

Understanding inclusion and advocacy

Exploring how we can all build belonging



Do you need to call someone?

Emergency

In an emergency or if someone is in danger

Triple Zero 000

Need to talk?

If you are in crisis, anxious or depressed and want to talk with someone

Lifeline: 13 11 14 – for anyone

Kids Helpline: 1800 55 1800 – for people aged 5 to 25

Carer services

Call the Carer Gateway Contact Centre for support and services:

1800 422 737 – Monday to Friday, 8am to 6pm local time

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Name:

How to use this workbook

In this workbook you will find activities, information, resources and opportunities designed to support the facilitated and self-guided coaching experience. How you use this workbook is entirely up to you. We encourage you to make notes, draw or scribble ideas and thoughts throughout. It is your resource and can be something you refer back to in future.

You can work through this booklet at your own pace. You can choose to explore the content with a coach, with a peer or someone you trust, or by yourself.

Throughout this workbook you will see the following icons:



indicates further information



indicates an activity you can complete



indicates an opportunity to pause for a reflection. You could discuss the idea with a friend or your coach, or you could write down your thoughts in your journal



You can download this workbook in PDF format.
Visit coaching.carergateway.gov.au

Speaking up is an ongoing challenge



Phoebe, 29, N.S.W.

I find it hard to step back and not get over involved. I don't want him to have to struggle.

For a long time, my partner was dependant on me. Now that his condition is improving, I find I still want to speak for him and do things for him. It's really hard to accept that I don't always know what's right for him.



Lee, 25, Vic.

I don't want my parents to think they have to worry about me too.

My parents have their hands full looking after my brother, so I've kept a lot of my problems and worries to myself. I wish I could tell them what it's like for me, without them feeling like they need to worry about me too.



Dinesh, 44, S.A.

I want to be involved in my daughter's care.

It has taken a while to get support services to include me in planning for my daughter's care; they used to just defer to her mother. It's hard when you can't attend the meetings because you have to work.



Sandra, 62, Tas.

I hope that by sharing my experiences, I can make a positive difference.

I share my story in the hope that I can help bring awareness to the rights and needs of carers. I want to see significant increases in funding and access for family and carer support services.



Kevin, 68, A.C.T.

Being a carer isn't something I really feel comfortable talking about.

Over the years I've lost friends because I usually wasn't available for social activities. I couldn't tell them it was because I needed to look after my wife. I was brought up to keep those things private.



Achan, 17, Vic.

What will happen when I'm not there to stick up for him?

I stick up for my little brother at school. He gets picked on and gets angry, then sometimes he gets into fights, so I have to step in. I worry about what will happen next year when I am not at school with him anymore.



Tracy, 38, W.A.

I've learned how to speak up for my kids' needs.

There are lots of doctors and workers I have had to learn to talk to about what my kids need. I am starting to think about how to get them to understand what I need too. It's a process but I feel like we are all working together.



What does it mean to have a seat at the table?

In this coaching session you will think about what makes a space inclusive. You will also explore your rights, how you might respond when you encounter exclusion, discrimination and stigma.

Topics:

- Inclusion, exclusion and discrimination,
- What is stigma and how is it relevant to carers?
- Advocating for the person you support, for others and for yourself.

By the end of this coaching session, you will be able to;

- Recognise your role in building and maintaining inclusive spaces,
- Understand the importance of advocating for yourself and know how you might do this,
- Understand how to effectively advocate with or for the person you support.

This workbook contains the following sections:

Introduction to inclusion and advocacy	8
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What's important to you?

As you work your way through this course, it can be helpful to keep in mind the things in life that are of the most importance to you. As you explore the topics, questions and activities, consider how your responses are shaped by the values you hold.

On the right is a list of values. The list is by no means complete, and the values included will mean different things to different people.

As you read through the next few sections and reflect on your own experiences, think about how these values might influence your choices and actions.



Read through the list and circle five values that are very important to you.

