



10 Top Tips

Practical information sheets to ensure people with cognitive disabilities have a real and equal Voice at the Table.

voiceatthetable.com.au



Voice at the Table History

In 2016, Sue Smith of the Self Advocacy Resource Unit (SARU), began working with members of the self advocacy groups Reinforce and Brain Injury Matters to design the first *Voice at the Table* project.

"We provide practical information to ensure people with cognitive disabilities have a real and equal *Voice at the Table.*"

This project was needed because so many self advocates were going to consultations and committee meetings that were not accessible to them!

The project was set up to train both self advocates and State Government staff in how to run an accessible meeting. Videos like 'The Good the Bad and the Ugly' were made.

The project was such a success that in 2018 further funding from the Department of Health and Human Services enabled the SARU to employ staff and continue the project.

Since 2020, the project has been running thanks to funding from the Australian Government – Information, Linkages and Capacity Building Program.

For more information about Voice at the Table, go to the website:

voiceatthetable.com.au

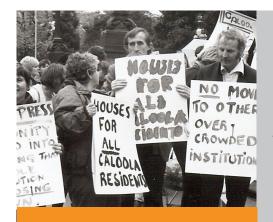
We would like to acknowledge all of the hard work and people who have created the 10 Top Tips resource.



Voice at the Table 10 Top Tips

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Nothing about us without us

We recognise the members of self advocacy groups who have worked tirelessly over the years for the right to live in the community and for equality and human rights for all.

Acknowledgement of Country We acknowledge the traditional owners and custodians of country throughout Australia and their continuing connection to land, waters and community. We pay our respect to them and their cultures, and elders, past, present and future.



What is Consumer Participation?



What is consumer participation?

Hard words in TIP 1 section

The meanings for hard words highlighted in **bold** in this section are below:

- consumer Any person who uses a service or product
- participation taking part in something
- laws are the rules. If you do not follow the rules you could be fined and taken to court
- **lived experience** what you know about the world because of the daily life that you have lived.

Quote

"I would love to see a person with a disability working alongside every single politician. I just think it would be a better world".

Colin Hiscoe, Reinforce Self Advocacy Group



Resources

- Commonwealth Disability Discrimantion Act
 https://humanrights.gov.au/our-work/disability-rights/publications/disability-discrimination-act-25th-anniversary-easy-read
- Victorian Disability Discrimination Act (2006)
- Charter of Human Rights and Responsibilities Act (2006)
- Disability descrimation Laws
 https://www.humanrights.vic.gov.au/for-individuals/disability/
- Consumer participation and engagement: The Health Issue Centre https://hic.org.au/consumer-engagement-resources-october-2021/



What is Consumer Participation?

Consumer participation is when organisations ask people with disability how things need to be done.

This should include how services are planned, delivered and run.

It means:

- voices are heard
- change happenss
- decisions are shared
- everyone is equal

Why does consumer participation matter?

It is important that everyone has a say about the decisions that affect their lives.

In Australia, there are **laws** that make sure people with disability have the right to have a say.

This means that Governments and organisations need to deliver services that are informed by people with a **lived experience** of disability.

People with disability are the experts in what they need.

Consumer participation is good for everyone. It uses the expert knowledge of people with disability to make services work the best for everyone.

Good consumer participation should:

- see people with lived experience as experts
- improve the quality of services, projects and programs so they meet the needs of everyone
- inform organisations of new issues, barriers and concerns
- evaluate the outcomes and quality of the service
- bring new ideas to the table
- explore new ways of doing things
- create new knowledge and develop new skills



What do I have to do to be prepared?



What do I have to do to be prepared?

Hard words in TIP 2 section

The meanings for hard words highlighted in **bold** in this section are below:

- committing means that you agree to do something
- **cognitive** means how your brain works to remember, think, feel, move and reason
- contribution is the part you play in bringing about a result or changing something
- mutual respect means that everyone respects each other.

