
CRUCIAL TIMES

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MAKING COMMUNITY LIVING A REALITY

When commencing the strategic planning for Disability Services Queensland (DSQ) sixty people from the community and government came together for two days to take stock of the issues facing the sector and DSQ. Early in the two days, Anne Cross had the opportunity to present some challenges to the forum and some of them are repeated in this leading article.

The Values Challenge

We live in times of rapidly changing values. On the one hand, modern *laissez faire* values have supported increased tolerance and an opening-up of opportunities for some people with disabilities. On the other hand, societal values are becoming increasingly utilitarian and harsh, with some very serious consequences for many people with disabilities, including some that are life-threatening. These values raise difficult questions about the "place" of people with disabilities in the community and it is likely that we will need to continue to promote and defend community living as an option for all people with disabilities. The question of who is responsible for the additional support that people with disabilities might need is also a values question. Is it people with disabilities themselves, families, communities, or governments? What is the mix of responsibilities? Changes in the welfare state, with a retreat from universal provision to a system of user-pays and selective targeting are all indications of a departure from a collective responsibility to a "privatisation" of social problems.

The Challenge of capacity

Rapid changes in the field over the last decade, and especially in the last few years, have significantly impacted on the capacity of people with disabilities, families, service providers and governments to manage important issues. In many respects, we have over-reached the capacity of the

field. One challenge is the critical need for additional leadership among people with disabilities, families, service providers, and governments. There is also a need to inform, support, and strengthen people with disabilities and families so that they are able to negotiate what they need from the community and government. This has always been important, but changes within service systems make this a critical issue. It is also true that there is insufficient technical and programmatic competence to translate ideas into practical schemes that produce good outcomes. Communities remain largely disengaged from issues and if community living is to be a reality, problems need to be defined differently and ordinary citizens need to become engaged in solving issues that affect people with disabilities.

Service Infrastructure Issues

In addition to the inadequacy of resources that are required to satisfy unmet needs, there are other important issues such as service systems that are marked by fragmentation, paternalism, and increasing chaos brought on by rapid change. Service approaches that are centralised, standardised, and technocratic increasingly dominate the field, further weakening the responsiveness of the community and ordinary citizens. Whilst much progress has been made with community services, there continues to be significant domination of the field by institutional practices and congregated services which are

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.

outmoded and have hidden costs in terms of the creation of dependency and the alienation of families and communities. In some areas such services continue to be on the rise. A systematic commitment to the development of community service infrastructure and direct funding of individuals should be a high priority. There continues to be poor responsiveness by many generic services provided by government, business, and the community.

Inadequate Safeguards

The vulnerability of people with disabilities, and the inadequacy of human beings and the systems that they create, mean that we always need to insert elements into our systems which take account of our individual and collective weaknesses. It is important that we insert

deliberate safeguards into our systems to protect people. Such safeguards would include: sufficient independent advocacy; strategies that strengthen the voice of people with disabilities and the capacity of others to listen; listening to the concerns of families and others, including staff; improved critical thinking; strong and robust policy; and continuing to work for a positive shared vision and strong positive values. ■

[A full copy of the paper *Challenges to the Community and Government* presented by Anne Cross, and an additional paper presented by the Strategic Leader DSQ, Libby Wherrett, *Challenges from a Government Perspective* are available from CRU on request.]

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FROM THE PRESIDENT

Mike Duggan

Recently, as part of a Selection Panel, I had the task of asking each person who was interviewed to talk about their values. I was trying to determine the driving motivation of each applicant. This role made me think about personal values and how they relate to the value systems of our society.

A dear friend of mine has a saying: “One of the most important things in life is to decide what is most important”. In other words, we must give life meaning. The meaning of life is spawned by our values. Our values influence our perceptions, form our aspirations, and guide our behaviour. Another friend uses the following definition of values: Our core values are those qualities which, for us, have intrinsic worth. This means that when

our actions are aligned with our most deeply held values, the things that we do are desirable or worthy for their own sake.