Hint: Try not to over think it; your first response is enough.

Acceptance

Family

Justice

Accuracy

Flexibility

Knowledge

Belonging

Friendship

Love

Challenge

Fun

Order

Comfort

Growth

Passion

Compassion

Honesty

Respect

Cooperation

Hope

Responsibility

Creativity

Humility

Stability

Dignity

Humour

Tradition

Excitement

Independence

Wealth

Everyone has the right to be included

The ability to participate in society, and to be free from discrimination and disadvantage is not just a good idea; it is a basic human right that we all share. This right is deemed so crucial that it is enshrined in the Universal Declaration of Human Rights and a number of other international treaties.

Being socially included means that people have the resources, opportunities and capabilities they need to:



Learn by participating in education and training;



Work by participating in employment, unpaid or voluntary work including family and carer responsibilities;



Engage and connect with people, use local services and participate in local, cultural, civic and recreational activities; and



Have a voice so they can influence decisions that affect them.

All people have the right to participate in society.

What makes a space inclusive?

An inclusive space is anywhere that assures the respect and dignity of all individuals. This means the space is welcoming, accessible and safe for anyone, regardless of age, ability, gender, culture or sexuality.

An inclusive environment is one where we feel valued and respected, have access to opportunities and resources, and can contribute our perspectives and talents.



Where do you feel comfortable?
What makes you feel comfortable?



Freedom: All people can freely express who they are, their own opinions and points of view, without fear of reprisal.



Safety: All people feel safe from physical and emotional abuse, harassment or unfair criticism.



Opportunity: All people are invited to contribute and participate. Each person's skills and talents are recognised and valued.



Expectations: People are treated as individuals in their own right, not as a representative of their culture, age, gender or ability.



Participation: Everyone can use the space appropriately. Language, finances and physical and cognitive abilities are taken into account.



Environment: The built environment (furniture, lighting, doors, paths, technology) allows anyone to use the space effectively.

What if a space isn't inclusive?

We've probably all had the unpleasant experience of being somewhere we felt we didn't belong or weren't welcome.

Being excluded has lasting impacts, particularly if someone is repeatedly or systematically excluded. Social exclusion can lead to feelings of rejection and low self-worth. In fact, exclusion and prejudice are considered key contributors to depression, anxiety and self-harm.

In a report to the World Health Organization, exclusion is characterised as "dynamic, multi-dimensional processes driven by unequal power relationships... at different levels including individual, household, group, community, country and global levels. It results in... unequal access to resources, capabilities and rights which leads to health inequalities."¹

Being able, supported and encouraged to participate in society, in the ways we choose, is fundamental to our wellbeing.

¹ Understanding and Tackling Social Exclusion, Final Report to the WHO Commission on Social Determinants of Health, Lancaster, 2008



A space is not inclusive if it blocks individuals from access to rights, opportunities and resources that are normally available to others.



Barriers to inclusion

There are many ways that people can be excluded from full access and participation in society.

There can be **physical** barriers making access impossible, or practical barriers, such as expensive costs or impractical scheduling or location. These barriers, when pointed out, can usually be easily acknowledged and rectified.

Social and **emotional** barriers to inclusion are harder to see and more difficult to address.

On an individual level, communication barriers or a person's level of confidence can be obstacles to inclusion. For example, you might be unable to ask for clarification because you don't understand the language or jargon being used in a conversation, or feeling unable to ask questions due to your status or social position.

On a larger scale, community attitudes, cultural traditions, civic systems and government policies can be obstacles to inclusion. Unequal access to resources such as housing, employment, health care and technology can result in people being unable to participate in society.



Discrimination

Social exclusion is often closely linked with discrimination and is when a person or group of people are treated less favourably than another person in the same or similar circumstances.

Discrimination can be against the law if it is based on:

- Age,
- Disability,
- Race, including skin colour, national or ethnic origin or immigrant status,
- Sex, pregnancy, marital or relationship status, family responsibilities or breastfeeding,
- Sexual orientation, gender identity or intersex status.

