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# 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.

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## EDITORIAL

This edition of *Crucial Times* speaks to many of the issues of our times. One reader recently suggested this newsletter should be called 'Brutal Times' in recognition of the turmoil of our times and the impact of global and local trends on the opportunities and well-being of people with disabilities. Indeed we do live in times in which the very lives and well-being of people with disabilities are constantly under threat. No one who cares about people with disabilities could feel complacent in the present reality and with good reason, many feel a grave sense of concern. Most of us are struggling to understand what is happening to the various social systems that support people with disabilities. Nowadays many people ask CRU whether they should try to change what-is, given the way in which the odds are stacked against vulnerable people. Ordinary people feel so small and inadequate when faced with the scale of the change and the complexity of our communities, systems and political world.

The fickleness of our political leaders and their callous disregard for the impact of their decisions on people with disabilities and their families still has the capacity to stun and shock even the most seasoned activist. For people who believe that we should be able to trust our political leaders, the deception about changes to

the institutional-reform agenda has been a confusing and bitter experience. Many contributions in this edition speak to the concern and anguish of people who face the tough road from residence in our institutions to community-living.

And yet there are many things which I see and experience daily that give me cause for hope. I see individuals with disabilities whose lives are changing and who are achieving things that still astound me. I meet people and families who continue to have high expectations and who push on regardless of the obvious hurdles. Daily I am aware of services that are working to arrange their resources to support people who rely on them. Mostly I am inspired by the many people who have committed themselves to the personal and public struggles of people with disabilities to have their humanity and citizenship recognised.

*"Mostly I am inspired by the many people who have committed themselves to the personal and public struggles of people with disabilities to have their humanity and citizenship recognised."*

Joe Osburn, who is visiting Queensland for several months from Indiana, takes up this point about the importance of personal commitment and relationships in his article on vulnerability and community living. ➤

CRU's Annual General Meeting this year was a great celebration of achievements, hard work, rich learnings, wonderful relationships, hopes realised and hopes dashed. As we journey into our ninth year as an organisation, it is a privilege to reflect upon and recognise the great strengths there are in people throughout Queensland. There are many, many people who are trying in all sorts of ways to protect and strengthen the position of people with disabilities throughout the State. Some are doing this in very quiet ways that only the most observant will discern. Others are putting their efforts into reform of local communities, while others continue to try to find those forms of paid service which show the most promise in supporting people to lead decent lives in the community. The contributions in this edition from SUFY and the Sunshine Coast Citizen Advocacy Programme tell of just two examples of groups who are committed to the presence of independent advocacy on behalf of people with disabilities.

One of the things that gives me great heart is the strong commitment of people to positive values and their readiness to grapple with the complexities of the practical implementation of positive ideas and schemes. As Michael Kendrick has said to us, such consciousness is not normative; it is something to celebrate and to continue to build on. More than ever, people with disabilities need to know they can count on some of us and they also need to have those people who are around them to be hopeful. There is no benefit to people with disabilities in our despair.

It is true that the threats are many and it is truly hard to discern what is really happening and to work out what needs be done to protect those gains that have been made and to keep pressing on. But staying close to people with disabilities and to others who are there for the long-haul, doing what can be done, sharing, reflecting and learning, will surely support us as we continue this important journey together.

*Anne Cross*

### *Committee Members 1995/96*

Mike Duggan .....	President
Aif Lizzio .....	Vice President
Margaret Ward .....	Secretary
Pam Rallings .....	Treasurer
Judy Brown	
Patti Dietz	
Janet Millward	

### *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



### **From the President's Desk**

I felt indeed privileged to present the eighth President's Report to the CRU Annual General Meeting on 13th September and would like to present some of the elements of that report in this issue of *CRUcial Times*.

