CRUCIAL TIMES

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10 crucial years

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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.

Community Resource Unit Inc.
Suite 5B, 19 Lang Parade
Ph: (07) 3870 1022 Fax: (07) 3371 3842
Auchenflower Brisbane Q 4066
Email: cru@uq.net.au

Editorial

In a few weeks time CRU will host a three-day Conference to mark its first decade in Queensland. The conference is an opportunity to renew and refresh the movement for authentic change for people with disabilities and their families. We anticipate, with great interest, hearing invited people from Queensland, other Australian states, America and Canada. The Committee and staff of CRU look forward to being in the company of so many people who are engaged in efforts to enhance and enrich the lives of people with disabilities.

In the last edition of **CRUCIAL TIMES**, we began to explore the contributions and potential of smaller community managed organisations which deliver services to people with disabilities. This edition continues that theme and identifies some of the stresses and benefits of working for a small agency and also some factors which might ensure that small agencies last. Readers will find some helpful insights into what we might mean by the word "quality", and why it is necessary to examine the assumptions that underpin any quality assurance systems or application of standards. Some of the articles help us to reflect on the last ten years, making us conscious of the great changes that have taken place in that time. Not all of the changes have been for the better, and there is a sense of disappointment that many of the gains made in the mid-eighties have been eroded. Other writers keep hope alive through their unfailing commitment to members of their families who have a disability, wanting a decent life for them with support arrangements that recognise the potential, dignity and worth of the person.

We hope you enjoy this special edition of **CRUCIAL TIMES**.

Pam Collins

Under What Circumstances Might Small Agencies Last?

Ross Womersley was asked this significant question and he suggests some important factors. Ross is the Manager of the Community Living Project in South Australia.

Several years ago no-one would have dreamt of even asking this question. In the disability sector, it felt as if small community based initiatives were popping up everywhere, born from the outstanding efforts of individuals who have a disability, their family members, and their allies.

These efforts were being welcomed, sanctioned, and even sought out by a series of governments who offered funding to support local communities to take action. For many people with disabilities and their families, the winds of change were blowing in a positive direction. Highly enthusiastic reformers emerged to help lead a number of these efforts. Legislation was introduced which expressed a vision that moved beyond oppression, to acknowledge that people who have a disability actually belong to, and should be seen as a valuable and integral part of our community. In the rush to partake in this process of reform, many small agencies quickly became almost entirely reliant on government grants for their capacity to do what they desired.

> **"The capacity for small agencies to help groups of people to come together, and to work out new and better ways of having a need addressed is now becoming more limited."**

Only a decade or so later, small agencies are now being accused of being inefficient and costly. Government grants increasingly come in a revolutionary new form in which service provision is put out to tender. This process is often complicated and competitive, has a very limited lifespan, and funding frequently comes with many strings attached. Agencies which successfully tender for funds may not even know anything of substance about the people it will serve. The capacity for small agencies to help groups of people to come together, and to work out new and better ways of having a need addressed is now becoming more limited.

The winds of change have been blowing again and the question of how many small community based agencies can be sustained is not far from our lips. Now the fear is that many of these outstanding efforts might not last.

I have an unfaltering belief that many existing small agencies will indeed last. There might even be a new generation of small agencies that emerge, some of which will be for-profit providers. I am equally sure, however, that in the current climate, many larger organisations will grow even larger and that some large organisations will grow rapidly in the short term (e.g. the recent emergence of the Salvation Army in the employment marketplace). Some commentators are saying that this rapid growth may in turn lead to the ultimate decline or demise of a number of these agencies.

Indeed, the larger the organisation, the less flexible and responsive it typically becomes. It tends towards bureaucracy and becomes driven by its own internal needs. It can lose its focus, be diverted from its mission, and misplace the ideals and goals that probably led to the establishment of the organisation.

Being small does not automatically protect an organisation from becoming highly formalised, impersonal, inwardly-focussed, or from ultimately becoming unhelpful to the people whose interests it was established to serve. However, being small does mean that these things are less likely. This is largely because the nature of small organisations means that they are generally more open to the influence of the people they serve. They usually interact with the people they serve in a more intimate way and are generally in a position where any actions they take are more transparent and therefore subject to closer scrutiny. Very often they retain a deep interest and commitment to the people they serve.