The greatest struggle for people with a disability comes from the fact that we are largely viewed by society in a negative light. Many things that are degrading and hurtful are derived from such social devaluation and because all human conduct is based on values, the real task is to encourage those values that are likely to ensure people with disabilities are accorded dignity and respect.

In understanding how dominant value systems in our society impact on the lives of people with disability, the following points are helpful. They

briefly outline four prevailing value systems and are drawn from the work of Errol Cocks.

Rationality relates to the almost total abandonment of superstition and belief in the supernatural, which in turn lead to the rise of materialistic science. The nineteenth century saw the emergence of dominant professional groups, particularly the medical profession. These professions were proclaimed to have special knowledge about disability and were accorded considerable influence and control over how people with disability were viewed. This system spawned the idea of institutionalisation and has played a significant part in the marginalisation of people with disabilities from mainstream society.

Economism is a value system that means a domination by economic considerations over all social considerations. It is concerned with production, consumption and the central role of markets. It marginalises people who are not seen to be productive and talks about the "willingness" or otherwise of society to support them. This has great implications for people with disabilities who are often portrayed as not contributing to society.

Individualism, as the term indicates, is a value system where the individual person has taken precedence over collective systems such as

communities, the group, or the nation. The rise in the importance of the individual has one of its greatest expressions in the notion of "choice". One of the implications of this value system for people with disability is that we may be perceived as limiting the choices of others because of the burden we represent.

Hedonism is a value system that is primarily concerned with pleasure-seeking, and discounting that suffering should exist in the world at all. People with a disability are severely threatened by such a view, because of the fact that suffering can more easily be aligned with disability than can pleasure-seeking.

What is the most important thing that impacts on the lives of people with disabilities? It is values. It is because we aren't valued that we are made vulnerable from the very moment of conception until we gasp our dying breath. Foetal life is under threat when there is the slightest hint that a disability exists, and a life that has incurred a disability is often regarded as a life that is meaningless, worthless, and a burden on society.

Given how these dominant value systems work, I think it is really important that everyone who supports people with disabilities continues to challenge these values. ■

FULL INTEGRATION - Myth or Reality?

Graham Schlecht reflects on community living and identifies some of the challenges that the field still needs to face. Graham recently retired from the Commonwealth Public Service after 25 years, and has had a long association with the disability field, having worked on the Steering Committee of the Handicapped Programs Review and as Director of the Commonwealth Disability Services Program in Queensland since 1988.

I vividly recall attending a meeting in 1988 and trying to explain to a group of parents that their sons and daughters would not necessarily have to live in group-homes or institutional settings when they were no longer in a position to care for them. The elderly parents in the group had expressed concern that changes brought about by the recent introduction of the Disability Services Act would rob their children of the opportunity to have a secure and safe environment in a group-home or hostel.

A colleague also raised the possibility that their sons and daughters might continue to live in the family home after their parents had passed away. This suggestion was greeted with raucous laughter and disbelief. One bellowed, "You public servants are away with the fairies!" Eleven years later, I wonder whether that group of parents would think differently. No doubt the maligned public servants would still be accused of being impractical, but I would hope that many parents now have a far richer view of the opportunities available to their sons and daughters. ►

My staff and I attended over a hundred meetings in Queensland during 1988/89, talking about the opportunities that had become available to people with disabilities as a result of the Disability Services Act. I might add that our perceptions at that time, about what was possible, have been shown with the passing of time to be quite limited. People with disabilities and their families have pushed the boundaries far beyond the mind-set of 1988 and will no doubt continue to push them much further in the coming decade.

Many people with disabilities are now living in the community of their choice. They are substantially better placed and most would not return to their previous abode no matter what the circumstances. However, many are still totally dependent on dedicated carers and the resources of one or two support agencies. Whilst the support and friendship of paid staff is critical to successful integration, this in itself will not provide full integration. Most are still not accessing the full range of community facilities that are available to others of their age group in society.

Whilst we have made some progress in the general area of participation there are very few examples of successful integration into the community. My guess is that only about five percent of people who have come out of institutions have been fully integrated into the community. I hope that this estimation is grossly understated, but I suspect that those who have been successful have done so by virtue of their own determination and exceptional skills and/or because they have a mix of supports in their lives that are not readily available to all people with disabilities. Access to sufficient financial assistance is, of course, a key element but the provision of dollars does not always guarantee successful integration.

