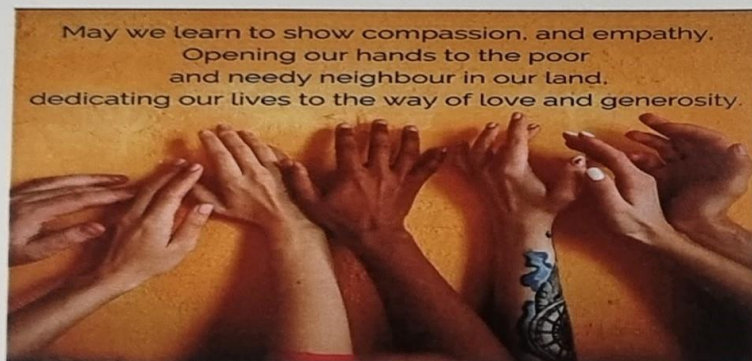




One of the greatest gifts anyone could
give another person
is to....

Have true belief in them



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Up to half the deaths of people with intellectual disability are preventable—Denial of hospital treatment

Jacob was 15 when he was first denied hospital treatment because the nurse didn't see the value in his life.

"When Jacob has to go to hospital we just don't know who is going to be there. We don't know if they are going to have a bias against people with disability." Linda, Jacob's mum.

Ask our politicians to back the National Roadmap for better health for people with intellectual disability.

Make sure you Like and Share this Video with everyone to help us End Deadly Disability Discrimination! See the video and find more information and how you can help on our website: <https://bit.ly/3LTK1j1> (copy and insert into search)



#enddeadlydisabilitydiscrimination #DeadlyDiscrimination #Budget2022Disability #DisabilityHealth #RoadmapActionNow #DisabilityAwareness #auspol #nswpol#CouncilforIntellectualDisability #CID

Why Citizen Advocacy is Important

People with intellectual disability are especially vulnerable to many bad things happening in their life because of a poor capacity to foresee the consequences of actions while at the same time being held in particularly low status in the eyes of western society as indicated by the extremely low expectations society generally holds towards such people. These low expectations might be generally said to reflect the rejection felt towards someone with an intellectual disability and the many negative images and ideas that accompany such rejection from within the minds of other people. Many bad experiences can befall a person because of the negative impressions and expectations of others.

This becomes a self-fulfilling prophecy starting with the negative ideas from almost everyone one encounters that plays itself out in real life events: being treated as an eternal child and other negative roles, being surrounded by other negative images that strip one of human qualities, having every aspect of one's life controlled by other parties even to the point of losing freedom, losing touch with the culture and learning mostly about what is strange and peculiar, but not knowing very much about what is ordinary and typical; having most-even all- of one's relationships with frequently changing and paid people; experiencing many events that can facilitate ones death.

These events are so negative and leave such dramatic social, emotional and sometimes physical scars, that they can be said to constitute "wounds".

Wolfensberger, W. (1992) The New Genocide of Handicapped and Afflicted People (3rd Edn) Syracuse, NY; and 2) Wolfensberger, W. (1998). A brief introduction to Social Role Valorization:

A high-order concept for addressing the plight of societally devalued people, and for structuring human services

This link to a short documentary about Citizen Advocacy from experienced leaders in Citizen Advocacy including the

originator of Citizen Advocacy, Wolf Wolfensberger.

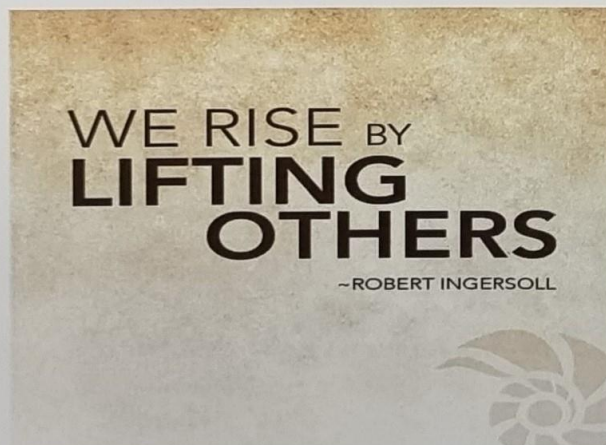
https://youtu.be/95vwvOb0_cI

These potentials and actual experiences leave this group of people especially vulnerable because they are not in a strong position to solve and resolve these events themselves, nor do they have other relationship commitments to do so; hence the need for Citizen Advocacy. (definition by the International Citizen Advocacy Safeguards Group in 1990)

Citizen Advocacy is a means to promote, protect and defend the welfare and interests of, and justice for, persons are impaired in competence, or diminished in status, or seriously physically isolated, through one-to-one voluntary commitments made to them by people of relevant competencies.

