



Supporting Decision-Making

A Guide for Supporters of People with an Intellectual Disability

Introduction

This guide will be useful when you are supporting a person with an intellectual disability to make decisions.

The guide incorporates the principles of the New Zealand Disability Strategy and the United Nations Convention on the Rights of Persons with Disabilities:

People with an intellectual disability have the same right to make their own decisions as everyone else.

People with an intellectual disability have the right to have the support they need when making decisions.

People with an intellectual disability have the same rights under the law as everyone who lives in New Zealand.



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Supported Decision-Making

All of us, at times, use the support of others when making decisions. We talk things over with our family and friends. We choose who we talk to depending on the decision being made.

Sometimes we seek expert advice, we look for information and we ask people we trust to help us.

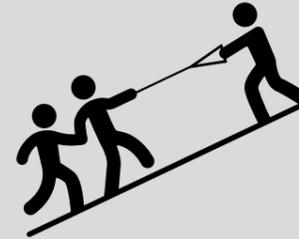
People with an intellectual disability will go through a similar process but may need additional support to make decisions.

Needing support to make decisions should not prevent people from exercising their rights and controlling their lives.

Family, whanau, friends, staff, workmates, volunteers, court appointed welfare guardians and/or property managers all have a role in supporting people with an intellectual disability to make decisions.

Our rights as citizens are real when we have:

PURPOSE



We follow our own direction and way of living.

FREEDOM



We follow our own path and can make decisions about our lives.

MONEY



We have enough money to live on.

HOME



We have a place where we belong.

HELP



We have family and friends around us to give us a hand.

LIFE



We get involved with our community, we give back.

LOVE



We have people who love us and can develop new relationships if we want to.

Good Support: The right people

Good support requires the right people to be involved at the right time.

Are there people the person especially trusts?
If they are not already involved, consider asking them to be involved in the decision-making process.

There may be times when an individual finds it difficult to say what they want because they are worried they will upset others or offend people who are important to them.

There may be times when the person is unsure, wants to say no, or changes their mind. Good supporters help people to have the confidence to express this and/or convey it on their behalf.

Good support is all about really understanding people and finding out what support works for them.



Good Support:

Know and understand

Knowing and understanding the person making the decision is essential. Good support is about helping people in ways that work for them.



Find out:

What is important **to** the person?

- People and their relationships
- Things they like doing
- Places they enjoy going
- Rituals and routines
- Their belongings
- Pace of life

What is important **for** the person?

- Health and safety concerns
- Physical health and safety, including wellness and prevention
- Emotional health and safety
- Listen to family, friends, support staff and other people who care about and know the person
- Written information such as a personal plan may help with understanding the person being supported.

If the person is choosing something that is risky; think about ways to make it safer.

