

## Editorial: Investing in the future - What one person can do

The articles in this edition of CRUCial Times are taken from speeches delivered at an event that CRU hosted in Brisbane in November 2017 entitled “Investing in the future: What one person can do”. The event was to both mark the fact that Dr Michael Kendrick has been visiting Queensland for 30 years and to reflect on some of the important leadership concepts that he has brought to us in that time. These ideas and frameworks have challenged, positively influenced, and continue to inform how we work with people with disability throughout Queensland.

The five speeches from that night have been converted to articles. Each of the speakers took a topic and spoke from their own experience and we have worked with them to convert those speeches into articles for this edition of CRUCial Times. Danielle Mason spoke of the need for values based leadership and spoke of the challenge of putting that idea into practice in her work in the sector. Narissa Wilson explored the concept of being in right relationship, drawing on examples from her own life where she directs a team to get the support she requires. Fletcher Tame, as a manager within a large human service, looked at the benefits of bureaucratic shielding and how that idea has shaped his day to day work and Bianca Gamble discussed the importance of building networks and having allies. As the mother of a young child with a disability she spoke of the many different layers of alliances and networks that will help her son, both around their family and much more broadly. In addressing the topic of what one person can do, Michael Kendrick reminded us that wherever we are, we have choices on how we conduct ourselves and what we focus on and that the actions of everyone count. However, as effective leadership is a collective pursuit not individualistic, a leader will need to work with peers and followers to create change.

Through the speeches, some strong and consistent messages emerged. We heard examples of taking a lead without waiting to have a formal role; saying what you need to, getting clear, taking action, being strong enough to apologise and to do better and to work with others to make things happen. From their different starting points and perspectives, the speakers painted a vivid, personal and hopeful picture of what we need in leadership in the future.



### AUG 2018 ISSUE 54

#### Editorial

Margaret Rodgers 1

#### Value based leadership: Staying true to what really matters

Danielle Mason 3

#### Reflection on Right Relationships

Narissa Niesler 6

#### Whose needs are being served: The benefits of bureaucratic shielding

Fletcher Tame 9

#### The alliances and networks of collective leadership

Bianca Gamble 11

#### What one person can and cannot do

Michael Kendrick 14



I also spoke, acknowledging Michael's contribution since his first visit here in 1987. He is perhaps best known for his workshops; his writing and teaching; insights and reflections and in more recent years the ten day Optimal Individual Service Design (OISD) course. As I said on the night:

"I am very aware that he has also quietly contributed many more things to the lives of people with disability in Queensland. He has worked with our government on evaluations, training, meetings and side meetings; and contributed his thinking to some very big issues. Over the years, Michael has put himself out to try to improve the lives of some of our most vulnerable Queenslanders, often in his own time, and I want to thank Michael for his generosity. He has connected us to each other, to the rest of the country, the rest of the world and challenged us and encouraged us to imagine better. I thank him on behalf of the many people who have benefitted from his input, those who joined us to celebrate with him and those who don't even know who he is, but whose lives are better and safer because he has been coming to Queensland for 30 years."

170 people joined us for the forum and dinner and we have included photos of the night.

**Margaret Rodgers**  
Chief Executive Officer



## CRU Board Members 2016-2017

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

## CRU Staff

CEO  
**Margaret Rodgers**

Senior Consultant  
**Lisa Bridle**

Consultants  
**Catherine Laherty**  
**Danielle Mason**  
**Hugh Rose-Miller**  
**Jen Mouritz**

Administration Officers  
**Kathleen Fleming**  
**Kim Jensen**  
**Bobby Noone**  
**Kerrie White**





# Value based leadership: Staying true to what really matters

Danielle Mason

**Danielle Mason** has worked in various roles in the disability sector, including as a support worker, team leader and coordinator after completing studies in Psychology. Her current role with CRU is focused on sustaining the work of the organisation into the future.

Danielle is particularly interested in the role of workers and services in the lives of people with a disability and uses Social Role Valorisation (SRV) theory to inform her thinking on how to be respectful and helpful. Outside of paid work Danielle is a mum to her young daughter and is a committee member of Values in Action Association. Danielle explored the need for values based leadership and reflected on the challenge of putting that idea in to practice.

## Value based leadership: Staying true to what really matters

No doubt you will have, like me, faced situations in your life where you just didn't know what to do. Or maybe there was a niggling feeling of doubt about whether you were doing the right thing or making the right decision. It's inevitable that we'll be faced with uncertainty in our lives and it's impossible to always get it right. But when my decisions and actions have been congruent with the values and principles that I try to uphold, that's when I have tended to sleep better at night and feel at least relatively confident that I'm doing the 'right' thing.

For me, values based leadership is taking on leadership, or showing leadership, in a way that stays true to the things that guide us, so that we are led to do the right thing, or to do good. Or as Moon puts it:

*"Moral leadership is guided by the shared principles and values that manifest in the noble qualities of human nature. It does not reflect any self-serving personal or political interests but benefits 'the greater good' of humanity and affirms the intrinsic value of every person, regardless of ethnicity, nature of origin, or station in life."* Hyun Jin Moon

That is, values or principles are the inner ideas or concepts that guide us, a framework that steers us in the right direction. If we hold positive, life affirming values then our actions and behaviour are also likely to be positive and will result in us doing good.

We often talk with people with disability and family members about having a positive vision for the future and I can see that a set of guiding principles could be similarly useful for workers. Without values to guide you then it's easy to flounder or flail, to make decisions on impulses or on a whim, rather than being driven by something deeper or more purposeful. Without values it would also be very easy to be lured off track; if we aren't clear on our principles and values, and what's worth standing up for, then we might just go with whatever seems popular. But that might not necessarily be the 'right' thing to do.



