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# ENGAGING WITH YOUNG CARERS

A GUIDE

## ABOUT CARERS NSW

Carers NSW is the peak non-government organisation for carers in New South Wales (NSW). Carers NSW is part of the National Carer Network and a member of Carers Australia. Our vision is an Australia that values and supports all carers, and our goals are to:

- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation.

[www.carersnsw.org.au](http://www.carersnsw.org.au)

<https://twitter.com/CarersNSW>

<https://www.facebook.com/carersnewsouthwales/>

## ABOUT CARERS

A carer is any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail.

Across NSW, there are approximately 854,300 carers,<sup>1</sup> and to replace the care they provide the NSW Government would have to spend more than \$25 billion each year.<sup>2</sup> Carers come from all walks of life, cultural backgrounds and age groups. For many, caring is a 24 hour-a-day job with emotional, physical and financial impacts that can also affect their participation in employment, education and community activities.

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<sup>1</sup> Australian Bureau of Statistics (2019) *Disability, Ageing and Carers, Australia: Summary of findings, 2018*, New South Wales Tables, Canberra.

<sup>2</sup> Carers NSW estimate based on Deloitte Access Economics (2020) *The economic value of informal care in Australia in 2020*, Carers Australia.

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## Introducing this guide

***Engaging with young carers: A guide* is part of a toolkit designed to help Carers NSW staff, stakeholders and partner organisations increase the participation of young carers (aged 25 years and under) in their research, consultation and capacity building activities.**

The Carers NSW Policy and Research team developed the young carer engagement toolkit in 2020 in consultation with a Project Advisory Group and all Carers NSW teams working directly with young carers. The toolkit draws on Carers NSW experience conducting a series of interviews with young carers held in 2020 to accompany the rollout of the Carers NSW 2020 National Carer Survey.<sup>3</sup>

Carers NSW developed this toolkit to ensure that the valuable knowledge, experience and connections gained during the Young Carer Research Project were maintained within our organisation and networks in order to inform future projects.

The focus of the toolkit is on increasing the involvement of young carers in research, consultation and capacity building activities conducted by carer-focused or youth-focused organisations. However, some principles may also apply to the provision of direct services to young carers.

In addition to *Engaging with young carers: A guide*, the toolkit includes the following resources:

- *Engaging with young carers: An overview*, a shorter outline of the key principles embedded in the guide intended to be a quick desktop reference or refresher for key staff
- *Engaging with young carers: A checklist*, a practical tool intended to help staff plan for young carer engagement step-by-step, based on the principles in the guide

The Project Advisory Group established for the Young Carer Research Project, whose insights and feedback closely informed the development of the toolkit, included key Carers NSW staff as well as:

- **Associate Professor Myra Hamilton** – Centre of Excellence in Population Ageing Research, University of Sydney (formerly of the Social Policy Research Centre, University of New South Wales)
- **Cathy Thomson** – Social Policy Research Centre, University of New South Wales
- **Dr Karen Hutchinson** – Australian Institute of Health Innovation, Macquarie University
- **Dr Abner Poon** – Faculty of Arts and Social Sciences, University of New South Wales
- **Paula Gleeson** – Centre for Carers Research, University of Technology Sydney
- **Amanda Sharma** – former young carer and Carers NSW Carer Representative
- **Alex Berger** – former young carer and Carers NSW Young Carer Leader

*Engaging with young carers: A guide* provides useful information and resources to inform young carer-inclusive carer engagement. Recognising and including young carers is central to the NSW Carers Charter<sup>4</sup> and *NSW Carers Strategy: Caring in NSW 2020 – 2030*.<sup>5</sup> Supporting young carers is also a key focus of Carers NSW Strategic Plan 2018-21.

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<sup>3</sup> Carers NSW (2020), *Young Carer Research Project: Summary of findings*, Carers NSW, North Sydney, available online at: [www.carersnsw.org.au/research/survey](http://www.carersnsw.org.au/research/survey).

<sup>4</sup> Schedule 1, *NSW Carers (Recognition) Act 2010*.

