RUcial Times

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			In	<u>this</u>	issu	<u>e</u>			
Edito	orial								1
Pres	den	t's R	epor	t					2
News	s Up	date							3
Inclu	isive	Edı	icati	on - 4	4 Y	ears	On		4
Proj	ect V	Vork	und	lerta	ken	by	CR	U	7
Educ	atio	n &	Dev	elopr	nen	t Pr	ogr	am	8
Book	Re	view							9
Key	ssu	es							10

EDITORIAL

In February, Bruce Uditsky, Executive Alberta Association Director of for Community Living in Canada, long term disability activist, and parent of two sons, one of whom has a disability, returned to Brisbane for a few days. He had previously been here four years ago for a conference on inclusive education. His visit offered the opportunity to reflect on what has happened during the past four years and on current Included in this edition of challenges. CRUcial Times are overall reports and reflections on Bruce's visit.

This editorial is dedicated to the key points he made in his lunch-time address *Key Challenges in the 90's*.

Bruce Uditsky argued that of all the key challenges of the 1990's, it is *life* and *relationships* that have a fundamentality and importance that are more basic than many of the issues that we struggle with in our reform of systems and services for people with disabilities and their families. No. 2 February 1995 Phone: (07) 870 1022 Fax: (07) 371 3842

Tracey Latimer, a 12 year old Canadian girl with severe disabilities, was killed by her father one Sunday morning while the rest of her family was at church. Bruce told the audience of an overwhelming outpouring of support across Canada for Tracey's father, and the strong arguments put that he should not have been punished for succumbing to the pressures of caring for a child with severe disabilities.

Notwithstanding one's identification with the anguish of the father, the killing of Tracey shows that a very significant number of Canadians can identify with the killing of disabled people. Infanticide is not new and unique; it is thousands of years old. What is troubling is that in our own times, forty years of struggle and activism for community living for people with disabilities, have not altered this basic instinct at all. Many, and possibly most, people believe that to live with a severe disability is a life not worth living.

Bruce's lunch-time address illustrated how deeply held this view is in a society in which people and life are valued more because of their utilitarian worth than their intrinsic worth as human beings.

"Why would you bother?" families are often asked when they explore the need for medical procedures that might improve the comfort and quality of their son's or daughter's life. The documentary on euthanasia in Holland, televised late last year, clearly illustrated the belief that life with severe disability is not worth living.

Across Australia, older people and people connected with someone who has terminal illnesses are arguing a case for euthanasia, assisted suicide, and living wills. The ground is being prepared for other people to determine that one's life is not worth living. The Bill presently before the Northern Territory Parliament and the promise to introduce a similar Bill into the South Australian Parliament next month are all a testament to the strength of feeling that already exists in Australia on these matters.

The killing of Tracey Latimer and the euthanasia Bills which argue a right to die, are not unconnected. They speak to a fundamental disdain for human life which is not productive, pain free or independent. Life, as Bruce Uditsky says, is truly a key challenge for us. A threat to the life of people with disabilities is a threat to each and every one of us. Not just because we might all live to be disabled, but because it puts a price on our life and relationships. Community living and community inclusion cannot work unless people commit to living their lives in relationship with vulnerable people.

Bruce Uditsky challenged us to look at ourselves, not just at others, and to remember that while we put effort into reform of our systems, at the same time our own relationships in community life are falling apart around us. Relationships that deeply evidence the valuing of vulnerable people and of each other are the essence of community living and are crucial to the opportunity to "live". The right to live, not the right to die, is a crucial issue for our times.

Thank you Bruce, for reminding us of these crucial issues. Anne Pross



CRU President's Report

When people eventually get to move out of institutions, it is often very similar to when a teenager leaves the parental home and protection

for the first time. On one hand he/she is filled with excitement and anticipation of a new, very different lifestyle; one which encompasses freedom, choice, autonomy, etc. On the other hand there are feelings of varying degrees of fearfulness and apprehension, even intimidation. However, there are differences between the average person leaving home, and a person leaving an institution.

For instance, if the former does make a mistake, often he/she will be able to cover up to such an extent that probably nobody will ever discover it. Whereas for the person with a disability, is anything private? He/she is virtually constantly 'on show', with people almost virtually waiting for mistakes to be made. Of course, this does great things to one's confidence!!