When we look at ourselves as an organisation, it could be said that CRU has a "change" agenda. If we acknowledge that we may not be able to effect change in all quarters, we must determine where we are going to focus our strengths and energies. For instance, should we concentrate on upper and middle levels of leadership in order to influence change, or is there a particular need to engage the upper levels of leadership in efforts towards their own renewal and sustenance? I believe that we need to accurately determine what sustains and energises us as an organisation as well as our change-agentry pursuits. We need to ask: What is it that unites our base? What are the uniting factors across our network? Our newsletter goes some way towards sustaining our network, but we need to do more. For instance, we may need to stage an annual conference.

During the coming year we are planning to bring together a group of allies from throughout the State. This will enable people the opportunity to provide support for one another, and to

establish a forum where common themes might be addressed as well as enabling us to develop and strengthen our base and constituency. On a larger plane, we also feel the need to be developing this network into a social movement - a community of people who share a common vision and common values. I strongly believe that we need to be very clear about what we do and for whom, otherwise we may confuse "the network" with "the sector", and may also mistake the nourishment and development of others for our own self-sustenance. It is very difficult, if not impossible, to nurture and sustain others if we are not doing the same for ourselves. I also believe that CRU should be endeavouring to move people to a new level of social discourse. Such a dialogue should have three pivotal themes:

- ◆ a new stage of expression of values at a systemic level
- ◆ leadership
- ◆ developing new levels of problem-solving capacity

This year CRU has undertaken the development of a strategic work plan. Under the guidance of task-master, Margaret Endicott, we are well on the way to the implementation stage. I want to express my thanks to the CRU staff and in particular to Anne. As Director, she juggles many items, of varying size and density, in the air at once. She also does pretty well at pit stops, refuelling and replenishing physical and emotional stocks of others - standing in for, standing beside, and standing behind others. Many thanks, Anne, for everything.

In the coming year we are planning on having a slightly smaller Committee. Having a smaller group can often lead to its being more focused and task-oriented. It was with regret however, that at the AGM we farewelled Rex Newsome who did not seek re-election. Rex has contributed a great deal to CRU over many years and has been a lifelong campaigner and advocate in the disability field. We wish Rex well. The Committee warmly welcomed two previous members who have joined us once again. To Margaret Ward and Pam Rallings we say "Welcome back!".

With best wishes to you all.

*Mike Duggan*



## Hope Takes a Temporary Setback!

**Beverley Funnell**

In the last edition of *CRUCial Times* I wrote of the re-emergence of hope in families throughout Queensland. Many families who have relatives living at Challinor Centre were working towards the safe return of their son, daughter, brother or sister to life within their community. As part of the process of preparing for this fresh start, a number of individual people from Challinor and Basil Stafford Centres had been allocated housing through the State Government. Quite a few of these people had been paying rent on the houses over a number of weeks, even months, in order to secure them. Planning was well advanced. Service providers were identified, co-tenants were being considered, and slowly but surely (and encouraged by reports of those who had gone before), families persevered as the achievement of their dream was almost within their grasp.

In these circumstances, it is quite understandable that the people involved should start to feel confident about their dreams being fulfilled. The institutional-reform program allowed families, who for many years had not dared to dream, to think about how life could be better for their relative. They were about to take hold of that dream. Welcome-Home and House-Warming parties were being talked about and planned.

*"My daughter's coming home!"*

*"He'll be only five minutes away from us when he moves!"*

*"Christmas is going to be really special this year!"*

*"Just think! She's going to have a real home. Her things, her friends, her family, her pace - a life at last!"*

Well, in these brutal times it seems that expediency rules. Nothing can be taken for granted. Families, patient beyond understanding, have learnt once again that rhetoric alone is empty and cheap. Families are discovering, almost with disbelief, that the Government Budget announcements of September signal a smashing of their hopes and dreams. Many are shocked to discover that, contrary to all that has been said and indicated, the Government is not proceeding to implement the plans and proposals which have

painstakingly been developed with individuals and families. The full extent of the disappointment is only being revealed a little at a time. We rejoice with those who have secured their funding while we cry with the vast majority who still wait.

