



**SWAN**

# Advocacy Tool Kit



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## 1. About SWAN Australia

SWAN Australia is the peak not-for-profit organisation in Australia, providing information, support, connection and systemic advocacy to families caring for a child with an undiagnosed or rare genetic condition. We represent an estimated 2500 children born in Australia every year without a diagnosis and the 1 in 12 children diagnosed each year with a rare genetic condition. Overall, we estimate around 350,000 children in Australia live with an undiagnosed or rare genetic condition.

We aim to reduce the isolation and emotional strain of raising a child with a chronic illness or disability by helping parents connect with other SWAN families. We provide parent information seminars, workshops, peer support events, and social networking opportunities where SWAN families can form lifelong bonds.

We provide a public voice for our families, campaigning for better community education and improved resources and pathways so that SWAN children can thrive.

## 2. Key areas of focus

This Toolkit was designed to empower SWAN parents/carers with tools and resources to advocate for their children. It focuses on advocacy in the following settings:

- Healthcare
- Social Services and Supports (including the National Disability Insurance Scheme - NDIS)
- Education

## 3. What is advocacy?

Advocacy is speaking up to support a cause, person, idea, plan, place or thing. It can be done in a variety of ways. As a SWAN parent/carer, the person might be you, your child or your family. The greater cause may be improving the lives of families who have children with rare or undiagnosed genetic conditions.

## 4. Why advocate?

There are many reasons why a SWAN parent/carer might advocate for their child. Some include:

- To help others better understand their child's undiagnosed or rare genetic condition.
- To help others understand their child's emotional, physical, sensory, cognitive and psychological support needs
- To stand up against injustice and protect their child's rights, health and well-being
- To bring about change so that their child can live their best
- To improve outcomes for the entire family

- To improve outcomes for the broader group of children living with undiagnosed and rare genetic conditions and disability.

**There is no right or wrong way to advocate.** There are two main types of advocacy: individual and systemic.

#### 4.1. Individual advocacy

Individual advocacy involves speaking up for yourself, your child or your family. SWAN parents/carers may take on this role themselves, as they have expert knowledge of their child's condition. Another option is to use an advocacy service or an individual advocate to represent you. You can advocate for your child by:

- By written or oral communication
- Meeting directly with a person or group involved in your child's care
- Sharing your story on social media or with the media

#### 4.2. Systemic advocacy

Systemic advocacy is speaking out on behalf of a group. Organisations with membership bodies such as SWAN do this. Here are several ways for you to engage in systemic advocacy:

- Attend group events.
- Sign petitions (online and paper).
- Join a Community Advisory Group (CAG) to share your perspectives. SWAN has a CAG that you may wish to nominate to be a member of.
- Participate in research to assist with collecting evidence for systemic change.
- Political lobbying.
- Submissions - SWAN writes a number of submissions to provide feedback on the experience its members (e.g. in relation to the NDIS). You can contribute to these submissions by sharing your experience and subscribing to google alerts to track their progress.
- Be active on social media engagement such as Twitter and tagging people who have the potential to make changes into your Tweet.

#### 4.3. Your well-being is important

- The need for advocacy often arises from your child being neglected, mistreated or misunderstood. Discrimination against your child might take a serious toll on your emotional well-being. This can motivate some people to advocate for change but might make others feel helpless. Either way, there are some ways to seek support.



##### **Tip 1**

***Recruit a support person who can be there for you before, during and after discussions.***

- A support person can:
  - Use cues to keep you stable and grounded during discussions.
  - Provide backup if your emotions get the better of you.
  - Provide another opinion or recall information that you may have missed.
  - Seek peer support during the process of advocating.
- Advocating for your child can be exhausting and triggering. Sharing this with others can help normalise feelings of anxiety and overwhelm.
- Information sharing can improve the way you advocate and save you time.
- Approach support organisations such as SWAN, who can assist you by guiding you to relevant resources.
- Practice in a role-play setting with a friend.
- Consider getting a professional to advocate on your behalf if:
  - You do not know where to start. Professionals can inform you of your child's rights and develop a plan with you.
  - You do not have the capacity to advocate. Parents may be time-poor or are not in the right headspace. Professional advocates are not as emotionally involved.
  - You can find an advocate through the [Disability Advocacy Finder](#), [Disability Advocacy Resource Unit](#) or [Disability Advocacy Network Australia](#)
- Consider talking to a therapist if you become burnt out or feel traumatised. [Carer Gateway](#) offers a free government counselling service for carers.
- Have a clear objective, and don't be defensive. Know the outcomes you want and if possible, provide supporting evidence for those outcomes.



