



Carers ACT response to ACT Community Services Directorate

Community Consultation

What is important for children and young people in Canberra?

June 2014

Carers ACT acknowledges that modern day Canberra has been built on the traditional lands of the Ngunnawal people. We offer our respects to their Elders past and present, and celebrate the Ngunnawal people's living culture and valuable contribution to the ACT community.

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Who is Carers ACT?

Carers ACT is a non-profit, community-based, incorporated association and registered charity dedicated to improving the lives of the estimated 43,000 carers living in the Australian Capital Territory.

These carers provide ongoing unpaid care for people with disabilities, mental illness, chronic conditions, who have palliative care needs, or who are aged and frail. Carers ACT currently provides direct support to around 8000 families through our counselling, information, respite support, education, social support and case coordination services. We continue to meet national accreditation standards for delivery of our services to carers at a high level.

Carers ACT has a constitutional mandate to represent the voices of carers to government and the wider community. We actively consult with a wide diversity of caring families on an ongoing basis to enable improved understanding of their needs, and enable better inclusion for them and the people they care for. Policy work in consultation, research and representation is kept separate from service delivery to ensure that the privacy of individual service recipients is respected. All carer participation in policy work is voluntary.

Carers ACT is a member of the National Network of Carers Associations, and works actively with other States and Territories to share knowledge and facilitate improved health and wellbeing outcomes for caring families.

Contents

1. Summary of recommendations	3
2. Introduction	5
3. Children and young people with a caring role in their family.....	7
4. Children and young people with a disability.....	15

1. Summary of recommendations

Carers ACT's recommendations in its response to the ACT Government's community consultation on *What is important for children and young people in the ACT?* focus on children and young people with a caring role, and children and young people with a disability. Appropriate, timely and responsive support provided to individuals with a disability, mental illness or chronic condition that also incorporate a whole-of-family approach will influence future health, social and economic wellbeing for children and young people in the ACT living in caring families.

Recommendation 1

Carers ACT recommends that the ACT Government includes an indicator in its key frameworks to identify their responsiveness in supporting children and young children with a caring role in the ACT through a family-centred and whole-of-government strategy. This strategy should address:

- How we raise awareness of children and young people with caring responsibilities to provide responsive early intervention through the Our Human Services and children and young people's plans.
- What training and assistance we provide for staff and service providers to identify vulnerable children and young people in families where a parent or sibling has a disability, mental illness or chronic condition so that appropriate family-centred services can be put in place to provide necessary support to increase the health and wellbeing of the family.
- What timely information and referral pathways we provide to improve support to young carers and their families, including unmet needs for home help, respite, transport and age- and culturally-appropriate young carer services.
- How we improve support for young carers entry into and during post-school training, further education and employment.
- How do we identify the specific support needs of young carers and their families whose circumstances and concerns may not be appropriately addressed, including young people of Indigenous and Culturally and Linguistically Diverse backgrounds, with the launch of the ACT NDIS trial on 1 July 2014.

Recommendation 2

Carers ACT recommends that the ACT Government regularly monitor its key human services and children and young people's plans for their responsiveness in supporting families of children and young people with a disability or mental illness in the ACT through a family-centred and whole-of-government strategy. This strategy should address:

- How we raise awareness of children and young people with disability to provide responsive early intervention through the Our Human Services and children and young people's plans.
- What training and assistance we provide for staff and service providers to identify families with children and young people with disability that have not been identified for referral to

the ACT NDIS trial and its assessment process and to support their appropriate referral and assessment.

- What timely information and referral pathways we provide to improve support to children and young people with disability and their families, including unmet needs for home help, respite, transport and culturally-appropriate services.
- How to identify the specific support needs of children and young people with disability and their families whose circumstances and concerns may not be appropriately addressed, including young people of Indigenous and Culturally and Linguistically Diverse backgrounds, with the launch of the ACT NDIS trial on 1 July 2014.

