

# WHY ADVOCACY MATTERS

A resource for families



*Expanding Ideas; Creating Change*

Anne Cross Leadership Initiative



**CRU**

*Expanding Ideas; Creating Change*

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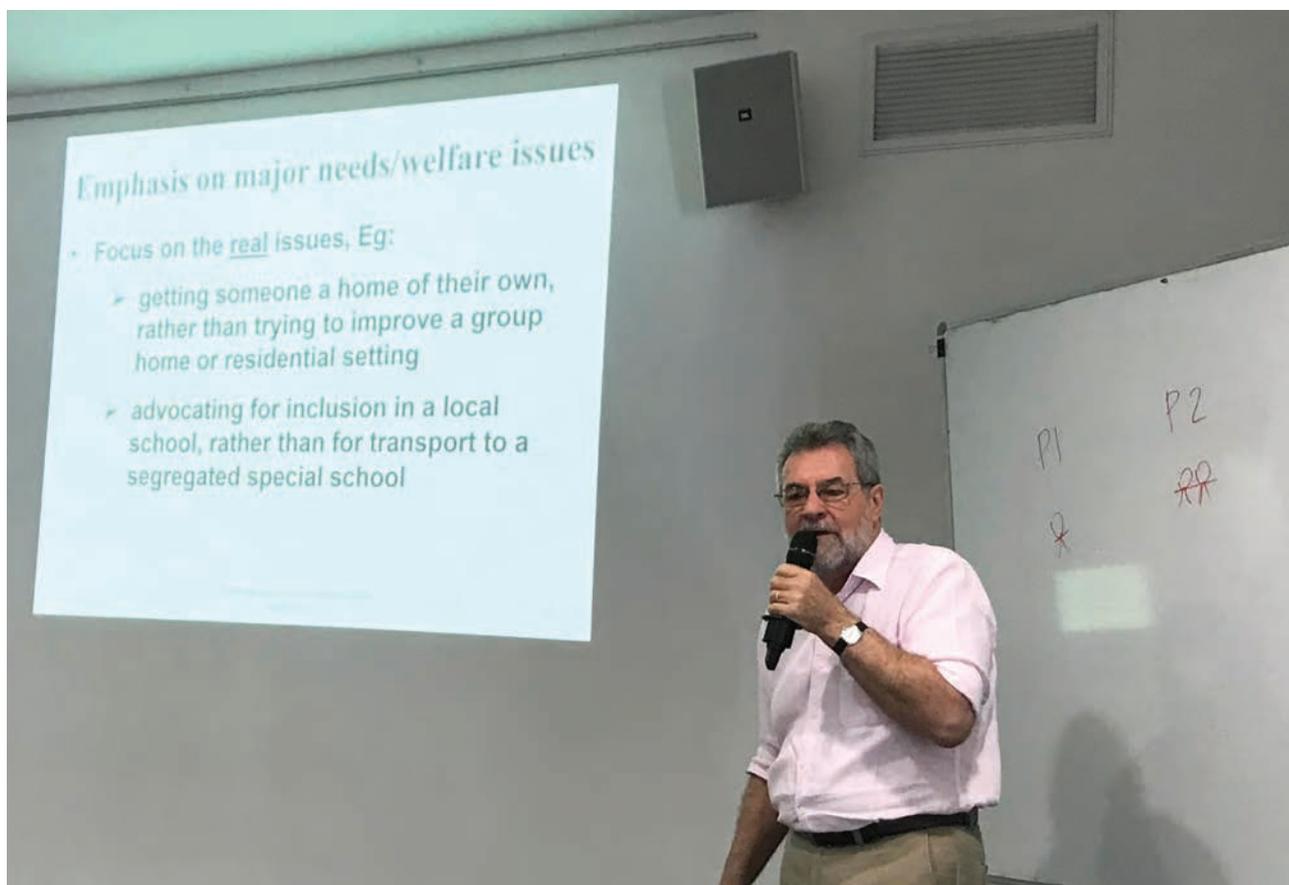
# Introduction

This guide is designed to help families and friends who are dedicated to advocating for their loved ones with disabilities.

