
CRUCIAL Times

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CONTENTS

Editorial	1
From the President's Desk	2
Featured Articles	4-8
Education & Development Program	9
Book Review	10

CRU MISSION STATEMENT

To challenge ideas and practices which limit the lives of people with disabilities.

To inspire and encourage individuals and organisations to pursue better lives for people with disabilities.

EDITORIAL

In this edition of *Crucial Times*, contributions have been invited from employment services. These contributions highlight many of the agency and systems issues impacting on their work: global restructuring of economies, difficulties in obtaining satisfactory job-matches, funding requirements, number-crunching, the entrepreneurial culture in employment services, the use of subsidies in the work place, the dis-incentives to the provision of services to people who are not easily placed or whose support needs are high or difficult to meet. Many of these issues are systems issues and are difficult to solve or even manage at the agency level. Some of the issues seem far removed from people with disabilities and their families, and yet they have an enormous impact on the opportunities made available to people with disabilities.

The growth in employment services and labour market programs obscures the reality that while there is more activity, and much more is known about supporting people with disabilities in work, little progress has been made in terms of real jobs for many people

with disabilities. What is even more worrying are the increasing dis-incentives for funding bodies and services to persist with creating opportunities for those people who pose significant challenges, either because of high support needs, fluctuating support needs, or long-term support needs.

While few people would argue the importance of work and the benefits it brings for most adults, there remains a readiness to accept that many people with disabilities don't need or can't manage work. There is also a belief that it is unreasonable to expect that people with disabilities will be able to find work when unemployment figures remain high. It is easy, when these attitudes persist, to ignore those who present greater challenges to employment services. Lack of successful employment reinforces the notion that work is only desirable for some people with disabilities, and that most people with disabilities require "day programs".

Current alternatives to employment are neither inspiring nor abundant. At the end of schooling few options are available, or else a combination of mostly inappropriate

services is offered. Late last year, a family told me of the "package" of services they had struggled to assemble for their son who was completing schooling. The package was comprised of two days at a HACC funded day-respite service which mostly served elderly people, one morning at a segregated recreational service, a few hours of "community access" from another service, and a few hours "in-home" support from yet another service. Such arrangements, which are not unusual, are often a nightmare of co-ordination for families. They provide inconsistent and irrelevant support for people with disabilities, and offer very little in terms of their needs for adult roles, stimulation and development. Even when people with disabilities have substantial support available for "community access", the results (when measured in terms of community integration, relationship development and adult roles), have mostly been disappointing. While specific interest and recreational pursuits can provide some valued roles and activities, they rarely have the same scope or benefits provided by employment. Employment remains the most acceptable role for adults in our society, if one is not engaged in full-time parenting.

While there is good reason to be cautious about overly optimistic or romantic claims about employment, it is important (as the featured articles in this edition show), to analyse, question, resist and manage those systemic and agency trends which reduce the possibilities of employment for people with disabilities, especially those with high support needs. As is true for all human services, the employment field needs to ensure that it does not distance itself from people with disabilities and their families, and it must guard against service bureaucratisation, imperialism and a weakened culture of dissent and criticism. ■

Anne Cross

Committee Members 1995/96

Mike Duggan	President
Alf Lizzio	Vice President
Gayle Richardson	Treasurer
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Patti Dietz	
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Melinda Rio	Admin Officer
Margaret Rodgers ..	Leadership Program Co-ord
Jane Sherwin ..	Consultant & Educ Prog Co-ord



From the President's Desk

The Mission of CRU is to challenge ideas and practices which limit the lives of people with disabilities and to inspire and encourage individuals and organisations to develop and pursue better lives for people with disabilities. So for CRU, one of our main dilemmas is: how do we most productively and practically influence the processes of change? I believe we must keep very positive in the attitude and approach to our work. Careful and precise planning is crucial. For example, over the past few years, the fostering of leadership development has been given a strong focus by CRU. This is for the very simple reason that because we are unable to do all the influencing and change-agentry, we must be in the "business" of supporting and assisting others to develop and strengthen the philosophies, networks and skills that will best equip them to engage in the process of positive change.

