

CRUcial Times

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Editorial	1
From the President's desk	1
One size does not fit all	2
A vibrant network of support	3
Advocating for change	4
Is bigger better?	5
Competitive tendering	6
The privilege of sharing	7
Valuing each other	8
EI's story	8
Pursuing the dream	9-11

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.

EDITORIAL

In this edition of *CRUcial Times*, we begin to explore the contributions and the potential of "smaller" community organisations which deliver services to people with disabilities in Queensland. The field of disability services across Queensland faces many issues, including the ongoing reform of services which are sub-standard or which do not reflect the principles and objectives of the Queensland Disability Services Act of 1992 or of the Commonwealth Disabilities Services Act of 1986. One challenge, however, lies in the need for a re-examination of the commitment to the existence and development of small, localised agencies which are either community-managed or consumer-managed. Two articles in this edition, by Beverley Funnell and Morrie O'Connor, highlight for us that the very existence of small providers is being threatened by the dominance of economic rationalism. The disability sector in Queensland will need to consider what it is prepared to strive for, and to safeguard, as we face internal and external challenges to the provision of quality services.

In Queensland, five large service providers receive 47% of the funds provided through the disability program of the Department of Families Youth and Community Care. The remaining 53% goes to 190 small and medium-sized agencies. Many of these agencies have developed since the Commonwealth legislation of 1986. Some of them have developed in order to fill service gaps, while many others were created as a way of developing different options for supporting people. Currently they serve many people with disabilities and families. They also provide opportunities for people with

disabilities, their families, and other community members to influence what happens.

During the last financial year CRU worked with, or had contact with, over ninety agencies throughout Queensland. With the support of the Department of Families, Youth and Community Care, CRU will this year explore further ways in which the contributions of small agencies can be strengthened. The benefits and challenges in community organisations are numerous. In this edition of *CRUcial Times* several families, people with disabilities, and committee members have contributed some personal accounts about why they are involved in small, localised services. In later editions of *CRUcial Times* we will further explore the benefits and challenges in this substantial part of Queensland's disability sector. ■

Anne Cross



From the President's Desk...

For one period of my life I lived in an adult residential centre with approximately seventy other adults who had disabilities. The institution was conducted on a custodial model dominated by routine, rules and regulations. Decisions were made by the staff and imposed on the residents.

Then a new person came into the role of Administrator. This person was considered quite progressive for that time. He wanted the residents to have more say in their daily lives. He encouraged residents to choose the décor of their bedrooms, select the menu for meals, and the 'big one' was for residents to be involved in the selection of staff. In order to achieve all of this, a residents' committee had to be formed. Being very eager about what was, at

that time, a new concept for us, I became the inaugural Chairperson. How well I remember that we had our meetings wearing our pyjamas. Naturally this wasn't of our choosing. This was solely for the convenience of staff. We all had to be in bed before the staff went off duty, and if we were 'pyjamatised' before our meetings, it was easier and quicker for staff to bundle us off to bed afterwards.

I believe that these meetings were quite significant to the development, and to the subsequent maturing of those residents who gathered. Initially progress was slow but steady. We spent many hours discussing food and menus. Maslow could tell us why, and I feel that it was necessary for people to have gone through this process. When I left that institution, there were people serving on all kinds of sub-committees, from food/menus (of course) to recreation, and even staff selection.

After leaving the centre and starting to re-establish myself in the community, I was invited to be

involved in the development of an advocacy group. I became the President of that organisation after its incorporation and held the role for four years. A similar process happened with a community-based accommodation support organisation.

I am now the President of CRU – an organisation that works for the promotion of positive change for people with disability. I find this very exciting – sometimes tiring - but still rewarding. One of CRU's major goals is to seek out and work with medium and small agencies who want to safeguard those elements which contribute to responsive service delivery.