*They told me she was coming out  
A life, a home a new beginning.  
We had our doubts you will recall  
We talked for hours, we cried, we drowned in  
tea.  
Sitting in the dark around the table  
Sharing jokes and stories about the past  
We said farewell, tears glistening, mosquitoes  
at our ankles  
A savage beast couldn't have snatched from us  
Our quiet, inexplicable joy.*

*Now sadness, anger, sheer pain tears at my  
centre  
The wasteland stretches out again  
Yet not quite as vast or barren as before.  
I recognise others on the landscape  
Others, versions of myself  
Holding so much within  
Saying so little  
Loving all the while.  
  
With love, hope never entirely vanishes  
In good company we will make it happen.  
Keep on, walk with me,  
Together the road will shorten before us.*

For Rosanne Ott, Ann O'Brien and myself these past nine months of getting to know the families and working alongside them has been some of the most important work we have ever done. We have had a rare and privileged opportunity to enter into their lives. We now understand, in a much deeper way, the vulnerability of us all but particularly the vulnerability of those who have a life experience that labels them as different and less valued. We have come to admire and respect these people enormously.

Many have been deeply hurt and continue to suffer as a consequence of inhumane public policy. In order to get the support and help they needed they had to surrender their relative to a system which has forgotten the meaning of 'service'. They were then forgotten and abandoned without support to continue in their

role as parent, sister or brother. A family doesn't stop being a family because one of its members is no longer living with them on a daily basis. Now that many families have found a voice and have decided to reassert their natural authority they are not going to retreat again into the background.

On many occasions I found myself sitting around a kitchen table talking and drinking tea with people who reminded me of my own family and relatives. I felt connected to them. We felt connected to each other. The reality is that we are all implicated; we are all connected. *They are us and we are them.* We all have a stake in the future. It is time to take charge of our future together - a future that includes the most vulnerable and their families. ■

## **"Well, Put Her Away!"**

Shirley Clements

These words were the usual reaction from my husband when I cried over our daughter, Jannyne. Social workers and doctors usually echoed that sentiment too, so from the time my beautiful baby was very young, I've had a sense of alone-ness. No one seemed to understand why I went to the lengths I did to give her every opportunity possible to have a normal life. Jannyne, named after my dear mother, is the third of six children. She went to a "special" school from the age of five, and basically did all the things that other children did, but I always had to force-the-issue with school inspectors and parliamentarians. I often needed to make doctors give her a chance to try treatment and medication which they offered to "normal" patients. Other readers will probably understand the longing to have the support of someone when you feel as if you are emotionally caving-in. You don't know which group to contact or which department or politician to see. As well as handling the "guilt", you have that sinking-feeling that you have come to the end of whatever it is you can offer that precious person who is always in your heart and mind. ➤

Jannyne went into Challinor about six years ago after a stay in a psychiatric centre. She was to be in Challinor "until her behaviour settled down", which only happened with strong medication. When I was told that Challinor was closing and that she had the opportunity to live in the community, but just wanted to come home, I was a bit apprehensive and wondered how I would cope. Who could I turn to? That old feeling of alone-ness was back again. Over a period of several months, I was contacted first by Project Officer, Elizabeth Wood, then one day late in 1995 I received an invitation to a meeting at CRU. The speaker was Beverley Funnell. My youngest daughter and I attended as we wanted to find out more about those leaving institutions and were hungry for all the information we could get. Unhappily, the meeting was disrupted by a small but vocal group opposed to the closure of Challinor. We wondered how anyone could want that place to stay open. Some time later CRU phoned to say they would like one of their support workers to come and talk to me. A date was arranged but I remember at the time thinking, "another exercise in futility". At the meeting I met Rosanne Ott and Ann O'Brien and other families whose relatives were either living in or leaving institutions. As we haltingly introduced ourselves, I saw the same haunted look I see in the mirror and realised others feel the same dedication to someone close to them. It's not wrong to want the best life possible for them or to want to protect them and it's not wrong or weird to want them in our life and to be part of theirs. No, we are not alone.