Another major focus of our mission is our Education and Development Program. This annual program includes events which are aimed at assisting people to attain a solid value-base so that they are more able to deal with issues that are highly relevant to the lives of people with disabilities. These events include *SRV* and *PASSING* workshops, *Social Roles Workshops* (which are presented in the context of relevant issues for particular regions or communities) and

an *Orientation Program* (for new workers in the disability field). The events also include a series of *Lunch-Time Seminars* in Brisbane when key issues are presented by guest speakers.

Recently, CRU received non-recurrent funding for a series of five workshops to be held in Brisbane, Townsville, Rockhampton and Toowoomba and the topics are: Leadership, Human Service Quality, Community Development, Inclusion, and Community Organisations.

Other avenues of CRU's work include support to agencies when a service may request support, guidance for organisational development, evaluation etc. The CRU Information Program includes our library service and the publication of *CRUCial Times*. Other CRU projects include our current involvement in a Pilot Project, which is exploring employment issues for two young adult women who have high support needs. The *Return to Communities - Focus on Families* project is another recent undertaking which supports the families of those people planning to move from Challinor Centre to a life in the community. For the past twelve months, CRU has also been involved the *Advocacy Development Project*. The purpose of this project has been to establish a framework for advocacy work in Queensland, using strategies that are consistent with building a strong, independent culture of advocacy in this state.

We can ask the question: are we doing enough challenging of the ideas and practices which limit individuals and organisations in developing better lives for people with disabilities? The short answer is, of course, no. Of an organisation such as ours, which currently employs four full-time and one part-time program workers, and has limited resources, it could be said that we are indeed fighting an uphill battle.

It will therefore depend on our attitude and approach as to whether or not we can make a difference to the lives of people with disabilities. In the near future CRU will embark on a process of planning for the next three years. In doing so,

we hope to ensure that we keep challenging the ideas and practices which limit the lives of people with disabilities. ■

Mike Duggan

CRU recently welcomed Rosanne Ott and Ann O'Brien who joined the "Focus on Families" project. They will work with Beverley Funnell during the coming months of the project.

Opportunity Knocks

Knock, knock. I'd like a job. (Let me in)
Where did you go to school?

Well, a special school. (Let me out)
Aren't sheltered workshops for people like you?

No. I'd like a job. (Let me in)
Why?

Other people my age work. I'm sick of poverty. I'm wasting my life. People see me as a burden, a charity case, useless. I want a job. (Let me in)
Why?

I want to earn money (for the same things as you). I want to meet people (for the same reasons as you). I want to do something useful (just like you). I want a job. (Let me in)
No. (Let me out of here)

Why? (Let me in)
My head says that you won't fit in. My heart says that you're not one of us. My purse says that you'll be too expensive to teach and support. (Let me out of here)

I'm sure I have something to offer. (Let me in)
Sorry, no. (Get out)

Knock, knock. I'd like a job. (Let me in)

Jane Sherwin

The following four articles are presented by people who speak from their experience as service providers. The topics raise many important issues, highlighting some of the problems faced by service providers and service users. There are, however, also many inspiring success stories and one such story is reproduced, with permission, as an insert to this publication.

Employment Services and Individual Empowerment

Those who were part of the period of great change in 1986, will remember the sense of excitement generated by the promise that disability services would clearly focus on the needs of individuals. The vision for the future, at that time, included employment services which would assume a leadership role by demonstrating to employers that people with a disability could participate competently in the workforce.

From the beginning, employment service providers have been faced with the challenge of satisfying both the outcomes-based requirements of government, as well as a satisfactory job-match needed by consumers. Such demands are often competing. It would be a rare service provider who has not known the dilemma of supporting consumers in work situations at the inevitable cost of alienating employers or the funding body. At such times the quality of the service is often dependent on the strength of moral leadership within that service and their willingness to keep to the stated purpose of the service.