The greater the degree to which any of these influences is actually present in a small human service, the greater the likelihood that these influences can positively impel the agency towards staying more focussed on the needs of the people they serve. Moreover, this would suggest that whenever decisions about changes in organisational arrangements are being taken, the test to which any proposed actions are put would automatically be: Is this actually going to be good for the people we serve, in the short term as well as the long term?

I believe that one of the things that will almost certainly lead to the long life of a small agency is a willingness to continually submit to the needs and interests of the people it serves. Small agencies simply cannot afford to become irrelevant to the people they serve. Furthermore, they should have no other reason for continuing. If any service were to become irrelevant to the people it assists, I could think of no better reason for closing the doors.

One of the things that can promote decreasing relevance is the pursuit of organisational growth – a commonly proposed panacea to the so-called inefficiencies of small agencies. Large organisations in particular have difficulty controlling a tendency to pursue growth for its own sake, only later to discover that growth adds complexity to the way an organisation functions and inevitably entails new dilemmas. Small agencies have a very real opportunity to actively choose not to respond to this god-like idol called growth.

This is not to suggest that there may not be circumstances where agencies want to, and should grow. All it attempts to do is to invite each of us to entertain the possibility that, at best, the virtues of growth may be highly over-rated and at worst, may hold a false hope. If growth does mean that a small agency becomes less relevant, less personal and less engaged in the real struggles in the lives of the people we serve, should we still take that path? I think we should not. ■

Committee Members 1997/98

Mike Duggan	*President*
Alf Lizzio	*Vice President*
Margaret Ward	*Secretary*
Janet Millward	*Treasurer*
Patti Dietz	
Elaine Stephenson	
Kelli Haynes	
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Staff

Anne Cross	*Director*
Silke Collisson	*Admin Officer*
Margaret Rodgers	*Leadership Prog. Co-ord*
Lake	*Admin Officer/Prog. Support*
Pam Collins	*Resource Consultant*
Beverley Funnell	*Consultant*
Jane Sherwin	*Consultant & Educ Prog.Co-ord*

From the President

In the previous edition of **CRUCIAL TIMES**, I referred to a time of my life in an institutional setting when, for the convenience of staff, residents were "pyjamatised" before attending residents' meetings in the evenings. Why did we want to attend those meetings anyway? In doing so, we were paddling against the stream, and it would have been easier not to cause the wrath of the staff. But something was driving us to do it; it was a demonstration of our individual and collective drive to somehow have a voice in influencing our destiny.

After escaping the institutional setting, I found myself strongly drawn to furthering those attempts. Shortly after re-establishing my rightful place in the community, I had the good fortune to be involved in the development of a supported acommodation service. I believe that in each of these stages of my life, a similar set of skills, strong resolve and vision was needed. Five or six years ago I became involved with the Community Resource Unit. I was drawn to CRU mainly because of its commitment to bring about positive changes for people with disability. CRU's resolve has always resonated deeply with me.

This month CRU is celebrating its first decade. Following the introduction of the Commonweath Disability Services Act, CRU virtually came into being on the crest of a wave. With this landmark piece of legislation we finally had a tool with which to bring about long-lasting, positive change for people with disability, for their families, and for human services who supported them. Unfortunately, however, the last ten years have been far from easy. Following the birth of New Federalism, legislative powers and monies were handed over to the States, or rather, they were promised to them. Each State was left to come up with its own version of the Disability Services Act but in the majority of cases, these versions watered down the original intentions of the Commonwealth Act.

Ten years is a time for celebrating those things which *have* been achieved by the many groups and individuals in Queensland who have sustained their efforts to bring about positive change for people with disabilities. Along with all those people who will help CRU to celebrate at our Conference, I want to say "Happy Birthday, CRU! And may all of us feel revitalised from the Conference because we have a lot of work ahead of us". ■

Mike Duggan

Some Questions About Quality

It is generally agreed that monitoring and evaluation are important safeguards. ***Anne Cross*** *identifies some important questions that are fundamental to any examination of what is meant by "quality".*

The "carrot" that has been offered to the disability sector in the Disability Reform package is the introduction of Quality Assurance systems. Of all the reforms, this initiative offers the most promise of providing something to the disability sector that directly supports the provision of services which are relevant to the needs of people with disabilities and their families. While the most asked question is: will this be funded? and the answer is that nobody knows, an informed debate about the concept of quality is important.