If we are sincere in our beliefs that there are true benefits to community-living over living in institutions, we must do our utmost to ensure that people with a disability are able to take full advantage of such benefits. Our advocacy must be aimed at things like:

- ensuring that positive outcomes for people with a disability are attained,
- studying current trends both here and overseas.
- learning from the past,
- the provision of appropriate resources, for instance:
 - sufficient personal care support hours
 - money for white goods, etc.
- housing appropriate, affordable, individual,
- ensuring that people don't become isolated in the community,
- establishing the necessary safeguards.

CRU's Mission is to challenge ideas and practices which limit the lives of people with disabilities. To inspire and encourage individuals and organisations to develop and pursue better lives for people with disabilities.

For CRU to be faithful to its Mission and to play our part in the Institutional Reform process, there is certainly going to be challenging times ahead of us. Our record speaks for itself, when it comes to 'tackling' the hard issues.

Mike Duggan

Committee Members 1994/95						
Mike Duggan	President					
Alf Lizzio	Vice President					
Rae Litzow	Secretary					
Janet Millward	Treasurer					
Judy Brown						
Patti Dietz						
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Pam Collins	Resource Officer					
Beverley Funnell	Consultant					
Rosanne Ott	Training Consultant					
Melinda Rio	Admin Assist					
Margaret Rodgers	Leadership Program Co-ord					
Jane Sherwin	Consultant					



Margaret Rodgers joined CRU in December 1994 as the Project Officer for the Leadership Development Program, which will be offered regionally in 1995/96. Margaret has enjoyed getting in touch with people from around the state - some of whom she had met while working with QPPD, the Queensland Spastic Welfare League and Mamre, and talking with them about how leadership can best be nurtured and sustained in their areas.

Margaret's experience as Co-ordinator and interim Co-ordinator of small community based services leaves her in no doubt about the need for the program for people who are confronted with the demands of a leadership role.

As a participant in the 1994 program in Brisbane, Margaret was able to reflect on her own experience as a service provider and committee member and learnt a lot from the experiences of people with disabilities and parents in their leadership roles. Her leadership project was on "Friendship". Following a hunch that friendship for people with disabilities is

often "idealised" she circulated a questionnaire acquaintances. to 35 friends. colleagues (anybody who would fill it in) to get a picture of people's experience of friendship generally. The results confirmed what she thought, i.e. the majority of respondents had 3-4 people that they can count on when things are bad; work was the most common place to meet friends; closely followed by introductions by other friends and family members. It also came across loud and clear that friendship often took a long time to develop, was not "automatic", and had its costs.

Watch this space in 1995 for more discourse on the topic of *friendship*

LIBRARY PROJECT -IT'S MAGIC

The development of the CRU library collection is well under way with the milestone some weeks ago of the one-thousandth entry on to the computer database. The database system is called "In Magic" and the comment was made by one of CRU's Consultants, when she embarked on one of the first searches through the computer system, that it was truly magic. She located the article within minutes, whereas she had been looking for it for many months.

It is exciting to report that the library system provides a valuable resource for CRU's work and to other agencies and individuals who have used it. The project is now in its final, colourful stage of completion. Guidelines for copying/lending are presently being drawn up and will be published in the next edition of *CRUcial Times*.





News Travels Fast

Shortly after the Moloney family's departure in November 1994 came the post cards, letters, then fax's to keep us up to date with their travels. From Fiji, Disneyland, the Grand Canyon and Mexico - Bronwyn has had plenty to write home about.

Now we have a photo album loaded with shots of *la familia Moloney* at their best. Terry, King of the Fast Food, the children making snow people and Bronwyn with a giant size mega Marguerite to start the New Year.

Last reports were from Guadalajara where they were marvelling at the art works of Mexico and entertaining the locals with conversation in Spanish. How do you order a *small* nachos again Bron?



LUNCH-TIME SEMINARS:

Key Challenges for the 90's

When Bruce Uditsky visited Brisbane with three weeks notice, it was a superb opportunity to have him deliver the first in a series of CRU lunch-time seminars. Eighty people enjoyed Bruce's thought provoking presentation on the two key challenges of Life (under threat for people with disability) and Relationships. Those who attended welcomed they commented that the opportunity to think about 'big picture' issues and to catch up with each other.

See Diary Dates for the next scheduled lunch-time seminars.

