

## Editorial: Building our Capacity for Inclusion

In this edition of CRUCial Times we want to explore the theme of capacity building. It has become part of our language in the disability sector and yet not many of us wake up in the morning and think “my goal is to build my capacity today”. If we do, it is maybe more common to think of building our capacity to do something practical or physical, like run faster or lift more. It’s less common for us to think about how we might intentionally build our capacity to expect more; to speak up more clearly; to stay on track or to decide what’s best; but these are some of the skills that can be required if you have a disability or someone you care about has a disability. There is a subtlety to the simplicity of this as it is different to what we often think creates change. This is not necessarily about more effort but a shift in thinking and understanding that can actually help us to achieve more or to improve what we are achieving.

In this edition, our five writers reflect on their experience of how this type of capacity can be intentionally built at a personal, organisational and community level. They don’t report setting out with a stated goal to build their capacity, however as they reflect back on their experience thus far, they share what has been helpful to them. Our board member Gerhard addresses the topic from his experience as a support worker and the importance of building capacity at different levels.

Some people can feel a bit insulted by the term capacity building if it is used to imply that they have a deficit or need to be fixed or improved in some way. Capacity building is not something that we want done to us. However, in Australia, as we transition from one system of providing support to another, we need all the capacity we can get to first imagine and then negotiate something different to what we have had before. From that base we also need new and different skills to make that a reality and to keep it going over time.

Capacity building needs to be tailored to individuals as each of us will build our skills and talents in our own way and at our own time, however capacity can also be built in a quantitative way. If two people can do more than one, then four can do more than two and so on, which not only increases quantity but can also help to embed strength and diversity. Two of our writers, Antony Jaeger and Deb Rouget describe collective capacity building both at the organisational and community level with both reflecting on what individuals can do within those systems.

Deb has worked for many years assisting people to build their capacity to welcome and include, and gives some great guidelines on where to start to influence this nebulous thing we call community. She reminds us that “The community” is not them or other, it is all of us. She explores how we can build

My mission in life is not merely  
to survive, but to thrive; and  
to do so with some passion,  
some compassion, some  
humor, and  
some style.

Maya  
Angelou

## APRIL 2018 ISSUE 53

### Editorial

Margaret Rodgers 1

### From the Board

Gerhard Tromp 3

### Staying on course and enjoying the adventure

Dave and Sandi Cohen 4

### Encouraging and enhancing community capacity

Deb Rouget 6

### Learning by doing: embracing opportunities for growth and adaptation

Brendon Donohue 10

### Building organisational capacity – the job that never ends...

Antony Jaeger 12

### Growth and hope: Creating structures that enable the good life

Heather Batt 14



community around and with the person and just as importantly not block or deter relationships with friends and neighbours. She describes how as supporters we are important role models to typical community members. Through our actions we can help to show others how to get the most out of a conversation or interaction with someone who lives with disability.

Antony Jaeger works for a large organisation and writes from his experience of the value of investing in building the capacity of staff and gives some sound suggestions on how to sustain that through the inevitable turnover and change. He explores the tension, with limited time and resources, of investing deeply in some people versus broadly in a large group of people. Expanding and supporting the champions, leaders and inspirers is critical but not enough.

Reflecting that Capacity Building happens in the real world in real time he challenges us to harness potential, support it and share it concurrently. This is fundamental to embedding a culture of capacity building and setting it up well for succession. He acknowledges the need to make this a priority and dedicate time to working deeply and broadly in the work we do today but also for the future.

Two families from regional Queensland share their stories of building their capacity over time. As parents, Dave and Sandi Cohen talk about equipping themselves and learning from others but also ensuring that they have new people on board too. They describe the importance of other people in building their capacity to create a good life for their daughter. In the early days they benefited from the advice of other families and now they are welcoming others to assist their daughter to build her own community. They are clear that sustaining capacity requires looking after the people who journey with you.

Heather Batt and her sister also live in regional Queensland. Disability has always been part of Heather's life and she traces how her thinking has changed over the years and some of the key experiences that have contributed to that. She explores how capacity building takes many forms and likens them to the variety of ways that construction can happen. It was a change in her understanding and thinking that gave her capacity to start to act differently and to build something new. In their own ways, she and her sister are both doing things today that they had never imagined.

Brendon Donohue is very clear that capacity building is not an academic exercise or an added frill. As a young man who is blind, he appreciates his limits and is keen to develop his capacity in many practical ways to increase his independence and to get the most out of life. He is also investing in developing his advocacy skills and is keen to use his skills and talents to advocate for others which is a great and common by-product of building our own capacity. I really appreciate the way that Brendon illustrates the power of others to both build and diminish his capacity as this is an important message for everyone who supports and stands with a person with disability.



Each of our writers describes the building of capacity as an ongoing and evolving pursuit that takes many forms. Each of them report that being able to tap into information and inspiration, as and when they need it, has made a big difference in how they navigate particular challenges and stages. They describe how as they have learnt more they have become more intentional in seeking out opportunities to keep building their capacity to learn and expand but also to keep going on an inclusive path. Given that often we don't know what we don't know, being open to and seeking out learning is perhaps the most important step to building our own capacity.

**Margaret Rodgers**  
Chief Executive Officer



## Investing in Support Workers

Being a support worker can be an incredibly fulfilling job - at least over the years I have found it to be. To be welcomed into people's family lives and homes and to have a very real and practical, positive impact on someone else's life has been very rewarding.

When many of us take on a role in support of someone with a disability, however, we bring with us the prejudices, devaluing beliefs and assumptions that our society has about disability. As these stereotypes are challenged we are in a better position to be effective support workers. This does not just happen by accident - it needs to be invested in.

Having the right values is where good support work begins - looking deeper and seeing a person for who they really are: someone with meaning; someone who can teach you something; someone who, like the rest of us, is just trying to live their lives. If a support worker is going to support someone well, they must have a belief in the intrinsic value of the person they're supporting.

Although values are deeply personal and cannot be imposed on us, through training we can question them and learn about the processes of devaluation of others and challenge our prejudices and assumptions. Once we have started to address some of our unhelpful thinking, we are more able to place the person with disability at the centre of their own life and support them to achieve their personal successes.

