

CRUcial Times

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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

Community Living: CRU's Contribution in 1997

Over the past decade or two, Queensland has experienced an unprecedented growth in the expectations and actions by people with disabilities, their families and others. There has been a great struggle to improve opportunities for people with disabilities to become part of the ordinary life of the community, and to have their humanity and citizenship recognised. The need for this "community living movement" is only necessary because the opportunity of living an ordinary life is denied in so many ways. It is no small task to marshal the heart and the will to overcome deeply held prejudices about people with disabilities, or to protect and enhance the lives of people with disabilities in a society that is increasingly individualistic and utilitarian.

During 1997 CRU's work will continue to support issues of community living. This seems to be particularly important at a time when energy is low and when there are more and more examples of people being isolated, segregated, congregated and abused. There has never been a greater need for all of us to stand beside, and to act with people with disabilities and their families.

All three editions of *CRUcial Times* during 1997 will carry contributions about community living. In this present edition, Trish Lunn and Jill Hole share experiences of supporting their children to get a real life. Their stories truly inspire hope and joy. Dot Hockey has written of her dream that her sister might live a more typical life after forty-four years in Challinor. Peter Millier has also shared some of his thoughts about the barriers to getting a real life when surrounded by low, and sometimes destructive, expectations. A warm and funny story is told by Penny Harland about becoming a member of Toastmasters, and Frances Carpenter reflects on some traps for service providers.

With respect to education, development and training, CRU has more than thirty workshops scheduled throughout Queensland this year. You might note that CRU has tried to deal with spiralling workshop costs by reducing the fee, which does not now include lunches. These workshops will offer opportunities for renewal and learning to the many committee members, workers and advocates involved in the community living movement in Queensland. Last year 1400 registrants attended CRU workshops throughout the State.

As many of our readers know, CRU has also been concerned with the development and support of leadership in the State, as it is impossible to move forward on important issues without good leadership. During 1997 CRU is

organising a number of events planned to support and develop individuals in their leadership roles.

Together with CRU, Values In Action Assoc. is staging an intensive "Summer school in Winter" event with Prof Wolf Wolfensberger. This event will cover many advanced issues pertinent to service provision in contemporary times. Members of Values In Action are organising the event and bearing the financial costs of administration as well as the financial risk of staging this international event. CRU's contribution is to donate some of Jane Sherwin's time, enabling her to co-ordinate the overall effort.

In 1997, CRU will continue its work with families of residents at Challinor, and is involved with many service reform and development projects. We are hopeful that the current funding round might enable us to develop a new series of educational events for co-ordinators and key management committee members, and to develop workshops for people involved in individualised service arrangements.

CRU's complete work plan for 1997 will shortly be mailed to CRU members and other interested people. If you would like a copy please let us know. Enclosed with this edition is a request for some feedback on *CRUcial Times*. This is our third year of publication and we would really appreciate your help in shaping it.

Best wishes from everyone at CRU, *Anne Cross*

From the President's Desk

People with disabilities have been congregated and segregated from the rest of society throughout history. The rationale for these actions has always related to the context of the particular period of time. Claims were made that it was for the benefit of the people with disabilities themselves, while at another time it was claimed that it was for the benefit of society itself. But whatever the real reason was, and is, institutionalisation of people does not work. Institutions are bad places, rife with blatant abuse and mistreatment of people. They engender and reproduce cultures of violence which, in doing great harm to individuals, degrade the whole society. Society pays a price in this way and the individual pays the price of a wasted life. In the last few decades we have started to ponder the folly of our ways and have begun to make a shift in our thinking. Those of us who believe that there needs to be such a shift are saying that we want to get people out of institutions and support them to assume their rightful place in society.

In this changing agenda are we always thinking about the best interest of the person who has the disability? If so, why are there so many people living lives of isolation, loneliness and of having to constantly battle for day-to-day survival? Under a guise of "empowerment", people with a disability are being forced into the task of hiring-and-firing

personal care workers, and of managing budgets and planning. These tasks are so demanding, that there seems little left to work on "getting a life" whatever that might mean for each individual.