<sup>5</sup> NSW Government (2020). *NSW Carers Strategy: Caring in NSW 2020 – 2030*

## Glossary of terms

**ABS:** The Australian Bureau of Statistics (ABS) is Australia's national statistical agency, providing trusted official statistics on a wide range of economic, social, population and environmental matters of importance to Australia.

**CALD:** Culturally and linguistically diverse. The Australian Bureau of Statistics (ABS) defines the CALD population primarily by country of birth of a person, main language other than English spoken at home, proficiency in spoken English, and Indigenous status (for those instances where the focus is not specifically on migrants to Australia). The ABS also recognises secondary variables in their definition of CALD, including ancestry, country of birth of parents, first language spoken, religious affiliation and year of arrival in Australia.

**Carer:** Carers NSW defines a carer as any individual who provides ongoing personal care, support and assistance to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail.

**Disability:** The NSW Disability Inclusion Act 2014 defines disability as "a long-term physical, psychiatric, intellectual or sensory impairment that, in interaction with various barriers, may hinder the person's full and effective participation in the community on an equal basis with others.

**Dementia:** Dementia is not a specific, single illness, but rather describes a collection of symptoms that are caused by disorders affecting the brain. Dementia affects thinking, behaviour and the ability to perform everyday tasks.

**LGBTQI+:** Lesbian, gay, bisexual, transgender, queer, intersex and other sexuality, sex and gender diverse.

**SDAC:** The Survey of Disability, Ageing and Carers (SDAC) is the most comprehensive national survey on carers conducted by the ABS. The survey estimates the number of and provides information about people who provide care to people with disability, long-term health conditions and older people.

**Stigma:** The World Health Organisation defines stigma as "a mark of shame, disgrace or disapproval which results in an individual being rejected, discriminated against, and excluded from participating in a number of different areas of society." A variety of personal or group attributes, notably cultural background or certain health conditions, can be, and historically have been, subject to stigmatisation by society.

**Young carer:** Young carers are children and young people aged 25 years and under who provide unpaid care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail.

# Understanding young carers

## Who are young carers?

Young carers are children and young people aged 25 years and under who provide unpaid care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Young carers can be, but are not always, the main provider of support (the primary carer).

Young carers provide a range of practical, specialist and emotional assistance which often exceeds community expectations of what a child or young person can and should be responsible for. The tasks undertaken by young carers can range from domestic duties such as meal preparation and cleaning, to personal care such as showering, to supervising siblings and providing emotional support.

Carers NSW has published a number of resources that provide further detail about the characteristics, experiences and support needs of young carers. These include:

- The *Young Carer Research Project: Summary of findings* report, available online at: [www.carersnsw.org.au/research/survey](http://www.carersnsw.org.au/research/survey)
- A fact sheet on young carers who responded to the 2020 National Carer Survey, available online at: [www.carersnsw.org.au/research/survey](http://www.carersnsw.org.au/research/survey)
- A Young Carer Policy Statement, available online at: [www.carersnsw.org.au/policy/changing-systems](http://www.carersnsw.org.au/policy/changing-systems)

## Key facts and figures

According to the Australian Bureau of Statistics 2018 Survey of Disability, Ageing and Carers (SDAC), in New South Wales (NSW):<sup>6</sup>

- There are approximately 83,700 carers up to the age of 25 years, which is 3.2% of this age cohort
- 11,600 (13.9% of young carers) are primary carers
- Young carers are just as likely to be male as female
- Just over 1 in 5 young carers live in a rural area
- Approximately 5% speak a language other than English at home
- Approximately 3% were born in a non-English speaking country

The SDAC does not report reliably on Aboriginal or Torres Strait Islander status, however other data sources indicate that up to 1 in 4 Aboriginal and Torres Strait Islander people living in NSW have caring responsibilities, which could amount to more than 35,000 Aboriginal and Torres Strait Islander children and young people.<sup>7</sup>

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<sup>6</sup> Australian Bureau of Statistics (2019), *Survey of Disability, Ageing and Carers, Australia: Summary of Findings, 2018*, Catalogue no. 4430.0, available online at: <https://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0>, last update 24 October 2019.

