



SUNSHINE COAST
**CITIZEN
ADVOCACY**

February 2018

When people ask me
“what do you do?”

I say

“whatever it takes”

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Annual General meeting and Christmas party

On Saturday the 9th December at the Palmwoods Bowls Club we had a really lovely day for our 2017 Annual General Meeting and Christmas party, with nearly sixty people attending.

Sadly two of our valued board members (Alison Hall and Bruce Smith) resigned their position on the board. On a happier note both are close by for us to talk with and gain support from if needed in the future.

On a brighter note Craig Agnew, Ronda Quin, Andrew Barton and Bob Lee continue their very valued role on the Board of Management.

The Christmas party was such a lovely afternoon with delicious food, good company and everyone looking relaxed and enjoying time together.



Happy New Year to you all!

What do we mean by inclusion

In 2017 it is not the norm for people with disability to be included in the general life of the community. Real inclusion can and does happen but is much rarer than it should be after decades of talk and having it as a stated goal in countless plans and endless documents. Most children are born included; they start their life as part of a family and a neighborhood or community. However, when the child or person has some difference, the rules change and their inclusion – their right to belong and be part of that family and community - changes. Being different is not the problem; but being treated differently simply because of the difference is.

Aspiring to inclusion, without a well thought out strategy to counter the blocks and barriers is not enough. Changing our own habits and the habits of the community requires a strategic approach.

When trying to define something its often useful to say what it is not; so we can say that being included in the community is more than just 'not being segregated in an institution'. Being present and visible is a good start but is not enough to be included. As Ann Greer (mother of 3 adults two of whom live with disability) would say, inclusion involves relationships, contribution, purpose and identity in a person's community.

We find ourselves now, not only with real inclusion being rare, but with many practices being called inclusion, when clearly they are not. Unfortunately, placing the words community or inclusion in the name of a segregated group or activity is not enough to make it inclusive. In a desire to be tolerant we can sometimes think that it is okay to have a variety of options for people, some of which are more inclusive than others. However Kathy Snow perspective is to bear in mind that *"any separate, parallel, segregated activity inadvertently sends harmful messages and, or reinforces prejudicial stereotypes: 'they' (people with disabilities) don't belong, aren't good enough, should be with their own kind, and more. In addition the apparent 'success' of any separate program breeds more of the same, as others think this must be the 'right thing to do.'*

Segregated groups and separated activities often start when we, as supporters have low expectations of the person's right to be in their community and the contribution they make when given a chance.

Separate groups are often set up in an attempt at kindness, based on the belief that children should be able to experience ballet or basketball or school but that they will not be able to

participate in the local existing groups and that their presence in those groups will slow down or hinder the progress of other children. We are worried that the child with disability will be teased or bullied. We tell ourselves and each other that community is not safe and that people are cruel. All of this can be true however opting for the false 'safety' of separateness and invisibility is not the answer. The energy and resources it takes to set up a separate world could be better directed to supports and safety nets in the community. "Inclusion occurs when we make excuses for why inclusion is not possible."

The alternative is to assume that the person belongs and will be present in their local places. Evidence shows when this message is communicated confidently more people than we might expect will accept that point of view and welcome the person. Ann Greer observes that most people are very happy to see people with disability present but they are not proactive in being welcoming towards them. She also suggests that some information on how people can be helpful equips them to be more welcoming.

People with disability do not learn better, are not necessarily happier and certainly not safer when they spend their lives in separate activities. There is also a lot of evidence of the increased happiness and self-confidence of people with disability who know they belong. An article written by Deanna Parker talks about the changes she observed when the person she supported was included in the local school.

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We need to remember that the things that make life good for people – acceptance, belonging, love, meaning – are the same whether you have a disability or not. Rob and Virginia Lonsdale describe how the local scout groups welcomed their son but also served as a launching pad to other community connections.

We are not talking about situations where people with disability choose to spend time with friends who also have disability who have shared life experiences, interests and hobbies. As Kathie Snow says "the issue is when we create separate, parallel segregated activities and call these inclusive; and in the process exclude people with disabilities from ordinary and truly inclusive activities.