Quote

"It is important to make sure all participants on a committee are aware of ABI and its components. Prior to the meeting have the person run a session about ABI. ABI is called the invisible disability because sometimes people assume if you can walk and talk you are O.K."

Peta Ferguson, Brain Injury Matters



Brain Injury Matters



What do I have to do to be prepared?

Committing to consumer participation is easy.

By involving people with **cognitive** disability we can have a say to improve the way things are done.

For consumer participation to work it is important that your organisation creates a workplace that values:

- **equity** Everyone is given the support they need to participate equally
- respect people are respected and valued for their contribution. Adults are treated as adults
- listening all opinions are actively asked for, listened to and discussed
- shared Learning consumer representatives and the organisation have the opportunity to learn from each other's knowledge and experience
- working communication communication between the organisation and the consumer representatives happens in a way that builds knowledge, understanding and mutual respect
- action create positive change based on what you learn from people.



Why do I need to know participants' roles?



Why do I need to know participants roles?

Hard words in TIP 3 section

The meanings for hard words highlighted in **bold** in this section are below:

- policies are ideas that are agreed on to make decisions
- privacy is not wanting your information shared
- confidentiality is agreeing not to share information
- professional conduct means behaving in a way that is acceptable in a workplace or meeting. Treating others calmly and with respect.

Quote

"It is very confusing (when I don't know what my role is on a committee) It makes me feel disheartened. Being a member of a committee you should know what is going on and be prepared. If you are not prepared you are just floundering."

Julyne Ainsely, VATT Graduate Training Team





Why do I need to know participants' roles?

Having clear roles allows people to do their job well and safely.

Clear roles also allow people to work well together.

The role of the Consumer Advocates is to use their expertise from lived experience to improve services.

It is important that the organisation knows what the role of the Consumer Advocate is.

The role of the Consumer Advocate is:

- representing how consumers think and feel
- making sure problems are heard and addressed
- giving feedback to the committee about their experiences as a consumer.

Organisations must tell the Consumer Advocate about anything the committee does or decides to do.

Please make sure the consumer advocate understands:

- how much work is involved
- the dates of the meetings
- how long this job will go for
- how they will be paid (including payment for out of pocket costs)
- where the meeting will take place (face to face or on a video call)
- the policies that relate to their work. For example privacy, confidentiality, vaccinations and professional conduct
- what the organisation does, the role of the Chair and the other people around the table
- if there is an interview process
- the COVID-19 standards required.



How do I identify and remove barriers?



How do I identify and remove barriers?

Hard words in TIP 4 section

The meanings for hard words highlighted in **bold** in this section are below:

- barriers are things or ideas that stop someone's access to something.
- accommodate fit in with the needs of someone
- discriminatory unfairly treating a person or particular group of people
- **traumatic** feelings are the emotional responses to a terrible event.
- fatigue is feeling very, very tired.
- **sensitive** is when someone is easily irritated or affected by things like light, sound, touch, smell or high emotions.
- **inclusion training** means training organisations how to include people with cognitive disabilities within meetings and the values of this.
- the Charity Model sees people with disability as needing someone else's help.
- **Medical Model of Disability** sees what's 'wrong' with the person and not what they need to live their life.
- capacity means what someone is able to do.
- jargon means words that are often used by professionals that not everyone understands.
- acronyms means a short way of saying the name of a company or place. They
 are made up of the first letter of each work. For example VATT is the acronym
 for Voice at the Table.
- out of pocket expenses are things you pay for with your own money.
- **honorarium** means payment in the form of a gift card to someone who has given their time and experience.
- environmental barriers are things in the environment that might get in the way of someone being able to fully participate in, or access the meeting.



How do I identify and remove barriers?

There are many **barriers** stopping people with cognitive disability to have their say on important issues.

Many of these barriers don't have to be there.

Steps to take

1 Ask people what their support needs are.

- Many disabilities are invisible and every person has different support needs.
- Make sure you know what each Consumer Advocate's support needs are so they can have an equal voice in the meeting.