<sup>7</sup> ABS (2017), *National Aboriginal and Torres Strait Islander Social Survey, 2014-15*, Catalogue no. 4714.0, available online at: <https://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4714.0Main+Features100022014-15?OpenDocument>, last updated 19 February 2019; ABS (2018), *Estimates of Aboriginal and Torres Strait Islander Australians*, Catalogue no. 3238.0.55.001, available online at:

Young carers vary considerably in terms of age, from young children, to teenagers, to young adults. Many research projects and capacity building programs specify a particular age range of children and/or young people, often for ethical purposes, since parental permission may be required under the age of 16 years, or in some cases 18 years. ABS data on young carers generally starts at age 15, which means that younger carers are excluded from these estimates.

Young carers are often 'hidden', meaning that they are less likely than older carers to realise they are a carer, or to tell others that they are a carer, or to be recognised by service providers as a carer.<sup>8</sup> For this reason, data on young carers is even more likely to underestimate the true young carer population.

## Know your audience

Before setting out to engage with young carers, a key step is to find out about the group(s) you plan to focus on. This can be achieved with some initial desktop research and informal conversations with service providers and community contacts. Some useful questions to consider are included below:

- **Which age group(s) would you like to engage with?**

It is important to ensure that the data sources and service options you consider fit with the age group(s) you have in mind. You may also need to consider whether the age group(s) you would like to engage with will require parental consent to participate.

- **Where do those young carers live?**

Young carers in different parts of Sydney, or different regions of NSW, may have very different demographic and other characteristics. Service systems can also differ greatly in different areas. Narrowing down your project or engagement to one or more specific areas may limit engagement on the one hand, but may also allow you to be more targeted in your engagement, as you can find out more about local demographic characteristics and service landscapes, and link into local networks that may assist you to reach young carers.

- **Where do young carers spend most of their time?**

Many young carers, especially those under the age of 18 years, spend most of their time outside of their caring responsibilities attending school and participating in related activities. Among young carers over the age of 18, some may be engaged in higher education, some in paid work, and others unemployed or outside the labour force due to their caring responsibilities. Knowing this will help you narrow down how to access the young carers you would like to engage with.

- **What support networks are young carers already engaged with?**

Although many young carers are not recognised by their schools, communities and service providers, they may still have contact with services relating to their caring role through which you could reach them. Understanding who they are likely to be caring for may help you to work this out, e.g. if caring for a sibling with a disability, a youth-focused disability service may be a useful contact point. Young carers who recognise themselves as carers may be connected with young carer groups and supports. Knowing how 'hidden' the young carers you

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<https://www.abs.gov.au/statistics/people/aboriginal-and-torres-strait-islander-peoples/estimates-aboriginal-and-torres-strait-islander-australians/latest-release#data-download>, last updated 31 August 2018.

<sup>8</sup> Carers NSW (2019) *Policy Statement: Young Carers*, available online at: <http://www.carersnsw.org.au/Assets/Files/Young%20Carers.pdf>

are seeking to engage with are likely to be will help you to tailor the language and communication channels you use. See page 14 for more information on language use.

- **Do you need to start from scratch?**

If you work for an organisation such as Carers NSW that already runs projects and events with young carers, consider whether existing networks, contact lists or programs may be able to assist you to engage with young carers ethically and efficiently before you broaden your search.

A useful starting point for answering these questions may be population statistics relating to young carers. The best sources of information on the number, characteristics and geographic distribution of young carers are:

- The Australian Bureau of Statistics 2018 Survey of Disability, Ageing and Carers (SDAC) – key results can be viewed and downloaded online at: <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/2018>
- The Longitudinal Study of Australian Children (LSAC) – key results can be viewed and downloaded online at: <https://growingupinaustralia.gov.au/research-findings/annual-statistical-report-2016/young-carers>
- The Australian Bureau of Statistics 2016 Census of Population and Housing – key results can be viewed and downloaded online at: <https://www.abs.gov.au/ausstats/abs@.nsf/mf/2071.0>

These sources however, have very different estimates of the total number and percentage of the population, who are young carers. This is due to the different ways in which they define caring, and the different numbers of children and young people they engage with. It is often necessary to cross-check different sources to get a realistic estimate.