**Tip 2**

***Go into an advocacy meeting solution focused and try and not be defensive. You want an outcome both parties are happy with.***

## 5. How to advocate for your child in healthcare settings?

### 5.1. General tips

- **Develop allies** - You are your child's best advocate but finding a healthcare professional (HCP) that knows you well and is willing to advocate on your behalf can be really helpful. This might be your child's paediatrician, a family GP, psychologist or [genetic counsellor](#). This person may also help with follow-up and hold other HCPs accountable.
- **Stay organised** - SWAN families live extremely busy lives. It helps to have a planner (hard copy or online) where you can set appointment reminders and record notes. You may wish to keep important documents (e.g., reports and medical scans) in a central place. Some families like to use a cloud stored file so they can access it at meetings from their phone.

- **Don't be afraid to ask for help** - Whether this means recruiting a support person, asking the HCP to speak in plain English or terms you are able to understand, or asking reception to make the appointment more accessible for you and your child or at a time that is manageable for you.
- **Provide positive feedback** - HCPs who positive contribute to your child's health should be acknowledged. This contributes to an environment where everyone benefits and encourages strong continuity of care for your child.
- **First try and solve the problem directly** - Sometimes you may need to complain externally or report medical negligence, which can contribute to higher quality care in future for your child and for others. Here are some useful links from each state on the complaints process: [NSW](#), [VIC](#), [QLD](#), [WA](#), [SA](#), [NT](#), [TAS](#), [ACT](#)
- **Always try and ensure clear communication** – Ensure everyone is communicated to respectfully and with a record of any meeting minutes. Try and document all communication in writing between the HCP involved and yourself as your child's advocate and/or with and an external advocate. This might involve following up on a face-to-face meeting with an email outlining and confirming the discussion of the meeting.

## 6. Advocacy during hospital admissions

Hospital visits can be stressful and traumatic for families, whether they are planned or unexpected. Below are some communication suggestions while your child is receiving care in emergency or other wards:

- The Australian Commission on Safety and Quality Healthcare have an excellent [information sheet](#) and [poster](#) on how to communicate with your healthcare provider when you are in hospital.
- If possible, encourage your child to speak up about what and how they are feeling. Be a spokesperson for your child when needed.
- In emergency care, a triage nurse will determine how urgently your child should be seen. Communicating crucial details about your child's condition may help them with this assessment.
- Introduce yourself to the nurse in charge, nurses, doctors and other HCPs attending to your child. Inform them of how they can best accommodate your child within reason.
- Use your connections within the hospital. Sometimes name dropping helps so that HCPs know who is usually involved with your child's care and who to contact for expert advice.
- Be familiar with your child's health management plan so that you can hold HCPs accountable.
- Hospital can be triggering for children and affect their behaviour. It can help to explain how being in hospital affects your child. If an HCP is intolerant and impatient, ask the nurse in charge for support.

- If your child regularly visits hospital due to their genetic condition, you probably have a good grasp of when your child needs to transfer to a different ward (e.g., from emergency to their regular ward) or be discharged. Some parents see major improvements in their child's overall health once they arrive back home. Speak to relevant nurses and doctors to create a discharge plan.
- The [NSW Health Department](#) has a useful resource by about preparing for hospital stays

During these times, you may need to advocate for your own well-being:

- Ask immediate and extended family for emotional and practical support. If school drop off and pickups are organised for your other children, this can be a huge relief. Don't be afraid to ask for help, most people are happy to oblige.
- Reach out to your support networks and peer support organisations. SWAN arranges hospital care packs or uber eats vouchers for families in hospital. If you would like some support or if your SWAN child is in hospital, please let us know so we can assist you. Please email [info@swanaus.org.au](mailto:info@swanaus.org.au) with the subject line: Support
- Contact your own therapist or a [carer helpline](#) if you are in distress.
- Many hospitals have a disability liaison officer (DLO) who can assist with coordinating healthcare for people with disability.

