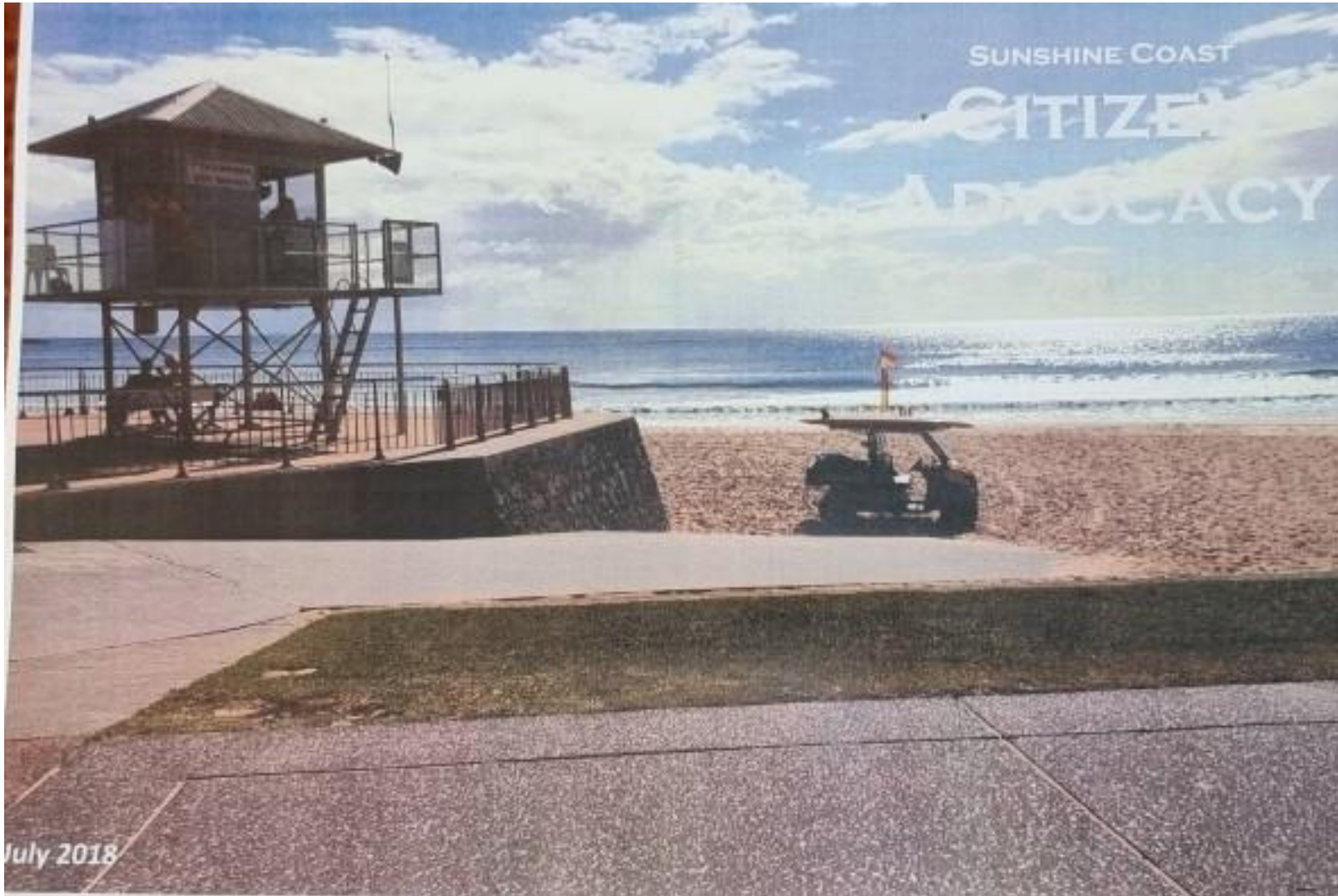


SUNSHINE COAST

# CITIZEN ADVOCACY

July 2018



When people ask me  
“what do you do?”

I say

“whatever it takes”

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## National Disability Insurance Scheme information days

In May we had the wonderful opportunity of having Heather Buck, a Citizen Advocate from South Australia, spend time with Sunshine Coast Citizen Advocates to talk about her experience in registering, applying and successfully receiving generous NDIS plans for two people with disability that she is the Plan Nominee for.