## Young carers are diverse

Children and young people who are caring for a family member or friend can vary greatly in age and stage of life, as well as a number of other personal characteristics, such as cultural background, sexual orientation, gender identity, ability and type of caring responsibilities. These differences are important to recognise both in order to ensure you are approaching the right group(s) of young carers in the right ways, and in order to ensure that you capture the diversity of young carers in your project. It may also be important to establish whether a young carer wants to be identified based on these characteristics, in order to protect their privacy and confidentiality.

When seeking to engage with specific groups of young carers, or a wide and diverse range of young carers, it is necessary to consider that groups like culturally and linguistically diverse (CALD) young carers, Aboriginal and Torres Strait Islander young carers and LGBTQI+ young carers may face additional barriers to identifying as young carers, and accessing support networks. This may make them more challenging to reach.

Another consideration when engaging with diverse young carers is that speaking to a researcher with similar characteristics or background, where possible, may help young carers to feel safer when sensitive subjects relating to the caring role are being discussed. For example, a female may prefer to speak to a female, or a young carer from a particular cultural background may feel more comfortable with someone else from that background. While this will not always be practical for staff conducting projects, or a priority for young carer participants, it should be considered during project planning and recruitment.

## Key principles for engaging with young carers

The following principles underpin the approaches and techniques outlined in this toolkit for engaging with young carers.

### Build trust and rapport

Building trust, rapport and affinity with young carers can be incredibly useful in securing their initial and ongoing engagement in research, consultation and capacity building activities. To achieve this, those involved in the project need to be approachable, friendly and patient. It is important to seek to understand and remember what the young carer says, and to respond accordingly. If you say you will do something, follow through; and do not promise something you cannot deliver on.

Paying attention to the experiences and expectations of young carers, and responding accordingly, can communicate mutual respect and support. Young carers often either repeat their story continuously in order to access support, or have never shared their story with anyone. In both scenarios, ensuring that their words are valued, believed and acted upon is important.

Some examples of how you could enhance your interpersonal skills for working with young carers include:

- **Practising active listening.** Pay close attention when a young carer is speaking to you and seek to understand their perspective, rather than giving advice. Reflect back to the young carer what they shared to ensure you have understood.
- **Using informal language.** Whether having a conversation or communicating in writing online or in a flyer, using language that is conversational and free of jargon will make you more approachable. There is no need to use youth-specific language, just plain English and a conversational tone.
- **Being up-front.** Honesty and openness enhance trust. It is important to explain clearly early on who you are, why you would like to engage with them, how (if at all) they will benefit from participating, and what requirements and risks may be involved.
- **Giving as well as taking.** A young carer may be taking time out from other responsibilities to participate in your activity, and sharing their story with you may take an emotional toll on them. Ensure you are ready to reciprocate in appropriate and transparent ways, such as by providing information about services, linking them to practical support and providing some form of reimbursement.

### Be carer-aware

Engaging effectively with young carers requires an understanding and appreciation of the caring role, and in that way differs from mainstream youth engagement. If carer engagement is not your organisation's core business, developing your knowledge about carers will help you to reach, and connect with young carers.

Some examples of how you could improve your carer-awareness include:

- **Reading about carers' experiences.** For example, on the [Carers NSW website](#), [Carer Gateway website](#), or in other published reports or articles.
- **Talking to carers and people who work with carers.** Most people know at least one family member or friend who has a caring role. Speaking with them respectfully may help you to

understand the rewards and challenges of caring. Organisations that work with carers, such as Carers NSW, may also be able to provide you with information.

- **Participating in formal education and training opportunities about carers.** [Carers NSW Education and Training team](#) delivers regular, free training on carer awareness and a range of topics relevant to carers. [Carers NSW Young Carer team](#) also works with schools, youth-focused service providers and other service provider to improve their carer awareness. The free online course, '[Identifying and Supporting Young Carers](#)' may also be of interest.