Extract from the ACT Children's Plan 2010-2014 p.9

Childhood and adolescence matter – Childhood and adolescence are critical periods of life where children's growth and development becomes the foundation for the rest of their lives.

The pathway from childhood, adolescence through to adulthood includes a series of changes and transitions. It is a period of enormous physical, behavioural, cognitive, and emotional growth and change.

Childhood is much more than just the pathway to becoming a competent and achieving adult. It needs to be a time for nurturing, love, play, learning, enjoyment, experimentation and risk-taking.

Parents, carers and families matter

– The environments in which children grow and the quality of the relationships they have are fundamental for children's healthy development and wellbeing.

Parents and families are central to children's lives and provide the most powerful influence and primary source of nurturing, support, connection, security, and assistance for children.

The support a family receives from their extended family and community is vital. We need to value parents and give them the support and resources they need to raise children.

2. Introduction

Carers ACT welcome the opportunity to respond to the ACT Government community consultation on *What is important for children and young people in the ACT?* to set a vision for a whole-of-government and whole-of-community approach to promote the rights of children and young people.¹

Carers ACT is the key organisation in the ACT providing specialist carer support services to the 43,000 carers in the ACT. We support carers through referral to services; provision of advocacy, counselling, information, respite, support, education and social support; and case coordination services. Our engagement with the many carers who have accessed our services over a period spanning more than 21 years and our membership of the National Network of Carers Associations, have provided us with an evidence-based understanding of, and insights into, the interests and concerns of Australian carers.

Accordingly, our response to this community consultation will focus on children and young people who have a carer role in their family, and on children and young people with disabilities. It is important to note that children and young people in a household where a parent has a disability or mental illness are at higher risk of disadvantage than their peers who are not in this situation.² They will also benefit from timely, holistic family support programs during their early life stages.

Similarly, carers of children or young people with disability can also experience disadvantages, including reduced employment opportunities, financial disadvantage and poorer health and wellbeing than non carers.

The definition of 'carer' used in this submission accords with the *Carer Recognition Act 2010* (Commonwealth) which states that:

(1) *For the purpose of this Act, a **carer** is an individual who provides personal care, support and assistance to another individual who needs it because that other individual:*

(a) *has a disability; or*

(b) *has a medical condition (including a terminal or chronic illness); or*

(c) *has a mental illness; or*

(d) *is frail and aged.*³

(A young carer is defined as a child or young person up to the age of 25 years old who provides informal care for a family member or another person with a disability, mental illness, drug or alcohol dependencies, chronic condition or who is aged.)

¹ ACT Government (2014) *Have your say on what is important for children and young people in the ACT*. Accessible at <http://www.communityservices.act.gov.au/home/what-is-important-for-children-and-young-people-in-the-act>

² Productivity Commission (2013) *Deep and Persistent Disadvantage in Australia: Productivity Commission Staff Working Paper*. Accessible at <http://www.pc.gov.au/research/staff-working/deep-persistent-disadvantage>

³ Commonwealth Government (2011) *Carer Recognition Act 2010 (Cth)*. Accessible at http://www.comlaw.gov.au/Details/c2010a00123/Html/Text#_Toc276377311

Carers ACT also acknowledges the *ACT Government Carers' Charter* that recognises the vital role that carers have in the lives of people they care for, raises awareness about the contribution that carers make and supports the ACT Government's commitment to better acknowledge and respond to carers' needs.⁴

The key outcomes of three ACT Government's frameworks for children and young people below provide robust benchmarks that will determine the success of its intent 'that all children and young people in the ACT have the opportunity to reach their potential, make a contribution, and share the benefits of our community' in relation to the 11,500 ACT young carers;⁵ and over 3,000 children⁶ and young people with disability or significant development delay receiving support from the ACT Government.⁷