When you ask those people who have been successful about their achievements you seldom get a comprehensive answer. They are too focused on what is next on the agenda to be reflecting on the past. The courage and determination that most of these people have shown would make a best-seller but their experiences are seldom heard. It would be good if someone was to document the story of how fifty people with a disability, for example, have achieved successful integration. This would help us to understand what it is that brings about successful integration, and would enable us to harness the information so that those people who have not achieved full integration could be supported to do so. Policy makers need

to build on basic ingredients so that the missing elements can be added through government and community programs.

One basic ingredient that I believe is seldom available is the input of a community worker. We need trained people who can work the community to facilitate broader integration of people with disabilities. Such a role requires more specific intervention than can be provided by supportive carers. While the person with the disability and the person's family and carers are key players, the community worker provides opportunities, direction and links to the community. This is a specialised role where the community worker strategically obtains a commitment to the full integration of people with disabilities from opinion leaders and key stakeholders in the community. This is usually done by matching the interests of people with disabilities to opportunities available in that particular community. The community worker prepares the way by assisting community members and the person with the disability to come together for their mutual satisfaction.

When Don Grimes, the father of the Disability Services Act, gave the Meares Oration in 1992 he spoke about *rigidity* and *over-caution*. In particular, he suggested that the principles and objectives of the Act should not be regarded as immutable. He stressed that they need to adjust and change as our society grows and develops. Most of us have had difficulty in finding the right balance when interpreting Objective 8 of the Act. This objective was designed to eliminate the whole-of-life control that many services had over clients in the Seventies and Eighties.

Ten years ago this was a much greater issue than it is now. With the development of advocacy, individual funding, and more individual service delivery, the nature of the service relationship between people with disabilities and their providers is, in most cases, very different. In recent years, I have witnessed many examples of people with disabilities being disadvantaged by a rigid application of Objective 8 in the Act. Most of these cases have resulted in the person with the disability having to suffer the inconvenience of finding other services, although their preference was to stay with their single service provider. I believe it is time to review the principles and objectives of the Act.

In the Meares address, Don Grimes also expressed concern about over-caution. He talked about the

excessive caution that can overtake politicians, policy makers and bureaucratic processes, for fear of being criticised if something fails. I believe we have been well served by our State politicians and bureaucrats in recent times and that the steady development of more individualised funding arrangements has firmly placed Queensland at the forefront of the more flexible funding models in Australia. The challenge is for the new DSQ agency to further extend this flexibility. ■

In the next edition of CRUCIAL Times, Julie Walder of Townsville will write about the role of community development work in local government.

BOB AND MICHAEL

Bob Lee recently spent time with a friend called Michael, asking him about the reality of community living, and he also made some reflections of his own about friendship.

Recently I visited a friend I met several years ago, whose name is Michael Condon. Michael is one of those people who is a good friend although we haven't seen each other for a few years. Michael lives in Gympie, a regional centre two hours north of Brisbane. I wanted to ask him about his experiences of "community living" and Michael, like so many people who have a disability, is always willing to freely give his time and experience for the benefit of others.

Michael had some banking to do before we settled down to have a drink and talk. As we walked down the main street of Gympie it seemed that just about everybody knew Michael and greeted him with warmth and affection. A few minutes later with the banking completed, we walked back to the car and I had the feeling that Michael could probably run for Mayor with his level of popularity.

In a quiet corner of the local pub we finally got down to business. Michael grew up in Gympie and until eight years ago lived with his family. In 1991 he moved into his own house close to the centre of town. I asked him what life was like, living in his own place. Since moving into his own home Michael has experienced sharing with other people, and living alone. His sharing experiences, as anyone who has shared a house will know, have been fairly mixed. Lyle lived there for a year or two and they got on well because they respected and valued each other. Michael learned a lot about household tasks from Lyle. Eventually Lyle moved from Gympie because of work

commitments but he and Michael stay in touch with each other. There have been other house sharing arrangements with varying degrees of harmony. Michael now lives by himself and while the option of sharing is still there, he says he will not be rushing into anything. He is very clear that things have worked for him because the house is his, and any decision about who lives there or if the arrangement is satisfactory is, in the end, up to him. Michael says he would not like to live in a situation where service providers make decisions about who he lives with.

