there is a removal of the basic foundations of family and friends, a person's defences are considerably weakened. If people are not nurtured to believe in themselves, they can fail to gain the inner strengths they will need for resilience in the face of rejection and opposition. They are unlikely to be proficient in dealing with difficulties and will probably lack the resources and connections which would assist them.

It is possible, I believe, for a person to re-build a sense of security and a sense of self-worth. It requires a great deal of commitment from other people who are willing to support the person in an intentional way. One of the most important components of this re-building, is having a place to call home, which is experienced as a place of comfort, refuge and safety. For a person to have a home of their own means having a place to be themselves, to relax, and to rejuvenate. It is a place where a person can collect possessions and keep them safe. It is also where a person attends to their health and well-being. Supporting a person to have a home of their own involves: support in finding and securing a clean, healthy, affordable place to live; support in maintaining that place; and supporting the person to develop a sense of ownership.

A person's self-worth is nourished by positive, repeated messages from a number of sources over a long period of time, usually through honest, accepting, supportive, long-term relationships. People feel worthwhile when they have the opportunity to contribute their individual gifts in life. Supporting a person to develop self-worth can be fostered by getting to know the person very well, assisting them to gain confidence through opportunities, and the practice of successful experiences and interactions.

There are many ways of assisting people to gain and strengthen connections with others. There are ways to reconnect family and friends who have been lost, and ways of strengthening existing relationships. A person can be supported to experience and develop competence in social interactions, and in identifying interests and personal qualities which are those things that typically connect people to each other. It is also important to take every opportunity to present the person in a good light and to support that person to do the same.

A person who does not have numerous other people around them will always be at risk in this world. Building safety in an intentional way must recognise this and acknowledge that such endeavours take real time and commitment over years, not just months; perhaps even the commitment of a lifetime. ■

The Adventures of Melinda Rio

When Melinda left CRU to travel throughout Europe and UK, she promised to keep in touch. Here are some sample adventures from her regular e-mail messages. *We spent a few days in London last week and walked around the monopoly board a few times.... we've met heaps of people.... the spirit at the hostels is really friendly.... Everyone's here for the same purpose, to travel and have a good time.... I'm having the time of my life, but it takes leaving home to know that's really where your heart is.... I'm in Sweden at the moment.... Since I last wrote we have hit Europe.... Sometimes it's hard work being a professional traveller, but mostly it's a breeze. I'm sure, like my time at CRU, that this time will be very influential in my life.*

ADRIAN'S STORY

A parent and a service-provider tell us some of Adrian's story as he reaches an important transition time in the life of a young adult who is moving from school to employment. New social roles have changed Adrian's perceptions of himself and the perceptions of others around him.

I was actually relieved when Special School ended as Adrian turned eighteen, because he had been bored and unhappy for the last three years of school. As his parents, we felt it was time for change. We were not sure what lay ahead for Adrian but we were determined that he would have more options than could be offered by a respite service or an adult-training centre. For the time being we were all relieved to be free of the daily hassle of the bus routine to Special School. Adrian could enjoy the peace and normality of life on our farm. We didn't need to think about the future, for a while at least.

As we began to think about Adrian's future, a meeting was set up with *Pathways*, and I must admit we were a little concerned about which direction this would take us, but the meeting was inspiring and encouraging. In the initial discussions with Adrian, it was explained that the role of *Pathways* was to assist young people with disabilities to make the transition from school to employment. They would focus on Adrian's individual needs and aspirations and support him to achieve them. I realised that for the first time, Adrian was being given the opportunity to make decisions as to which direction he would like to take. Adrian was treated as an individual and I realised that this support was going to build his self-esteem and self-confidence. Adrian was eager to begin.

Some initial plans, by which it had been hoped Adrian would be supported to explore new social experiences outside of the family unit, were unsuccessful. Further meetings were held with the *Pathways* co-ordinator, Kerri, and Adrian began to show interest in finding a job. Although there are many opportunities for work on our family farm, we thought it was best that Adrian be given opportunities outside the farm where he could learn the responsibility of going to work and holding down a job. Kerri introduced us to *Horizons*, a competitive employment service, and with the two services working together, Adrian met Ian with whom he immediately felt comfortable.