As well as learning to refine values, there are practical skills to support that can be learned. For example, the parents of one of the people I supported sent me a free online learning resource called 'Every Moment Has Potential'. One of the modules described a 'hand-over-hand technique' where a support worker guides a person through the actions of a task. I went on to use this technique to support a man in his early forties to make his own morning coffee. With my hand over his, he scooped the coffee and sugar out of their containers into a coffee cup, poured the boiling water and milk in then stirred it together. As we were doing this he would turn to me smiling from ear to ear. By the end he was shaking with joy at the fact that he had made, or at least had some meaningful involvement, in making his own coffee. I was surprised at how great an impact it had on him.

For many people with disability, support workers are a key piece in building a 'good life'. This role is deeply influential so it is important that as workers, our capacity is invested in and that is true whether we are employed by a person with disability, their families or an organisation. As support workers we can also actively invest in ourselves to be better at what we do.

With a combination of these practical skills and a solid values base, our capacity to bring out the best in those we support, despite any barriers they may face, becomes greater and greater.

**Gerhard Tromp**

Director



## CRU Board Members 2016-2017

<b>Sharon Daley</b>	Chair
<b>Matt Stone</b>	Secretary
<b>Sherryn West</b>	Treasurer
<b>Josey McMahon</b>	Director
<b>Luke O'Sullivan</b>	Director
<b>Gerhard Tromp</b>	Director
<b>Fletcher Tame</b>	Director

## CRU Staff

CEO
<b>Margaret Rodgers</b>
Senior Consultant
<b>Lisa Bridle</b>
Information Consultant
<b>Hugh Rose-Miller</b>
Consultants
<b>Suellen Welch</b>
<b>Catherine Laherty</b>
<b>Jen Mouritz</b>
<b>Danielle Mason</b>
Administration Officers
<b>Kim Jensen</b>
<b>Bobby Noone</b>
<b>Kerrie White</b>
Administration Support
<b>Kathleen Fleming</b>



# Staying on course and enjoying the adventure

Dave and Sandi Cohen

**Dave and Sandi Cohen** have been sailing together since the 1970's. They resumed a more traditional lifestyle to raise their family of four children and deal with the increased complexities of two children with a rare metabolic disorder.

They have both recently retired from permanent employment to develop a commercial organic farm and provide a more adventurous and rewarding lifestyle for their daughter Rebecca. In their spare time Rebecca is helping build the new family yacht.

In this article they share the strategies they use to ensure they are ready to make the most of new opportunities and enjoy themselves along the way.

## Staying on course and enjoying the adventure

### *Attitude equals the difference between ordeal and adventure.*

*Sailing quote from inside a storm*

Sailing has taught us resilience, preparedness for almost anything and the importance of careful planning with ample provision for the unexpected. Above all it has taught us to just keep going in close to the desired direction even when it seemed impossible to keep going (that is if you want to survive of course). We needed at times to consciously develop an attitude to stay alive and thrive.

Nobody should pretend that having a disability is easy, nor is it easy to have a family member with disability. This experience brings out the best and worst in people, not unlike sailing a small boat across a difficult ocean, something we used to do a lot before having children.

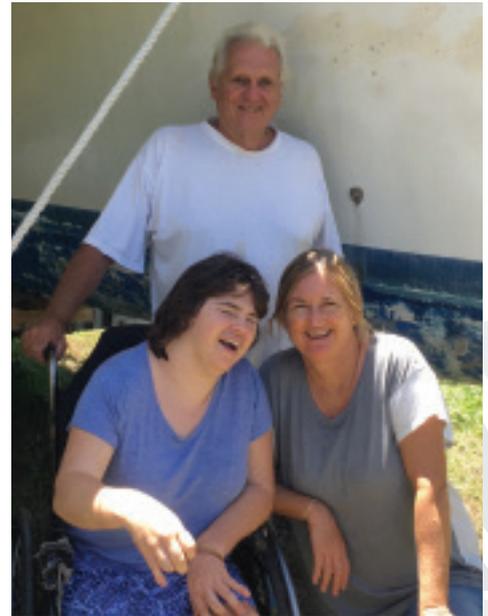
What's this got to do with disabilities and capacity building? It's the same attitude and very similar skills.

So how does all this capacity building and sailing talk work in reality? We are lucky to have 4 children. Our youngest daughter Bec has very high support needs. Her sister, Samantha, who had the same disorder died some years ago, so we are aware that things can go wrong unexpectedly. Our combined family aspiration for Bec is to have the best possible life and this has brought our entire family closer together.

Fortunately we met families that had been on this journey before us and acquired some very useful advice from them and we feel very fortunate to have had this support. That advice included:

#### **Have a plan.**

Just like sailing it helps to have a destination or at least an idea of where you want to go and what you may encounter on the journey, even if you don't get there or get sidetracked into other adventures along the way. Work through the natural or typical phases of life and remember a good life for your family member means a good life for everyone involved with them. The reality is the journey takes on a



life on its own. It is important to be flexible and able to adapt and enjoy the unanticipated adventures along the way.

#### **Get equipped.**

You have to work out what skills and equipment you need to at least start out. If wheelchairs don't do well on sand then you need different equipment. There are some great homemade beach contraptions around and always someone willing to help. Mucking about on boats doesn't work if you aren't prepared to learn some new tricks or can't pattern through some movements. Once you can learn to pattern through new things it opens up a world of getting to new places. We have discovered new horizons of possibility off the beaten track will attract like-minded adventurers who'll enjoy the ride with you. And if the going gets a bit too tough we have found there is always a friend nearby willing to help (possibly someone you have never met before who might become a new best friend). It doesn't really matter if it is on a boat

or having an adventure with the top shelf in a supermarket from a wheelchair, just give it a try and work out how to make it work.

Just do it – with preparation, planning and forethought. You have to be doing things for things to happen.

#### **Look after the crew.**

Relationships are everything. Single handed sailing is much harder work and not nearly as much fun compared with doing the same in a group. There will likely be a team of workers involved with your family and to get the best performance out of everyone you need to create and manage the right sort of relationships for your purpose. It's important to remember to really look after the special relationships with those closest to you. And it's a good idea never to forget the importance and power of the fun word – just like attitude, fun can be the difference between an ordeal and an adventure.