### 6.1. Advocacy during medical appointments



#### **Tip 3**

***Come prepared for your medical appointments.***

- **Come prepared for the appointment** - You and the HCP are both experts. Preparing for an appointment will help you to provide and receive vital information. What do you wish to get out of this appointment? Come in with a clear sense of purpose that you can share with the HCP.
- **Be prepared to re-tell your story** - to create a clear picture of your child's situation. SWAN families tell their story to multiple specialists: GPs, nurses, allied health and specialist doctors. This can be exhausting, but it's important to hit the reset button each time, especially during the search for a diagnosis. You may develop an elevator-type pitch that answers questions such as:
  - When did you first notice your child wasn't developing typically?
  - What have you observed in your child physically, intellectually and behaviourally?
  - How are they progressing through milestones?
  - Who have you seen prior to this appointment? Who referred you?
  - What sort of testing has your child already done? E.g., IQ, behavioural, physical
  - What clues do you already have or what do other HCPs suspect?

- **Be prepared to answer questions** - Each HCP will ask different questions, as they are looking for symptoms within their area of expertise. Before an appointment, it helps to refresh your memory with your child's symptoms. Some questions might confuse you. If you are confused about a question, don't be afraid to ask for clarification.
- **Bring a list of questions with you** - Appointments can be nerve-racking and long, which makes it easy to forget your questions. A written list is a tangible reminder. You may wish to print two copies, one for yourself and one for the HCP.
- **Bring all necessary documentation** - Often receptionists will inform you of what you need to bring in advance, e.g., medical scans and reports. Make sure to bring these with you and any other documentation that you think is relevant. It can help to organise these in a folder or carry them in a designated appointment bag.
- **Organise a support person to join you** - We have already mentioned the benefits of this. During the diagnosis journey, medical appointments can be monumental, particularly receiving test results. Sometimes these appointments can cause you to feel strong emotions, so it helps to have someone who can help you get home safely.

## 6.2. Actively engage during the appointment

- **Take notes** - You may wish to jot down key words that will jog your memory. You don't need to take extensive notes that will distract you from the actual appointment. Most HCPs will provide a follow-up letter.
- **Don't be afraid to ask questions** - If you don't understand what the HCP is asking, ask them to repeat the question. If they are using medical terms that you're not familiar with, ask them to explain in simple terms. Many HCPs will have helpful analogies to help you understand, so help them tailor the session to your level of medical knowledge.
- **Don't be afraid to correct the HCP for the sake of accuracy** - Many HCPs will use information from your referral letter, but it might have been missed information or have inaccurate details. They also may mishear you during the appointment. Correcting them might be crucial for your child's health.

## 6.3. Follow-up

- Gain clarity about the next steps. You might need to book another appointment with reception, or you may expect to hear back from the HCP by a certain date. It helps to note dates down in a diary or on your phone.
- Ask for a follow-up letter if your HCP does not mention it.
- If the HCP plans on referring you to someone else, ask for good recommendations.
- If you do not receive an expected call, it may be worth calling the practice and following them up.
- Thanking the HCP for their time and expertise can help you foster a positive relationship that could serve you well in future.
- What support groups does the HCP recommend for you?

#### 6.4. Advocating for treatment

You may need to advocate for continued treatment or request changes to your child's treatment plan.

If you would like your child's treatment to continue:

- What positive changes have you seen in your child?
- What improvements have other HCPs (e.g., speech pathologists and OTs) reported? Bring reports with you.
- How is your child improving at school?
- If your child was part of a drug trial that ended, you may ask if or when they get access to these medications.

If you would like to request a change to your child's treatment:

- What concerns do you have about the current treatment plan?
- How do the results currently compare to the treatment goals?
- What side effects are you seeing in your child?

#### 6.5. What can I expect from health care professionals?

You can expect your clinician to be courteous, introduce themselves and actively listen. If you feel your HCP is not treating you and your child with the respect and attention you deserve, you might speak directly to the HCP or their team (reception or other members of the department). Here is a [Communication Guide for Clinicians](#) that gives you an idea of what to expect. Key responsibilities include:

- Conveying empathy
- Participating in a two-way discussion
- Helping support the patient's decisions
- Helping patients come to terms with uncertainty or complexity.

After waiting a long time for a genetics appointment, uncertain results can be frustrating. For example, when a [variant of unknown significance](#) (VUS) is found in genetic testing, this means there is not enough data to confirm whether a gene change causes your child's condition. Whilst you cannot always expect answers from clinicians, you can expect a clear explanation.