While Michael enjoys the privacy and freedom of living alone, he also misses the companionship of having someone else around. He often spends time talking over the fence with his neighbour who occasionally helps with advice and practical assistance, but Michael says it gets lonely at times. I got the impression that being lonely can end up costing money too. For example, because Michael uses the phone a lot to talk to people, the bill can easily become excessive. And as there is no public transport for visiting the people he would like to see, taxi fares can become expensive.

I wanted to know more about this loneliness because it didn't quite fit with the image I had of Michael in the main street an hour earlier. Didn't some of those people come to visit, and weren't some of them people who knew him well? Well, no. While lots of people in Gympie know Michael through social contacts and respect him and his family, there are few of the loyal and reciprocal friendships, which are valued by most of us, in

Michael's life just yet. As he said, "There are lots of people who are friendly but not friends. My idea of a good friend is someone you see every day".

Michael's family is his greatest support. Just as most of us do after leaving the family, it is often the place we return for unconditional love, good food, the use of a washing machine, and some help with the consequences of poor budgeting. It is important to Michael that his family is living close by so they can easily visit each other. Michael and his family recently experienced a great loss with the untimely death of his father, Sven. Sven was father and friend to Michael and a driving force in Michael having his own home for independence and future security. Michael misses his presence and his guidance.

Michael was keen to discuss with me his new role as a member of the Queenslanders with Disability Network, a new organisation set-up to represent the interests of people with disabilities across Queensland. Michael is a member of the steering

committee and his participation will involve a considerable amount of travel as he attends meetings throughout the state with the other nine committee members. The opportunity for travel and for meeting new people is something that Michael is eagerly anticipating. He is well known for his capacity to contribute, and the Network will gain many real benefits from his enthusiasm and his willingness to put effort into helping others.

After dropping Michael at his house and starting my drive south, I reflected on how right it is that Michael's family is proud of him and his achievements, and how the people of Gympie should be proud of the tall young man they often see and greet in the street. I also reflected on when I might see Michael again, and remembered the unintended irony (well, I think it was unintended) of one of his comments about friends, "Sometimes I have good friends but I don't see them enough - maybe once a year." ■

TWO MEN AND ONE FAMILY

The following five stories tell how an ordinary family became intimately involved with two men who had a vision for better lives. In helping them to realise their dreams, the family developed a relationship with each of the men that has deeply enriched their own lives. Paul and Warren have recently moved into their own housing units in the New Farm community.

RALPH Our local church pastor mentioned that he had been asked to conduct a service at Sevenoaks. As a family we decided to attend the service with a few other church members. Prior to this we had very limited involvement with the residents of Sevenoaks, other than having invited them to a few Pony Club events held on the grounds opposite their residence.

After the service at Sevenoaks I felt extremely disappointed as there seemed to be very little interaction or communication with the residents. As a family we wanted involvement but didn't understand how this could be instigated. I found it easy to blame the church but what I did not understand at the time was that we, as ordinary members of the church, had the responsibility for any interaction. All it took was the simple but significant act of our son, Richard, to visit Sevenoaks and eventually to arrange for Warren and Paul to come to our house for an evening

meal. This simple invitation began the cementing of a lasting friendship.

After some time, Paul and Warren commenced regular attendance at the Kenmore Community Church and I was recently told by one of the Elders that the privilege of having Warren and Paul has been one of the best things that has ever happened to the church. I can also say that our personal relationship with Warren and Paul is one of the best things to have happened to our family.

MARILYNNE My part of this story began when our son, Richard, asked if he could bring two friends home for dinner. From that simple request, a relationship of love and trust has grown with two very special men who have come into our family. They have enabled me to grow beyond my greatest dreams; Paul and Warren have shown me how to listen with my heart and not just with my ears.