Under Australian federal legislation, discrimination is against the law when it occurs in an area of public life such as clubs, schools and shops, or in the workplace.



For more information, download *A quick guide to Australian discrimination laws* from the Australian Human Rights Commission.

Visit humanrights.org.au and search for “quick guide”

What is stigma?

Discrimination is when someone is treated in a negative way because of their circumstances. Stigma is when someone is viewed in a negative way because of those circumstances.

Stigma is a mark of disgrace that is associated with a particular circumstance, quality, or person.

Stigma can be **external**; sometimes called social stigma, or **internal**; sometimes referred to as self-stigma.

Stigma can be seen acted out on a small scale through unkind words, accusatory or suspicious glances and being left out of events or activities.

On a larger scale, stigma can be experienced through things such as higher insurance premiums, lack of appropriate health care or the denial of human rights.

Stigma robs people of opportunities that others in society take for granted.



The effects of stigma

Stigma results in:

- problems of **knowledge** – ignorance or misinformation – e.g. “Those kind of people are dangerous.”
- problems of **attitudes** – prejudice – e.g. “That’s right. Those kind of people are dangerous.” This can lead to emotional reactions e.g. “Because they’re dangerous, I fear them.”
- problems of **behaviour** – discrimination – e.g. “Because they’re dangerous, I will avoid them.”

Being the focal point for these problematic attitudes, behaviour and knowledge can have devastating consequences on many levels. There are negative impacts for the individual who experiences discrimination as a result of stigma, but there are also consequences for their family and the wider community.



Individual

- Social isolation
- Unemployment
- Poverty
- Homelessness
- Distress



Family

- Relationship breakdowns
- Isolation
- Unemployment
- Stress
- Grief and loss



Community

- Economic impacts
- Relationship breakdowns
- Discrimination
- Conflict
- Cultural Impacts



Self stigma

We can tend to internalise the attitudes and beliefs of the society and community that surrounds us. Self-stigma happens when we believe and accept other people's negative, inaccurate views about ourselves; we internalise their prejudice and our self-esteem and self-belief suffer greatly.

If we are told that we are less worthy of respect or inclusion often enough, we might start believing it. This can have a significant impact on how we feel and how we behave.

Experiencing self stigma means that we start to:

- view the world as a place where we don't belong,
- expect to encounter stigma and exclusion,
- feel that the search for opportunities to participate in the community is pointless,
- see working on improving our situation as futile.

Each time we run into stigma from others, the negative feelings we hold about ourselves are reinforced, which in turn leads to further isolation and damaging behaviours. This is the vicious cycle of stigma.



The stigma of being a carer

As carers, we might feel that people disregard or look down on us because our experience is different from theirs.

There are many negative stereotypes associated with being a carer.

Carers commonly report that:

- People don't really know the extent of what they do,
- People assume that they are a paid professional care worker,
- People think that they want to avoid getting a job,
- People think that they are just using the carer role as a way to claim benefits,
- People treat them with pity,
- People think they are 'an inspiration' or 'superhuman.'

These are examples of stigma. You might encounter this stigma in how you are treated by family, friends, strangers and or service professionals.

How can we overcome stigma?

Changing entrenched negative attitudes and stigma in society, or within our family, or even inside our ourselves is a process. It takes time and persistence, but it can be done! Think about some of the expectations and attitudes that our society has altered their views on.

There are three ways we can change attitudes and effectively combat stigma, whether on an individual level or in a society: education, contact and advocacy. All three are essential.



Education: Many stigmatised attitudes are the result of ignorance. Providing access to information and facts helps reduce fear. Education might come via schooling, the media, the government or from each other.



Contact: Meeting, seeing and hearing from people who are the subject of stigma allows for understanding, connection and breaks down stereotypes. Contact might be face to face or come through the media or internet.



