

# THERE

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IS NO GREATER DISABILITY IN SOCIETY THAN

# THE INABILITY

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# TO SEE

A PERSON AS MORE.

June 2019

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SUNSHINE COAST  
**CITIZEN  
ADVOCACY**



See the ABLE  
Not the label!

"Disability only becomes a tragedy  
when society fails to provide  
the things needed to lead  
one's daily life."  
- Judith Heumann  
ActiveMind

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## Why Many People With Disabilities have a Greater-than-Usual Need for Freely-Given Relationships

For most of us, freely-given relationships are an intrinsic part of our everyday reality, to the extent that we often take them for granted. While we may be involved in a range of relationships with people from different walks of life, the most meaningful ones are usually those which are freely-given relationships and are of vital importance to – a sine qua non of (indispensable condition) – the human identity.

Yet, that reality somehow becomes distorted in relation to the lives of people with disabilities. In the culture of paid formal services for people with disabilities, for instance, the need for clients to have and maintain freely-given relationships may not be recognised, acknowledged, or considered as important. Often, even if there is not an outright denial or dismissal of this universal need, it is regarded as something of a fill for clients with disabilities.

In sharp contrast, central to the concept of Citizen Advocacy, is the deep conviction in the power of unpaid commitments made by ordinary citizens in enriching, changing, and even saving, the lives of people with disabilities. Indeed, we could argue that many people with disabilities do not “merely” need freely-given relationships, but – given their social situation – have an intense or greater-than-usual need for such relationships.

Reviewed below are some realities which intensify the need of people with disabilities for freely-given, unpaid commitments. Doubtless, these realities confer a sense of meaning and motivation to people involved in various roles in Citizen Advocacy. Incidentally, they can also serve as a salutary and sober reminder to those Citizen Advocacy programmers in Australia which are currently considering, or already undertaking, additional activities that dilute, degrade, or displace the exclusive Citizen Advocacy focus of facilitating freely-given relationships by and for people.

- 1) Given that some emotional needs can only be addressed in freely-given relationships, such relationships are particularly important to people with disabilities whose social world is typically comprised only or mainly of paid personnel.

It is no profound revelation to state that certain needs can only be addressed within freely-given relationships. By definition, some fundamental, universal needs such as the need for love, acceptance, and friendship cannot be bought and sold like commodities; for these feelings to be real, they must be freely extended and received. Whereas we all need and thrive on freely-given relationships of this nature, the intensity of need is greater for people with disabilities who have been deprived of many, or any, such relationships – perhaps for all of their lives.

Sadly, for many people with disabilities, the only source of relationships may be with people who are paid to be in their lives. And, of course, if someone is involved because it is part of their employment, such paid relationships can never address those needs for which is freely-given. For example, if a person hungers for but lacks friends, and therefore has an intense need for friendship, having paid staff who are friendly is simply not the same thing as a real friend – whose motivation for, and duration of, involvement is not financial remuneration or other conditions of employment.

Hence, for people who have few or no freely-given relationships, the need for – and positive impact of – such relationships is that much greater.

In all probability, none of us have escaped some form of rejection in the course of our lives, and can recall (perhaps with painful clarity) the feeling of not being wanted.

But it is likely that for many, rejection is not an all-too-frequent occurrence, and the hurt it induces can often be assuaged by the knowledge that there are some others around who are accepting and supportive of them.

### Why Many People With Disabilities Have a Greater-Than-Usual Need for Freely Given Relationships continued...

In contrast, for many people with disabilities, systematic and endless rejection – whether by one’s family, the immediate neighbourhood, the community, or the larger society- is a life defining and indelible reality.

Whilst rejection may take many forms of expression, if the feeling of being rejected is a familiar and recurring one to a person, it can be deeply wounding – particularly in the absence of those important relationships which are a comforting reminder that at least someone else accepts and cares for the person.

Therefore, for people with disabilities who have been rejected relentlessly, to the point where perhaps only paid people will be with them, freely-given relationships are all the more important to heal or minimise the pain of such wounds, and to validate their self-worth.