Citizen Advocates strive to represent the interests of a person as if they were the advocates own; therefore, the advocates must be sufficiently free from conflict of interest.

Citizen Advocates are supported by the Citizen Advocacy office, and choose from a wide range of functions and roles. Some of these commitments may last for life.



Freedom and Responsibility: Why Advocate Independence is Crucial in Citizen Advocacy Adam (A.J.) Hildebrand

Citizen Advocacy relies on the watchfulness of individual citizens who will promote justice for vulnerable people. To be truly watchful and vigilant, citizen advocates must be independent. Citizen Advocacy puts its trust in competent, valued, independent citizens who are not afraid to speak up and be heard.

People with disabilities and other devalued people often have a variety of people and organisations that exert great influence over their lives, such as family members, service providers, or even friends. The reason why advocate independence is so important is that there are always some competing interests in any given situation. A conflict of interest does not necessarily mean that one person's interests are valid and another person's interest invalid, or that one person is good and the other bad. Two parties may both have legitimate interests that compete with one another. For example, a residential service provider has an interest in providing a service at a reasonable cost so as to stay within an agency budget, and yet one or several of its residents may need extra support beyond what the agency can afford. Another example is that agencies have an interest in protecting their reputations, so incidents of abuse or neglect by a service-providing agency might not receive public attention.

Advocates need to be aware of such conflicts, and promote the interests of the protégé when those interests are at risk of being compromised. It is therefore important that advocates be independent of the agencies and service providers who have controlling interests in the lives of protégés. Another feature of advocate independence is that advocates are independent of the protégé's family and friends. This kind of independence sounds counterintuitive, as the province of family responsibility towards vulnerable family members is almost sacred ground. However, not all families in all circumstances or at all times act in the best interests of a vulnerable family member. Being independent of the interests of a protégé's family (or of a service provider) does not necessarily mean that an advocate has to have an adversarial relationship with them. When a family does have the best interests of its family member at heart, an advocate can represent the interests of his protégé in ways that help the protégé's perspective to be seen and heard.

Sometimes it takes an “outsider” to help the family see the protégé’s point of view. This does not necessarily mean that a family is ill-intentioned; For example, a family member may be exhausted from keeping vigil at a hospital or nursing home and needs to get some rest — which competes with the protégé’s need for someone at the bedside.

A more worrisome example is when a distraught family member of someone with complex medical needs might regard the person who is suffering as “better off dead.” A family member may even say something to that effect, although the words uttered in such situations are rarely so stark. One may instead hear phrases like “low quality of life” or “she would not have wanted to live this way.” In our present medical culture, such words are sometimes used to justify inappropriately withholding or withdrawing needed treatment or even food and water. Most conflicts of interests in families are not so dramatic, and may involve what freedoms a person is allowed, or how someone’s money is handled, planning (or lack of it) for the future, and other concerns that fall within the domain of family life.

A word of caution: families have always been — and for most people will continue to be — a primary source of support. An advocate needs to tread lightly before interfering in a family’s business, but there are times when someone outside the family needs to raise a voice on a person’s behalf. Ideally, this is done by someone who has relevant standing in a person’s life — an advocate whose relationship is tried and true.

The independence of advocates means that advocates have the freedom, and the responsibility, to decide whether or not to become an advocate, what they will do, and when they will do it. However, advocate independence does not mean that advocates are left on their own without support. Citizen advocates should be able to rely on competent, knowledgeable advice from their local Citizen Advocacy office, and at the same time be free to make their own judgments.