Last year a draft proposal for Performance Based Funding was released. The introduction of the measures proposed in the draft will change the way in which current employment services are delivered. "Performance Based Funding" means that a payment is made to services at particular intervals marked by the achievement of milestones such as assessment, interviews, initial placement, and three months of continued employment. The new arrangements will provide for long-awaited individualised funding which will be portable so that consumers will have the option of moving to

other services along with their funding to ensure continuation of support. While it could be anticipated that such changes will greatly empower service users in their dealings with service providers, there are some worrying trends which may work against user empowerment. If you have high support needs or are considered not to be job-ready, then you may be hard-pressed to find alternative service providers willing to extend a welcome. There has also been a worrying emergence of a new entrepreneurial culture in employment services. Because small

'perhaps the time has come for some strong external support for individuals who use employment services'

services are increasingly seen as not being viable, amalgamations and private operations are either being encouraged (or at least tolerated) with little or no consumer consultation. The language of the employment industry is also changing. We are hearing about corporate structures, organisational needs, and project management teams. We don't hear quite as much about consumer consultation and participatory decision-making.

Changes to service organisations should be in response to consumer needs and consistent with the vision of 1986 in order for individual funding to effectively strengthen the accountability of services to their service users and to the whole community. There need to be at least some alternative options available. The real danger is that because of the direction the industry is now taking, by the time individualised funding is in place, the options available to service users will be minimal. Michael Kendrick, in his work on ensuring quality in human services, makes the point that services need to have internal and external safeguards to ensure quality. With steadily diminishing government resources available for monitoring service quality, perhaps the time has come for some strong external support for individuals who use employment services in order to ensure that desirable but elusive empowerment actually occurs. ■

Bob Lee

Employment Services in a Rapidly Changing Environment

Global restructuring of economies has, and will continue to have, a significant impact on the business community. In turn, volatile business conditions will impact on employment service operations and their effectiveness to continue to place people with disabilities into employment.

What is it about this global restructuring that has such impact? In a nutshell, it is change. As a society we seem to be faced with change nearly every day and at the best of times we are reluctant, by nature, to change let alone when the magnitude of change effects us in so many ways. Rapid change is occurring in lifestyles, technology, and complex social systems, as well as in careers we may plan and philosophies we hold.

In his book, *Liberation Management*, Tom Peters uses the metaphor of a "circus" to describe how businesses should be conducted for best effect. He suggests that businesses should be flexible

and fluid, up-scaled and down-scaled according to projects. They should also be totally customer-focused and each part of the business should know its exact role. If Tom Peters' metaphor indicates the future direction of business, how will the business of providing employment services fare?

'a business which is predominantly process-oriented leaves little room for the consumer to be considered'

More to the point, how will consumers fare in a "circus" environment? Even if the environment does not become as volatile as predicted, staff and consumers of services must deal with a changing environment in which agency management has two major responsibilities: to think strategically and to think in terms of fundamental values.

Strategic thinking should always focus on consumer needs and it requires

management to look at issues vertically, horizontally and globally in order to achieve outcomes that assist consumers to achieve their own personal goals. The difficulty in a changing environment is that strategies may continually need to change as new revolutions in technology and opportunities become available. Management in a changing environment has to ensure that enough attention is given to strategic thinking. Importantly, service management should also be constantly thinking of fundamental values. In a rapidly changing environment our values are tested and re-tested and can be eroded to the point where we lose our sense of purpose. Loss of purpose leaves the way open for the processes of management to dominate, and a business which is predominantly process-oriented leaves little room for the consumer to be considered. ■

Peter Callaghan
CQ Personnel Services
Rockhampton

'I have serious concerns about the current dominant fashion of macho, competition-driven "progress" and the intensity with which these economic frameworks are promoted. These frameworks are particularly dangerous because alternate views are denied, ridiculed or ignored. The "social" has been relegated to such a low priority that it's almost completely off the agenda. The dominant ideas of competition and deregulation of markets, and the attacks on the redistributive roles of government are not only dysfunctional but positively dangerous. They are part of an oversimplified dogma which can destroy a truly civil society in pursuit of the cashed-up individual.'

Eva Cox in her ABC Boyer Lecture series *A Truly Civil Society*.

The Employment Playing Field - Levelled by Governments, but also Land Mined

IPMACT employment service has been operating in Townsville for just over three years. From the beginning, there was a clear intent to offer a service which was open to all people with a developmental, sensory or psychiatric disability of a significant nature, regardless of the level of support needed. The goal of the organisation was: paid, valued employment in individual jobs for people with a disability. Consequently, Impact never fitted neatly into the prevailing patterns of either CETAP or SIJ service types.