Upon reflecting on my own guiding values, I realised I have some higher order values like:

- Treat others as you wish to be treated.
- A belief in all humans being equal and having inherent rights.
- The importance that I place on acting with integrity and honesty.

Then there are some specific guiding principles that I could identify that relate to my work with people with a disability, things like:

- People with disability should be part of ordinary communities alongside their peers.
- Individual, one-person-at-a-time approaches are preferable to congregated service responses.
- The person with disability should be kept at the center of their own life so that the authority and decision-making rests with them and their family or close friends.
- Paid support shouldn't get in the way of freely given relationships.

Through this reflection I came to realise that these values haven't always been what have guided me. My values have been shaped and refined over the time that I've worked in this sector. They've been shaped by the people I've been surrounded by, the experiences I've shared, and the learning opportunities I've been exposed to. While I can't speak for everyone I would guess that this is a common path for many workers entering into this field.

When I started working as a support worker I was most definitely floundering with no guideposts to show the way. I wasn't really quite sure what my role was in people's lives and looking back I can see that I held plenty of unhelpful assumptions about people with a disability. Luckily for me I was exposed to Social Role Valorisation (SRV) training pretty early on and a light bulb came on. I now understood what I was supposed to be doing as a support worker - helping people to have access to the good things of life. Something in that training resonated with me. I've heard it said a number of times that SRV isn't values training, but it is training that engages our values. It shines a light on our thinking and brings to consciousness the beliefs we hold that may be either helpful or unhelpful.

I then began to seek out more and more training to help inform my practice. I started to spend time with more and more people that had their own very clear set of values based frameworks that gave them a foundation for their lives, the life of a family member, or in their work roles. In this way my thinking and beliefs were shaped by the people who've gone before me - people who have shown leadership by acting in accord with their values.

It's through my association with these values based leaders that I've developed into the person that I am today. Some of those people have been teachers and presenters, others have been supervisors, colleagues or mentors, and others have been the people with disability and families that I've worked alongside. It's through their example that I'm encouraged and kept on track in my efforts to be clear on my own values so that I will hopefully make a positive contribution to people's lives. Knowing that our behaviour flows from our thoughts and beliefs, whether they're conscious or unconscious, we can spend time fine-tuning our moral compass so that our actions are likely to be in keeping with those principles.

All of this got me thinking about what I've done to demonstrate values based leadership. I wondered, "Had I done anything at all?" "Do I have anything to share with others that's worth talking about?" What came to mind most easily were the times when I realised I hadn't been acting in accord with what I was telling myself was important. It's in these moments that I came face to face with my values and had to decide to act differently.

For me, one of these occasions was during the Optimal Individual Service Design (OISD) course, led by Michael Kendrick. As I sat and listened to what was 'optimal' I was thinking about how I'd been relating to the family of one of the people that I was supporting at the time.

The mum and I had a tense relationship, to say the least. She had high expectations about how her son was to be supported and I often fell short of those expectations. I was convinced that I knew what was best and would regularly challenge his mum's wishes. With all the power of the organisation and my role titles behind me, I was rude, domineering and dismissive of her opinions.

*Without values to guide  
you then it's easy to  
flounder or flail, to make  
decisions on impulses or  
on a whim, rather than  
being driven by something  
deeper or more purposeful.*

When Michael talked about 'power over' relationships during the course, I felt ashamed of my behaviour towards this family.

When Michael checked-in with me one day during the course I told him that I wasn't feeling too great when reflecting on how I'd been acting. He looked at me and calmly said something along the lines of "well, you could make a commitment to work differently with people from now on." A pretty simple statement but it had a huge impact on me.

So I resolved to do things a little differently. I listened to the mum's concerns. I apologised when the service or the team or I made mistakes. I made an effort to remain calm in our conversations and keep emails pleasant. I tried to put myself in her shoes and consider her point of view more often and I tried my best to resolve issues in ways that met her needs and the needs of her son, rather than thinking only of the needs of the staff or the service.

It wasn't easy to do and I didn't always get it right, but I think I did better than I had been. By the time I moved on from that role four months later the mum and I had a pretty good working relationship. We decided that I would stay in contact with the family to continue to support them during what was a bit of a tricky period. This was a pretty huge turn around, simply from shifting my own behaviour to

be consistent with the values that I espoused earlier – that the authority and decision making rests with people with disability and families and the notion of treating others as you wish to be treated. What I also learned was that when I treated the family better, they were then more willing to work collaboratively with me and treated me much better in return.

No doubt I will again be faced with similar ‘ah ha’ moments into the future. Although it is painful, acknowledging that my actions are inconsistent with my beliefs allows me to continue to learn and grow and become clearer on what’s right and wrong.

Staying true to my espoused values doesn’t come without some effort. For me, the thing that is most helpful for keeping me on track is being around people that have a shared sense of the values that I think are important. I’m fortunate to work for an organisation that encourages conversation and reflection about what drives our work and leads to positive outcomes for people with a disability. In my committee role with Values in Action I work with others to further the use of SRV. Not only do these groups of people set an example of how I would like to be but they would also let me know if I was not acting in accord with those shared values.

*Not all actions that are consistent with values-based leadership have to be large acts or big, public announcements of what one stands for... Taken together, each of our individual acts can result in much bigger changes.*

Secondly, spending time reflecting on my own values alone and with others is invaluable. The process of articulating my values, shining a light on them and looking back on my actions trying to work out if the two were lining up was deeply insightful for me. What I learned was that it’s ok to admit when you could do better and decide to make that happen. Perhaps this process of reflection will also help guide my future actions in the moment, rather than just looking back at what could have been done differently.