As I look around at our gatherings at CRU, I see your tears when we let you glimpse our pain. I know our stories need to be told and that other hearts can be touched. So thank you all for giving me the support for strength and courage when I needed it, and for linking me with other families who are going through the same things. That old sense of alone-ness is gone forever. I hope I'll never again wither up or shut up if I ever hear the words, "Well, put her away!". ■

## Why the

## IR process

Bill Garsden



Throughout the Institutional Reform (IR) debate, there has been much discussion about where people with a disability should live, how we should live, whom we should live with, and what is safe and what is not safe. Much of this debate has occurred without us, the actual people whose lives are being discussed and decided. If you spoke to people with disabilities, they would probably say: "So, what is new? Other people have always decided what should be done with us. They have decided where we should live, how we should live and the model by which we should live."

For a long time, those very decisions have been made by professionals and politicians without reference to us. People with a disability are locked away, out-of-sight and out-of-mind. As a community we cannot continue to lock away, isolate or exclude those people whose disabilities present "challenges". That locking away is the first expression of being devalued and once devalued, the community turns a blind eye to inhumanity and injustice. It happens little by little, like a rising tide. This is a community issue and there must be community answers.

Why then do we continue to keep such institutions open? For whose benefit are they maintained? Should the decision maker be a parent, a doctor, a teacher, a service provider or a policy maker? Would you allow any of these people to make key decisions in your life without reference to you? Would you let anyone else decide the model for your life, without you? The answer, of course, is a resounding NO!

Those of you who attended the IR conference in Brisbane heard stories from people with disabilities whose lives have been affected by institutional life. Who would not have been moved by the plea of the woman who made such a poignant cry for help to move out of the institution where she now lives?

We also heard from a young woman, whom I will call Judy. Since leaving an institution Judy has become a successful mother of three, but her institutionalisation severely affected her relationship with her own family, particularly her father. Her children are now denied a



grandfather and, sadly, he is denied his grandchildren. For her, the years spent in institutions placed her life on "hold". Her life, she said, only developed when she left the institution. That is the human outcome of institutionalisation. The system inhibits personal development and achievement and does permanent damage to families.

Another story was told by a man I will call Wilt, who is now living in the community. Institutionalisation from childhood denied him a family life, and as an Aborigine, he grew up separated and alienated from his people and culture. Wilt now feels he is in cultural limbo because the cultural links and bonds will never be rebuilt. Those years can never be recovered.

What is the solution? It is to close the institutions and allow the residents to live typical lives in our communities. We need *total* closure and are not talking about knocking down the big institutions and building mini-institutions. They are not typical homes and residents are still isolated from the community. The culture of the institutions prevails. It moves in with the first staff change. We have to be wary of this model, particularly when it has been proposed for construction within the boundaries of an existing institution, in the case of Challinor.

Mini-institutions, like group homes, only become an attractive choice when compared to existing institutions. Desperate people make desperate choices. If faced with the choice between Basil Stafford and a group home, most would take the group home. If funding for more appropriate choices was available, such group houses would cease to be attractive. It needs to be continually emphasised that ninety-seven percent of people with disabilities live in the community. For the remaining three percent there are solutions.

Families need to be provided with appropriate information and support to allow them to reach a fully informed decision. Parents and family members need to be sure that any decisions they make are in the best interest of the person they represent. Where family support and involvement are present, the outcome will be a partnership. Families also need more support options. I often hear parents say that if they had more support, they would not even look to institutions. For them, the only assistance offered was institutional care. If this all-or-nothing model was

replaced with a range of user focused family and community support options, then the need for institutions would rapidly fall away.

Most importantly, the people with disabilities will also need to be presented with adequate information and support for their decision making. This might involve moving through a number of community based living arrangements before an appropriate one is found. We shouldn't be afraid of such "failures". Most people experiment with lifestyle choices before they settle on one in which they find comfort. If appropriate choice and support are available, then an appropriate community lifestyle will eventuate. Most important, however, is that the decision-making process must have us, people with disability, participating in the process.