## Be inclusive

When engaging with young carers be sure to take into account the many barriers young carers can experience accessing services, and seek to minimise these wherever possible. Planning for and responding to the varying knowledge, confidence, resources and experience of different young carers will enable you engage more successfully.

Some examples of how you can ensure you are inclusive include:

- **Providing multiple options for how to participate.** For example, face-to-face and online engagement options; anonymous and identified participation options; and interactive and more passive participation options.
- **Providing opportunities for young carers to identify their needs and preferences.** When registering young carers to participate in your project, include questions (where appropriate) such as: whether they need financial assistance or replacement care for the person they care for in order to attend, whether they have physical access requirements and/or need an interpreter, or whether there is anything else that might help them feel comfortable and supported.
- **Respecting their time.** Young carers are often very busy due to balancing their caring responsibilities with their education or employment, as well as maintaining a home and social life. Many young carers also have very fixed availability when participating in education, extracurricular activities or paid employment. Children and young people often do not have much control over their schedules. It is therefore important to ensure that you offer appropriate and flexible times to participate and limit the time inconveniences on young carers.
- **Recognising that things might come up.** Many young carers sign on to participate in something but at the last minute are no longer able to attend due to a change in their caring responsibilities or other circumstances. Make sure young carers are aware there is flexibility and understanding, if things change at their end.
- **Communicating in age-appropriate ways.** Ensure all documents and resources are written at an appropriate level for the particular age group(s). In formal research, a particular score may be required by Ethics on the documentation submitted, to ensure they are written at an age-appropriate level. The '[Flesch Kincaid readability tool](#)' provides guidance on this. See pages 12-13 for more information on age-appropriateness.
- **Prioritising cultural safety.** To ensure that CALD and Aboriginal and Torres Strait Islander young carers are included, ensure that interpreters, translators and/or bilingual workers can be engaged where appropriate (see *Engaging with CALD carers: A guide* for further advice on this), ensure that diverse backgrounds are openly valued and discussed within the project, and seek input from trusted community leaders and individuals within the relevant communities when developing your project and recruiting participants.

## Be flexible

Engaging with young carers successfully requires a growth mindset that allows you to be adaptive in the face of challenges and change, and responsive to feedback and new information. It also requires self-awareness and self-reflection to inform continuous improvement.

Some examples of how you can ensure you are being flexible include:

- **Planning for generous timeframes.** Working with children and young people can be unpredictable, and caring responsibilities can add even more complexity. Ensure you include plenty of additional time when planning your project milestones to ensure that at each step of the project you can adjust your approach if needed.
- **Scheduling regular reflection.** Schedule regular meetings with all involved in the project, to learn and share successes and challenges about current engagement approaches.
- **Enabling ongoing feedback.** Asking the young carers you are engaging with how they are finding the process, and offering a range of opportunities to provide feedback, will help you to assess whether your approach is working.

## Be ethical

When working with any vulnerable group, especially children and young people, ethical practices must be paramount. It is important to be aware of your organisation's policies and procedures, and your obligations in relation to legislation and best practice frameworks. For research projects, specific additional ethical requirements may apply. Working with children under 16 years, can also carry additional complexities.

The National Statement on Ethical Conduct in Human Research lays out merit and integrity, justice, beneficence, and respect as the four guiding principles for ethical conduct. These principles should be incorporated in any research activity and applied to any program, project, or evaluation.

Principle	What does it mean?	How could we implement it?
Merit and integrity	The merit of the expected project outcomes, the appropriateness of the chosen methodology or approach, and the skill and conduct of the staff delivering the project.	Using the <i>Engaging with young carers: A checklist</i> tool in developing the project and supplementing this with a checklist that refers specifically to the relevant policies, procedures and frameworks in your organisation or field.
Justice	The fair recruitment and treatment of participants as well as the fair distribution of benefits and outcomes of a project.	Clearly outlining expectations and possible risks in communicating with participants, providing all participants with equal opportunity and remuneration (where applicable).