My reason for giving time and energy to the small organisations in which I have held office over the years is that I try to encourage as many people as I can to become involved in the change process, and to have a say in ensuring positive changes for better lives of people with disability. ■ *Mike Duggan*

ONE SIZE DOES NOT FIT ALL

Very often, important things are not recognised until they are lost forever. This is as much true of services and groups in our communities as it is of individual people whose worth we may only fully appreciate when they are no longer present. It appears that, as human beings, we are not always able to recognise the real merits of things while we are immediately affected by them.

We are presently witnessing the disappearance of many services from within our communities, and the very nature of our communities is changing as a consequence. Small district hospitals, schools, and local branches of large banks have all come under the heavy hand of rationalism. The economies-of-scale argument holds great sway. This phenomenon is relatively easy to understand when it is applied to the manufacture of products (which is where its usage originated), but its application to services in which relationships between people are central to the transactions, is of fundamental concern. In human services, one-size certainly does not fit all.

Small organisations have considerable potential to make positive contributions at an individual and family level, as well as at a community level in our society. It is essential that we begin to name their important characteristics and qualities so that we can safeguard what we will, inevitably, mourn if they pass from us.

In Australia we have a long history of people coming together to solve problems and meet needs.

Community organisations are part of what Eva Cox calls "social capital". She says that such groups are usually run democratically; people participate because they want to; their processes involve members working together on tasks, developing trust, and engaging in mutually rewarding relationships.

In small community services people can be known more personally, thus increasing the likelihood of supports being highly relevant to the person's needs. Local services can support people to stay in familiar surroundings and to remain a part of their network of family and friends. In this way, it is more likely that people with disabilities will be seen as "one of our own" in our communities.

Community organisations can remain small enough to avoid the difficulties associated with over-professionalisation and highly formalised systems. People in community management roles provide an important opportunity for ordinary citizens to manage issues which they are concerned about.

Small community organisations are currently facing internal and external pressures. Internal pressures upon service agencies have been mounting over many years. Maintaining a positive vision, staying focussed on the people being served, and grappling with difficult issues are perennial internal challenges for community organisations. Fatigue, lack of competent leadership, loss of vision, and failure to listen to the people being served are all examples of some of the things that limit the capacity

of community organisations to achieve their potential.

Overlaying these internal stresses are increasing pressures which often distract management committees from their fundamental purpose, and redirect their energy towards external requirements such as funding bodies and industrial regulations. On top of this we are now seeing the impact of market values on human services. The economic-rationalist language of competitive tendering, managerialism, purchaser-provider, outputs, and efficiency, is presently heard in much of the discourse around human services.

Following trends in Britain and USA, governments in Australia are shedding many of the roles and responsibilities associated with welfare and social services, looking to non-government and private interests to take up these services. John May from the University of Queensland believes that it is important for community organisations to resist attacks on their roles as non-government entities. He

says these organisations need to assert their autonomy and uniqueness, and not be treated as "little fingers of the state", because they are autonomous representatives of community, and not simply a convenient conduit for public services.

It is not the purpose of this article to glorify community organisations in a sentimental way. Those who are involved with them will testify to the challenges they face and the deficiencies they frequently try to overcome. In spite of the difficulties, most of them persevere in their efforts to provide an appropriate response to the life situations of people with disabilities. The spread and diversity of service provision in Queensland is quite unique in Australia and one of which we should feel proud. It is important, however, that we understand what is at stake, and not take things for granted. Let us not lose them before we have learned to appreciate them. ■

Beverley Funnell

A Vibrant Network of Support

Margaret Ward tells a story that shows us what is possible when there is a commitment by services to be responsive.

By their very nature, the needs of people with disabilities and their families are forever changing. It is one of the greatest challenges of service provision to offer meaningful support and to meet those changing needs.

Now that our daughter Mena is aged eighteen we consider ourselves experienced service users. We have had our fill of Education, Therapy, Early Intervention, and Respite. We have used State wide, Regionally Structured, Centre Based and Outreach services, managed by Client Service Co-ordinators, Area Managers, and Regional Directors. We have been promised positive consumer outcomes, more effective and efficient service provision, and greater capacity through output based funding, service standards and service accountability. In most cases these promises were empty.