Ian has helped Adrian to develop in many ways, both socially and physically. The first steps were to build Adrian's confidence with decision-making, and to help him prepare for employment. Ian also took Adrian to swimming lessons and other activities in the community. We have begun to see a change in Adrian already, even though these activities are only in their early days. Adrian begins his first job in casual employment this month and he is really looking forward to this big step in his life. We are very proud of him and his fight for a valued role in the community. I hope that this is just the beginning for him, and that with the continued support of *Pathways* and *Horizons*, he will realise a future that includes a rich social life, friendships, a job, and his acceptance as an individual in his own community.

Helen Chapman

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At *Pathways*, we recognised that the main issues for Adrian were around the geographic isolation of his home. Adrian had been "bussed" to Special School at the nearest town, rather than having been able to continue to attend his small, local school where he would have developed relationships with his peers. We also recognised the need for Adrian and his family to move slowly in this transitional stage, and to gain confidence with each success. Some steps weren't successful and we went back to the drawing-board once or twice.

Now that Adrian has obtained employment in town, his perception of himself is changing and so are the perceptions of other people. Adrian is beginning to stand-up for himself, to ask for what he wants, and to say what he doesn't like. He interacts confidently with old and new acquaintances and shows a great sense of humour in social settings. As his competencies and self-confidence grow, the people around Adrian see him in new, positive ways.

Kerri Romano

Life is More Exciting When You Have a Voice

Luke, now aged nineteen, tells us about the impact of gaining the means of communication.

The silent scream stayed in my head and never left the boundary of my brain. For fourteen years I had been telling people "Hey, it's me. I really am here. Listen to what I'm saying."

Others said: *You know I don't think he really understands a lot of what we say to him. I think we need to keep it simple. If we can just teach him to sign for what he wants, we will have done our jobs as his teachers.*

I don't need to learn how to sign for drink, food and toilet. I don't care about those things! I am fourteen years old - where are all the other fourteen year old boys in my community?

Hey, I met a wonderful lady, Rosemary Crossley, and she spoke to me. Yes, to me, can you believe it? So there is another way to communicate when you cannot talk, and it doesn't necessarily mean that if you can't talk, nobody is interested in you.

One night I said to my mother: "I cannot go back to that place (special school) because they make me feel like I am an unlovely thing".

She went up to the local high school to enrol me there. So that is where all the other fourteen year old boys are!

Life is more exciting when you have a voice. You can choose the things that you want, and say "no". I like to gossip and I like to have jokes with my friends. When people ask for my opinion, they are seeing me as the man I am.

Sometimes I wish that I could talk to anybody at anytime. I put great effort into using my Canon, and I get tired out.

I really love it when I can order my meal at a restaurant, and I don't have to eat what someone else thinks I want to eat.

It is great to be able to share with someone why I am laughing, or why I feel upset or angry.

I have the greatest time when I am with my friends now that some of them can use my Canon with me. It is great to be able to talk about all the things that I would not talk about if my mum was assisting me with my Canon. ■

Luke Topfer

To the Next Horizon and the One After That

By Joan Hailstone

The last issue of *CRUcial Times*, with its topic of the Community Living Movement, was both timely and important to all families who are committed to the struggle for a real life for their sons and daughters with disabilities.

As one of those families, we have no problem using the word "struggle", because we still struggle (especially in the area of funding), along with our daughter, Susan, for those experiences and opportunities that are meaningful to her life. The past nine years have been a time of great personal change in ourselves, as Susan's parents. This change has been in unison with the changes in Susan's own life as a young woman discovering what real life and real relationships might look like to her. One thing we have known with certainty during these years is that Susan did not want to live in a residential service with nine other young adults who also had intellectual disabilities and high support needs. Susan had tried that kind of arrangement but did not want it. What she wanted was something that was neither available nor even considered appropriate at that time - a home of her own where she had a sense of place, and where she could continue the struggle for an ordinary life.

I agree with the statement "there are no short cuts to a typical, ordinary, real life". It has been two years since Susan moved from our family home to a rented home of her own with the support of a responsive service who, along with family and friends, share a commitment to her as a member of the community. We certainly had no illusions that living in a home of her own would automatically produce all the necessary lifestyle changes for her. Susan has lived in the community all her life and yet her adult life (unlike the lives of her sister and brothers) was not opening out, but was actually closing in on her. As Susan's sister and brothers developed acquaintances, close relationships and friendship networks, then married and had children of their own, Susan's life was becoming increasingly isolated. Nothing began to change, however, until we decided the most valuable contribution that we could make (beside loving her), was to mobilise ourselves and others to assist Susan to make real changes to her lifestyle. We had to look realistically at the risks that this process might bring for Susan, but we also knew that she didn't want to continue being a fringe-dweller and watching others fulfil their expectations, while never really belonging to the wider community herself.