Principle	What does it mean?	How could we implement it?
Beneficence	The project should work to benefit the group(s) involved in some way, and the costs of participating need to be outweighed by its benefits for those involved and the community/ies they represent.	Being outcome-focused in developing the project, embedding evaluation that seeks feedback from participants about their experience, incorporating some form of reumeration or recognition for participants (where applicable), and communicating clearly the anticipated benefits for individual participants and their communitie/es during recruitment.
Respect	Having due regard for the welfare, beliefs, perceptions, customs and cultural heritage of participants, as well as their privacy and confidentiality.	Using the <i>Engaging with CALD carers: A checklist</i> tool when working with CALD young carers. Also treating personal information confidentially for all young carers, and removing identifying information from project reporting wherever possible.

## Young carer engagement: Practical tips

### Legal requirements

Any person in NSW who intends to work or volunteer with children and young people is required to obtain a Working With Children Check (WWCC). This involves a National Police Check (criminal history record check) and a review of reportable workplace misconduct. A WWCC is valid for 5 years, however applicants are continuously monitored.

If applying as a paid employee or someone who is self-employed, there is a fee for the WWCC. If applying as a volunteer, a student or for a professional placement, there is no payable fee. Applicants can visit the [Service NSW website](#) or visit their local Service NSW branch.

Other states and territories in Australia, and other overseas jurisdictions, will have similar systems in place, however the details may differ. If you are not sure what the requirements are where you are working, contact a government agency or other organisation that works directly with children and young people for advice.

### Working with schools

In NSW, conducting research in schools must be approved through the State Education Research Applications Process (SERAP). It is important to allocate adequate time in your project plan to accommodate this process if you aim to work with school aged young carers. It will take time to prepare the required content and can take up to six weeks from the date of submission to receive notice of the final decision. Proposals which have been rejected may be revised and submitted as a new SERAP application, which may take additional time. More information about this online application process is available on the [SERAP online portal](#).

School staff are bound by their Principal's approval to promote external projects involving students, and approval is generally more likely if the project also has formal ethics approval. Building relationships and trust with a particular school, or schools, over time may also allow for greater engagement by school staff and families in supporting the project. Having trusted Departmental personnel who liaise directly with school staff (e.g. through Principal Network meetings, wellbeing networks) may also be valuable for longer term engagement.

### Age-appropriate activities and communications

As noted earlier in this guide, it is important to be aware of the diverse contexts of specific age groups, especially the difference between school-aged children (up to 16 years), school-aged young people (16-18 years) and post-school aged young people (19-25 years). These three cohorts can vary considerably in relation to characteristics such as literacy and numeracy skills, hobbies interests, education and employment status.

While it is not helpful to stereotype different age groups, these differences need to be considered and explored when developing and delivering a project, as activities and communications that may be engaging and appropriate for one group may be unappealing or uncomfortable for another. For example, using a specific social media platform may attract a younger or older age group of young carers; and specific colours and imagery may appeal to a younger or older age group.

Consulting with staff and organisations who have current experience working with these age groups will help you identify these differences, as will speaking to children and young people in the target age groups themselves. Youth culture tends to change over time, so insights should be as up to date as possible to support effective engagement.

Another consideration when engaging specific age groups is the upper limit of the young carer definition. While 25 years of age is the cap, it may be beneficial to be flexible with this in your recruitment if you wish to include insights of recent young carers, whose experiences may still be very relevant.

Conversely, if it is important to maintain the cap of 25 years – or 18 years in projects focusing on school age young carers – consideration should be given to the duration of involvement in the project and whether participants may ‘age out’ before it is completed.

Questions to ask when determining the age-appropriateness of project activities and communications include:

- What does this age group spend the majority of their time outside of the caring role doing? E.g. school, work, higher education.
- Where does this age group gather (in person and virtually) with their peers?
- Where and how does this age group seek support or advice?
- What level and type of language is relevant and appealing to this age group?
- What kinds of images and graphics are familiar and appealing to this age group?

## **Giving young carers a voice**

Young carers themselves are the leading experts in their own interests, preferences and support needs, so they should ideally be included in a project from the beginning to the end. Involving children and young people in the design and development of a project, as well as in the delivery and evaluation of the project, is a key way of ensuring that your project is a success and seen by young carers as representative of their experiences. Ensure an interpreter is available where required in order to include young carers from CALD backgrounds.