As supporters, when we find a welcoming place in community, it can be tempting to want to direct everyone with a disability to that place, thereby compromising the experience for everyone concerned. Kathie Snow shares the idea of natural proportion as a litmus test of inclusion. She suggests that an inclusive environment is one that reflects the "natural proportion" of people with disabilities in our society, so if the percentage of people with disabilities is greater than the natural proportion in any environment or activity it is not inclusive; it represents an artificial environment.

With this in mind, we need to understand our role as families; friends and workers, as we 'ask' on behalf of a person and our writers have useful reflections on this. Our writers recommend starting, or staying in the local and ordinary world when children are young as everyone is learning about where people belong at that stage. It's important for the child with disability but equally important learning for children who don't have a disability. Virginia and Rob Lonsdale are clearly very thoughtful and strategic about what they want for their seven year old son and how they can help him to be known and valued at school, in the neighbourhood and at Scouts.

We have grown up in a world which has normalised the segregation of people with disability and denied us all the opportunity for relationships to develop. We need to think differently if we are to counter this. The general community is not accustomed to welcoming people with disability so our role of inviting them into relationship is a critical one.

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A number of writers also note that our workforce needs to change to support people to be included.

As a service manager, Ann Greer reflects that when supporters portray the person they support as needy and deficient, rather than attractive and competent, it denies the community the opportunity to see people with disabilities as gifted, talented and attractive human beings. She recommends supporters to look at the persons strengths, passions and interests and use these as the platform to ask on behalf of the person with disability. Deanna Parker recognizes the volume and value of preparatory work needed to increase the chances of success but cautions against waiting for the perfect time. Her article also reinforces the importance of having people work together.

Peter Gregory highlights the need for supporters to understand the organisational blocks to inclusion and to reflect on their role in this - whether as a support worker or manager, or even as a family member.

As we reflect on what each of us can do to make the promise of inclusion a reality for all people with disability. This editorial and other articles in the Community Resource Unit newsletter (CRUCial Times—issue 51) remind us that it wont just happen. It requires more than us just liking the idea of inclusion and hoping it will happen. Reversing the habit of inclusion will require each one of us to be very clear, strategic and thoughtful about who we ask, how we ask and what we ask for.

Margaret Rodgers
Chief Executive officer

There are a number of excellent supporting articles that go with Margaret's article in the CRUCial Times.

These can be found Online -
<http://cru.org.au/crucial-times-51-inclusion/>

Ironically this protection for a perceived vulnerability has left many people with Disabilities profoundly vulnerable

Big mud Puddles and yellow dandelions

When I look at a patch of dandelions, I see a bunch of weeds that are going to take over my garden.

My kids see flowers for mum and blowing white fluff you can wish on.

When I look at an old drunk and he smiles at me, I see a smelly, dirty person who probably wants money and I look away.

My kids see someone smiling and they smile back.

When I hear music I love, I know I cant carry a tune and dont have much rhythm so I sit self consciously and listen.

My kids feel the beat and move to it. They sing out the words. If they dont know them, they make up their own.

When I feel the wind on my face I brace myself against it. I feel it messing my hair and pulling me back when I walk.

My kids close their eyes, spread their arms and fly with it, until they fall to the ground laughing.

When I see a mud puddle I step around it. I see muddy shoes and dirty carpets.

My kids sit in it. They see dams to build, rivers to cross and worms to play with.

I wonder if we are given kids to teach or learn from? No wonder god loves the little children!

Enjoy the little things in life, one day you may look back and realize they were the big things.

I wish you big muddy puddles and sunny yellow dandelions!

Author unknown

Views from within: A reflection on institutionalisation

The issues of congregated and segregated living are highly relevant to me: I have spent fifteen years of my youth in a variety of institutional settings and the last fifteen years of my adult life living within my community. These experiences leave me very clear about what constitutes a real life. I want my life to be rich with experiences. Being isolated, congregated and segregated did not afford me ordinary experiences liked being loved, making a meaningful contribution to my community, working and seeing different places; I missed out on many things that help a person grow.

Many families face difficult decisions in providing the best possible care for their sons and daughters with disabilities, as well as trying to meet the needs of their other children or siblings. My family's decision to send me to an institution was based on my need to be educated and to have access to therapy services. This meant that I was separated from my family for the school year. In turn, it limited my ability to contribute to both my family and my community.