CRU would like to acknowledge the contribution of Rebecca Altaffer in the development of this booklet. It was a pleasure to collaborate with her to draw on the ideas and writings of her father, Jeremy Ward. Her efforts and the generosity of the Ward family have helped to ensure that these messages will remain relevant and accessible to people with disabilities and their families now and into the future.

Throughout his life, Jeremy emphasised that people with disabilities cannot always rely on their rights being upheld. It is likely that family will remain steadfast beside their loved ones when no one else will; this is why advocacy matters.

This booklet offers practical and emboldening advice to help you advocate for your family member and work towards a more inclusive and valued life. We hope the principles outlined here will be valuable as you stand by your loved one and walk towards a shared vision full of possibility.



Jeremy Ward.

# Acknowledgements

We acknowledge the traditional owners of all the lands on which we meet, work and live and recognise this land always was and always will be Aboriginal and Torres Strait Islander land. We pay our respects to elders past and present.

These booklets have been developed as part of the Anne Cross Leadership Initiative, a partnership between Uniting Care Queensland (UCQ) and CRU, created to honour the contribution of Anne to UCQ during her years as the Chief Executive Officer. The initiative aims to contribute to strong, principled leadership amongst people with disability and families across Queensland to work towards better lives for people with disability.

“

No matter how important the rights of people with disability are, and no matter how important UN declarations and conventions are, advocacy will still always be needed.

Jeremy Ward

”

# WHAT IS SOCIAL ADVOCACY?

The Macquarie Dictionary describes advocacy as “an act of pleading for, supporting or recommending”. It also describes an advocate as: “one who pleads for or on behalf of another”.



“

...speak up and act in a committed and loyal manner to work for a better life for their loved ones.

”

# Social advocacy is more than pleading a cause

Social Advocacy is a concept developed in the 1960s, principally by Professor Wolf Wolfensberger. This term extends the dictionary definition beyond merely “pleading a cause”. Instead, it recognises that meeting the needs of those with “heightened vulnerability” (Cocks and Duffy, 1993, p. i), including people with disability, requires extra focus, commitment, and intensity.

Wolf Wolfensberger described Social Advocacy as,

“Speaking, acting and writing with minimal conflict of interest on behalf of the sincerely perceived interests of a disadvantaged person or group to promote, protect and defend their welfare and justice by:

- being on their side and no one else’s,
- being primarily concerned with their fundamental needs,
- remaining loyal and accountable to them in a way which is emphatic and vigorous, and
- which is, or is likely to be, costly to the advocate or advocacy group.”

(Advocacy Development Network, 1999, p. 1)

## Family Advocacy

This book focuses on family advocacy, a form of social advocacy that is usually undertaken by family members. However, the term family can also include close friends who step up to advocate in a voluntary or freely given way.

Of course, other types of advocacy may be necessary (e.g. paid advocacy) but do not represent family advocacy. And there are other protective mechanisms (e.g., safeguarding and quality support) that play a valuable role but are not advocacy.

We hope this guide will help family members speak up and act in a committed and loyal manner to work for a better life for their loved ones.

## Natural authority of families

Families have a natural authority as the result of knowing, caring about and taking responsibility for someone with a disability. Families know their family members the fullest and the longest and will bear the consequences of service failure.

When families are faced with people in roles of authority, it has been helpful to remember, and call upon, their natural authority when acting in the interests of their loved ones (Kendrick, 2013). Families have always stood with and for their valued family members and have critically shaped for the better our society’s treatment of people with disability.