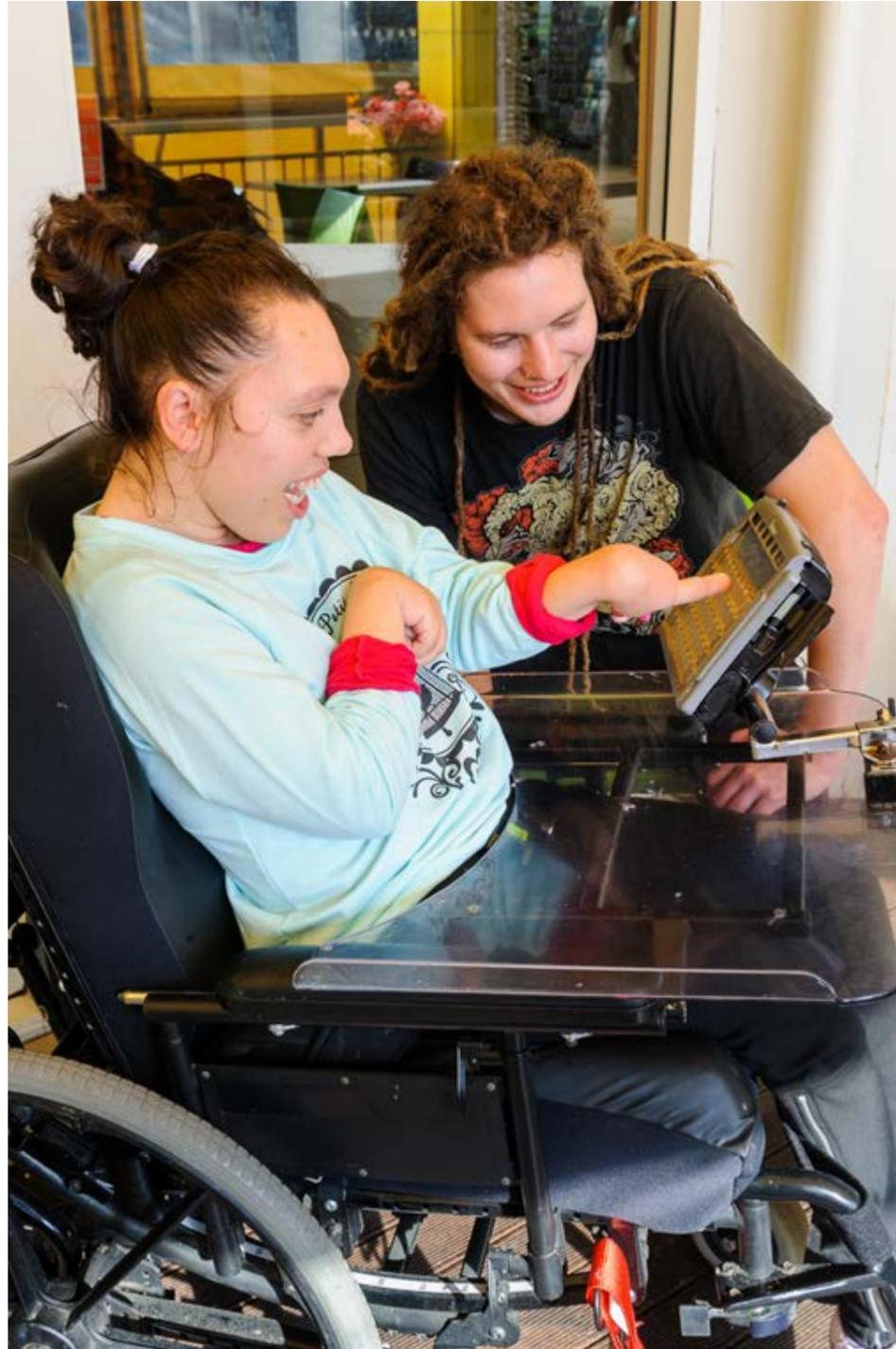
Only intervene if a person is making choices that are seriously risky. Keep out of things that are none of your business.

Good Support: Communicating

Good supporters use whatever it takes to help people communicate and be understood.

All people communicate in some way. An individual may have their own unique style and ways of talking, and some people may not use words at all.

People might use assistive technology, signs or communication books. People may be able to let you know their likes and dislikes by their body language, facial expressions and what they do.



Family members, friends and support staff will already know the person's communication style and preferences.

If you are new to the support role for an individual, take time to get to know the person and the ways they communicate. Be aware that some people may express themselves differently in different situations with different people. There may be times of the day when it is better to talk with the person, or places where they feel more comfortable.

Some people find it hard to tell others what they want. It is important to listen carefully and get to know and understand their way of communicating. When the person's words and behaviour don't match, listen to what they are saying by considering how they behave.