Despite meeting professional expectations, sometimes your clinician might not be the right fit for your child. If they are someone you will meet with regularly (e.g. a paediatrician), it might be worth trialling a few different people.

### 7. How do I advocate for my child in school?

Inclusion both inside and outside the classroom is crucial for children as they learn and develop life skills. How do you know whether your child is achieving their learning goals and participating socially?



#### **Tip 4**

***Develop positive relationships with staff and parents who will be good allies for you and your child.***

## 7.1. Ways to help your child learn

### 7.1.1. Develop positive relationships at the school

- Establish a positive relationship with the school principal. This may further encourage them to invest in your child's development and check in with the class teacher.
- Introduce yourself to the class teacher and/or your child's support worker each year to open an ongoing dialogue.
- Actively participate in parent-teacher meetings.
- Develop mutually supportive relationships with parents whom you believe will be good allies for you and your child.
- Encourage co-involvement at meetings that concern your child's individual learning plan (ILP). You may invite therapists such as OTs, speech pathologists and/or psychologists. You may want to consider bringing your child along.

### 7.1.2. Stay up to date with your child's individual learning plan (ILP)

- Familiarise yourself with short and long-term goals.
- Ask about your child's progress and how to help them reach their goals.
- Check in with your child.
- If necessary, provide suggestions to improve the plan.
- Encourage your child to participate in extra-curricular activities.
- Talk to your child about what interests them.
- Communicate with the leaders of these activities about ways to enhance inclusion.
- Check in with your child to see how they are going.

### 7.1.3. Check in with your child

- Your child is the primary information source! If your child has the capacity to communicate with you, ask how they are going at school and how their friends are. For children who have trouble opening up, communicating or are non-verbal, you may get a sense how they're going at school through their overall mood and behaviour.

## 7.2. Schools should support your child with funding and transitions

As a SWAN parent or carer, you are juggling a million and one things, including caring for your SWAN child and their siblings. It can be hard to stay on top of everything. Educators should be transparent and proactive in their communication with parents. It is also the school's responsibility to apply for funding that makes learning accessible for your child e.g., an education support staff person during school hours.

Schools also need to support students through educational **transitions**: from primary to secondary school and secondary school to higher education or employment. [A guide by the Victoria Department of Education](#) suggests that the student's transition plan requires input from the entire student support group: the student, parents, principal, primary and high school teachers. Raising Children

Network and Amaze have also put together resources on [starting secondary school](#) and [supporting the transition of autistic students](#). Schools should be proactive in creating and implementing transition plans, and you have a right to speak up should you feel these plans are not effectively followed.

Secondary schools should also be aware of the options for school leavers with disability, such as [school leaver employment supports](#). According to a [paper](#) written by Special Education Teacher Monika Bray, children with disability have unequal access transition supports. Transition plans should be tailored, evidence-based and implemented over time.

### **7.3. Discrimination in schools**

Sadly, discrimination can and does occur in schools outside of the parent's control. Examples include:

#### **7.3.1. Issues with enrolment**

- SWAN families have reported trouble getting their child into a mainstream school that makes appropriate adjustments.
- Schools indicating that the child is a burden or danger to other students.
- Trouble applying to special schools when IQ is the sole indicator of a child's needs e.g., an IQ of 70 does not mean the child can cope in a mainstream school.

#### **7.3.2. Issues with funding**

- Having to strongly encourage the school to apply for funding in the first place.
- Schools using that funding in ways that do not benefit the student specifically.

#### **7.3.3. Neglect of the students' needs**

- Failing to appropriately adapt educational resources or physical spaces.
- Allowing children to go unnoticed.
- Creating ILPs that are uninformed, are not tailored to the child or that lack effective measurable outcomes.
- Lying or refusing to take accountability when something goes wrong at school.

#### **7.3.4. Unreasonable Punishment**

- Unfair consequences for behavioural or learning difficulties related to the child's condition
- Academic punishment when the student takes time off school e.g., for medical appointments, therapies, or their mental health.

#### **7.3.5. Social exclusion**

- Bullying from peers or teachers.
- Teachers acting as bystanders when bullying occurs.
- Unavailability of a support person during recess/lunch to help the child develop social skills and forge meaningful relationships.