Often when we think of institutions we think of large buildings, built on the edge of town, filled with hundreds of residents. We assume that the absence of these monoliths means an absence of institutional practices. Yet many of our current support models, including group homes, innovative housing, and the alternative living service are simply smaller institutional systems. It is not so much the dwelling type but the systems we choose to use within them which can inhibit the residents' lifestyle opportunities.

Regardless of their size, institution - like settings are lonely places. The physical design can be clinical and sterile in nature. The workers are often unfamiliar to the residents and are often seen as rented strangers by residents or tenants. The environment in these instances is simply not welcoming and conducive to social interaction and meaningful relationships with people of our choosing.

Many institutional settings are not located well in relationship to other community facilities and services. This means it can be harder to pop out for a loaf of bread or to meet people down the street. These services tend to dominate peoples lives. They can act as a one stop shop encompassing most or all life domains.

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Views from within: A reflection on institutionalisation - continued.

Institutions are extremely regimented by design and will often meet industrial requirements before meeting the needs of people they claim to serve. It is therefore not surprising that people in these circumstances might begin to exhibit so called 'challenging behaviors'.

As individuals, we like to believe that we have a certain amount of autonomy to decide the functions, activities and stimulus that occur in our lives from day to day. People who are congregated and segregated are often withdrawn from such liberty and instead receive case managers and programs. The types or even the quantity of activities offered may be shaped not by the persons preferences, but by how rosters are developed and implemented. Every detail of activity is documented, scheduled and prescribed, usually by other decision makers.

Congregated and segregated settings also deny people opportunities for social interaction. In the institution, I was not allowed from the premises unless I was in the company of an adult, nor was I able to bring friends to the premises. Other than school holidays we had three outings a year to various tourist destinations. By contrast I now have the independence to decide with whom I interact, how often and for what purpose. This is what I call autonomy.

Another common experience in institutional settings is the long periods of time of inactivity, or time wasting. The routines are so focused on meeting functional needs such as eating toileting, or showering, that little attention is paid to development needs like having fun, learning or developing social skills. The contrast for me now in the community is that I am constantly finding new ways to have fun, readily learn through education and employment opportunities, and socially I am able to do the same as my peers.

My experience in institutionalised settings have led to my fundamental belief that everybody has the right to participate within his or her communities, including both social and economic participation. Where we live, how we live, and with whom we live are individual choices. We survive with a disability or disadvantage; these should not be the predominant drivers that determine a decent life.

Nigel Web

What makes a good advocate?

The most important thing about any Citizen Advocacy relationship is the quality of the "match".

Once we have identified the needs of the person with disability who needs support, we can determine what qualities, skills and life experiences are likely to be desirable in a potential advocate.

Almost always things like gender, age and where you live are fundamental considerations when finding the right person to play a specific role in someone's life. Experience tells us that if we get these basics wrong, the relationship has little chance of working out.

Beyond that, it is very much whether you have the:

- Personality
- Attitude
- Character
- Personal Experiences
- Professional Experiences
- Life Skills

We will spend time with you, talking about you and your life experiences and gaining an understanding of what you might bring to a Citizen Advocacy relationship.

- We **don't** require any formal qualifications or training.
- We **don't** specifically seek out people with previous experience in caring professions or human services.
- We **don't** look for people who know a lot about disability.
- We **are** looking for people with a sense of social justice.
- We **do** want people who are willing to make a long term commitment.

The specific knowledge and understanding you need to have in order to undertake a role as a Citizen Advocate will be provided through the Orientation process and the ongoing support of the Citizen Advocacy staff.

Do you know someone that could be an advocate?

Do they have the right qualifications?

If they have a good heart and belief that all people wish to be treated with dignity and respect, then the answer is 'yes'. No specific or formal qualifications are required; indeed many citizen advocates have no previous experience of people with disabilities.

Citizen advocates are ordinary people, doing ordinary things of EXTRAordinary importance.

Do they have enough time?

Yes! Many citizen advocates work full time and weave the role into their busy lives. In the office we carefully match the time availability, interests, gender, location and resources of a potential advocate with those of a person with disability. (We don't want to set anyone up to fail.)

Can they commit?