- 3) Given that typically people with disabilities experience much relationship discontinuity, freely-given relationships are more likely to endure over time.**

Another defining characteristic of the relationship world of people with disabilities is the social discontinuity created by people entering and then disappearing from their lives – often, never to be seen again!

Nowhere is this reality more glaringly exemplified than in agencies which provide services such as accommodation and employment to people with disabilities, where usually the number and frequency of turnover of staff is inordinately high. Whether by design or circumstance, there can be considerable upward or lateral mobility of staff within a service; or staff may simply leave to pursue better career opportunities or for other reasons.

This pattern of ever-changing staff necessarily means that any relationships which are formed with service-recipients will be as ephemeral as footprints on the beach. Such come-and-go relationship disruptions can, in turn, cause great anxiety in people with disabilities, with the question of the tenure of the next staff member hanging over their heads like the sword of Damocles.

- 4) Given that typically people with disabilities are cast in the role of passive clients in paid services, freely-given relationships usually provide the opportunity to contribute, rather than just receive**

For people with disabilities who must rely on formal services to address some of their needs, the culture of such services commonly habituate them to becoming passive clients. Even where the client role is valid, and the service is needed, the very nature of staff/client dynamics will generally inhibit,

not encourage, any tendency of service-recipients to also contribute. Further, depending on the type of service, the lines of demarcation of the respective roles of staff and client may be so pronounced and rigid, as to strictly forbid any responses from clients which are perceived as crossing the line of recipient status.

Relations in a freely-given context, on the other hand, tend to be transacted less unilaterally. By virtue of the role which people assume in freely-given relationships, there is likely to be greater expectation, encouragement, flexibility, and opportunity for all parties to contribute. Indeed, certain roles within freely-given relationships thus offer the opportunity to contribute, and to have their contribution recognised.

- 5) Given that typically people with disabilities are not positively perceived in society, freely-given relationships can confer social value on, or accord certain valued roles to, them.**

Our society does not identify with, and ascribe positive value to, people with disabilities. Lamentably, in a myriad of ways, people with disabilities are reminded that they are “different from,” “not as valuable as”, or “lesser than,” other members of society. Given their devalued status, it is of greater importance for people with disabilities to be positively perceived and treated as well as others who are not devalued, and for whom therefore the need for a (more) valued social image is unlikely to be of life-shaping consequence.

Freely-given relationships offer a means of conferring social value on people with disabilities. In the context of social roles, certain valued roles – such as that of friend or family member – are only accessible in freely-given relationships.

And because freely-given relationships are accepted as a familiar and valued expression of the social nature of human beings, people with disabilities in such relationship roles are apt to be perceived as similar to, and having the same needs as, other citizens. Another corollary is that people in freely-given relationships will be seen as valuable enough for others to want to voluntarily associate with them.

On the other hand, interpersonal identification with, and positive valuation of, people may be more difficult if the only relationships they have appear to be contrived and conditional on payment.

In fact, consistent with the proverbial expression that people are judged by the company they keep, members of the public are likely to interpret the substitution of paid relationships for freely-given ones as vindication that people with disabilities "need" or "deserve" such a relationship fate—since they are apparently different from, or less valuable than, others.

Clearly, then, freely-given commitments made to people with disabilities can transmit positive messages about their value and innate humanity.

**6) Given that typically people with disabilities are particularly vulnerable, freely-given relationships can provide independent representation and protection of their interests.**

People with disabilities constitute one group in society which is particularly vulnerable to a range of harmful experiences. Whereas no human being is impervious to harm, people with disabilities are more vulnerable because the probability of bad things happening to them is higher, and the impact of the hurt is greater.

Some of the reasons which heighten the vulnerability of people with disabilities include the following:

- (a) As noted earlier, given the dominant values of our culture, people with disabilities are considered to be less valuable than others, perhaps even expendable; b) the nature of their disability may mean that they experience functional limitations, or they are otherwise reduced in personal resources (e.g., being less able or willing to speak for themselves);
- (b) they may be long-term, even life-long, clients of human services which can inculcate passivity and dependency; (d) they often have few or no competent allies to stand by them; (e) and they are apt to be hurt repeatedly, with each successive wound rendering their residual defences progressively weak.