2 Make sure information is accessible.

- Information needs to be in Plain English so that it is easy to understand.
- If asked for, information needs to be given in Easy English. (See Tip 5)

3 Make sure communication is clear.

- Ask the Consumer Advocate how they want to be contacted.
- Remember that the Consumer Advocate might:
 - not have access to the internet or email
 - find it hard to speak on the phone
 - have support needs for reading and writing.

4 Be aware of social barriers for Consumer Advocates.

- · It can be scary being the only Consumer Advocate at a meeting.
- · There are many things that can make people feel insecure, like
 - not knowing where they have to go
 - not knowing what they should wear not knowing if people will accommodate their disability
 - feeling like they have the responsibility of speaking on behalf of all people with a cognitive disability
- These things create barriers that stop people from feeling confident and having their say.
- Make sure there are at least 2 Consumer Advocates at meetings.



Steps to take (continued)

5 Be aware of social barriers for organisations.

- If there has been no disability inclusion training, people may not have experience speaking to someone with a cognitive disability respectfully. (ie like an adult).
- Don't assume anything about a Consumer Advocate. Have a conversation and ask them questions to find out more.
- Don't operate out of The Charity Model or Medical Model of Disability because these are discriminatory.
- These Models see people with disability as:
 - people who need to be helped
 - people who don't have the capacity to make informed decisions.
- Many barriers are caused by these approaches for people with cognitive disability.

6	√	Checklist	
		Before the meeting	
		All documents are accessible	
		Consumer Advocates get all of the information at least 1 week before the meeting	
		Consumer Advocates are sent accessible reminders about the meeting	
		During the meeting	
		Make sure the meeting does not move too quickly and allows for everyone to have a say	
		All Agenda points are summarised at the end of each point	
		That hard words are explained and put on a list	
		Any jargon is fully explained	
		No acronyms. Use the full name of the organisation	
		See Tip 8 for more tips	



Steps to take (continued)

7 Be aware of trauma informed barriers.

- Many Consumer Advocates have had traumatic experiences in their past.
- This can mean they may:
 - find it difficult to trust professionals
 - believe they won't be listened to
 - not want to tell their story (and they should not have to)
- It is important to think about these points.
- It is important to make meetings the safest places they can be for people emotionally as well as physically.

8 Be aware of financial barriers for people.

- Life on a low income is difficult. Many Consumer Advocates live on a Disability Pension.
- People may not be able to afford:
 - travelling to meetings
 - covering the cost of buying lunch
 - phone and internet access
- These are some of the payment options you should consider.
 - Cover out of pocket expenses for participants
 - Ask people how they would like to be paid
 - Payments may need to be arranged in a way that does not affect the person's pension
 - Some people need to be paid with an **honorarium** /gift card so it does not affect their pension
 - Some people do not like to be paid with gift cards.



Steps to take (continued)

9 Recognise physical and environmental barriers.

- Sometimes people with cognitive disabilities also have physical disabilities.
- It is important to ask the Consumer Advocate about their physical access needs.
- Think about the location of the meeting.
- Are there:
 - stairs?
 - narrow doorways?
 - potential trip hazards?
 - accessible toilets (and accessible access to the toilets)?
 - long distances between public transport and the venue?
- Is there enough space in the meeting room to stand up and walk around?
- Some people are sensitive to sound or light.
- Give thought to:
 - the meeting room lighting
 - any sounds or buzzing in the building
 - where the windows are
 - where people need to be seated (this may be close to the door)
 - the fact that some people with an ABI experience fatigue.



Quote

"Acquired Brain Injury (ABI) can be so many different things and have so many effects including

- physical impact: the need for walking sticks and wheelchairs to the unseen effects such as
- tiredness
- memory
- noise sensitivity and light sensitivity

(For) some people with ABI it helps to... have meetings in the morning and regular breaks."

Francesca Lee, Brain Injury Matters







How can I be welcoming?



How can I be welcoming?