Finally, if you are a player in this whole debate, ask yourself, "Would I be happy with what I am proposing for this person?" ■

## Communality and Vulnerability

Joe Osburn

The thoughts I want to offer in this article about the role of communality in the life of vulnerable people draw heavily on the teaching of Dr Wolf Wolfensberger, the writings and example of Jean Vanier, and my own involvement with families over the years.

To begin with, we need to acknowledge that anyone who lives is vulnerable, in the sense that human life encompasses both the risk and the reality of some kind of hurt. No one on this earth ever lives a life free of any painful experiences. Thus, some vulnerability is a normative part of the human condition. At the same time, let us also acknowledge that some people are far, far more vulnerable than others. In fact, the entire life existence of some people is one of "heightened vulnerability" which means not only that they have probably already been wounded in the first place, but are also more likely to be wounded again and again, and with wounds that are deeper, life-defining, and inescapable. For example, some people are likely to experience the rejection or even

abhorrence of other people throughout their lifetime. Thus, not only do many people experience a greater *degree* of vulnerability but also a totally different *kind* of vulnerability, one which transforms the course of their lives, and creates fundamental existential differences between them and their fellow (normatively-vulnerable) human beings.

Therefore, when I use the term "vulnerable people", I am not talking about everyone. I am talking, rather, about groups and individuals who are especially likely to be wounded in some way because of life conditions or personal qualities that are not valued in and by society. Included are people who are poor, elderly, chronically ill, physically or mentally impaired, and many others.

If one believes in heightened vulnerability, then one would have to conclude that devalued people are and always will be vulnerable, regardless. This conclusion has two big implications for people who are genuinely concerned about certain individual vulnerable people. One is that they have no sound basis for complacency about any social arrangement for vulnerable people, including all the living situations, work schemes, and educational structures, all the laws, systems, departments, agencies, and programs. The other implication is that they should always be inclined to look critically at any such social arrangement for vulnerable people. Unfortunately, the very kinds of social arrangements so often looked to with great hope by so many people often have long records of poorly addressing the needs of vulnerable people (or of inflicting great harm upon them), such as the following sources:

*The Government* - which has become more depersonalised, in spite of many people's belief that it is the one thing they can always count on. Also, government is notoriously fickle, as is now being exemplified by governments all over the Western world racing to dismantle their long-established social supports, thereby abdicating both their rightful role of protecting their most vulnerable citizens, and even the very ideal of doing so.

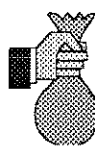
*The Law* - which is quite limited, in that it cannot enforce goodwill in people's hearts and thus "good laws" may often



accomplish little more than unintended negative responses toward the people they are meant to help (e.g. "backlash").

*Professionals* - whose allegiance is always demanded by the social structures which sanction their professional roles, even when that ultimately brings harm to vulnerable people. Families talk about how hard it is to find a "good" doctor, therapist, social worker, teacher etc., by which they often mean nothing more than one who will listen, really listen, to them.

*Business* - an icon of the new "economic rationalism", which glorifies the creation of great wealth for corporate managers of nursing homes, prisons, psychiatric centres, community residences, schools and hospitals, and commodifies vulnerable people.



*The Community* - which, in human service parlance, is meant to convey the idea of an open, integrated lifestyle in the midst of others, sharing common access with fellow citizens in valued opportunities to live, work, go to school, recreate, shop and so forth. Community is often contrasted with "institution", which connotes an existence in a closed, controlled setting, separate from the valued world. At best, one might be able to say with some degree of confidence that vulnerable people are generally better off in the community, but community presence in and of itself is no guarantee of their safety, nor of their well-being, nor especially of their experience of the good things in life.

In spite of major flaws in so many relied-upon social arrangements, there is also a natural tendency to seek out good and to push for change. In part, this is a question of strategy.