### 7.3.6. What should I do if discrimination occurs?

- First, try to solve the problem within the school by setting up a meeting with your child’s teacher and/or principal. The Australian Government - Department of Education has a [fact sheet](#) to help prepare you for these consultations. If the school is not listening or making necessary changes:
  - Seek support from a peer support or advocacy organisation. SWAN writes letters on behalf of members when problems cannot be solved at an individual level at school.
  - Employ an [advocate](#) who can raise issues without being emotionally involved and can support you if you feel intimidated or silenced.
  - Make a complaint with the Department of Education or your state’s ombudsman. The Australian Government Department of Education has a [fact sheet](#) for complaints processes in different states. Sometimes the education department has a vested interest in complaints being withdrawn. For this reason, SWAN advocates for the establishment of an Independent Commission for Abuse in Schools.
  - Take your complaint to the media.
- It can help to be familiar with your child’s legal rights when advocating for them. Here is a list of resources that may help:
  - The [Disability Standards for Education 2005](#) (reviewed in 2020). These are also known as “The Standards”.
  - The [Right to Education](#).
  - [The Disability Discrimination Act](#) and the [Guide on Getting an Education](#).
  - [Rights of People with Disability](#) including the [Convention on the Rights of the Child](#).
  - [Raising Children Network](#).
  - [Australian Centre for Disability Law](#).
  - Resources from the education departments of each state: [NSW](#), [VIC](#), [QLD](#), [WA](#), [SA](#), [NT](#) and [TAS](#).

## 8. How do I navigate the NDIS?

### 8.1. About the NDIS

- The NDIS is a government scheme that provides funding to individuals with disability. Please see the [NDIS website](#) for information on the scheme, including accessible videos. For children under 7 years old, you consult with an early childhood partner under the [early childhood approach](#). For children 7 years old and above, you consult with a [Local Area Coordinator](#) (LAC) or NDIA planner.

- If you are new to the NDIS, you may wish to confirm your child's [eligibility](#) and understand your role as their [nominee](#). To [apply](#), you will need to fill out an [access request form](#). Here is a useful resource for [creating your NDIS plan](#). Your first plan review will be 12 months after you receive your first plan. Plan reviews are meetings with your LAC or NDIA planner where you look at your plan and how it's helping your child achieve their goals. To continue to receive funding, you need to show that these supports are essential for your child. This is the main way you will engage your advocacy skills!
- Most SWAN families have a strong grasp of the NDIS and have attended several planning meetings. SWAN also has a number of fact sheets on our [NDIS page](#) to help members at various stages (e.g. applying or preparing for their planning meeting). These include:
  - [Becoming an NDIS participant](#)
  - [Background to NDIS planning meetings](#)
  - [Preparing for your child's NDIS meeting](#)
  - [The planning meeting](#)
  - [Useful tips](#)

## 8.2. Understand how supports are funded

- The NDIS only funds “reasonable and necessary supports” (Section 34 of the NDIS Act). To understand what this means, see the [criteria](#) on their website.
- When identifying what supports your child needs, consider the following:
  - How are the supports reasonable and necessary according to the criteria? e.g. , will they save money long-term?
  - Are they recommended by my child's therapists?
  - What are the consequences of not receiving this support?
  - What exactly does my child need? e.g., how experienced should the therapist be?
- When creating or reviewing a plan, you meet with an LAC who then presents the plan to be approved by the NDIA. Advocating strongly to your LAC means that they are more likely to strongly advocate for you.
- Plans generally last one to two years but can be extended in some circumstances. You can request a one-year plan if your child's plan will need to change during a transition period (e.g. primary to high school)

## 8.3. Prepare for the planning meeting

- For every support you request for your child, ask the question - have I got supporting evidence to justify it. It can help to prepare a document with an ask and evidence column.
- Be willing to repeat your story, as there is a high turnover of early childhood approach partners, LACs and planners.
- Prepare a plain language fact sheet about your child's genetic condition and if they are undiagnosed, a dot point list of symptoms.
- Talk to other participants/nominees in advance to get ideas about supports and/or advocacy tools.