INCLUSIVE EDUCATION ~ 4 YEARS ON



Some Parent Perspectives



Having agreed to write this article in response to Bruce Uditsky's second visit to Brisbane, I am finding it difficult to know where to begin as so much has happened since his first visit in 1991. Perhaps some reflection about the impact that Bruce made in 1991 upon myself and others may be an appropriate beginning.

I have spoken publicly about the gut feeling that I experienced when my son Brendan was born 12 years ago. Somewhere inside me there was a warning bell concerning the need to ensure that Brendan must always remain in the mainstream if he were to survive in the "real world". However, after having had no trouble accessing kindergarten and pre-school opportunities for Brendan, my initial concerns resurfaced when we encountered enrolment barriers at the local State School which my older two children had attended since Year 1. Although the school was low-set with wheelchair accessible facilities and there was a willingness by the school to accept Brendan's enrolment, however, Special Education representatives intervened with arguments for Brendan to be enrolled at a school with a Special Unit that was miles from our home. They did their best to deflect us away from our first choice with offers of taxi transport and Special Teacher Aids, but we held our ground with the final decision for enrolment being left up to the school. Brendan started in Year 1 in 1989 at the local school with no school support and the Blue Nurses assisting with his daily personal needs.

In 1991 the conference presentation *Coming*, *Ready or Not* was advertised and I knew I had to be there. Bruce Uditsky was the keynote speaker. Everything he said confirmed what I believed in for my own child, and his words brought an awareness that unlocked the narrowness of my focus to the possibility of inclusion for <u>all</u>.

It was a revelation that raised the consciousness of all who listened but, of course, there were those who didn't want to hear. The vision, the strategies and the emotional experience challenged and impressed the participants to such a degree that the Inclusion in Education movement was seeded.

Four years down the track and Bruce's words are as relevant as ever. Sadly the title *Coming*, *Ready or Not* is still a reality for many children accessing the education system even though Departmental policies and Human Rights legislation have been put in place. Recent publicity has described a lack of resources as being paramount to the argument for and against, and yet there has been an allocation of funds to support inclusion. There are, however, an ever growing number of educators who are gaining in experience and are supportive of inclusion.

Four years down the track the Queensland Parents of People with a Disability (QPPD) Inclusion Network has flourished since its humble beginnings as a small number of us meeting together to decide, "Where do we go from here?". Many who attended that first meeting are still involved with the QPPD Inclusion Network and meet regularly. Bruce's visit to QPPD in mid-February was an opportunity to bring others who have stepped back from the front-line to hear his message again.

The QPPD Inclusion Network has developed into a state-wide network of people committed to the principle of inclusion and is respected for its clarity of vision and unwaivering stance on inclusion being a right for all.

Four years down the track our personal struggle for Brendan's inclusion has been bumpy to say the least. Following 5 years of highs and lows within the State system, we transferred Brendan to the Catholic Education System, and so far we haven't looked back. His older sister attended a Catholic College from Year 8 and we fully intended to follow suit with our sons. However, as the culture of the local State School evolved, we felt it prudent to transfer our boys to the primary section of the Catholic College that they were both booked into for High School. Brendan is now in Year 7 and his older brother is in Year 10 at a school which welcomed the enrolment of both boys and bent over backwards to accommodate Brendan's special needs.

Bruce Uditsky's message seeded a movement that has supported and shared my vision, given me the courage to continue when it would have been easier to "go with the flow", and he introduced me to people who will remain lifelong friends.

Thank you, Bruce.



Donna Ball

In 1991 when Bruce Uditsky visited Brisbane my daughter attended a local school with a split placement between the regular classroom and the special education unit. Then, most teachers thought she should have more time, if not a full placement, in the unit, while I thought she should be totally integrated in the regular classroom. Placement in a High School seemed out of the question.

Four years later in 1995 my daughter attends a local High School and is fully included in a Grade 9 class. She was given the same choice of subjects at the end of Year 8 as other students. Anita has an Intellectual Disability and has her class work modified. She has an alternative school-based assessment which looks at the positive gains rather than the negative deficits. Seeing her now it is hard to imagine that placement in a High School was once considered to be in the realms of fantasy.

Four years further on in 1999 where will my daughter be? She will finish High School in 1998, then what paths will be open to her? As a High School placement was thought to be in the land of fantasy in 1991, is it also fantasy to consider a place at University in 1999? Maybe, just maybe, they will be ready for her!