In the five years that we have been friends, I have been privileged to share the pain and the frustration of institutional living. I have felt the confusion and the slow coming-to-terms with a transition from life in an institution to life in community housing, as well as the wide range of emotions that has been experienced by each of the men when finally moving into their own homes. During these years we have laughed and cried together, shared meals, and learned to accept each other in good times and bad times. We have sung and danced together, and have prayed and worshipped together.

Together, over five years, we have been involved in lobbying for the purpose-built housing which had been promised to Paul and Warren when deinstitutionalisation was introduced by the Queensland government. Both Warren and Paul seemed to be constantly rebuffed; their housing was always going to be built in "the next financial year". We wrote to cabinet ministers and, as governments and policies changed, we kept writing. We met with numerous professionals who came and went – Occupational Therapists, Coordinators, and Social Workers. Large files of correspondence were compiled and much heartache was experienced.

The housing project was commenced in late 1998 and, each Tuesday, for almost twelve months Warren would travel from Sevenoaks (with his recreational support worker) to spend the day watching its construction from the opposite street corner. For Warren, this was the experience of a dream-come-true; the culmination of a lifetime's desire to have a home of his own.

Problems during construction delayed the final inspection but Paul and Warren were ecstatic that the housing was nearing completion. However, not all things in life go exactly as planned and a fortnight before the final inspections, Warren and Paul were informed that their requests for Adult Lifestyle Support packages had been refused. This assistance, provided in the form of paid support, was needed in order for Paul and Warren to begin living independent lifestyles. For each of them, it seemed the end of the road. Their requests to the Department of Family Services were consistently refused and there seemed nowhere else to turn.

We all felt desolate, but Warren and Paul were then advised by their service provider, the Cerebral Palsy League of Queensland, that a public Cabinet meeting was to be held the

following weekend in their area. We decided to ask for a deputation to see the Minister, Anna Bligh, and we got it! With only a few days to organise, Paul and Warren prepared their deputation using files and records from the past six years. The Cabinet meeting was very public; it was held at the local R.S.L. Club with each minister at a table surrounded by advisors. This was very daunting for two men in wheelchairs and limited verbal communication, and for an advocate who finds it difficult to articulate when confronted by people skilled in public debate and oratory. I think we all knew this was our last chance. With the Cabinet meeting on a Sunday and the final inspection of the new homes the following morning, we all realised that if there was no lifestyle support funding then there would be no move to the new housing. We were extremely nervous.

The Minister, Anna Bligh, and her staff were very gentle with us. They moved from the official table to sit with us, listened carefully to our deputation, and took our large files of correspondence. The Minister herself assured Paul and Warren that they would not lose their new homes and we were all assured that we would hear from the Department within the coming week. We left with a glimmer of hope.

Final inspections of the new housing units were exciting. We were all delighted with both of the spacious and carefully planned units that had been built to accommodate each man's individual needs. Hoping that all would go well, and that somehow the lifestyle funding would be found, we went ahead and booked ourselves into a CRU workshop, which we expected to find helpful in assisting people to prepare for a move into the community. We were further encouraged in this when the League offered to support us to attend the workshop.

True to the Minister's promise, the Department phoned to say that they were working on the issue and they kept us informed as they continued to try to find some funding. We really enjoyed the CRU workshop, participating in each session, but we certainly disrupted the third and final session. About half-way through the session, my mobile phone rang. It was a call to say that non-recurrent funding was to be provided to Warren and Paul so that they could move into their homes. It was extremely difficult to contain our feelings. Warren laughed, Paul tried not to laugh and I felt my face would crack because of my constant smile. Jane Sherwin, the workshop facilitator, said it was the

best news ever received in a workshop, and there were congratulations from many people.

With the support of the League and some wonderful staff, Paul and Warren have made the transition to their new homes, with very little trauma. They have had input into staff selection and have found the move itself to be almost effortless.

At the time of writing this, Warren and Paul have been in their new homes for three weeks. They have already been out-and-about in the local community and have hosted a wonderful house-warming party. Paul and Warren are enjoying life in their new homes – two wonderful men, now living ordinary, typical lives.