Fundamental to any discussion about quality assurance is the question: what is meant by "quality"? In one sense, no monitoring system can actually assure quality. For example, the presence of quality assurance systems may tell us something about how well organised a particular program or agency is, yet tell us nothing about the relevance or quality of the program to each person served by that program.

Struggling with what we mean or understand by "quality" must precede the selection of systems that are used to measure quality. Traditionally, the word quality meant excellence or superiority, yet increasingly it is used to mean the relative nature or standard of something. It is often used in reference to a poor-to-excellent continuum, with all stages expressing some level of attainment of quality. The so-called quality assurance systems which are now in vogue grew out of the need in various manufacturing industries to maintain quality-control, mainly by comparing the output with a sample that was deemed to be of the desired quality. But such conformity in human services would not denote a program of high quality.

If a service is genuinely good, then it must be of distinctive benefit to each person being served. While in many ways all human beings need the same things, our needs are multi-dimensional and the particular expression of those needs will be unique to each of us. Therefore the relevance of what is provided by a service has to be relative to the needs of each person being served.

In order to discern "quality" and "relevance" in relation to the people who are served, we need to deeply consider such questions as: Are the people being served actually better-off? Are their physical needs being attended to? Are their positive roles being defended, enhanced and extended? Are their skills and competencies being utilised and extended? Is the person encouraged to exercise an appropriate level of autonomy? Is the agency guarding against further risk or harm coming to the person? Does the agency respect and enhance the person's positive relationships with family and friends? Can the agency see the potential in the lives of the people being served? Does the agency have a clear sense of the scope of its responsibility?

Underpinning all these questions is the importance of determining what is **optimal** for any individual. If an agency does not have a view of what is optimal, then it is probable that it will not reach a high level of excellence. If all the people employed by an agency do not share the view of what is optimal, then a high level of excellence will be unattainable. Quality primarily comes from people, not organisations. The personal qualities of staff are crucial to the quality of a service. Quality will reflect the collective and individual strengths of the people involved in the provision of service. It will also reflect the power of assumptions, expectations and ideas about the people being served.

What is of concern to me is that many evaluation systems measure trivial components, rather than ones that are important, and use **minimal** rather than optimal standards. They serve bureaucratic, political and managerial needs, rather than the need to genuinely seek improved service quality. They measure what is said or documented, rather than what is done, and are based on low expectations about what is possible for the people being served. They accept mediocrity as the norm, and many do not even make explicit the many assumptions which underpin any evaluation.

If the efforts in Queensland to introduce service evaluation in a standardised way are to support quality improvement, then it is critical that the notion of excellence is not lost to the formalised, routinised checking of easily-measured things. The quest for quality must focus on better lives, and not just on better processes. ■

Creating A Personalised, Local Service

Beverley Funnell introduces some inspiring families with whom she is presently working.

In February this year, a group of families from northern and western parts of Brisbane came together, united by a desire to have a service established that would respond to the needs of their sons and daughters with disabilities in a way that is respectful and personalised. Mostly they are families whose relative does not have an existing supported-accommodation service or if so, the family has serious misgivings about the quality of the support being provided. This group has come together because they do not want "just another service" but one that develops from the inside out, creatively shaping itself around the person, the person's family and friends, and situated in their local community.

Naturally there is some nervousness and uncertainty about what might be involved in creating a new service. From a group of about thirty people, a core working group has been formed, which will steer the developmental stages of the new service. It will take a lot of work but the families are determined to see it through. I am inspired by these families and am very pleased to be part of the working group. I am impressed by the fact that after many years, they have remained steadfast, hopeful and determined to achieve quality support for their family member.

Four of them have agreed to share their stories, which follow.