What *is* this community that most of us are part of? What's good about it; what's bad about it? Is it a place where there is no pain or struggle? Of course not, but with all its failings, it's still where most ordinary people choose to live with the "knowns" and the "unknowns". For Susan, and with Susan, we took the risks. We put in place all the safeguards we could, and then took every opportunity that came along to support her day-to-day life in her own home. What we knew, almost from the first week, was that Susan was where she wanted to be. All those years of planning were worthwhile. How we celebrated that change in her life!

The challenge now is to focus on the continuation and expansion of her lifestyle. Susan's own total commitment continues to give us affirmation that we are on the right road. Even the extraction of three wisdom-teeth did not prevent her from loudly stating, "I want to go back to my house now" as we assisted her out of the dental surgery. I continually have a sense of surprise and delight that my most vulnerable daughter has such strength and determination about her own life, although this was previously dismissed as an undesirable trait for a person with a disability.

Our own struggles seem almost insignificant when we recognise what leaps-of-faith Susan has taken in the last few years. Susan now has a few precious relationships and friendships that have developed as we stepped back from her life. There needed to be room for other people to become a significant part of her life. Those people need to be welcomed not only by Susan but also by her family. Whenever we gather with Susan at her home we still celebrate our successes and then ask, "where to from here?" We don't always know how we will achieve the next step, but we do know it won't work unless we share, with Susan, a vision of what her life might look like. We don't argue about whether the step is possible or not, but like Susan, we make a leap-of-faith, believing that together we'll make a start, and if an idea doesn't work, we'll try again.

Susan's life is by no means a fairytale-come-true, but we know with growing certainty that as we listen to what Susan says of her life we have time yet for finding ever better ways for her to continue her journey. For many years now I have avidly read stories and articles from many parts of Australia and other countries that have been written by people involved in some form of community living movement. Recently I have been reading *The Gift of Hospitality* by Mary O'Connell and as I sat to write this article, I kept coming back to her words: "Community, finally, is no different for people with disabilities than for any of the rest of us. It is the free space where people think for themselves, dream their dreams, and come together to create and celebrate their common humanity." ■

Dreams & Aspirations

Helen Williams

As I write this, I'm sitting looking at an invitation to my daughter's anniversary party. Wedding anniversary? No, it's the anniversary of her moving to her own home four years ago. Nothing very unusual about that, you say. However, Merryn is multiply disabled with very high support needs and earlier in her life I could never have imagined, even in my wildest moments of idealism, that she would ever be able to live a life that was independent.

All parents have dreams and aspirations for their children and these differ according to the needs, interests and abilities of each family member. Dreams and aspirations are rarely easy to achieve, particularly in a complex world and when economic imperatives seem to have most sway. Can you image, then, how I feel when I see my daughter achieving things far beyond my greatest hope.

Merryn is almost thirty-seven years old and lives in her own home with three friends. She goes shopping, does her banking, goes out to lunch, goes walking and swimming, travels by public transport, and goes regularly to hear a particular entertainer at a local Leagues Club. Merryn makes her own greeting-cards and helps make gifts for our family. She loves to supervise the cooking of her evening meal.

I can almost imagine the thoughts of parents of a disabled family member reading this and thinking: *This person is exaggerating,* or, *Merryn must live in a miracle-house where, when you cross the threshold you instantly gain abilities you didn't have before.* No, the writer is not exaggerating but, yes, in some ways Merryn does live in a mircale-house, not in the sense of offering instant cures, but certainly in the way of achieving participation in a great lifestyle.

These achievements have come through the work of committed and dedicated staff who see their role as enabling Merryn to live as normal a life as possible in the community, and who take the time to pursue the goal of community involvement and participation for her.

Just to set the record straight, when Merryn does the banking, she does not fill out her withdrawal-form, but she goes to the bank, waits in the queue, and goes up to the teller. In other words, the carer constructs the situation where Merryn is able to participate to the maximum of her abilities in normal lifestyle events. For a multiply disabled person who has few of the skills needed to survive in our complex world, the perception of participation is a great achievement and a joy to all those involved.