# WHY DO PEOPLE WITH DISABILITY NEED ADVOCACY?

When so much lip service is given to “inclusion” and “valuing diversity”, families can be surprised (and distressed) to find that their loved one is still treated differently and more vulnerable to exclusion, unfair treatment, and devaluation. Despite positive changes for people with disability, advocacy is likely always to be needed.



“

One of the most life-limiting assumptions is that people with disability need to be separated from their community because of their difference or needs.

”

# Why advocacy is needed

This section identifies why you might be compelled to advocate for your family member and/or friends.

## Values of our society

People with disability are often subject to negative judgments because they fail to live up to our society's dominant (if unspoken) values, e.g., to be healthy, beautiful, wealthy, young, competent, independent, and intelligent. In contrast, people with disability can be seen as sick, poor, dependent or a burden, a menace, unproductive, childlike, and incapable of growth. These negative and devaluing stereotypes can shape how a person with disability is treated. They can be subject to low expectations, and lesser or discriminatory treatment is seen as “good enough”. Even paid service professionals often fail to identify the critical yet subtle impacts of their own unconscious attitudes towards disability.

One of the most common life-limiting assumptions is that people with disability need to be separated from the community because of their difference or needs. Most people are expected to complete high school, continue their education, start a career or family, and live independently. However, children with disabilities are often directed towards a different path from a young age. We know from experience that this 'special' path commonly leads to rejection and isolation from community, leaving vulnerable people with few, if any, meaningful relationships that would safeguard them from inheriting a story of abuse and neglect.

**For example:** *The assumption that “David would be better off in a special school” will limit people’s expectations of him. After years of not being included, it is unlikely people will think David should go to mainstream TAFE class or University post-school. Consequently, it is more likely that people will expect and plan that he will transition to a day program for other adults with a disability, risking further isolation from his community.*

The good news is that both children and adults can be purposefully positioned or pivoted back onto the **ordinary and valued path** of their siblings and similarly aged peers. That pivoting and positioning takes the form of advocacy.

## Impact of individual factors

While social attitudes are a significant contributor to the need for advocacy, individual circumstances can also contribute to heightened vulnerability.

An individual can be more vulnerable because their impairment prevents them from communicating what is happening to them, recognising their own mistreatment or having a degree of physical independence. Some people will target or exploit this vulnerability.

An individual can also be more vulnerable because they lack other protective factors – such as wealth or social standing. Thus, a person with disability who is economically or socially disadvantaged is particularly likely to receive lower standards of service, have their rights ignored and have no way of challenging unfair treatment. People may even become accustomed to “lesser” treatment.

## The impact of services

Services have been indispensable, but all services have limits.

**For example:** *A small number of services trying to meet all David's needs might be a cause of isolation from other people. Despite well-meaning service workers, no service can meet David's needs for close personal relationships, love, and security over the long haul. Over time, staff turnover will be disruptive and may cause a drift in missions or values, meaning the “service” changes from what David originally chose.*

## Rights don't cover everything!

Perhaps the starkest example of why advocacy is needed is that not everything people need can be insisted upon as a “right”.

“Not everything that is needed is covered by a “right”. [...] There is no right to a responsive, family-oriented disability service in every community. There is no right to always have a teacher who welcomes children with disability in their classroom. There is no right to be accepted into a local sporting club. There is no right to have understanding neighbours. People with disability cannot rely on their rights being routinely upheld. Thus, when rights are ignored or not honoured, or non-existent, people with disability need “something more”. That “something more” is advocacy.” (Ward, 2012, p.3)

# WHAT TO ADVOCATE FOR

The question of what to advocate for may at first seem obvious. But the opposite is often true. Identifying the ‘what’ will be vital in building and maintaining an ordinary, valued life for your family member or friend with a disability.