▸ Craig's Family

by Anne Roveta

Last year, subsequent to some very traumatic events, we removed Craig from the residential service where he was living, and brought him back home. We are now pursuing a dream for our son – a dream which we are working to turn into a reality. To many people this dream is simply a right which all of us expect for our children, but because of Craig's disability it is a right for which we have to plan, work for, and advocate on his behalf.

Our dream is that Craig will be able to live in a home of his own, sharing it with a person of his choice. It includes the desire we have to safeguard him from all forms of abuse or exploitation. Our vision also works towards the creation of a small community based agency in which Craig will be known personally. The service will be committed to safeguarding him and will assist him to live a lifestyle that suits his own interests and needs.

During the present transition stage in which Craig is living at our family home, we are endeavouring to form friendships which we hope will act as a safety-net and support for Craig's future. We are also focussing on developing skills which we think will increase Craig's feeling of self-worth. Every person is entitled to feel the satisfaction of achievement, the joy of shared interests, and the comfort of friendship. This support will continue during the period in which the new service is being developed.

In this transition period, we are very fortunate to have the help of a group of wonderful young people who are providing in-house support. Craig now spends time each week involved with people with whom he is compatible, and engaged in activities which both enjoy.

There are many reasons for the success of the relationships between our son and his new support-workers. There is mutual respect and liking. From Craig's point of view, this has occurred largely because the workers have taken time to know him, to find out his interests, as well as to find out what causes him to feel anxious or afraid. They have also been prepared to listen to, and to act upon the knowledge which we, his parents, have accumulated over Craig's lifetime. Joint activities have been successful because they have been approached in a positive, enthusiastic manner.

The key to success has been in the quality of support workers. These are the qualities we are looking for in the new service which is being developed. ■

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The following writers, who have strong connections to CRU, w

▶ Lesley Chenoweth

As I think back on the first day of CRU I remember feeling apprehensive yet thrilled to be part of something that would surely be an exciting task, even if it was quite formidable. It took courage to undertake a lot of the work. There was fear and resistance to many changes, and I think there are still elements of that.

After ten years CRU has shown that it is a serious long-term player. I think it has been able to do that by sticking to a set of core values and beliefs and by being constant in its central activities of training and development. But CRU also stretches itself to include new projects such as the Leadership Development Program and its publications. Along the way CRU and its people have steadfastly built a community across the state and beyond. They have some thoughtful insights to offer on change, on the power of stories, and on the contributions made to our communities by people with disabilities and families. They also understand the value of celebration. I wish CRU well!

▶ Carol Holt

As I reflect on my eleven years in the Department of Families, Youth and Community Care, as it is presently known, I am aware that I have witnessed many significant milestones including the Commonwealth Disability Services Act, the Commonwealth/State Disability Agreement, and the Queensland Disability Services Act. These major changes have required the government and non-government sector to develop a new way of working together.

CRU has played a significant part in this process. I feel very privileged to have been on the steering and management committee when CRU was being developed. Since that time CRU has been a leader in articulating and responding to the needs and concerns of the disability sector. I congratulate CRU on their achievements and like to think that the theme-words for their 10th Anniversary Conference, "Gathering the Wisdom, Enriching the Spirit, Embracing the Future" reflect part of my own personal journey as a worker in the disability field. While it is for others to judge my contribution, any wisdom I may have gathered has been a result of all the strong and wise people I have known.

CRU's MISSIC

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al years

asked to reflect on ten years of CRU's presence in Queensland

▶ Catherine Raju

My memories of the past ten years of CRU are as someone "on the edges", as an early committee member and, at various stages, as a client of its services. The memories are selective, sometimes intense and, in reflective moods, filled with feelings of gratitude for the difference CRU has made to the lives of people with disabilities and families like mine in Queensland.

I don't know what the next ten years will hold for CRU. It is true that the lives of many people with disabilities and their families have changed for the better. But the current state of funding, government attitudes, and the dangerous element in community thinking about respect for life generally means that we still need people committed to a role that will "challenge, inspire and encourage".

▶ Rae Litzow

Ten years ago I was new to the disability field. Keen to learn, I soaked up new ideas. When CRU came into existence I remember going to a meeting at Yungaba where Anne Cross and Margaret Ward spoke. I was very impressed with their knowledge and their vision.