Many of the jobseekers and people who are supported in work by the service are known to board members and there is great power in this. Amongst board members, there is a significant body of knowledge and experience about the needs of people with a disability and about the provision of human services. This knowledge-base has been increased recently by a manager with a strong background in business. The strength of vision of the organisation has been underpinned by its clearly articulated values and beliefs regarding the employment of people with a disability. The organisation has always been driven by strong teamwork involving the board, the manager and the job co-ordinators.

This unified strength sustained Impact through its "annus horribilus" in the 1994/95 financial year, when it often appeared that every job prospect turned to candy floss. During those rather dark days the entire board and staff went on a weekend retreat to carry out a post mortem on our failures and to identify our strengths. We saw that a plethora of subsidy schemes, job guarantees, case management and place-and-train assistance for all unemployed people had effectively neutralised any compensatory advantage that supported employment initiatives had previously represented for people with disability. We also identified the fact that these universal schemes had been initiated almost immediately after our own service was established. We came to the inescapable conclusion that we had two alternatives: admit defeat and close up shop or work damn hard to get better at every detail of what we do. We chose the latter. We also reaffirmed our goal and our belief in the capacity and talent of our jobseekers. We offer the following perspectives on three issues which, we believe, may also strike chords with the experience of others.

To Subsidise or not to Subsidise, that is the question

In a culture which does not see people with a disability as productive members of the work force, the chances of finding real, paid employment in line with people's aspirations often look very grim. In a work culture where many people with a disability are being supported into everything BUT employment (e.g. volunteer work, unpaid work experience, subsidised employment with no guarantee of ongoing work), it makes it very difficult to convince employers of the wisdom of employing jobseekers with a disability. Impact does not "sell subsidies" but if an employer enquires, eligibility is acknowledged and the employer is directed to CES to arrange it. The outcome of our staying out of the process has often resulted in CES advising employers that the jobseeker is also eligible for paid work experience. This comes about through CES workers having targets to meet in accordance with internal quotas. As a consequence, what started as a real job becomes a work experience program.

'There is an enormous sense of failure and loss when a job finishes. Too many people with a disability experience failure as the norm.'

The implications for the jobseekers and Impact are enormous. The actions of CES effectively negate Impact's work in building the image of people with a disability as productive workers and, in every instance, the outcome of these actions by CES has been that the employment ended after the work experience and the subsidy ended. Those people who might comfort themselves with the idea that the jobseeker at least got a chance to experience work first-hand are wrong, we believe. There is an enormous sense of failure and loss when a job finishes. Too many people with a disability experience failure as the norm. Impact has tried to do "least harm" by not colluding in this process.

Coupled with this "human side" of the subsidy issue, Impact has been confronted with the magnitude of the situation when individuals with quite significant disabilities get subsidy-based employment without a long term commitment from the employer. Many of Impact's jobseekers require more on-the-job support than those people who are usually served in CETAP style services. The implications of providing full time, on-the-job training for a number of months to an individual, only to have to repeat this training

in another job when the subsidy or paid work experience runs out, is a major resource issue for small organisations.

It should be emphasised that our philosophical difficulties with subsidies do not mean that jobseekers are never placed in subsidised employment, or offered paid work experience. A paid work experience program has often been used as a tool when an individual has career ambitions that are not backed up by any experience of work, or if we want to know more about his or her support needs on the job. When paid work experience is undertaken, all stakeholders are encouraged to call it what it is: paid work experience, not a job. There has been a vigorous debate within the organisation about the implications of encouraging employers to take on a person for paid work experience. Employers are not asked about paid work experience until after we have fully explored their willingness to take on an employee in open employment.

Public Service entry maze

There are some important issues that relate to Equal Employment Opportunity (EEO) and special entry requirements. Townsville is a public service town with state and federal bureaucracies regionally based here. Many "quality" jobs representing stability and good work conditions which we want for people with a disability are in the public sector. Impact has invested considerable staff, time, and other resources in pushing the issue of the entry-maze to state and federal public service for people with a disability. For the most part, it seemed that there was a wide gap between the rhetoric and the reality of EEO policies and special entry schemes for people with a disability. Federally, the process has been simplified and explained more clearly. Currently, two service users are working in federal government departments with another position likely to commence in the near future.

