

FACT SHEET



IMPORTANT – This Document only provides general information.

It is not intended to be a substitute for you getting your own specific legal advice.

Wills and future planning for parents of people with intellectual disability

All parents are concerned to provide adequately for their children. Parents of people with intellectual disability are even more concerned about this - how can I best provide for my son or daughter with intellectual disability when I'm gone?

Many people believe a person's future is best guaranteed if the person's entitlement to the Disability Support Pension is maintained and for this reason parents sometimes limit their son or daughter's ready access to cash. This can cause problems because it is difficult to predict what the needs of the son or daughter will be in the future. Facilities and services may close or fees may increase to the point they exceed the pension. New ways may become available to improve the person's lifestyle which cannot be obtained if the pension is the person's only source of income.

1. What if a person does not have the capacity to manage money?

Before preparing a will, parents need to consider the capacity of any beneficiary with intellectual disability to manage any money or other property left to them. It should not be assumed that a person with intellectual disability is incapable of managing a gift. In each case parents must consider the size and complexity of any gift they plan to leave and their own son or daughter's capacity to look after property, understand its worth and whether or not they are vulnerable to exploitation by others.

Even if it has been decided that a person lacks the capacity to manage money, you can still leave money (or other property) to the person in a will as there are several ways to structure a will to protect the interests of such a person. For example, parents can leave a share of the estate in a trust. This means appointing people, called trustees, to manage and use the fund for the person with intellectual disability (known as the 'beneficiary') in the way specified in the will. Parents can also say what happens to any unspent part of the trust when the person with intellectual disability dies.

2. What factors should parents consider when setting up a trust?

If a trust is created, parents need to consider how much freedom, referred to as 'discretion', the trustees will have in deciding whether and when to spend money on the person with intellectual disability. If too little discretion is given, the trustees may not be able to respond appropriately to changing circumstances.

The choice of trustees is vitally important. The trustees should have some understanding of intellectual disability and some knowledge of the individual's needs and likes. The Intellectual Disability Rights Service has dealt with cases where trustees have been unwilling to meet very reasonable requests for money. This has arisen from factors such as trustees mistakenly thinking that a person's disability will prevent the person from appreciating a holiday, nice furniture and even decent clothes and shoes.

Parents should also carefully consider the possibility of any potential conflict of interest in selecting a trustee. For example, if a family member is appointed as a trustee and the will provides that the trustee will receive any unspent part of the trust when the person with intellectual disability dies, then the trustee may find it difficult (if not impossible) to act solely in the best interests of the person with intellectual disability. It is usually better to have more than one trustee.

If parents do not know anyone they would like to have as the trustee, they can consider appointing the Public Trustee or a private trustee company. Some parents may consider appointing two trustees to act together, one with knowledge of the person and the other providing a more "objective" view - each to act as a balance for the other. For example, if the estate is large, a professional, such as an accountant, may be an appropriate trustee along with someone who has direct contact with the person with intellectual disability.

Parents may also consider the option of setting up a special disability trust to operate during their lifetimes or commence when they die. In order to set up a special disability trust, there must only be one beneficiary, and that person must have a 'severe disability'. Further, special disability trusts can only provide for the 'care and accommodation' of the beneficiary. 'Care and accommodation' does not include lifestyle needs like clothing, entertainment and household goods.

There are some advantages to setting up a special disability trust, such as:

- assets in the trust up to a certain amount (currently above \$500,000) will not be counted by Centrelink when assessing the person with intellectual disability's eligibility for a pension;
- income from assets in the trust up to a certain amount (currently above \$500,000) will not be counted by Centrelink when assessing the person with intellectual disability's eligibility for a pension BUT will be counted as taxable income against the person by the Australian Taxation Office, and
- immediate family members can gift up to \$500,000 into the trust and still be eligible for their own pension

However, parents should also be aware of some possible problems and difficulties associated with special disability trusts:

- once money is in the trust it cannot be withdrawn or used for anything other than the purpose of the special disability trust, and
- depending upon a person's particular circumstances, asset amounts, Centrelink thresholds and income tax consequences, a special disability trust may not put the beneficiary and their family in a better financial position than other future planning arrangements

3. Are there other options?

Trusts are not the only option. For example, parents could leave a share of the estate directly to the person with intellectual disability with the request that the executors of the will make an application to the Guardianship Tribunal for the appointment of a financial manager if, at the time of the parent's death, the person with intellectual disability does not have the capacity to manage the share of the estate left to him or her.

The reading materials and contact details listed at the bottom of this facts sheet provide further information about the options available and the issues which need to be considered when appointing a trustee.

Legal advice should always be sought when drafting a will which creates a trust.

4. What if parents leave the family home to an organisation or government department?

Some parents have considered leaving their home (or other property) to an organisation or a government department in the expectation that such organisation or department would then provide services to their son or daughter for life. This can lead to many problems and should be avoided. For example, the organisation may encounter financial problems and be unable to continue to provide services, or the needs or wishes of the person with intellectual disability may change such that the department is no longer able to meet those needs or wishes.