The heightened vulnerability of people with disabilities necessitates vigorous advocacy to safeguard their interests and effective advocacy to safeguard their interests. Effective advocacy is more likely to arise from freely-given relationships since (a) people choose to become, and remain involved in the relationship, and therefore usually have a higher level of commitment to, and a commensurate preparedness to, advance the well-being of the party whose interests require

representation and (b) the unpaid nature of the involvement allows for greater independence of representation since a significant conflict of interest—obligations attached to receiving remuneration—is removed.

The quagmire of conflict of interest can be underlined by invoking the example of paid workers of service agencies for people with disabilities, whose interests in maintaining an income can clash with, and take precedence over, the interests of their clients. For instance, if the agency is pursuing policies which are injurious to clients, the desire to retain employment will almost invariably prevent staff from speaking out against their employer, consistent with admonition: "Don't bite the hand that feeds you."

Admittedly, freely-given relationships will not be devoid of conflicts of interest entirely, since it is impossible to eliminate all such conflicts in human affairs. But at least freely-given relationships avoid one of the most compromising sources of conflict of interest—monetary compensation—thus increasing the probability of independent, robust advocacy.

Citizen Advocacy is an important response to the intensity of need of people with disability for freely-given relationships. For those who have never or rarely, experienced freely-given relationships, Citizen Advocacy provides them with such an opportunity. And for people whose circumstances heighten their need for freely-given relationships, that opportunity may be their only lifeline.

**Mitchel Peter**

## SUNSHINE COAST CITIZEN ADVOCACY RECENT FREE WORKSHOP - EFFECTIVE PLANNING PROCESSES -

Sunshine Coast Citizen Advocacy held a free workshop to assist advocates, protégés, family members, and others involved in Sunshine Coast Citizen Advocacy. This workshop on effective planning processes was facilitated by Bob Lee.

For people with disabilities and their families, the past few years seem like they have all been about the "NDIS", the new way of funding services. There have been high expectations from most of us, joy and celebrations for some, and hard work, frustration and disappointment for many.

Participants in the workshop heard how citizen advocates and family members had carefully planned for their dealings with NDIS staff, had gathered hard information to effectively argue their case, and had successfully negotiated a package of funding which gives the people with disability they are representing, a shot at the good life they deserve.

Participants learned a step by step process which could result in a simple document that demonstrates to NDIS planners that careful attention has been given to...

- identifying the individual needs of a person with disability,
- being clear about important personal goals,
- What outcomes can be expected, and
- What actions need to happen for those outcomes to be achieved.

Having a clear, concise plan for how the NDIS can help a person with a disability get the "good life", gives those who develop the plan real credibility, and provides planners with an invaluable tool they can use to genuinely respond well to people's needs.

We thank Bob Lee for a very informative and interesting workshop, Bob Lee was the Coordinator of the Sunshine Coast Citizen Advocacy Program from 1996 to 2016, and

is now an advocate and Legal Guardian for a man with disability who is on his way to his goal of living a good life.



Paid Support will continue to  
be an important component  
of life for many people,



but funding will never buy  
friendship, belonging,  
intimacy or commitment!

# Historical Events



We need to study history because, as the French philosopher Etienne Gilson (1884 – 1978) put it, history is “the only laboratory that allows us to see the consequences of big thoughts.”

However, in order to really learn and benefit, from history, it is important to read about the past not with the modernistic attitude of snobbishness and even arrogance towards our ancestors (e.g., “How could they have been so stupid/foolish/benighted/prejudiced/etc.?”), but with an attitude that is willing to acknowledge similar, or even worse, stupidities, foolishnesses, prejudices, etc., today, and that is willing to take from the past whatever is of benefit, and instructive.