From: Hildebrand, A.J. (2004). One Person at a Time: Citizen Advocacy for People with Disabilities, Brookline Books, MA. Adam (A.J.) Hildebrand was a Citizen Advocacy co-ordinator and editor of the Citizen Advocacy Forum.

Why Citizen Advocacy Relationships Are So Important

Adam (A.J.) Hildebrand

Freely-chosen relationships have great significance for people with disabilities, as they do for everyone. When a family member, neighbour, friend, church member, co-worker, is committed to a person with a disability, life tends to go better for that person. The presence of someone willing to look at the world through the eyes of a person with a disability and who will act from that person’s perspective can influence what kind of life that person will have. Sometimes, the presence of an ally is the difference between whether a person lives or dies, such as when a devalued person who is highly vulnerable is in a hospital or nursing home.

We have discovered through our work in Citizen Advocacy that there are people in our community who can and will strive to make a difference through a personal, committed alliance with a person wounded by social devaluation. There are people who, given the opportunity, will use their common sense, get involved, and share their lives.

I do not imagine a utopian world where life is comfortable and good for everyone, but promoting voluntary commitments between people with and without disabilities is one way of helping people find hope and meaning in their lives. On their own initiative, or through Citizen Advocacy and similar relationship making enterprises, ordinary people from all walks of life have refused to allow the world to convince them that some people are less valuable than others. Through Citizen Advocacy, people around the world have made personal commitments to their fellow human beings with disabilities and have discovered that “they” are us.

From: Hildebrand, A.J. (2004). One Person at a Time: Citizen Advocacy for People With Disabilities, Brookline Books, MA. Adam (A.J.) Hildebrand was a Citizen Advocacy co-ordinator and editor of the Citizen Advocacy Forum.

National Standards for Disability Services

Making sure that people with disability receive good quality services.



Standard 1: Rights

You have the right to be treated fairly when you use disability services.



Standard 2: Participation and Inclusion

You can take part in the community and feel included when you use disability services.



Standard 3: Individual Outcomes

Your service supports you to make choices about what you want to do. You can work toward your goals.



Standard 4: Feedback and Complaints

You can tell people what you think about the services you receive.



Standard 5: Service Access

Finding and using services is fair. You can access the services you need.



Standard 6: Service Management

Disability services should be managed well.

An important principle of Citizen Advocacy - Clarity of Staff Function.

We have looked at Citizen Advocacy program positioning advocates to be as clearly independent as possible, thus protecting their activities from coercion and the potential for making adverse compromises.

Another set of safeguards against the undermining of advocate capacity is via the role of staff. Staff (coordinators) are to perform functions that support rather than compromise the strength of the citizen advocate. For this to occur, the boundaries that separate a staff role from that of advocates is needed. For instance, staff might be drawn into attending a meeting for and on behalf of an advocate who can't attend, but such efforts only serve to undermine an advocate's role. If an advocate can't attend a meeting, then the meeting date/time gets changed to one where they can!

Having clarity regarding the function of staff ensures such boundaries do not get over-stepped, to the detriment of a citizen advocacy relationship. It's the staff role to focus on the wellbeing of the program overall in building and supporting many good matches. In contrast, citizen advocates maintain a focus on the needs of their protégé. Building an effective and diverse program that represents the broad array of people needing advocacy is a fulltime job. But staff, in learning about individual protégé's can sometimes be tempted to start intervening in a prospective protégé's life, rather than recruiting and orienting a citizen advocate who can do that in a much more capable, independent and sustainable way.

Another staff function related rating, considers whether staff, as part of their paid function, become involved in performing other forms of advocacy. People's experiences and needs can extend beyond the capacity of any single approach, and so a tempting solution is to launch other forms of advocacy activities, for example, systems advocacy or direct paid advocacy. We are not saying that these or other forms of advocacy are not worthwhile, only that trying to undertake such activities by the same staff performing a citizen advocacy function, will usually result in an inability to make many or even any, good matches.

Sadly, these events are the very thing that have led to the closure or cessation of many Citizen Advocacy programs in Australia. For so many prospective proteges, this has meant the loss of their best and only chance for having a freely given relationship with anyone, but also in this case, a valued defender.