Decisions

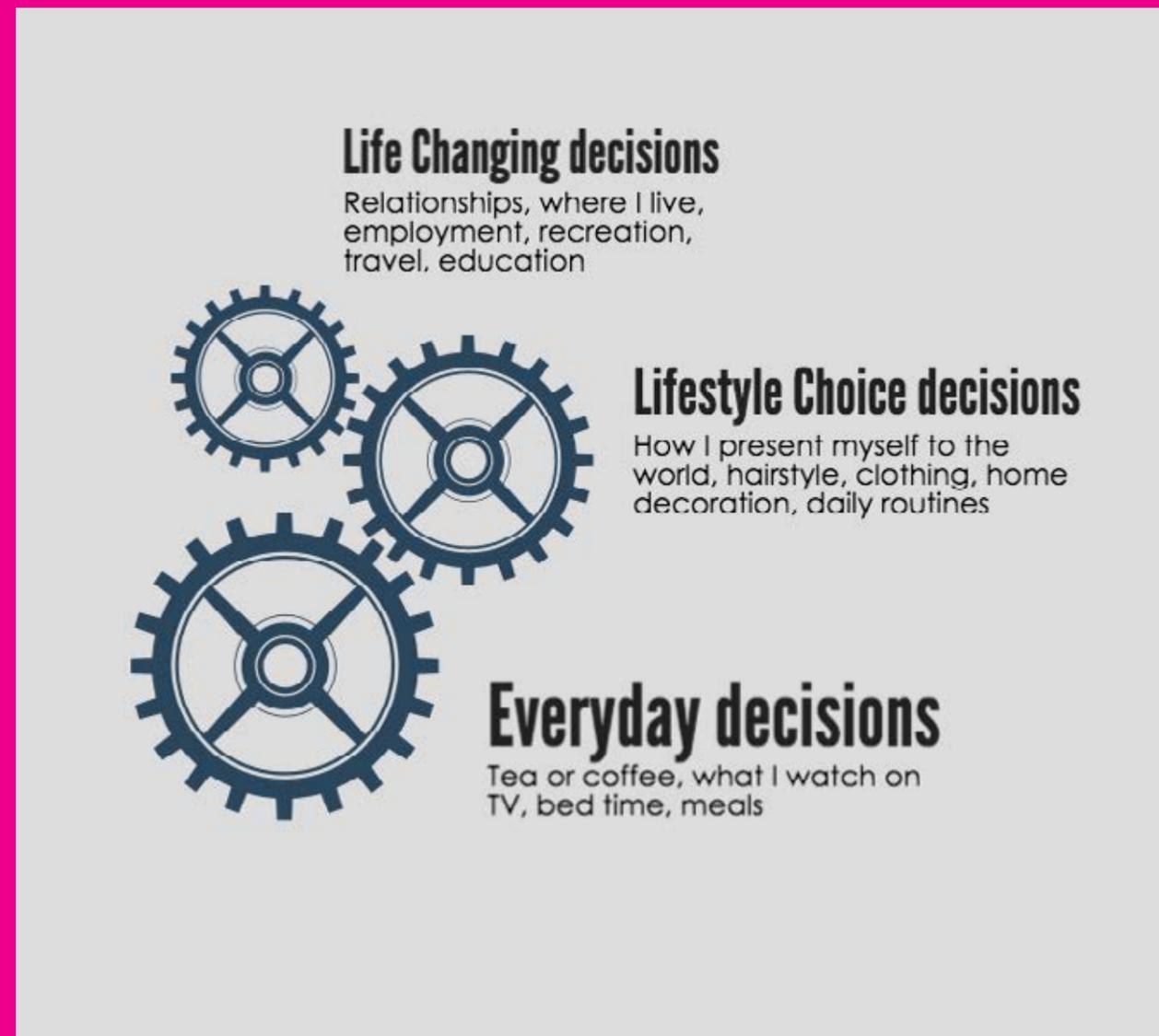
“Making decisions takes practice. You can’t decide where to live or other big decisions if you have not made decisions about everyday things like what to eat and what to wear.”

Decision-Making Steps

Skills needed to make decisions have to be practiced. The decision-making process is always the same.

1. Accessing easy to understand information
2. Exploring options
3. Making decisions
4. Acting on decisions

It is a good idea to record what you have done as a supporter, to show how support was provided, who was involved, what and how options were explored and the preferences that people had. Use these guidelines in a flexible way and adapt them to suit the person being supported.



Choices may be linked

e.g. if I choose to eat junk food all the time my decision to play sport will be compromised. If I spend a lot of money on DVDs I will not be able to afford a holiday.

1. Accessing easy to understand information

Having relevant and easy-to-understand information is critical to people making informed decisions.

What is the decision about?