“

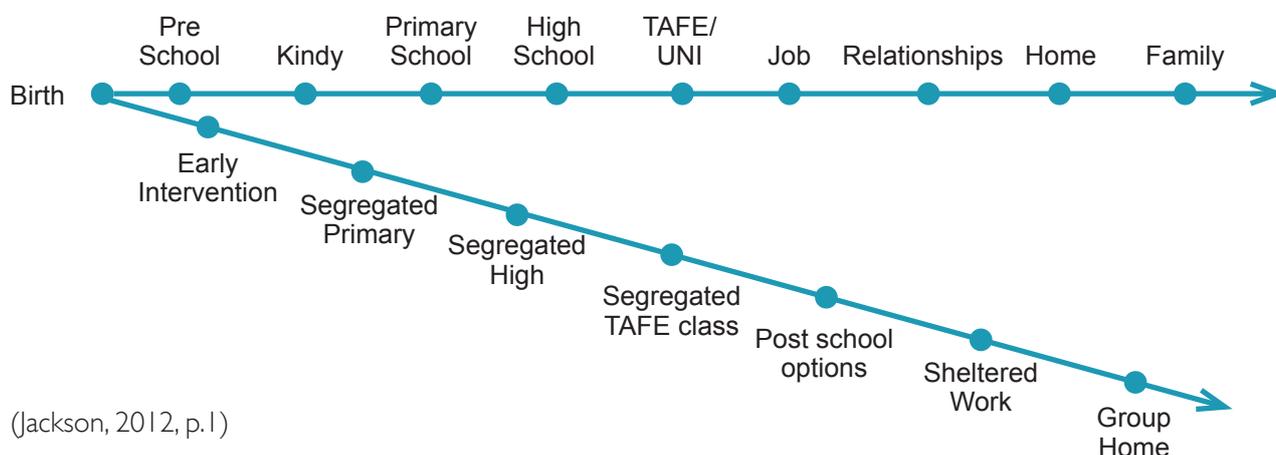
Successful advocacy needs a vision that extends possibility and sums up an ordinary valued life.

”

# Considerations for deciding what to advocate for

Here are three factors to consider: staying off the special path, sincerely perceived needs and, having a vision.

## Staying off the 'special path'



The 'ordinary' path (as opposed to the 'special' path) is more likely to deliver typical valued experiences, inclusion in community and opportunities to be known and valued. The downward trend of the 'special path' reveals the distance someone must jump to live an ordinary life. The jump is worth the work at any point but the younger a person with a disability is, the smaller gap there is to travel from one path to another. **It is never too early or too late to choose an inclusive life path or to start advocating for that inclusive life.**

## Sincerely perceived needs

Our best intentions may conflict with the wants and desires of the person we are advocating for. This complexity has been a topic of many family members acting on behalf of the sincerely perceived interests of a person with a disability. Here are two principles which have guided families in this instance:

- **Making decisions with, not on behalf of** – when making any decision we encourage you to include the person for whom you are making the decision, into the conversation.
- **Important to and Important for** – learn what is important **to** the person first, and then, what is important **for** them. If there is a conflict, attempt to find a workable balance. (Sanderson, n.d.)

**Example:** *Since moving out from the family home, Joan loves to order fast food through UberEats, once or even twice a day. The service says Joan is an adult who can make her own choices, but the family is concerned about the impact on her diet/health and her bank balance. The family want to support Joan to enjoy her independence but know this particular habit will have negative consequences in the long term and speak up to the service. They are now working with Joan's support team to help Joan understand healthy eating, make fast food a "treat" rather than daily practice and support Joan's independent choices in other areas.*

## A Vision

Successful **advocacy needs a vision** that extends possibility and sums up an ordinary, valued life. Simply put, a vision is a clear picture of the life you want the person to live. If there is no clear vision, then there is every chance you will be advocating for simply 'more of the same' dressed in different clothing.

But what does a vision look like and how do we start?

### Some questions to begin with are:

- What do I really want for my child?
- What does my child want for themselves?
- What do we want to stay away from?

Your answers to these questions will shape your vision.

To create a vision, it's crucial to let yourself dream without being influenced by others' limiting beliefs. Immerse yourself in this process and envision an ordinary, fulfilling and valued life for your loved one.

