

Supporting young carers
carers supporting
Identifying
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Identifying and supporting
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A guide for service providers

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**Family &
Community Services**
Ageing, Disability & Home Care

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About this resource

Identifying and supporting young carers is a resource for staff in government departments and non-government organisations who need to know more about young carers. This resource provides basic information about young carers, their potential needs and services they can be referred to for assistance.

The majority of service providers involved in the 2010 Young Carers Pilot Project have found it to be easy to understand and practical to use.

The resource is also available on the Ageing, Disability and Home Care website at www.adhc.nsw.gov.au. You can download and print off a separate document for including local contacts.

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1 Who are young carers?

Young carers are children and young people up to the age of 25 years who provide care and support for someone who has a disability, long-term physical illness, mental illness, drug or alcohol problem. They can be family members, students, friends, neighbours and employees.

The 2003 Australian Bureau of Statistics Survey of Disability, Ageing and Carers¹ reported that there are 750,000 young carers in Australia and 90,200 young carers in NSW. This represents four percent of all people aged less than 25 years in NSW. Of these, 59 percent are male and 41 percent female. This is likely to be an underestimate, however, as the survey did not cover children under the age of 15. It also relied on parents allowing young people aged 15 and over to be personally interviewed. The 2009 survey indicates that there are now 850,000 young carers in Australia. Statistics by state have not been released at the time of writing.

¹ Australian Bureau of Statistics (ABS), 2003, Survey of Disability, Ageing and Carers: Summary of Findings, Cat. No. 4430.0, Canberra: Australia.

Young carers can be primary carers or secondary carers. The Australian Bureau of Statistics² defines a primary carer as a person who provides most of the informal care and assistance to another person who has one or more disabilities, often intellectual or a physical disability. The assistance has to be ongoing, or likely to be ongoing, for at least six months and be provided for one or more of the core activities of communication, mobility and self care.

² Australian Bureau of Statistics (ABS), 2008, A Profile of Carers in Australia, Cat. No. 4448.0, Canberra: Australia, p107.

Young carers who are primary carers are most likely to be providing care to a parent or a child with a disability or chronic illness. The majority of young carers live with care recipients who are also their parents. The ages of young carers vary but generally fall between nine and 18 years.

While the majority of young carers are secondary carers, a significant number are primary carers. They report that the reason for them starting caring is through their sense of family responsibility; there is often no one else available to take on the caring role. Most young carers are also full time students.

Care recipients report that a significant number of young carers are their sons or daughters. Many care recipients need significant levels of support and can only be left alone for a very short time.

Secondary carers provide less intensive assistance and, among the young carer population, are more likely to be assisting their parents to care for a sibling who is chronically ill or has a disability.

2 Tasks performed by young carers

While young carers may be performing similar tasks and have similar needs to older carers, their individual needs may differ.

Young carers often perform the same types of tasks that older carers perform and at similar levels to adult carers. These may include:

- domestic activities such as cleaning the house or washing clothes
- household management such as food shopping or conducting repairs
- financial and practical management such as managing household finances, making appointments or communicating with service providers
- personal care such as bathing and dressing or administering medications
- emotional care such as supervising someone or listening to someone's problems
- sibling or child care such as taking an older sibling to and from school or monitoring homework.

These categories of tasks are also useful when assessing whether or not a young person has caring responsibilities and the extent of those responsibilities.

3 Impact of caring responsibilities on young people

Young carers are expected to grow up quickly and many learn to live with an unusual level of responsibility for their age. Young carers, particularly those with primary caring roles, are required to be mature beyond their years. Those providing care for a parent may find that normal parent/child roles have been reversed.

In addition, young carers generally don't know what services and supports are available to help them with their caring role. Even if they are aware of services, they may not have the skills and knowledge required to access them. Many report that they do not receive respite or other carer support.

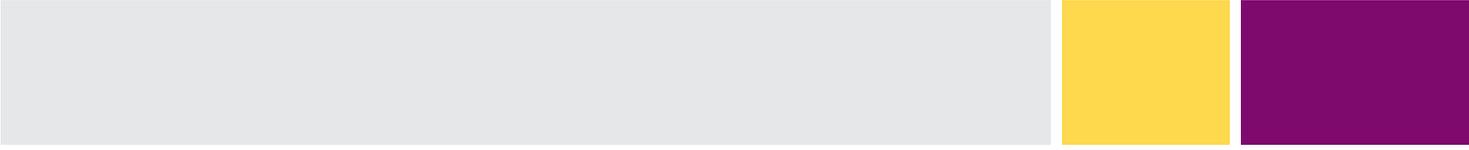
Being a young carer can provide both positive experiences and additional challenges for the child or young person. Some of the benefits of being a young carer can include a greater sense of belonging to the family, feeling valued, developing better living and communication skills and having greater sensitivity and empathy towards others. Young carers who receive adequate support in their caring role are more likely to report positive benefits.