Help the person understand what the decision is about, what it means for them and that they have a right to be involved and have a say.

The person may need support to look ahead, to imagine and see how things might be different.

Be clear about the options

Some options may be familiar and other ideas may require exploring. Check everyone involved has the same understanding of unfamiliar concepts and words. Be realistic, none of us have unlimited choices.

The constraints

Make sure you understand and can explain the possible outcome or effect of some choices.

Give information in a way the person understands

The supporter and others involved must be prepared to present ideas several times and in a variety of ways. Information needs to be easily understood at all stages of the decision-making process.

Take care that the person is not overwhelmed with too much information at one time.

- Use ways the person prefers to receive information. This might involve using a number of different formats and could include easy-read, pictorial, talking, DVD and practical experiences.
- Other information could come from friends and peers.
- Include information from actual experiences and different options.

Allow some time, then check that the person has understood.



Allow enough time

- Take as much time as it needs for the person to understand the information, to go back over information, check their understanding and whether there are questions or further information the person wants.
- Think about the right time to meet with the person. Consider: Where is the person comfortable? What time of day is best for them?

2. Exploring options

Exploring options helps to identify what the person wants.

Understanding and communicating what are the important things to the person.

Here is an example of options being explored about where a person might choose to live:

- Living in a home. Privacy, space, having friends and family round for a meal, having people to stay overnight
- Where the home is. Close to work, public transport, able to walk to places, being able to see friends, going shopping, close to family and whanau, having good neighbours, belonging in the local community
- Who they live with. With others, on their own, the age of people they are living with, the gender of people they are living with
- Any cultural or religious preferences or requirements
- What are other relevant people saying? Friends, family, staff
- What has the person said in the past? Check things like their personal plan or anywhere goals/dreams may have been recorded.



Finding out more

- Is staying living where they are currently an option? With the same people or with different people? With the same staffing and support arrangements or with different staffing and support arrangements?
- What are the options if the person wants to move from where they live currently?
- Has the person had a chance to talk with peers, housemates? With friends who are in different living situations, such as flatting, about what they like, don't like, what works well, what they get help with?
- What new skills does the person want to learn?
- What supports will be available or need to be found?
- Are there any financial considerations that need to be considered?
- Are there any safety considerations that need to be considered?
- What further information do family and other supporters want to know?

Trying things out

It is hard to make decisions about things you haven't experienced.

People can make informed choices when they have had lots of experiences:

- Consider arranging some real life experiences. This will help the person and others understand better what different options involve
- Consider new roles and responsibilities the person could try out
- Invite people who have already experienced what is being considered to tell their story. They may be able to help the person to try new things
- Have you considered observing the person in different situations to see what they are happy with?
- Think creatively: can technology be used to meet some of the needs, wishes or preferences the person may have?

Just because someone has seen a range of options it doesn't mean they have found the right thing for them. As with all of us, it is ok to say 'no' and have that decision respected.

3. Making decisions

Consider all the information from already explored options, newly gathered information, trying things out and what has been learnt from past experiences. Then you can look at all the options.

Weighing up the options

- How does the person feel about the options proposed? Happy? Excited? Not sure? Comfortable? Unhappy? Worried?
- What can be learned from past experiences so that things will work out better if they are tried again?
- What do family and others involved think about the options?

Consider mapping out the pros and cons of each option using pictures.

Be aware that one decision may trigger a chain of further decisions that need to be made.

The preferred option

- Which option is the best of all of the choices available?
- Will this option support the person's well-being in doing the things they choose to do?
- Will it support them to take risks sensibly so they can do what is important to them?

Sometimes people may want something that is not fully possible.

Think about breaking the goal down into smaller steps or suggesting alternatives within the same goal.



4. Acting on decisions

Make sure everyone is clear about the decision that has been made.

The decision, and what happens next, should be recorded in ways that the person can understand.

Sometimes the decision is big and may take time to happen or be arranged. Make sure this is understood by everyone.

Stay in touch, check in frequently so communication lines remain open, information is shared and people do not become anxious, frustrated or think they have been forgotten.

What happens next?