People with a disability must be supported to dream (perhaps for the very first time) and to grow in self-confidence. This requires time and encouragement and the permission to make mistakes and to learn from these mistakes. Too often people with disabilities are expected to be super-human and if one small mistake occurs or something goes wrong, the label of "failure" is instantly applied.

To enable a life of quality in the community, the vulnerability of people with disabilities must be acknowledged and safeguarded and their life experiences understood. We should strive to ensure that we do all that is in our power to make the community as welcoming and as inclusive as we possibly can, while developing and maintaining innovative, flexible and responsive approaches to service provision. Through CRU programs, we hope to engender and encourage these approaches to supporting people with disabilities in their growth and development.

With best wishes,

Mike Duggan

Committee Members 1996/97

Mike Duggan	President
Alf Lizzio	Vice President
Margaret Ward	Secretary
Janet Millward	Treasurer
Pam Rallings	Committee Member
Patti Dietz	Committee Member
<i>The Management Committee farewells and thanks Judy Brown for her valued contribution over the years.</i>	

Staff

Anne Cross	Director
Pam Collins	Resource Consultant
Silke Collisson	Admin Officer
Beverley Funnell	Consultant
Melinda Rio	Admin Officer
Margaret Rodgers	Leadership Prog Co-ord
Jane Sherwin	Consultant & Educ Prog Co-ord
Ann O'Brien	Project Worker

The Struggle for a Real Life

Peter Millier

Whenever I have a discussion with an individual or group about what a typical, ordinary, "real" life looks like, we quickly agree on the broad outlines: the way we live our lives; our families, intimate relationships, children, close friends, pets, acquaintances; homes, jobs, education, recreation, worship, celebrations; a sense of citizenship, belonging, community, contributing, mutuality, reciprocity; sadness, struggle; connections to our past, belief in, and hope for, the future; learning and growth. The details may be different in degree or kind, but we easily identify in the lives of others (and they in ours), the essential elements of a real life.

Something seems to change, however, when we either discuss, aspire to, or try to organise or support a typical, ordinary life for, or with, a person who has a disability. Although the intent is usually good, the homes, friends, schools and jobs for people with disabilities do not look quite like the home we would want to live in, the friends we would want to be with, the schools we would want our children to attend, or the jobs we would want to go to each day. When any of the elements (either individually or collectively) of our typical lives are used as a measuring stick, people with disabilities seem, for the most part, to be leading very "atypical" and "unreal" lives. Why is this so?

There are probably many reasons, but some are fundamental. Firstly there is the assumption made by people in society generally, and in human services in particular, that people with disabilities are not like the rest of us and so will not learn, grow and develop in the same way and therefore will not achieve a "real" life. An acquaintance of mine, who has cerebral palsy, recalls with great clarity her early school days when she was the only person in her class who was not asked what she was going to be when she grew up. Assumptions such as these are usually the starting point for a life which is lived on a parallel set of tracks whereby the person can see the real world, and experience some parts of it (for example, be part of a real family) but never really belong to that world in the typical, ordinary way that non-disabled people do.

Another barrier to a real life is the assumption that the service system can somehow replace or supplant natural, freely-given relationships which are the very substance of our own lives. I sometimes ask people to imagine what it would feel like, and how they might respond, if a human-service worker was to knock on their door, introduce themselves as the local area case-manager, and offer to help prepare a plan for them. This is not to suggest that some of the things that human-services have to offer are not needed, but what is at issue is the

assumption that human-services are relevant in such domains as relationships, the building of individual, family or community capacities or in having control over one's life. There is mounting evidence that precisely the opposite is more likely to be true.