A vision for an ordinary, valued life might include:

- **Typical**, every day, aspects of day-to-day living
- **Independent** living arrangements (a home of their own)
- **Inclusion** in their local community (nothing 'special' or segregated)
- Emphasis on **their personal interests** and passions

## ACTIVITY

Write down your vision so you can tell others:



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“

The future belongs  
to those who believe  
in the beauty of their  
dreams.”

”

Eleanor Roosevelt

To access further resources visit [www.cru.org.au/whyitmatters](http://www.cru.org.au/whyitmatters)

“We talked of our vision for Mena to live as full a life as her sister and brother and for her to leave home and live independently when the time was right. We spoke of our dream for her to have a proper job, with proper pay, so she could enjoy the social interaction and friendship that comes with work, and to be seen to be contributing and to feel valued for what she could offer. We talked about our vision for her to have real friends her own age. We dared to say we wanted her to enjoy intimate relationships, love and marriage. For someone like Mena, all these visions made an ambitious picture and one that was generally believed impossible for people with the challenges she faced in life.”

“

Drawing on what we had learnt, we fine-tuned our vision to one simple statement: that Mena would be a valued citizen in her local community.

Every word of “valued citizen in her local community” was important and meaningful.

”

Jeremy Ward



# ELEMENTS AND PRINCIPLES

There are seven elements of social advocacy that have been instrumental in guiding families as they act on behalf of their family member with a disability.



“

Remain on the side of your family member with a disability.  
... Stand against the powerful .... Stay biased.

”

# Elements of Family Advocacy

These principles were established by Wolf Wolfensberger and have proven to be helpful in guiding families towards advocating for their family member's best interests.

You may confidently refer to these elements going forward.

**They are:**

1. Being on the side of the disadvantaged person
2. Emphasis on major needs and welfare issues
3. Fidelity, especially over the long term
4. Having minimal conflict of interest
5. Vigour of action
6. Cost to advocate
7. Being mindful of the plight of those even more in need than those for whom we are advocating

## 1. Being on the side of the disadvantaged person

Remain only on the side of your family member with a disability. Try not to be distracted by claims of, or on behalf of, others in a similar situation (e.g., other children in the same classroom). To be successful, you will likely have to stand with your family member against the powerful and remain biased on behalf of your family member.

*Carly attends a meeting with her daughter's school, and the teacher who is coming back to work from maternity leave is clearly stretched. Carly feels concern for the teacher, but also knows her daughter is struggling without enough consistent support in the classroom. She maintains her positive relationship with the teacher but continues to advocate for her daughter's reasonable adjustments in class.*

**Questions to ask:** Can I put myself on the side of the person with a disability?  
Am I biased in their favour? (If yes, Good!)

## 2. Emphasis on major needs and welfare issues

Focus on the central issues first. Then, referring to your family member's vision, identify what issues are fundamental in keeping them off the 'special path'. For example, finding them a home of their own rather than trying to improve a group home or residential setting; advocating for inclusion in a local school rather than for transport to a segregated special school; seeking out a real job rather than advocating for a better day service.

**Questions to ask:** What are my loved ones' real needs? Am I concentrating on that which fits their vision for an ordinary, valued life or am I skirting around the edges?

## 3. Fidelity, especially over the long term

This element is often referred to as "stick-with-it-ness". It means "don't give up", even if you never achieve the outcome you were hoping for. When you show fidelity, you show others, including your loved one with a disability, that you will stand by them even though results may be slow or non-existent. This is powerful modelling.

**Questions to ask:** Should you change focus when things get tough, or should you stick with your existing goals?

## 4. Having minimal conflict of interest

This element is at the core of effective advocacy. Nevertheless, it can be a blind spot, and it is easy to see why. Every situation presents more than one person's interests. Families are complex, and so are our individual lives. Therefore, it is important to examine our interests, identify any conflicts our interests have with the interests of our family member with a disability, and, if possible, minimise these interests for the sake of effective advocacy.

