



Australian Government  
Department of Social Services

# Planning for the Future People with Disability

Improving the lives of Australians

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## Introduction

### What is this booklet about?

A major concern for a carer of a person with disability is how the person they care for will be supported in the future when they are no longer able to provide the love, support and care themselves. This is of greatest concern to parents of children with high support needs. Most people with disability are capable of making their own decisions or contributing to the decision making processes about their own future needs, support and care. However, some family members with disability will have a low level of control over their lives and will therefore not be participating actively in the decision making process.

Research indicates that many people wish to make private financial provisions for the future care and accommodation needs of a person with disability but do not understand the steps they should take to plan for the future. This booklet has been written to assist people in finding information and support to plan for the future wellbeing of a person who has high support needs. It has been designed to assist families to consider the issues involved in making decisions based on sound knowledge. It encourages families, particularly parents, to take into account their own future needs as well as those of their son or daughter with disability.

The information aims to assist families to plan future arrangements for the ongoing care of their family member with disability that is positive, sustainable, flexible and fulfils the wishes of both the person with disability and their family where possible. The issue of whom to trust for advice and ongoing involvement in the plan can be a major issue for families and can affect their ability to make decisions.

Information in the booklet raises questions and provides possible responses to future planning issues. This booklet is a guide only and you should get appropriate legal and financial advice before implementing your plan.

### Outline of this booklet

The booklet is divided into sections to assist families to navigate the options available when implementing a plan for the future. While systems can be set in place to safeguard the financial future of their family member, planning for the future requires much more than just an understanding of the legal processes available. Planning for the future is about taking steps now to put plans into place, and not just about when you are older and can no longer provide the level of care the person needs.

The booklet is divided into six sections:

**Section 1: Future planning: things to consider** helps families to think through some of the issues to consider when planning for the future of their family member with high support needs and encourages families to take a 'whole of life' approach to planning.

**Section 2: Planning for the future: choosing the right option** is about the options available to families when planning for the future and is written in a question and answer format to assist you to find information relevant to your needs.

**Section 3: Setting up a trust** examines how to set up a trust to provide for a family member with high support needs and contains questions and answers about trusts.

**Section 4: How to access legal and financial advice** gives advice on how to access legal and financial advice and includes information sheets to provide lawyers and financial advisers with information they may need to best advise you.

**Section 5: Useful contacts** provides information on other available support services and gives some suggestions for further reading.

**Section 6: Planning templates** provides a care plan checklist for you to complete with your family, and an information pro forma to complete and provide to your lawyer.

## Some points about how this booklet is written

### **Questions and answers**

The questions and answers in this book are the questions parents and other family members most often ask about future planning.

### **Assets, money and property**

In this booklet, the assets of people or trusts will be referred to as their assets. **Assets** used in this way can include land or real estate, money, shares or any other type of asset. Lawyers may also refer to assets as property.

## Section 1 – Future planning: things to consider

In order to provide for the future of a family member with high support needs, it is important to spend some time reflecting on what your hopes and dreams are for the future for that person and also what hopes and dreams they hold for themselves. This is creating a vision to enable you to put plans into place that aim towards fulfilling that vision to the best of your ability. There is no 'one size fits all' as each person will have their own hopes, dreams and wishes.

As families face the issue of how to provide a sustainable future and safeguards for their family member, their access to information to support them in their decision making may be limited to advice from lawyers or financial planners who themselves may be ill informed in this area. Many people with disability are now outliving their parents, so preparing for the future is now more of an imperative than it was in the past. Each family has diverse needs according to its circumstances.

People and their families can be proactive in planning for the future. The key is to create a clear vision of what this future might be and develop a plan to make it happen. As parents it is important to ask the question: 'What outcome does my son or daughter desire for the future support and what do I hope and wish for him or her?' It is beneficial for parents to include other family members when reflecting on this question so that siblings and others have input into the process. Work as a family and involve your family member with disability as much as possible.

To avoid conflict later on, ensure that there is discussion on what the needs of each family member are now and in the future. However, keep the focus on the person with disability. It is vital that wherever possible the family member with disability is given the opportunity to have as much input as possible into what their vision is for their own future and that they are given the support to realise this vision.

A person's level of cognitive understanding will impact on their ability to participate in this decision making. While reflecting on the vision and planning for the future it is essential to keep the person with disability at the centre of your focus.

Thinking about providing a sustainable future for your son or daughter with disability can raise many fears and concerns. It may be useful to look to someone in your network or your community for support and guidance when considering these issues. Give some thought to where you might find this support. Develop a 'wish list' of all the things your family member desires as this will help you and others who may come after you, to make sound decisions for their wellbeing. Update this list as the person's age and circumstances change.

Planning for the future support for a person with high support needs is not just about what will happen after you die. Our lives are uncertain and your plan may need to go into effect tomorrow rather than some time in the distant future. There are circumstances where it becomes desirable to make provision for a person at an earlier time – for example, if there is a significant risk that the principal financial provider may become unable to continue to manage the affairs of the person with disability due to illness.

A secure and sustainable future for your son or daughter with disability will be more likely to be achieved if they have other people in their lives who are committed to assisting them in the long term. As part of your planning you may wish to set up such a group, often referred to as a 'support circle' or 'personal network'. A support circle or personal network can include family, friends, and others committed to your family member, for example an advocate who is close to the person or a church elder.

Before you see someone for legal or financial advice it is important to work out what you need (goals and plans) as much as possible. If you have a plan already, it is easier to access advice that is relevant to your situation. The clearer your vision, the easier it is to plan and to stick with the plan. There will be many challenges to fulfilling the plan, including responses from people and organisations that aim to discourage you. Having your family and others outside your family supporting your vision will help you to maintain your direction. Once a plan is well developed it can be updated regularly to reflect the changing needs of your family member with disability.

Here are some ideas for the kinds of things you may want to consider, as a starting point. Be explicit when working through this checklist. It may not be possible for all the goals you identify to be achieved, but do not allow this to stop you planning and working towards a positive outcome for the future.

- What are the hopes and dreams of the person with disability and your hopes and dreams for them?
- How does the person currently communicate their needs?
- What accommodation will satisfy the needs and desires of the person?
- What is important to maintain their valued social relationships and interactions and what do they desire for the future in terms of relationships?
- What activities do they enjoy at present or desire for the future?
- What are their likes and dislikes or sensitivities (be specific and include food, music, environment, people)?
- What are their learning and educational needs?
- How can we, or others, support the person to achieve their hopes and dreams?
- Other special needs.

A copy of this checklist for you to complete is available in Section 6.

