

ADVOCACY CHEAT SHEET



"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

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. 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. 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.


11. 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 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.


12. 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.

13. DRESS WELL

Consider 'conservatism corollary', a concept within the Social Role Valorisation 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.

14. 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.





15. 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!

16. 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.

17. 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 overreacting. 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.