Not all actions that are consistent with values-based leadership have to be large acts or big, public announcements of what one stands for. Sometimes they’re the everyday decisions that we make to act in certain ways and through our actions we might also set an example to others in the process. Taken together, each of our individual acts can result in much bigger changes.



## Inspiring, Connection, Acting for Change

3 events to mark 3 decades  
26th & 27th October 2018

This year CRU celebrates its 30th Anniversary.

We invite you to join us on Friday the 26th & Saturday the 27th October for three events to mark three decades.

[cru.org.au/3decades](http://cru.org.au/3decades)

**BRISBANE CONVENTION AND EXHIBITION CENTRE**



### EVENT 1 Friday Workshop

Being Realistic Isn’t Realistic:  
Discovering Potential,  
Realising Dreams

International presenters Norman Kunc and Emma Van der Klift are well known disability rights advocates. They will deliver an inspiring workshop.



### EVENT 2 Friday Dinner

A dinner to celebrate 30  
years of CRU

Connect, share and remember in order to look to the future with hope and optimism.



### EVENT 3 Saturday Forum

Honouring the Past:  
Embracing the Future

Six storytellers, from a range of perspectives, will focus on the outcomes of some of the change strategies CRU has invested in over 30 years.



# Reflection on Right Relationships

Narissa Niesler

**Narissa Niesler** (née Wilson) is a leader, designer, manager and someone who is passionately focused and committed to inclusive communities for people with disabilities. For the past decade professionally, Narissa has led highly productive teams within the IT sector and founded a small web and graphic design business.

Narissa is based on the Sunshine Coast, has recently married and is a passionate foodie. She advocates and manages her own supports and services which she has been self-managing since 2009. Narissa spoke about the concept of right relationship and drew from her experiences of managing her own team of support and the lessons she has learned.



## Reflection on Right Relationships

For our four month wedding anniversary, my husband Steve and I received a surprise gift from my niece Isabelle. She had drawn us a picture of the characters Anna and Kristof from the movie Frozen because the characters “are in love, just like Auntie Rissa and Uncle Steve”. This picture, and the lovely message that goes with it, demonstrates that in her world, relationships and love are freely chosen for all. In her world she doesn’t see me in my wheelchair, as being any different. She just sees me.

Relationship is defined as “*the way in which two or more people or things are connected, or the state of being connected*”. There are so many layers to my web of networks that it helps me to have filters for what each relationship is and how it sits within my life.

For me, there are two types of relationships that exist; personal and functional. My personal relationships are with people I have chosen to be a part of my life in a valued way because I like that person and have built trust with them over a period of time. These are people such as my husband, family, friends and members of my community.

My functional relationships exist to serve a specific purpose. They are generally relationships that have parameters and a certain element of order and structure to them. I have functional relationships in my professional life, such as those within my business, but in this article I am focussing on the relationships with my host providers and support workers.

Relationships are, by their nature, quite personal and carried close to our hearts. For me, the concept of right relationships within my supports and services are those that are valued and empowered. So when I was first asked to explore the topic of right relationships, it challenged me because it all seems like such common sense. It is how healthy relationships should be.

I have been fortunate to have parents that really paved the way for right relationships in my life. I did not really think about my family’s principles when I was growing up, but looking back I can see they were really quite intentional and have shaped who I am now. These are principles such as respect, honesty, freedom, teamwork, exploration, sharing and celebration. For me, these principles are the foundation of a right relationship.

Even with the best of intentions, relationships can be messy and like all things in life they change and take different forms over time. I have had functional relationships grow into personal ones; albeit with a lot of intentional nurturing and sometimes stepping around some of those grey areas. On the flip side, I have had a personal relationship grow into a functional one which led to upheaval in my life.

At the age of 17 I moved out of home with no paid support. I lived with friends in a share house and it was these friends who informally



met my support needs. This meant that at this point in my life these personal relationships, which made up 90% of my relationships, were fulfilling the functional role of meeting my day to day physiological and safety needs. As these personal relationships slowly morphed into functional ones they broke down and I was suddenly left in a vulnerable situation. As the friendships came to an end, so did my supports and living arrangements.

It was at this point I started building a more sustainable and secure future for myself, eventually securing paid supports. With the introduction of support staff in my life, I really had to start taking the lead with the relationships in my life and being very clear and intentional with them. I had to learn how to compromise, negotiate, influence and manage my interests so I could continue to live an independent life.

Up until this point my parents still assisted with negotiating my functional relationships. I don't think there is ever a point where family step down but this was definitely a time where I had to step up. I needed them to hand over the unspoken authority so I could become ultimately responsible for creating and maintaining these important relationships. I had to focus on my vision of inclusion and share this with the people that were about to come into my life in a very functional way.

I definitely did not get it right in the beginning and it took a lot of trial and error to get where I am today. There were lots sleepless nights, tears, phone calls to mum and moments of doubt questioning why I was putting myself through this. I asked myself, 'is living independently really worth it or should I just succumb to the institutionalised pressure and go to that group home?'

After two years of receiving support from a traditional service provider there was fractured trust and angst surrounding the delivery of my supports: we had a different vision of my future. After searching for a service who matched my DNA, I found them! They embrace my constantly changing goalposts and collaborate with me on creative approaches that ensure my supports and services are delivered in ways that uphold my vision.

My service works with me like any good mentor. They get excited by my hopes and dreams, they share the successes, they challenge me in ways which keep pushing me forward and I know they have my back.