**Hint:** there is rarely a clear answer!

Jenny works as a casual teacher's aide at her daughter's school and wants her daughter to join the school choir with her classmates. However, her daughter's personal teacher's aide is not available during choir practice. The music teacher who leads the choir has requested that Jenny not bring her daughter unless she has an aide. Jenny doesn't want to cause any trouble since she also works in the music teacher's class during the day.

While there is rarely a clear answer, it looks as though Jenny will need to **a. Identify her conflicts of interest and b. Decide how to minimise these to advocate for her daughter.** In examining her interests, it is also important to tease out what is a genuine interest and what others might perceive as a conflict.

Jenny considers volunteering to be her daughter's voluntary teacher's aide out of regular hours to avoid having to ask for 'special privileges' for her daughter. However, in this instance, despite whether Jenny feels she can separate her paid role from her voluntary role, people may perceive her as having a conflict of interest. She must also decide if she didn't have a dual role (as employee) if she might insist more strongly on her daughter's right to support. Therefore, Jenny must consider whether the real or perceived conflicts are so great they compromise her role as her daughter's advocate.

**Questions to ask:** Are you mindful of conflicts of interest and trying to minimise these?

## 5. Vigour of action

Remembering that a better life begins now, you will need a sense of urgency. You will need to take the lead, often initiating meetings and tasks, bringing people together to improve your family member's life. In doing so, you will likely be doing more than what is done routinely for someone else in a similar position, acting as vigorously for your family member as you might for yourself. This doesn't mean initiating conflict or inciting anger, although conflict may appear. It does mean not just waiting until you are asked for your opinion and allowing yourself to get stuck in a state of inertia. Instead, to be effective, you will need a degree of urgency, enthusiasm, and depth of feeling in the pursuit of your family member's vision.

**Questions to ask:** Are you active and vigorous in your efforts to achieve your goals for your family member with a disability? Does it feel as though you are 'bending over backwards'?

## 6. Cost to advocate

While being with your family member should not be seen as burdensome or costly, undertaking true advocacy often comes at a cost. However, feeling your advocacy is "costly" is often a sign you are on the right track – and doesn't usually mean you are "doing it wrong". Costs may include a loss of time and other resources. Emotional stress; bodily demands; social disgrace, rejection, and ridicule are common costs. Impacts to your self-esteem; self-certainty; socio-economic security, and possibly, physical safety can also be seen as costs of advocacy. While this paints a negative view of the role of family advocate, it may be helpful to note that many families have exceeded their expectations as advocates, bringing to fruition their vision and dreams for their family member, inspiring others, and changing the fabric of society as it relates to people with disability.

**Questions to ask:** Are you considering the cost of advocacy and anticipating and planning for this where possible? Are you looking after yourself and connecting to others who will support your vision? Showing vigour, loyalty, and tenacity does not mean you need to burn out – you will be less helpful to your family if you do.

## 7. Being mindful of the plight of those even more in need than those for whom we are advocating

While we should ensure we are always on the side of our family member, we also need to be mindful of those who might be in even greater need (e.g., in advocating for your child's inclusion in their school, think about how the interests of other children with a disability at the school can be protected, especially those with higher or different needs). This element also asks us to be mindful that someone else in the same context needs to be (where appropriate) included in the conversation about their welfare - i.e., 'nothing about us, without us'.

**Questions to ask:** Am I willing to consider the welfare of other people with disabilities who live, work or learn in the same context as my family member? Do I know how to seek independent advocacy for someone in this situation (without losing vigour in my own advocacy pursuits)?

# Tips and Strategies

Even if you have a clear vision and knowledge of advocacy principles, becoming an advocate can still feel overwhelming. To help ease the process, we've gathered some valuable strategies from experienced families to help you advocate more effectively. As one Mother often reminds us, "**Advocate smarter, not harder**".

