

Self Advocacy and Safe Story Sharing

A guide for Organisations



About this resource

This resource is for organisations who want to work with people with disability to create change.

This resource was created by people with intellectual disability from the *Positive Powerful Parents Self Advocacy Group* and the *Self Advocacy Resource Unit (SARU)*.

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A note for self advocates

This resource has some hard words.

The hard words are in **blue**.

There is a list of hard words and the meaning on page 7.

About Self Advocacy and Safe Story Sharing

This resource is a guide for organisations who want to work with self advocates. It was made by people with an intellectual disability from Positive Powerful Parents Self Advocacy Group.

Many people with disability have experienced abuse, neglect, **exploitation** and discrimination.

Abuse, neglect, exploitation and discrimination make life hard for people with disability and have long lasting effects.

People with disability share their stories of abuse, neglect, exploitation and discrimination to create change for others.

People with disability who share their stories to create change are called self advocates.

Sharing stories can be hard; it is emotional work that can leave self advocates feeling upset long after they have finished sharing.

Self advocates have created 10 rules for safe story sharing. Please follow these as a guide to help protect self advocates and make sure they get the support they need.

10 Rules for Safe Story Sharing

It's all about respect, support and equality

Rule 1

Speak and write to us using language that we can understand

When speaking with self advocates please speak in Plain English and avoid using jargon and **acronyms**.

If you must use words that are difficult to understand, please stop to explain what you mean and pause regularly to check in and make sure everyone understands what is being said. Many self advocates prefer to receive written information in Easy English. Please see the *Working with people who use Plain and Easy English Factsheet* for more information.



Rule 2

Tell us what you want to know and why you want to know it

Share the following information when you contact self advocates and be prepared to answer any questions:

- Why you want this information and the benefits that will be had by sharing
- Where this information is going to go
- Who is going to see it

Self advocates do not want to share their stories unless they know why, where and who. This helps to build trust.



Rule 3

Find out what support we need and want

Talk to the self advocate about physical and emotional support needs.

It is important that self advocates choose their own support person and that this has been organised before an event or meeting.

- At the beginning of any meeting remind the self advocate that the information they share is up to them. It is okay for a self advocate to leave out any part of their story that they do not feel comfortable sharing.
- Remind the self advocate that they are in control and can stop sharing anytime they feel uncomfortable.
- If a self advocate becomes upset pause and ask them about how they are feeling. Check if they would like a break and what support they need.



Rule 4

What we say in the room stays in the room

Do not share stories with anyone else unless you have permission to do so.

Self advocates' stories are confidential. Please respect the privacy of people with disability who have chosen to share their story.



Rule 5

Protect our identity

Consider how revealing a self advocate's identity might negatively impact their personal relationships, safety, reputation and the impact on families.

Sometimes self advocates share stories with an understanding that their identity will not be revealed. If a self advocate requests that you protect their identity, it is important that you respect that. It is everyone's job to make sure story sharing does no harm and has no negative consequences.



Rule 6

De-briefing time is important

Allocate 1 hour for a self advocate to de-brief with a support person after sharing a personal story.

If a self advocate has gone to your place of work, please make sure there is a private space they can use to de-brief after the meeting.



Rule 7

Follow up with us and find out how we are after the meeting

Let self advocates know how you have used their information and how they have been helpful.

It can help self advocates to feel better about the information they have shared if they know it has been of benefit to others. If a self advocate is feeling flat or distressed, think about the resources that your organisation has to offer, such as an **Employee Assistance Program (EAP)** service.



Rule 8

If you take notes, please send them back to us to check if we are happy with what they say

Check that you have the right information.

In the past, self advocates have had their words and stories **misinterpreted**, and people have not always been happy with the way their words have been **portrayed**. Making sure you have the right information supports self advocates to ensure their **perspective** is heard and no harm is done.



Rule 9

Think about payment

Include travel time, de-brief time and support person needs when working out financial **compensation**.

Self advocates are often willing to share their stories without payment if they think it will benefit other people, but it is good to remember that they do not have to. If you are being paid to meet with the self advocate and your organisation or work is going to benefit from the information, it is good and equitable practice to think about how you might compensate the self advocate for their time and the personal toll that this work takes.



Rule 10

For filming and sound recording, follow rules 1-9, and consider the tips below

- Always tell people where the video is going to be shared and who it is for.
- Ask the person sharing their story if they need any support and what that support is.
- Always ask the person if they want their face and identity revealed, or only their voice, or if they want their identity protected. Use creative ways to ensure people's stories are respected and protected as necessary.
- Make sure the people you are filming or recording know what you are going to ask them about before you begin the interview. It is good practice to send the questions beforehand so self advocates have time to prepare.



Last note

When working with self advocates who are sharing stories of abuse, neglect, exploitation and discrimination, think about what you would need and want if you were sharing this sort of personal information.

When sharing difficult personal stories people need support, respect and kindness. Private rooms, cups of tea, biscuits, tissues and **appreciation** are reassuring ways of treating people with respect and dignity.

List of hard words for self advocates

Exploitation means someone takes advantage of you.

Acronyms are letters that stand for words. For example: NDIS stands for National Disability Insurance Scheme.

De-briefing means talking about something after it has happened.

Employee Assistance Program (EAP) is emotional support for workers.

Misinterpreted means taken the wrong way.

Portrayed means the way you look to others.

Perspective means your side of the story.

Compensation is money for your time and effort.

Appreciation means being valued.

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