What facilitates the creative approaches to my supports with my service is; we share the same values and vision. Their service values and visions walk side-by-side with my core values and vision for my life. There is a common understanding that service delivery doesn't have to be perfect because life isn't perfect but we do what's best at that given point in time.

There is a common understanding that we all do what we can to ensure the sustainability of my vision. The collaboration is clear because both the service

***The collaboration is clear because both the service and I know what is expected of each of our responsibilities surrounding the business of my supports.***

and I know what is expected of each of our responsibilities surrounding the business of my supports. Because the expectations are clear service systems are not an imposition and keep my vision at the heart of service delivery.

When I first moved out of home and I had little formal support, only 10% of my relationships were functional. Whilst now up to 70%, the functional relationships in my life service a very specific purpose, with order and structure that I influence.

These functional relationships have a real impact on my quality of life, so when my biggest asset is not operating in line with my vision, breaks or moves on, I can get emotional, upset and frustrated. The best version of me does not shine through and my basic physiological and safety needs are not met and therefore during this time I become more vulnerable. It is at these times the safeguards I have developed come in to play and I can rely on my plans B, C and D.

Self-managing supports and services is definitely always a work in progress and every day I endeavour to improve how I operate and manage them. Over the years, I have become more skilled at recognising functional and personal relationships and the role they play in my life and this helps me to address issues that arise in a more timely and specific manner.

***With the introduction of support staff in my life, I really had to start taking the lead with the relationships in my life and being very clear and intentional with them.***

Some strategies over the years that have helped me to achieve respectful functional relationships are to:

- **Be clear about the purpose of the functional relationship – both at its conception and as it continues over time.** I make sure I keep my personal relationships and life sacred. One simple strategy of not merging the two worlds is to not add anybody to my Facebook that I have a present functional relationship with. When that relationship is no longer a functional one it may become a personal one, but that is a choice I make depending on my relationship with them.
- **Review my functional relationships.** Have honest discussions and make plans to move forward from the stuff that is not working anymore. This could be applied to any context whether it is the big picture stuff with my service or the day-to-day stuff with my support team.
- **Trust my safeguards.** They are there for a reason and can alert me to things I might otherwise dismiss. My safeguards are everywhere, intentionally. They are the people in my inner circle such as my husband and family. People in my broader circle who are safeguards in my community, such as the neighbours on the corner who I wave to on my walk, the friendly faces at my local shop, people at the local coffee shop or the ladies at yoga. However, don't forget the most important safeguards, the ones I choose, my friends.



• **Ensure I employ the right people.**

By employing and engaging with people who are the right fit for my vision, it saves me a lot of time and energy in the future.

• **Invest in the people who support my vision.**

Sharing a meal with those I am close with is a core value of mine. I have a gathering every 6 to 8 weeks with all my supporters - paid and unpaid - where we gather, share a meal and communicate. We don't talk about the nitty-gritty of my supports. We look at team building philosophies, reflect, strategise and align ourselves with the common goal – my vision.

My mum has always said that it is up to us to educate those I work with on how I want my supports and services to be, so it is important that we operate from a very honest and open platform. It is equally important that the people I work with are willing and open to learn about, and get on board with, my vision and align with its DNA. If things are not working out then I need to speak up and work with and educate those people.

As we aim for greater levels of empowerment for people with disabilities the concept of right relationships goes to the heart of this issue. I have seen how respectful and functional relationships help develop greater personal fulfilment, belong and have assisted in my own self-actualisation. Ten years ago if I didn't refuse the suggestion of a group home, take the leap to invest in my future and build the right functional relationships, then Isabelle's picture of her Aunty and Uncle would look very different.





# Whose needs are being served: The benefits of bureaucratic shielding Fletcher Tame

**Fletcher Tame** has worked in community services for over twenty years; around half that time in management roles. His work in the disability sector began in 2010 and shortly after he attended an Optimal individual service design (OISD) course, facilitated by Michael Kendrick & CRU.

Fletcher strives to find, make and improve ways of using systems to support people, instead of the other way around. Fletcher spoke of how, as a manager within a large human service, he applies the notion of bureaucratic shielding to his day to day work. Fletcher is a director on CRU's board.

## Whose needs are being served: The benefits of bureaucratic shielding

Humans have, for a long time, organised themselves and their resources into bureaucratic structures to get things done. Unfortunately these structures can easily become almost self-sustaining to the point where more effort is required from people to support the system rather than the other way around. It's the tail wagging the dog.

In human services this can mean that priorities and "what's important" moves away from serving people to something else. This phenomena of 'process before people' is a potential vulnerability of all systems and is not restricted only to large service providers.

"Formal" disability services and supports are almost entirely funded and delivered via bureaucracies (large and small). It follows then that even with the noblest of intentions, disability services delivered in this way are inevitably prone to deliver the darkness of 'the system' along with any light that comes with 'pure' support.

As the old state-based bureaucracy is on the way out and a new federally administered bureaucracy is coming in, service providers are re-organising and restructuring themselves accordingly.

While I can accept that this is probably required in order to improve what we have been doing to date, I am left wondering how do we do that without that impacting on the people we serve? I think bureaucratic shielding is a big part of the answer.

I first heard of Bureaucratic Shielding at an Optimal Individual Service Design (OISD) course in 2010, run by CRU. The concept was something of an epiphany for me. I was new to the disability sector and confused as to why I needed to know about building codes, fire safety, CPR, food preparation - and why did everyone I work with put so much time and effort into stuff that didn't seem to have anything to do with people? The course helped me put my reality into a different context and reassure me that I wasn't the one missing the point of our work.