Independent living for my daughter is a great success. Its success has been a challenge to my limited faith. It did not come overnight but took a number of years of planning and lobbying. It still requires some family involvement but we would not want it any other way. ■

Thank You For Your Feedback

In the last edition of *CRUcial Times*, we included a feedback form, so that readers could let us know what they thought about the publication. We received approximately 90 replies which will assist us to make the publication relevant to you.

Sincere thanks to all those who provided such valuable feedback.

A Conversation with Tricia

Patti Dietz

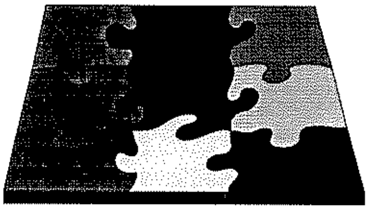
We were sitting at the dining room table enjoying our morning coffee and discussing your upcoming thirtieth birthday arrangements when the phone rang. It was Pam from CRU asking if I would write an article for *CRUcial Times* on the subject of living in the community. "How ironic", I thought because we had just been discussing the birthday venue. I had suggested a hall with easy access for your friends who use wheelchairs and room for a DJ. You had a different idea. The local club was your choice, after all, you use it on a regular basis enjoying the music, poker machines and dining facilities. It seemed the obvious place to you.

My mind flashed back to the time of your birth, as I clearly remembered the prognosis: "extensive brain damage, limited life span with no hope of any normal development". The recommendation was life in an institution. You had already received the "reject" stamp.

What has brought about the miracle of a lifestyle that is entirely different from that prediction? An environment of a loving family who refused to accept the "reject" stamp, and who exposed you to the community and offered the same opportunities experienced by your siblings. You have already completed two courses at TAFE college and are planning this year to join an art class, a movie group and a drama group, as well as undertaking a course in communication at TAFE. The achievements have not come about without love, commitment, and the belief that we all deserve the right to develop a quality of life in our local community.

So, Tricia, where to from here? We will keep dreaming the dreams, despite the struggle of keeping together a network of people to ensure you continue to be part of the community. As a family, who thirty years ago were given no hope, we now know that nothing is impossible. After all, I am sitting here having coffee with a miracle of self-determination who has a strong sense of importance in the world, a deep sense of purpose in life, and who carries the knowledge of having made-the-difference in the lives of those who love you. ■

Finding the Right Support Worker



Leanne Burke

This article is based on the experiences of a small, community-based accommodation support service. The purpose of the service is to provide individualised assistance to people who have high support needs, and it aims at supporting the person to make the same lifestyle choices as other citizens are able to make.

People who have high support needs can utilise a range of formal and informal supports to achieve the things they need and want. They will require help or support with practical arrangements, with making and sustaining relationships, in doing ordinary things, and taking advantage of opportunities that arise. The person requiring support will also have hopes, dreams, likes, dislikes, values and beliefs.

An individualised support arrangement means that the selection process for choosing support workers will differ in each instance. Sometimes workers are found through word-of-mouth because they have certain attributes and qualities, but it is important to note that one support worker is not going to be able to fulfil all the needs of one person. If a decision is made to employ a new support worker, an advertisement is usually placed in a local paper. The advertisement emphasises such qualities as "an energetic, creative person" when describing the kind of person being sought for the position.

During the selection process it is almost impossible to demonstrate to the potential worker the complexities of the work they will do. The question "what does it mean to support a person with a disability to live in a home of their own and make a lifestyle of their choosing?" does not have a simple answer. Our aim is to attract the type of person who may intrinsically understand the "developmental" nature of their support role.

What can an applicant expect if they answer an advertisement by making a phone enquiry? In this instance, the Co-ordinator of the service becomes the first contact for the advertised position. The applicant will receive general information about the lifestyle of the person seeking support, and for the matching process to begin, there is also a need to gather information about the applicant themselves. This information includes such things as: their experience and knowledge of the needs of people with disabilities; their interests; what they have to offer; what they value; and what their motivation was in responding to the advertisement. The applicant will also meet the person they will support, and that person's family and friends. They will also spend time with the person to be supported and perhaps meet other support workers, before a decision is made.

Recently our organisation advertised for a support worker. About thirty people responded and potentially, all had something to offer. All lived close-by and had varying skills and talents. The one characteristic which was missing from the list of applicants, was someone who was in the same age group as the person to be supported. However, after the short-list was finalised and interviews had already been arranged, we received one further application. The applicant was given the opportunity to express why she thought she should get an interview. What was striking about her response was that she identified herself as being in the same age group as the person who was to be supported and said that "older people" did not relate well to that age group.

