Learning Guide

Advocacy and self-advocacy

Name:

Workplace:

23385 Demonstrate knowledge of advocacy and self-advocacy in a health or wellbeing setting

Level 3 4 credits
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Introduction

An advocate is someone that supports a person on their behalf and for a particular issue or idea. You may be asked to assist in advocacy. Whether you are advocating on behalf of someone else, self-advocating or supporting a person to self-advocate, there are strategies to follow.

How to use your learning guide

This guide supports your learning and prepares you for the unit standard assessment. The activities should be used as a general guide for learning.

This guide relates to the following unit standard:

- 23385 Demonstrate knowledge of advocacy and self-advocacy in a health or wellbeing setting (level 3, 4 credits).

This guide is yours to keep. Make it your own by writing notes that help you remember things, or where you need to find more information.

Follow the tips in the notes column.

You may use highlight pens to show important information and ideas, and think about how this information applies to your work.

You might find it helpful to talk to colleagues or your supervisor.

Finish this learning guide before you start on the assessment.

What you will learn

This topic will help you to:

- understand the role of an advocate.
- use the process of advocacy.
- support and assist a person in advocacy.
- support and assist a person to self-advocate.
What is an advocate?

An advocate is someone that supports a person on their behalf and for a particular issue, idea or person. It may be for something simple such as returning a faulty product and asking for a refund, or it may be for something more complex like asking an organisation to change their policies in order to improve a person’s quality of life.

It may involve talking to people, writing a letter, contracting the relevant authorities, attending meetings, taking part in a protest, distributing education material, making a submission to a formal body, or any form of communication that expresses the need for change.

A professional advocate will have special training in representation, lobbying, change management, human rights, mediation and conflict resolution.

The highest level that advocacy can take is approaching the media or organising public demonstrations or protests. This level requires very strong collective action and needs to be undertaken with great care.

What kind of issues need advocacy?

In the context of a health or wellbeing setting, the kind of issues that require advocacy may be linked to the Code of Rights.

For example, a person may feel that:

- they, or their culture, are not being treated with respect.
- they are not receiving services of an appropriate standard.
- not enough is being done to assist them to communicate effectively.
- choices are being made on their behalf that they do not agree with.
- a complaint is not being listened to, responded to or actioned.

**Code of Rights**

The Code of Health and Disability Consumers’ Rights (1996) is often more simply called ‘the Code of Rights’ or ‘the Code’. There should be a copy in your workplace.
To help resolve complaints in the health and wellbeing sector, a free, independent advocacy service is available throughout New Zealand through the Health and Disability Commissioner.

You can find out more information about this on the website http://advocacy.hdc.org.nz/

A person may also ask a colleague, family member, a friend or you to advocate on their behalf. As a support worker, you may also be asked to support the person to self-advocate.

The roles and responsibilities of an advocate include:

- listening to a person’s concerns and being responsive to the person.
- providing information to the person about their rights
- helping the person problem-solve, identifying what they want and how best to get it.
- helping a person to gain information and using that information in the way the person wishes.
- speaking on behalf of the person.
- using negotiation and conflict resolution skills.
- challenging unfair assumptions, stigma, discrimination or disrespectful behaviour towards the person being advocated for.
- identify any risks.
- helping a person recognise and use their own skills.
Where is your nearest advocate located?

How can a person expect to be treated by an advocate?
Self-advocacy

What is self-advocacy?

Every time a person speaks up for themselves, they are practising a form of self-advocacy. It is a process (either in writing or verbally) of informing the other party of your issue/problem and getting action from the other person or organisation to improve the situation.

The more that is known about the issue or problem, the better it can be understood and the easier it is to explain.

By taking control of an issue or problem that is affecting you, you are aiming to empower yourself. This means that you are taking control of events that have been causing you concern or disempowering you.

The difference between advocacy and self-advocacy

Advocacy is a wider term that can include self-advocacy. With self-advocacy it is a ‘two-way’ process. In advocacy there is a third party involved and the process becomes a ‘three-way’ process.

Advocacy involving a third party usually occurs when the issue is complex.

Self-advocacy involves an issue that is personal to you and is usually simple enough to be resolved without the help of a third party, for example, returning a faulty product and asking for a refund.

Complex events or dealing with authorities or bureaucratic processes are more likely to need a third party. Language barriers may also influence the choice between advocacy and self-advocacy, along with the age and health status of the person seeking (or needing) resolution.
Empowerment and disempowerment

Empowerment is about having a feeling of confidence in your ability to bring about positive changes in your circumstances and in your life. You develop confidence in your own abilities and feel that you have control over decisions that have an impact on your life.