### So what is Bureaucratic Shielding?

To me, Bureaucratic Shielding is the actions a person can take to intentionally protect people from the destructive, de-humanising, incoherent or largely irrelevant aspects of organisations and systems.



This means working in a manner, and behaving in a way that promotes interpersonal focus and connection, over the impact of non-personal systemic and organisational factors on people. This applies to the people we serve, their families and supporters as well as paid staff.

Examples of this include:

- using plain English instead of jargon and technical language;
- being transparent, available, approachable and not only relying on formal meetings to discuss issues;
- creating space for teams to talk about how their support is/isn't being effective, instead of focusing on organisational matters;
- not overloading workers with a set of tasks, checklists and procedures so that they are so busy they don't have time speak to the person they are there to support;
- not putting organisational needs and funding considerations ahead of people's human needs. For example, making people who have never met and may not even like each other, live in forced co-tenancies.

## What action have you taken because of it?

Because it is so easy for systems to focus on their own needs and not the needs of those they support, we need to be ever-vigilant; this is always a work in progress. That said, I'd like to highlight five actions that can help:

**1. Awareness** - Being aware of and reminding myself of the real reason this work is important. What I do must somehow lead to a person's life improving. It's not about getting my paperwork done.

It's also about being aware of the context in which I work and the extent to which it impinges on what I do and am asked to do. Legislation, funding, service agreements, industrial matters and office politics are part of the program in many ways and can be very important for the organisation. As a manager they are my responsibility; they are not the responsibility of the people who use our service and we should not pretend they are.

**2. Pushing back** - A CEO I once worked with said "ask yourself what is the link between what I am doing now and benefit for people with disability. If you can't see one, then ask yourself if you should be doing it at all".

Sometimes, you need to say 'no, I'm not going to do that'. I am not advocating being rude or pushy but rather being clear about what your purpose is and how your activities deliver on what your role has promised to deliver. So say no, where you need to.

**3. Absorbing** - Inevitably things will come to you that you cannot push back, so you absorb it.

For example, you call the department on behalf of that family; you take the time to explain the funding to the person because the email was too complex; when Workplace Health and Safety want to train support staff in asbestos management - your senior management group gets the training because there are fewer of them, they are already in the office and they will pass the info on in a way that individual teams need, thus protecting their time and resources for people and their families.

**4. Co-create** - If it cannot be avoided, find ways to make the bureaucratic processes more relevant, helpful or accessible to the person you support.

Recruiting staff can and should involve the person receiving support, or at least a family member. Rostering, how funding is used, what and how support is actually delivered are all things that can almost entirely be dictated by the person and their family, with some assistance from paid staff. It doesn't have to be the other way around.

**5. Equipping** - It is not uncommon to see the intent of protecting people being taken too far, resulting in a person who is perfectly capable of much being limited to very little. Bureaucracies are part of life and it can be helpful for people to learn how to deal with life rather always be shielded from it.

Giving ideas, encouragement, information and your time to facilitate someone's learning about the system is essential in helping them to drive their own outcomes. You don't have to be qualified, or a genius, or super-knowledgeable about it all. You just need to commit and follow through in enabling a person's growth and independence when it comes to system-wrangling, making their own decisions and speaking for themselves.

*Because it is so easy for systems to focus on their own needs and not the needs of those they support, we need to be ever-vigilant; this is always a work in progress.*

## Why is this concept important for leaders in the future?

It is important to point out that most leaders are not in management roles, so we must not leave this only to that group.

Australia's new national funding scheme promotes choice and control within a market driven by participants. Customer service is the framework de jour. This is a major shift in how services are provided when in reality, a lot of people have never been seriously asked before what they want or how they want it done; or aren't listened to respectfully when they do express their wishes. There is a conundrum for service providers as they adapt their models to fit the new scheme and navigate this period of change whilst meeting the timely hopes and aspirations of those they serve. They need to be clear on their purpose and priorities because what people really need is time and respectful, abiding commitment, not Policy Direction to get them through this.

The ongoing corporatisation of community services has highlighted the dual tensions of "Money vs Mission". These things are essentially incompatible and have always been, but this combination is now "the way things are". This is why more than ever, we need to be able to identify and deliver what is important to people and their families and do that in a financially sustainable way. We need to find ways to meet the needs of individuals without commodifying them in the process.

Being very clear about the purpose of your work, your role in it and what success looks like - as measured by the people you serve - is critical. Being aware of how quickly systems and bureaucratic requirements can become all-consuming and the importance of keeping focus on what matters to people will guide us all in what is to be shielded and what is to be embraced.

So when it comes to Bureaucratic Shielding, what one person can do is stay aware; push back; absorb, co-create and equip because a better life is unlikely to be achieved through asbestos management training.



# The alliances and networks of collective leadership

Bianca Gamble

**Bianca Gamble** is a mother of three children. She is determined to create a full and valued life for her 8-year-old son Liam, who has Down syndrome. She believes in the power of Family Leadership and works to influence others to pursue an inclusive life for their family member. Her current focus is advocacy for all children's right to an Inclusive Education.

Bianca has a background in Psychology and Human Services, is an active member of CRU's Disability Leadership Project and the QLD Collective for Inclusive Education (QCIE). Bianca discussed the importance of building networks and having allies when in engaging in change.

## The alliances and networks of collective leadership

My son Liam is only 8 years old, so it really wasn't that long ago that I was holding him as a newborn. At that time, I had absolutely no appreciation for the efforts made by a community of people to ensure that he would have the chance, like his siblings, to lead a good life.