Hard words in TIP 5 section

The meanings for hard words highlighted in **bold** in this section are below:

- environment is what is around us
- facilitator is a person who helps a group of people to work together
- encourage means to give someone the emotional support to do something they think they cannot do
- evaluation is finding out what worked well and what could be improved.

Quote

"Before going into a meeting, it would be really nice if the Chairperson could introduce themselves to you".

Lisa Brumtis, VATT Graduate





How can I be welcoming?

Before the meeting

It is important that the Consumer Advocate feels comfortable in a new environment.

The Chairperson or meeting **facilitator** needs to make contact with the new Consumer Advocate before the meeting.

They need to:

- introduce themselves
- explain that it is their job to make sure everyone has a voice
- explain that it is their job to make sure everyone feels included
- let the Consumer Advocate know it is okay to ask questions during the meeting
- tell them about who else will be at the meeting
- encourage the person to come and speak to them in the break with any issues they have.

At the meeting

- make sure there is someone to welcome the Consumer Advocate when they arrive
- start the meeting with introductions and encourage everyone to explain why they are involved
- allow time for everyone to say a bit about themselves and what they are interested in.

After the meeting

say thank you

Ask the Consumer Advocate:

- were your access needs met?
- did the meeting go well?
- did you feel included?
- did you have your say?
- were you listened to?
- were your opinions respected?
- how can the meeting be improved?

Evaluation

Make sure that feedback is used to improve the meetings and let the Consumer Advocate know what changes have been made.



How do I provide information that everyone can understand?



Providing information

Hard words in TIP 6 section

The meanings for hard words highlighted in **bold** in this section are below:

- accessible Information is information that is able to be read and understood by the people you are working with
- communication is the act of moving information from one place or person to another
- minutes are the notes taken about what was said during a meeting
- presentations are a speech or talk in which an idea, or piece of work is shown and explained to people
- handouts are the papers that are handed out showing the main points of the talk or meeting
- data is collected information about a certain thing. It is often organised in graphs or charts for may include facts, numbers or measurements.

Resources

SCOPE Access and inclusion eLearning
 https://www.scopeaust.org.au/services-for-organisations/access-and-inclusion-for-businesses/education-training/access-and-inclusion-elearning/

Quote

'Send out all the information before the meeting and have someone sit with us and go through the agenda and the minutes. Please use Easy English from the word go."

Amanda Millear, Reinforce





How do I provide information that everyone can understand?

Information that meets the access needs of people with a cognitive disability is called **Accessible Information**.

First things first

- 1. Ask the consumer advocate how they like to receive written **communication**.
- 2. Make sure that the consumer advocate has time to go through the information well before the meeting starts.
- 3. Be there to support the consumer advocate to understand the information if they need it.
- 4. Make sure you ask the consumer advocate if the information meets their needs

Accessible documents

Documents you need to provide in accessible formats are:

- agendas
- minutes
- reports
- presentations
- emails
- handouts
- data

Making information accessible

Everyone with a disability has different communication needs.

You may need to use

- plain English this is a way of writing that is simple and clear. It uses short sentences and avoids language that is hard to understand.
- easy English this uses pictures and simple text.
- audio this uses an audio app to read out the text.
- video a video is made of someone reading the information.

During the Meeting

Have a hard words list during the meeting.



What support do I need to offer?



What support do I need to offer?

Hard words in TIP 7 section

The meanings for hard words highlighted in **bold** in this section are below:

- mentor is someone who can support a person and has knowledge and information they can share
- contribute means to give something to a group. It could be time, money or ideas
- presentation is a speech or talk in which a new idea or piece of work is shown and explained to an audience
- confidentiality means to keep what is talked about private and not to be talked about outside the meeting
- **experienced** is when someone has learned skills over time.

Quote

"She writes down notes, we make a time later on and we go over what has been said. I think it [having a support worker] encourages you to have a say."

~ Patsie Frawley
Participation in Government
Disability Advisory Bodies in
Australia: An Intellectual Disability
Perspective.





What support do I need to offer?