The most difficult part of the process is turning the hopes and wishes of the person with disability and your hopes and wishes into a clear and concise plan.

If this is your first attempt at planning, you will need to continue to work through the ideas for your plan and adapt them over time.

If you have already established a plan, this booklet and the issues raised may be useful to help you review, update and refine your plan.

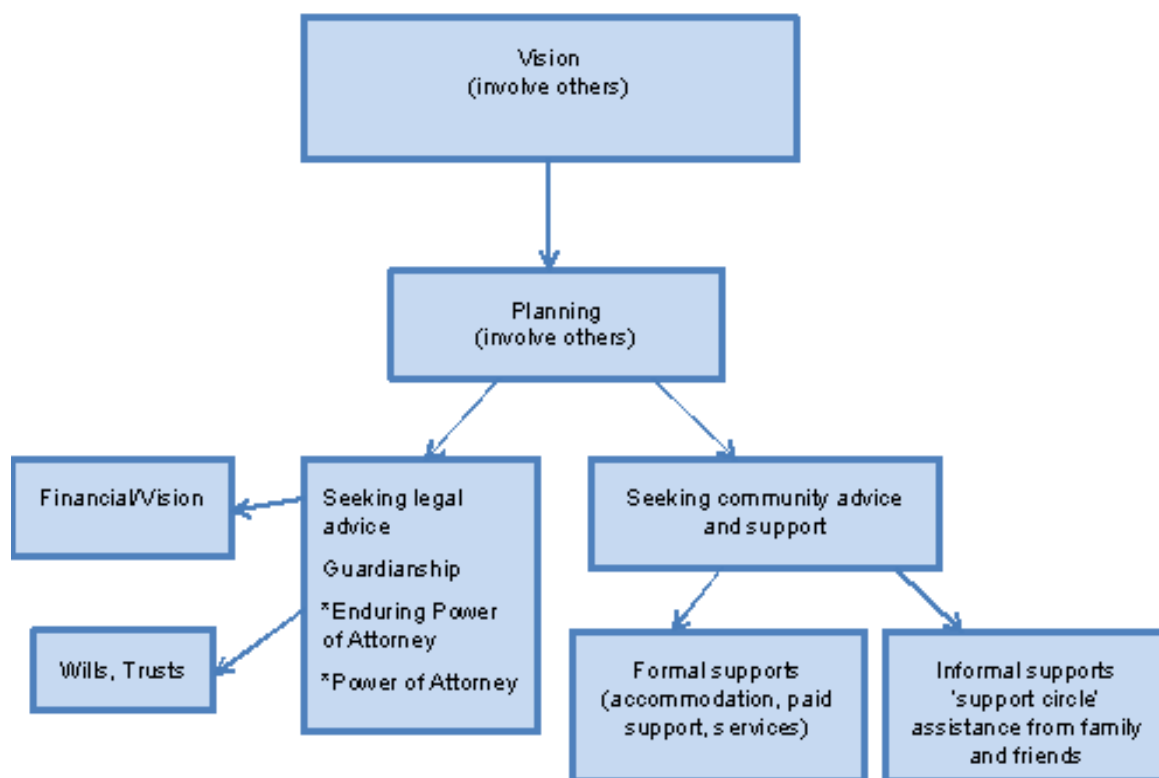
Once you have taken the planning as far as you think you can, consider whether you might like some further advice from a lawyer or financial adviser on how it may work.

This is a summary of some things to keep in mind when working out how to provide for your family member. Many of these issues are covered in greater detail further on in this booklet.

- Keep the family member with disability the central focus of the vision and planning, and involve them in the process as much as possible.
- Include other people in talking through the vision and the plan. These others will ideally include siblings, other family members including extended family who are close to the person with disability and others who provide support and care to the person with high support needs.
- Look at the steps needed to achieve the vision – these steps make up your plan.
- Gather information and advice to assist you in your planning.
- Create a plan that includes all the steps to achieve the outcomes you have identified – developing a plan allows you to have more control over what is going to happen in the future.
- Take a ‘whole of life’ approach when developing a plan. This is not just about how a person will be provided for financially but about how they can fulfil their hopes and dreams and have a lifestyle that reflects these.
- Take one step at a time as building solid foundations will create a more sustainable future for the person with disability.
- Talk to others in your community or network and consider setting up a ‘support circle’ or ‘personal network’, with the purpose of safeguarding your family member and your vision in the long term.
- Before you see someone for legal or financial advice it is important to work out, as far as possible what it is you need (goals and plans).
- Remain flexible to challenges and change.
- Develop a ‘wish list’ to assist others (who have authority) in making decisions on behalf of your family member with disability.



## Planning Process



\* Important, especially for parents of young children with disability

## Section 2 – Planning for the future: choosing the right option (questions and answers)

### Why special planning for disability?

You do not **have to** make any special arrangements for a family member with disability. Whether you need to think about special arrangements depends upon **the abilities of the person with disability, the resources available**, and your wishes for the future.

If the person with disability is able to manage their own money or manage money with informal assistance, it is less likely that you will need to make special arrangements. You can use family resources the same as you would for family members who do not have disability. You can give assets to the person with disability through your will or a trust just the same as you would do for other members of the family – usually by a direct gift.

However, there are two main reasons why it might be a good idea to make special arrangements.

- If the disability affects the person's mental capacity (such as intellectual disability, brain injuries, mental illness or dementia), the person with disability may need help to manage assets or money.

You may need to provide for this. Different options for doing this are discussed below.

#### Example

Kwame has an intellectual disability. He works, lives in a unit and can look after himself day to day, but needs help with money. His sister Rose helps him manage his money, including paying bills and weekly budgeting.

This arrangement looks like it will continue. Kwame's mother, Grace, decides to give Kwame half of her estate, confident that it will be well looked after by him with Rose's help.

If Kwame did not have Rose to help him, or if his disability were more severe, Grace would have to decide who to appoint to help look after Kwame's share of her estate.

- Sometimes you will want to keep more control than usual over how family resources are used in the long run, even if the person with disability can look after their own affairs. You may want to control how family resources are used after the person with disability no longer needs them.

For example, because the person with disability has greater needs than other family members, you might want to let the person with disability use a larger share of your estate than your other children who do not have disability. However, after the person with disability has died, you may want whatever assets are left to go to your other children or your grandchildren. To achieve this result rather than leave it to chance, you may need to make special arrangements.

#### Example

Fred and June have four children. Their daughter Jessica has a physical disability and does not work. Fred and June feel that she needs greater support than her sister and brothers.

They decide to set aside 75% of the estate, in a trust set up by their will, for Jessica's use, to buy a suitable house and leave some money to cover other expenses. The other three children share in the remaining 25%.