- The *Young People's Plan 2009–2014* – a plan to improve outcomes for all young people in the ACT aged 12 to 25 years. Its five key priorities are:
 - health, wellbeing and support
 - families and communities
 - participation and access
 - transitions and pathways
 - environment and sustainability.
- The *ACT Children's Plan 2010–2014* – a plan that focuses attention on the needs of ACT children aged up to 12 years and their families. Its six building blocks are:
 - opportunities for children to influence decisions about their lives and their community, and to actively participate in their communities
 - advocacy, promotion and protection of children's rights
 - processes to assess the impact of law, policy and practice on children
 - regular monitoring of the state of children's health, wellbeing, learning and development
 - services, programs and environments that support children's optimal development and enhance parental, family and community capacity
 - effective governance mechanisms across government and community.
- The *Human Services Blueprint* – a framework to ensure that Canberrans receive the right service, at the right time and for the right duration. It has three key strategic areas:
 - creating a better service experience

⁴ ACT Government (2011) *ACT Carers' Charter: Caring for carers*. Accessible at http://www.communityservices.act.gov.au/disability_act/family_friends_and_carers

⁵ Gays M (2002) *Lifetime of Caring: ACT Schools-based Young Carers Survey*. Research undertaken by Marymead Child and Family Centre indicates the number of young carers aged 15-25 years in the ACT is estimated at around 7,600, or 10% of ACT's young people. However, it is thought that this number is a substantial underestimation, and a more accurate number is around 11,500.

⁶ There were 3,170 children receiving services under ACT Therapy in 2011-2012. The number of young people with disability and development delay up to 25 years would increase this figure.

⁷ ACT Government (2013) *A Picture of ACT's Children and Young People 2013*. Accessible at <http://www.children.act.gov.au/publications.htm>

- improving economic and social participation, especially amongst disadvantaged Canberrans
- making services sustainable.

3. Children and young people with a caring role in their family

Who is a young carer, or a child or young person with a caring role^{8,9}

Children and young adults have always provided care for younger siblings, frail elderly grandparents, sick or parents with physical or psychosocial disability and other household members. However, the identification of ‘young carers’ for academic and social policy focus is relatively new (since the late 1990s in Australia). The National Network of Carers Associations was a key advocate for improved identification of young carers and their support needs.

The increased awareness of this population group by governments resulted in the provision of support programs (primarily through the national Young Carer Information and Respite Program¹⁰) and young carer research funds. However, there is still insufficient whole-of-government policy development or investment in specialist services¹¹ to make a significant reduction in the level of care provided by young carers. This is reflected in Australian and international research and young carer comments that indicate when a young carer’s family is not adequately supported by appropriate services young carers need to fill this necessary services and resources gap.

The annual economic contribution by carers in Australia in informal care to family members and friends is estimated at over \$40 billion.¹² While there is no figure for the economic value of care provided by young carers families, communities and governments gain significant benefits from young carers’ informal care by reducing the cost to families and governments of alternate residential and community care services, as well as contributing to the wellbeing and resilience of their family.

According to Access Economics young carers also make enormous sacrifices, giving up what can be millions of dollars of lifetime earnings in order to provide the care that their parents need.¹³

⁸ Some literature and organisation prefer the use of children and young people with caring responsibilities over the use of ‘young carers’ as young people and their families are more likely to recognise that they perform the role or activity of caring than take on the identity or label of ‘young carer’.

⁹ While there is discourse about whether being a young carer violates the human rights of children and young people our response is not addressing this issue, rather that children and young people with caring responsibilities need to be adequately supported through systematic program and policy development.

¹⁰ The intention of the Young Carer Information and Respite Program is to supplement existing programs, not to replace them.