The roles played by both the servers and those served often create a mutually reinforcing, and mutually dependency-making situation whereby the person with a disability learns not to become too competent in case the support or love of the other person is lost. The worker, on the other hand, learns to be objective and professional and not to become too personally involved, and to speak to and about the person who is served in ways which make it quite clear who is in charge and who is the boss. The community learns from this how to treat a person with a disability. In this cycle, the person with a disability becomes reinforced in the role of client as well as in the sense of where she or he belongs. Of course the roles played by server and served are not always so overt. The roles are sometimes masked by the language of "friend", "co-worker" or "house-mate", concealing their true nature. It is partly deceit, but more often than not it is merely self-deceiving. Usually people in the community know, only too well, the true nature of the relationship.

Often the language of "rights" and "choice" is used to convey the impression that a person with a disability is leading a real life. Under this disguise some people have been left unsupported in the community or merely dumped while others have been exposed to crime, drug and alcohol addiction and, ultimately, to prison or death. More often though, it is the case that the purported rights and choices are merely a mirage. Most people with disabilities have little choice about where they live and with whom, and what they do by way of work or leisure. The manager of a supported employment project I recently visited was asked if workers were able to resign from their jobs. He said it was possible, but probably for only one day as the person would quickly be sent back to work by staff at the group-home because "they had to go somewhere and they could not stay at home."

The seductiveness of the "typical" and the "ordinary" is so powerful that there is a great temptation for workers, parents and advocates to try to re-create them outside of their natural context. The need to be loved and to belong is so strong in us that many people with disabilities will play their part in the charade in the hope that, somehow, this is the "real" world. The reality is that people who are already extremely vulnerable and wounded may simply have another wound added.

There are no short cuts to a typical, ordinary, real life. Our lives are the sum of all the typical experiences we have had, how we have integrated these experiences, and what we have learned along the way. A "real" life cannot be invented or commanded into being.

"There are no short cuts to a typical, ordinary, real life. Our lives are the sum of all the typical experiences we have had."

It cannot be the product of an individual service-plan. What is typical and valued in our society does serve as a useful and worthwhile frame-of-reference, but the problem for many generations of people with disabilities has been that the framework for reform has not been what is typical and valued. Rather, it has been a history of flawed reform, usually attempting to improve on previously flawed reforms, any of which had their origins in institutions and institutional practices.

It is important that we do not pretend that creating typical, valued lives for people with disabilities is easy or that it can be conveyed by fine words and promises, or by some new type of program. The struggle for a real life must be real. ■

It Is Possible

Trish Lunn

As I write this, I look forward to next Sunday when my daughter, Emma, will celebrate her twenty-fifth birthday. She will celebrate this milestone with her friends and family at her own home, and it will be a double celebration as it also marks the fourth anniversary of Emma and her house-mates moving into their own home.

Five years ago, a group of parents whose sons and daughters have very high support needs, set about achieving a dream. Our vision was that if our children were to move out of the family-home they need not spend the rest of their lives in institutions, but could continue to be part of the community where they grew up. Although sharing a home, the four people all lead separate lives away from home.

Where Emma now lives is truly her home representing the things that mean "home" to all of us. As I look back over the four years I realise Emma has personally grown and matured. Although not actually acquiring any added skills, she has a self-assurance she did not possess four years ago. Emma is blind and deaf and it remains a mystery to me how she learns and knows some of the things she does. I believe she internalises the positive attitudes shown towards her by the people who support her.

While Emma's home base is important to her, she certainly does not stay at home. She is out and about every day, able to do so with support from a community-access service, a recreation service, support from her own home, and her precious Sunday afternoons with her father.

For Emma and the people with whom she lives, the sharing arrangement works well. Because of their very high support needs, it is necessary to pool their funding to achieve adequate support. Even if it was possible, from a funding aspect, for Emma to live on her own, I would have grave concerns regarding the monitoring of her service because Emma is extremely vulnerable and cannot tell us if all is not well. I believe the particular model of the support which Emma receives in order to live in her own home, incorporates that important element of monitoring and provides a safety-net. Involvement by families is welcomed and Emma and her house-mates are actively involved in selecting the people who come into their home to support them. I have heard the concerns that a lifestyle in the community is not possible for people with high support needs. The example of Emma and her house-mates shows that it is. It is possible. ■

The Dream for My Sister

Dot Hockey

I cannot yet say what it is like to have my sister Renee living in the community, but I am able to reflect on what it has been like to have a sister living in an institution for forty-four years, and to tell readers my dreams of life with her OUT of the institution.