Rather than leave property to the organisation or department, parents can create a trust and instruct the trustees to investigate allowing an organisation or department to use the house for so long as services are provided to their son or daughter. If the organisation or department fails to keep its side of the bargain or if the needs or wishes of the person with intellectual disability change, the trustees would then have the power to sell the house and use the proceeds in a more appropriate way for the benefit of the person with intellectual disability.

5. What if there is no or inadequate provision in a will for a person with intellectual disability?

The Succession Act 2006 (NSW) gives a court the power to alter a will where the will maker (also called the ‘testator’) has not made adequate provision for the “proper maintenance, education and advancement in life” of a spouse, son, daughter or certain other dependents. It is important that applications be pursued promptly. A person who has questions about this should get legal advice.

6. Can parents appoint a guardian in their will?

Parents can indicate in their wills who they wish to act as the guardian of their children. The guardian’s powers only apply until the child turns 18 years old.

Many parents assist their adult sons and daughters with intellectual disability to make decisions about their lives (for example, where they live) and to manage their finances.

Parents are sometimes concerned about who will provide this assistance after they die. The least restrictive alternative should always be considered first - for example, another family member may be able to provide this assistance. A parent may wish to include a phrase such as "I request X assist my son/daughter in his/her life." Such "requests" are not legally binding but they are an indication of the parents' wishes, which can be very important if an estate is contested in court.

If these informal mechanisms are not available or are unworkable, an application can be made to the Guardianship Tribunal for the appointment of a formal guardian and/or financial manager. A guardian or financial manager will only be appointed if the Guardianship Tribunal is satisfied that the person with intellectual disability cannot make his or her own decisions, that no less restrictive/informal assistance is available and that it is in his or her best interests that a guardian or financial manager be appointed.

Even if a parent has been formally appointed by the Guardianship Tribunal to be the guardian of his/her adult son or daughter, the parent cannot pass this authority on to another person in a will or otherwise. Only the Guardianship Tribunal (or the Supreme Court) can appoint guardians for adults. However, parents may like to name in their wills a person who they would wish to be their son or daughter's guardian. This will help the Tribunal or Court decide who the new guardian will be.

7. How can you find out whether a person has been left anything in a will?

The Intellectual Disability Rights Service often receives requests for advice about what rights people with intellectual disability have if they have been treated unfairly or not provided for at all in a parent's (or other family member's) will.

If you suspect that a person has been treated unfairly in a will or has not received his or her entitlement under a will, you should first discuss the issue with the person to find out:

- does she or he know anything about the will?
- does she or he want to know more about his/her rights under the will?
- is it alright for you to discuss the matter with other family members who may know more about the will?

If the person wants to know more about the will and agrees to having the matter discussed with family members, ask the family for a copy of the will. If the family refuses or if the person with intellectual disability does not want the family to know about his or her concerns, a copy of the will can be obtained from the NSW Supreme Court (as most wills have to be approved by the Supreme Court before they can be carried out by the executors). The Intellectual Disability Rights Service, your local community legal centre or the Registrar of the Probate Division of the Supreme Court may be able to assist. Try to find out as much information as you can about the deceased person including his or her full name, last address, date of death and the date on which probate was granted. The more information you can get, the easier it will be to locate a copy of the will. Another way of finding out who is handling the deceased person's estate is to keep an eye on the legal notices section of the paper.

If a person does not have the capacity to make an informed decision about whether to pursue the matter, an application can be made to the Guardianship Tribunal for a guardian or financial manager to be appointed to do so on their behalf. Before doing this, consideration should be given to discussing the matter with any family members who may have information about the will in an attempt to resolve the matter informally. It may also be appropriate to seek legal advice on the desirability of settling the matter or taking it further.

Once you obtain a copy of the will, you should contact a solicitor for assistance in interpreting the will.

8. Where can further information be obtained?

- Questions of Rights: A guide to the law and rights of people with an intellectual disability (2nd edition), Redfern Legal Centre Publishing, 1998 (Available from the Intellectual Disability Rights Service)
- Booth, Stephen, When I'm gone: An introduction to wills and estate planning for parents of people with an intellectual disability, Redfern Legal Centre Publishing, 1999. This book aims to provide parents with the full range of options available to them in estate planning so they are better placed to fully and properly instruct a solicitor in drafting their wills
- Booth, Stephen, "Wills for Parents of People with Intellectual Disability", Lawyers Practice Manual, vol 2. Most Lawyers have this manual and would be well advised to consult this chapter
- Booth, Stephen, "Providing for a child with intellectual disability" (1996) 34(1) Law Society Journal, 63.
- Intellectual Disability Rights Service, ph 9318 0144 (Sydney) or 1800 666 611 (freecall) weekdays for legal advice.
- Community legal centres - for information about the legal centre closest to you contact the Combined Community Legal Centre's Group ph 9212 7333
- Law Access NSW is a NSW wide telephone information, referral and advice service. All calls are answered by information officers who can explain, legal aid policies and services, how to apply for legal aid and how to get help with your legal problem
- Legal Aid – contact your local Legal Aid Office to make an appointment. Offices numbers are available of Legal Aid's website, or via the Central Office ph (02) 9219 5000