#### **Be independent and self-reliant.**

Somewhere along the disability journey we needed more assistance. We discovered Asset Based Community Development (ABCD Kretzman & McKnight, North West University, Chicago), a process of discovering, contributing to and drawing from existing capacity in the community. It involves working with the available strengths, analyzing and utilizing the resources already available and working together and purposefully for a common objective. We quickly realized that capacity building wasn't about the money but what you could achieve with clever use of the resources you could lay your hands on.

#### **Keep ship shape.**

A government policy of capacity building depends on families and people with disabilities having the right attitude. The government can't just make it happen. No one else can build your own capacity – the best government can achieve is to help you create the environment for this to occur.

And if it doesn't occur; if we choose to be dependent on government support; if we choose to be at the whim of an ever changing kaleidoscope of government policy; if we choose to give up our independence and freedom to make choices, it is difficult to imagine how anyone could have a life rich in experience and value. Money helps but is not the objective and in fact may on occasions complicate matters.

#### **Adjust your attitude.**

Just as in sailing when the going gets tough and things are looking grim, it becomes time to remind ourselves that attitude equals the difference between ordeal and adventure. We need to learn to adjust our attitude, gather our available resources and utilize them skillfully. Keep trying to do it better all the time, but don't push yourself too hard and get swamped in the process. This is what capacity building means. It's about developing or finding whatever you need to enjoy the adventure.

Bec is 23 now and living in her own place with the support she needs. As a family we are always trying to find ways for Bec to be a part of whatever is going on – sporting activities, mucking around on boats, going to the beach, enjoying music festivals or dancing to the max at outrageously noisy parties. She has to

***This is what capacity building means. It's about developing or finding whatever you need to enjoy the adventure.***

be one of the gang and participate as much as possible - not be sheltered or secluded.

Because Bec can't speak, people can underestimate her. Where people make an effort to communicate with Bec in her own way they discover a beautiful, witty young lady and are themselves changed by that experience. She is a great teacher and these moments express Bec's own personal capacity and her ability to build the capacity of others.

Her neighbours were a little nervous (read terrified) when we introduced them as they had previously not known a person with a disability. With time, introductions and support they now drop over all the time sharing morning or afternoon tea or telling jokes and tall stories. Bec is having a great time and so are the neighbours.

Is this called capacity building? Probably, but it's all just part of the adventure if you have the right attitude and a little bit of help to pick up the right equipment and skills. Early on we were fortunate to learn from other families who had charted their own courses before us and we're still learning to this day: from other families we meet, ideas we hear and importantly, from Bec. The sailing isn't always smooth and sometimes we got blown off course, but with more experience comes greater confidence to back ourselves and try new things. And no one can do it for you; besides, you wouldn't want them having all the fun.



# Encouraging and enhancing community capacity

Deb Rouget

**Deb Rouget** has been involved with people with a disability and their families for over 30 years. In 2003, Deb was integral in the development of Belonging Matters which sprung to life as a catalyst to prevent the exclusion of people with a disability from their communities and enable individuals to enjoy a fulfilling life that is well embedded in community, relationship and citizenship. Since that time she has been the CEO of Belonging Matters. Deb has also been keen to foster advances that leave people who have a disability and their families with greater control over their lives.

## Encouraging and enhancing community capacity

From the moment we're born it's an expectation that we will be part of community. Most of us are immersed in an intricate web of social relationships that arise through numerous and varied social contexts, situations and opportunities. Community is not somewhere else that we go to. However, people with a disability have faced a long history of exclusion and rejection, living isolated lives in institutions and special programs. Increasingly people with a disability are present in our communities, however, being present in the community doesn't always mean a person is part of it and that you feel accepted and belong. This article provides some advice on what people who support people with disability can do to build the capacity of the community to include.

### Begin with moments

From the onset it may seem daunting to build the capacity of the community, however starting with well crafted "moments" can make the task less overwhelming. Starting with one small opportunity or moment can be the seed to many other opportunities that follow and flourish.

### It's a bit like a dance!

Some years back, Butterworth et al (1999) described whole of life planning for people with a disability as "More Like a Dance." Our work to support inclusion is a bit like a dance. Just like most of us know what dancing is, we may not have had the opportunity to master the steps. As a teacher you step in, encourage and let people know when they're doing a good job. You know people might not get it right the first time, so you provide respectful feedback and advice on mastering the steps. You offer plenty of practice but you don't take over. When people have mastered the dance, you step back and let others take the lead. All the while you know that it takes time to learn how to dance but you have faith that people will dance.

### Recognise and harness the potential of community

Often, we hear people say that the community rejects but in 30 years of working alongside people with a disability I have found this to be rare when people are



supported well. The community has great potential to welcome people if supported and guided in their efforts. Once people get to know each other as people, preconceived judgement fades and relationship has the chance to grow.

Time and time again I hear community members say "of course you're welcome", "I'm a better person for knowing this person", "our workplace is a better place", "I have always wanted to assist but I didn't know how" or "nobody asked". Community is not a panacea for every unmet need, but we need to work harder to connect those who have had a long disconnection from each other.

It's time for us to reach out to community, invite others in, support and encourage people's efforts, embrace potential and view everything as an opportunity for people to get to know each other through work, education, clubs, neighbourhood and so on.

## Common interests

At the heart of any community group is a shared interest. It's what brings people together, it connects people. It may be a shared goal, a passion, a cause that's close to one's heart, a political action group, religion, work interests, sport and so on. One only needs to search [www.meetup.com](http://www.meetup.com) to see how many special interest groups exist. Therefore, the discovering and harnessing of what people love and share in common is not only an entry point but the glue that binds members together. Once people share their interest it provides an opportunity for people to get to know each other in terms of the interest rather than focusing on the differences between people. For example, a love of Formula One cars, collecting clocks, craft, the environment etc. If you're a Melbournian, the football is shared by many and connects people, even if they don't play the game. The sharing of common interest is also a good strategy for people who may have difficulty in communicating. Often sharing an interest doesn't rely on verbal communication but an expression of joy and understanding. The "sharing" is the connector.

## Find the contribution

Going to an event or being present at a club, association or workplace is not enough. It's important to harness the person's skills and contributions and as supporters make suggestions of meaningful contributions. Emily loves going to the footy and then joined the banner making group as she loves craft.