I remember the visits we made over many years to see Renee at the institution. They were not frequent visits but were a torture for all of us. My father, an orphan, hated any form of institution and stayed away as much as he could. So my mother took four young children on a long, dusty train journey and tiring walk, which took hours each time we visited. My mother always phoned to let the centre know we were coming but we still had to go to the office to register and then wait an hour or more for Renee to be prepared for our visit. During this wait Mum would clean us up after the long trip, feed us and try to keep us



quiet. Because it was like a hospital, we were expected to be quiet and still. We were then escorted through smelly, noisy, dank wards, past people in cages or rolling about on concrete floors, and into a room where Renee had been placed for our visit. The room was then locked. Four tired, irritable children confined to a small, hot, smelly room was a recipe for disaster and these visits are not fondly remembered. We all knew Renee was "backward" so there was no real encouragement to know her as a real person. We were never informed of how she was progressing. I now know she was, in fact, deteriorating and not progressing. Insufficient physiotherapy, lack of stimulation and individual care saw a severe physical deterioration for Renee.

As we grew up, most of our friends never even knew about our big sister. People didn't own-up to having a "retarded" member in the family and as Renee lived at Challinor no one could ever get to meet her or know her. And we, her own family, really do not know Renee in a close, personal way. When I moved far from Brisbane I made yearly visits with a sense of duty. I did love Renee and wanted to visit, but for many years I had no idea how

much she appreciated my visits or any other family contact.

Over the years conditions improved at Challinor and some years ago Renee moved to a more open area with staff trying to make Renee's living area more home-like. We can now arrive unannounced and visit her where she lives rather than in a visitors' room. But it is still like a hospital with its communal living and little privacy. Our visits are not private affairs as we are joined by many other residents who sometimes demand the attention we want to give to Renee. We have learned from staff that Renee treasures family contact and that she is far more mentally advanced than we had ever dreamed was possible.

It has been a long drawn-out process to plan Renee's move from Challinor to the community, and a struggle which is common to many families, but the Housing Department has recently signed a lease with Renee and two other co-tenants on a house that is just four kilometres from where I live. I drive past the house often and enjoy imagining what Renee's life will be like when she moves into her new home.

Renee will definitely have a say in the decisions that will be made in establishing her home. In collaboration with Renee, family members will help choose the carers who will support Renee and the two other women. We will be able to visit often. We will be able to buy gifts for Renee - special things like ornaments, framed photographs, plants and flowers and essential-oils - the list is endless. We hope she may be able to have a pet. We will be able to read to Renee and listen to music with her. If she is not in the mood for a visit from us she can tell us to go. It will be no inconvenience to return at a better time.

I can only say what I hope life will be like for Renee and her family when she finally leaves the institution, but I pray that we will all have an opportunity to make up for the years of separation, and that Renee will begin to experience the many things most of us take for granted.

It is not just for Renee that we fight, but for all those people in institutions who want to be out, and for those in the community who need others to pave the way and prove that even people with very severe disabilities can live in the community. ■

Delivering One Of Life's Successes

Jill Hole

At this time of year, many young people will be starting the next phase of their lives, having left school-days behind. These teenagers are now eagerly but anxiously anticipating either employment or attendance at a tertiary institution. Our son, Matt, is one of these young people.

At this stage it is not necessary for Matt to attend a tertiary institution, because incredible as it may seem to us, his family, Matt is about to enter the world of work for three days each week. He starts work shortly as an offsider to a group of couriers who are owner-drivers contracted to a large transport company.