## FAMILY ADVOCACY CHEAT SHEET

1

### Have a clear vision

We need to be clear about what we are advocating for. Are you advocating to further your vision (i.e., to be a valued citizen) or are you advocating for a dressed-up version of 'more of the same'?

**HINT:** Your vision for your family member with a disability may encompass many things while also drawing a line above anything that puts you back onto the 'special path'.

2

### What are your 'bottom lines'? What will you accept and not accept?

There are some things you simply won't accept because they place your family member with a disability in danger of mistreatment. For example, you might not accept any shared living arrangements that are not explicitly chosen by your family member (i.e., a group home). Or you might not accept paid support from a service whose values don't align with your family's.

**HINT:** Together, you might write down your 'bottom lines' and keep them close.

3

### Use the recognised processes where available

Try to follow the line of communication expected of everyone. Don't escalate unwisely.

**HINT:** The more 'ordinary' your communication is, the more reasonable your request will sound.

4

### Don't be reactive or escalate conflict

Anger or hurt are valid but they are best processed in a way that keeps you and others free from conflict. Expressing anger in public or sending harmful emails is unhelpful to your family member for whom you are advocating.

**HINT:** If you find it hard to remain calm in stressful situations, consider taking someone else with you or sharing an email 'not to be sent' or 'to be sent later' with a safe person.

**5**

### **Be respectful, truthful, and “above reproach”**

Staying respectful and trustworthy may not guarantee success but you are more likely to have your natural authority respected and to reduce the likelihood of retaliation if/when conflict does eventuate.

**HINT:** If you are unsure whether you are acting ‘above reproach’, imagine someone you respect (such as a family gone before you!) and ask yourself this question - “What would they do?”

**6**

### **Identify key people you need to influence**

Despite the natural authority of families, people with formal roles of authority do have the power to make decisions in your favour.

**HINT:** Consider how the influence of your respectful yet vigorous action on behalf of your family member’s interests might positively influence those with decision-making power.

**7**

### **7. Rehearse your ‘advocacy stance’**

When you have high expectations for inclusion and belonging, you can come up against “naysayers”. In many instances, family advocates who challenge the status quo find themselves relegated to the role of ‘outsider’ and ‘troublemaker’. Nevertheless, stay firm and have faith that persistent efforts offer the best chance of success in the long term.

**HINT:** Rehearse your advocacy stance with people who you trust, and who support your family.

**8**

### **Be prepared for challenge, criticism and pay-back**

Families often find people and organisations react ‘defensively’ when faced with requests for better treatment of people with disabilities. At times, this comes up quite unexpectedly. Families have learned through experience, to choose carefully who to trust and who to keep at a safe distance when acting on behalf of vulnerable people.

**HINT:** Be prepared that some people and services are unpredictable.

## 9

### Anticipate the counterarguments

Hearing counterarguments to your requests for inclusion or basic care may leave you feeling defeated or lacking confidence in your mission which, in turn, may make it difficult to stay focused on your vision. Plan for the naysayers and, above all, don't react!

**HINT:** Imagine what the counterarguments to your requests may be, and write your intended responses down, keeping in mind your bottom lines. You may choose to carry these responses in your pocket or keep them up on your wall. Either way, have your script ready for when you need them.

## 10

### Be prepared for the costs of advocacy

The costs of advocacy are wide and varied. These costs can be reduced by using and practising these strategies, caring for yourself and, by staying close to people you trust.

**HINT:** The costs of advocacy may be managed through preparation and discernment. Stay connected to those who share your vision.

## 11

### Be meticulous in your records

As with all forms of advocacy, take notes of what was said, promised, or agreed to in phone calls and meetings. These records will be the backdrop to staying on track, remaining vigorous and planning for any counterarguments in the future.