Only they know that! To avoid a potentially wounding experience for the person with disability, being a citizen advocate does require a long term commitment (some of our matches having lasted for decades). Not everyone can make that commitment but do please ask us about other ways to help (some shorter term roles and or crisis roles)

**You may be only one person in the world,
but you may also be the world to one person!**

Upcoming Events

Morning Teal

An opportunity for us to come together, meet each other, share knowledge and experiences!



First Thursday of every month
(next one being Thursday the 1st February
between 10am and Noon.

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

What is intellectual disability?

The term Intellectual Disability refers to a wide range of conditions such as Downs Syndrome and autism. The disability may be apparent at birth or become apparent during a later stage in life when a person is developing.

The causes of Intellectual Disability are varied. Whilst it is true that some forms of Intellectual Disability can be genetic, result from an injury at birth, occur during the pregnancy as a result of the mother contracting a virus or having dysfunctional metabolic functions, there are many unknown causes.

What we do know is that the environment and social systems in which a person with an Intellectual Disability lives, works, goes to school and the role of family, friends and services are strong influences in either enhancing or restricting their growth and development as competent and independent members of our society.

We also know that like everyone else, people with Intellectual Disability have emotions and feelings, need support and love and will respond to different people and situations in varied ways. In a nutshell people with disabilities cannot be categorised as responding in the same ways and developing at the same rate.

If a person has an Intellectual Disability it may be that:

- Their ability to express themselves verbally and in writing could be at a reduced rate or below that which is considered to be a reasonable level of communication skill.
- Their listening skills and/or capacity to fully understand what someone else is saying to them may be impaired.
- Their perceptual and intuitive skills may be limited which results in poor judgement on what is appropriate or inappropriate behaviour, dangerous and/or unacceptable situations.
- Their capacity to form relationships and reciprocate within those relationships may be limited, but it must be recognised that there are many people with Intellectual Disabilities who respond with great affection and have good interpersonal skills.
- They may, though not necessarily, be unable to perform personal care activities such as personal hygiene, dressing and feeding without some support or guidance.

Understanding another person better

These questions provide one basis for clarifying and organising one's understanding of another person's history, situation, and needs. Keep these questions in mind as you get to know the person with a disability for whom you will be an advocate.

What relationship does this person have with his/her natural family? At present? Throughout his/her life?

What set of roles does this person have in his community? How have these roles changed over the last few years?

Who are this person's friends? What sorts of things does he/she do with them?

What relationships does this person have with people who don't have identified disabilities (e.g. neighbours, church members, co-workers, fellow learners, etc)?

What contributions does the person make to other people's lives?

What are this person's greatest competencies? Which of the person's skills and attributes are needed and wanted by others?

How do members of the public respond to this person? Is he/she vulnerable to any negative stereotypes? How does the person presently manage potentially stigmatizing characteristics?

What has this person's life experience been like? Where has he/she lived? What sorts of work has he/she done? Where was he/she at school and what sort of education has he/she had?

What future(s) does this person look forward to? What are his/her dreams and aspirations?

What sort of decisions does the person make? Which values does the person seem to relate to in making decisions?

What does the person enjoy doing? How can you help their life be better?

The Value of just being there ... for each other!

Human relationships have seasons, high and lows, ebbs and flows. The protégé-advocate relationship is no different. Advocates will frequently and repeatedly grapple adverse life matters which often make it challenging to maintain their connection with and involvement in the life of their families, friends and ultimately their protégé. However relationships formed via Citizen Advocacy, unlike other forms of advocacy are akin to the organic relationships formed with family and friends. That is, the Citizen Advocacy model facilitates long term and even occasionally lifelong relationships between and advocate and a protégé.

It is this element of the Citizen Advocacy model which recurrently proves invaluable. As the majority of the trials and tribulations which may transpire in our lives when, viewed in relationship to the timeline of ones life, whilst varying in intensity are generally short lived. Recently I waded through what I identify as being the most distressing occurrence to have transpired in my adult life. The breakdown of a relationship which resulted in the loss of a greatly valued friendship. The ramification of this permeated throughout every fiber of my being and every aspect of my existence. Nothing mattered. Friendships were forgotten. Weight was lost. Little energy was put into anything. Especially not relationships with those I once enjoyed the company of. After all, what did I have to offer anybody? Especially my friend and my protégé? I didn't call my protégé for our biweekly chat. Days turned into a week. A week into a few.