Advocacy: Calling out injustice, discrimination and stigma where it exists is essential. This is the role of advocacy. Advocacy aims to influence political, economic, and social systems and institutions.



What is advocacy?

Most people understand the concepts of education and contact when we speak about combatting stigma. The activities associated with advocacy are less well recognised. Simply put, advocacy is taking action to publicly support or recommend a particular cause.

Advocacy refers to activities promoting and supporting basic human rights and the right to services and information.

The actions involved in advocacy are quite broad. You can:

- Be an **advocate**, as in 'Rachael is my advocate'. If you are an advocate, you actively support another person's cause.
- **Advocate**, as in 'I advocate for carers being involved in evaluating the program'. To advocate is to provide active support to another person's cause.

By the nature of your role as a carer, you are an advocate. Your insight, experience and knowledge allows you to see the impact when rights and needs are not respected.



Levels of advocacy

All carers find themselves in situations where they need to speak up about how someone is being treated, whether it be the person, or people, they support, others in similar situations, or the way they themselves are being treated.

The situations where advocacy occurs are varied. It can help to think about advocacy as operating on different levels.

- **Self Advocacy**, where an individual speaks up for their own needs and rights.
- **Peer Advocacy**, where more than one person speaks up about the needs and rights of their peers (for example, carers addressing the needs or rights of other carers).
- **Systems Advocacy**, where activities are targeted at the systems and structures that are influential in creating or maintaining injustice and inequity.

Carers are often called upon to talk with doctors and service providers, friends and family, corporate and government bodies, or to speak out in the media in order to address inequality, prejudice, unfair treatment and discrimination. This is advocacy.

The heart of advocacy

Advocacy isn't simply stamping your feet and yelling loudly until you get what you want. Advocacy is about pursuing fairness and equal access to human rights. The beliefs and values that underpin all kinds of advocacy are important to understand. If we are familiar with the true intentions of advocacy, we can develop our skills as effective advocates.

**Rights, justice and equality of opportunity:**

The pursuit of rights, justice and equality of opportunity is critically important for all people.



Lived experiences: The lived experience and knowledge of service users and carers should be recognised, valued and respected. It can contribute to improvements.



Self-empowerment: The ongoing process of acquiring and using knowledge and skills builds sustainable and enduring self-empowerment.



Balance of power: The balance of power between service users and their families and those they deal with is inequitable, unacceptable and culturally and structurally sustained.



Speaking up: Generally, people prefer to express their own position rather than have other people represent them.



Working together: Individuals can inspire others and prepare the way for important changes. Collective advocacy, however, has greater potential for achieving significant outcomes than uncoordinated individual actions.



VALUE
OUR
FUTURE

WOMEN
DEMAND
EQUAL
PAY
NOW!

Value every child.
Value every education.

Value
Value

BIG
STEPS
VALUE OUR FUTURE

BIG
STEPS
OUR FUTURE

BIG
STEPS
VALUE OUR

Systemic advocacy

Systemic advocacy is about working for long-term, lasting improvement by creating social change. Creating this sort of change involves influencing and altering legislation, government policy and community attitudes – the systems that allow inequality and injustice to exist.

It often takes the involvement of many people, working together, over a long period of time to effect change.

Large scale movements for social change, like the campaigns for marriage equality, indigenous land rights, or voting rights for women, are great examples of the results of systemic advocacy.

One of the most significant pieces of legislation that has come about as the result of systemic advocacy for the rights of carers, is the *Carer Recognition Act, 2010*. This act of Australian Federal Parliament aims to increase recognition and awareness of the role carers play in providing daily care and support to people with disability, medical conditions, mental illness or who are frail aged.



You can read more about the history of the *Carer Recognition Act, 2010* at the Australian Parliament website aph.gov.au, search “Carer Recognition”

Advocating for others

As carers, we often need to 'go into bat' for the person we support. Sometimes we literally need to be the voice of the person we support in order to ensure that they are treated with respect and afforded the dignity they have a right to.