The state government (through Family Services) has just completed a pilot employment project for people with an intellectual disability. It is similar to the federal initiative but recruitment and assessment processes make it difficult, perhaps even impossible, for people with an intellectual disability to demonstrate their potential and skills. What we have effectively been doing in dealing with entry issues is "systems advocacy". We could be criticised for going beyond our role, but who else is to do this? It is difficult to "charge" our resources against a particular job placement but we believe we are

justified in continuing such activities in order to meet our longer term goals.

Funding Issues

On the whole, Impact has enjoyed very cordial relations with the funding body. They have been prepared to "hang in there" and not indulge in the number-crunching exercise which so often works against the best interests of people with a disability.

'The rewards are evident in seeing people with a disability prove to themselves, their families and the community that they, too, can have productive, ordinary lives and plans for a future.'

It has been very pleasing to repay their consideration with much healthier activity reports over the past seven months. Relations can, however, be strained by the pressures that funding bodies put on organisations such as Impact to undertake proposed initiatives. The disheartening experiences of 1994/95 made our organisation very cautious about taking on more funding. In three years, we have only agreed to take on extra funding for special interest groups on one recent occasion. Accepting extra funding would have resulted in queue-jumping, disadvantaging original jobseekers who had been waiting for some time. Our stance on the issue often puzzled the funding body and placed us in a position which could easily have been interpreted as our organisation simply being "difficult".

Impact has viewed the first three years of operation as a seed-sowing exercise. We have always acknowledged that social change takes time, and promoting the concept of people with a disability as productive and valuable workers certainly comes within the definition of social change. The strong philosophical stand taken by us now appears to be reaping rewards. Employers show a far greater openness when job co-ordinators call and the concept of people with a disability as workers seems to be seen as less astounding than before.

Recent successes in getting and maintaining real jobs for real pay has given the organisation a shot in the arm and encouraged renewed efforts. There is no doubt as to the power of providing such support to people with a disability. The rewards are evident in seeing people with a disability prove to themselves, their families and the community that they, too, can have productive, ordinary lives and plans for a future. ■

Anne Greer & Sharon Yoxall
IMPACT, Townsville

Avoiding the pattern of "perpetual trainee"

From the very beginning, it was important to us to develop a culture of respect towards jobseekers. Our experience had led us to believe that many services actually hurt people. We wanted a program which projected positive images of the people we serve. We aimed to develop a program which engaged in genuine activities, was truthful, and rewarded people for their efforts. Six years on, 210 jobs later, and with a staff of eighteen, we have begun to see the potential for a local service.

Steps is a non-metropolitan employment program on the Sunshine Coast with a rural and resort influence. As part of the fastest area of growth in Australia, it also deals with the impact of suburban growth. In March 1990 a group of parents gathered together to look for employment options for their sons and daughters. The mission of the organisation was to identify and support young adult people (between the ages of 17 and 25 who had a mild to moderate intellectual disability) to find and keep employment. Six years later, *Steps* has broadened its mission and now works with people of all ages and varying types of disability.

'the work life of a person with a disability can revolve around the notion of training and the pattern of a perpetual trainee'

Opportunities for service users are found in education, trades, traineeships and skills development programs. Employment may be full-time or part-time and is paid according to awards. We are able to get support from employers that allows people to try different occupational options. The Supported Wage System has delivered opportunities for some jobseekers. Presently twelve people are being assisted in this program. Each of these jobseekers had previously found it difficult to

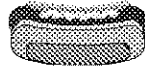
perform all the tasks required in a job or to keep up the pace of the work site. We believe this system will work well for some people but it needs to be marketed well and developed as an option. Unlike work trials and work-experience, where an employer makes no contribution towards the wage, the Supported Wage System delivers a real job with a contribution from the employer. We are constantly aware that the work life of a person with a disability is in danger of revolving around the notion of training and the pattern of a perpetual trainee. We need to guard against this pattern if people are to have the experience of the full rewards of work-life. ■

Sue Bradnock & Eric Jones
STEPS, Sunshine Coast



CRU congratulates the management and staff of Virginia Palms International Motel at Boondall, one of the few accessible Brisbane conference venues. They have gone out of their way to make us really welcome and comfortable when we have used their complex as a training venue. At our request they recently modified two villas to improve wheelchair access. They then took the initiative of making minor modifications to a further eighty rooms during refurbishments and are open to carrying out further modifications over time.