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*"Communalities are joined together in a genuine interdependency in which the communality itself is the first line of defence for vulnerable members."*

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Where do we put our energy? What might be most good? What might we be able to rely upon most? The strength of any social



arrangement depends on how the people involved care for one another. For vulnerable people, the strongest social arrangements are always found where valued (relatively non-vulnerable) people have made personal relationship commitments to them. Therefore, one of the very best strategies must be to form small communalities of committed people around vulnerable members.

There are many examples of such communal arrangements. Some are very small and local. Others are larger, such as the l'Arche movement of handicapped and non-handicapped people living together, inspired by Jean Vanier. Many parents have come to realise that the best answer to their question, "What will happen to my child after I'm gone?" is to build up long-term relationship commitments between their child and family members, friends, advocates, and other valued people who, by intention, form a communality of interpersonal relationships committed to the person's welfare.

Ideally, such communalities can have the following qualities:

- ◆ A communality of people who have made intentional relationship commitments to one another can engender and nurture in its members a longing for one another's well-being.
- ◆ As relationships are developed, an authentic interpersonal identification can take place between members of the communality, in which members invest themselves in other members.
- ◆ In communalities, members achieve "standing" in one another's lives, in which there is much latitude for trust, credibility, and acting on behalf of one another.
- ◆ Communalities are joined together in a genuine interdependency in which the communality itself is the first line of defence for vulnerable members.
- ◆ Communality rests upon mutuality among members based on an understanding that all are in-this-together, that each member has certain obligations to the other members, and that all have something essentially important to contribute to one another and to the community as a whole.

In spite of the fact that some communalities may be small, and comprised of ordinary, imperfect people, they often are very resilient and have great power to address the needs of their vulnerable members. Reasons for these strengths include: most communalities have very clear reasons why they exist; while they are not free of the conflicts-of-interest that plague virtually all social arrangements, they are much freer of them than most others; and they are very good at renewal, which they accomplish in some of the following ways:

- ◆ **Taking stock and learning.** Good communalities are always asking themselves "how are we doing? how can we do better?". Informal means of doing this are used almost daily and are often nothing more complicated than just talking things over with someone. On a formal basis, this kind of questioning is often done through external evaluations.
- ◆ **Explicit commitment.** One very powerful means of strengthening the communality is to provide regular occasions for its members to explicitly renew their commitment. For example, in some communities where this is done, members may make commitments of one year, three years, or a lifetime.
- ◆ **Hospitality.** Many or most communalities are not "closed" in the sense of being self-absorbed or unwelcoming to outsiders. On the contrary, they are open and welcoming because the multiplicity of members offers so many points of human contact and natural opportunities for inclusion.
- ◆ **Celebration.** Good communalities are very keen on having fun, on recognising and imparting joy, and are able to find good reasons for getting together to do this (birthdays, commemorations, trips, meals and outings of all kinds). In these ways, communalities develop and mark their own customs and traditions.

At their best, communalities make manifest the inherent value of being in relation to people who are likely to be rejected and devalued. Their existence is irrefutable testimony that the value of at least these (and, by extension, all) vulnerable people is recognised and deeply appreciated, and thus has a claim on all of us. Such an example indeed offers hope where it is much needed. ■



# Changes at SUFY

Over the last two years SUFY has undertaken a shift from self-advocacy to individual-advocacy. This has come about because SUFY has identified a number of inadequacies with the self-advocacy model and recognised the huge need for individual-advocacy.

SUFY emerged in Queensland at a time when advocacy was a newly recognised phenomenon in Australia. Along with most other self-advocacy groups, SUFY believed that it was inexperience and lack of skills which prevented people with a disability from speaking out alone about their own interests. Therefore, self-advocacy took the role of formal training and peer training in a supportive, non-interventionist environment. It was presumed that people so trained would then advocate for themselves, coming together for group advocacy when the issue compelled.