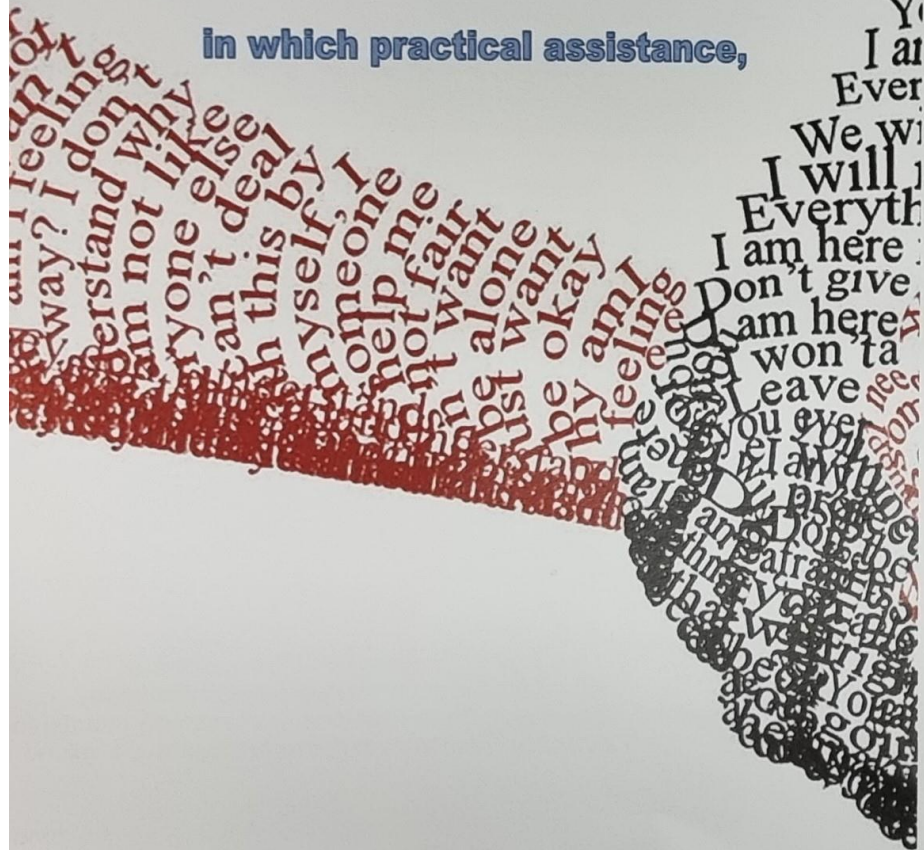
Typically, 'the easy' drives out 'the hard', and for Citizen Advocacy to be done well, it needs the full attention of people who are not diverted into other, perhaps easier forms of advocacy.

Citizen Advocacy respond to neglect,

vulnerability and loneliness by encouraging

and supporting lasting relationships

in which practical assistance,



support and friendship
can result in richer,
safer lives for people with
intellectual disability

Citizen Advocacy Stories -

Some examples of what citizen advocates do?

A Citizen advocate has helped his/her protégé pay his bills, stay on budget, and to save a little money every month for something fun.

Advocates and protégés can get together socially, run errands together and enjoy one another's company.

Strongly advocating for Protégé for certain services to take the needs of protégés seriously and also raise issues of neglect/duty of care/and accountability

Citizen Advocates have made themselves known to support services and its staff so that they know someone was looking out for their protégé, and also visited on a regular basis to monitor what was happening in protégés life

Providing ongoing safeguards and protection to their Protege by going to meeting with healthcare providers, accommodation providers and service providers to ensure their Protege is listened to and decisions are based on what is best for the Protégé

Some advocates Include their Protégé in the advocates family Christmas celebrations and other family celebrations helping their protégé to feel part of their family

Advocates have become formal guardians when a Protege needs someone to protect their interest more formally, instigated guardianship review mechanisms and interim orders to protect protégés who have an intellectual disability, who have no family support, and who depends on our human service system to provide him with a place to live and other supportive services.