Elaine Stephenson

My pen was doodling while waiting for Bruce Uditsky to give us his 'Four Years On' presentation. It never ceases to surprise me as it hit me yet again how much my emotions are integral to my parenting. The poem I jotted says a little of this

Bruce, the parent and advocate, excites me to push on yet further for opportunities like tertiary education open learning after 'school's out'. Thanks Bruce for challenging yet again my ideas of the possible. What will the next millennium bring? David will be in Year 9 looking forward to University??? And looking back for perspective, David, now in Year 4, was in a separate special education class when Bruce was last here in 1991.

Mary Waldie

four years ago disability frightened *me* my son was disabled ... *not*

he could make it in the mainstream maybe if we tried ... and tried ... and believed ...

I sighed it's hard on the edges

it hurts on the edges I cried

what's this I heard inclusion for all uditsky urged

but ... but david just barely scrapes 'in' for him? for her? mon dieu how can it be?

his mum her dad, now I see wanting just like me ...

wanting just like me ...

four years on your son and mine making for the mainstream

such ability has me grinning it's right I cry

every ability makes me beam it's pride I smile

though it's hard work I stride

your son and mine disabled ... not your son and mine ... enabled

from "being on the journey" ... © Waldie 1995



he next time, as a parent you feel isolated, alone or defeated it might be helpful to recall that the struggle you have engaged in for your child is to the benefit of us all. Our communities, our children who will grow up to be adult members of those communities, require schools which imbue the principles of inclusive education. Michael Fullan, an internationally recognised Canadian educator, has called for teachers to be moral agents of change. He suggests that educational reform is dependent on committed individuals (e.g. parents and teachers) working collaboratively, as the educational system cannot reform itself. It is time now for all those parents who support inclusive education to be recognised by schools and educators as educational partners leadership in By building a bridge between reform. movement and the school reform inclusive education, positive and needed change may be more readily realised.

Bruce Uditsky



As part of the Regional Education and Development Program, CRU has conducted five workshops throughout Queensland entitled *Social Roles: A Crucial Issue*. One of the places we visited was Goondiwindi......

ON THE ROAD AGAIN

As departure time for the journey to Goondiwindi approached we were pleased to look back on a successful series of regional workshops held throughout Queensland. In particular the workshop, *Social Roles: A Crucial Issue*, has attracted a wide audience of people from a variety of interesting communities including the Gem Fields near Emerald and Islands in the Torres Strait. The word was out via the bush telegraph and an extensive mailout, that CRU was presenting in Goondiwindi.

Feedback from the workshops has indicated that the exploration of the social roles for people who are marginalised by society has been useful learning for people with disabilities, parents and workers. The presentation format which was spaced over an evening and one day, gave participants time to think about their own roles in life and then consider the possibilities for people who have not had similar opportunities.

Although we did attempt to find venues that were accessible and air-conditioned, not all the centres had these comforts. Let it be noted that in some places the temperature soared when CRU visited, and it was very encouraging to have all the participants with us at the end of those days.

Much of the learning came from people in the groups sharing their own stories. This was helpful for us to become familiar with the history of services and the experience of people in regional communities.

We look forward to further contact with people we have met throughout the regions. Let the good life <u>Role</u> on!

Rosanne Ott

Post Cards from the Regions

On February 10 and 11, Community Resource Unit visited Goondiwindi, a small town in western, rural Queensland, and offered our district new and challenging ideas via a workshop *Social Roles: A Crucial Issue.* The value that such a workshop can hold for isolated areas will hopefully never be underestimated.

Whilst I cannot attempt to speak from the viewpoint of every person in our community, it's great to have the chance to communicate some aspects of disability from my perspective as a Support Worker in a small country town. Isolation is more than geography. It means isolation from a wealth of services, resources and people with similar experience. Most importantly for me, however, is the absence of regular stimulus which might challenge, reaffirm, extend and/or develop opinions about disability. It is the isolation from IDEAS which tends to make professional development and life experience occur in a vacuum.

It is the isolation from IDEAS which tends to make professional development and life experience occur in a vacuum.

The community spirit is great and the support from interested parties such as school special needs groups, families with people with disability, etc., has kept things alive out here. But in terms of regular contact with CURRENT thought, political movements/trends, latest developments, etc., there still remains a loud silence.