The trust deed states that after Jessica has died, the house and any other money that is left is to be divided between Jessica's children and Fred and June's other grandchildren, so that each branch of the family ultimately shares equally in the estate.

To decide whether any special arrangements are necessary, and what those arrangements should be, you need to think about the abilities and needs of your family member with disability. You need to consider what issues may arise and how they can be resolved. You also need to think about the needs of other members of your family.

You can talk to the person with disability to find out what they want to happen before deciding what to do. You can also talk to other people in your family or in the network of people who know the person with disability.

Your assessment will be an individual assessment based on specific circumstances: every situation is different and there are no right answers.

The starting point is your vision of what you want to be available to look after the interests of your family member with disability into the future, after you have gone. This will help you decide how can you best set that up while you are still around to do it.

### How important is it to have a will?

A fundamental question is what assets you will leave to a family member with high support needs and in what form.

It is very important to have a will in place and to get assistance from a lawyer in making a will. There are a number of reasons for this.

- If you do not have a will, when you die your assets will be distributed in the way that the law determines in the state where you live or where your assets are. These are called laws of intestacy and will not give consideration to the special needs of a person with disability. This may leave your family member with disability seriously under resourced to provide for their future. Provision is made in all states (for example, in NSW it is the *Family Provision Act*) for a person with disability to apply to the court to obtain a larger share of the estate (this also applies when there is a will) but it is very stressful for a person to have to take this action.

If a person with disability is not able to make decisions by themselves, action can be taken by a 'next friend' – usually by a financial manager appointed by the Guardianship Tribunal or by the Protective Commissioner (each state/territory has its own title).

In many cases where there is no will, the family will agree on how the assets will be divided without going to court. If this happens a 'deed of family arrangement' is prepared by a lawyer and takes the place of a will. If the person with disability cannot have input into the decision making, a financial manager can be appointed to represent their interests.

- By having a will you have the security of knowing that you have set in place your hopes and wishes for the future support and care of your family member with high support needs. It provides you with a safeguard to ensure that the plans you have developed continue to be implemented.

You should see a lawyer to draw up a will. A lawyer can help you to make sure that you include all the things you want in the will, that you understand the consequences of what you have written, and that it is written in the correct way. As many lawyers are not experienced in providing advice to people who have a family member with high support needs, and may not be up to date with disability and social services, it is worth spending some time finding a lawyer who understands these issues.

A will should be regularly reviewed and updated to allow for changes in your circumstances. For more information on wills see Section 3.

### Can I give assets directly to the person with disability?

This is certainly an option, either while you are alive or through your will. It is the way in which people most often transfer their assets to other family members. If you are thinking of doing this, consider the following:

- **Will the family member with disability need assistance to look after their assets?**

Can the person look after money in the bank or look after a house, including paying rates and other expenses, dealing with maintenance and insurance and so on? Would they be vulnerable to exploitation or abuse if someone tried to 'rip them off' or somehow take over their assets? To the extent that the person needs support, is it available or do they need a financial manager?

• **Is it fair, balancing their needs and the needs of others?**

Look again at the example on page 10. If Fred and June gave 75% directly to Jessica without any further control, is that a fair way to do things, considering their other children? The assets would then be Jessica's, and she could leave them to whomever she likes in her will (or if she can't make a will, they would automatically pass to her closest family member). That might be the way you would want things, but maybe you would want your assets to be distributed more evenly, in the interests of other family members in the long run. Talking things over with your children and including them in the planning may prevent resentments arising.

• **If you are thinking of giving away money while you are alive, do you have enough additional funds available for your own needs, especially as you get older?**

Is your retirement fully funded so that you are not likely to need those assets at all? Once assets are given to someone else or put into a trust, they are no longer yours and you cannot rely on getting them back. A parent of a person with high support needs may be used to putting the needs of their son or daughter before their own and not consider the impact of giving away their assets on their own future wellbeing.

**Are there tax implications in planning for the future?**

Taxation is a highly complex area as there are various taxes at both the Commonwealth and state levels that need to be considered when planning (for example, Commonwealth taxes include income tax and capital gains tax; state taxes vary from state to state and may include land tax and stamp duty).

This complexity makes it impractical to provide more than just a brief summary of some of the key areas. One of these complexities is that taxation is dependent on your personal circumstances and, as such, specific taxation information cannot be provided in this booklet.

**It is essential that you seek appropriate professional advice to be clear about the tax implications of your plan.**

Tax	When it may be applicable
Capital gains tax – may apply to any situation where there is a change in property or legal rights.	<ul style="list-style-type: none"> <li>• when you transfer an asset to a trust</li> <li>• when the trust sells an asset</li> </ul>
Stamp duty – payable on the transfer of specific assets from one party to another. Stamp duty is not payable on property that is inherited through a will.	<ul style="list-style-type: none"> <li>• when the trust purchases an asset</li> <li>• when the trust receives an asset by way of transfer</li> </ul>
Income tax – payable by individuals and trustees of trusts based on their assessable taxable income.	<ul style="list-style-type: none"> <li>• when the trust revenue is greater than its expenses</li> <li>• distributions from the trust to any beneficiary</li> </ul>

**Are there Social Security implications?**

If the person to whom you give assets receives an income support payment, their payments might be affected by receiving those assets.

As you have no guarantee about possible changes to your circumstances in the near future, before you give assets to your family member with disability, find out about the potential implications on your, and their, income support payments.

## What about financial management orders or guardianship orders?

By law, once a person turns 18 years of age, they are no longer under the guardianship of their parents whether they have disability or not. If a child is under the age of 18, a parent can appoint a guardian in their will. Once their child turns 18 a parent cannot appoint a guardian for their son or daughter even if they have high support needs.

Your family member may not need a formally appointed guardian or financial manager if they have a committed group of people to assist with decision making.

If a person with disability is unable to manage his or her own affairs, it is possible:

- to have a financial manager appointed to make financial management decisions on behalf of the person with disability; or
- to have a guardian appointed who can make decisions on other life issues (such as health care and other services, where the person will live, and so on).

This can be done under legislation in **each state and territory** such as the *Guardianship and Administration Act* in Queensland and the *Protected Estates Act* in NSW. The person appointed can be an individual, including a family member. However, a body such as the Guardianship Tribunal will only make an appointment if the person with disability has a current need. You could apply to have a financial manager or guardian appointed while you are alive, or you can suggest in your will that this occurs.