The applicant was interviewed by the service co-ordinator, three family members and two friends of the person to be supported. At the interview, it was discovered that the applicant had no experience with people who have disabilities, but she was willing to do whatever it took to provide the support required. The person to be supported was not present at this interview because on previous occasions she had demonstrated that she didn't like it when a group of people sat around a table and talked a lot. A morning-tea was held a couple of days later to allow her to make a final decision about who she would like to support her.

It can sometimes take months before the person to be supported is really sure of their preference, but it is extremely important that there is very good matching between the person needing support and the person providing that individualised support. ■

REAL LIFE

Rachel Johnson
& Regina Parley

The work of *Connections* strives to facilitate opportunities and experiences that allow the natural emergence of friendships to take place between a person with a disability and members of their community. *Connections* emerged out of *the Mamre Family Link Program*, and while that program proved successful for many families in establishing long-term friendship and support for their sons and daughters, it became clear through talking with families, that a new and different approach was needed. We began to place emphasis on addressing life-style issues for young people in order for them to have increased opportunities to meet people, to make life choices, to participate in their community, and to build relationships.

Social isolation and lack of friendships are often real issues for young people to overcome. Whenever we hear stories about a young person's life being changed by means of simple, typical opportunities, we are motivated to keep overcoming the obstacles.

One example of this is of a young woman who expressed a great interest in meeting people her own age in her local area. Through her interest in theatre productions, *Connections* supported her to become involved in a local theatre group. After three months of hard work and rehearsals, she took part in a production. Her photograph appeared on the front page of the local newspaper; no reference to her disability was made. The most important aspect of her involvement was the opportunity it provided for her to meet friends of her own age with similar interests and goals, and to develop friendships that extended beyond the activity itself.

It is within the context of simple life opportunities such as having a friend to call upon, a gathering to go to, or plans for the weekend, that each of us gains a sense of belonging and participation. Support for a person with a disability to develop this sense is not about taking the person out into the community once a week, or giving the person choices as long as it's between 9 am and 5 pm. It is about the person being with others, enjoying that time, valuing the person's gifts and encouraging their heart, all of which can be achieved without reliance on paid relationships or token involvement. As workers, we not only need to have a friendly relationship with the person we are working with, but we also need to be creative in facilitating opportunities for that person to meet other people and form relationships in typical ways.

Forming friendships with people we support is not the role of paid workers. If a relationship is a paid relationship, it is not friendship as such. We have a vital role to support people to form natural relationships with others.

Our work at *Connections* provides many opportunities to witness people growing and developing as their lives change. Life inclusion, as opposed to just community inclusion, is what this is all about - real freedom of choice, real dreams, and real hopes. ■

RECOMMENDED RESOURCES

Pam Collins

The CRU Library has resources on many topics. I have highlighted two articles which relate to some of the issues raised in this edition of *CRUcial Times*. To request copies of articles, or any other resources, please contact me by phone or fax at CRU.

1. *Integration,* Chapter 6 from: Leisure, Integration and Community by Hutchison and McGill, 1992.
   This chapter defines integration and explores the area of friendship and relationship building. It also clarifies the common misinterpretations of integration and the assumptions behind the continuum model of service delivery.
2. *A Framework for Thinking about Choice and Responsibility,* by Clarence Sundram, 1994.
   This article focuses on the need for finding ways to promote informed, voluntary choices of people with disabilities, and to provide options that allow them to meet self-identified needs. The article provides some practical ways of dealing with "choice".

The Booker Award winning book, Last Orders, by Graham Swift is well described as "a deeply affecting story of unremarkable people bewildered by the plainness of death and the complexity of living". This passage is reproduced with permission from Macmillan.

It wasn't as though I expected to see her. It wasn't as though it would look any different, because June was there, from all the other homes and hospitals that are an undertaker's regular port of call. Homes, Hospitals and Hospices, where people hexpire. And the worst are the Homes, since you know they aren't homes at all, it's just a sweet-sounding name for a clearing-station for the handicapped or the old, or a stand-in for that word you mustn't use any more; asylum. And you know that for lots of them it wasn't such a short stay, that this was where the deceased ***lived*** *maybe most, maybe all of their life, and that life, in this case, meant a kind of death, a kind of not having a home to go to.*