### "One person at a time"

Often human services assist groups of people with a disability to access the community. e.g. group shopping, swimming programs. Even Neighbourhood Centres operate "special groups" for people with a disability. In this instance, people are physically present but often remain isolated in "their group" and interaction on an individual basis with other community members is limited. The notion of assisting "one person at a time" to pursue a unique interest or a passion, makes it more conducive to building genuine reciprocal personal relationships with other citizens.

Just a word of caution - once a club, workplace or association has had some success with including a person with a disability, their natural instinct seems to be to want to do more. Often, they will think it's a good idea to create a "special group" for people with a disability. It's important to be able to explain the risks of congregating people as they will be seen as different or "special".

## The art of asking

Ric Thompson (2005), in his article on "The Art of Asking", states that when we come to "asking" we often enter into a period of silence and apprehension. We need to be prepared to ask as it's vital to building the capacity of community. Thompson also puts forward John McKnight's suggestions about needing to understand the reasons why we are asking, who to ask, how, when and where to ask. We have found, as Thompson suggests, many people in the community have never been asked. When they're asked, encouraged and supported the community has responded very positively. Especially when it's a question of promoting or sharing a common interest. The larger or more unclear "the ask" the more daunting it can be for people. Thus, you might avoid asking someone to become someone's friend but the friendship may emerge from being asked to

share a common interest. Not every time we ask we achieve what we want. People may simply not be able to help at the time. If this is the case we should use the opportunity to ask if they know someone else who could assist.

## Valued roles as a means to enhancing people's connection

It is when people are a part of community and take up valued roles within our society that they become accepted for who they are and what they contribute (Wolfensberger, 1988). When a person with a disability takes up a valued role in a club, association or workplace, many of the negative assumptions about people fade away and the person's abilities shine. For example, Warren is a member of his local Salvation Army. He is also a volunteer in the café. Cameron is employed as a Receptionist for a business group. He also does the banking and mail run for the business. This connects him to countless people who see him in a valued role. Brodie is a music student. He is also a member of a school band. We have found that concentrating on valued roles shift attitudes about what people can do, embeds people in the culture of an organisation, enhance people's contribution and competence and ensures people become an integral part of an organisation so that they're missed if not present.

***Once people share their interest it provides an opportunity for people to get to know each other in terms of the interest rather than focusing on the differences between people.***

We often find that using “role communicators” from Social Role Valorisation theory (Wolfensberger, 2013) can be useful to engage and build capacity.

Given clubs, workplace or associations all have their own unique culture, who are the **people** the person can learn and model from? Who are the elders? How is information and learning passed on? How does the person access these typical means and ways of learning?

What does the person need to know about the **physical setting**? Are there places that are “off bounds”? Is the physical setting accessible? Where do people have breaks? Are there adaptations that would increase the person’s contribution? Where are things kept and how are they put away? Who can tell you more about the physical setting and what do you notice?

In regard to **appearance**, does the person have the appropriate dress or uniform? What might be needed for certain roles e.g. gloves in the kitchen, no shoes in the temple, washing hands, cleanliness and hygiene?

**Timing of activities** is important. Most people develop relationships through repetition, so being and doing things at the same place and time every week is helpful. It’s this consistency that assists people to get to know each other over time. There are other timings that are specific to certain places and it’s important that the person knows about these. For example, members always stay and pack up after everyone else has gone (Clubs, associations and workplaces love people who go the extra mile). Are there any rituals e.g. drinks on a Friday night, coffee in the morning? Who knows about the timings and could teach the person about these expectations?

What **language** does the person need to know? For example, at the footy a person needs to know to what a “speccie” or “screamer” means, especially if they attend an after match celebration. Who knows the language and could teach the person?

### **Discovering culture to build the person’s competency in the eyes of others**

All clubs and workplaces have their own specific culture, processes and ways of doing things (Hanger and Dileo, 1993). Sometimes the culture of an organisation can be subtle or unstated, however going against the culture can get people off side. Asking members to explain workplace, club or association culture can be useful for guiding a person into the group. It is important to invest time and build relationships with key members as they will give you clues about what may not seem obvious, and often become an anchor point to harness the person’s skills, contributions and inclusion. They will also encourage other members and potentially address any concerns. Recently it was discovered, by talking to the head chef at the restaurant Matt works for, that to “blow off steam” the staff go lawn bowling together. By mentioning that this is something that Matt would like too, he was immediately invited to attend.

### **The importance of role modelling**

So much of what people learn is through role modelling. If people are unsure of how to act or what to do they will look to you for guidance. How you interact, respect and teach the person a new skill. Even how to respond in a tricky situation. It’s important that you also pass on what you know about how the

person communicates and learns. For example, “Katy loves jewellery that’s why she is admiring your necklace through touch” or “Kevin learns best when tasks are broken down and written on a checklist”.

### **Deepening relationships**

Secondary interests can also be harnessed as a way of deepening relationships. For example, two people may go to the same craft group but through conversation they discover they also enjoy the same types of movies and thus an invitation is offered to the movies. Conversations may also lead the person to asking for a lift, discovering a fellow member is going away and needs their mail collected or dog fed, offering a favour or an invitation to dinner. This is how we build connection. A person may need some assistance to offer, invite and communicate, however, if this is modelled and supported, people will feel that it’s something they can pursue.

### **Getting the match right**

Over the years I have learnt how important it is to get the “match” right between the person and their support workers. The match is not only important in regard to values but also the task that needs to be done. For example, if you want someone to help you become a member of the local footy club you wouldn’t ask me, however there would be many Melbournians, unlike me, who love footy. They understand the culture (including the written and unwritten rules) and can therefore better seek out valued roles and build relationships over a beer!

If you want to pursue abstract art then you want support from a person who knows about abstract art. If you want to pursue Acapella singing then you want support from those who know

about Acapella singing. If you want to study astrology you want support from those who know how to study and better still know about astrology. The specific interest area can be just as important as values and it enables the support person to blend in like a chameleon.

Another important “match” is age. You don’t want an older motherly person assisting someone to join a “rap” group. This may put the other members of the “rap” group offside. However, if you had a young “rap” artist supporting the person, the other rappers will be much more open and inclusive.