A financial management order may address concerns about management of assets given to the person with disability. A financial manager or guardian is someone who will 'look out for' the person with disability. In considering who you would like to fill these roles, the same considerations arise as in choosing a trustee, but while you can have a say in who is appointed this is ultimately a decision for the Guardianship Tribunal (or other relevant tribunal), which might consider someone else better suited to the task.

## What about a power of attorney?

An attorney is appointed by a legal document called a power of attorney. An attorney is a person you appoint to take care of your financial and assets matters if for some reason you are not available to make decisions, or if you can no longer make those decisions. This means that they can operate your bank accounts, pay your bills, and buy or sell assets or shares on your behalf.

## Who can make a power of attorney?

**You can** appoint an attorney. This would allow someone to do the things you are currently doing for your family member with disability while you are still alive but no longer able to do these things yourself. This will be important if you later develop dementia or can no longer make decisions.

You may want someone to look after your interests and to look after the interests of the person with disability as you would. You need to include directions to the attorney about using your assets for the benefit of your family member with disability, as well as for your own benefit.

**The person with disability can** appoint an attorney (to make decisions on his or her behalf) if he or she is able to do so. Like a financial manager, the attorney could help with financial management and decisions.

However, if the person with disability is able to control his or her own affairs sufficiently to be able to appoint an attorney, you and other family members are less likely to have concerns about their ability to manage their affairs in the future.

**The person with disability cannot** appoint an attorney if he or she has impaired decision making capacity. If the person with disability cannot understand the nature of a power of attorney and its implications, they will not have the legal capacity to sign such a document. In that case, a power of attorney is not an option for managing their assets.

## What are the options if I decide not to give assets directly to my family member with disability?

If a direct gift is not suitable, then the other options are:

- to **informally** give the assets to a third person for the benefit of the person with disability, or
- to give the assets to a third person to use for the benefit of the person with disability **on a formal basis**. This is called setting up a trust.

An example of **the informal approach** would be a gift of assets to a third person in a will – for example, leaving all of your estate to one of two children with the expectation, either stated in the will or just ‘understood’, that the child who inherits will look after the child with disability.

Hoping that someone else will ‘do the right thing’ with assets over which they have absolute control can give rise to many problems. Such an arrangement is very uncertain. You cannot be sure it will benefit the person who has disability, and it may give rise to a range of other problems such as a challenge to the will.

### Example

Yee Min has two children. Her son, Tim, has high support needs and cannot look after money himself. Her daughter, Sue, does not have disability. Yee Min thought that Sue would look after Tim, although she had not discussed this with Sue and said nothing about it in her will. Yee Min’s will gave everything to Sue.

In fact, Sue took no interest in Tim after their mother died and did not use any of her mother’s money for Tim’s benefit. Even if Yee Min had told Sue what she expected, or said in the will ‘I would like you to look after Tim’, Sue would not have any legal obligation to look after him.

(In a situation like this, Tim might challenge the will, with the help of someone else in his life such as a service provider or advocate.)

The formal approach of using a trust is much better than the informal approach. The following section of this booklet provides you with more detailed information about setting up trusts.

## Section 3 – Setting up a trust

There are many different kinds of trusts and a lot of things to think about before setting up a trust. This section aims to help you decide whether a trust is right for you.

The booklet '[\*Special Disability Trusts – Getting things sorted\*](#)' provides detail on Special Disability Trusts and how the income support and tax concessions can help families wishing to provide for people with severe disability.

A copy of the Special Disability Trust, Model Trust Deed which provides compulsory clauses and assists in setting the parameters of the Special Disability Trust can be found on the Department of Social Services website at [Model Trust Deed](#).

The following information will give you a general understanding about trusts.

### What are the basic issues with a trust?

A trust is a legal concept which involves arrangements which can look complex but are really quite simple.

**A trust is a legal obligation placed on one person, called the trustee, to look after the assets of the trust for the benefit of another person or a number of people, called a beneficiary or beneficiaries.**

Some people treat trusts with suspicion because trusts are often used to reduce tax. Trusts of this sort can be very complicated. This use of trusts means that tax rules affecting trusts can be difficult to manage.

**However, it does not mean that a trust is unsuitable for providing for the needs of a person with disability.**

In fact, a trust is a very good way to control assets for the benefit of a person with disability. A trust can continue to look after some of the interests of a person with disability after your death. It is a structure you set up to operate before or after your death, which can continue into the future.

If you have decided to use a trust to provide for a family member with disability, the main decisions that you will need to make are:

- Who will be the trustees?
- How will I divide up my assets to deal fairly with the person with disability and other members of the family?
- What accommodation and care options should I provide for?
- How much discretion and direction do I give the trustee?

These questions are discussed in this section.

### What do trustees do?

There are established rules about the rights and duties of trustees and the rights of beneficiaries.

The nature of a trust is to separate the **power to control assets** from the **right to benefit from those assets**. Generally speaking:

- the trustee has the right within the guidelines set up by the trust to control and administer the assets, **but only for the benefit of the beneficiary**; and
- the beneficiary has the right to benefit from the assets, but not the power to control the trust assets.

The person with disability can therefore benefit from the assets without the risks involved in having direct control over the assets. These risks include:

- exploitation or abuse, if the person with disability is vulnerable;
- not making the most of the available assets; and

- what might happen to the assets after the death of the person with disability, especially if the person with disability is not able to make a will.

### Example

Jeannine sets up a trust for her assets. Her nephew Sam will control it as trustee for the benefit of her son Ben, who has disability. It will be Sam's decision whether and when to use the trust money. Ben can ask Sam for money, or other people (such as other family members or care workers) can ask on Ben's behalf.

Sam can use trust money for Ben's benefit even if Ben doesn't ask for help. It will be Sam's decision how to invest money: whether to invest mainly for the long term or to keep some or all of the money available for Ben's needs, depending on what Sam thinks Ben's needs are likely to be.

### How is a trust set up?

If you are establishing a trust to operate while you are alive, you need to have a **trust deed** prepared.

The deed is a legal document which:

- identifies who is the founder of the trust, who is the trustee and who benefits from the trust (called the beneficiaries);
- provides details of how the assets of the trust are to be used for the beneficiaries; and
- sets out the various powers of the trustees.

You can also set up a trust through a will so that the trust will not begin until after your death. You could do this by writing it into your will or by referring in your will to a separate document containing the full terms of the trust.

**Before setting up a trust, you should get appropriate legal and financial advice.** Using a trust deed, for example, the Special Disability Trust, Model Trust Deed may not work for your particular circumstances.

### Who should I appoint to be the trustee?

**The appointment of a trustee is probably the most important decision you will make when setting up a trust for a person with disability.**

**Legal structures do not ensure people will do the right thing. Therefore, choosing people who will do the right thing is extremely important.**

The trustee is the person who will make decisions in your place, so you should ensure that they understand and share your views about how your family member can best be looked after by the trust. Your trustee should be someone who will make decisions consistent with your wishes, so far as you can foresee.