¹¹ Ilsley B (2014) *Unfinished Business Public policy and children in families with a person with a disability or mental illness Discussion paper*, Carers Victoria. Accessible at http://www.carersvictoria.org.au/Assets/Files/cvic_discussion_paper_unfinished_business_march14_online.pdf

¹² Access Economics (2011) *The economic value of informal care in Australia, 2010* for Carers Australia. Accessible at <http://carersaustralia.com.au/storage/Economic-Value-Informal-Care-Oct-2010.pdf>

¹³ Access Economics (2011) *ibid*

Young carers in the ACT

An accurate number of young carers (children and young people with a caring role aged 25 years and under) in the ACT is difficult to obtain. Some data collections have statistics on the number of people aged 15-25 years who are defined as young carers, but it is understood and known that there are children under 15 years who are providing a caring role in the ACT.¹⁴ For example, Carers ACT provides young carer support to 58 children aged 6-10 years.

Literature also refers to ‘potential young carers’:

... These are young people living in a household with a child or adult with a disability, long-term health condition or impairment, which is ongoing and restricts everyday activities, and hence, may be involved in the care or support of that person or may have more intangible responsibilities ... These young people may not have identified as a carer for two reasons: first, they may not have self-identified as carers themselves; or second, they may provide support and assistance for activities other than the core activities of self-care, communication and mobility.¹⁵

In Australia, the majority of young carers (89%) live in the same household as the person as the person they care for. They are more likely to be caring for a parent (65.9%) and more often this will be a lone parent mother.¹⁶ This occurrence is considered the direct result of a lack of available informal care from other adults in sole parent families, either for the parent who may have a disability or other children in the family with a disability.¹⁷

Carers ACT services data indicates that 62 per cent of young carers it provided support to cared for a parent, 31 per cent cared for a sibling and 5 per cent cared for both a parent and sibling. Seventy per cent of young carers supported by Carers ACT also live in a family with at least one other young carer. In this situation, the older child normally adopts the primary carer responsibility for a parent, and caring for a sibling is normally shared with a parent.

The impact of caring on children and young people

In 2009, the former Australian Department of Families, Housing, Community Services and Indigenous Affairs commissioned the Social Policy Research Centre, University of NSW to prepare a report on current knowledge of this little recognised or ‘hidden’ group. It discovered that care being provided

¹⁴ In 2012, there were 74,800 carers under 15 years and a further 231,200 carers aged 15 to 24 years, making up 2.8% and 8.6% of all carers in Australia. For carers under 15 years, 45.2% were males and 53.2% were females. For carers aged 15 to 24, 49.3% were males and 50.4% were females according to Australian Bureau of Statistics’ *Caring in the Community, Australia, 2012* released 25 June 2014. Accessible at <http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4436.0Main%20Features22012?opendocument&tabname=Summary&prodno=4436.0&issue=2012&num=&view=#Chapter2>

¹⁵ Australian Government Department of Social Services (updated April 2014) *Young carers in Australia: understanding the advantages and disadvantages of their care giving*, SPRC Research Paper 38. Accessible at <http://www.dss.gov.au/about-the-department/publications-articles/research-publications/social-policy-research-paper-series/number-38-young-carers-in-australiaunderstanding-the-advantages-and-disadvantages-of-their-care-giving?HTML#analysis>

¹⁶ Australian Bureau of Statistics (2009) *Survey of Disability Ageing and Carers*

¹⁷ Australian Government Department of Social Services (updated April 2014) *ibid*

by young people was widespread and that the impacts of providing care without support were often significant. Other studies and reports also identify that caring can disadvantage young carers, including their future outcome.^{18,19} Disadvantages affecting young carers, or children and young people with caring responsibilities include:

- They are more likely to live in households with low incomes that experience financial disadvantage.^{20,21}
- There can be an adverse effect on school retention, and entry into post-school education, that also impacts on their employment opportunities.²²
- They and their family are at risk of child protection services intervention if insufficient family-centred supports exist.
- Depending on their caring responsibilities and lower household income participation in friendship networks, social, sporting and other recreational activities, with resultant impacts on social connectedness and personal health and wellbeing are reduced.
- Young carers can also experience stigma because of their caring role, or living in a household with a parent or sibling who has a disability or mental illness.
- Young carers can be at risk of mental illness, including depression associated with their caring role and family financial disadvantage.