Despite my long-held belief that there are few things more tiresome than long accounts of how clever little Johnny is, and how he got there because of his clever parents, in my case I think it is safe to say that we, as a group of friends, family and workers, have supported Matt to crack the beginnings of a life of employment.

So what? you say, Why wouldn't a young man with a ready smile, loving family, wonderful friends, good health (most of the time) and who firmly believes that the best place for him is working in his community, be employable? That's what we all said too, and now we know that what is expected for young people in the community includes those who, like Matt, have complex disabilities.

This article is not the place to write of the struggles Matt has had in trying to change the mind-set of many professionals in employment services for people who have disabilities. It is sufficient to say that we, as Matt's family and supporters, decided to go-it-alone and to approach employers directly. It was difficult, but we are glad we did it. The outcome is that Matt now has a place to work. This is thanks to Erin, the courier-services receptionist and despatch clerk, for opening doors since the day we made our first tentative approach. She has proved to be an enthusiastic, committed supporter of young people seeking work opportunities in the courier industry. She actively and successfully promoted Matt's application and offered encouragement to the drivers to give Matt a chance. ►

As Matt's parents, we realise that the doors to community-based employment for people with a disability need to be pushed a little harder before they open, but with the support of people like Erin we now know it is possible. We also realise that Matt's co-workers may need time to get to know Matt and his ways. For the moment, however, we are delighted to be among the many parents who are celebrating their children's conclusion of school-days and the beginnings of adulthood.

How Matt responds to this opportunity is yet to be seen, but if it is similar to his response throughout an eight month period of work-experience with another courier service, he will live up to expectations - not because we want him to, but because he knows that this is what he wants to do at this point in his young life. ■



Finding The Blind Spot

Frances Carpenter

I often wonder how it happens. Somehow we, as a community, go from the statement, "I know a guy with a disability who needs a place to live; let's see how we can help" to the statement, "Let's get together and make up a group with this person and nine others in a similar situation". There *seems* to be a connection; one of those things that hangs around in the blind-spot of our thinking. We put all the spices together in the pantry, and all the businesses in the central business district, so somewhere there is a belief that people with a disability will want to live together.

There are, of course, some structural reasons. For example, government will not fund the \$5000 needed to modify one person's home, but they will provide \$150,000 to build a new supported-accommodation unit for ten people. The community often looks to these "models" for guidance in a complex world. People in the community look to government for leadership but the government just returns their gaze.

Yet good things do happen, usually on a small scale and with a lot of thought and care. It could come from a good neighbour, close friend, a helpful person, or a good human-

service worker. Mother Teresa says that there are no great acts, only small acts done with love.

How, then, does it happen that we go from small acts done with love for someone, to human-services which modify the person who is in need, to fit into a service. As closely as I can determine, it goes something like this: Somebody helps someone else, then another person who needs help is told of the helpful person, and then another is told, and another. Success happens often enough for a reputation to build and suddenly the helpful person, or people, is overwhelmed with requests. It occurs to someone that a group of people ought to come together around the issue, and should form a committee and apply for some funding. In this way they believe they can hire any number of helpful people and help any number of needful people. A public meeting is held, people have their say on the issue and a committee is elected. The committee meets, puts together a constitution and a submission for funding. Funding is granted. They've made it!

I think this is where things can go wrong. There now exists a group of helpful people who are no longer closely in touch with the people in need. They have been so busy formulating policies and chasing funding that they don't have time to be directly helpful. In fact, the needful people have been waiting so long for the helpful people to return and continue helping, that they are a bit annoyed. No one really wants to contact them because there is not yet anything to offer them, so the planning goes on without them. It seems easier to plan without knowing the people, and statements are made about being "generic but flexible". Policy documents are written as well as job-descriptions, and advertisements are placed for workers. Workers are employed. Some of the helpful people are long since gone, having decided to go back to just helping people, but the others are bogged down in administrivia.