RICHARD When I asked Warren if he would like to write his story about moving into his house, he said he thought it might be a good idea but about half-way through, when it was going into some depth, he gave up interest. Warren has had a difficult and sometimes painful past that he doesn't like to bring up very often and he is definitely someone with a firm eye on the future. So in keeping with Warren's style, I will just keep this story short and to the point. Warren communicates using a pictorial board.

WARREN I have just moved into my new house at New Farm, the first real home I have ever had, and I am very happy here. I have not liked many of the places I have had to live in the past as they have often been very sad places. About seven years ago I was living in an institution and when someone offered me the chance to move out of the institution and into my own home, I jumped at the chance straight away. I thought the move would happen quickly but didn't realise how long it would take or how much determination I would need to keep the whole plan moving.

It was touch-and-go for quite a while with the Housing department and the need for funding and support staff, but by sending many letters and telling people in every way I could, the message finally got through and things began to happen.

Of course I have had a lot of help on the way and am happy to have made some good, lasting friendships with the people who have supported me through this. For me, these are all very important things which I am always working at - having a happy home and an exciting life, and having good friends to share it with.

PAUL It all started in 1993 when I decided to move out of the institution that I was living in. At the start I thought that I would like to go to the Gold Coast, but it was too far away from my family and friends, so I decided to go to New Farm in Brisbane. I met two people from CRU and I told them that I would like to move to the New Farm area and they asked, "Who would you want to share with?" Well, I thought long and hard about it and said, "I would like to share my house with Warren Haren". But no one told me how hard I would have to fight to get into my new house.

In 1993 I met a beautiful family – the Warner family. It all happened because of one of the family, Richard. He didn't know what to do with himself so he came to the Adult Day Centre. When I first saw him in the manager's office, I thought, "Oh, no, here goes another hippy" but when I got to know him I thought, "He is not too bad". That Christmas he asked me to his place for Christmas lunch and dinner. Needless to say I was nervous because I didn't know what to expect, but to my pleasant surprise they were very kind. When I got to know them better I thought, "This is the craziest family I have ever met!"

But back to the intended move – I got hundreds of letters asking me if I was still interested in the house at New Farm. I was getting tired of always replying "Yes". First of all I wrote to the Housing Department. In those days the Housing Department put me at the bottom of the list. I waited a while but there was no answer to my letters so I said to myself, "O.K. that's the last straw!" and got really determined and wrote a couple of letters to the minister. But they really just ignored me. Of course I got a reply, but it just said the same thing, "we will get back to you" over and over! Needless to say I was not happy with this so I went through the whole thing again and this time I got a better reply. The Housing Department rang me one night when I was at the Warner's house and a person from the Housing Department brought out a set of floor-plans. But they were not right and I asked an Occupational Therapist that I knew, who was studying architecture, to help me with what I needed. In the meantime I waited and waited and finally after a long wait, I have moved into my new house and I'm looking forward to the things to come. ■

“GATHERING THE WISDOM” – A TRIBUTE

The CRU publication, “Gathering the Wisdom” was launched in mid October and Veronica Brady, literary critic and social activist, was the guest speaker at this important event. Here is Veronica’s tribute to the book and its writers.

Adrienne Rich writes, “The rules break like a thermometer, quick silver spills across the charted systems; we’re out in a country that has no language, no laws” and goes on to say that “whatever we do is pure invention. The maps they gave us [are] out of date by years”. But this book, and the conference it records, gives us hope, because it reminds us of the thermometer – traditional, even ancient though it may be, which takes the temperature of the abiding realities of human dignity - the thermometer of the heart.

This is a book about memory – the first thing which tyrants destroy, because memories are often the best guide to a different future. The memories recorded in this book are powerful and powerfully creative. Stories such as those told by Don Grimes, the politician who pioneered the Disabilities Services Act in 1986, and the story of CRU itself as told by Anne Cross and Margaret Ward, sum up this creative power as do the personal stories of Mike Duggan, Pam Rallings, and Nicola Schaefer to name a few. The stories of neighbourhoods and communities such as Homes West, Mamre, and the people of Townsville who battled for people with disabilities in their community, all tell of those who were “willing to go the extra mile to ensure that the rights of people with disabilities were upheld.” All of these stories speak of courage, vision, intelligence and a deep conviction of the reality that every human person is sacred and a centre of value for her or his own sake – a reality that we ignore at our peril. They speak of the success of making things different.