Young carers and education

A Carers Australia 2013 report states that carers aged 15-24 years are less likely to participate in study—at school, university or TAFE. It is estimated that approximately 40 per cent of young primary carers participate in study compared to approximately 60 per cent of young people who are non carers. Young carers aged 19-24 years are less likely to have completed Year 12 or equivalent (66%) compared with non carers of the same age. They also had low satisfaction with their opportunity to participate in higher education,²³ and once young carers had completed their caring role only a small proportion undertook further education.²⁴

¹⁸ Ilsley B (2014) *ibid*

¹⁹ Institute of Child Protection Studies (2010) *Exploring the needs and support of young adult carers living in the ACT*, for Carers ACT. Accessible at www.carersact.org.au

²⁰ In 2012, 59.6% of carers aged less than 15 years and 52.8% of carers aged 15 to 24 were residing in a household with equivalised gross household income in the lowest two income quintiles according to Australian Bureau of Statistics' *Caring in the Community, Australia, 2012* released 25 June 2014. Accessible at <http://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4436.0Main%20Features22012?opendocument&tabname=Summary&prodno=4436.0&issue=2012&num=&view=#Chapter2>

²¹ Although Canberra households are considered to have higher household income than other jurisdictions the ACT Government has identified that there are gaps of disadvantage and marginalisation can be amongst its relatively affluent communities. From its *Community Services Directorate Discussion Paper: Towards One Human Services System with you at the centre*

²² Australian Bureau of Statistics (2014) *Caring in the Community, Australia, 2012* *ibid*

²³ Carers Australia (2013) *Young Carers in Tertiary Education*. Accessible at www.carersaustralia.com.au

²⁴ Bray JR (2012) *Young carers in receipt of Carer Payment and Carer Allowance 2001 to 2006: characteristics, experiences and post-care outcomes. Occasional Paper no.47* Australian Government Department of Families, Housing Community Services and Indigenous Affairs. Accessible at <http://www.dss.gov.au/about-the-department/publications-articles/research-publications/occasional-paper-series/number-47-young-carers-in->

The needs of young carers

The needs of young carers are varied and depend on their particular family circumstances. Young carers tell Carers ACT and researchers that one of the best ways to assist them is for their family, including the person with a disability, mental illness or chronic condition, to be better supported through relevant services (including income support). This means that governments and service providers need to consider both the needs of young carers and the support needs of the family member(s) with a disability or illness concurrently. Unfortunately, these supports are often in separate programs and delivered by different service providers, and have different assessment requirements and program eligibility.

Carers ACT strongly believes that to achieve the intent of the ACT Government’s conversation with children and young people, strategies to incorporate a whole-of-family or One Human Services approach are paramount.

Carers ACT programs for young carers encompass services to support the young carer and their family:

- information and referral
- flexible respite including assistance with tutoring, school camps, driving lessons and personally tailored support in their caring role
- counselling and support groups
- intensive case management for young carers at risk
- where relevant, referral to services (such as Home and Community Care and disability services) to better support their family.

Table 1. A checklist about the status of many young carers in the ACT

What do you think is important for children and young people in Canberra?	
From ACT Government, Time to Talk, Question 1 in Developing a Commitment to Children and Young People Survey	
All Canberra children and young people	Evidence-based reality for many Canberra young carers
Being treated equally and fairly, and supported to exercise my rights	The lack of understanding about the needs of young carers and their needs for family-centred early intervention, young carers can face inequality and unfairness at school and ability to access support programs, and with little support to exercise their rights
Being cared for	Even though young carers indicate their caring role can strengthen their relationship with the parent they care for they can have responsibilities, including caring for siblings, that non carer peers