Supporting a person to self-advocate involves helping them to become empowered, by increasing the capacity of that person to make choices and turn those choices into action.

Empowerment challenges what we think about power, helping, achieving and succeeding. It is a process that is similar to a path or journey and is one that develops as we work through it.

Disempowerment is the feeling that you do not have control over the decision making in your life. It is feeling unable to change things that are causing distress or discomfort or affecting your ability to do certain things.

It is when people feel disempowered that they may need someone to advocate for them. Alternatively, they may need support so that they can take control of the issues that affect them and advocate for themselves (self-advocacy).

Empowerment and advocacy

Outlining exactly what the problem is and coming up with a plan to deal with the problem is the beginning of empowerment. A person can start to take responsibility for events and issues that have been affecting them or making them feel disempowered.

By becoming empowered a person can become an equal partner in decisions that may affect health, wellbeing and quality of life.

Empowerment happens regardless of whether a person chooses to self-advocate or they get someone to advocate for them.
Think of a time when you have advocated for someone else. What was the issue and how did it affect their quality of life?

How did the advocacy situation make the person feel - empowered or disempowered? Why was this?

What was the result of your advocacy for someone else?
The advocacy process

Advocacy or self-advocacy can be seen as a process.

- An event or situation occurs that affects you in a negative way.
- You feel that you have lost some or all control over a situation.
- You make a decision to seek help to change or rectify the situation.
- You begin a process of advocacy or self-advocacy
- You take the first steps to changing the situation.

There are a number of areas that need to be considered concerning advocacy. These apply whether you are advocating for another person (or group of people) or for yourself. They also have to be considered when you are supporting a person to self-advocate.

These areas are:

- respect.
- communication.
- planning.
- information gathering
- evaluation.
Respect

If you are supporting a person to self-advocate, you have to respect the person’s:

- choice.
- decision-making.

Respecting a person’s choices means putting aside your own opinions and points of view and listening and supporting the person in their choice, even if you disagree with them. By showing this respect, you helping to empower the person to feel good about managing an advocacy issue.

Not showing respect for a person’s choices during self-advocacy will have a disempowering effect and the person may simply ‘give up’ and not continue with the self-advocacy process.

Respecting a person’s decision-making means that you do not question it even if you do not agree with the decision a person has made.

By showing respect for the person’s decision-making, you will help them develop confidence in their own abilities and feel in control over the decisions that have an impact on their life. You are helping them to feel empowered.

Communication

Effective communication is essential between you and the person you are supporting to self-advocate or advocate for. It is also important to communicate clearly the person’s issue with the other party who may be taking a different view.

Things that need to be clearly communicated are:

- exactly what the issue is.
- what the person wants to achieve.
- any relevant information that affects the issue.

The way in which an issue is presented during an advocacy process can help resolve the issue. The wording of letters, complaint forms or emails needs careful consideration. If you are supporting a person to self-advocate, they may need you to help them with the wording of a letter or email so that they are clearly expressing what they want.

Always speak calmly and confidently. Be polite. If writing a letter or email, be specific and stick to the facts. Never send or reply to an email when angry or upset. A hasty response may undo a lot of good work already done.
Language and cultural barriers to effective communication may have to be resolved by the use of an interpreter or cultural advisor who can translate language and provide an insight into any cultural difference.

Many situations which involve a cultural component are day-to-day matters where being well-informed and having a better understanding of cultural needs help reduce or even eliminate the issue.

In some cultures, for example, it may be inappropriate for a woman to self-advocate and a man may need to speak on her behalf. In Māori culture, it is important that the wider family/whānau is involved in a decision-making process and time needs to be allowed for discussion and decision-making.

You may need to use negotiation and conflict resolution skills when communicating.

Follow up. Don’t let too much time go by between phone calls or letters or other correspondence. Follow up conversations with a letter confirming what was discussed.

Write

What is the link between communications and showing respect for a person’s choice and decision making?
Planning

When you are advocating on behalf of someone else, self-advocating or supporting a person to self-advocate, there are a number of steps that are useful to follow in making a plan. These are:

1. Make sure that the issue or problem is properly identified and well researched. This is the information gathering process.

2. Decide who needs to be advocated to and find out how to make contact with the person or people who will be hearing your concerns.
   - Identify the person or people who can either change the issue or solve the problem, or who can refer you to someone who can.
   - Follow the chain of command. Deal with the person responsible for the issue that involves you and if you do not get the result you want, go up to the next person in the chain. Don’t go right to the top straight away.
   - If the person you are supporting to self-advocate is dealing with a large organisation or government department, they are likely to have a referral process in place. If there is a process, it is important to follow it. Otherwise the process may stall.