His current opportunities, education and belonging at his local school, and general rights as a human being are not due to the efforts of one individual, but to an alliance, who have challenged the deeply embedded inequities within our society, to make his ordinary life a reality.

They are people who share a common belief and vision, moving our society forward to create change. I could not be more thankful for the ground that has been made, while at the same time, being so aware of the distance we still have to go.

When Liam was a baby, my contacts, relationships and networks were not nearly as intentional as they are now. I was referred to various early intervention services, introduced to "special" activities and found myself in a variety of different circles. The messages were mixed and much of what I was seeing and hearing did not sit well. I was becoming aware of the very different life outcomes for people with disability, with Liam's diagnosis and development seeming to be of major relevance. It was confusing and unsettling to say the least, being led to believe that my son's opportunities in life, may be restricted by factors beyond our control.

When Liam was around 18 months old, I was lucky enough to meet a parent, Lisa Bridle, who spoke about her teenage son in a way I had not heard before. She talked about his wonderfully ordinary life being full of typical experiences, and a vision for his future that was not predetermined or limited by low expectations.

This conversation was the very beginning of my realisation that full and equal participation, access, opportunity and inclusion in all facets of life, are



fundamental human rights and that people with disability are being deprived of these rights in so many areas of our society. A perspective that is so obvious, yet still eludes so many. This new found awareness made me utterly disappointed in the ableist world that we live in, and gave me such clarity at the same time.

I was soon introduced to CRU, which in time, led to the discovery of a whole network of people who share some really core beliefs and values; who see the beauty of diversity - appreciating people with disability as equal members of our society, deserving of so much better.

When Liam was approaching kindergarten age, there was an expectation that he would attend the Special School's Early Childhood Development Program (ECDP), rather than or in addition to Kindergarten. This was an expectation that I felt from many different people, believing that it was most appropriate and suitable educational setting for Liam, being a child with developmental delays.



I was repeatedly questioned by our paediatrician, therapists, and even other parents of children with disability, as to why I would deny him such a beneficial opportunity. A segregated environment was not what I wanted for him as his precursor to school and not where I wanted my 3 year old to spend his time. Despite being quite sure of my own judgement, I felt the pressure to conform to society's expectations of what was the right setting for a child with a disability. It was the connections that I had made with that network of people that gave me the confidence to say "no". At that time I needed the support of others who understood my reservations and what was offered did not align with our desire for his life to take a typical path. Although I feel even stronger in my convictions now, I know that this support will give me strength to stand up for Liam's rights, in the future.

We are seeing such a growth in the disability industry with new specialist schools, fads and technology, as well as disability specific sports, activities and social options. I can completely understand how parents find it difficult to decline invitations and opportunities that are presented in such a positive way, by "well meaning" people who claim to have your child's best interests at heart. Like those who have been there for me, I hope I can be that support for other parents when facing these barriers to inclusion.

I just feel so fortunate to have had the opportunity to meet and learn from so many thought provoking individuals and organisations, gaining valuable information and insight. My family and I have benefited enormously from these connections. We have learned so much over the last 6 years, about what contributes to a good life. About the importance of having a clear vision for Liam's future and choosing the path that will get him there. We are implementing this knowledge in our lives, making very intentional decisions to ensure that Liam is included fully in school and community, and participating in all aspects of life as a 7 year old boy.

I have a clearer perspective of where we are today, by learning more about the history of disability in our country and the gradual shift that is occurring. As my appreciation has grown for those who have fought for change, so does my desire to contribute. Not only do I want a full, rich and meaningful life for Liam, but also this inclusion and equality for our society as a whole. The segregation, rejection and devaluation of people with disability is a major systemic issue which requires collective action.

When asked to reflect on the topic of "Alliances and Networks" it took some time to really get my head around what this concept means for me and my family. It felt a little odd to be referring people in our life as 'allies and networks', when I really just think of them as important relationships. For the purpose of trying to paint a picture, I'll divide these relationships into two categories: both SO valuable in creating the life that we want for Liam and our family.

Firstly, we have the important people in our everyday life. Our family and friends who we love, as well as teachers, parents and children at school, families at Joey scouts, Liam's soccer coach and teammates – just to name a few. These people in our life may not be vocal in advocating for inclusion, but their language, attitudes and actions speak volumes.

As I said, Liam's life is so ordinary and these relationships and friendships are developed in the most natural way and at this point, they rarely if ever involve conversation about Liam's disability or our desire for him to be included. We just expect his participation like our other children, and for him to be involved in absolutely anything and everything that a boy of his age should.

We are absolutely intentional about building these relationships, but again, in a very typical kind of way.

We get together with kids from school for parties, playdates, get-togethers at the park. I volunteer in the classroom, chat to parents at pick up and drop off, at school events, at the kids' after school activities. I meet other Mums for coffee, lunch dates and ladies nights.

I am so aware of how these relationships within our community are having such a positive influence on Liam's life – and understand how important they are and will continue to be into the future.

I should point out that we are very conscious about investing our energy into the relationships I've mentioned, as this is where we want our life to be, and where we expect Liam to have relationships as an adult. I see an increasing tendency, particularly in this age of social media, to form connections and social circles with other families who have children with the same diagnosis. I can understand the desire to have these connections, however, I can also see how placing time and energy into being part of a separate "disability community" would interfere with and detract from leading an ordinary life.

Secondly, there are my relationships with others who are not generally a part of our day to day life, yet also play such a valuable role in achieving our vision for Liam.