On the contrary our Family Support service has met our needs. It is community based, has the trust of our family, is informal and creative in its processes, and ready to respond to our changing needs. I believe that these characteristics make it successful.

In 1990, Jo came to us as a Family Support Worker. She quickly fitted into the rhythm of the family, meeting our extended family and embracing the little activities and rituals which were important to us. Jo introduced Mena to her own family, and involved Mena in her interests and activities, and even though she no longer works for us, her relationship

continues. Seven years after coming to us, Jo meets Mena at an art class once a week, is involved in the planning of her goals for next year, and often invites Mena to dinner or for a weekend.

Mena's connections in the community have expanded through her involvement with Jo, not only through the relationship with Jo as a paid worker, but also through Jo's ongoing friendship with Mena.

On the occasion when we met Judy, as a new Co-ordinator of the service, we invited her to dinner. She was pleased and felt this was an honour. After dinner our boy, Jonny, presented some chocolate as a treat. It was melted and squishy. As it was handed around, each child scooped a fingerful and passed it on. When it reached Judy all eyes were on her. Without flinching she scooped her serve and passed it on. She was accepted.

It was important that she gained the trust of the whole family and this allowed us to share our concerns and to work with her in providing the right support for us.

A few years ago, one of our worst fears came true; I became very ill and was suddenly hospitalised. The family was heading into chaos and we had little capacity to call for help, let alone to plan for what we needed. Somehow, through the grapevine, Judy heard of our situation and approached us with offers of assistance. I think we were incoherent, yet without fuss, extra support was found and put in place for us. ►

Informal, fast and appropriate action saved the day for us. We were amazed at what is possible when there is a commitment to being responsive.

Now that Mena is a young woman she is developing her own friends and interests. I have noticed that a considerable number of people who Mena has contact with, have actually met her through our family support service. Years later they remain in Mena's life not because they are paid but because she is good to know and fun to be with.

Our family has benefited from the receipt of good services. I believe that, in turn, Mena has enriched the lives of those people who have taken the time to know her.

We began planning for Mena's adulthood. Our need for support as a family was changing, and becoming Mena's need for personal support as an adult in her own right. This meant the use of new services, new people, and new ground rules. We made a transition to another service who will be looking at providing Mena's accommodation support in the long term.

This transition was relatively painless for two reasons. The first is that we were clear about what works for us: small, local, family-driven, responsive and flexible service. This made the choice easy. God bless the families who had done the ground-work ahead of us, and had developed such a service in our locality. The second reason was the civilised, friendly manner in which our family support service transferred to the new service (with the collaboration of the funding body) the funds previously dedicated to us. I remember the moment well. The business was done over coffee and choc-chip cookies on our front porch. How fitting.

With the new arrangements in place it seemed that we no longer needed this family support service that had been so faithful to us. Or did we?

As I write, Mena lies in hospital having an extended and painful procedure. Her morale is low. We are tired from sleeping-over at the hospital, yet she wants us there. I have just had a call from our former family support service asking: "Can we help?". I no longer wonder how they know about situations, but rather answer with relief, "Yes, please".

Each day someone is at the hospital with Mena on a voluntary basis, keeping her Bob Dylan CDs playing, her legs exercised, and her spirits up. These people are not any of the hundreds who met her through those earlier, large services. They are people in a vibrant network which emanates from that small community based family support service who know and value Mena, and who are likely to be her most valuable asset, and the best safeguard she will have in the future. ■

People with disability advocating for change in the community

*Three committee members talk
about their contributions.*

When I was invited to join the original committee of *Queensland Advocacy Inc* in 1987, I had some knowledge about advocacy through my involvement with *Greater Achievement for Disadvantaged People* in Ipswich and with *Self Advocacy Support Service* in Brisbane. I went to the first meeting on a Thursday night and little did I know that my Thursday nights would be taken up for a very long time. I became involved because this new group encouraged people with an intellectual disability to have a say in the organisation. This was a new idea because the concept of advocacy was still quite new. Everyone was learning about it, and for once, I was not the only new person.