For about 30 years, Walter E. Fernald was an advocate of eugenicist policies, and virtually persecuted mentally retarded people. He said the most awful things about them which might easily have contributed to the genetic alarm period culminating in genocide. However, in 1918, he repented, and during the last 6 years of his life, he recanted his life-long position. This undoubtedly bespeaks of an extraordinary grace of the man, and also of much courage. What was it that changed his mind? One thing was that he saw that retarded people were much more capable of growth, development, and performance than he had believed. But perhaps more important was something else which he said in 1918: “Some of the sweetest and most beautiful characters I have ever known have been feeble-minded people... We have clearly slandered the feeble-minded. We know that a lot of the feeble-minded are generous, faithful and pure minded.”



In the 50 years between 1924-1975, seventy two thousand inmates of six state mental institutions in Virginia were sterilised, almost all without their consent and many even without their knowledge. For instance, they were told that they had appendectomies (Washington Post, 28/8/85; item supplied by Jerry Kiracofe). This number does not even seem to include devalued people in the state sterilised outside of the institutions.

Few people are aware of the fact that the reason King James invented a new coin in 1633, the farthing (worth a quarter of a penny), was to create a coin that people could give to the poor without actually giving a great deal (Miller, 1991)

Mary Mallon was an itinerant cook who worked in New York around 1900 and boasted that she never washed her hands. She herself was immune to typhoid, but passed it on to at least 1400 other people. Because she persistently refused to cooperate with health authorities, she was eventually confined for life, and earned immortality in the history of medicine as “Typhoid Mary” (SHJ, 18/6/93).



During the 1940s through 1960s, Herta Loewy wrote a series of 4 books (published in the US) on retarded children, mostly for parents. She was among the first to do so, but was not always helpful. For example, she hinted darkly and repeatedly that retarded children should not be allowed to have dolls: doll play leads to sexual misbehaviour! Dr, if your retarded child is disobedient, throw him fully dressed into a tub of cold water which will quiten him down swiftly. And certainly don't play baby games with a retarded baby!

In 1796, the English physician Edward Jenner first dared to infect a farmer's son with cow pox, and later with human smallpox. The child got a mild case of pox from the cow vaccination, but did not catch the smallpox. This experiment was the basis for the mass inoculation against smallpox that eventually eradicated the disease. However, Jenner was mortally afraid that the child might catch smallpox and die, and when the child did not, he was so relieved and grateful that when the child grew up, he built him a house, and with his own hands planted roses for him in his garden. It is interesting to contrast this touching gesture of gratitude with those that people might show in our own day.



At the brand-new modernistic Bronx Developmental Centre for the mentally retarded, built in the early 1970s, many windows of client areas extended down to the floor plane. When the architect was asked why he had designed the windows in this fashion, he said that he had travelled all around the world looking at other institutions, and everywhere he went, he noted that retarded people were sitting on the floor.

Training Institute Publication Series (TIPS), Oct./Dec. 2004



## Death of Common Sense

Today we mourn the passing of a beloved old friend, *Common Sense*, who has been with us for many years. No one knows for sure how old he was since his birth records were long ago lost in bureaucratic red tape.

He will be remembered as having cultivated such valuable lessons as knowing when to come in out of the rain, why the early bird gets the worm and that life isn't always fair.

*Common Sense* lived by simple, sound financial policies (don't spend more than you earn) and reliable parenting strategies (adults, not children, are in charge).

His health began to deteriorate rapidly when well intentioned but overbearing regulations were set in place.

Reports of a six-year-old boy charged with sexual harassment for kissing a classmate; teens suspended from school for using mouthwash after lunch; and a teacher fired for reprimanding an unruly student, only worsened his condition.

It declined even further when schools were required to get parental consent to administer Panadol to a student; but, could not inform the parents when a student became pregnant and wanted to have an abortion.

Finally, *Common Sense* lost the will to live as the Ten Commandments became contraband; churches became businesses; and criminals received better treatment than their victims.

*Common Sense* finally gave up the ghost after a woman failed to realise that a steaming cup of coffee was hot. She spilled a little in her lap, and was promptly awarded a huge settlement.