Thank you, Virginia Palms



LUNCH-TIME SEMINAR SERIES

The last of the 1995 Lunch-Time Seminar Series, *Threats to the Lives of People with Disability*, was presented by **Jennifer Fitzgerald**. For a period of approximately two years, Jennifer has been engaged in *Queensland Advocacy Inc.* project work which aims to understand current practices in respect to end-of-life decision-making in the lives of people with disability, as well as to understand the value structures which underpin those decisions. Jennifer presented personal reflections from her writing, thinking, reading and discussions about these issues.

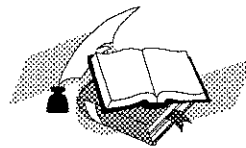
Jennifer reminded the audience that, historically, threats to lives of people with disability are not new, but she stressed that threats are coming from new sources and are operating at a number of levels. At one level, there are practices which have their origins within the medical system (abortion, non-treatment of newborns and euthanasia). At another deeper level, these practices have their own cause. They are occurring as a result of social changes which are rapidly transforming the landscape of our society.

We are living with ethical uncertainty, says Jennifer. For better or worse, in the Western world, we are witnessing a breakdown of Judeo-Christian values at the same time that the ideological framework of Communism has also crumbled. Values which previously only defined our economical interactions have now become an ethical code for a whole range of human interactions. We have embraced utility, economic rationalism and control. For people with a disability this means that when we "quality control" the human race, it is *they* who must go. We reject the "imperfect" by removing it before it emerges, through selective abortion, or by discarding

it after birth, as well as through the withholding of treatment or by euthanasia.

Jennifer says that we have lost our "wisdom tradition" and that if we are to grapple with ethical complexities we need to rediscover it. We will not find easy answers, she says, because ethics are not neat equations or mathematics. Nor does Jennifer think that a contractual approach (such as living wills) will give us just and humane results in these crucial issues. Rather, she says, it is in the reclaiming of our wisdom tradition and our instinctive morality that we will find the answers. Ethical problems, says Jennifer, are too important to be left to experts! ■

Note: All papers which have been written during the project, including a full version of the one above, are available from *Queensland Advocacy Inc.* by phoning (07) 3236 1122.



CRU'S EDUCATION & DEVELOPMENT PROGRAM

The 1996 Education and Development Program offers an exciting range of opportunities for those who are new to CRU events, as well as for those who have participated in past events. Through the topics presented and the people who present them, we hope to strengthen and support values, ideas, practices and networks which lead to people with disabilities being welcomed into and participating in community life.

The *Orientation Program*, *SRV Theory*, *PASSING*, *Social Roles workshops* and the *Leadership Development Program* will continue to be presented during 1996.

A new program of five workshops will be presented in Brisbane, Townsville, Rockhampton, and Toowoomba. This program has been

developed in light of consideration of important topics for positive change, the training needs of people in services throughout the state, and it capitalises on a return visit to Australia by **Michael Kendrick**. Michael will present two new workshops: *An Exploration of Leadership* and *Quality in Disability Services*.

Another new workshop, of particular interest to committee members and service co-ordinators, is one which examines the role and purpose of community organisations. This *Community Organisations* workshop will explore the strategies

necessary to stay focused and responsive. Given the importance of finding ways for people with disabilities to become true members of their neighbourhoods, workplaces and so on, CRU will also host a two-day workshop exploring community development skills.