SUFY is an organisation for people across a range of disability-types, with particular emphasis placed on those who have been labelled as people with an intellectual disability. Over the years, several key people involved in SUFY observed that:

- ◆ Training does not seem to lead to great changes in the lives of people who have been labelled as having a disability (particularly people with intellectual disabilities), especially when it does not confront issues regarding a person's life predicaments such as conditions in a hostel or sheltered workshop.
- ◆ Despite their involvement in self-advocacy, many people with a disability remain in very oppressed circumstances such as social isolation and threat, poverty, lack of opportunity and continued discrimination.
- ◆ Traditional self-advocacy groups draw together groups of people with a disability, thereby potentially compromising their status and value in the community. This congregation could also be further exacerbated by mistaken separatism.
- ◆ Having one devalued person advocating alongside another devalued person (perhaps even more devalued) seldom works as both people are often belittled and cast down.
- ◆ Some people with a disability do, however, experience personal growth and empowerment through their commitment and involvement in self-advocacy.

These reflections, observations and reassessments together with an earnest commitment to protect the integrity of SUFY as an advocacy organisation capable of understanding and responding to people who have been labelled as having a disability, underpin the development of an individual-advocacy focus. SUFY is currently advocating for many individuals who are placed at great personal risk of abuse, isolation and exploitation. We have found that these risks are increased if the individual is residing in institutional or centre-based care.

In line with the changes of our advocacy efforts, SUFY members at the last Annual General Meeting decided to alter the name of the organisation so that it is in keeping with our individual-advocacy focus. The name, Speak Up For Yourself Inc. was altered to Speaking Up For You Inc., and 'SUFY', the name we are most commonly know by, was retained. With a new name and individual focus, the future of SUFY as an individual-advocacy organisation is indeed looking very positive. ■

*Greg Wagner*

For more information contact SUFY on (07) 3832 0718

**Bob Lee**

The following article describes the establishment of the first, funded Citizen Advocacy (CA) programme in Queensland. The concept of CA is defined for readers:

Citizen Advocacy is a movement which aims to recognise, promote and defend the rights and interests of people with intellectual disability. It does so by finding and supporting caring, responsible citizens who are prepared to act voluntarily to make a positive difference in the life of a person who may be lonely, face difficult challenges, or be in a risky situation. Each Citizen Advocacy relationship is unique. The "Citizen Advocate" may, for example, offer his or her "protégé": friendship; new experiences and opportunities; and in some instances, spokespersonship and protection from abuse. A Citizen Advocacy programme carefully matches Protégés and Citizen Advocates to ensure that there is a good match between the needs and interests of the Protégé and the abilities, resources and commitment of the Citizen Advocate. Citizen Advocates are usually recruited by a CA program and are provided with orientation, support and resources, and assistance to gain further knowledge.

In late 1990 a group of citizens on the Sunshine Coast came together to discuss and promote the notion of advocacy for vulnerable people in the local community. The result of these discussions was a two-day workshop with thirty-eight participants focusing on Citizen Advocacy as a response to the urgent needs of a number of vulnerable people with intellectual disabilities who live on the Sunshine Coast. Subsequently an association was formed which sought funding to establish a Citizen Advocacy programme. The association was incorporated in 1994 and is known as *Sunshine Coast Citizen Advocacy Programme*. In June this year it received funding to establish an office and employ programme staff. It commenced operation at its Woombye office in October. The programme expects to establish at least six protégé advocate relationships during the coming year. The management committee meets on a fortnightly basis to study Citizen Advocacy principles and plan the programme's operations. The learning process undertaken by members of the management committee has been lengthy and comprehensive. Committee members have established networks with similar

programmes in other states and overseas and have visited some of these. Training events have included Citizen Advocacy Programme Evaluations (CAPE) and Social Role Valorisation. Several committee members participated in the National Conference on Citizen Advocacy in Melbourne in February. The committee also received enormous benefit from the visits of Professor Zana Lutfiyya from Canada and Adam Hildebrand from the United States. They also expect to benefit from the considerable experience of Heather Hindle, formerly of the Victorian Citizen Advocacy Resource Unit.