	don't experience. There can also be lack of self-identification as a child if their parent has reduced capacity to provide a meaningful parental caring role
Feeling safe and protected	The family vulnerability of some young carers mean they fear intervention of child protection services, as well as sometimes the need to manage challenging behaviour of siblings with disability, or parents with disability, mental illness or alcohol and drug issues
Being informed, participating and having my opinions heard	In relation to their caring role young carers often indicate this is not the situation, even though they have a key responsibility as a member of the care team
Being able to choose and practice my beliefs, culture, language and/or faith	Some young carers in an Indigenous or culturally and linguistically diverse family do not have access to culturally sensitive and responsive services and support
Being able to choose my friends and to play	Young carers can face stigma at school and social isolation. They indicate it is sometimes difficult to have friends to their house or develop friendships and participate in recreation because of stigma about being a carer or having a family member with a disability or mental illness. (However, they also say that school can be a place to be with friends as well as providing a break from caring)
Having privacy	For some young carers their caring responsibility and family composition may restrict them enjoying their own privacy at a level enjoyed by non carers
Having extra care and support so that I may live a full life	This is not always the experience of many young carers because of the constraints of their caring role, household composition and lower household income, and lack of awareness of their caring role
Having my basic needs met (e/g food, clothing, rest and a safe place to live)	Many young carers live in households with financial disadvantage that can reduce access to these basic needs ^{25,26}
Having access to health care and an	Young carers are at risk of poor mental health and

²⁵ Carers ACT Young Carer Program staff reported that some young carers they support are at risk of homelessness.

²⁶ Nationally, a small number of young carers (10,931, with 213 young carers in the ACT) receive Australian Government carer income support. The majority receive the Carer Allowance = \$118.20 per fortnight – see Bray RJ at footnote 24. Recent media coverage suggests that young carer income supports are at risk. Carers Australia is currently negotiating with the Australian Government about the impact of its budget announcements on New Start and Youth Allowances and employment in relation to the needs of young carers.

environment that helps me stay well	physical wellbeing because of their caring role ²⁷
Having extra care and support so that I may live a full life	Many young carers do not enjoy this opportunity as a consequence of their caring role and, or, financial disadvantage and their family household composition ²⁸
Accessing quality education and learning opportunities that help me to develop my talents and abilities	Not all young carers are able to enjoy this opportunity due to their consequences of caring role and family circumstances even though many aspire to higher education ²⁹

Although our response to this conversation focusses on the vulnerability of children and young people who have a caring responsibility **not all individuals** in this population group are vulnerable. Also, the vulnerability of each young carer will be determined by their household composition, extended family and friends and their household's income status.

A discussion paper by Carers Victoria – *Unfinished Business* – states that:

Many young carers **are not vulnerable** and additional attention from services of the protective kind may be unwarranted and counterproductive. On the other hand, service system improvements that identify and support more children who experience negative impacts associated with caring would be most welcome. Currently, young carers are all too often hidden from child and family welfare services. Consistent with previous discussions, parental disability or mental health problems may be better candidates for triggering offers of support – if services are able to be both child-centred and family-focussed.³⁰

It is also important to acknowledge that young carers associate benefits with their caring role – including closer relationship with the parent they are caring for, increased life skills because of their responsibility for household and personal care tasks, and the knowledge that they are providing assistance to support or maintain the cohesion of their family unit.

Importantly, a 2013 report from the Productivity Commission stated that while some evidence suggests that what distinguishes high risk children from other children is not exposure to a specific risk factor, but rather a life history characterised by multiple familial disadvantages that span social

²⁷ Half of all lifetime mental health disorders emerge by 14 years of age and three quarters by 24 years of age, and these are likely to be related to stress and vulnerability to mental illness according Mission Australia's *Youth mental health report June 2014*. Accessible at <https://www.missionaustralia.com.au/research-page/young-people-page?view=docman>

²⁸ Regular disposable income and low household income can influence access to sufficient housing, nutrition, medical care and impact a child's health, education and self-esteem, stated by the ACT Government in its *A Picture of ACT's Children and Young People 2013*, *ibid*.