- Allocate plenty of time for your meeting! They average one or two hours. You may need time either side of the meeting to get into the right headspace and wind down.
- Consider postponing your meeting if you feel unprepared.
- Prepare and gather necessary documentation.
- Prepare a Participants and Farers statement
- Gain as much input as you can from your child as you
  - Develop goals
  - Identify supports and list them in order of priority
- Identify what supports you need. List them according to priority.
- Develop a weekly schedule that gives a clear picture of your child’s life, including sleeping patterns. The more information, the better.
- Review of your current plan: identify what’s working and what isn’t.
- Specialist and other reports. If you have a good relationship with your child’s HCPs, you can ask them to share the letter with you and provide feedback.
- Use a pricing sheet to determine how much your child’s plan costs. This should be roughly similar to prior NDIS plans. If not, you may wish to re-do the calculations or make adjustments.

#### 8.4. Communicate effectively during the planning meeting



##### **Tip 5**

***Come to your meeting prepared! The more evidence you have to justify funding, the better.***

- Use your prepared materials to:
  - Discuss what supports you need and justify them!
  - Show what is working well and not well.
- When discussing your goals:
  - Use NDIS-friendly language such as “safety, independence, building the capacity”. You can get a sense for this language on their website
  - Keep your goals broad.
- Explain any underspend in your last plan e.g., you may have minimised contact with therapists during high-risk COVID periods.
- If you are required to answer questionnaires on behalf of your child such as the [PEDI-CAT](#), paint the picture of your child’s worst day. This will help you receive funding that matches your child’s needs.
- Bring a support person if needed such as support coordinators, therapists or family members.
- Bring your child if it is appropriate. Having them there may help you advocate or distract you, so it depends on your circumstances.

## 8.5. What if my child's plan is not enough?

There is currently a significant backlog of requests for plan reviews and advocacy agencies are at capacity. For these reasons, SWAN recommends doing everything you can to achieve your ideal plan the first time. However, this can be out of your control. There are two main reasons why participants might need more funding:

- A change in circumstance. If something happens which changes the type and amount of support your child needs, you can ask for a plan review. Refer to the NDIS website [change in circumstances](#) page.
- You receive a funding cut. This is unfortunately a common issue for SWAN families.
- The first step is to request a [review of your planning decision](#).
- If you do not receive a desirable outcome from the review, you can appeal the decision with the [Administrative Appeals Tribunal](#) (AAT). The [Department of Social Services](#) can support you with the process by providing an advocate and funding in certain situations.

### 8.5.1. Tips when appealing your decision:

- Be solution oriented. Appealing a decision can feel like an intimidating process. To reduce the power imbalance and encourage constructive conversation, it's important to suggest solutions for each of your concerns.
- Present evidence to justify your concerns. The more evidence the better e.g. reports from schools, physicians and therapists
- Contact SWAN for some tips on how to prepare for a meeting with the AAT.

## 9. How can I advocate politically?

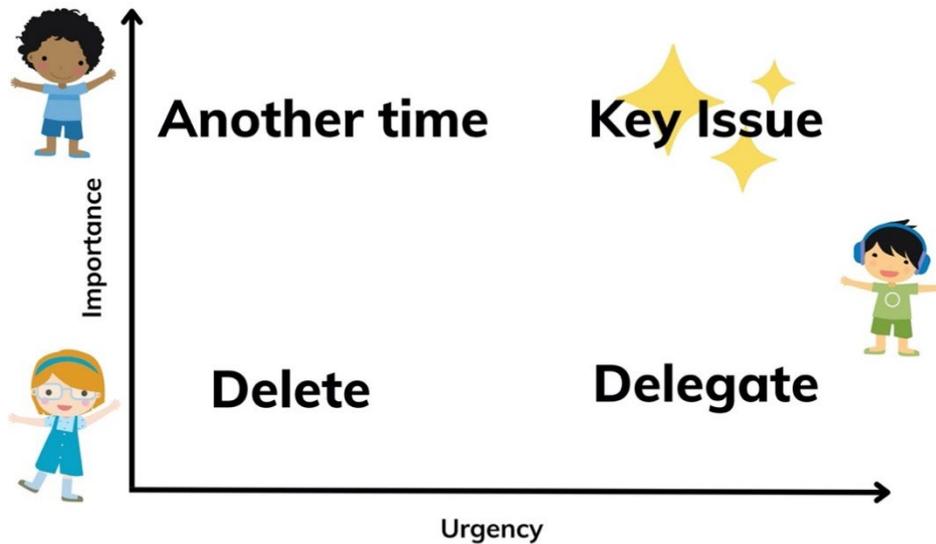
Political advocacy can be individual or systemic advocacy, (speaking out about a cause on behalf of a group). There are opportunities for you to engage in political advocacy either independently or through organisations such as SWAN. Often organisations with a common purpose will collaborate to amplify their voices!