It was wonderful to have so many people come along to hear Heather's experience, thoughts and advice. As citizen advocates you may have a role to play in the NDIS by ensuring that your protégé receives fair treatment in their dealings with National Disability Insurance Agency - (NDIA) and the range of services and individuals who provide services with NDIS funds.

As Heather said, "I probably don't need to tell you that a huge difference in better response by services is a great possibility when an advocate is involved in the process!"



My NDIS experience has been quite positive, but I am aware also of "not so good" experiences for people with intellectual disability who have not had the benefit of a citizen advocate in their corner".

This Event was made possible due to the wonderful support from the Heritage Community Bank - Palmwoods.

**Thank you! to the 'Heritage  
Community Bank - Palmwoods'  
for supporting for this event**

## PEOPLE!

We used to believe that people with disabilities needed services and the question we asked was

"how can communities help"?

What we have learned is that people really need communities and the question is

"How can services help"?

Connie Lyle O'Brien (1992)

## Why Advocate?

"Unless someone like you cares  
a whole awful lot, Nothing is  
going to get better. It's not."  
- Dr. Seuss, The Lorax



### Citizen Advocacy not what you expected?

While being a citizen advocate rarely turns out to be exactly what we might have anticipated, for some the experience is so far outside their expectations, that they question their role with the program. One frequently identified issue concerns a lack of communication from the protégé (*those who have intentional communication skills*), to the advocate, which can result in self doubt and disillusionment for the advocate. It may be helpful to know this issue is a common one and rarely has anything to do with the personality or abilities of advocates. So why does it happen?

Let's try to look at it from the protégé's point of view. While not all, there are many people with disabilities who have grown up in an environment where their self confidence has been hindered by others around them making all the decisions for them; where they will live, how their money is spent, what doctor they will see, daily routines set out for them. Decisions are regularly made on their behalf, which over a period of years, results in learned helplessness, undermining self-confidence and restricting independence. Although this may have occurred with the best of intentions, the ability for an individual to self-initiate any task can be heavily diminished.

When we apply this to communication it may manifest in relationships that seem to be totally one sided. An example, maybe your protégé never calls you on the telephone but waits for you to call. Sometimes they may even wait for you to initiate the conversation before speaking at all. *It takes confidence and a belief that what we have to say is of value before we talk with others and this is something that advocates may take for granted.* Usually the protégé is happy to hear from you and may talk willingly but leave you wishing they would sometimes call you instead. It has little to do with you the advocate, your personality or ability to fulfill the role.

However, you may still be left feeling that the person with whom you are matched remains uninterested in you or your efforts to get to know him or her.

Continues page 5

### Citizen Advocacy not what you expected?-continued

Once again it is always helpful in the first instance to try to see the situation from the point of view of the protégé. Personal relationships can be tricky for any of us. Can you remember as an adult the last time you made a new friend? Take some time to think of the social skills you need to invest in a new friendship or maintain an existing one. For a protégé who may have few ongoing relationships in their life the opportunities for learning these skills can be minimal even non-existent.

Further examination of the quality of advocacy you are providing may be worth a look. Do you identify and respond to the needs of your protégé? Can you speak up on their behalf when something appears not as you think it should? Are you prepared to follow through on issues you believe important to your protégé? Are you accessible to the protégé and encouraging of the relationship with them? Do you imagine their quality of life would be diminished or at risk without an advocate? If you answered yes to any of these questions then you are doing just fine!

Support for your relationship with a protégé is always at hand through the staff of the Citizen Advocacy program who have every confidence in you as an advocate before you were matched. Advocates are carefully selected by the program so trust in the faith that staff have in you.

Continuous support is regularly available because nobody ever said it was going to be easy and in fact a good advocate will ride across a bumpy ocean from time to time. Advocacy is rarely what we thought it would be but always a deep learning experience about ourselves and others. Never lose sight of the value of the relationship you have generously allowed to exist with the potential to achieve untold good in our community.

Written by Bernice Jurgait, - Advocate

We make a living by what we do,  
But we make a life  
By what we give.     Winston Churchill

### What is the problem

Why is it that there are so many people in our community who are set apart, excluded and forgotten? The 'problem' as defined by the norms and values of our culture. In a culture that values health, wealth, productivity, achievement, beauty, intelligence etc, those people who are perceived as lacking in these qualities (people who are 'sick, poor, unproductive, unsuccessful, ugly, stupid') tend to be devalued, seen as having less value, perhaps even as less than human. Our culture has defined such people as needing specialised 'care', and has invented sophisticated ways of setting people apart via segregated services and creating 'client worlds' for people to live in.

