

## NEWSLETTER DECEMBER 2016

### CHAIRPERSON

Hello everyone

Christmas and New Year greetings to you all. It was wonderful to see many of you with your protégés at the Citizen Advocacy Auckland Christmas party a few weeks ago.



The Board was sorry recently to accept Kevin Rogers' resignation, due to ill health, after 25 years faithful service to Citizen Advocacy Auckland. We will miss his considered comments, enthusiasm and humour at meetings but look forward to seeing him often.

Wishing you all safe and happy holidays.

Regards Debbie  
Chairperson Citizen Advocacy Auckland

### COORDINATOR

#### *Professional Development in Australia*

In November I was fortunate to participate in an evaluation of Capricorn Coast Citizen Advocacy in Queensland under the leadership of John Armstrong. Immediately afterwards I joined a two day Citizen Advocacy study group with people from Citizen Advocacy programmes all across Australia. Topics presented and discussed included crisis advocacy, programme independence, advocate and protégé recruitment, what Citizen Advocacy is not, positive interpretations of impaired people.

I will share more detail in 2017 newsletters. Meanwhile here are a few basics of which I was reminded:

- The importance of Citizen Advocacy programme independence - of services and other potential influences.
- Advocates act independently of services, the Citizen Advocacy programme and family.
- Vulnerability is defined as the potential for bad things to happen and is related to lack of relationships, being alone, isolation.
- The powerful preventative effect of having an advocate - at the extreme, an advocate can prevent their protégé from being made dead.

- For this reason it is vital that all the people in a protégé's life are aware they have an advocate.
- Although the programme and citizen advocates defend rights, we do not focus on a rights based approach.
- Our primary focus is on promoting and protecting the interests of people whose wellbeing is at risk. As Dr Wolfensberger said, "You can die with your rights on."

Both events provided me with the opportunity for huge learning to bring back to our programme. Thanks to the board of Citizen Advocacy Auckland for supporting me to develop my knowledge, understanding and skills in this wonderful programme. I also strengthened our connections with CA coordinators, board members and friends of CA. Paula, the coordinator of Citizen Advocacy in Adelaide, and her husband recently stayed with me as they embarked on a trip around New Zealand.

### *"Susan's Holiday"*



A big thank you to Susan and Sue for allowing us to show the documentary film "Susan's Holiday" at the Christmas party. This professionally made short film is about Susan's first trip to the snow in Tongariro National Park that she took with Sue and family recently. Susan and Sue described the planning and saving involved and noted within the trip a number of additional 'firsts' for Susan such as eating breakfast out in a cafe, and staying a night in a motel. The film was very well received (note enthralled faces glued to the big screen) and many people said afterwards how inspired they were.

### *Thank you and Happy Christmas*

Thank you to the Board, advocates and friends of Citizen Advocacy Auckland who have been on hand to support me in my first year in the role. Best wishes and Happy 2017 to you all! I look forward to initiating more follow along with advocates and providing you with any support in the background you would like to help you improve the lives of your protégés. Advocates - please contact me!

### *Instrumental Advocacy in Qld with a New Zealand connection*

While in Queensland, Rhonda, an advocate and board member at Sunshine Coast Citizen Advocacy told me about her journey with her protégé Maggie. It is a beautiful story of life-changing expressive and instrumental advocacy. Rhonda started out getting to know Maggie over a weekly cup of tea. She observed Maggie's difficulties with eating and initiated changes that also gave Maggie choices in what she ate. Over time she saw that Maggie was attracted to action sports rather than the sedentary craft activities she had been offered and she tried jet skiing and other thrilling pursuits. Rhonda became Maggie's legal guardian and eventually located her long lost family in New Zealand. The article below, published in the Community Resource Unit newsletter, is a summary of this amazing story. Uplifting holiday reading!

Jules





# Forming friendships and finding family

Ronda Quinn

**Ronda Quinn** is a retired Inclusion Teacher who lives on the Sunshine Coast. Her business card lists her job as 'Possibilitarian.' She believes people at risk of being devalued by their community need opportunities to develop real friendships with members of their local community. She has been an advocate with Sunshine Coast Citizen Advocacy for six years.

## Forming friendships and finding family

While driving home after a long working week my tired mind began tuning in to snippets of a dialogue on the car radio. The phrases I heard intrigued me: "being a loyal and accountable advocate and promoting, protecting, defending the rights and interests of people who have intellectual disability." My ears pricked up with curiosity. The speaker was Bob Lee, Coordinator of Sunshine Coast Citizen Advocacy. What I heard about in that radio discussion was the respectful nature of a mutual relationship that could develop over time, empowering both parties.

I contacted Bob Lee and we had a lively discussion on the principles of advocacy. He explained the goals of Citizen Advocacy: to take actions which result in a better life for the person with a disability, to give them a fair go and to be treated with respect as valued members of our community. I signed up.

During advocacy orientation I learnt that having an advocate could position a person with disability in a place of equal status with the other parties involved in their lives, such as their service provider or the Department of Disability Services. It is the task of the advocate to vigorously represent the interests of the person with disability to those third parties. People with intellectual disability and limited informal networks may need an advocate to act on their behalf due to their weakened ability to represent themselves to other parties, who may have no understanding of the person's needs or wishes.