My protégé after not hearing from me for some time, initiated contact. What was I to say? Sorry came out a lot. Then the truth poured out. He wasn't angry that I hadn't been in his life. He missed me. Me?! After this the realisation dawned on me. Sometimes all I had to do was just be there. Like he was for me Waiting

Through all the seasons, the highs and lows, ebbs and flows. There are going to be times when I feel no use to my protégé but sometimes all it takes is a phone call and some honesty. I had discovered the greatest tool employable to the problems encountered in the course of an advocate/protégé relationship - is perseverance. To this day I utilise this lesson as there have been times since where I have felt less than up to the job but I always just make that call and simply say G'day.

(Written by an advocate)

The real world

In the real world, people die for their freedoms.
In the field of human services, they hold conventions
or invite each other to conferences.

In the real world people learn from each other,
help each other, and protect each other,
In the field of human services one must be
Licensed to teach, certified to treat and commissioned to protect.

That which is considered good about the real world
naturally unfolds.
That which is considered good about human services
is professionally controlled

Citizen Advocacy cannot offer you riches,
But it can offer you the chance to change the world
for a person with a disability,
'One person at a time'.

Pumpkins are pumpkins, aren't they?

By Eileen Roth

Pumpkins are pumpkins, aren't they? Well maybe not. After a recent event I've had to rethink how I perceive them. At least one of the ones I've been given was solid gold. At least that was what it was worth to me. You see, I help out at a haven for men who are down on their luck and about 18 months ago I noticed a man who kept himself apart from everyone else. When he had money he drank it and seemed to have lost interest in everything. Every Tuesday morning when I went in I would look him up and stop for a few words and every so often I would slip him a few extra bikkies to have with his morning tea.

One morning when he seemed a bit more receptive than usual, I handed him the biscuits openly and appointed him official cookie taster. Of course the other men paid us out severely but it got a grin out of him. After that I started noticing little improvements. He started shaving on a Tuesday morning and even combed his hair. Eventually he got himself together to rent a little flat and even acquired a cat. I like cats too so now when we meet we have something common to talk about.

Back to Pumpkins Now that he has a flat he also has a neighbor with whom he has made friends and someone gave him a second hand bike. Apparently his neighbor likes gardening and planted a pumpkin vine which produced several fine healthy pumpkins. Being a nice kind person he gave two of them to my friend who promptly put one of them in a shopping bag, hopped on his bike and brought it down for me. He was so happy to have something to give to me and I was thrilled that when he had something to give (probably for the first time in many years) that he saw fit to give it to ME! Pumpkins aren't just pumpkins mate! They can also be a gift from the heart and therefore worth much more than gold.

Citizen Advocacy is bittersweet. Witnessing the depth of how people have been hurt in life, and at the same time appreciating the capacity of the human spirit - for the fullness of life and love, is bitter and sweet. The bitterness of the pain and suffering in people lives is matched only by the meaning that is found in sharing both joy and sorrow.
Tom Kohler

Friendship

It may seem obvious how fundamental the need for friendship and connection is,

and one could ask why we even need to talk about this. The stark reality is that many people with disabilities are lonely.

For some, the only people who really know and appreciate them are family members. Others have no one in their life other than people who are in a paid capacity

People at risk of being devalued need opportunities to develop real friendships with ordinary members of the community.

Such friendships enhance their image and their competence, and improve the quality of both people lives.

Society has a tendency to look out for the community at large rather than looking at an individual and their issues.

Will Campbell said that we put in a global sprinkler system while the person next to us is dying of thirst.

Citizen Advocacy is about giving a cup of water and letting others organize the sprinkler system.

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 – VW
- 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.

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.

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Board Members are

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Vice chairperson
Ronda Quin -

Treasurer
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Andrew Barton -

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Program Coordinator -
Donna Duncan

Assistant Coordinator -
Les Pearce

Administration Assistant -
Rachel Irvine

“Attacking people with
Disabilities

Is the lowest display of power
I can think of”

Morgan Freeman