A Consumer Advocate may ask for an inclusion support worker to support them in the meeting or ask for a **mentor** from the organisation.

1. Inclusion support worker

People with an intellectual disability (ID) or an acquired brain injury (ABI) may want a support worker to work with them before, during and after the meeting.

It is important that the Consumer Advocate either

- selects their own inclusion support person
- has the power to say yes or no to a support worker the organisation chooses.

2. Inclusion support workers role

The inclusion support worker's role is to support the Consumer Advocate in the way they ask to be supported. Their aim should be to make their support 'invisible' to others.

The role is **not** speaking for the person they are supporting and **not** adding their own thoughts in the meeting.

Before the meeting

- ask the Consumer Advocate how they would like to be supported before, during and after the meeting
- go through the agenda and any written information
- talk through and note any issues or questions that the Consumer Advocate wishes to raise
- prepare, practice and review any information the consumer advocate might need to present
- talk through any worries the consumer advocate might have
- provide accessible information, when asked, to support with decision-making.



During the meeting

- take notes, when asked, for the Consumer Advocate
- provide advice when asked
- clarify or explain information when asked
- remind Consumer Advocate of questions or issues they want to raise.





After the meeting

- meet with the Consumer Advocate to talk through the meeting
- write up notes in Easy or Plain English when asked
- ask for feedback from the Consumer Advocate on the support provided
- respect confidentiality.

3. Mentoring

Some organisations, boards and committees may choose to use mentors.

A mentor is an **experienced** board, committee and or working group member whose role is to use their knowledge and skills to support a new member to understand their role.

Mentoring is about sharing and learning from each other.





Does everyone understand?



Does everyone understand?

Hard words in TIP 8 section

The meanings for hard words highlighted in **bold** in this section are below:

- mentor is someone who can support a person and has knowledge and information they can share.
- acronyms are a short way of saying the name of a company or place. They are made up of the first letter of each word.

For example - VATT is the acronym for Voice at the Table.

- confuse is when you do something to make someone else not be able to think clearly
- **jargon** is words that are often used by professionals that not everyone understands.
- chair is somebody who is in charge of making the meeting run well for everyone.

Quote

"Ask the person if they need regular breaks, make sure you don't talk over people, record minutes using dot points and don't go off topic."

Advice from Brain Injury Matters



Brain Injury Matters



Does everyone understand?

A Consumer Advocate may ask for an Inclusion Support Worker to support them in the meeting or ask for a **mentor** from the organisation.

To run an accessible meeting you need to:

1 Have the agenda in Easy or Plain English

- Ask the participants what their access needs are.
- Give the same agenda to everyone if someone asks for the agenda to be in Easy or Plain English.

2 Put a few short breaks in the agenda

- Build breaks into your agenda.
- Check in with people to see if they need another break.
- · Short breaks allow everyone to refresh.
- It is important for some people with an ABI who have fatigue to have a few short breaks during the meeting rather than just one longer one.

3 Allow time

- · List agenda items in order of importance.
- Make sure you leave enough time to talk through all the items on your agenda.
- Decide which items can be left for the next meeting if you run out of time.

4 Explain each agenda item

 At the start of each new agenda item, the chair should explain the topic to be discussed.

5 Make sure everyone understands

• When you have finished an item on the agenda, go over it to make sure that everyone understands what has been talked about.



To run an accessible meeting you need to:

6 Tell people it is OK if they don't understand

- Encourage people to speak up if they do not understand something.
- This benefits all meeting members, not just people with a cognitive disability!

7 Avoid jumping from item to item

- The meeting should follow the order of the agenda.
- Don't jump to random agenda items.
- If new ideas come up the chair should add them to the end of the agenda.

8 Leave space for comments after each agenda item

- Ask each committee member if they have anything more they would like to say about each item.
- This makes sure that people who may not be confident to speak up in the discussion can have their say on each topic.

9 Read out any material not sent out before the meeting

- While having new material at the meeting is not best practice, sometimes it does happen.
- Make sure you give plenty of time for people to understand what this new material means.