This may sound merely inspirational but in fact it is profoundly and crucially practical. If humanity is to survive on an increasingly over-crowded and endangered planet we must learn the art of living, which is the art of loving, of mutual respect, and kinship. As Mike Duggan, in his chapter, puts it: “Could pride, arrogance, and an inability to listen be a greater obstacle to

‘partnership formation’ than impaired speech, mobility, intellect or emotion?”

In this sense, the conference, and the ideas expressed at that event, offers a model of the kind of society to carry us into the new Millenium with confidence and hope. It will also keep us in tune with the dream of a decent society in which everyone has a right to “a fair go” - the dream which used to inspire this country.

The book’s title is important - *Gathering the Wisdom* – not, we note, gathering the knowledge, much less gathering the information. The word

wisdom means abiding deeply in that which is the case. A wisdom society is very different from an information society. Our present society is preoccupied with facts, figures, abstractions and slogans based on the exaltation of signs at the expense of the reality of things, and on the illiteracy of the heart that this induces. But a wisdom society dwells in and on the reality that all human beings, indeed all living things, share the one life on one small and fragile planet suspended in infinite space, and that we must care for one another or die.

“All of these stories speak of courage, vision, intelligence and a deep conviction of the reality that every human person is sacred and a centre of value for her or his own sake”

As Stephanie Dowrick said so powerfully at the conference, our culture has an ingrained fear of the reality of our vulnerability, perhaps because it lacks the wisdom we have been talking about. But this fear of vulnerability, expressed in power as domination, and happiness as the accumulation of things, is affecting the planet as well as each one of us. To survive, we must dream a different set of dreams – one based on the reality of who we really are and where we really live.

People at the conference knew this, implicitly or explicitly. Kevin Cocks, for instance, argues that the kind of leadership that CRU has worked for – and which, I would suggest, our society and world needs – comes from “a passionate commitment to the spirituality of people whose

lives have been a struggle yet who hold on to hopes and dreams”.

Of course the hard-headed, who are often also the hard-hearted and usually dislike the word “spirituality”, will sneer at this vision as being idealistic and impractical. But the onus of proof is on them to show that this is so. Our present society is manifestly failing to meet the human needs of a large number of its citizens and is also threatening to destroy the natural world on which we depend. What if it were the case, as William Blake would have it, that ultimately the world is not round, nor is it flat; rather it is human shaped, that is, its state reflects our values and our notions of “reality”?

What if, as Don Grimes asks, we have let others, who are less wise than many here who have learned their humanity through suffering, hope and love, set our horizons and define the terms by which we live? What if the history that matters is not the story of the winners? What if it is the story of those who seem to be losers, who suffer, struggle, and are often oppressed or humiliated, and who keep on believing in, and living out their humanity, and keep reminding us

that “no one is an island” and that if one person is diminished then we are all diminished? This is the history CRU has been making and continues to make.

CRU’s achievements, as well as its dreams, may seem small on the world scale. But real power, as Mike Duggan reminds us, has to do with quality not quantity, and abiding change comes from the grass-roots and from the vision and energy that is derived from faith in life, hope and love. We may not be able to change the world but this book shows that it is possible to change ourselves and our neighbourhoods, and that should be a start. It should also point us in the direction that we all need to go as we cross the boundary into a new century and look for new direction; the kind of direction spelled out by the new director of the Brotherhood of St Lawrence, Fr Nic Frances, when he wrote that the task facing us is to “support the bringing about of a nation that has at its heart the values of justice and love, a nation that can take a lead role in how a new world may be ordered”. ■

“Gathering the Wisdom”

Two Book Reviews

Some other comments and recommendations have been written by two people from the field who were asked to review the book.

DIMITY PETER

Dimity lectures at the School of Special Education and Disability Studies at Flinders University.