**HINT:** Develop a system for recording and filing handwritten and/or typed notes and emails related to your endeavour. Nothing is irrelevant.

## 12

### Dress well

Consider 'conservatism corollary', a concept within the Social Role Valorization framework which refers to the compensation for disadvantage and vulnerability. In this context, it is about family advocates 'dressing well' and 'looking the part' to help compensate for any devaluing directed toward your family member with a disability.

**HINT:** When meeting with people in roles of authority consider taking a briefcase, wearing makeup, or using another highly valued approach to presenting yourself in your family member's community.

## 13

### Seek support from others

Many families of people with a disability have sought help from other family members and friends during important transitions in their family member's life. Others have maintained a structured support network consistently for many years. Parents and siblings have a wealth of experience to share in the realm of advocacy and we have found this type of mentoring to be instrumental in shaping the lives of younger families embarking on the various stages of their young child's life.

**HINT:** Don't be a lone ranger – ask for help.

## 14

### Show appreciation to those who help or support your vision

Showing appreciation will nurture the networks of support growing around you. The more people you have by your side, the softer the fall on hard days, or when advocacy becomes particularly costly. Those people that come out of the woodwork in tough times often remain lifelong friends!

**HINT:** Sincere appreciation can go a long way, providing friendship and relief in unexpected ways!

## 15

### Pick your battles

Preserve your energy by choosing which of your family member's needs are the most fundamental and necessarily advocated for now. Without using discernment, families can become overwhelmed by a backlog of to do lists.

**HINT:** Identify which battle, if successful, is the most likely one to keep you moving towards your vision and be effective in staying on the regular, valued path.

## 16

### Trust your intuition

Some parents and siblings have found it difficult to trust their intuition when it involves their loved one with a disability. They have questioned their own natural authority as family members and, at times, asked themselves if they really are over-reacting. Your conviction to the vision you built with your family member will guide your intuition.

**HINT:** If you think you are being done over, you probably are.

For a printout of the Family Advocacy Cheat Sheet visit [www.cru.org.au/whyitmatters](http://www.cru.org.au/whyitmatters)

## What defeats us?

Advocacy will sometimes feel impossible, but it is important to state that no advocacy is wasted. On the contrary, families who advocate make a difference. Someone you may never meet has benefited from your willingness to stand up for your child's quality of life – whether you were successful in that instance, or not.

Nevertheless, being on the firing line is difficult. Knowing what might get in the way will help you navigate the terrain. Some things that defeat families include:

- Lack of vision, focus, and clarity about what you are advocating for
- Forgetting the advocacy principles
- Poor preparation
- Competing priorities
- Limited time available for advocacy
- Not keeping accurate records
- Not looking after yourself – letting stress get in the way



Jeremy with his sisters Tricia and Margaret.

## Conclusion

There are many reasons why people with disability need advocacy, but advocacy alone is unlikely to change oppressive circumstances and attitudes. Nevertheless, it is not an optional extra – it is essential for promoting, protecting and defending a good life for your family member with a disability.

We encourage you to stay positive, hopeful, and focused on your bigger vision. Here are some final reminders:

- Aim to review the definition and principles of family advocacy, for they will help you see the forest for the trees.
- Stay aware of any conflicts of interest and focus on what and who you are advocating for. Your vision is your compass!
- Review your strategies to be well prepared: never go alone; keep good records; seek support; and look after yourself.

These points will keep you in good stead. Finally, celebrate your achievements! Whether or not you can see an immediate outcome, taking action and standing beside vulnerable people is a great achievement.

**Best of luck to you, and may you find courage and friendship along the way.**

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“

If you want inclusion ... believe in it, fight for it. Advocating for your child is a muscle; it gets stronger the more you do it. Soon you'll be less grateful that you were offered a seat at the table and become a bit more pushy about what you want for your child. This will stun you; it will probably stun others around you. You'll realise you had a hidden street fighter inside of you.

Meredith Irish

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