***We are presented with the potential for positive change and achieving true inclusion, and contributing to this societal shift can only occur by being informed and connected.***

They are the relationships and connections with individuals and organisations who are actively and intentionally delivering the inclusive message and working towards our shared desire for equality. Being connected with other parents who are also choosing this typical path is invaluable. These relationships make pursuing an ordinary life far more achievable. Not only does it make the journey feel possible, but helps to know that we are not alone: being able to ask for advice when things get tricky and always having someone available who will understand and relate to the complexities of what we're facing is incredibly helpful. It is also helpful to have these people on hand, ready to pour you a glass of wine when experiencing the inevitable highs and lows.

Being recently involved in the formation of the Queensland Collective for Inclusive Education (QCIE), I am seeing first-hand the potential of collective action, created by a network of individuals who share a common passion and drive. Although it is only early days, we are engaging in meaningful discussion and development of very deliberate actions, a task that would be impossible individually. We are very aware that our strength and authority is greater as an alliance, while valuing what we are each able to contribute individually. We are conscious in our efforts to challenge and influence perspectives. We understand that influencing others and gaining allies is a necessary part of increasing the momentum and power of our movement.

**Leaders in the future need to be aware of our history and be connected as allies to the previous generation of leaders - learning from their experiences, while developing an awareness of the challenges that lie ahead.**

Looking into the future, the concept of "Alliances and Networks" is extremely necessary for leaders to fully understand and appreciate at this time, as funding systems change in Australia. We are presented with the potential for positive change and achieving true inclusion, and contributing to this societal shift can only occur by being informed and connected. Leaders in the future need to be aware of our history and be connected as allies to the previous generation of leaders - learning from their experiences, while developing an awareness of the challenges that lie ahead.

As Michael Kendrick once said:

*"It is collective leadership that creates and sustains the social movements that transform our world and we must see that we are part of something bigger than ourselves, yet see that each of us can make a difference".*



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)



# What one person can and cannot do

Michael Kendrick

**Michael Kendrick** - In 30 years of visiting Queensland, Dr Michael Kendrick has become well known for his many contributions to improving the lives of people with disability. He is best known for his workshops, writing and teaching, as well as working with service providers, academics and government through evaluations, training and engaging in discussions.

Michael continues to be a close associate of CRU and uses his extensive networks to connect us with allies both locally, nationally and internationally. At the event, Michael reminded us that our individual actions do matter and when we work together we can achieve great things.



## What one person can and cannot do

### Leadership

We tend to think of leadership as something solely conducted by an individual independent of others, but it really is not that simple. Leadership is ultimately manifested collectively through people acting together, one person at a time, around a common interest. The great gift of leadership is that we all potentially have a role to play in it: when we co-operate with collective leadership, we make it stronger and the opposite is true – i.e. by refusing to join in collective action we weaken such action. It is through the lens of our interdependence and interconnectedness that we can act together for good or harm depending upon what our values actually are. In this sense leadership always reflects choices taken about values and morality, including both poor and virtuous choices.

### We are connected

Everything we do influences each other. Indeed, the great deception of human existence is that we are distinct individuals; separate people solely doing our own thing. In western culture we have developed an emphasis on atomized individualisation which creates the idea of “I am me, and you are you” and that we are separate rather than connected. The idea that there is a “we” can easily get lost.

The truth is we cannot afford to see ourselves as separate autonomously self-sustaining individuals, because we never were. Indeed, we cannot get what we need in life without attending to the needs of other people; interdependence is integral with the deeper humanity and viability of our existence. Look at how our lives are enriched, not by one person or two persons, but by all kinds of people each in their own way. Similarly, look at how often we can only achieve something when others join with us.

### What brings us together

What brings us together is shared values; the sense of a common destination that we ought to be moving to. These values help shape our vision of where we want to go. Initially, shared action is all about commonly held ideas and thoughts, but when we put these thoughts in to action, when we commit to our values and vision for what’s possible, then we are creating shared leadership. The shared decision to act on specific values and vision creates collective leadership. When things are “made to happen”, it always requires the common consent of people to values, vision and the direction of leadership as such an accord enables people to come together.

We are frequently challenged to learn how to best work together. Restraint, love and fairness to others all have parts to play because little is gained and much is lost by exacerbating conflicts between individuals and groups when it comes to acting together. At times, there is the momentary satisfaction of venting anger and rage, but what’s after that?



Heightened conflict, intensified disharmony and ultimately war.

Collectively, we can sacrifice for one another, rather than to put ourselves first, and that moral choice creates communality and cooperation. Western societies are not often described as having a culture of sacrifice for others, but when we look at how people actually live within their communities, families and relationships, they are not, for the most part, living solely an ethic of “me first”. There are other “pro social” ethics at work.

### Collective action

Most of the major issues of this world are bigger than any one person and this can lead people to question whether their personal thoughts and actions can have any meaningful impact in creating positive change. This downplays the heightened power of our actions, however small, when we work together towards a common objective. To quote Roger Waters, “each small candle lights a corner of the dark”. We each have one small candle and that one candle does bring light to the world. That’s the empiricism of our reality and there is something deeply meaningful in this creation of “shared light”. Each child is born; each human being makes a difference.

Collectivities make a difference. It is not individuals acting alone that make a difference; it is individuals creating and nurturing alliances that make a difference. Everything notable that we have achieved has been because of people pulling together. Most of us are nameless when we do that; but it is when people move in the same direction, that we change the world for better or worse. To revisit the metaphor, when we choose to gather together the light from our candles combines to shed more light than any one candle ever could. Similarly, we have also created “shared darkness”, not by acting together, but by making harmful collective choices.