As a committee member I have been involved in the publication of a *QAI* book, an advocacy support team, lobbying government departments, attending national conferences in Adelaide and Canberra, and planning a Social Advocacies Event with Wolf Wolfensberger.

QAI has been very much a part of my life. The organisation has influenced me and given me a greater understanding of the many issues which impact on the lives of people with disabilities. I believe I have made a contribution because the organisation values what people with disabilities have to offer.

Donna Best



I have been a member of *SUFY* for a long time. I have been a committee member and Treasurer. *SUFY* means *Speaking Up For You*. As you can see, David is a member too and we both like it very much. *SUFY* has just celebrated the first 10 years. I love being in *SUFY*. I get a lot out of it. I think talking about *SUFY* will give you some idea of what to expect from it when you go there. You can expect to be welcomed.

Anne Low

I was a committee member of *SUFY* for four years. One of the most important things I was involved in was to lobby government for better access to public transport for people with disabilities.

David Low

IS BIGGER BETTER?

David Hurse of Cairns looks at this question.

David is a community member of a management committee in a small service.

Retailing practices suggest that "bigger is better" as giant supermarket chains overwhelm the existence of small convenience stores. But it is not always the case; some shoppers still prefer the personalised attention they receive from their corner store.

If recent events in Cairns are any example, the same applies in the field of service delivery to people with disabilities. Last year a large service agency gave short notice that it would withdraw provision of services to twenty-five service users. Needless to say this gave rise to a desperate situation. The Department of Families, Youth and Community Care responded quickly and Endeavour Foundation offered temporary assistance during a transition period. The Department contacted all the people affected by the withdrawal of service, offering them alternative arrangements with other agencies. The majority of them chose to transfer to what they perceived to be the relative security of large organisations, but five of them did not.

Three of these five people went against the popular choice as they saw an opportunity to take the future into their own hands. They asked for the development of a new agency and offered assistance in setting it up. The remaining two soon joined them. The objective was to establish a small organisation which would provide more personalised attendant care, more immediacy of response, and give a greater sense of independence to individual users than is possible by larger agencies.

A meeting was convened and interested people were invited to attend. The original group now grew to nine and a Work Group was formed. A Management Committee was formed of seven people: three clients of the new service; a support worker; two people with disabilities who are not clients of the service; and a community member who is a polio survivor. All are committed to

providing quality care to the five clients of the service, with a minimum of funds being absorbed by administration costs. The service employs a Co-ordinator who is responsible for the employment of Support Workers. The Co-ordinator works from her home, with office equipment provided by the service. Accounting functions are performed voluntarily by the Treasurer who also works from her home and in close collaboration with the Co-ordinator.

One of the great advantages of the organisation is its composition and size. It is small, and the Committee is comprised of people with disabilities who are therefore sensitive to the needs of their clients. Because of the size and structure there is a strong element of group support and personal relationships.

Ironically, some of its weaknesses also lie in its composition and size. For example, it is sometimes physically impossible for people, because of the nature of their disabilities, to regularly attend Committee meetings, and on occasions a quorum will not

be formed. This has the consequence of decision-making being difficult and absentees losing their sense of belonging to the process. Absentees may also be affected by feelings of guilt in "letting down the side". All of this has the potential to overload the Co-ordinator with tasks which could otherwise be delegated within the group. Small services have to fulfil the same formal organisational functions as larger organisations who usually have more resources such as full-time Accountants and Administrative officers.

If our organisation continues to be successful it may encourage other people with disabilities to take the future into their own hands. If this is the case, they may be persuaded, along with our Cairns group, that while "big" may be "good", it is not necessarily "better". ■

The basic supports that we have in our community have only been achieved through the work of people who have identified a need, and then worked together to improve the situation.

Des Ryan, Rockhampton

What does Competitive Tendering add to Community?



Morrie O'Connor, who has worked with a community organisation for many years, was asked this question. He says that the following elements may well be added to the community.

Distrust. A research-study by the South Australian Council of Social Services noted that many community organisations had reported an increased distrust and secrecy between such organisations in a competitive tendering environment.