Young carers who do not receive adequate support in their caring role may find that every aspect of their life is affected. Some of the challenges young carers report include³:

- absences from school resulting in disruption to school work and social networks
- difficulty completing homework or putting enough effort into school work
- difficulty doing normal things with peers, such as spontaneously going out with friends
- difficulty 'fitting in' with peers who have different experiences and expectations
- difficulty with bullying at school because of their caring role and/or the particular illness or disability of the person they care for
- additional personal stress because of high expectations from family members or themselves, combined with pressure to keep family 'worries' private.

Providing support to young carers so they have choices and opportunities in education and employment are priorities for the NSW Government. This commitment is contained in the *NSW Carers Action Plan 2007-2012*.

³ NSW Department of Education and Training (2003), *Being a carer, being a student & being a kid. Supporting students who are carers*, Student Welfare Directorate, Sydney, p4.



This commitment is also highlighted in the *NSW Carers Charter*, Schedule 1 of the NSW Government's *Carers (Recognition) Act 2010*:

(g) Children and young people who are carers have the same rights as all children and young people

(h) Children and young people who are carers face additional difficulties and burdens and should be supported in overcoming these difficulties and burdens

The recent *Carer Recognition Act 2010* of the Australian Government also highlights a commitment to young carers. In Schedule 1 – *The Statement for Australia's Carers*, statement 2 provides for:

- *Children and young people who are carers should have the same rights as all children and young people and should be supported to reach their full potential.*

This support will lessen the likelihood of social isolation for young carers.

4 Hidden young carers

Many young carers are 'hidden' or unknown to services. Young carers remain hidden for a number of reasons, including:

- services failing to identify them as carers due to their age
- parents fearing child protection intervention
- parents not allowing the support of services in case their authority is undermined, they are judged by services and/or have a strong desire for privacy
- not self-identifying as a young carer, so not understanding the potential benefit of services for them.

By ensuring young carers and their families are adequately supported, agencies will help to protect young carers against:

- low participation and success in school and employment
- socio-economic disadvantage
- isolation
- poor health and emotional wellbeing
- impaired social development
- limited friendships
- difficulties when engaging in intimate relationships
- difficulties becoming independent
- a significant lack of opportunity and choices.

5 Support for young carers

Not all young carers require support to be able to continue in their caring role, while others do not want to be a young carer at all. Some young carers and/or their parents also resist the young carer being identified as a carer.

For young carers who require assistance, service providers can play an important role. Consider the following when supporting families:

- be aware that in households where a family member has a chronic illness or disability, children may be young carers
- ask family members about caring responsibilities, never assume
- acknowledge young carers and include them in discussions, as appropriate
- recognise the role of young carers within the family and the impact your service provision and interaction with the family may have on them and their family
- listen to the young carers and believe what they are telling you
- tell them what is happening in emergency situations. If a parent is being taken/admitted to hospital, find out what other support the children have in place
- provide age and culturally appropriate information to young carers or tell them where to get information they need about a disease or disability or available services for themselves and/or their family member
- ask young carers what would help
- be as flexible as possible in the options you provide
- refer them to services that can help them and their family
- remember that looks can be deceptive and even the most composed young carer may be struggling on the inside.

6 Services to help young carers

While some young carers do not see value in being referred or may even refuse referral, there are programs and services for young carers in NSW funded by both the NSW and Australian Governments. These include specific services for carers and general youth services.

6.1 Carers NSW Young Carer Program

The Carers NSW Young Carer Program aims to improve the lives of young carers and their families by helping young carers to access:

- the Carers NSW young carer website
- a quarterly newsletter
- telephone group counselling
- face-to-face counselling
- telephone support/information/referrals
- information about young carer activities and camps.

The Carers NSW Young Carer website can be found at www.youngcarersnsw.asn.au. It provides useful information for young carers, their families, friends and professionals, including:

- available services and resources for young carers and how they can be accessed
- facts and statistics about young carers in NSW
- young carer activities and camps
- jokes and stories
- an online discussion forum for young carers
- newsletters and online bulletins
- links to other useful websites.

6.2 Young Carers Australia website

Designed primarily for young carers, this website allows young carers to access information, share ideas and stories, talk to other young carers and keep up to date on news and events.