²⁹ There is also a lack of awareness by teachers and other students of what caring entails, and this can create discrimination against young carers, as well as a lack of inflexible teaching practices a study of ACT young carers found.

³⁰ Ilse B (2014), *ibid*

and economic disadvantage this relationship is not deterministic – this is, that changed circumstances or opportunities can alter the outcomes for a child in this situation³¹.

Young carers and the National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) recognises that young carers are providing informal support for people with disability and psychosocial disability and has outlined provisions for their ongoing respite support:

- If you care for a person accessing government-funded disability or mental health programs, the provider of the program will tell you [young carer]³² when the National Disability Insurance Agency (NDIA) will be in touch to complete an assessment for participation in the scheme.
- If the person you care for becomes a participant in the scheme, supports [the young carer's] under the program can be included in their individual plan. You [the young carer] can then continue to seek supports from the Commonwealth Respite and Carelink Centres.
- If the person you care for is not receiving disability services, you [the young carer] can use the My Access Checker tool on our website to see whether they may be able to access assistance from the scheme.
- If you care for a person who doesn't become a participant in the scheme you [the young carer] will continue to have access to the program and receive your current level of supports.³³

Other guidelines for the NDIS include:

- If another system is responsible for a support, the scheme cannot fund that support, even if the system responsible does not provide it.
- Not stepping in to replace other systems is a critical principle of the scheme to ensure people with disability continue to have access to mainstream systems and the scheme is financially sustainable.

Carers ACT has provided data about clients caring for a person with a disability and psychosocial disability with potential eligibility for the NDIS, as have other agencies in the ACT. As the Young Carer Factsheet above indicates, the person being cared for by a young carer may not be receiving disability or mental health services or they may not be eligible for the NDIS. Carers ACT is concerned that there is a likelihood of unintended consequences from 1 July 2014 with the launch of the ACT NDIS and during its full rollout, and with the transfer of the majority of ACT disability services and funding to the NDIA. These include:

- Children and young adults caring for a parent with a disability or mental illness may not understand that the NDIS is being introduced and be aware that this may impact on any support services they and their family are currently receiving.

³¹ Productivity Commission (2013), *ibid*

³² Young carer inserts in italics are by Carers ACT.

³³ National Disability Insurance Scheme (2013) *Respite Support for Young Carers of People with Severe and Profound Disability program?* Accessible at <http://www.ndis.gov.au/document/657>

- The support that children and young adults caring for a parent and, or, a sibling with a disability or mental illness may not be fully understood by the NDIA assessor, particularly if a parent is reluctant to disclose the level of care and support they are receiving from their child or children.³⁴
- The likelihood of an increase in the number of children and young people not being identified by other agencies, or service providers, as needing whole-of-family support or individual support services if the person they support is not assessed by the NDIA, or referred to alternate services.
- The potential for increased vulnerability of children and young people in Indigenous and Culturally and Linguistically Diverse families because of the above factors, and cultural sensitivity of their family and community to discussing or disclosing disability or mental illness.
- The adequacy of ACT disability and mental health funding to provide an appropriate level of service delivery to families where the care recipient is not eligible for an NDIS package.

Recommendation 1

Carers ACT recommends that the ACT Government includes an indicator in its key frameworks to identify their responsiveness in supporting children and young children with a caring role in the ACT through a family-centred and whole-of-government strategy. This strategy should address:

- How we raise awareness of children and young people with caring responsibilities to provide responsive early intervention through the Our Human Services and children and young people's plans.
- What training and assistance we provide for staff and service providers to identify vulnerable children and young people in families where a parent or sibling has a disability, mental illness or chronic condition so that appropriate family-centred services can be put in place to provide necessary support to increase the health and wellbeing of the family.
- What timely information and referral pathways we provide to improve support to young carers and their families, including unmet needs for home help, respite, transport and age- and culturally-appropriate young carer services.
- How we improve support for young carers entry into and during post-school training, further education and employment.
- What tools we need to identify the specific support needs of young carers and their families whose circumstances and concerns may not be appropriately addressed, including young people of Indigenous and Culturally and Linguistically Diverse backgrounds, with the launch of the ACT NDIS trial on 1 July 2014.