So there it is; from small acts done with love, to offering a service into which the person must be fitted. But I still think about it. It's in my blind-spot too. How *do* we stay humble and simply keep asking, "How can I help?". ■

How a person with vision and hearing disabilities became an active Toastmaster

Penny Harland

For many reasons, I was keen to join the local Toastmasters Club. I hoped this would provide opportunities to meet people from different walks of life and perhaps make new friends. I also thought Toastmasters would offer intellectually challenging experiences which could broaden my range of skills in relation to communication and public speaking. Another reason for joining was my desire for sheer fun and enjoyment.

Prior to attending a Toastmasters meeting, I had to address my own support needs. Owing to my dual sensory impairment of vision and hearing, I needed a qualified interpreter to translate the spoken word into tactile finger-spelling on the palm of my hand. Since I possess intelligible, expressive speech, it is necessary for an interpreter to translate only what others say. I also needed some physical assistance to move around the environment. Meeting these special disability support needs presented some major obstacles, as government-funded services in Queensland which cater for the needs of people with dual sensory disabilities were non-existent. Although the Qld Deaf Society offered limited support for accessing essential services, recreational activities were classified as failing to meet this criterion.

The only way I could obtain assistance with interpreting was to pay for it myself, and as the fees totalled sixty dollars per meeting, they were almost prohibitive. The next problem was the recruitment of qualified interpreters with experience in deaf-blind finger-spelling. Such people are in short supply and even fewer are available for evening work. Eventually I located a small number of interpreters who could take turns in accompanying me to Toastmasters meetings each fortnight.

After becoming a Toastmaster, all my original optimistic expectations were realised. I came to know and appreciate many interesting people and my participation provided numerous opportunities to develop new skills and strengthen self-confidence in my ability as a communicator. On the first evening, the task of recording every "ah" and "um" uttered during the meeting was given to me. I was very

apprehensive about the role and about having to report at the end of the evening when members are fined for each "ah" or "um" they have uttered.

However, having successfully accomplished this task on the first occasion, I felt much more comfortable and relaxed about doing it the next time.

Another challenge was my participation in table-topics where speakers are required to talk for ninety seconds on a surprise topic known only to the table-topic master who selects topics and nominates speakers. One evening, during table-topics, I was asked to talk about "speed guns".

"Club members developed a more realistic understanding of people with disabilities, gradually losing their initial nervousness about approaching me."

Someone else may think this a relatively simple undertaking, but for me it was not the case. A person who has experienced severe vision and hearing impairment since early childhood misses numerous opportunities for incidental learning which others take for granted. Never having heard of speed-guns, I spoke about them as weapons and not as speed-detectors. Imagine my embarrassment and dismay when my interpreter explained what speed guns really were! Toastmasters certainly offered a wealth of fun and pleasure even if this was sometimes at my own expense.

Participating in a Toastmasters club was beneficial not only for me, but also for other members. Club members developed a more realistic understanding of people with disabilities, gradually losing their initial nervousness about approaching me. Some members even mastered the manual alphabet. When I presented a good speech or performed a task well, other members were encouraged and inspired by what could be accomplished by a person with disabilities. ■

IS JAC A GOOD RESIDENTIAL SUPPORT WORKER?

Jane Sherwin

A critique of the character, Jac, in the SBS series Housegang, whilst acknowledging that some of the shortfalls might be due to script or acting.

Could Jac become a role model for residential support workers? I hope not! Imagine having to put up with her happy-happy enthusiasm and her vacuous expressions, especially first thing in the morning or at times of personal pain. Chloe is quite right when she says to Jac, "all you ever do is come to work and go home again".

Jac appears to be, if anything, a custodian or possibly a trainer. At times she steps over her role boundaries. For example, she trains one young man to be a competitive swimmer (why not use a qualified coach?). She fixes her motorbike in their home (whose home is it anyway?). She acts like their best buddy and encroaches on their personal property (she walks into their house and bedrooms without knocking) and their personal space (she kisses Belinda, a woman with an intellectual disability, on the forehead - what two women connect via foreheads, except if one is in a parent role?).