**Intentionality is needed to build relationships**

Once a person is pursuing their interest in the community, if we do not focus our efforts on intentional relationship building, then its development is left to chance. Many individuals with an intellectual disability will need assistance to

**Once a person is pursuing their interest in the community, if we do not focus our efforts on intentional relationship building, then its development is left to chance.**

pick up on social cues and advance a friendship in a way that occurs naturally for many people. Keeping our eyes peeled for people who constantly show interest in the person, finding out a bit more about them and offering invitation will assist in the further development of friendship. We need to assist people to nurture their relationships so they can flourish.

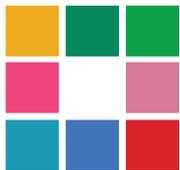
There is nothing out of the ordinary in what I have outlined here. We are social beings and thus are wired to learn and live by the social pattern and norms of a community and we do this every day, albeit unconsciously. We do this to find purpose, fit in, build relationships and become connected within our communities which is why, when assisting others to take their place in community, we need bring these processes in to our consciousness. In doing so we create fertile ground from which connection, love and friendship can spring and this is something we all benefit from.

**References**

Butterworth, J., Hagner, D., Heikkinen, B., Faris, S., DeMello, S., and McDonough, K. (1999). *More Like a Dance Whole Life Planning For People With Disabilities*. Institute for Community Inclusion a University Center for Excellence at Children’s Hospital, Boston and University of Massachusetts at Boston Graduate College of Education. Training Resource Network, Inc: St. Augustine, Florida.

Hagner, D. and Dileo, D. (1993). *Working Together: Workplace Culture, Supported Employment, and Persons with Disabilities*. Brookline Books: Cambridge, MA

Thompson, R. (2005). *The Art Asking*. Community Resource Unit: Brisbane



Bringing the good life to life



**Have you seen our website designed to resource people to bring the good life to life for people with disability?**

This website contains a broad selection of articles, videos and ideas drawn from CRU’s existing resources and over 20 new short films. It also has lots of interesting content from around Australia and the world. The content is useful for people with disability, their families, friends and the people who support them – both paid and unpaid.

This resource will be helpful to people as they prepare for the roll out of the National Disability Insurance Scheme (NDIS). There is one page dedicated to making the link between this initiative and the opportunity it provides to make life better for people.

The website contains 7 pages that cover the following topics:

-  **The Good Life**
-  **Getting Started**
-  **Including Others**
-  **The Role of the NDIS**
-  **Funded Services and Support**
-  **Blocks and Barriers**
-  **Keeping on Going**
-  **The Bigger Picture**

visit [www.thegoodlife.cru.org.au](http://www.thegoodlife.cru.org.au)



# Learning by doing: embracing opportunities for growth and adaption

Brendon Donohue

**Brendon Donohue** is a Brisbane-based advocate, traveller, volunteer and accessibility consultant. In this article Brendon looks at how his capacity for independence has grown over time and what has helped and hindered this development. He shares insights about how he builds his own capacity and how the actions of others can further diminish this.

Brendon lives in the inner city and has just returned to the work force. He is committed to lobbying for the removal of barriers to accessibility for blind and vision impaired Australians, ensuring that legislation and policies surrounding accessibility are properly implemented and upheld.

## Learning by doing: embracing opportunities for growth and adaption

My lack of eye sight does not stop me from living on my own, travelling overseas, working and volunteering, but I am only able to do these things because of an ongoing investment in my capacity - both from myself and others. The more I learn and develop new skills the more independent I can become. Being blind, a physical approach works well for me - I learn best by doing. This is why I am so deliberate at challenging myself and learning new things. For me, independence is the goal for capacity building - it's the end game.

My parents have influenced me a lot in this regard. They are both blind and knew the importance of not treating me any differently to my two sisters who are both sighted. My sisters made mistakes and I made mistakes and we all had the opportunity to learn from them.

When I started primary school I was confronted by very different attitudes. I went to school expecting to be taught but the school didn't believe someone who was blind could learn and so they made compensations which denied me opportunities to learn.

I was taught amongst sighted students but their resources were not suitable for me. The school had resources I could have used but the teachers did not know how to work with them. This was made worse because I frequently had relief teachers - no teacher knew what the previous teacher had done and this led to gaps in my education. I did the homework to the best of my ability, but I would get in trouble at school because my homework wasn't completed. The expectation was my parents would help me but we weren't supported to do this.

For some reason we still don't understand, the principal in primary school would not let me use 'the unit' (for students with disability) and this denied me a chance to learn in the way that I needed to, such as learning to read and write Braille. Obviously this was a huge barrier to my learning and it still impacts me as an adult.

The school also made decisions about my education without telling me or my parents. On the day I was due to do NAPLAN (a standardized test for all Australian students) I found out my teacher had exempted me from the test without consulting me or my family. They didn't even think my parents were capable of making those decisions!

It was also very hard to make friends in primary school. No effort was put in to help me (and the other blind students) join in during our breaks and our taxis home left at 3pm so we couldn't stay back and play with our classmates.



One good thing that came out of primary school was that in year two I learnt how to use a computer. The school gave me everything I needed, including screen reader software and 'talking typer', which taught me how to touch-type. I enjoyed exploring the computer and became adventurous with technology. My parents gave me space to make these mistakes and learn from them and so I learnt how to navigate computers and how to control them. After I repeatedly deleted the wrong files, I even learnt the financial consequences of paying someone to rebuild my computer.

I was first enrolled at my local high school but it was a terrible environment. The teachers did not listen to me and I was bullied by the students. My grandmother and I lobbied the Education Minister and eventually they let me enroll in a different school.

My new high school was so different. I was not just talked at, but I was given the means and the resources to learn what I needed to learn to navigate the world. I was expected to learn and do the same tests as everyone else. The support from my family and school were brought together and the school had a much more willing approach to my education.

I had always taken pride in my work, but the school pushed me further. I remember one of my teachers who would often say “you can do this and you will”. Once she gave me a book in braille and sat there patiently while I read it over and over again until I got it right. I’m sure it did nothing for her, but it built my capacity to read.

This was so encouraging. In time I was able to tell the school more about me and what I wanted to achieve which in turn helped the school to put in place the structures so that I could achieve. It motivated me to think outside of the box and think ‘hmm, I really want to do that school activity - how can I do it?’. The school’s response was ‘let’s see if this can be achieved or not’ and we would then have a conversation with the teachers and see if it would work.