Destruction of collaboration. One of the sources of "social capital" in a community is the collaboration and sharing of resources between community organisations. This sharing and collaboration, which can actually enhance the way in which people receive services, becomes threatened in a competitive framework.

Decline of service quality. John Quiggins, well-known Australian economist, argues that at least part of any saving made through competitive tendering is actually made through a reduction in service quality. In a summary by the Industry Commission (1995/6), the results of a number of Australian and overseas studies on the effects of competitive tendering unanimously showed, in the overseas studies, a predominance of quality reduction.

Unemployment and under-employment. Competitive tendering savings are largely made by reducing the numbers of workers providing the service (downsizing), and by reducing the conditions of the remaining workers. While reductions in the numbers of workers, and the

casualisation of work often leads to reduction in service quality, these now unemployed and under-employed workers become reliant on the community through unemployment benefits. Unemployment and under-employment are some of the major factors in growing inequality in our society.

Inequality. If Australia has one social icon in which it takes pride, it is the high degree of social and material equality that has existed for most of its citizens. Competitive tendering is part of a set of beliefs about the "benefits" of competition, but it might actually lead to the development of much higher levels of social inequality. This inequality has been increasing over time. For example, between 1976-1992 the economic middle-class shrank from 65% to 40% of the population, while the economic upper-class rose from 15% to 30%, and the economic lower-class rose from 20% to 30%.

If we accept growing inequality, it will put at great risk our social fabric, our sense of peacefulness and security. Communities which embrace inequality become horrible places for most people, particularly the vulnerable.

These are the things that I believe competitive tendering will add to the community. ■

CRU Committee Members 1997/98

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

CRU Staff

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

The Privilege of Sharing

Helen Carty found that while it is possible to resign from a committee, it is impossible to resign from relationships, shared experiences and common values.

In 1991, I accepted an invitation to become a member of the *Mamre* Management Committee. The *Mamre* Community began in Brisbane in 1981. It grew out of a desire to share in the lives of people with disabilities and their families, and to respond to their needs. Today, it is a Family Support organisation, built on a foundation of Christian community. It provides a range of services, including parent and sibling support, respite care, in-home support, and a community link program. But primarily, it seeks to respond individually to each family and their particular circumstances and dreams.

The simple answer to the question of why I joined the *Mamre* Management Committee is: "Someone asked me to". However, the reasons for my responding positively are a little deeper than that. I had known of *Mamre* and its work for some time and was strongly attracted to the ideals expressed in its work and Charter – the ideals of hospitality, inclusiveness, and honouring the unique gifts each person has to offer. In many ways there was a close fit between my own life experiences and beliefs and the philosophy of *Mamre*, which meant that I barely hesitated in accepting the invitation.

My membership of the Management Committee was unusual in that I was not already a member of the *Mamre* Community. My family had never received support from *Mamre*, and I had never worked within the organisation. Having someone without vested interests, or any connection to the history of an organisation can be positive for a Committee; perhaps it adds more balance and objectivity, and a new perspective. However, this did make it more difficult for me to begin to know people, to form bonds, and to feel at-home in *Mamre*.

While these things took some years to build, it was an enormously rewarding aspect of my years on the Committee. My awareness that these bonds were slowly developing was certainly one of the factors in my remaining on the

Committee for six years. Although I left the Committee in 1996, my connection to *Mamre* continues. It is possible to resign from the Committee, but impossible to resign from relationships, shared experiences, and common values. One of the most difficult aspects of being on a Management Committee is a strong awareness of being accountable and liable, while feeling an amateur and inexperienced. Add to this the pressure of having little time for huge amounts of work, and the feelings of resentment and frustration certainly mount.

The positive side of these challenges is that I gradually acquired a new range of insights, skills and experiences which, while never seeming quite adequate to the tasks ahead, were still valuable learnings for me. There was also the sense of satisfaction when various tasks and projects were completed.

There is no doubt that the responsibility of managing community organisations in this increasingly complex world is enormous, particularly in the face of funding shortfalls and rapidly changing policy environments. The difficulties need to be weighed against the value of community organisations, which can remain small and flexible, and build real relationships with the people whose needs they seek to meet, while representing the requirements of government.