For example:

- If you believe that the available funds should be distributed in a generous way and take into account all aspects of a person's life, it may not work to have someone as trustee who does not believe that it is important for people with disability to have holidays, or to have a TV or CD player.
- If you believe your family member with disability should live as independently as possible, it may not be a good idea to appoint a trustee who thinks people with disability should live in an institution or a group home.

So the first consideration is choosing a trustee who is sympathetic to the needs and wishes expressed by your family member with disability, to your vision of the future, and to your approach to the issues that matter to you. If you involve others in your vision and planning, as discussed in Section 1, it is more likely that you will have identified a person who is suitable to be a trustee. If you have developed a 'wish list' for the person with high support needs, this can assist the trustee to continue to make decisions in the best interests of the person. You may also wish to have more than one trustee.



However, there are also other features to bear in mind which it may be useful to have in a trustee.

- **Youth:** if the trust is to last for the lifetime of the person with disability, it is sensible to appoint a trustee of roughly the same age as the person with disability. They are then more likely to be around for as long as the person with disability.
- **Business sense:** if a person can understand business and legal or financial advice, they may be a good choice as a trustee. Their skills will enable them to look after the trust effectively over a long time.
- **Independence:** ideally, the trustee will have no conflict of interest which might cause the trustee to look after his or her own interests, or those of the people close to him or her, rather than the interests of your family member with disability.

### Example

An expectation of inheriting any money not spent on the person with disability could give rise to a conflict of interest: the less spent on the person with disability, the more the trustee inherits in the long run.

An involvement in an organisation which provides accommodation for the person with disability could give rise to a conflict of interest. The trustee's position with the organisation might override the interests of the person with disability if there is an issue about where the person should live or a complaint against the organisation.

Choosing trustees who are independent provides a useful safeguard to ensure that they serve the best interests of the person with disability.

- **An interest in the person with disability:** it is very important to have a trustee who knows the person with disability, is in regular contact with him or her, and is well aware of his or her needs and interests. A trustee who relies on second-hand information about what is needed will not be as well prepared to administer the trust. The trustee needs to keep up to date with changing ideas and knowledge about how best to support the person with disability.
- **Compatibility:** if there is more than one trustee, the trustees need to get on well with each other. Any serious dispute among trustees can end up in court, and it is highly desirable that this doesn't happen.

Having all these qualities is the ideal; however, it is not essential. It may be difficult to find one person with all these qualities. Some of these qualities may be more important to you than others. You may want to choose more than one person as a trustee so that you have a combination of qualities to best suit your needs.

### Who could be a trustee?

These are the options for appointing trustees, and some of the pros and cons.

- **Family members:** the brothers or sisters of the person with disability are of the same generation and usually have a close interest in the welfare of their sibling. They are therefore a natural choice as trustees. However, family members may have a **conflict of interest** because they often stand to benefit from whatever funds are left over after the death of the person with disability.

**This is not to say that many family members would not 'do the right thing' in all circumstances**, but it is an issue to think about. Many parents say they trust their children but don't know whom they might marry. Expectations of family members as trustees should be discussed within the family to avoid problems.

A possible conflict of interest is a reason why you might **balance a family member as a trustee with someone more independent**. Aunts or uncles or cousins of the person with disability may be more independent because they are less likely to have a future financial interest. Family members are less likely to charge fees for their services than other potential trustees. (If the trust is a Special Disability Trust, immediate family members cannot be paid for their services.)

- **Friends or other people involved in the life of the person with disability:** friends often have a close interest in the life of the person with disability without having any conflict of interest. They may therefore be good trustees, or one of a number of trustees, providing a useful balance. Encouraging a strong network of people around your family member with disability may provide good candidates for trusteeship later on (or could mean that the informal network will be sufficient without setting up a trust).
- **The Public Trustee or private trustee companies:** the Public Trustee in each state and territory, or private trustee companies, can provide trustee services and are very experienced at doing so. They can be expected to have an objective view about what will be beneficial in any circumstances and substantial financial ability.

The Public Trustee and trustee companies will charge fees for their services (this may be money well spent for the advantages that they bring) and do not have any close personal interest in the person with disability. They will rely on other people providing information as a basis for deciding where to use the available trust funds. This means that the trustee companies will be more remote, especially if there is no other trustee actively involved with the person with disability.

- **Professional advisers:** your lawyer or accountant may be another candidate as an independent trustee, but they are likely to charge for their services and may not have any direct involvement in the life of the person with disability or knowledge of disability issues.
- **Corporate trustees:** your advisers may recommend that you should set up a company to be the trustee. In that case, the considerations about who should be a trustee will apply to the people who will be directors of that company.

Considering these various candidates, it is sometimes necessary to make difficult choices and there may well be no right answer.

### How many trustees can I appoint?

You can appoint more than one trustee to get a spread of skills and abilities. For example, you could appoint as trustee a family member who has regular contact with the person with disability and also appoint a trustee company which has the financial capacity to look after the trust assets and will be around for the life of the person with disability.

Or you could appoint three individuals who provide the different qualities that you need and also may keep each other honest about advancing the interests of the person with disability.

#### Example

Margaret has an intellectual disability and needs help managing money. Her mother, Christine, considers whom she can appoint as trustees.

Margaret's brother, Paul, takes a close interest in Margaret, and Christine is confident that he would always do the right thing for Margaret, even though he will receive anything left in Margaret's trust after Margaret dies. However, Paul is only 20 and not very good with money himself, though Christine thinks he will mature as he gets older.

Christine's sister Julie gets on very well with Paul, and Christine thinks she would be a good balance to Paul, as a trustee.

Christine's accountant, Bruce, has also been involved in planning her financial affairs to ensure Margaret's future is well looked after. Christine also considers him as a trustee.

She decides to appoint all three because of the mix of independence and close involvement with Margaret. She also thinks they would get on very well together and feels it is worth paying Bruce for his professional time.

There is no limit on the number of trustees you can appoint but, from a practical point of view, more than three is not desirable.

The advantage of three trustees over two is that any disagreement can be resolved by the majority (only if the trust deed or will allows this) so there is no deadlock.

## What if the trustee dies or can't accept the appointment?

You can specify in the trust deed or the will who can appoint extra trustees or replacement trustees. This will often be one or more of the trustees themselves. If a situation arises where there is no trustee, the Trustee Acts in each state and territory specify who is to take over, and if those provisions don't work the courts are given the power to appoint trustees.