I learnt that a proactive approach to learning is invaluable. I learned the process of learning and gained the confidence to challenge myself.

Because I was living a long way from school it made it harder for me to make friends. I would sometimes stay back after school, but I didn’t want to ask my friends to drive me home afterwards. I would catch a bus to the train station, then catch a train to the city then another bus home and then walk from there. These days my phone helps me navigate the world and catch public transport, but back then it was much more difficult.

My high school teachers went out of their way to help me be included. I became involved with drama after school and the teachers would help me get home afterwards. This was huge for me. We had a creative arts teacher who would find valuable things for me to do in the school plays. I would hold up props, ring bells during scenes and have lines. Whilst they may seem small, they were important for the show and very important to me.

A lot of the students would pitch in and assist. For instance, during the three minute scene changes the students would help me change costumes. This didn’t happen immediately but once they saw I was committed over a number of weeks they just got in and helped me. The teacher’s didn’t need to ask.

I also learnt more about me. I learnt what political party I like. I learnt what animal rights were. I learnt about making decision on where I want to live, and how I wanted to live and who I wanted to live with. I learnt about education and what it was like to be an ordinary student. I had the opportunity to dream big and explore my interests. Travel is a good example of this. In primary school I would not have dreamed I could go overseas on my own when I was 21 but high school set me up for that.

At the end of school I was given a big book on employment - in Braille. It asked me about my goals, beliefs, whether I wanted to work in a group or on my own. It made me look deep within myself. It was a sort of a launch pad of what to do. The high school even bought in disability employment consultants to talk with us about our options after school.

On the back of my technical knowledge and experience with computers I got a job out of high school as a technical officer for the screen reader software I used. This gave me an opportunity to deepen my technical understanding of online accessibility and build networks with that community internationally. After 2.5 years I was made redundant and like all good 21 year olds I spent my payout on a trip overseas. I took myself, on my own, to an assistive technology conference in the United States and I got to meet some of the people I had worked with in my previous role. Upon returning home, I came back to reality and I had to look for work again.

I have since achieved many different qualifications but work is still hard to find. People still believe that because I am blind I will not be able to do basic

tasks, despite my provable skills and experience. I have even had this issue applying for volunteer roles. I am a committed volunteer and have many weekly roles I engage with. I enjoy being able to give something back to my community, it gives a chance to get to know people and network.

I live on my own and have to look after myself. This includes things like cooking and cleaning. As I get older I have realised no one is fully independent; you can’t do everything on your own. Similarly, I used to spend three hours on a Friday night cleaning my house - and I never did a really good job of it. I’ve now hired someone to do it and my house is cleaner, I’m less stressed about it and I can focus on things that are more important to me.

Given I am blind, I have to use all of my different skills: my hearing, my taste, my touch and my intellect. By developing these skills they become more attuned so not having sight is less of a concern to me. However my own capacity has its limits and there are some real barriers to my independence that are often made worse by the actions of others. I am involved with advocacy because these issues affect other people as well as me.

My independence is important to me and I am committed to challenging myself so I can build and grow my capacity. I work hard for it and yet I am frequently reminded of how the outside world can diminish my capacity for independence. This can be people who doubt my competence, a system I rely on that changes without considering my needs, or a poorly designed job application form or website/App that forces me to seek help from others unnecessarily.

Growing and learning to adapt is an important skill I have learned over time. This could be seen as a silver lining to some of the barriers that have been put in my way, but through my advocacy I hope we can make the world more equitable so barriers are not there in the first place.



# Building organisational capacity – the job that never ends... Antony Jaeger

**Antony Jaeger** is currently the NDIS project manager at St Vincent De Paul Society NSW and has worked in a variety of roles in the community sector. After studying psychology and philosophy at university, he began supporting people with disability to become more connected to their community, and to work with families to build their capacity and confidence.

In this article he looks at how strategies for building and sustaining the capacity of staff can be embedded within an organisation. By creating such a workplace culture, staff will ideally be better placed to build their own capacity, and that of the people they work with.

When not at the office, Antony enjoys spending time with his family, attempting to surf, and reliving his youth on an 'old man's' motorbike.

## Building organisational capacity – the job that never ends...

Organisational capability and the building of capacity in others, is generally considered to be a 'concrete' concept. When we look to build capacity within organisations, we need to focus on the collective development and the empowerment of individual employees. Building capability and indeed trust in and between our employees is useful for their personal growth, but more critically we see these benefits flowing on to the people with disability we support.

Sustaining this capacity within an organisation, however, is a little more ethereal in practice.

It is important to remember that building capacity is almost always a person to person process. It may sound obvious, and it may sound trite, but the key then is to invest in 'people'. While pamphlets, checklists, workshops and the like are all very helpful, and can definitely help with the guidance on how to do things, it's 'people who help people'. When asked by someone "how did you find the workshop?", or "what made the meeting a success?" (or not), it's usually the person, their enthusiasm, their passion, their focus on the things that matter, that is remembered. It's not so often that we hear "they had the best flowchart I've ever seen!". That's not to say that great resources by themselves can't be the conduit, it just helps if they are matched by the right person.

Let us imagine for a moment that at any point in time, an organisation has a certain proportion of individuals employed who build capacity in others very well, and by their own virtues inspire and empower others. We might call these people our champions, leaders, or inspirers. Let us next propose that we want this group of 'empowerers' to grow, develop and expand.

The question then arises as to our strategy, or how we plan to do this. Are we seeking to invest deeply in a smaller group, in the hope we can leverage these skills and capabilities, or rather to share the investment and resourcing more broadly. Or are we attempting to do both things concurrently? Let's call this the depth vs breadth argument.



This challenge is one of the most common for all organisations, including outside of human services.

At its core, it's about harnessing potential, supporting it and sharing it. These 3 aspects, happening concurrently, are fundamental to embedding a culture of capacity building. This ongoing effort is particularly important if capacity building is a secondary focus for roles or organisations, as it can often be relegated to a "nice to do" or a "if I get time I'll do that" activity for people.