Citizen advocacy could involve representing a person's best interest in making formal appeals, for example, to a medical specialist, a housing department or a service provider. When a person's life decisions are in the control of third parties, he or she is susceptible to things going very wrong. An independent, unpaid advocate who has no divided loyalty or conflict of interest can act on their behalf during a crisis when uninformed decisions are being made that may have a detrimental effect on the person's life.

By having a deep awareness of the nature of the person's vulnerability, an advocate can also act in advance to prevent crises from arising. An advocate commits to a long term relationship with their charge which enhances trust.

I was matched with Maggie in November 2009 and from our first meeting we just seemed to click. Although Maggie is unable to speak she can make herself understood through gestures and facial expressions indicating a yes or no response. I was immediately aware of her strong sense of self and her desire to be in charge of her own life. We started getting to know each other through weekly visits to her house for a cuppa.



There was little information about Maggie other than that she had been in an institution overseas as a child and was informally adopted by a person who brought her to Australia. On that person's death, Maggie was vulnerable, alone with no support and had no voice to represent herself. We talked over what we came to call "me being her person in her corner" and we began building a connection and a loyal friendship.

During visits I began to gain some insight into what Maggie was up against. I realised I had never had to deal with the kinds of things she had to deal with on a day to day basis. It wasn't just a matter of poor treatment and lack of choice. I saw that she was never going to get to experience the things I got to experience. I decided I would need to stay involved over a long time, taking action to ensure things did not go wrong for her.

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Maggie had some urgent and practical needs which I talked over with her. I had observed that she had difficulty swallowing and drinking liquids and was at risk of choking. I bought her a container of thickener for liquids and asked workers to cut up her food into smaller portions. Eating and drinking was then safe and more pleasurable. Even seemingly small changes can result in a much safer and better life; I made a simple book of photos showing options of food and activities and she demonstrated her ability to make choices to her support workers. She began to vocalise loudly when workers did not use her book and allow her to choose. Maggie had found her voice and decisions would no longer be made without her regard.

Our relationship grew into a mutual friendship. We often went out together for coffee and lunch. Maggie made it clear that she enjoyed my company and welcomed my friendship and support. She also made it clear that what I enjoyed doing was a bit tame for her and it wasn't long before she began requesting we do more interesting things together. While on a riverside picnic she saw a jet ski and requested a turn and then another and another. I have come to know her as a person who loves the feel of speed and enjoys risk-taking sports. Instead of the craft-based activities she had been doing for years Maggie now goes swimming, surfing, wheelchair-dancing and sailing instead.

With my support Maggie lodged a complaint against a service provider and was able to select a provider more suited to her needs. As time went on we dealt with her protracted tenancy matters and had funds released for her to go on holidays.

Over the period of six years that I have known Maggie, I have become more able to predict the unique and special features of her needs and Maggie has built her trust in me. Our long term advocacy relationship and friendship became a bridge from the devalued world into the valued world. As our relationship developed, it was natural that Maggie's circle would grow as my family and friends got to know her. Maggie began to flourish. She started using an iPad to communicate and has her own Facebook page. Together we worked out a plan to start addressing her desire for a relationship. She bravely invited a male friend out on a date to the movies and they are now enjoying each other's company on romantic dates as partners.

Being wanted, needed and loved was something Maggie yearned for. As an adopted person who was unable to tell her story she longed to belong somewhere and to someone, as she once had in her childhood. Her cultural heritage had been lost to her long ago when she came to Australia and yet she remained emotionally connected to New Zealand through music.

On April 19th 2014 I was granted legal guardianship of Maggie and we celebrated with friends over a glass of champagne. Guardianship allowed us to explore further dimensions of Maggie's life without requiring the consent of a third party. I sent out certified copies of the guardianship order to a variety of government agencies requesting any documentation of Maggie's background and arrival in Australia.

Maggie had told me she could remember her family of origin and yet there

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was no paper trail of her heritage. A chance comment led me to a copy of an extract of entry for her birth. It showed that her family surname was not registered at her birth; however, it did contain the name of both of her parents. An internet search led to a descendant's page and contact with Maggie's ten siblings was made. Unfortunately both of her parents had passed away but her siblings were overjoyed to be reconnected with their sister who had been taken from them 38 years before. Maggie always knew who she was and who she belonged to. She had waited patiently for me to find out.

Recently Maggie and I flew home to her family reunion which was full of tears and joy. Maggie is now making arrangements to live near her family permanently. She is taking legal action to have her family of origin surname recognised as her legal surname. At last she has family photos to put on her wall, sisters and brothers to Skype with and family plans to make. I look forward to relinquishing my guardianship to one of her sisters.

When Maggie no longer needs me to be her advocate I will have an enduring role in Maggie's life as her friend. I see her as a gifted and unique person of extraordinary strength. I have gained much from our friendship and our relationship will continue to be reciprocal. I have grown as much as she has or perhaps even more by knowing her. She and Citizen Advocacy have taught me what's important in life. Who else gets the opportunity to do what she allowed me to do? I was not just a trusted friend; I got to act as a moral activist on her behalf.

Footnote from Jules (December 2016):

Maggie now lives in New Zealand near her family. She loves and is loved by her extensive whanau. Rhonda and Maggie remain close friends.