The website also provides information for families, teachers and other professionals. The website can be found at www.youngcarers.net.au.

6.3 Centrelink

Young carers may be eligible for Carer Payment or Carer Allowance.

Carer Payment provides income support to people who, because of the demands of their caring role, are unable to support themselves through substantial workforce participation. Young carers generally don't meet the Carer Payment eligibility that limits the total hours in work, study or training, including travel time, to 25 hours per week.

A person is eligible to receive Carer Payment if in the home of the person they care for, they provide constant care for:

- a person aged 16 and over with a severe disability or medical condition or
- an adult with moderate care needs and supervision of their dependent child if this child is either under six years of age or; between six and 16 and receives Carer Allowance or
- a child under 16 years with a profound disability or medical condition and extremely high care needs or
- two or more children under the age of 16 with a severe disability or medical conditions that together have extremely high care needs

and:

- the income and assets test is met, and
- the young carer and person cared for meet residency criteria, and
- the total hours used for paid work, study, or training including voluntary work and travel time do not exceed 25 hours per week

The Carer Allowance is a supplementary payment, in addition to wages or other income support payments, for parents or carers who provide daily care and attention to adults or children with a severe disability, medical condition or who are frail and aged. The Carer Allowance is not income or asset tested so it may be paid in addition to wages or other income payments, including the Age Pension. Application for the Carer Payment requires a report from a doctor or health professional.

Although age is not a legislative factor in receiving these payments, many young carers (especially those under 18 years of age) require assistance from a parent or other adult to successfully negotiate the system.

For more information on Centrelink and the payments visit the Centrelink website www.centrelink.gov.au

6.4 Young Carers Respite and Information Services Program

This program supports young carers up to 25 years of age who are at risk of not completing their secondary education or vocational equivalent due to the demands of their caring role.

There are two components:

- **Respite services and age appropriate support through Commonwealth Respite and Carelink Centres (CRCC)**

These services mainly benefit school age young carers who have significant caring responsibilities. Support includes educational, social and recreational activities e.g. time off to study for exams, tutoring, skill development such as cooking or budgeting, school holiday activities and help in the home. For more information, phone your local CRCC on 1800 200 422.

- **Information, advice, peer support and referral to counselling through state and territory carer associations**

These services are available for all young carers up to 25 years to help them manage the challenges they face in their caring role. More information is available from your local carers association by phoning 1800 242 636 (free call) or visit the Young Carers website at www.youngcarers.net.au

7 Young carer assessment

Specific assessment tools for young carers are not necessary when service providers conduct a whole of family assessment. The whole of family assessment collects information about the care recipient and their family, including parents, children and siblings as relevant.

The assessment identifies the key daily living activities that the care recipient requires assistance with and who in their family provides this assistance.

8 Consent

Consent of the family or person holding parental responsibility is needed before information about them or their children and young people with a disability is released to another service provider by a professional. Depending on their ability to understand, children and young people with a disability are involved in making decisions about the release of information or visual images, as far as possible.

Information about children, young people and families should only be shared between services and agencies with the permission of families or when there is a legal or legislative requirement.

Where there are concerns for the safety, welfare and wellbeing of a child or young person, the new chapter 16A of the *Children and Young People (Care and Protection) Act 1998* clearly prioritises the safety, welfare and wellbeing of a child or young person over an individual's right to privacy. Such information may be shared between prescribed bodies⁴ without the consent of the child or young person or their family and without the involvement of Community Services.

It is best practice to inform a child, young person or their family that information may be provided to another organisation if needed, but only if workers believe that it will not:

- jeopardise a child/young person's safety, welfare or wellbeing
- place the worker or child/young person at risk; or
- where staff are unable to contact a parent or carer and the matter is urgent.

More details about information exchange, including fact sheets, checklists and letters to use, are available on the Department of Premier and Cabinet *Keep Them Safe* Website at www.keepthemsafe.nsw.gov.au

Where the child or young person is known to Community Services, organisations may be requested to provide information to Community Services under Chapter 16A of the *Children and Young Persons (Care and Protection) Act 1998*. Alternatively organisations can seek information from Community Services under Chapter 16A. Please contact your local Community Services team or check the *Keep Them Safe* website to obtain further information.

⁴ Prescribed bodies are organisations specified in Section 248(6) of the *Children and Young Persons (Care and Protection) Act 1998*.