To ensure that the trustees are people of your choosing (so far as you can), it is important to specify who the replacement trustees will be or how they are to be appointed.

## Some important practical issues when setting up a trust

There are two general issues to bear in mind in setting up a trust.

### **If you are setting up the trust while you are alive, can you afford to put assets into the trust?**

That is, can you do without those assets in your retirement? Once given to the trust, you will not have the power to control those assets in future or have them back for your own benefit. They will have been committed to the benefit of the person with disability.

#### **Example**

Silvio and Anna want to provide for their son Marco who has disability. They are retired and have a house and some money from their super. They think they will go to live with their other son Tony, sell their house, then put the money in trust for Marco. They see a financial adviser who points out that, if for any reason they can't stay with Tony at some future time, they will have a problem: they will not be able to get the money out of the trust for their own use, so they may not be able to afford other retirement housing.

They might decide to set up the trust for Marco now but not put much money into it. Their adviser tells them about the costs and paperwork involved in operating a trust, which they need to balance against the feeling of security they will get from having set up the trust now and knowing that they have done the best they can for Marco.

They decide instead to keep the money in investments in their own name, just in case they ever need it, and to put money into trust for Marco through their wills, after both of them have died.

- **Trusts do not create options which do not otherwise exist.** While setting up a trust structure may be beneficial, this depends on either you or others having assets which they are willing to put into the trust for the benefit of the person with disability. The powers of the trustee are limited to the assets within the trust. Appointing a person as trustee for a person with disability does not give that person any rights in the nature of guardianship or financial management with respect to any assets directly owned by the person with disability.

#### **Example**

James has disability because he was badly injured in a car accident and he is unable to work. He owns his own home and has a reasonable amount of money that he saved before the accident. James is able to manage most of his own affairs with assistance from his sister Susan.

Susan decides to establish a trust for James and appoints her daughter Sarah as trustee. Sarah wants to protect James, as she is concerned that he is being exploited.

Being trustee of James' trust doesn't give Sarah the right to control James' personal assets. The options are to work with James to help him protect his own money or to apply to the Guardianship Tribunal in the relevant state to have a financial manager appointed for James (which could be Sarah or someone else) to control his money.

## How do I divide my assets between family members?

If the person with disability is your only child, this will probably not be a big issue: you can give your whole estate to your son or daughter, via a trust or your will, without concerns about competing claims.

However, if the person with disability is one of a number of children, parents and other family members need to consider carefully how they look after those other children as well as the person with disability.

Usually, the general structure will be:

- establish how much will go to each child of the family;
- put the share of the person with disability into trust (now, or through your will); and
- include a provision for assets still held by the trust, when the person with disability dies or no longer needs the assets, to go to other family members or to a charity, or whomever else you consider appropriate.

Deciding how to divide your assets between family members can be a very difficult question that depends on matters such as:

- what assets are available to divide – the more there is, the easier it will be to balance everyone's interests;
- what assets the person with disability owns in their own right and what income they are likely to receive in the future;
- what accommodation arrangements have been made for the person with disability and how secure those arrangements are;
- whether your house, often the main asset, needs to be kept for the person with disability;
- social security considerations, including the possibility that there could be changes to the social security rules in the future;
- possible changes in services available for people with disability, government or private, in the future;
- whether you need to provide additional resources for the person with disability and postpone the interests of the other children until the person with disability has died or otherwise no longer needs the support of a trust; and
- the needs of other people in the family, such as younger children who need to complete their education or adult children who also need support.

Giving most of your assets to a trust (for your son or daughter with disability) could result in a very long delay before your other children benefit. Much will depend on whether they are well established and providing adequately for themselves or whether they need assistance. Different people will resolve these problems in different ways: again, there is no right answer.

For some parents, the best solution is to give more to their son or daughter with disability because their needs (or uncertainties as to their needs) are greater and they have less opportunity to provide for themselves compared to their other children. Even if a person with disability has what appears to be secure accommodation, if these arrangements change it may be necessary to fund accommodation privately, which can be very expensive, so creating a reserve fund for this could be a priority. Paying support costs to supplement government funding can also be very expensive.

Other parents feel that equal division is the right thing to do, to be fair to everybody: the disability is not a reason for one child to get either more or less. Some parents decide to give a larger share of their estate to the other children if the child with disability has appropriate housing that is likely to continue to be available into the future.

Your decisions might change at different times as your circumstances change.

### Example

Alex and Rita have two children: Anne, 12, and Peter, 15. Peter has an intellectual disability. It is hard to determine what arrangements Peter will need. If anything happens to Alex and Rita while Anne is still young, Anne will also need support to finish her education. Alex and Rita decide to split their estates equally and to appoint trustees to look after Peter's share and also to appoint trustees for Anne's share (who can use the money to pay for her education) if she is less than 21 when Alex and Rita die.

Ten years later, Alex and Rita reconsider their wills. Anne is now well on the way to being independent. Peter is living in a group home and this seems likely to continue indefinitely. However, Alex and Rita feel that, as Peter might have a greater need for funds in the future if his housing arrangements ever have to change, it is appropriate to now give him two-thirds of their assets.

There are too many possible arrangements to go into more detail here. What will suit your vision and circumstances is a matter for careful consideration when preparing a will or setting up a trust. Appropriate legal and financial advice can help you to look at your particular situation.

It is important to openly talk through these issues with everyone concerned (including the person with disability so far as possible) and arrive at an agreement as to what will happen. This will ensure that there are no surprises for anyone after your death.

### How do different forms of accommodation fit into this?

There continues to be strong demand for supported accommodation and respite for people with disability. The Australian Government recognises that there are many different models for the delivery of these services. Models may include shared or individual arrangements or a mixture of both: various levels and types of support services; as well as other particular features to suit the needs of individuals. As people with disability are all unique, no one model will suit all individuals. Therefore a tailored approach is necessary.

States and territories continue to work, in response to the needs identified by people with disability and their families, to provide more appropriate options for people with disability. There is no 'one model fits all', the best way is to provide a range of accommodation options to suit individual needs. These options include: independent living with some advocacy sharing with another person, with or without disability, with support as needed; independent accommodation with individual 24-hour support provided by state/territory departments; or remaining in the family home with advocacy and support as needed.

Some families are looking at providing sustainable accommodation for their family member by exploring, with other families, a model where resources are pooled to provide appropriate shared living arrangements. There are a number of very small family developed and managed organisations which are using innovative methods to develop accommodation options for their family members with disability which blend both informal and formal support.