Some core beliefs of Citizen Advocacy:

All people have abilities

All people are worthy, and entitled to personal relationships and experiences.

A professional sub-culture has developed during the past fifty years which has defined people with disabilities as needing professional, institutional care, whether these be institutions out in the middle of nowhere, or right in the centre of town.

Two generations of citizens have grown up with the myth that people with disabilities 'need' professional care. There is a grain of truth to this. Professional competence is important for it is certainly important for someone who is an expert on adaptive mobility equipment to bring his knowledge and expertise to bear on the mobility problem. In another realm, if someone has severe emotional problems, a therapist can help put such problems in perspective, and may even be able to assist his or her client in finding healing and renewal.

The problem is not that professional services are not needed to help address some needs, the problem is that professional services have usurped the prerogative, and the responsibility, for meeting many needs which by definition must be met by 'ordinary' people. The most basic need, which by definition must be freely-given, is the need to be loved. Love cannot be bought and paid for, nor can it be forced. Love is neither a requirement, nor a duty in a job description.

Continues page 7

#### What is the problem? Continued.

Love cannot be prescribed. Love, if it is love, can only come from one heart to another, from person to person. While to some people, this may sound trite, it is essential truth. All people need friends, not just friendly staff, but friends. We all need a home, not a place that is home like' by home. We all need something meaningful to do. Most people find these things through people who are part of their lives – family, neighbours, friends and associates. Obviously we all want people in our lives because they care about who we are as people and have faith in our capacities, abilities and gifts. We need to take the obvious seriously.

Many people have become subtly convinced that people with disabilities need to live in special places, with other special people, riding on special vans, going to special activities and who in short are made to live in a special world. When these dynamics are combined with a fear of the unknown, a fear of differentness, then not only are people with disabilities separated physically, but socially. They become "those people".

"Those people" come to be seen as so different that many ordinary experiences, such as having a friend, owning a house, having a job, learning how to read, are not expected to happen – not expected by service providers or by families, or by neighbours or sadly, even by people with disabilities themselves.

The combination of dynamics described above results in a disenfranchisement of both people with disabilities and people without disabilities. Disabled people are seen as powerless clients who must have 'programs' administered to them.

Neighbours and friends are seen as 'not qualified' to do anything relevant for the needs of people with disabilities.

The mythology of a professional culture develops its own language and fancy acronyms that convinces families, neighbours and people with disabilities that their world must forever be a world of therapists, counsellors, aides, doctors, house parents, resident advisors and so on.

*Continues page 8*

#### What is the problem continued.

As one friend of ours put it, "there are two kinds of people, clients and staff".

When people with disabilities live in a clientised world, routines and roles become well-established. People (including clients and staff) are expected to act in certain ways. Anyone who deviates from these expectations is at risk of being severely punished, either overtly or covertly. For example, someone who refuses to screw nuts and bolts together day after day at an activity program may be seen as non-compliant. Someone who is expressing anguish over never having been loved may be interpreted as psychotic. Staff members who step out of their professional role are cautioned against 'getting too close to clients'.

Fortunately (ironically), we have found that there are people in our community who have not been socialized into the professional human service subculture. There are also some human service workers who do not identify with the professional mythology and who are able to keep their professional role in perspective. There are people who can and will strive to make a difference through a personal, committed relationship.

There are people who, given the opportunity, will use their common sense, get involved and share their lives.

More core beliefs of Citizen Advocacy:

It is incorrect to assume that people with disability have their needs adequately met by the human service system.

People with disability should be part of the community and live as independently as possible.

Adam Hilderbrand— One to One Citizen Advocacy



Our new office!  
Unit 6/36 Maud Street,  
Maroochydore





### Morning Tea!

An opportunity to check out the new office, come together, meet each other, share knowledge and experiences!

First Thursday of every month  
(next one being Thursday the 5th July  
between 10am and Noon.

(For Protégés, Advocates, Advocate Associates or  
any other interested party).

### Why Invest Common Sense, Passion And Persistence In Citizen Advocacy?

The images created about people with disability by the media, human services efforts, and in literature often support negative stereotypical attitudes. From these attitudes come our actions or our choice not to act. Personal relationships between people allow us to reconsider our stereotypes.

Many people who are devalued – that is, seen and treated as negatively different – need to be protected from conscious and unconscious prejudice and discrimination.