### 9.1. How do I decide what to advocate for?

There is a lot of political noise due to modern technology and social media. Here are some ways to create a strong and clear message:

- Start with a long list of issues and narrow them down. Prioritising key issues helps to strengthen and structure your argument. The Eisenhower Matrix is a visual tool that helps you determine what to prioritise. Something that is both urgent and important is the highest priority.

# Eisenhower Matrix



- Target your audience according to what your key issues are. You might write to the Minister of Health or the Minister for the NDIS about health and NDIS concerns (respectively).
- Decide which platform will most effectively convey your message e.g. does my target audience use email, twitter or other forms of social media? Can you use multiple platforms to get your message across? If you are teaming up with an organisation, what platform do they generally use?
- How exactly can your target audience help? If you provide suggestions, they may have an idea where to start.
- Use consistency and repetition. If you are contacting a person or group multiple times, be consistent about your message and the platform you use.

## 10. What methods can I use to advocate?

### 10.1. Write to or meet with politicians

- Local MPs
- Ministers or deputy secretaries of government departments
  - Department of Social Services
  - Department of Education, Skills and Employment
  - Department of Health
- Before you meet with a politician, please feel free to reach out to SWAN at [info@swanaus.org.au](mailto:info@swanaus.org.au) or refer to this toolkit for advocacy tips. SWAN also writes supporting letters for members engaging in political advocacy.

## 10.2. Approach the media

- You can share your experience through a media release to raise awareness and gain political attention. To achieve a publication, you may wish to approach a national advocate such as [The Australian Council of Social Service](#) or a news outlet. Some SWAN members have been in the media for issues such as the NDIS, and we can help you champion your cause.

## 10.3. Use social media

- Social media is a great platform for sharing media publications. SWAN families are typically time poor, but you can still make a difference by sharing articles, adding your own commentary, and tagging politicians.
- The 'retweet' and 'quote tweet' functions on twitter make this form of advocacy particularly efficient. You may also wish to share posts on Facebook, Instagram and LinkedIn. A good place to start is following accounts that are strong advocates for disability and rare disease.
- If you are motivated to create your own social media content, you may wish to share your experience through a combination of photos, videos and written content.

## 10.4. Petition and/or rally

- Some political campaigns will use all three of these methods to bring groups together to fight for a cause. Every Australian Counts is a campaign that has used these methods to fight for and defend the NDIS. They held several in-person and online events such as discussion forums and rallies. Attending group events and telling your story helps build the evidence base to justify change. Petitions are a quick and accessible way to contribute to a cause, which you can usually sign online.

## 10.5. Contribute to submissions

- SWAN writes [submissions](#) on behalf of its members to provide feedback on their experiences (e.g., the experience of SWAN children at school). These are often addressed to politicians and changemakers. You can contribute to submissions by sharing your experience or joining the Community Advisory Group CAG that reviews them.

## 10.6. Follow election campaigns

- In the lead up to elections, [SWAN advocates for issues](#) that are important to members, asking the government for change. As a SWAN member, you can take part in our campaigns by:
  - Personalising our campaign letters and sending them to politicians
  - Sharing posts about our campaigns on social media
  - Bringing the key issues to meetings with your local MPs or candidates

## 10.7. Participate in research

- This is a more subtle form of political advocacy. Research findings can inform new health, education and disability policies. By participating in research, you can help improve systems to better support children with undiagnosed and rare genetic conditions. Please see our website for [research opportunities](#).

## 10.8. Stay informed!

- If you are interested in advocacy and support, SWAN recommends subscribing to a variety of newsletters that are relevant to your family and can help you stay up to date. These include:
  - [SWAN](#)
  - [Association for Children with a Disability](#)
  - [Raising Children Network](#)
  - [DARU](#)
  - [Source Kids](#)
  - [Reframing Disability](#)
  - [Amaze](#)

## 11. Concluding Message

Advocacy is all about using our voices to champion positive change. As a SWAN parent/carer, you may feel you have no choice but to advocate for your child, which is no easy task. SWAN Australia hopes that this Toolkit deepens your understanding and gives you the tools to advocate successfully. If you have questions or need support at any time, please reach out to us at [info@swanaus.org.au](mailto:info@swanaus.org.au).