I am still working in services for people with disabilities. When I look back, I know that I owe a lot of my development to CRU. They have been there to challenge and support me.

Congratulations to the many people who are a part of CRU, and particularly to Anne and Margaret who had the vision at the beginning, and who continue to look ahead.

▶ Graham Schlecht

While some of us have focussed on the shape and size of the trunk of the Queensland disability tree, and others have focussed on the strength of the branches and the colour of the leaves, CRU has quietly worked at strengthening the whole tree. CRU has involved itself with all stakeholders and has endeavoured to prepare all of us to add value in what we do, so that people with disability can live their lives more fully. CRU has been instrumental in nurturing both growth and quality and this has left our tree in good shape. We Queenslanders look forward to another ten years of healthy growth for the disability tree with CRU ever vigilant in its support.

STATEMENT

the lives of people with disabilities.

o pursue better lives for people with disabilities.

Mary's Family by Marion Deveney

In 1992 our daughter, Mary, was a full time university student in permanent, part-time employment caring for people with disabilities. During that year she was involved in a car accident and came home a year later severely intellectually disabled. Mary was completely mobile, but had no speech, no object recognition and no comprehension of language. Hospital staff, who had been extraordinarily competent and caring, felt that some improvement might occur over the following year or so. The teenager who was a full-time student, chairperson of a student organisation, and dedicated carer now needed full-time care herself.

As her parents, we thought of our own mortality and began to discuss the possibilities for Mary's future. We wanted Mary to always be cared for in the emotional and physical security of home. We also wanted to be part of a joint effort to choose Mary's carers. Such activities as going to church and shopping were enjoyable events in Mary's life but we hoped these could be expanded to include other activities with the support of workers.

We believed our expectations for the future were simply a Utopian dream until the co-ordinator of the respite service spoke to us of a small community organisation called *Homes West*. We were invited to meet other families who are in a similar situation to our own, to see if our aspirations could be achieved. We met at CRU and found that a common thread in our lives was a burning desire to see our sons and daughters live as independently as possible in a setting which is as little different as possible from that of other people. Each of us is looking for lifestyle support which will enhance the dignity of our sons and daughters who are unique, treasured individuals, able to make valuable contributions to their community.

Our Steering Group now meets regularly. We are formulating our needs, as well as the expectations we would have of a service. It will be a service which respects the value, dignity and personhood of each individual it will support. The role of families will be essential in major decisions, including the selection of staff.

Hopefully, in a future edition of **CRUCIAL TIMES** you will read of a successful outcome. ■

> ***"Each one of us is looking for a lifestyle which will enhance the dignity of our sons and daughters who are unique, treasured individuals, able to make valuable contributions to their community "***

Maria's Family by Elsie Burke

The Steering Group I have joined holds the belief that a small service has a chance of achieving the vision we hold for our sons and daughters. One of the things that always strengthens my resolve to keep participating in the struggle for a better life for people with disabilities is when a group like this forms.

As parents of adult sons and daughters we want them to have choices of whether they leave home to share accommodation with friends, get their own home or continue to live in the family home with support which acknowledges their adulthood yet safeguards their vulnerability.

The contribution that my daughter, Maria, has made to the lives of her family and to others, knows no limits. All this has been despite epilepsy, severe intellectual disability, having no speech, and very limited opportunities, as well as having spent seven precious years of her life in an institution. My heart still goes cold when I ponder how I allowed that to happen. How can we justify the separation of a child from her family simply because she has disabilities?

Maria continues to overcome barriers. Her love for her family is unconditional and her circle of friends enriches her life. Maria now has her own home unit and support staff, and her family and friends continue to address the complexities that surround people with disabilities, wanting them to have a life in the community over which they exercise control.

Along with other families who have formed this new group, we believe our dreams for our sons and daughters can become a reality. ■

Chris's Family

by Pam Watson

I believe that as long as you are a parent you are always going to want to be somehow involved in the life of your child. However, if your child has a disability, that degree of involvement is very different and lasts a lot longer - forever. What I am trying to do for my son, Chris, is to set in place safeguards that will enable him to lead a life similar to that of his brother and sister, or anyone else of his age.