*Common Sense* was preceded in death by his parents, *Truth and Trust*, his wife, *Discretion*; his daughter, *Responsibility*; and his son, *Reason*.

He is survived by three stepbrothers; *I Know My Rights, I'm A Whinger* and *I am A Victim*.

Not many attended his funeral because so few realised he was gone!

## Advocating Strategies

Let us suppose that a citizen advocate has established a relationship, knows the person for whom he or she is an advocate fairly well, tries to look at the world through that person's eyes, has made a commitment, is prepared to make sacrifices, and has relevant standing in the person's life. With these in place, a citizen advocate is ready to "represent the person's interests as if those interests were her own" through words and actions.

An advocate who takes action to defend and support someone defines himself as a defender and supporter. When these actions emerge through seeing the world through the eyes of the protégé, the advocacy relationship is personal. Citizen Advocacy is always personal in the sense that it is face-to-face, eye-to-eye, and person-to-person.

### **Treat people, including adversaries, with respect.**

This is one of those things that should go without saying. However, speaking up for someone you care about raises understandable emotions and in the heat of the moment, those emotions can take over and become counterproductive. In Citizen Advocacy, advocates are encouraged to be passionate as they promote justice, yet passion must be constructively directed. If one expects the person being advocated for to be treated with dignity and respect, then one needs to show that same respect for the dignity of the person on the other side of the table. This does not mean that the vigour of one's advocacy should be watered down or weakened. It is possible to be strong, passionate and respectful at the same time.

### **Ask questions**

Speaking up for someone almost always means asking questions. I will not prescribe the details of what kinds of question an advocate should ask, but I will make a few suggestions regarding the style and posture of question asking. First, avoid making assumptions based on limited information. Ill-informed questions based on incorrect assumptions can damage the credibility of an advocate in short order. Asking questions is a fact-finding exercise. Examples of such questions are, "When has so-and-so last seen a doctor? What was he (or she) being seen or treated for?" Once one has the factual information that is needed in a given situation, then an advocate can formulate questions that are of a more challenging nature, such as for example, "So-and-so hasn't seen a doctor for six months in this facility, why is that?" Or,



"The doctor who saw so-and-so spent ten minutes with her and didn't check for bedsores, what can we do about that?" I do not mean to insult the reader's intelligence by giving such basic advice, but if advocates rush in without good information, their efforts may be doomed from the start.

#### **Give people the opportunity to do what is right**

An advocacy principle that can provide balance and help avoid unnecessary conflict is that when possible, the people one is advocating against should be given the chance to do the right thing. That is, an advocate should not immediately assume that human service workers would not be fair and responsive.

While it may be that the service system will not respond or provide what is needed, sometimes failure to respond is more a function of regulations or oppressive social policy than it is the actions of individual service workers. Also, unresponsiveness is often due to naïveté, incompetence, pride, and/or unconscious devaluation by individual human service workers.

However, people cannot respond positively unless they have an idea of what a positive response might be.

#### **Expect co-operation, but do not be surprised by resistance.**

When an advocate speaks up for the interest of a particular protégé, the advocate may find that he or she is up against formidable forces in the protégé's life. When an advocate speaks up vigorously, the resistance from service providers may be equally vigorous. In fact, sometimes the response to advocacy may be disproportionately aggressive; for example, in response to simple questions or concerns, an advocate may be forbidden access to her protégé.

On occasion, one might encounter a service provider who appreciates the limits of the service system, and who therefore appreciates the watchfulness and advocacy of private citizens – but this is rare. More often, advocates will be met with defensiveness and resistance. Like most of us, administrators, bureaucrats, and service workers generally do not like being challenged or having demands made of them. Resistance can take a variety of forms. It may be passive, where one is told, "Thank you for bringing this to our attention, we'll get right on it," and then little or nothing happens. People may also resist out of pride. In the face of such resistance, advocates need to be prepared to hold their ground, and to escalate their advocacy efforts with careful, measured responses.

Advocates must bear in mind, however, that sometimes human service workers would like to respond, but are unable to do so because of limitations of the service system, lack of funding, or policies handed down from above.