Non-for-profit organisations rely on donations to fund advocacy services for their members. Please consider [donating to SWAN Australia](#) so that we can continue to advocate for our members empower them through peer support and access to resources.

### 11.1. Summary of Useful Tips for Advocating

- Recruit a support person for before, during and after discussions.
- Go into meetings with a solution focus and try and not to be defensive.
- Come prepared for your medical appointments with a list of questions.
- Develop positive relationships with staff and parents who will be good allies for you and your child.
- Prepare evidence to justify funding at your NDIS planning meeting.

## 12. Useful Links

### 12.1. Understanding advocacy

- [What is advocacy?](#)

### 12.2. Finding an advocate

- [Find an advocate | Disability Advocacy Network Australia](#)
- [Find an Advocate](#)
- [Disability Advocacy Finder | Ask Izzy](#)
- [Students with Disability: Advocacy and Networks - ADCET](#)

### 12.3. SWAN Resources

- [SWAN Australia](#)
- [SWAN Newsletter](#)
- [SWAN advocates on key issues of concern](#)
- [SWAN writes a number of submission on behalf of SWAN families](#)
- [SWAN Australia - join research projects](#)
- [SWAN resources on NDIS; fact sheets NDIS](#)
- [Becoming and NDIS Participant](#)
- [Background to NDIS Planning Meeting](#)
- [Preparing for your NDIS Meeting](#)
- [The Planning Meeting](#)
- [Useful NDIS Tips](#)
- [SWAN donate to make a difference](#)

### 12.4. Healthcare resources

- [Genetic Counselling - Allied Health Professions Australia](#)
- [Services and support | Carer Gateway](#)
- [Planning your hospital stay](#)

### 12.5. Health Complaints

- NSW: [Health Care Complaints Commission](#)
- VIC: [Health Complaints Commissioner](#)
- QLD: [Make a complaint - Office of the Health Ombudsman](#)
- WA: [Health and Disability Services Complaints Office](#)
- SA: [Health and Community Services Complaints Commissioner](#)
- NT: [Patient complaints and compliments | NT Health](#)
- TAS: [Health Complaints Commissioner Tasmania](#)
- ACT: [Health Services - ACT Human Rights Commission](#)

### 12.6. Disability and Education Rights

- [Rights of people with disability | Attorney-General's Department](#)
- [Disability Standards for Education 2005](#)
- [Disability Discrimination Act 1992 - Department of Education, Skills and Employment](#)
- [Complaints Processes - Department of Education, Skills and Employment](#)
- [Education rights: children with disability | Raising Children Network](#)
- [Right to education | Attorney-General's Department](#)
- [Education - Australian Centre for Disability Law](#)

- [DDA guide: Getting an education | Australian Human Rights Commission](#)
- State Departments of Education: [NSW](#), [VIC](#), [QLD](#), [WA](#), [SA](#), [NT](#) and [TAS](#)

### 12.7. Communication

- [Effective Consultation with Schools](#)
- [Communicating with your healthcare provider when you are in hospital](#)
- [Communicating with your healthcare provider when you are in hospital - Posters](#)

### 12.8. NDIS Website

- [What is the NDIS?](#)
- [Am I eligible | NDIS](#)
- [Guardians and nominees explained | NDIS](#)
- [The early childhood approach | NDIS](#)
- [LAC Partners in the Community | NDIS](#)
- [How to apply | NDIS](#)
- [Creating your plan | NDIS](#)
- [Reasonable and necessary supports | NDIS](#)
- [Change in circumstances | NDIS](#)
- [How to review a planning decision | NDIS](#)

### 12.9. NDIS Appeals

- [Administrative Appeals Tribunal](#)
- [NDIS Appeals | Department of Social Services, Australian Government](#)

### 12.10. Other websites

- [Australian Council of Social Service](#)
- [Australian Commission on Safety and Quality in Health Care](#)
- [Association for Children with Disability](#)
- [Raising Children Network](#)
- [Disability Advocacy Resource Unit \(DARU\)](#)
- [Genetic Support Network of Victoria](#)
- [Child Unlimited](#)
- [Amaze](#)

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