Generally, we will find the easy part of this approach is the identifying of our leaders and inspirers. They are usually doing these things as part of their natural practice, and seen by peers as the go-to person for advice, ideas or direction.

The more interesting part of this embedding work is harnessing this energy, structurally making time for this group to share, learn, push boundaries, and even more pertinently, to bring others in with a view to succession planning. Succession planning is defined as "a process for identifying and developing new leaders who can replace old leaders when they leave, retire or die" and this is essential

to build on and sustain the capacity good work that has been achieved. We so often hear about succession planning in business and corporate circles: I would argue that capacity building within community organisations is no different.

Aside from questions of life and death, without a strategy of actively developing the broader pool of talent and potential within the organisation, we run several risks.

One is that the expertise and wisdom is centralised (or siloed), and so the learnings do not spread. Secondly, when opportunities to learn and push one's own boundaries (e.g. running a workshop, chairing a difficult meeting, etc.) are not shared around, this further limits the breadth of exposure. As with the people we support or provide services to, we learn by doing. Watching, observing, assisting are all helpful in formative learning, but it's when you do it that all the pieces fall into place.

Without a succession plan, and assuming we have taken the depth strategy above, we can potentially find ourselves short on expertise and experience in a very quick space of time. Organisationally, people come and people go. When we invest deeply in some but not in others, this can leave us exposed in both the delivery and knowledge fronts.

So, putting depth vs. breadth to the side, what are some key truths to success, and exactly how do we embed the work?

### Strategy and Structure

**Create a way for people to come together.** This should suit your organisation, and your culture, but most importantly should be the most effective way for you to 'join together and lead'. Structured meetings with an agenda may suit, or far more casual catch-ups may be appropriate. Either way, create a forum, and then sustain this forum. It will give the members an avenue to share, learn and refine practice, and importantly, signals to others within the organisation the importance of the work.

**Make sure the right people are part of it.** Expertise and passion should be accompanied by authority (ie. decision making ability) and influence. Without both of these things, you will risk having a lovely talk fest that is not empowered to act, or alternatively a team that is moving and doing but not grounded in truth, or what stakeholders need or want.

**Give people roles and responsibilities.** Action things and hold people to account. The biggest obstacle to success is an internal view that the group doesn't DO anything; that it's just another navel gazing event.

### Share the story and keep learning

**Tell people what you are planning to do, what you have done, how this has made a difference.** Give people a picture of how the capacity building work had an impact, big and small. This may be through direct feedback, quotes, sharing stories at team meetings, getting families and others to come and present.

**Invite others in, and do this regularly.** Capacity building happens in the real world, in real time. Ask all people to contribute their experiences, successes and challenges. Just because I'm not part of the 'group' doesn't mean I'm not part of the work. This points to the untapped potential and speaks to future leaders within the organisation.

**Be critical and constructive.** Don't just complain or shy away from giving feedback. If someone needs to know that the way something was delivered didn't work well, or could be improved upon, then respectfully do this. Expect the best, and aim for the best. Analyse your successes and failures and learn from them.

Stay close to the ground. Talk about real events, real challenges, and real solutions. Wherever possible, don't talk in hyperbole, semantics or 'funder-speak'. Capacity building is a concept, not a catch all. If someone developed the skills to say no, to complain, to choose a different person, to ask for better, to expect better, then say that instead.

### Holding true to the Vision

**Remember things are often quite fluid.** Organisational utility (and indeed integrity) can ebb and flow. Just when things are going along smoothly, there is change afoot. People leave, priorities change and enthusiasm wanes. Things fall off the radar. It creates despondency. But always remember that people within organisations DO want to be part of the work, they want to focus on building capacity with others, they know people have the capability to make their own decisions, to create positive futures.

**Expect the 'naysayers'.** Assume there will be blockages, and a lack of buy in from some quarters. Not everyone will share the vision; this does not make the vision less true. It just makes it a bit harder to achieve. Your priority is not their priority. And vice versa.

**Further to the previous point, 'sell the outcomes' internally.** Not just to those who are already sold, but to those who may not be. It may mean re-framing the investment with respect to its returns. Let's imagine a senior manager questioning "why we are spending all this time and energy on capacity building work – we don't have the resources?!". We could say "because it's important, and people need the investment, etc., etc." or we could say that by building capacity we will have X less phone calls, Y less emails, and Z more time in the long run by empowering others.

So, when considering organisational capacity: think deeply and broadly; think of those here today and those tomorrow; and think of the challenges as hard, but very much worth it.



# Growth and hope: Creating structures that enable the good life

Heather Batt

**Heather Batt** is a mother, wife, teacher and a committed lover of nature. In this article Heather reflects on her own capacity building journey with her elder sister, Myrtle. She explores how our structures of belief and thought are shaped over time and how capacity is built as our relationship to these structures grows and develops.

Heather lives in a 'beach infested' town in central Queensland. Recent opportunities have enabled Heather to witness Myrtle unfurl her wings and emerge into a new life of colour and joy.



## Growth and hope: Creating structures that enable the good life

### Zen Tower

*Selecting and stacking smooth, rounded beach stones, so perfectly formed by waves pounding over time - each stone solid and beautiful, balancing on the larger one beneath.*

*A zen tower of serenity and balance.*



### Timber House

*A timber house frame built on a slab - designed, cut, measured and constructed to plan.*

*Safe and secure.*



### Sandcastle

*Hands dribbling wet sand making magical sandcastles with unexpected towers and turrets.*

*A masterpiece of the moment, gone with the next tide.*



### Snowman

*Enduring biting cold to crush ice and slap snow into a snowman that's not quite as imagined.*

*Gnome-size or garden giant, depending on how long you and he can endure the climate.*



## Capacity building.

**Building** means creating. Creating happens in various ways.

Sometimes it's through careful selection of what is found naturally around us according to what feels and looks right. We rely on a personal sense of completion and satisfaction which can alter as we build, as circumstances and environment change.

Creating can be taking a fistful of sand, letting it trickle onto a specific place, guiding where it may fall and watching the ordinary become magical.

Or it can be bitter experiences that create something new in us that we try to make sense of. Such creations are often transient, a cold structure that gives way when warmer experiences come into our lives. They meet a need at a point in time but are reactive, fragile and created out of urgency.