Abuse and neglect exist in all human service efforts. Interested outsiders are one way to monitor and lessen this reality.

The most predictable outcome of current human service spending and practice is organized segregation. This has kept people apart and unknown to one another. Personal relationships between people help to overcome fear, myth and discomfort that come from people not knowing one another.

The best interests of an individual person may be different than the best interests of the organization offering assistance, the person's family or the collective cause of social change. Citizen Advocacy always only focuses on individual people.

Much of the care and response that has traditionally existed in community life is being replaced and driven out by professionalized services. Citizen Advocacy tips the scales back toward personal response and community responsibility.

Personal relationships are built on common interests and depend on common bonds to sustain them. This challenges the illusion of difference.

Personal commitment is the most conservative and potentially powerful form of action available over long periods of time.

Reprinted from: *The Citizen Advocacy Forum*, June 1998



## Advocate/Protégé Contact—how much?

A question sometimes asked by advocates is how much contact should they have with their protégé. The answer is that there is no set amount of time. As in any relationship, whether with family or friends, contact varies depending on what is going on at the time.

The difference with advocate/protégé relationships is that when the protégé needs the support of the advocate, the advocate does their best to be there for their protégé. It is possible for an advocate to do a few things and then step back for a short while. Contact isn't necessarily maintained weekly. You may visit your protégé or it may not always be possible to make a commitment to be with someone on a frequent, regular basis for the long-term and, in order for the relationship to endure over time, we must be creative about how our relationship is developed and sustained.

It is important to understand that no two advocacy relationships are the same. You may know an advocate who has very regular personal contact, where advocate and protégé are very much involved on a social level. You may also know of an advocate whose personal contact is less frequent, where the advocate acts as a guide, mentor, or assistant to the protégé to work through difficulties and issues which may confront them, such as providing practical assistance to a person who is looking for work or who is wanting to move into a flat or house.

It goes without saying that your relationships are what Citizen Advocacy is all about, but we know that, like in all relationships, there are always going to be highs and lows, good times and bad times, that's what makes it all worthwhile. "It is the greatest of all mistakes to do nothing because you can only do a little. Do what you can."

If people could really see  
the value of giving  
they would offer  
a part of every meal.

Buddha

## WheelChair Village

Imagine a town full of physically impaired people, all wheelchair users. They run everything: the shops, the factories, the schools, the television studio, the lot. There are no able bodied people, so naturally, when the town is built the community decides that it is pointless to have ceilings 10ft high and doors that are 7 foot high, "it's just a lot of wasted space that needs heating" they say. So the ceilings are built at 7 foot and doors at 5 foot. In every way they design the place the way they want it, and over the years these proportions are standardised by regulation.

One day a few able bodied people come to stay. One of the first things they notice is the height of the doors. And the reason they notice this is because they keep hitting their heads. They come to stand out by the bruises they carry on their foreheads. Some doctors, psychiatrists, and social workers become involved. The doctors do extensive research and conclude in their learned reports that the disabled-abled bodies suffer from loss of or reduction of functional ability and the resulting handicap causes disadvantage for restriction of activity.

Working parties are formed. Many professionals and caring people are worried about what becomes known as the problem of the able bodied. Throughout the town there was a rapid growth of real concern. Specially strengthened helmets are distributed free to the able bodied to be worn at all times. Orthotists design braces which give support and relief while keeping the able bodied wearer bent to a normal height.

Finding employment is a major problem for the able bodied. One man, for instance, applies to become a TV interviewer but he must have a special medical examination when he applies for the job.

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### WheelChair Village continued.

The doctor, naturally, points out in the report that it would be rather strange to have a TV interviewer with a bent back who wears a helmet all the time. Of course the man doesn't get the job and is advised to accept the limitations of his disability. Finance, of course, becomes a major problem. Various groups of compassionate wheel chair users get together and form registered charities. Twice yearly they hold a collection day, and of course there is the annual telethon, and the Miss wheel chair quest. Upturned helmets are left in pubs and shops for people to drop their small change into. There is heightening support for organisations such as The Society for Understanding the disabled abled bodied. There is talk of founding special homes. But then one day it dawns on the able bodied that there is nothing actually wrong with them, just that society excludes them. They form a union to protect themselves and complain against segregation. They argue that if ceilings and doors were raised, there would be no problem. But this, of course, is a foolish suggestion. You cannot deny disability.