3. Decide what needs to be said and the way in which it will best be presented.

4. Consider whether outside assistance is needed.

5. Consider how you will be able to tell if the advocacy process is working (refer to the section on Evaluation).

How long do you expect each step to take? Reviewing stages should give you a good idea of the overall timeframe that might be required.
Information gathering

If you are supporting a person by advocating on their behalf, or to self-advocate, you are very likely to be involved in the process of gathering information. The more information you have, the better you will be able to understand the issue and advocate from a position of empowerment.

You need to clearly identify the issue and what the goal is. Make sure you write things down and that everything is related to and focused on the issue and on the goal or goals. Goals can be refined and you can plan exactly what you need to do or support someone else to do.

You need to collect evidence that will support the case. Assess and gather any information about the issue that you think is relevant. Focus on the goal and be as specific as possible.

If you, or the person you are supporting, are speaking to someone over the telephone, it is a good idea to write down what you are going to say before you make the call.

Making a call

Make sure you have all the information before you make a call.

Be familiar with any information you have gathered. Read through it carefully. Sources of information include:

- family/whānau.
- outside agencies and support people.
- media (television, internet, newspapers, magazines).
- documents such as the Code of Rights or an organisation’s policies and procedures.
- relevant legislation.
It may be necessary to work with another person or agency at some stage of the information gathering or advocacy process. Knowing what outcomes have been achieved previously by others can be valuable when planning an advocacy process.

You may need to arrange meetings or network with other people. Get others to join your efforts if it is necessary and possible. Ask some questions, for example, what is the general community’s view of the issue?

It may be helpful to ask questions, such as:

- Is the issue an issue for one person, or does it affect a wider group of people?
- Is it possible to approach anyone else for assistance or information?
- Are there any legal precedents, legislation or policies that may help the case?
- Are you following the policies and procedures of your workplace or organisation, for example, by using a complaint form?

Make sure you know what any policies and procedures are if you are dealing with a company or organisation. This will help you to contact the correct person and/or lay a complaint in the correct way.

A complaint is a common method by which to start an advocacy process. If you are supporting someone to self-advocate, you may be able to help them decide what to say to someone to make an informal complaint, or to write a letter or fill in a form to make a formal, written complaint.

**Complaint**

There is often emotion involved in complaints. It is necessary to gather information and focus on the facts when complaining.
Here is an example of a form an organisation might use to record complaints.

Think of an example of a complaint a person might make. It doesn’t have to be real. What do you think the response might be? Fill in the ‘details of complaint’ and ‘response’ sections on the form with your example.

**Complaints Form**

<table>
<thead>
<tr>
<th>Informal Complaint</th>
<th>Formal Complaint</th>
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<tr>
<td>Date:</td>
<td>Time:</td>
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<td>Name of consumer:</td>
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<td>Contact details:</td>
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**Name of person making complaint:** (if other than consumer)

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<th>Relationship to consumer:</th>
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<td>Addressed to:</td>
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<td>Service representative receiving complaint</td>
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**Details of complaint:**

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**Response:**

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**Signature of consumer:** (or person complaining)

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Evaluation

During the advocacy process, you should have outlined what the issue is and what you think the solution to the issue should be. You have chosen and considered the most effective way to communicate.

Keep a record of the responses you receive. You may need to allow a reasonable amount of time for someone to respond before taking the process further.

Always make a note of the names of people you contacted, what you talked about and the date that you communicated with them.

If you speak to someone who says they can’t help you, make sure that you ask them who can help you. Keep a copy of any written response you receive by letter or email.

Consider an alternative or follow-up step that you can undertake if the first one is unsuccessful. If a letter of complaint doesn’t receive a response, for example, you could follow it up with a phone call or write a letter to request a meeting.

Once you have feedback from the initial contact, you need to go back and evaluate the outcome against what you initially set out to do. This will let you know whether or not the process is working.

Asking questions may help with your evaluation. Such questions may be:

- Do you need to change your goal?
- Do you need to re-evaluate your strategy?
- Do you need to do more research and gather more information to support your claim?
- Is there someone else that you need to call on to help?
- Are you more likely to get the result you want by going through a different process?

If supporting a person to self-advocate is not achieving the desired result, it may be necessary to advocate on their behalf. Outside help from an agency or organisation might be needed. The services of a professional advocate might become necessary. Be prepared to change the style of advocacy if the process seems to get ‘stuck’.

Be persistent in getting information, negotiating, and seeking action or change to help achieve the goal.