What I am saying is, thank you to CRU for seeing the need to outreach rural areas.

Pam Finedon



People in the disability arena in *Central Queensland* are currently involved in many activities directed towards fuller integration in our community for people with disabilities. These include:

A construction project which has the full participation of the future tenants who are doing the planning of two 2 bedroom units. The tenants and the support group are in the process of selecting the land, designing the buildings and preparing to manage the property.

There have been several trips out in the maxi-taxi to view possible building sites, all tumbling and wheeling in and out of the cab to move on to the next site. Cruising Rockhampton in this style has proved to be a great way to hold a mobile meeting. After each building block was viewed we were able to discuss the pro's and con's while being driven to the next. It didn't take long to short list! However, the final negotiations are beginning to seem endless.

An invitation to key persons in town to join us for a social evening where we share the experience of difficult access to buildings. They will 'acquire' a serious disability for the night and receive a short list of tasks to achieve throughout the evening. Rockhampton, like many provincial cities has extremely poor access to social venues and places of business. The goal of this group is to continue to raise public awareness of these issues.

The Community Training Network, in conjunction with the team from CRU, is planning *Theory* and *PASSING* in Rockhampton, between 19 and 28 April. The venue is the Central Queensland University. Further information from Jude Hose on (079) 227 117, or the CRU office on (07) 870 1022.

Jude Hose



A TOPIC FROM TRAINING: Assumptions and Stereotypes

The following is an extract from one of CRU's training programs.

One of the topics in a recent workshop conducted by CRU looks at that very human characteristic of making assumptions. A group exercise highlights how all humans, when seeing or perceiving someone or some group, make assumptions which lead to stereotyping. If we believe the stereotypes, homeless kids are drug taking and dangerous; single mothers are careless reproducers who rip off the welfare system; and people who are unemployed are dole bludgers.

While this might sound humorous, the repercussions of being stereotyped can be profound. People are more likely to be judged negatively once they have the label of disability and/or are perceived as being negatively different. This can set the person on a 'disability'

path', and one of the experiences on this path is being the subject of stereotyping. Once a person is stereotyped, he or she loses aspects of his/her individuality. There is nothing about the individual nature or characteristic of the person that makes them deserving of harmful treatment. As someone said, 'stereotyping is a substitute for taking the time to know a person'.

Historically, stereotypes or roles into which people with disability are cast include: *object*, *sick, menace, child, burden*, and *object of pity*. If the assumption is made that people with disabilities are sick or diseased, then services provided will probably have a medical orientation. If the assumption is made that people with disabilities belong with their own kind, then they will be grouped with other people with disabilities. If the assumption is made that people with disabilities can't learn, then the consequence for the individuals will be lowered expectations and 'special' programs, and so on.

As human service workers or family members, we can observe or experience the effects of stereotyping and assumption making. For example, if, when a person with a disability is out shopping and it is assumed that the person can't communicate, all questions will be directed to the person's companion. If a prospective employer assumes that a person with a disability is more likely to have accidents or will cause conflict in the workplace, then the person with a disability is more likely to meet great resistance from an employer.

The challenge for us is to <u>not</u> provide further examples for the community which reinforce the stereotypes that are held at an unconscious level. We need to ask ourselves: Are we giving negative messages about people's image or competence through the service we are providing? Do we, for example, use language that perpetuates stereotypes, or plan activities in which people are grouped together in ways that reinforce negative images?

A further challenge is for us as *individuals* to recognise what stereotypes exist at a subconscious level. We too, have been subject

to all of the messages which socialise us into believing the false assumptions about people with disabilities and the stereotypes.



A future *CRUcial Times* article will explore the consequences of negative assumptions and stereotypes.



Book Review

Dead Man Walking

by Helen Prejean, CSJ Fount Paperbacks, 1993

This eyewitness analysis of the death sentences in the United States chronicles Helen Prejean's extraordinary relationship with two prisoners under the death sentence and her initiation into the macabre rituals of death row. This is a book full of pain: crimes that defy description and the rage, horror, grief and fierce ambivalence that follows.

It is an important book. Its subject, capital punishment, is an important issue. America can boast: the highest confinement rate in prisons in the world; it is one of two western countries that has the death penalty on its statute books. It also costs more to kill a prisoner than it does to keep them alive for the rest of their lives.