An advocate has strongly advocated for their protégé to maintain a quality, well thought out and positive contact with their own children for over 20 years

An Advocate has 'strongly' advocated for their protégé to receive appropriate and life saving medical treatment that wasn't being

An Advocate helped his Protégé not only organise a holiday but went on holiday with his protégé who had never had a holiday, but although had money sat in his account wasn't allowed to use it! He really loved the holiday, being himself, meeting people and getting away from support workers and the group home living. They now go away on a more frequent basis.

An Advocate gave advise and guidance, and motherly love, to assist a young lady to organise how she could continue to live independently in her unit after her main support family member had to leave.

Some Advocates ensure they are, at the very least, the one person in the world that their protégé can truly trust, confide in, feel secure with and build a friendship that has no conflict of interest and sometimes the only real friend they have ever had.

Advocates have ensured that a protégé's and family were supported to work with Centrelink to be reimbursed for unpaid social security payments.

An Advocate has assisted a young protégé to get their first ever job, to feel the interview process and the excitement of gaining valued employment. This young lady is now a valued member of the businesses and is building her network of friends and acquaintances

An Advocate and her family are showing a young man what a real family looks and feels like. Many of the Advocate family are involved including husband, children and grandparents. He visits their home frequently and is very much part of their family. They have a wonderful relationship and making wonderful memories for him and the Advocate.

An Advocate helps her protégé manage her finances and has been a mentor around marriage, parenting and family issues for many years during some difficult times but also some very happy times.

This is just a sample of what Citizen Advocates and their Protege can do, the things we have seen happen to change the lives for people with intellectual disabilities and their Advocate are just wonderful.

Management Committee update

Firstly I'd like to thank those of you who attended our AGM last December at Palmwoods. As you know our Committee are volunteers too and it's always a delight to meet up with the Sunshine Coast Citizen advocate community.

While our main focus is to support Donna and Les in their Citizen Advocacy practice as defined so well by Wolfensberger, your committee also provide a governance role which also includes maintaining adequate funding and that we budget and spend these funds appropriately, ensuring our program has quality systems that pass third party audit to Australian Standards, and that the program undertakes the key office activities critical for a healthy Citizen Advocacy program.

Our broad backgrounds and perspectives provide a context to the external factors impacting on our Program, our Advocates and Proteges and each other. We celebrate the many successes of advocates and proteges as we work together to get the best outcomes we can with the many challenges and opportunities that are often heightened for our Intellectually impaired community members. Personally, it's always rewarding and interesting and occasionally remarkable.

At our January meeting James Rostas tendered his resignation from our committee. It was a difficult decision for him as he had enjoyed serving the program and had every intention continuing. However his situation has changed and he openly shared his reasons with us. With much regret our Committee accepted his resignation and will support him as best we can with the challenges he expects to in his ongoing Advocacy role.

Diversity in our Committee is valued and we now have an opportunity for you to consider joining our committee. If you feel you have experience with Citizen Advocacy, have some business or Board experience, and are in a position to volunteer to support many vulnerable community members, then please given the office a call. If you're unsure then call anyway!

Craig Agnew

Independence and/or Interdependence? A Citizen Advocacy Perspective

In the human services and in advocacy for people with disabilities, terms like "interdependence" and (especially) "independence" — and their adjectival siblings, "interdependent" and "independent" — are used, it would seem, indiscriminately and insouciantly. Of course, understanding the context in which the terms are applied is crucial; with that caveat in mind, we can cite some examples.

For instance, it's not unusual to hear some service workers in disability agencies claiming that they can act as independent advocates for their clients. They can't. They can't because there is a tension, which may not be resolvable, between pursuing the interests of their clients and pursuing their own interests, including keeping their jobs. How many service workers will challenge any systemic practices that are harmful to the service recipients, if doing so may jeopardise the job security of the worker ?

So, what is in the interests of the clients may not be in the interests of the service workers. Both interests may be valid, but there can be a clash or conflict of interest. Something has to give. And it's typically the interests of the clients, the least powerful party, which will be sacrificed on the altar of expediency, to preserve the interests of the service workers or their agency.