Consider whether it may be possible to establish, or tap into, a youth network with whom you can consult and check ideas and plans to ensure they are age-appropriate. Possibilities for this include:

- Recruiting and upskilling young clients and/or staff in your organisation for this purpose
- Setting up a Project Advisory Group that includes one or more young carers from within your networks
- Tapping into existing youth forums and advisory groups convened by your local council, local health district or a youth-focused agency such as the Advocate for Children and Young People (ACYP)
- Working with Carers NSW to engage young carer Carer Representatives – specially trained volunteers aged 18 years and above who are provided with a sitting fee for such opportunities

Young carers could be engaged to review project plans and materials, engage participants through their own personal networks, provide feedback on the results and reporting, and help evaluate the delivery of a project. They may even be involved in co-authoring and co-presenting project findings.

Young carers who are involved in these capacities should be formally recognised and/or rewarded for this contribution where appropriate, such as through a certificate of participation, written acknowledgement in a report or a sitting fee or gift, within organisational guidelines.

## Remunerating participants

Young carers are often balancing a range of responsibilities and their time is valuable. Providing an incentive (e.g. gift card) or some form of sitting fee, where appropriate, is a key way to recognise their time and acknowledge the value of their contribution. Where such reward or remuneration is included, documentation, fair process and internal approval is particularly important.

Any costs involved in participation, such as travel, telecommunication costs or meals, should also be reimbursed to prevent any unnecessary barriers to participation or embarrassment for young carer participants.

## Using plain language

Young carers who do not identify as carers can be the most challenging to reach. They may be isolated, busy or experience other barriers due to their caring responsibilities. They may also fear stigma and exclusion if they disclose their caring role, and be daunted by the potential emotional impact or distress of discussing the challenges of family life.

One key way of reducing these barriers is in choosing language that is not carer-specific. The term 'carer' or 'young carer' may not be recognisable to all young carers. Flyers and other promotional materials can therefore be more effective using plain language that focuses on specific tasks and relationships. For example, instead of 'Are you a young carer?' a tagline like 'Do you help look after your brother or sister?' or 'Do you help Mum and Dad around the house?' may resonate more.

## Leveraging existing networks

Another way of reaching hidden young carers is through tapping into existing services and networks (young carer specific and more general) where trust and connections have already been established. Examples include:

- Carer organisations that work with young carers such as Carers NSW and other Carer Gateway Service Providers
- Young carer networks and support groups run by NGOs and local councils
- University student welfare departments, clubs and associations
- Local Health District Carer Program teams
- Youth services such as PCYC, YMCA and YWCA
- Networks, services and interagencies that focus on women or men, gender and sexuality diverse groups, CALD communities, Aboriginal and Torres Strait Islander communities
- Chemists, pharmacies and GP networks
- Community centres, libraries and other local council facilities
- Religious groups and networks
- Recreational and sporting clubs, teams and venues

While community contacts and service staff can provide great opportunities to connect with young carers, strategic and persistent engagement is required, as many are busy and under-resourced.

These 'gate keepers' to young carers can also be understandably protective of the children and young people they work with, and may be reluctant to provide access to a new team or organisation.

Building trust over time by keeping in contact providing information, resources and support to assist them in their work will make them more likely to assist. Some may also need more information and/or training about young carers in order to understand the importance of the project.

### **Involving experts and champions**

A key way to ensure that contacts and partners understand the project and are committed to assisting with promotion and delivery is through involving them in design and/or implementation. Some projects are well suited to a project advisory group or steering committee that includes representatives from key sectors and fields that relate to your project. Inviting individuals and organisations with direct access to young carers in the project from the beginning will likely give them a sense of ownership and encourage them to provide active feedback and support.

Be sure to set expectations clearly from the beginning of the project regarding what they are expected to contribute, how often (if at all) they will be expected to attend meetings and whether there will be any reciprocal support or remuneration as a result of their involvement. It is also important to acknowledge and involve them in reporting and dissemination of findings.

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