Does your caring role require you to advocate for the person you support?



Yes:

The person I support requires me to be their voice because they:

- are unable to communicate
- have a cognitive impairment

Refer to page 40



No:

The person I support doesn't require me to be their voice because they are able to:

- communicate
- understand consequences

Refer to page 42



I am required to be the voice for the person, or people, I support

Due to illness, impairment or disability, you might be required to speak up for someone else; to literally be their voice. You might be the main person to talk to doctors, nurses, case managers or others.

You can advocate on behalf of the person you care for to make sure that services are provided professionally and that rights are respected.

If you want to advocate effectively, it helps to:

- gather accurate information about the problem,
- know your rights and the rights of the person you are caring for,
- decide the best way to approach the service provider – will you use phone, email, letter or in person?
- be assertive,
- be focused – be clear on what you want,
- listen carefully to responses, suggestions and guidance, and take notes.



Know your rights:

visit carergateway.gov.au and search “legal rights for carers”



Supporting someone to advocate for themselves

Sometimes we don't need to speak for someone else to show them we support them. Instead, we can choose to be an ally; someone who is like a team mate who will stand by their side.

Being an ally is about showing genuine support and solidarity. It is a role that requires knowledge, reflection, listening and self awareness.

Tips for being an effective ally:

- Be aware of the ways in which you have privilege. How might that privilege colour the way you see the world and your expectations?
- Listen. Seek to understand before seeking to be understood. Be aware of assumptions and judgements you might be making. Are those assumptions fair?
- Don't attack or belittle others for having different viewpoints. Just because you disagree, doesn't mean the other person is wrong.
- Always get permission before speaking on behalf of someone else.
- Speak up. Silence is often taken as agreement or acceptance.



Self-advocacy

When we think of advocacy, we tend to think first about advocating for the needs of others. But what about your own needs and rights?

Self advocacy is important. Carers commonly report feeling being dismissed or overlooked. Being able to identify, communicate and protect your own needs and how you wish to be treated is an essential aspect of your own health and wellbeing.

Being a self-advocate helps you:

- identify concerns and problems,
- know who to speak to and how,
- be confident enough to speak up.

Advocating for your own rights and needs helps you to develop self confidence and self esteem, independence, dignity, self respect, empowerment and the strength to guard against exploitation and abuse.

The confidence and skills needed to speak up about how you want to be treated is something that develops over time and takes practise.

Circles of influence

Our actions and words have an impact on the people around us. Whether it is through direct teaching, or by setting an example, we can have an impact on the beliefs, knowledge and attitudes of others.

We can choose to have a positive influence; to intentionally work towards creating the kind of world we want to live in.

Earlier in this session we explored the way that stigma can be like a ripple on a pond. Positive changes can work the same way. We can be the change we want to see.

So, where would you like to start?



**I want to
self advocate**

Page 48



**I want to
advocate for
someone else**

Page 50



**I want to
advocate for
my community**

Page 52

Advocating for myself

Speaking up about what you need is often really challenging. Learning to identify and then communicate our needs often doesn't come naturally; it's something we need to keep practising.

Suggested actions

- What are your needs? Consider using a journal or chatting with a friend or counsellor to work out what you want and how you want to be assisted. Think about various areas of your life including time, health, money and goals.
- Know the facts. Gather up to date and accurate information about your rights and entitlements. It always helps to have documented evidence about any situation you intend to speak up about.
- Prepare. Discuss and plan your approach for contacting the person, service or organisation that is not treating you fairly. You might do this with a counsellor or a friend. You could consider role playing the scenario.
- Self advocacy is about empowerment. It takes time to build confidence to ask for what you want. Start small by practising making decisions about small matters.



The self-guided coaching session 'Communication skills' has some handy tips on how to approach uncomfortable conversations with service providers, employers, family and friends. For more see the resources section at the end of this module.