10 Make eye contact with everyone

This allows people to feel seen it also supports them to speak up.



To run an accessible meeting you need to:

11 Ask one question at a time

- This allows time for everyone to think about and answer the question.
- Slow down!
- Everyone in the meeting needs to speak slowly and clearly.

12 Use language that everyone can understand

- Don't use jargon and acronyms.
- When difficult words have to be used
 - explain what they mean
 - put them on a 'hard word list' where everyone can see them.

13 Make sure everyone has a say

- Ask people who have not said anything if they have anything else to add. If they say no, then move on.
- Remind the group to let everyone have a chance to talk.
- Make sure that only one person speaks at a time.

14 What is the vote about?

 If there is going to be a vote, make sure everyone understands what it is about.



Has everyone had a say?



Has everyone had a say?

Hard words in TIP 9 section

The meanings for hard words highlighted in **bold** in this section are below:

- **influence** means that you can tell someone to do something by the way your voice sounds, your face looks or by the way you hold your body.
- encouraged means to give support to someone so they can do something.
- outcomes are results or things that happen because of the meeting.
- **body language** is the messages that other people get through the way you hold yourself and your body.
- **tone** is the way your voice comes across to other people and the message this gives.

Quote

"I have been to lots of meetings where I didn't get my say and that stinks in my opinion" ."

~ Amanda Millear, Raising Our Voices 3CR Radio show





Has everyone had a say?

It is important that everyone gets to have their say at the meeting if they want to. When you have everyone's ideas, your meeting **outcomes** are so much better!

It is helpful to remember:

- it might take a few meetings before people feel comfortable speaking up
- let people speak for themselves
- do not speak before they finish
- give people time to answer.
- body language and tone of voice can influence how people respond to an idea, vote or question.

Here is a check list of questions to ask yourself during a meeting.

- 1 Has everyone around the table/screen had a say?
- 2 Have people had time to ask questions?
- 3 Have you given people time to think about and share their ideas?
- 4 Have people been encouraged to say what is on their mind?
- 5 Have you let the group know that it is OK to disagree?



How do I evaluate the meeting?



How do I evaluate the meeting?

Hard words in TIP 10 section

The meanings for hard words highlighted in **bold** in this section are below:

- evaluate means to look at something and judge how good it is
- process means the actions or steps taken to get something done
- outcomes are the things you expect to happen because of your project
- goals are the things you want to achieve
- **short term** means changes that have happened straight away
- long term means changes that will take a longer time to make
- questionnaires are a set of questions that collects important feedback
- statistics are when information is shown with numbers or graphs



How do I evaluate the meeting?

Why do we **evaluate**? To make sure the meetings have been accessible for Consumer Advocates.

Consumer Advocates always need to be part of the evaluation process.

Types of evaluation

1 Process

Evaluate the meeting process

- at every meeting
- at the end of the project

Every Meeting

At the end of each meeting ask a set of questions to check that people's access needs are being met.

Questions you could ask:

- What was the meeting like for you?
- Did you understand the information you were given?
- · Did you think your ideas were listened to?
- · Did you have an opportunity to speak?
- Were your access needs met?
- What could be changed?

At the end of the project

Questions you could ask:

- Did everyone feel more confident by the end of the project?
- Did the group work well together?
- What worked well?
- What could have been improved?



Types of evaluation

2 Goals

Were the goals for the project met?

Questions you could ask:

- Were the purpose, aims and objectives of the project met?
- Did we get the information that was needed for the project?
- Were there any outcomes that were not expected?

3 Outcomes

What changed because of this project?

- What were the short term changes?
- What were the long term changes?
- Did they fit the goals of the project?



Tools you could use for evaluation

- Storytelling
- Exit interviews (either face to face, over the phone or video call)
- Questionnaires
- Feedback
- Photos and videos
- Statistics
- Reports either written or filmed

RESOURCES

Creative Victoria and Effective Change
'Evaluating Community Arts and Community Well Being'
http://creative.vic.gov.au





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