When looking at how a trust can support accommodation options, it is important to understand that creating a trust, either while you are alive or through a will, does not create new resources. To have reasonable certainty as to the accommodation available to a family member with disability, you need to make these arrangements yourself so that they are ready when needed. It is also important however, to leave the trustee with enough flexibility to respond to the person's changing wishes and needs, and to new ideas about how to best support the family member with disability.

For people with intellectual disability who are 'in the system', with accommodation provided by a service organisation or government which is likely to continue to be available, this issue might seem to be resolved. However, there is always the possibility that the situation may change in the future. For example, the current accommodation may no longer be suitable in 10 years' time or the service organisation may close down or change how it provides services.

For parents whose son or daughter with disability still lives with them at home, the issues will be about continuing to provide care as the parents get older. However, a sudden change of circumstances may arise when the parents die and the person with disability needs to move into strange new accommodation.

Organising access to whatever form of accommodation is appropriate and available is a very important step. It is advisable to do this before the trust or will comes into effect. You will need to give the trustee(s) the power to obtain whatever form of accommodation is suitable, with guidelines as to what you would like to happen if it is feasible.

You may need available assets for:

- insurance, rates, maintenance and other expenses related to housing; and
- the necessary care and support services.

There is no point in providing housing for the person with disability if the means do not exist to keep that housing or to support the person with disability staying there. If there is insufficient money available for these things, your arrangements will not last and assets may have to be sold to fund the purchase of something more appropriate. The money to pay expenses might come from income from a trust or from the money of the person with disability, such as earnings, savings or social security payments.

Support or care services will often cost a lot of money, especially if services are needed for many years. If you intend to provide for these expenses through your will or a trust, you will need to consider the likely costs and plan finances to cover such services for maybe 30 or 40 years. Private funding of these services in full will be impossible for many people as they will not have sufficient assets to cover the cost. They will have to consider the services available through government or non-government organisations and consider what contribution they can make to get the best arrangements they can afford.

### Special disability trusts

To assist families with estate planning, the Australian Government has legislated to provide social security and veterans' affairs means test concessions, where specific conditions are met, for certain gifts and for trusts known as Special Disability Trusts. Anyone can establish a Special Disability Trust for a principal beneficiary with severe disability as long as the legislative conditions are met.

The focus of the Special Disability Trust measure is to encourage people to make their own provision for accommodation and care costs, for family members with severe disability. A Special Disability Trust may help with this because the social security concessions may resolve concerns about how funds held in a trust may affect social security entitlements. However, if the assets are limited and reduction of social security entitlements is not a significant risk, a Special Disability Trust may not be relevant. For detailed information on Special Disability Trusts refer to the booklet [\*Special Disability Trusts - Getting things sorted\*](#).

### Can my trust arrangements or my will be challenged?

When you are trying to balance the factors considered above, there is also a background issue to consider: **the possibility that a close family member who feels unhappy about the way you decide to divide things up may challenge your decision after your death by disputing your will.** This may still be an issue if you set up a trust to operate while you are still living rather than doing it through a will. Transactions undertaken before you die can sometimes be challenged and set aside as part of a challenge to a will.

If you decide to leave a large share of your assets to your son or daughter with disability, other children may argue that you have not made proper provision for them. Even if you leave your estate to your children in equal shares, one of your children could still make such a claim. Claims of this kind can result in expensive court proceedings, and the legal proceedings are typically paid for by your estate.

There is no way to be absolutely certain that your will won't be challenged. The best approach is to discuss the issues and agree within the family how the future needs and desires of the person with disability will be managed. Discussing the issues within the family, and if possible with other key people in the person's life, will assist all family members to reach agreement on acting in the best interests of the person with disability.

If you would like to talk to someone about disagreement or conflict in your family, you could access the family mediation and counselling services (see Section 5).

Your legal adviser may prepare an explanation of the reasons why you have divided your estate which can be included in your will or a separate document. This may reduce the likelihood of a challenge.

**However, providing properly for your family member with disability is an important matter.**

The possibility of a dispute about it should not stand in the way of doing what you think is right. After you have carefully considered the options with the benefit of professional advice, the fact that other people will be unhappy about what you do should not stop you making the arrangements which seem the best to you. If there is a dispute, the executor of your will can try to resolve it without the estate spending a lot of money on legal expenses.

**Should I set out in detail in the trust what I want to happen?**

You can include much or little detail as to what you would like the trustees to do for the person with disability. If you specify what the trustees **must** do, there may be problems if circumstances change in ways you did not think about.

You cannot foresee all the possible situations the trustees will have to deal with, 20 years or even 10 years in the future, because there are too many unknown factors. In setting up trusts or wills, you can only do the best that you can with the resources and information available.

**It is generally desirable to give a lot of flexibility to the trustees to enable them to have full and free decision making power in whatever situations might arise. Providing them with guidelines about how you would like things to work for the person with disability will enable the trust to provide flexible solutions rather than being too rigid.**

You have to strike a balance to control the actions of the trustee to a reasonable extent and at the same time not being overly detailed. You can do this by giving some general guidelines in the trust deed or will about how the trustees should go about their duties. The deed or will can say that the welfare of the person with disability must be the paramount concern of the trustees. That is, it is not the trustees concern to save money for whoever will receive what is left in the long run. The guidelines can express the general policy you want them to follow and tell them who they must consult.

**This booklet does not go into the pros and cons of how trusts are taxed; however, there is some information in the booklet '*Special Disability Trusts – Getting things sorted*'. This is a matter for specialist legal and financial advisers.**

**How do I pass on everything I've learned about the needs of the person with disability?**

Too much detail doesn't fit easily into a will or trust deed, especially if the detail may change. One way around this is to prepare information to be given to the trustees to assist them with their task outside the trust deed or will. This could be the written account of all the things you know about what is good or bad for the person with disability and how they communicate their needs and wishes: activities which the person likes or dislikes, what they can and can't do for themselves around the house, what support they need to participate in activities, medications and therapies, who provides services to them and so on. You can change it and update it as things develop.

While this information, and your preferences on various subjects, will not be legally binding on the trustees, it will be invaluable for helping the trustees to do the best for the person with disability. Of course, your family member with disability will often be able to say these types of things for themselves, to a greater or lesser extent, and that too is something which the trustees should be directed to take into account.

You may wish to look at the [Emergency Care Plan](#) template which is provided by the Department of Social Services.

## Section 4 – How to access legal and financial advice

### Finding a lawyer

Lawyers may be very good at giving legal advice regarding making a will or establishing a trust but less knowledgeable at understanding the needs of people with disability and the current situation regarding social and disability services. When trying to find a lawyer appropriate to your needs it is useful to ask other families, or people you know who are in a similar situation to yours, how they have gone about finding a lawyer and if they have a recommendation.