When I reflect on my involvement over the six years with *Mamre*, the variety of experiences is remarkable. At times there was an overwhelming sense of humility when confronted with the human capacity for suffering, surviving, giving, and celebrating. But finally, I am left with a sense of privilege in having shared and witnessed, in a very small way, the lives, joys and struggles of people with disabilities and their families, and the vision and commitment of the people who have chosen to build a responsive and welcoming community to support these families. ■

Valuing Each Other

The writer of this article, who prefers not to be named, believes that small services in the Queensland community have a proven track record, and offers an example.

People with disabilities in Queensland, including myself, have been struggling to have their needs met in an adequate, respectful, just, and dignified manner and I offer an example of how a group of people organised themselves so that some of their support needs were met.

The service to which I belong has been assisting about twenty people in South East Queensland for several years. We are a diverse group of people with varying types of disabilities. We lead our lives privately and with as little intrusion as possible.

We are connected by our desire to have our needs met. Some of us were at risk of being admitted to nursing homes. We had shared ideas and visions about opportunities and potential, and had a belief that we could manage our own lives if given support and adequate resources. We also shared the belief that the people who use the service were skilled, experienced and competent, and showed a willingness to support each other. As a group we had the motivation and energy to work together for the service.

This energy and willingness allowed us to focus on particular tasks such as planning for the future, writing policies and employing staff. Examining our values, actions and performance, we explored other ideas and options for service delivery. Friendships, allies, and links were developed in the Brisbane

community, Sunshine Coast, North Queensland and Toowoomba. We shared experiences and information, and assisted the setting-up of other services.

After several years of operation, we were more than capable of putting our ideas into practice through the development of management skills. For some of the people who used the service this meant being involved more intensely at a committee level. People working at this level committed themselves to being active in guiding the service and providing feedback.

The whole group, where possible, met periodically in workshops to discuss issues, to write and review policies, and to plan. Everyone developed skills and experience in stating their needs clearly and in teaching and directing staff at the service level as well as the direct-support level. Some people, for various reasons and at different times, chose to stay separate from the larger service level and proceeded to live their lives and manage their own service in their own homes, in their own way. Individual people chose the time that it suited them to be involved at the service level.

Throughout every aspect of the work of our organisation, we have a set of values that are its driving force and strength. We strongly believe in the value of one another, and in the uniqueness, richness and very being of each one of us. ■

El's Story

Daisy Kellie tells her daughter's story.

Our daughter, El, was born in September 1956. She arrived feet-first and had to struggle to survive. Later we learned that she had suffered brain damage.

On Mother's Day last year, El, at the age of forty-one, started to communicate. The first word she spelt was "Mum". There had been a lot of help from her friends to achieve this amazing event as El has no verbal language.

El did not go to school like other children; she was assessed as unable to be educated and was excluded from the Endeavour Foundation (formerly Sub-normal Children's Welfare Association) because of the extent of her disability. El spent her first twenty-five years at home with little or no support. It was a very frustrating time in her life.

In 1981 some families and supporters opened an Activity Therapy Centre but later found that this was not the ideal answer for the people we supported, and we gradually looked at individually supporting people according to their needs. This suited El more.

The best part of El's life happened when she left centre-based care in 1991 and was supported from her own home. For the past three years she has lived in a self-contained flat under our high-set house. She chooses her own support workers and makes choices as to when and what she does. El's father and I still provide the greatest part of her support. There are a lot of people with great skills who have helped us along the way, and still do.

El has given her permission for me to tell her story. ■

Pursuing a Dream

Colleen Dolan of Cairns shares the story of pursuing the dream of an ordinary life for her daughter.

All parents of a son or daughter with a disability inevitably wonder: what will happen when we are no longer here? When our children are young we can involve ourselves in their education, include them in the lives of our other children, make certain we celebrate birthdays and generally go on with our lives, putting that thought in the background. But it is always lurking there and when our child becomes an adult the thought becomes persistent. About ten years ago my husband and I decided we must tackle this problem. As a starter I went on an organised tour of adult accommodation facilities conducted by a major disability service provider.