As a University educator, reviewing “Gathering the Wisdom” provided me with an opportunity to reflect on my teaching. I believe that there are three critical insights to be imparted to students: a personal identification with people who have disabilities; a sense of where we have come from; and a vision of the future we are working towards in partnership with people who have disabilities, and their families. This book speaks to all of these critical points in ways that are both accessible and stimulating.

In promoting the capacity of students to make an interpersonal connection with a person who has a disability, it is important that it is done in such a way that they can begin to understand, respect,

and acknowledge the perspective of the person with the disability. This level of insight will be enhanced when reading the chapter by Mike Duggan, “*Reflections on my Life*”. He invites readers to “see past and through my disability. For it is when this moment arrives – not before – that we can encounter one another as truly human beings”.

The same notion is explored in the chapter “*Remembering our shared Humanity*” by Stephanie Dowrick who says, “The key factor is surely whether (and how) a human connection is established, and whether (and how) there is a commonality of interest and purpose”.

The life experiences that are retold in chapters by Mike Duggan, and Marg Schroder, and by parents such as Carolyn Friend, and Joan Hailstone present very personal accounts of injustice,

discrimination and hardship, but they also tell of the efforts that have enabled dignified and self-respecting lives. All of these accounts are important testimonies in the process of confronting our own humanity and finding commonality and mutual purpose. These stories are important because such stories often remain untold or hidden from our consciousness. The recounting of the stories is important in creating a political climate where discrimination and devaluation are described and acknowledged in order that they might be redressed.

“The stories in this book have a universal application and will be a valuable resource”

Because it is important that we do not forget the struggles of the past in order to safeguard our future, the chapter narrating the closure of the Maryborough Disabled Persons Ward is an important historical record. Christine Douglas and others tell a story of pain, struggle, courage and hope that lasted more than twenty years. The lessons from this experience are important as thousands of Australians with disabilities continue to reside in institutions, many of which are as brutalising as the ward in the Maryborough Hospital. Institutions are a part of our past but are also a part of the present, and advocacy which is based on community living principles remains as important today as it was five or ten years ago.

Visions for the future are encapsulated in chapters such as those written by Pam Rallings, Nicola Schaefer, and Joan Hailstone. They have provided rich and diverse examples of how, through hard work and a dogged focus on the wellbeing of the person who is at the centre of each story, service models can and do change for the better.

This book is an expression of the hard work that has been done and the many achievements that have been made. It is both a celebration and a documentation of the solidarity between people with disabilities, their families, their supporters and professionals, all bound by their common purpose.

BARRIE O’CONNOR

Barrie is the Director, Institute of Disability Studies at Deakin University and former lecturer in disability studies at QUT.

“Gathering the Wisdom” is a book that inspires and illuminates changes in the way we think about people with disabilities in our community and how we support them. It is a confronting and challenging celebration of change processes that have been at work over the past decade. The book resonates with many voices that attest to valued lives. It tells stories of adults who chose to grow beyond their parent’s home, who challenged the limiting life of institutions large and small, and who entered community life spaces with dignity and purpose.

Readers will find stories of parents who believed passionately in better ways of coping with the hopelessness that systemic lethargy engendered. There are stories of allies inside and outside of established systems who stood shoulder-to-shoulder with vulnerable people to advocate for change. There are narratives that express values and philosophies that informed change, and tell of enlightened government policies and legislation that drove change, and of the many players whose roles as individuals or members of collectives inspired change through the constancy of their beliefs and persistent behaviour.

The stories in this book will replenish depleted energies and nourish fresh avenues of endeavour. They reveal multi-layered strategies adopted by many players for achieving worthy goals. They speak of enriched communities and they caution against economic and social policies that repress the human spirit. This book is also a record that serves as a timely reminder that vigilance is needed to sustain the gains that have been so painstakingly won.

The stories in this book have a universal application and will be a valuable resource for people with disabilities and their families, for service agencies, tertiary education institutions, and professionals who are engaged in the struggle to find better ways of developing inclusive communities. They show what can occur when people push their dreams to reality. ■

“Gathering the Wisdom” can be purchased from CRU for \$25 (plus P&H) Ph: 07-3870 1022