Other times building is planned, according to rules and measures with specific materials and tools, with expected outcomes within typical timeframes. At these times our actions are considered and we feel in control.

Who we create with can impact what is built. Some building happens solo, some requires a team of experts, some invites friends and families in to assist while others attract strangers who want to join the project.

The dictionary defines **capacity** as "the ability to hold; the full potential; the amount contained".

**Capacity building** therefore infers creating more ability, more potential, expecting more.

Capacity building in my life has happened through various experiences and taken many forms.

A strong family work ethic and this motto set me on my capacity building journey:

*'Good better best, never let it rest, 'til your good is better and your better best'.*

Born in the early 60's, my childhood was a mix of stereotypical families and conservative social policy (e.g. White Australian policy) and new thinking that tested these (e.g. communes and greenies). With two siblings one attending a 'subnormal school' and the other an 'opportunity school' as they were known in those days, people with disabilities was my normal. I remember being in awe of the teachers in those schools – their total focus on the individual's needs and ability to function as much as possible in normal social settings equipped with life skills common to all. We attended many school functions so we were conversant with various disabilities and how to have a good time regardless of them. Inabilities were downplayed, ability was encouraged.

*My eyes were opened to see the value of my sister; someone whom I had come to see as a burden with nothing to contribute. I saw what she loved, what she did for others and how her existence created worthwhile outcomes and values.*

For me, university education promised financial and philosophical freedom. My post-hippy era lecturers introduced me to the wonders of Piaget and Bruner's theories of learning and I silently pledged to assist children to be their personal best. As an enthusiastic, young teacher, I soon developed a strong sense of justice. This capacity building was like the timber structure – designed for me and the future I wanted. Bureaucracy often got in the way of some great educational opportunities and I learnt to hack relentlessly through red tape. I realised institutions, despite meeting their own objectives, often failed to meet the needs of the individuals they were created for.

The year I worked as a relief special needs teacher in a mainstream P-12 school, I was introduced to formal assessments used to determine level of capacity (disability). I noticed a gap between my thinking and other professionals. Being involved with people with disabilities had given me an appreciation for the fact that people are people, regardless of capacity, stereotype or perceptions. Those life experiences while growing up were like the strong stone tower in me, constructed by a greater, unseen hand.

During parenting, my children taught me much more than my degree. I learnt to stop worrying about deficit and work with ability. I concluded that established systems settled for less for minorities, often laying blame for the system's inadequacies on those vulnerable individuals. Authorities believed they themselves had full rights regardless. I discovered through various experiences, including my sister's, that institutions can be as small as a home or as large as a prison. Our experiences within the disability sector were like snowman

constructions, built under extreme conditions on icy experiences – a poor resemblance of a real life. Thankfully these efforts dissolved once warm human services gave us more sunny experiences to build with.

Getting help typically relied on focussing on what my sister couldn't do. Utilising that help meant I had to portray a positive picture of her to promote productive approaches to really meeting her needs for the life I knew was possible. Advocacy became part of everyday life during the bitter times - often a thankless, soul-destroying pursuit. Baring yourself and your aspirations seemed to lead to bearing more alienation, restrictions and anxiety. Hence I sought help from other sources. Disability-friendly advocates and organisations built my capacity to challenge and to persist in my hope for societal change.

I prioritised intentional learning experiences. A paradigm shift occurred for me at my first workshop by an organisation called Pave the Way. My eyes were opened to see the value of my sister; someone whom I had come to see as a burden with nothing to contribute. I saw what she loved, what she did for others and how her existence created worthwhile outcomes and values. I saw how community could support her and how she could contribute to community. I saw ability not inability. I began relating to organisations like CRU that existed because of their lived experience and desire to help others. I had the formwork of a building I felt I could trust.

It was the deep quality Optimal Individual Service Design (OISD) course (developed and lead by Michael Kendrick), that reinforced that foundation. This profound course taught me much about myself and how we can help people with disabilities dream a different dream and how, collectively, we can help make that dream a reality – a reality that one day will be commonplace. This course drew on all my experience and knowledge, and gave me opportunity to learn from so many others. Addressing 20 universal needs, I learnt to see past previous, limited belief systems, seemingly set in stone. I saw the world that is often built-up around the person with a disability. I also saw a different world that a person can build for themselves.

It gave me courage because I felt I was not alone – others had done and were doing this. I learnt it wasn't funding, but what you could do with that funding, that made change happen. This gave me the foundation on which to imagine what life could be like for my sister and capacity to believe in dreams.

Through attending workshops in preparation for the National Disability Insurance Scheme (NDIS), a new way of funding support in Australia, I could see hope for a good life through the introduction of funding based on need. A journey benefits from knowing your destination - but requires faith to take a first step and keep going. That first step was demolishing the ugly structure that had been built around our sister. This was messy and overwhelming but pure grit got me through. I learnt so much about the power of services in that experience and it was obvious self-managing was the only option that would give us the autonomy we needed. This understanding greatly enhanced my capacity to act.

The introduction of the NDIS, has resourced us to focus on assisting my sister to enjoy a full, rewarding life based on her goals, her desires and her strengths. This assistance, apart from the funding, relies on our capacity.

Over time, our capacity is increasing, building on the capacity gained through experience. Some of this learning naturally follows from doing, whilst other learning is intentional and planned. Through reflection we can see how our experiences and knowledge, over time, have contributed to building our capacity.

Desperation often brings the opportunity to attempt structures that may not be forever but allow us to dream - like grabbing sands of time and creating castles. By thinking outside what had been offered to my sister, good and ordinary dreams and aspirations (previously not thought possible) were set and outcomes previously dismissed have been achieved. The framework and foundation are solid, yet the building, like all art, can be crafted over time. With clear objectives for guidance, I have learnt to trust my 'instincts', and just do it, trusting that the 'how' will happen. Others have joined the journey. People who love the dream and the creation of its reality are far more capable and important to have in our life than those who solely rely on their label of 'expert'.

I have capacity I never thought possible, yet it's like it has always been there - like the building materials, the rocks, the sand or the snow, the knowledge that comes over time has helped me organise that capacity into a structure that acts as scaffolding for my sister to build a valuable life of her own. We have a structure that enables action; action that enables change and we are finding that this change brings good outcomes for my sister, myself and our community.