Jac does seem to show a willingness to stand by people with disabilities, albeit in a patronising way. What would make Jac a gem would be a melding of sound values and wonderful practical talents. She would be able to walk the line of guiding yet standing behind; standing behind yet standing alongside; speaking up yet knowing there are times to be silent; seeking opportunities and pursuing them; connecting with others and not dividing; and serving and tending, not owning and directing.

The character of Jac is a reminder that the role of a residential support worker *appears* to be straight forward when it is actually fraught with complexities. Human service leaders and workers are required to consider the capacities and needs of the client, and the consequent role-boundaries and areas of responsibilities of the worker. ■

CRU'S EDUCATION & DEVELOPMENT PROGRAM

Readers will have received a flyer advertising the CRU Education and Development Program for 1997. The following discussion of the program provides some information about the how-and-why the 1997 program was developed. CRU has selected the topics for the year's program based on the identification of what we think are the key challenges facing all those involved in the lives of people with disability. The program draws on the expertise of visiting guest presenters and CRU staff.

Two of the topics in *Series '97: Key challenges, Service design and decision making and Management Committees* are particularly relevant to co-ordinators/managers and to members of management committees as they deal with some of the issues at the heart of service provision. Those people who are involved in the lives of people who have an **intellectual disability** will be particularly interested in the third workshop in this series. Jane Sherwin, Beverley Funnell, and John Armstrong will present this series.

The three-day **Social Role Valorisation** (theory) event will be presented for those who are interested in understanding the ways in which society and human-services treat people with disabilities and who are interested in changing societal perceptions of people with a devalued status. This particular program will also be a very useful "introduction" for those who are planning to attend the Wolfensberger course in Brisbane during July. The **Social Roles** workshop, in turn, provides an overview and introduction to SRV theory, highlighting the importance of valued social roles.

The theme for the **1997 Lunch Time Seminars** is "Keeping hope alive" and presenters will tell illuminating stories of success and courage. It is easy to lose hope in the current social, political and economic climate but we have found that it helps to understand these dynamics and to hear inspirational stories.

Michael Kendrick is making a return visit to Queensland and will present three lecture/workshops. One of these is on the topic of **Safeguards** (those practices, mechanisms, actions or relationships which ensure the protection and enhancement of the needs, rights, interest and lives of people with disabilities and their families). The other two are on the topics of

Mental Health and on the **contribution that can be made by an individual** to the lives of people with disabilities. Michael's skills include his capacity to "read" our society and the human-service system, and to accurately name their components and complexities.

We look forward to seeing you at these events. This is a reminder that CRU attempts to enable the attendance of people with disabilities, parents and those experiencing financial hardship by offering partial and full bursaries depending on available funds. If you have any queries about the 1997 program, or if you have requests for workshops which CRU develops for specific groups, please contact Jane Sherwin at CRU. ■

CRU supports the Wolfensberger course by enabling Jane Sherwin to act as the overall co-ordinator. Values In Action Assoc. carries the full financial responsibility for this event and also funds the administrative work carried out by Silke Collisson.

Ten Good Reasons for Attending The Course to be Presented By Wolf Wolfensberger

- 1 You wonder about human services and their capacity to always stay on track and offer quality service.
- 2 You are trying to understand the turmoil in society and in the human service system.
- 3 You are in a leadership role (or others see you in a leadership role) and you want to be better equipped.
- 4 You want to expand you knowledge beyond SRV and PASSING.
- 5 Wolf has been voted by his peers to be one of the most influential contributors to the area of intellectual disability.
- 6 Wolf formulated the theories Normalisation, Social Role Valorisation (SRV) and the evaluation instruments PASS and PASSING.
- 7 SRV Theory, underpinned by well-founded social science, has had an enormous impact on Australian legislators, leaders and human service practice.
- 8 Wolf developed the concepts and practice of citizen advocacy.
- 9 Wolf's contemporary work concerns itself with the importance of social advocacy, the sanctity of life and moral issues in serving people with disabilities and other vulnerable people.
- 10 You have heard so much about Wolfensberger - now hear him for yourself!