The first house we visited was described as a ten-bed residential. It was well presented, clean and tidy. One area contained a kitchen, lounge, dining-room and supervisor's flat which was separated from the ten bedrooms by a well kept courtyard. All very nice indeed, so why did I feel uneasy? Was it perhaps the number of bedrooms?

Our group consisted of several parents of people already using the facilities we visited, and one mother proudly opened the door to her daughter's room where there was a collection of dolls on display. It was a beautiful room and everyone responded with an "ooh" and "ah", but the thought flashed through my mind: all of this girl's possessions are in one room.

This thought lingered in my mind as we travelled by bus to the second facility. I thought of the possessions of our own daughter, Lynette. They were spread throughout our house: her tapes and records in the cupboard next to the sound-system in the lounge; her bean-bag in front of the TV; her framed photos in the display cabinet in the lounge room; her tennis racquet, skate-board, and bike helmet in the sports cupboard downstairs. And what about her exercise-bike? What would need to be left behind if she were to have all her possessions in one room?

At the second facility we were served morning tea in an attractive lounge room and it seemed that no expense had been spared on the

new lounge suite. But the shortest member of our group had difficulty in getting up out of her lounge chair and we wondered: how do residents manage, and were they considered when this furniture was chosen?

Arranged on the walls were various artefacts. I remarked on these and the residential supervisor said "They are ours, from our holiday in New Guinea". We learned that residents were only allowed in the kitchen to help with cleaning-up after meals because the supervisor liked a clean kitchen, and as we left the residence the supervisor showed us what she referred to as "our office". I left with the feeling that it was also their home.

At the third facility we visited, the transfer of a resident was being made to another facility where she would have a smaller room. The young woman had her own furniture but the new facility had been furnished by the organisation and consequently arrangements were being made for the disposal of her furniture. She had not yet been told of this as she was expected to take it badly. I thought of my own daughter's Queen Anne bedroom suite and writing-table which had been her sixteenth birthday present. I thought of how she loved it, and how she cleaned it every Saturday morning. These thoughts caused me to leave the group and go for a walk in the back garden.

"Everyone has the right to lead an ordinary life and some people need more help than others."

In the bus on the way home, several parents expressed their appreciation to the representative of the organisation for providing these wonderful facilities. I was silent, however, and when I arrived home I said to my husband: "Lynette will never go to a residential. She would be like a bird with its wing clipped. She would not be happy". And then I cried. ▶

Over the next months I did a lot of soul-searching. I slowly realised that the people living in the residential were not living an ordinary life. Their lives were regulated. Their meal times were controlled by staff rosters and their meals were prepared for them. They had certain times for retiring to bed and for rising in the morning. They always moved as a group and they travelled together in the organisation's bus to a sheltered workshop or an activity therapy centre. They worked together and came home together. In other words, they lived, worked, and played together. They could not even decide with whom they lived because that was determined by a waiting-list. To make matters worse, some of the facilities had a "respite room" which would be occupied by someone for periods ranging from one to three weeks, so they were continually living with a virtual stranger in what was their home.

Neither was the room which residents occupied really their own. They could be shifted from one facility to another, depending on the needs of the organisation. They had a room in a house – not a home – and could exercise no control over their own lives. As a matter of fact, decisions about their lives could be made by people over a thousand kilometres away, who did not even know them.

I decided I could change these things and got myself elected to the board of the organisation. These were good people and they would listen, I reasoned. What I did not realise was that they would not understand. I became known as a trouble-maker and radical, and eventually realised that my efforts were a hindrance, so I decided to leave the organisation and direct my efforts into trying to create a service which would enable my daughter to lead an ordinary life.

Of course I was not alone in this as other parents had travelled the same road. We banded together and after several attempts, were successful in obtaining funding to pursue our dream. Our organisation was named *Real Living Options*. Only people who can look beyond the disability and see the real person can share our

dream. This does not mean that we pretend the disability does not exist. On the contrary, we say that everyone has the right to lead an ordinary life and some people need more help than others.