There may be understandable reasons why a service provider does not, or cannot, meet certain expectations, but that does not objectively change the reality of the situation for the protégé. A citizen advocates role is to concentrate on "what", not "why". That is, the advocate must focus on what the person's actual situation is, rather than on the reasons that a human service provider may give for why something is like it is- even when those reasons are legitimate.

Being clear about what a person's life is like in the present circumstances can sometimes lead to a new direction in resolving a problem. For example, some citizen advocates have given up on the human service system and instead brought the protégé to their home. Or, advocates may push to higher levels of authority to create a solution that no one at lower levels could have thought possible.

Going against the stream in dealing with a powerful bureaucracy can be unpleasant. Advocates are often described by professional human service agencies as irrational, "too emotional", or "too attached."

People in power do not like to be embarrassed or have their reputation put in jeopardy – who does? Also, as I have mentioned, there is always a danger that a service provider will retaliate against the protégé, whether consciously or unconsciously. The nitty-gritty of advocacy is often eye-opening for advocates. We need not anticipate all that a citizen advocate might face, but suffice it to say that the independence of the advocate is a crucial element in raising a strong voice in the face of injustice.

An advocate must be prepared to absorb some of the same devaluing responses that her protégé has had to contend with for years or even a lifetime.

A word of caution: advocacy for the sake of advocacy, or advocacy for the sake of working out some agenda on the advocate's part (revenge, anger, pride) is usually not helpful to the protégé. There is nothing about being an advocate that make the citizen advocate morally superior or even necessarily right. The moral goodness or rightness of an advocate's actions must be objectively based on the best interests of the vulnerable person whose concerns and wellbeing are at stake. Advocates who pound on tables and raise their voices in self-righteous anger or pride can cause irreparable harm. An advocate may have a valid reason to pound on a table or raise his voice when more diplomatic efforts have failed, but generally an advocate will be far more effective with a careful, serious, respectful yet firm approach that gives people the chance to respond positively before stepping up to more adversarial advocacy methods.

Often the benefits of one's engagement may only come after a long period of time, perhaps many years.

#### Seek out support

A citizen advocate would do well to occasionally spend time, alone or with others, reflecting on who the person is for whom he or she is an advocate. Advocates find themselves facing situations they never would have imagined. For these and other reasons, advocates need support.

This does not mean that advocates need to become quasi-professionals and advocacy experts.

They need moral support, common sense and information. Being a part of someone's life, and having influence in that person's life, are serious matters.

This is especially true when one's actions, or one's failure to act, have consequences in a person's life. A key role of the Citizen Advocacy office is to assist citizen advocates to think through what their role and actions will be in what are sometimes very difficult situations.

A citizen advocate has, or should have, access to a Citizen Advocacy office that can provide such support, although the Citizen Advocacy office need not be the primary or even the most important source of support. Support from an advocate's own personal networks, such as family, friends and co-workers, has many advantages in that it builds upon natural ties and relationships, is likely to be available in the future, and it widens the circle of people involved in the protégé's life.

Seeking out support is particularly important when health issues are at stake. The dynamics and dangers that devalued people face in a hospital setting or nursing homes will often present themselves in confusing, even deceptive ways, and having someone to talk to who understands those dynamics is extremely important.

Opening one's life to a devalued person will bring unexpected lessons. One will not learn these lessons from books. Yet a person must be open in order to learn. Pride is a great obstacle to learning, to stand before a person who has a mental handicap, a person who cannot read or write, has never read a book, has little knowledge of the way of the world, and to regard that person as one's teacher takes humility. To set aside preconceived notions about what makes a person valuable calls one to be humble to the truest sense of the word.

**ONE PERSON AT A TIME**—By Adam (A.J.) Hilderbrand. —  
This book can be loaned from our resource library

#### 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 societally 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 Maroochydhore,  
Nambour, Caloundra,  
Mooloolaba, Buderim,  
Coolum, Noosa and the  
Hinterland areas.

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WHAT IF  
I CAN   
DO IT?