- Who may need to be involved?
- What supports will be needed to assist the person to manage the changes?
- How long will it take?

Making decisions work

Will trials or visits be helpful?

Are supports needed to make the decision work? Are those supports identified and available?

Will the person need new skills to make the decision work?



Review

After the changes have occurred, make a plan to check how the changes are working. If not, what might need to be done to improve the situation?

Sometimes things turn out differently than planned or hoped.

Sometimes the person may have been tentative about their initial decision and may change their mind.

Help along the way

Sometimes things might not go as planned.

Think about revisiting earlier steps.

- Were all options considered?
- Has anything changed?
- Are there new ideas that could be considered now?

No Exceptions

Everyone, including those who don't speak, has a right to make decisions. People may need the thoughtful assistance of a representative (sometimes known as a substitute decision-maker) to support their decision-making at various times. This must not stop people from making choices where they are able.

Thoughtful Assistance

1. Capacity - Assume I have the ability to be in control
2. Specific - Even if I cannot make some decisions, I may be able to make others
3. Selection - If I need a representative I should be able to pick them
4. Suitable - My representative should be right for me and my needs
5. Best Interest - My representative must look after my best interests
6. Involvement - I have the right to be involved
7. Review any arrangements and make improvements



Circle of Support

A Circle of Support is a group of people who come together in friendship to support the person with a disability to make decisions and to make those decisions work.

Circle of Support members are not usually paid support people. The circle meets regularly and whenever possible the person with a disability sets the agenda.

Members of the circle may take on different roles, for example, some may be skilled in employment, others in housing, recreation, clothes shopping, technology and so on.

Decision-making support is about having the right person to support the decisions being made. A circle of people who know the person well can ensure this can happen. Having a Circle of Support keeps the person's best interests at the centre of all decision-making.

Excellent information about establishing a Circle of Support can be found in the "Believing in Better" workbook.



A personal copy of the workbook is available free to keep for families of young adults (up to 24 years of age), or can be borrowed from the IHC library.

To access the free book offer or to borrow:

Email: librarian@ihc.org.nz

Phone: 0800 IHC IHC (0800 442 442)