In the disability advocacy culture, too, we hear people refer to the importance of independence, but not only in the context of avoiding or minimising conflicts of interest in achieving desired advocacy goals. In self- a d v o c a c y circles , or example, complete independence in everyday functioning is promoted as an achievable, if not already- achieved, unnuanced objective of self advocates. Outright independence, not interdependence, is the uncompromising position of some self-advocates. However, one of the many silver lining lessons that the dark cloud of COVID-19 has taught us is that it's critical for us to rely on — and be responsive to — each other, instead of adopting an intransigent individualism. Where does Citizen Advocacy, as one form of personal advocacy,

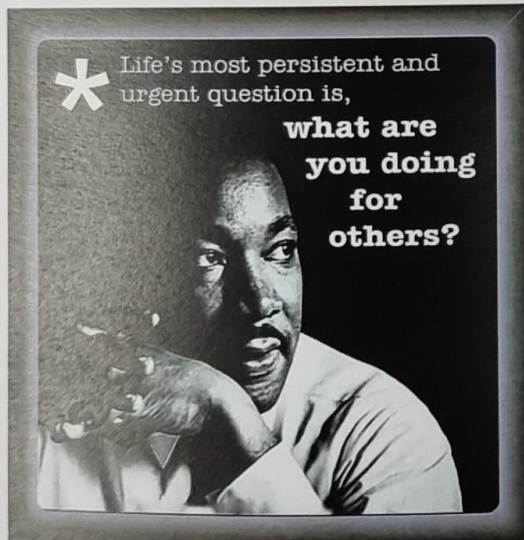
stand in regard to considerations of interdependence and independence? A couple of core assumptions underlying the concept of Citizen Advocacy are relevant here.

Citizen Advocacy is largely about relationships and representation.

In the relational domain, one of the assumptions of Citizen Advocacy is that human beings are, and should be, interdependent. That is, interdependence is both a self-evident and a desirable characteristic of the human condition. We should accept, as well as strive for, interdependence. In practical terms, we should readily give help to, and receive it from, others.

Mitchel Peters

The Newsletter of the Citizen Advocacy Trust of Australia - November 2020



Citizen Advocacy

Citizen Advocacy is a group of local citizens who are concerned about the many people with disability who live in this and other communities who have no friends and family, or who might rarely, if ever, see their family.

Citizen Advocacy believe that what these lonely and isolated people need most in their lives, is to have ordinary citizens from their own community reach out and to offer friendship and guidance. They need someone to know they are there, and care about them.

So why do we need this. Well, we know that when someone moves to a community like this, they will quickly get to know their neighbours and shopkeepers. They might join community clubs and interest groups and maybe church services, before long they will become part of the community.

Unfortunately, many people with disabilities might live in communities for years but never actually be part of them. That is our loss! People with disability too have much to offer any community - time, energy, humour, friendship - important things that are often in short supply these days.

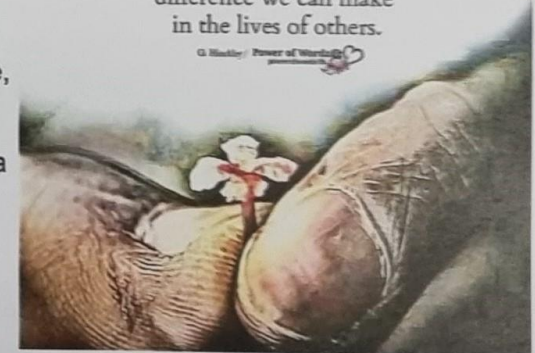
When people with disability who live here are invited to become part of the community, it will be enriched by their Presence, and all of us will benefit.

Citizen Advocacy provides a way for caring responsible citizens to engage with a person with a disability who needs to be welcomed and valued in this community.

Being humble

means recognizing that we are not on earth to see how important we can become, but to see how much difference we can make in the lives of others.

© Healthy Power of Words



Why do we do citizen advocacy?

A great list of reasons why... let us know if you agree and want to learn more...

Every person matters. If we believe that, we have a responsibility – an obligation – to protect one another.

Every person has talents and gifts – and contributions to make.

There are strong forces at work in our society that undermine that assumption:

- patient (medical)
- problem (social work)
- project (civic/religious)

We believe in the person as a doorway toward stronger a stronger community.

The world we live in chooses to segregate/separate people viewed as different or less valuable.