For some time I have had a goal that Chris will be in his own home by the time he is twenty-one. Whether or not I achieve this is another thing, but I believe it is important to work to some sort of time line. Chris is leaving school this year and we have other things happening in parallel with this event. Part of this is to look at how best to utilise the *Moving Ahead Program* for Chris. He should be able to enjoy a flexibility of lifestyle in the same way as others of his age, and does not belong in a day-respite centre, sitting idle. Being a part of meaningful things such as work or a TAFE course, socialising with friends, and having a home is what most people aim for, and there is no reason why Chris should not have the same. Like any individual, Chris is a contributing and benefiting member of the community.

Like many other parents, I do not wish to be burdened by the fear of the future - a future when I am no longer able to participate in Chris's life. I can only hope that being involved in the setting up of a service which will be committed to Chris as well as understanding the importance of the involvement of his family and friends, will put safeguards in place to ensure a decent life for him when I am no longer here. ■

Small Agencies: The Pressures And Benefits

Jude Hose, of Rockhampton speaks about her experience as the Co-ordinator of a small agency and describes some pressures and benefits.

Community managed agencies have an important contribution to make to the disability field. Ordinary people, who see a need, are able to take authentic ownership of specific issues. They can do mighty things, simply because their involvement is their chosen action.

I was a member of a community group which sought funding for the provision of flexible support, tailored to the needs of the individual. After nearly five years I found myself on the other side of the desk, realising that sharing the planning, decision-making and crafting of policies at a committee level is a far cry from actually implementing them at a service management level.

> **"Even though community managed agencies hold enormous promise for good service provision, much depends on the quality of staff."**

While relationships in any agency develop more easily when people are working together for a common goal, it is in the context of a small community based agency that one is more likely to hear, first-hand, the life stories of people with disabilities who have experienced rejection, discrimination and exclusion from real life.

Community managed agencies, by using personal contacts, family networks and the wider community, provide a unique style of assistance which reflects the local culture and enables service users to remain a valued part of the local community. The support provided can be more flexible, can respond quickly according to circumstances, and importantly, it keeps control of the situation in the hands of the service user, thus avoiding the stresses inevitably connected with highly formalised structures.

Even though community managed agencies hold enormous promise for good service provision, much depends on the quality of staff. Lifestyle Assistants who choose to make a commitment to small agencies are unique in their desire to do the very best they can in order to provide quality one-to-one support. Their generosity of spirit in applying themselves to difficult situations, often at the oddest of working hours, is way beyond the requirements of most careers.

Community agencies are unique. They represent the outcome of combined voices of ordinary citizens who have seen a need in their community and have been motivated to do something positive about it. There are many challenges, but the rewards of community based agencies lie in the knowledge that the clients are gaining a service which enables people with a disability to live within local networks, and places them in control of the changes which take place in their lives. ■

Three support workers also speak about their work in a small agency, describing some of the pressures and benefits as they experience them.

Kaye Cumming *Brisbane*

Along with four others, I provide support for a thirty-year-old woman who has her own home and an active social life.

A major aspect of my work is to join various groups and become involved in the local community with the person I support in order to help her establish friendships. The aim is that she will eventually become involved with members of the group, thereby making it a totally independent experience for her.

One of the difficulties in these situations is knowing when and how to be helpful, while at the same time encouraging the supported person to be more independent and allowing other people the space to interact with her. For example, people tend to see the worker as the group member, instead of the person who is being supported. It is frustrating to attend an activity week after week, and feel that while the supported member is liked, she is not really seen as an active member of the group.

Sometimes I find it difficult not to let my own personality and preferences influence my judgement of situations. Because I have supported the same person for almost four years, each of us knows how the other is likely to react to particular situations. Therefore one of the greatest challenges is to remain focussed on how the supported person is enjoying the experience, and to not let my own impressions, fears or prejudices negatively influence her.

I am proud of the fact that I work for such a pro-active group of people and I have felt a shift in attitude since I have become a permanent staff member of the organisation. I feel that I am now more part of the organisation, with responsibilities towards ensuring its continued existence. For example, under industrial arrangements, the organisation now has to find the resources to provide staff with holiday and sick-pay so, in order to lessen the strain on the organisation, we tend to swap rosters if we are ill in order that only one wage needs to be paid. We also try to link our recreational leave to times that fit in with respite-care and family time.