Advocating for the needs of someone else

Speaking up about the needs of others can be frustrating and challenging.

We also need to check that we are working in the person's best interest and not overpowering their right to self advocacy.

Suggested actions

I am advocating for someone else:

- Know your rights and the rights of the person you are advocating for.
- Be clear about what is needed, including when, how and why the problem or situation needs to be addressed.

I want to support someone else to advocate for themselves:

- Talk with the person you are supporting. What do they want and how do they want to be treated? Try to listen more than you speak.
- Can you help connect the person you support with peers? Being around others who have a similar experience can help people see what's possible.



Visit the Carer Gateway at carergateway.gov.au and search "Advocacy". For more see the resources section at the end of this module.



Advocating in and for my community

There are lots of ways you can get involved in advocacy that promotes long term social change in, and for, your community.

Suggested actions

- Learn how to share your lived experience through speaker's networks and programs. Many organisations are looking for people who are willing to share their story in speaking engagements.
- Health and community organisations actively seek to recruit carers to positions on representative committees, organisation boards, as ambassadors or to be involved in consultative or service design.
- What are you passionate about? Research online or via local support agencies to see what networks and advocacy organisations are working in the space you are passionate about. Do they have regular meetings you could check out or a newsletter you could subscribe to?
- Consider holding an event to raise awareness for a charity or organisation you are involved in, or would like to be involved in. Many not for profit organisations provide resources to assist you to organise marches, rallies and fundraising events.



Visit the Carer Gateway at carergateway.gov.au and search "Advocacy". For more see the resources section at the end of this module.



Action plan

After reading through the case studies and information in this session, choose one specific, realistic and achievable thing you would like to do with regard to your situation.

Refer back to the page earlier in this workbook where you identified the values that are important to you. Write them in the space provided below.

When you create your plan, think about how the action you want to take will express, support or align with your values.



Action: Write one thing you'd like to try

Why do I want to do this? What is your reason? What do you want to achieve?

Who will I do this with? Who might help you with this? Who might be involved?

When will I do this? Be precise as possible. Can you name a day and time?



Now that you have finished this coaching session, we encourage you to spend a few minutes putting down some of your thoughts or talking through some ideas with your coach or someone you trust. You can write your ideas on this page or in your coaching journal.

You could write or chat with someone about:

- Issues you see as requiring advocacy,
- How you might address stigma in your immediate environment.

This workbook represents a significant amount of time and energy that you have dedicated to your own wellbeing. It is an important part of your journey and worth hanging on to. Keep it somewhere that allows you to revisit it whenever you need to.

You can also come back to look over, check in on, revise or change your action plan. You can even re-do the activities or share some of the information or resources with friends.



The websites listed in this section provide additional, specific information that is related to the content found in this workbook.

Your coach can help you to access these resources or you can explore them for yourself.

Advocating for myself

- Information and resources about Speaking up on Carer Gateway:
The Carer Recognition Act, 2010 – Speaking up – Carer Gateway:
carergateway.gov.au/speaking-up
- The self-guided coaching session 'Communication skills' has some handy tips on how to approach uncomfortable conversations with service providers, employers, family and friends

Advocating for someone else

- Information and resources about Advocacy on the Carer Gateway
- How to Advocate for Yourself and Others factsheet from Aged Rights Advocacy Service Inc. sa.agedrights.asn.au/files/229_aras_advocate_for_yourself_2013.pdf
- The Kit – A guide to the advocacy we choose to do
carergateway.gov.au/what-is-advocacy

Advocating in and for my community

- Information and resources about Advocacy on the Carer Gateway
- Voices Together voicestogether.com.au
- Disability Advocacy Network Australia dana.org.au
- The Kit – A guide to the advocacy we choose to do
carergateway.gov.au/what-is-advocacy

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NOTES

NOTES

Handwriting practice area with 25 horizontal dotted lines.

Phone: 1800 422 737 (Monday–Friday, 8am–5pm local time)

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