It is also an important book for anyone interested in *moral action*. It tells the story of the dislocation of personal values and work place values ... of people "just doing their job", who personally abhor the killing of people, but who participate anyway. It also demonstrates sharply how in systems, individuals often don't take responsibility. Somehow the system is responsible, and no individual is!

A gripping book which should be read by anyone interested in moral action, and how our systems dislocate people from their own humanity.





One of the major challenges for Queenslanders is to keep the vision of what is possible for <u>all</u> Queensland children. Bruce Uditsky, in an interview on ABC Radio National during his recent Australian visit, said:

In Alberta, it has in many ways been easier for young people with intellectual disabilities to become included in University than to have been included in their regular schools because there has not been a whole industry of segregation to dismantle as there is in the schools.

Now there's a VISION!

A CHAT WITH BOB LEE

Bob Lee, after working for the Queensland Spastic Welfare League for fourteen years, left to take up a leadership position with Epic Employment (Lutwyche, Brisbane) during 1994. Bob is also a member of the Reference Group for CRU's Leadership Program.

Catching up with Bob from time to time always proves to be an occasion for lively and stimulating discussion. Bob has the knack of seeing beyond the obvious and getting to deeper layers of meaning, while most of us are still struggling with the superficial. He usually succeeds in getting me to look at an issue from a different perspective.

Chatting to Bob about the recent visit by Bruce Uditsky reminded us both of an earlier conversation at a workshop last year, where the matter of 'influence' was discussed.

Influencing our society in the direction of becoming more welcoming, accepting and inclusive of people who are devalued, is clearly going to require sustained effort over period. Making significant long а а difference in what is possible for people with disabilities in our society is, and will continue to be, a complex and demanding pitfalls. task and one abounding in diversions and possible perversions.

Bob points out that the complexity of achieving change means that people involved in advocacy and other change strategies will need to operate at three different levels. These levels are the individual and family level, the community level and the broader level of social and systems change. The pitfall in this is that those working at one level may not fully appreciate the importance of working at the other levels. Therefore those involved at a systems level, for example, may, if not well aligned, lose touch with the efforts at the individual level.

There are particular pitfalls that await those who seek to have influence at the political and bureaucratic levels. Bruce Uditsky also alluded to these. As soon as advocates feel comfortable walking in the 'corridors of power' seduction becomes a greater possibility than previously.

The greatest challenge at the moment is at the *community level*. Bob believes that there is a vagueness about what we actually mean by 'community'. There are also many myths about community that we may still carry with us from our childhood and from stories of the past.

Bob asks: is community still a geographic notion or has it actually changed as our population has become increasingly mobile? Bob thinks it may be *communities of interest* and of *shared purpose* that for many people have become significant in terms of providing a sense of identity and belonging.

Becoming clearer about what community may mean is crucially important for those working currently to assist people to return to 'community' as part of the Government's institutional reform process. Accessing community disability services is definitely not guaranteed to lead people into the promised land of 'community.' In fact the notion of 'community services' is quite misleading. The notion may suggest that the acknowledged and 'community' has responded to the identified needs for support that some of their members have. The reality is that there is usually insufficient ownership of responsibility and willingness beyond a small band of people who tend to be seen as a 'special interest' group within the community.

Influencing communities on behalf of people with disabilities is something that requires urgent attention. We need to get smarter at it, but first we need to get to grips with what we are actually talking about. As a starting point we need to get back to basics and try to figure out what is important in our own lives. We need to have a strong sense of the ordinary and the typical and assume that this will have relevance and that it will bring value and richness to the lives of people that, as a society, we have failed and continue to fail.

Beverley Funnell

Institutional Reform

One of the crucial issues which will be on the Queensland agenda for some time is the *Institutional Reform* process. Integral to this process is the understanding of "community" and "community membership". There is <u>no</u> argument. **People with disabilities belong in the community**. There is however, naiveté about the capacity of the community to respond in the most helpful ways to people with disability, and about how best to enable community membership.

Bruce Uditsky recently highlighted some pitfalls:

- what we do not want is the closure of institutions to be a conveyor belt to the community
- "the closure of an institution should be just one outcome of people getting an ordinary life" (as opposed to closure being the primary goal)
- "the independent living movement has frequently led to individual independent isolation"

It is Queensland that is being reformed, not simply the institutions. Are we up to it? We are, indeed, in crucial times.

Jane Sherwin