In addition to staff meetings, I also attend the Circle meetings. This "circle" of people is comprised of family and friends of the person who I support, along with the service co-ordinator. They come together to discuss long-term goals and the strategies for achieving them. They make the major decisions regarding the life of the supported person, and drive it in a particular direction. This helps me to see the overall picture of what they hope and plan for her future. It puts my job into perspective and I find their energy and enthusiasm inspiring.

Mark Chesterfield *Townsville*

I have found the benefits of community based work are both abundant and varied. Foremost in my mind is the understanding I receive from those assembled around me. They also live with the pressures of demanding roles, yet their support is never far away.

In my role as a lifestyle support worker, I appreciate the opportunities afforded to me and to the families with whom I work, and I have a strong sense of being supported by all the people around me. This is in direct contrast to my previous role as a residential care worker which often left me with a sense of confinement, similar, I believe, to how people under the care of larger institutions must feel – those same people I previously worked for, but not with.

Mark Wellington *Townsville*

For the past year I have been employed by a small, community managed organisation, working with a family to support one of its members.

Despite being employed to assist an individual, it is evident that this person impacts more emotionally and physically on the family unit than any other member. Through the collaboration of the agency with the whole family, other family members affirm and consolidate any new, developmental experiences of the person receiving support, enhancing the effectiveness of the support.

During the past few months, successes have become more regular, and expectations higher. The work is supported by a small working group of parents, co-ordinators, workers and, at times, outside expertise or advice.

Although there are external pressures on the organisation, and issues tend to come and go, the family and I have the confidence of knowing that the organisation is dedicated to helping a young man to reach his potential. The only real pressure that I face in my job as principal worker, is to *not* feel that I have made a difference.

Karna's Story

During the recent evaluation of a small service in North Queensland CRU identified how the agency had responded to a family in the local community. The story is told here by Karna's mother, ***Manja Larsen*** *of Atherton Tableland. Manja believes that the effectiveness of the service lies partly in the fact that the committee is mainly comprised of parents, who are very clear about what is needed.*

Our daughter, Karna, was born with cerebral palsy and epilepsy in 1978. Karna uses a wheelchair and has very high support needs. She is unable to speak or do any self-care. Karna went to Special Kindergarten and later to Special Education units until she was eighteen years of age.

Only in the last two years of high school and after our involvement with *Tableland Community Link* did Karna spend some of her time in "normal" classes at her school. Suddenly students from Karna's school would say "Hello" to her in the street. That had not happened before. Karna began to be known in her community.

When I first became involved with *Tableland Community Link* and learned about their belief that people with high support needs should be part of their community and live fulfilling lives, I could not see that it was possible. The only things I could see for our daughter's future was to either work in a sheltered workshop, go to a day-respite centre, or stay at home with me for the rest of her life, or mine. There was not much for me or the rest of the family to look forward to when Karna left school because everything was different from other families, and much more complicated it seemed.

In Karna's last year of High School, the co-ordinator at *Tableland Community Link* could see that the few hours each week of "community involvement" for Karna would not be enough to give us any kind of normal life. They assisted us to make a submission for individual funding for Karna, seeking thirty hours of support each week. To our amazement we received the funding and when Karna left school a new life began for her.

Tableland Community Link, in conjunction with us, employed lifestyle support workers who were of similar age to Karna. Each day they take Karna out, or spend time at home. To date, there are four different places in town where Karna and her support worker have been doing voluntary or paid work for a few hours each week. Karna has been attending a self-development course where people have enjoyed being able to spend time with her, so all this benefits not only Karna but her community as well. After Karna started attending the course, a new ramp was added to the building, making access easier for other people as well as Karna.

Karna goes to most places that other people of her age group go. I believe that in being part of her community, Karna helps people to understand her and that this encourages tolerance and many other qualities in people that are sometimes forgotten in everyday life.

There are times now when I am introduced as "Karna's Mum" and the person says, "You know, Karna who works at...". ■