Recommended Reading

Pam Collins



The CRU library has resources on many topics. I have highlighted abstracts from two articles which relate to some of the issues raised in this edition of CRUCial Times. To request copies of these and any other articles, please contact me at CRU.

COMMUNITY AND ITS COUNTERFEITS

Interview with John McKnight

John McKnight claims that society is composed of two distinct domains: an institutional domain, governed by legal, contractual and administrative norms, and a community domain, where citizens associate for their own purposes, and people matter for themselves. These two domains, though they may occupy the same space, are of radically different kinds. The integrity of the community domain is often entirely overlooked in the rush to treat perceived problems with institutional solutions. In the process, communities gradually lose the capacity and the confidence to do things like care, console, correct and counsel, which institutions have taken over. That, according to John McKnight, is more or less where we are today, with incompetent institutions trying to do more than they can or should, and undermined communities doing less.

SUPPORTED LIVING: WHAT'S THE DIFFERENCE?

by John O'Brien.

Supported living is a simple concept in danger of being complicated. Its simplicity is elegant: a person with a disability who requires long term, publicly-funded, organised assistance allies with an agency whose role is to arrange or to provide whatever assistance is necessary for the person to live in a decent and secure home of the person's own. [This paper sets out some clear principles for the ways in which support should develop opportunities for a typical life in the community.]



Goodbye to Challinor Centre (and to heartfelt reform?)

The time has come to stop using the term "institutional reform". The term, which had questionable validity under the previous government's program, has now lost its usefulness entirely. The pragmatic manoeuvres by government which we have witnessed during the past twelve months scarcely constitute a program of reform. Reform can be defined as an intentional effort designed to bring about change that is needed and highly desired in order to replace an existing situation which is deemed unsatisfactory or inappropriate. Reform means something deliberate and conscious, stemming from a change of heart.

The present government inherited a "reform process" put in place by the previous Labor government whose program, although limited in vision and directed more at emptying institutions than on creating community supports, was nevertheless a considered attempt to deal with some of the clear failings of institutional care. When the present government came to power early in 1996, it responded favourably to those people who opposed the reform process and who succeeded in halting it or at least slowing it down. The government announced that Challinor and Basil Stafford centres would not be closed. The government then partially restored the process of deinstitutionalisation in pursuit of wider interests when it sold the Challinor centre for a university site.

Instead of a reform-driven program, based on a clear policy, the government has simply made responses to individual families associated with Challinor and Basil Stafford centres, who strongly and consistently lobbied for their relative to move from both centres. The government committed funds to enable personalised community arrangements to be developed for those individual people. However, the government is yet to announce its proposed

arrangements for those people who do not have plans approved and funded, or for those people whose families have wanted to retain institutionalised care for their relative, and there are now strong indications that mini-institutions rather than personalised homes will be provided in these instances.

As we pointed out in the very first edition of *CRUcial Times* (Feb 1995) closing institutions does not automatically ensure that people will get decent lives, so we must ensure that reform is going to mean real change - a change of heart and not just a different setting and staffing arrangement.

It is important we recognise that what is currently happening around the closure of Challinor is not government led reform. In fact, at a system-level, it cannot be regarded as reform at all. It is important to acknowledge this even though, at an individual level, many Challinor residents will potentially benefit. To not acknowledge what is happening may lead to a false sense of security where complacency can easily follow, putting at risk the opportunities for those people moving from Challinor and Basil Stafford centres. If there is to be no conscious and deliberate rejection of the segregation and congregation of people with intellectual disabilities, and no real commitment to supporting them in more humane ways, then it is inevitable that the institutional practices which we abhor will reappear in another form.

Beverley Funnell

At the end of March, Melinda leaves CRU and Australia for two years of travel throughout the UK and Europe. We wish her safe and happy travelling. CRU welcomes Laee to this important administrative role.