The issue is not really what one person can do, it is what one person can do in relationship with others. This not a question of “me or you”; it is ultimately a question of “us” joining forces on so many of the things that might benefit human lives.

If we accept that each person has free agency, it means that each person can decide to make choices that could benefit the wellbeing of themselves and others. It means that our individual decisions create who we are going to be. That is the great privilege of free choice and yet this is also deeply troubling because we often enough make the wrong choices both personally and collectively. We cannot predict the future even as we shape it by our many decisions that are taken not knowing what will come of them.

Individually and collectively, what we do decide and then do can be harmful or not, so the source of virtuous conduct is to first do no harm and then seek to do what is good. We can both define ourselves by what we are going to do, but also by what we are not going to do. So it is important to remember we can always say “yes” to good things even when many others do not.

***It is not individuals acting alone that make a difference;  
it is individuals creating and nurturing alliances that  
make a difference.***

Another obstacle to collaboration is that we are in struggles with each other. So in the same vein, we can decide to engage in alternative ways. We can say, “Let us reduce the conflicts between ourselves and others. Let us reconcile our differences. Let us forsake the things that lead us to war and to unhelpful opposition”. History is rich with examples of people and groups who have done this. We could consciously decide, “Let us not make a bigger drama out of this than we have to.” It will add goodness to the world whenever we sincerely act to reduce the level of interpersonal and intergroup conflict.

### Virtuous conduct

“What one person can do” is to live as a truthful human being. It is easy to be deceptive, but we can often be truthful in a helpful way. Nonetheless, it is not easy to challenge the many myths, lies and deceptions that are present in our individual and collective lives. For instance, people working in the human service sector, often say “we are ONLY here to help the people we serve”, i.e. that is our primary purpose and agenda. Obviously, this claim is much too simplistic, self-serving and not the full truth. We are also here to take care of our colleagues, maintain the budget, complete the staffing roster, abide by the rules around our funding and so on. It is important we keep our own rhetoric in check. That task may only be accomplished by regularly challenging ourselves to uphold a greater degree of truthfulness.

So everybody can be in favour of anything, until there is a price to be paid for it. That said, people are more likely to do something when they are prepared to pay the price. Truthfulness will also come with its own costs.

Equally, there will be a personal price to pay for doing no harm, as harmful conduct may often be richly rewarded. Are we individually and collectively prepared to pay what it costs to resist harmful conduct? Even to speak simple truths has at times cost people their freedom and even their life. Principled conduct can sometimes cost people their careers, their incomes, friendships and allies, future opportunities and prospects and similar impacts upon others associated with them. What would we give up for doing the right thing? These are questions that we will always have to face.

One person can take the lead and risk the consequences, whilst others elect to play it safe. Both choices may have merit. Which option we choose is a deeply personal question for us. We can also always ask ourselves, “could/should I/we have done better?” or simply avoid that question of ourselves. We can work for many years to uphold and realise a dream, while others may choose to avoid any dreaming that will involve too high a personal price. Again, both decisions may have merit. Action is important, but so is dreaming and imagining better. Both may be required. How much will be achieved in the world if we do not dream and why might it be important to take the time to look beyond what we are currently doing, to what could be? These are all questions really of our bottom line, our guiding compass.

### The leadership of turning up

If you have created a party and nobody comes, what does that mean? Movements of change did not make the headway they did because the likes of Mandela and Gandhi simply created a party for people to come to; the party happened because people turned up - this individual and ultimately collective conduct made the change happen. So let us be clear that the leadership that was offered by those leaders was the invitation to come to the party. If nobody came then no change would happen. But change has happened. Positive social movements have made a difference and this is truly inspirational.

So the fact that some prominent people called for decision and action is not really all there is to leadership. That is a piece of leadership. It is also leadership when people say, “I had better be at that party because it matters to me and to people around me”. So in this sense, we are back to the interconnectedness, the interdependence of us on each other, to be a movement together, to see that none of our efforts are really wasted, even though it seems we get up every day and struggle hard to try to do the right things and struggle with doubt. But when we look back at it, from a longer period of time, we may see that was not a waste of time. Seeds were planted as we moved forward even if it was not yet the right time to reach an ultimate kind of outcome.

Do not ever think that your showing up for the party was a waste of effort, as you are not the one to judge. Your showing up and your contribution and your gift; your candle “lighting a corner of darkness”; is potentially an act of leadership. Only time will tell what the effect of it is.

We cannot afford for people to feel like what they care about, what they are concerned about, what matters to them, what is good, does not somehow count. Each of you matter in countless ways and in ways that you cannot easily measure as you are doing it.

### Conclusion

The greatest tragedy would be to think that you do not matter. That is a struggle that we have all been a part of: that everyone matters. Everyone is here for a purpose; everyone is loved and valued; and everyone somehow, in their own way, changes our world. It is a mysterious thing that I do not pretend to understand. I can just appreciate it, from the revelations of so many lives; and the gifts that people give to so many lives. Somehow, there is a logic and value in seeking to be good human beings and we must not break faith with it.

So in this sense, this is really about our movement and our faith that the life of each human being somehow matters. How we can make a difference somehow enriches all of us, even though it is not always clear how that works.

There is still the fact that if we do not dream of better, we have condemned ourselves to life as it is today. We have committed to things as they are and the decision to dream is the decision to depart from the inadequacies of today, to something that could be better. Dreamers are the source of liberation from the oppression of the moment and the things that are holding us back at any point. Even so, it normally takes courage to look beyond today, to something better and to be and do something that gets us and others to “better”.

***Your showing up and your contribution and your gift... is potentially an act of leadership. Only time will tell what the effect of it is.***