With such a range of workshops offered throughout Queensland, we are looking forward to meeting new participants and re-connecting with participants from past events. ■

Jane Sherwin





Book Review

Home At Last: How Two Young Women with Profound Intellectual and Multiple Disabilities Achieved Their Own Home

By Pat Fitton, Carol O'Brien and Jean Willson

What a great sense of timing this book has! For Queenslanders, *Home at Last* has arrived in the midst of large-scale activity aimed at returning people with intellectual disabilities to Queensland communities after long periods of residency in two large State institutions. I believe this book will provide a much needed contribution to the thinking and debate about how best to support people with multiple disabilities to live safely and happily among us.

Many of us who support institutional reform in Queensland still have serious concerns about whether the non-government sector has the know-how, capacity and desire to provide appropriate quality supports to people with multiple disabilities. Many of us know it can be done if the commitment is matched by the necessary resources and the relevant know-how. However, there is a shortage of successful, innovative examples that have been documented for wide dissemination. Enter *Home at Last!*

I am really excited about this book. It provides an antidote to the persistent pessimism which insists that congregate residential settings are appropriate responses to the needs of people with multiple disabilities. Frequently, when stories are told about people who have profound intellectual and multiple disabilities living in ordinary community housing and supported by services, many people assume that the storyteller must be using a different definition of 'profound disability' or 'high support needs'. They may then conclude that the individuals they know who are described in these same terms are far more disabled, and that consequently these arrangements couldn't possibly work for them.

Within the first few pages of the book, however, there is no doubt whatsoever that this is a story of two young women (Kathy and Victoria) who have very complex medical requirements and are in need of assistance with all aspects of living on a twenty-four hour basis. The authors devote

over twenty pages to describing detailed aspects of the care and support required by Kathy and Victoria.

Many people will find this book extremely useful. It is written by two parents in collaboration with a trusted professional colleague. These three women have been the driving force in making a dream become a reality for Kathy and Victoria. Practical, down-to-earth readers will love it because it is overflowing with 'what' and 'how'. Visionaries and big-picture thinkers will also like it because it provides inspiration and hope. The underlying philosophy, or the reasons why such an endeavour was embarked upon, come through very clearly in the book. Early in the account it is established that the parents were not satisfied with the quality of care their daughters had received over many years and in many different residential settings. The underlying conviction is about the entitlement of people, regardless of their level of ability, to have a pattern of living which is meaningful, dignified, relevant and based on those things which are available to the vast majority of the population. Over time, the parents developed the idea that Kathy and Victoria would have their own home. The book records and describes how this was actually achieved, creatively using the resources which were available.


This book is commendable on many different levels. Firstly, it is well written and easy to read. It is full of knowledge and wisdom learnt from experience. It has comprehensive details of the processes involved in setting up a home for the two women. Planning and financing arrangements are well covered as are the many issues associated with community involvement, staffing and operational policies. One of the most laudable qualities of *Home at Last* is its avoidance of romanticism. It does not pretend that achieving a personal home for two young women with multiple disabilities is an easy task. It gives real insight into the challenging realities of creating new patterns of living for people who have been largely excluded from their own neighbourhoods.

The book makes a major contribution to the development of quality practice by addressing the issue of involvement by family, advocates and allies in service delivery. Much of what we have learnt in recent years about supporting people with disabilities to negotiate life in the community, outside of institutional settings, has grown out of work done for adults with physical disabilities. In these situations people are expected to be able to direct their workers and the workers are not expected to make judgements about the person's lifestyle choices.

The parents felt their daughters' lifestyles could be further enriched... Above all they wanted their daughters to be settled and secure in their living arrangements so that as their parents became incapacitated or died, they would not have to cope with fundamental upheavals in their arrangements as well as bereavement.

(Introduction to the book)

The support worker is there to empower the person. People who have a significant intellectual disability and who cannot direct their own staff, are dependent on other people making judgements about what is in their best interests. For these people the empowerment approach is less relevant. Decisions will be continually made by others thereby rendering people with multiple disabilities vulnerable to the power and authority of others. This book clearly establishes that open practices and the involvement of family and other key people in the planning, monitoring and evaluating of services are important components in safeguarding against neglect, abuse and injustice.

Finally, this is *not* a book to be read once then put aside. It will be valued as a guide and a reference. It is a book to be turned to frequently in order to be inspired and challenged about what it may take to ensure that people get decent lives. Hopefully, it may even help readers to actually do this for someone they know. 

Beverley Funnell