*All disadvantaged groups need  
advocacy - privileged groups  
get it without looking.*

Wolf 79/Husberger 1993

### Community Resource Unit. (Including preparing for the NDIS)

Community Resource Unit Level 2, 43 Peel Street, South  
Brisbane Ph. 3844 2211 Website [www.cru.org.au](http://www.cru.org.au)

The Community Resource Unit has an excellent website, containing a broad selection of articles, videos and ideas drawn from CRU's existing resources and over 20 new short films.

It also has lots of interesting content from around Australia and the world. The content is useful for people with disability, their families, friends, advocates and other people who support them – both paid and unpaid.

This resource will be helpful to people as they prepare for the roll out of the National Disability Insurance Scheme (NDIS). There is one page dedicated to making the link between this initiative and the opportunity it provides to make life better for people. <http://cru.org.au/ndis-ready/>

The website contains 7 pages that cover the following topics: The Good Life, [Getting Started](#), Including Others, The Role of the NDIS, Funded Services and Support, Blocks and Barriers, Keeping on Going and [The Bigger Picture](#).

The website has editions of their information brochure called **CRUCial Times** on line – in this months edition the focus is mainly on Capacity Building, with five writers reflecting on their experience of how capacity can be intentionally built at a personal, organisational or community level.

**WEBSITE - <http://cru.org.au/>**

## "Tears and Laughter"

Dr Wolfensberger said, that Citizen Advocacy is a "tears and laughter movement". Tears and laughter happens in moments that are real.

Deep commitment to role and or protégé

He has no one else who cares  
I will do whatever needs to be done  
I just look at him as if he was me  
I would be there if he needs anything  
I have given my heart to this relationship  
Now she realizes that someone cares, that I care

"The expressive aspect carries the instrumental aspect"  
(Dr Wolfensberger)

It is important to understand that the heart will stay where the head will never stay. The head will only stay where it makes sense. If our commitment is made on an intellectual level, we will be faithful only as long as it seems logical for us to be there. For the heart, it does not have to make sense. The heart is the seat of fidelity. But the heart is not logical. It does not make decisions based on principles and values. It does not reflect.

The heart can make errors that can cause great harm while having the best of intentions. The head can make errors by ignoring the feeling and emotions that are important in a situation. We must ensure that there is always a strong connection between the two, the head and the heart. When two people become a source of life, of joy, of energy for one another—anything can happen.

The expressive (the heart) carries the instrumental (The head).  
If the bond is there, competence will come.

## Office resources of interest

### BOOKS

- From behind the Piano – The building of Judith Snow's Unique Circle of Friends
- Observing, Recording, and Addressing personal Physical Appearance by means of the Appear Tool
- Suppression Stories
- A guideline on protecting the health and lives of patients in Hospitals – especially if the patient is a member of a socially devalued class
- Oliver Twist has asked for me – The politics and practice of getting justice for people with disabilities
- Duty of Care – Who's responsible?
- Social Role Valorization – Advanced issues in SRV Theory
- A brief Introduction to SRV – WW
- Public Policy Private Lives
- Talking about A series of Community Conversations
- The Homes West Experience – steps to independent living for adults with a disability
- One person at a time – How one agency changed from Group to Individualised services
- The Forgotten Generation
- The Inclusion Papers – Strategies to make inclusion work
- Christmas in Purgatory
- On being the change we want to see – Volume 3
- Standing by me – stories of Citizen Advocacy

### DVD's

Living a good life  
Circles of Support  
A history of human services, Universal Lessons, and Future implications  
Advocacy for People with Disability

Please note: The Sunshine Coast Citizen Advocacy policies are available to anyone who would like to view them – Staff members are available to read the policy's to you if you need the assistance.

## Sunshine Coast Citizen Advocacy

### Sunshine Coast Citizen Advocacy

Is funded by the Department of Social Services

The program operates in and around Maroochydore, Nambour, Caloundra, Mooloolaba, Buderim, Coolum, Noosa and the Hinterland areas.

#### Office Address

Unit 6/36 Maud Street  
Maroochydore

Phone : 5442 2524  
Program Coordinator  
mobile:  
0418 714 695  
Office: 5442 2524

**Office Hours :**  
8.30 a.m.-4.30 p.m.  
(Monday-Friday)

### Board Members are:

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Craig Agnew -

Vice President  
Ronda Quin -

Secretary  
Bob Lee -

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Andrew Barton -  
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### Program Staff:

Program Coordinator -  
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Assistant Coordinator -  
Les Pearce

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Assistant -  
Rachel Irvine