If you are not able to get a recommendation, some states and territories have legal centres which specialise in providing services to people with high support needs. However, most states and territories do not have these centres, so contacting a [Community Legal Centre](#) or the Law Society where you live may be the best place to start.

If your lawyer is not familiar with advising on issues related to the area of disability and estate planning for a person with high support needs, you may need to educate him or her. If you have a well-developed plan you can tell the lawyer about the things in your plan that you won't change and the things that you need advice on.

Once you have worked out a structure with your lawyer, ask the lawyer's advice on whether you should seek further financial planning advice.

### Information to take to the lawyer

#### **Your information:**

- full name, address and occupation;
- full names and ages of children;
- what the situation is in life (marriage, children, work status and occupations, housing) of your children without disability;
- if you are setting up a trust to operate while you are alive, your social security status;
- approximate value of your assets: your house, other financial assets, expected superannuation, etc;
- if making a will, how you would like to split your assets among the potential beneficiaries;
- if setting up a trust to operate while you are alive, how many assets you want to put into the trust;
- whether your house needs to be kept for the person with disability;
- who you would like to appoint as trustees;
- whether you want to provide for remuneration for the trustees;
- whether there are any particular things you want to give to anyone such as other family members and friends; and
- whether you want to nominate who should be appointed as guardian or financial manager for your son or daughter with disability, if he or she ever needs one.

#### **Information about the person with disability:**

- type and degree of disability, care and accommodation arrangements: at home, within a system, other service providers;
- how secure these arrangements are and how long they are likely to last;
- what degree of support is required and where you expect that will come from;
- social security arrangements and how much they are relied upon;
- assets owned by the person with disability in his or her own name; and
- could he or she make a will.



## Finding a financial planner

Knowing who to trust to assist you in making financial plans can be a major source of anxiety for family members. Knowledge about disability and issues related to future planning may not be in the range of expertise of many planners. If you decide with your lawyer that you would benefit from advice from an accountant or financial planner, and you do not already have a relationship with such a person, a good starting point is to ask around amongst other families in your situation and amongst your networks to find out if they have information or advice in this area. They may be able to recommend you to someone.

Most financial advisers have limited knowledge about the issues facing a family who are providing for a family member with high support needs. When choosing a financial adviser, ask about their personal experience with advising people in your situation. The [Financial Planning Association of Australia](#) can assist you in finding an accredited planner in your area. They do not, however, have information about a planner's expertise in the area of planning and disability.

The Australian Securities and Investment Commission's Moneysmart website has information on [Choosing a financial adviser](#) and a number of publications including [Financial Advice and you](#) which is a guide to finding a financial adviser.

Apart from taking your plan to the adviser, think about what sort of income you would need to generate in order to provide for a family member with high support needs into the future. Also take information on what other benefits a person is eligible for and accommodation options that will help the adviser develop a financial plan that clearly responds to your needs.

## Section 5 – Useful contacts

### Legal Advice

See legal centres and law societies in your state or territory.

### Financial Advisers

Financial Planning Association of Australia website, [Find a Planner Service](#) or phone 1300 626 393.

Australian Securities and Investments Commission (ASIC).

[Moneysmart](#) (financial tips and safety checks) is the consumer website of ASIC. Contact their [Infoline](#) or phone 1300 300 630.

### Further reading

Booth, Stephen 'Wills for Parents of Person's with an Intellectual Disability', chapter 12.1 in Lawyers Practice Manual (NSW), Redfern Legal Centre/LBC Information Services (looseleaf service).

Booth, Stephen, 'Wills for People with an Intellectual Disability', chapter 12.1A in Lawyers Practice Manual (NSW) Redfern Legal Centre/LBC Information Services (looseleaf service).

Booth, Stephen, When I'm Gone: an introduction to wills and estate planning for parents of people with an intellectual disability, Intellectual Disability Rights Service, June 1999.

People with Disabilities – A legal information manual for West Australians, People with Disabilities WA (Inc), May 2004.

Residential Property Ownership for disabled persons in Western Australia, Deacons, June 2003.

**Disclaimer:** this booklet is not providing specific legal advice to any reader. Readers should obtain their own legal advice particular to their circumstances.

## Section 6 – Planning templates

### Future planning checklist

Before you see someone for legal or financial advice it is important to work out as far as possible what it is you need (goals and plans).

Ensure that there is discussion on what the needs of each family member are now and in the future, but keep the focus on the person with disability. It is also important that the family member with disability is given the opportunity to provide as much input as possible.

Here are some ideas for the kind of things you may want to consider as a starting point. Be explicit when thinking through this checklist. It may not be possible for all the goals you identify to be achieved. Do not allow this to stop you planning and working towards a positive outcome for the future.

### Issues for consideration

What are the hopes and dreams of the person with disability and your hopes and dreams for them?	
How does the person currently communicate their needs?	
What accommodation will satisfy the needs and desires of the person?	
What is important to maintain their valued social relationships and interactions and what do they desire for the future in terms of relationships?	

<p>What activities do they enjoy at present or desire for the future?</p>	
<p>What are their likes and dislikes and sensitivities (be specific and include food, music, environment, people)?</p>	
<p>What are their learning and educational needs?</p>	
<p>How can we, or others, support the person to achieve their hopes and dreams?</p>	
<p>Other special needs.</p>	

**Information to take to the lawyer:**

Your information:

Full name, address and occupation.	
Full names and ages of children.	
What is the situation in life (marriage, children, work status and occupations, housing) of your children without disability?	
If you are setting up a trust to operate while you are alive, your social security status.	
Your assets (\$ approx): <ul style="list-style-type: none"><li>• house,</li><li>• financial assets, and</li><li>• superannuation.</li></ul>	
If making a will, how would you like to split your assets among the potential beneficiaries?	

<p>If setting up a trust to operate while you are alive, what assets do you want to put into the trust?</p>	
<p>Will your house need to be kept for the person with disability?</p>	
<p>Who would you like to appoint as trustees?</p>	
<p>Do you want to provide for remuneration for the trustees?</p>	
<p>Are there any particular things you want to give to anyone?</p>	
<p>Do you want to nominate who should be appointed as guardian or financial manager for your son or daughter with disability, if he or she ever needs one?</p>	

Information of the person with disability:

Type and degree of disability, care and accommodation arrangements: at home, within a system, other service providers.	
How secure are these arrangements, how long are they likely to last?	
What degree of support is required and where do you expect that will come from?	
Social security – how much is that relied upon?	
Assets owned by the person with disability in his or her own name.	
Could he or she make a will?	