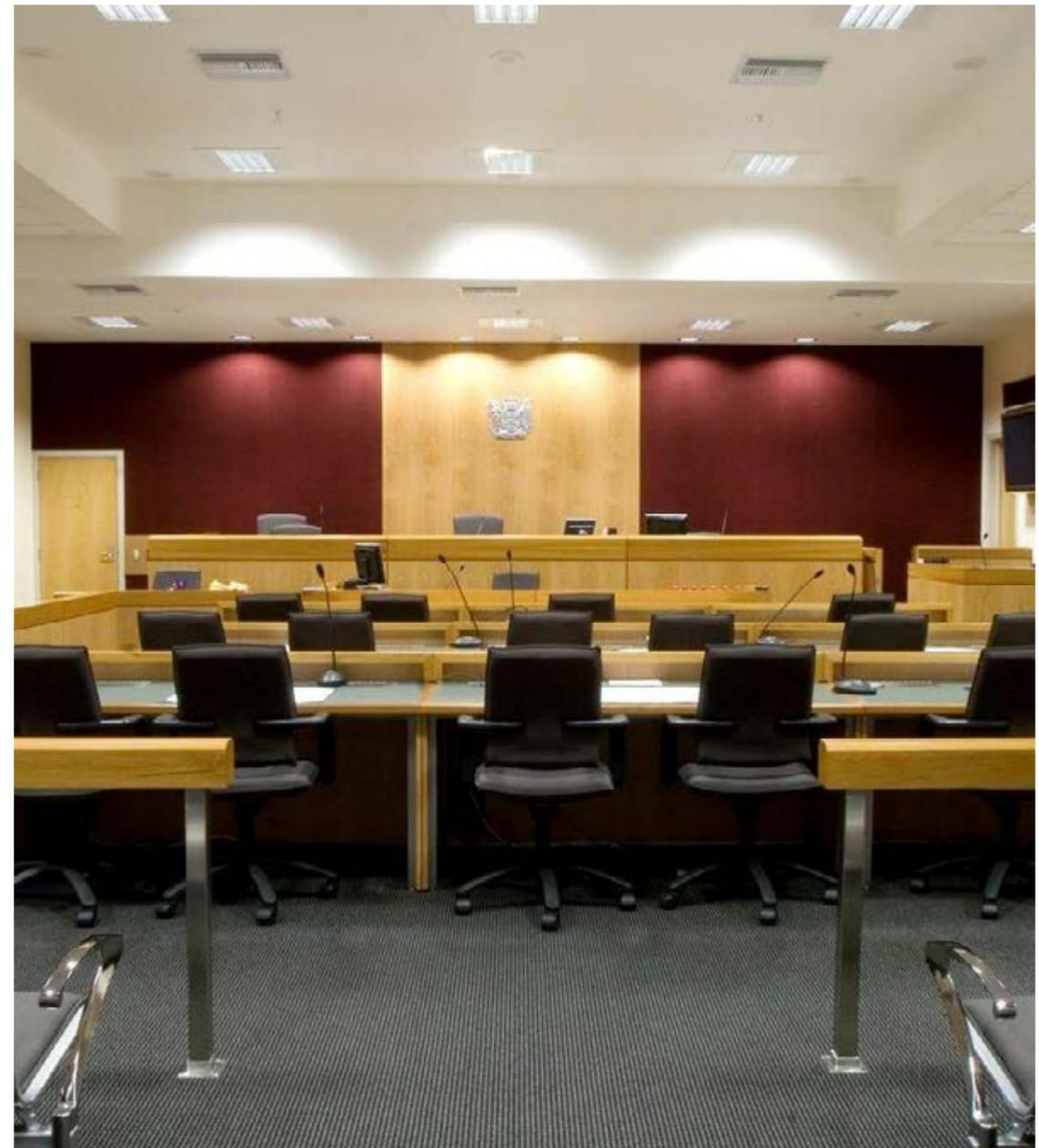
The Protection of Personal and Property Rights Act 1988

The United Nations Committee has recommended that New Zealand begin the process of moving away from substitute decision-making models to models and laws that require disabled people to be supported appropriately to make decisions on their own behalf to the extent that is possible.

You may have been advised or believe personal orders under the Protection of Personal and Property Rights Act are appropriate for your situation.

This law intended that any substitute decision-makers appointed (welfare guardian and/or property managers) ensure that every effort is made to involve the person who is the subject of those orders to make decisions about their lives. The Act is underpinned by strong principles of protection of people's rights and is not intended to be used to control people's lives.

Therefore it is important that welfare guardians, property managers and property administrators act in ways that are consistent with the intent of the legislation.



Welfare Guardians must:

- Promote and protect the incapacitated person's welfare and best interests (the court must be satisfied that the person lacks capacity)
- Encourage the person to develop and use whatever capacity they do have
- Encourage the person to act on their own behalf wherever possible
- Help the person to be, as much as possible, part of the community
- Consult with the person and with other people who the welfare guardian thinks can give competent advice about the person's care and welfare and consult with the person's property manager if there is one appointed

A Welfare Guardian cannot:

- Make decisions about marriage or adoption
- Refuse consent to medical treatment
- Consent to ECT, surgery involving the brain or medical experiments

Property Managers administer property for people who are partly or completely unable to manage their own property affairs.

Property Managers must:

- Act in the person's best interests
- Enable and encourage capacity and intervene as little as possible
- Consult with the person and other interested parties
- File annual financial statements, including detailed statements of receipts and payments to the court, which are then examined by the Public Trust. There is a fee charged for this but an application can be made to the court for this to be waived

Property Administration may be an appropriate and less onerous way to support the management of a person's property, income or benefit. Property Administration orders can be made by the Family Court for items of property worth less than \$5000, and/or an income or benefit less than \$20,000 per annum. Property Administration orders do not require annual financial statements to be prepared for the court.

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The following publications assisted with the development of this guide.

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IHC Advocacy works with groups and organisations to develop resources and learning events that supplement and/or build on this Guide to Supported Decision-Making.