9 Young carers at risk

⁵ *Child Wellbeing and Child Protection: NSW Interagency Guidelines* will be published in stages throughout 2009-2011 and will eventually replace the *Interagency Guidelines for Child Protection Intervention (2006, revised 2009)*. The sections of the *Child Wellbeing and Child Protection: NSW Interagency Guidelines* that have been developed are available at www.keepthemsafe.nsw.gov.au. The previous edition of the Guidelines is still available at: www.community.nsw.gov.au. Please refer to both websites to obtain up to date information.

International research recognises that interagency cooperation is a key factor in protecting children and young people at risk of harm. The *Child Wellbeing and Child Protection NSW Interagency Guidelines*⁵ provide practical guidance on interagency cooperation in child protection. These guidelines help professionals and agency practitioners work together across agency boundaries when responding to child protection concerns.

All staff who provide services to children and young people are mandatory reporters. Reports to Community Services must meet the new threshold of “risk of significant harm”. Any child suspected to be at risk of significant harm must be reported to the Community Services Child Protection Helpline (132 111) which is open 24 hours a day.

The Mandatory Reporter Guide (MRG) was developed to help mandatory reporters who have concerns about possible abuse or neglect of a child or young person to make a decision about whether or not to:

- report their concerns to the Community Services Child Protection Helpline; or
- consult their Child Wellbeing Unit; and/or
- seek assistance from other services.

The MRG is available as an online tool at www.keepthemsafe.nsw.gov.au

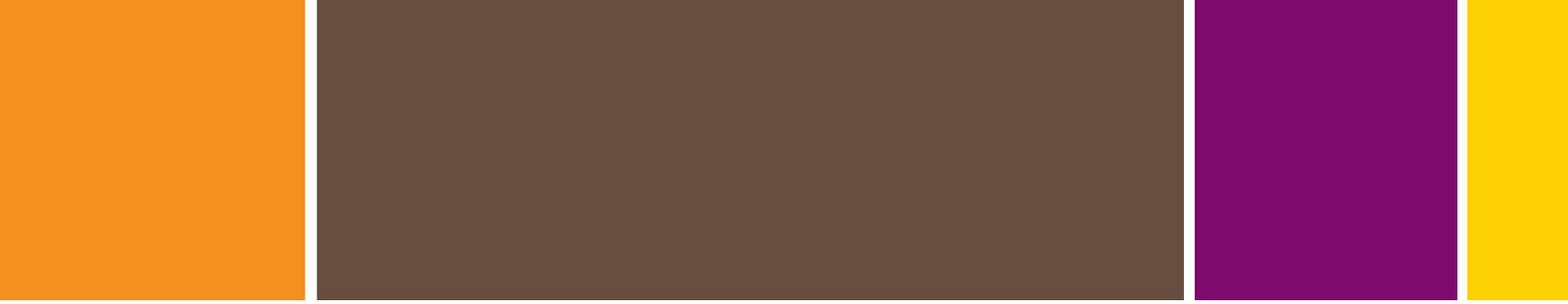
Child Wellbeing Units have been established within NSW Health, NSW Police Force, Department of Education and Communities and the Department of Family and Community Services (which includes Housing NSW and Ageing, Disability and Home Care as well as Community Services). Child Wellbeing Units provide information, advice and guidance about the new threshold of “risk of significant harm”.

Where concern about the safety, welfare or wellbeing of a child or young person falls below the new mandatory reporting threshold, government and NGO agencies need to work together to support vulnerable children, young people and their families to access available mainstream and disability specific services.

For more information and updates about the *Keep Them Safe* initiative, including information for mandatory reporters, interagency guidelines, and frequently asked questions, please see the website at www.keepthemsafe.nsw.gov.au

10 Contact details

Service	Web	Phone
Carers NSW Young Carer Program	www.youngcarersnsw.asn.au	(02) 9280 4744 or 1800 242 636
Centrelink – Disability, Sickness and Carers	www.centrelink.gov.au/internet/internet.nsf/individuals/carer_index.htm	13 27 17
Commonwealth Respite and Carelink Centres	www9.health.gov.au/ccsd	1800 200 422
Translating and Interpreting Service	www.community.nsw.gov.au/for_agencies_that_work_with_us/policies_and_procedures/translating_and_interpreting_service.html	13 14 50
Young Carers Australia	www.youngcarers.net.au	
24 hour Child Protection Helpline	www.keepthemsafe.nsw.gov.au/new_systems_and_services/child_wellbeing_units	132 111
Keep Them Safe Child Wellbeing Unit	www.keepthemsafe.nsw.gov.au/new_systems_and_services/child_wellbeing_units	(02) 9704 4700
Children of Parents with Mental Illness (COPMI)	www.health.nsw.gov.au	(02) 9391 9000



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