Being separated from community sets up barriers and devalues people's perceived worth. This leads to more rejection and negative stereotypes. This devaluation is dangerous and puts people in harm's way – at greater risk of being hurt. An example is a merry-go-round on the playground where the safest to be is in the middle and most dangerous place to be is on the edge.

Coming into a reciprocal relationship with a person who has been devalued opens up powerful opportunities to learn. That learning process teaches us that a lot of what we thought or grew up believing isn't true. Example: peeling the layers of an onion.

We are inviting people into relationships where there will be great joy and also suffering. That is a difficult journey.

But, we also assume that, if asked, a certain number of people will choose to go on that journey and make a commitment to the well-being of another person. The relationship will be built on our common interests, not our differences.

And personal commitment is the most powerful form of action over time.

Linda Wittish ,August 23, 2019 ashley About Citizen Advocacy, Advocate View

A VALUED ROLE: THE GIVER OF GIFTS

It was fluffy, cute and green: a small, friendly crocodile in the form of a soft toy. No threat to anyone—or was it?

In this instance, the answer was a definite ' Yes' for the recipient was our adult son, Mark. Mark is well into adulthood, so you would think that a soft toy would pose no problem. However, it is easy for people to categorise someone like Mark, who needs support to live the life that people typically take for granted.

With that label and role comes lowered expectations and, in turn, Mark is made more vulnerable. Recognising this, we have tried hard to surround him with positive imagery; imagery that reflects who he is and what he likes; imagery that confirms his status as a man who has been experiencing life for well over 30years and is now an uncle.

We learnt that its important to be constantly as the potential is there for things to quickly come undone. That's where the crocodile came in.....

Mark was keen to join the tens of thousands of people who flock to Sydneys Royal easter Show each year to see the animals, visit the exhibits, watch the performances and buy showbags.

Like may others, Mark is drawn to "sideshow Alley with its colourful booths, lots of excitement and spruikers enticing passers by to 'have a go' and test their skills and maybe win a prize. The highest scores are likely to be seen hefting around oversize soft toys, with the prizes getting smaller according to ones score.

We realised that 'having a go' was important for Mark and that he was likely to win a prize or prizes of some kind. So we were concerned that Mark storing his soft toy at home would reinforce the 'forever' child role in the eyes of his visitors and support workers. So we did some brainstorming and came up with a plan that would turn the threat into an opportunity: we enthused Mark with the idea of trying to win prizes to give to his nephew Cooper and niece Rachel.

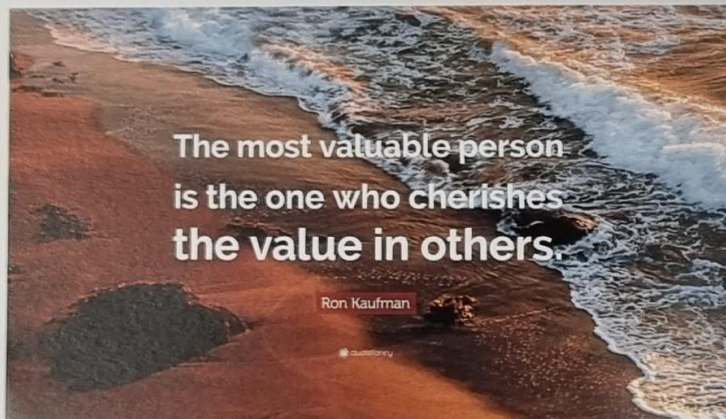
Mark now had a new motivation to win. However, to be sure of keeping his positive image intact, we had to consider how he would get any prize home. To cover this, we made sure that a large bag was on hand to cope

with prizes of all sizes, thus ensuring he wasn't seen walking around with a huge soft toy.

When Mark won his first prize, he chose the crocodile as he knew Cooper liked crocodiles. Choosing the next prize was a little trickier, but he found a soft velvety fabric flower to give to Rachel. By agreement, the third prize he won (a plastic space shooter) has been put away for Mark to give when Cooper is older.

The potential negatives had been turned into positives, It was quite touching to see Mark proudly present Cooper and Rachel with the prizes he had won, and see their excited responses, confirming his role as a giver of gifts.

By Wendy McGlynn



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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