Our dream, has in part, been realised. We do have our support service up and running. We support eleven people in ten households across Cairns and in adjoining towns. The people we support choose where they want to live and whether they want to share with a friend or live alone. Some of the people we assist still live with their parents, some people live in units attached to their parents' homes, and some live in units which they own, while others live in rented accommodation. Most importantly, they all live in what is their own home.

Small community services have, in the main, grown up as a result of intensive efforts by those who had an unmet need: parents, caregivers and people with a disability themselves. In grappling with their problems they have endeavoured to put into the community a service that will meet their needs. While never losing sight of the individuality of all users of the service they have acted collectively to fulfil a dream.

Connie Young, Mackay

The people we support have lifestyle assistants who help them in their household chores. They have their own bank accounts, and do their own shopping. They choose and cook their own meals and decide on their meal times as well as deciding when they will retire to bed and rise in the morning. They do the ordinary things that all of us do every day, the only difference is that assistance is provided to do this. Some people need very little assistance from our support service, and others need a great deal.

The people we support choose their own lifestyle assistants, with help from their families and from a short-list compiled by our Co-ordinator. We try to match age, gender and personality where possible so that they can move freely in the community, not in a group with a supervisor, but as two people of similar age out-and-about in normal activities.

Some of the people who are supported by our service have ordinary jobs and some do voluntary work. Some people are seeking employment and some choose not to work. We may be involved in this aspect of their lives – it all depends on what is requested of us. We simply respond to requests for assistance.

For each one of us, an ordinary life is made up of many small decisions we make as

individuals and not bound by restrictions of group living, in fact, we would not tolerate such restrictions. Often people who live in group facilities express their frustration with such restrictions and are then placed on behaviour management programs. Very few large service providers ask themselves: are we getting it wrong; should we be doing things differently? To the contrary, their attitude usually is: "we are the experts".

Unfortunately our present government appears to support a traditional congregated and segregated approach. Expressions of interest are presently being called in the Cairns area for centre-based respite care. No doubt it will be supported because desperate people accept anything. I can't help thinking of all the money it will cost and how much difference might be made to people's lives if that money was used for individual support.

Recently I was studying a graph produced by Queensland Parents of People with a Disability (QPPD) which shows that less than 5% of people with disabilities want centre-based accommodation support, and over 90% of people with a disability want community-based lifestyle assistance. I wonder when governments will ever learn how to offer good support. At the very least, we should be able to ensure that individual lifestyle assistance receives a fair share of available funds.

Ten years down the track, I look back on the enormous amount of work it has taken to

establish our support service and wonder if it has been worthwhile, but I can walk down to my daughter's unit and be greeted with "Hi, Mum". I read her diary while she gets drinks for us. I can then talk to her about events that have happened since I last called on her. From the diary notes I can remark on how clean the curtains look, or ask to see the new plant in her garden, or if I can hear her new tape. This is very similar to what happens when I visit my other daughter. The difference is that Lynette needs to have her activities recorded in a diary so that these natural conversations can take place between us. Our dream has come true.

What will happen when we are no longer here? I don't know the answer to that but neither do I know what will happen to our other children. All we can do is build a service which is based on our philosophy of an ordinary life. Lynette is living that now and her skills in all areas are gradually increasing. We can build networks around her and have procedures in place, and trust that these safeguards will meet Lynette's changing needs during her lifetime.

People often ask of our service: "What sort of service does *Real Living Options* provide?" and are surprised that we have no glossy brochures advertising ourselves. The answer is that we do not tell people what we can provide to them. When we are speaking to someone who is seeking our assistance we ask, "What type of assistance do you need from us to enable you to lead an ordinary life?" ■

An Invitation

For those people who might be interested in some of the topics which have been raised in this publication, or other related issues, CRU is able to provide access to relevant resources through:

- Extensive library material
- Educational courses
- Training programs

We invite you to contact us for information on how you can access these resources.

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