The management committee and staff of the Sunshine Coast Citizen Advocacy Programme acknowledge that they have much to learn about Citizen Advocacy. The new Co-ordinators, Bob Lee and Stacey Pye, will visit other programmes in NSW late this year in order to benefit from the experiences of other co-ordinators. Those involved in the programme recognise that, as the first Citizen Advocacy Programme to be funded in Queensland, they will be the focus of much interest and come under considerable scrutiny. ■

# Reflections on the 'Inclusion' workshop

Reflections on the 'Inclusion' workshop

My colleagues and I recently had the pleasure of spending about six hours in the company of Ann Greer who presented the CRU workshop on *Inclusion*. Ann, who lives and works in Townsville, is the parent of two young adults with disabilities. She related some very thought-provoking experiences as a parent and as a Co-ordinator of a support service for people with disabilities. Ann presented a number of innovative strategies for the inclusion of people with disabilities in their communities, providing us with creative ideas to be put to use in our respite service for guests and family members.

By its very nature, respite care must be a confusing situation for a person with a disability who also has difficulty communicating. Not only does the person have to contend with other guests coming and going all the time, but staff members also constantly drift in and out. Consequently, communication between guests and staff can become difficult and frustrating and sometimes, not surprisingly, causes undesirable behaviour. Ann's suggestion for a gesture-dictionary for two young lads who have developed their own "language" with help from their family and school teachers has proved very effective. Our staff now know that when Deon wiggles his fingers in a particular way that he wants Red Rooster chips, and that when Andrew strikes his fists together, he is saying he went to the gardens today and watched workmen mowing.

Ann's own experience and expertise also confirmed some of our own methods for developing communication techniques. For example, in order to ensure that our guests have a pleasant and comfortable holiday at Kalkiah, we include a series of photographs in the files of each of our guests, showing preferred ways of transferring, eating, exercising etc. These are updated with the guest and family as necessary. The strategy is used to assist new staff members to learn the correct methods, and to refresh the memories of existing staff. Guests are usually included in this up-dating.

Another method has proved to be successful for one particular country visitor and her family. A calendar with large date-spaces is used to record short details of outings and activities as well as the day-to-day happenings of her holiday stay. When the visitor returns home, she can show her family what she experienced and enjoyed during her stay.

The CRU workshop on *Inclusion* was a very positive experience. Ann Greer presented ideas and solutions to the many communication problems faced by services every day. She did this in such a comprehensive and creative way that she is to be congratulated. ■

*Wynne Schwick*

Kalkiah Respite Care Service, Rockhampton

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## CRU'S EDUCATION & DEVELOPMENT PROGRAM

"Series '96: Key Challenges" is drawing to a close, as four centres in Queensland participate in the last of five workshops each. It has been wonderful to read the reflections of participants in *CRUcial Times*.

The topics chosen for this series were ones that we had observed as important issues for all: quality in human services; the development of leaders especially moral leaders; the use of a community development approach as opposed to the development of social structures; community membership for people with disability; and the "positives" and "challenges" for community organisations.

The topics were highly relevant to a wide range of people, and were deliberately repeated throughout the State. Approximately 1000 registrations throughout Queensland were received for this series. CRU recently held a four-day Orientation Program in Brisbane which was fully attended. Evaluation forms have been very positive. The workshops were

very content-rich, that is, full of information that requires reflection and discussion for some time after the close of the workshops. We are currently planning the schedule of events for 1997.

*Jane Sherwin.*



## Stop Press Stop Press

A major event is scheduled for July, 1997 in Brisbane. It will be co-ordinated by Jane Sherwin and co-hosted by CRU with Values in Action Assoc. **Wolf Wolfensberger**, Susan Thomas and an Australian presenter will be conducting an eleven day course relevant to human services in the modern world. This is a unique opportunity to hear from the people who have made outstanding and long-lasting contributions to human service delivery and the lives of people with disability. Contact Jane Sherwin on (07) 3870 1022 if you would like more information.

Wolf will also be presenting a 'Social Advocacies' event. Contact QAI on (07) 3236 1122 for details.

## Stop Press Stop Press