³⁴ We know that some families and young carers fear the possibility of family breakup and alternate care arrangements for the children if authorities become aware of their family and household situation.

4. Children and young people with a disability

Supporting children and young people with a disability and their family

The majority of carers supported by Carers ACT care for a child, young adult or adult (this can be a partner or parent) with a disability or mental illness. Along with the need for independent supported living options as children grow into adulthood, the key concerns for parents of children and young adults with disability are their education pathway, employment and social engagement opportunities.^{35,36}

Carers ACT regularly consults with carers in the ACT and a recent client services evaluation found that:

Many parents of school-aged children with a disability want an education system that understands the demands of their caring role and the particular needs of children with a disability. They also discussed the role of schools in raising awareness about disability and carers. Frustrated by both the lack of resources for school children with disability and the inadequate training for teachers in the area of disability, carers noted both the immediate impact and the long term effects of an education system which leaves their children behind.³⁷

The ACT Government's *A Picture of ACT's Children and Young People 2013* includes an outcome for adequate family support services to meet the needs of parents with a child or young person with a disability through accessible Therapy ACT services and accessing coordinated locally based services through ACT's Child and Family Centres.³⁸ The government's rationale is:

Families with a child with a significant developmental delay or diagnosed disability are under significant stress. Support from therapists can assist children and young people to function more independently and assist families with additional strategies to best support their child.³⁹

This rationale is supported by Carers ACT findings from focus groups and conversations with carers, particularly in relation to the needs of their child and young adult during their schooling.⁴⁰ The *Better Support for Children with Disability Program* is an Australian Government initiative that was introduced in July 2011 in recognition that young children with disability would benefit from early

³⁵ Carers ACT (2012) *What Carers Want! 2012 Act Election Campaign*. Accessible at <http://www.carersact.org.au/what-carers-want>

³⁶ Carers ACT (2012a) *Annual Client Evaluation Report 2011-2012*. Accessible at <http://www.carersact.org.au/Assets/Files/External%20Client%20Satisfaction%20Report%202012.pdf>

³⁷ Extract from Carers ACT (2012a) *Annual Client Evaluation Report 2011-2012*, *ibid*

³⁸ Caring for a child or young person with disability can impact on the whole family, particularly siblings. These include the time parents spend caring, the cost associated with medication and special equipment or services, and the reduced opportunities for families to participate in activities if there is insufficient respite and other support.

³⁹ ACT Government (2013) *A Picture of ACT's Children and Young People 2013*. Accessible at <http://www.children.act.gov.au/documents/PDF/A%20Picture%20of%20ACT%20Children%202013.pdf>

⁴⁰ See Carers ACT (2009) *Review of Special Education Services in ACT Public Schools* for detailed discussion about issues relating to appropriate education and appropriate resources, including post school options. Accessible at http://www.carersact.org.au/Assets/Files/special-education-services-public-schools_2009-06.pdf

intervention support to assist their transition to education. In the ACT registration is coordinated by Carers ACT.⁴¹

For young children this early intervention approach for children with disability is critical to maximise this achievement, particularly by receiving the right support, at the right time and for the right duration.^{42,43}

In a 2012 Carers ACT study many carers stated that if they had the support of Carers ACT earlier in their caring role, they may have been better able to cope with the stress which they experienced.^{44,45} This reinforces the need for early assessment of children with disability and for early intervention services to consider the needs of the children or young adult with disability in their family context to ensure that a whole-of-family and whole-of-government support is provided.

Children and young people and the National Disability Insurance Scheme

With the launch of the ACT NDIS trial on 1 July this year, individuals, families, and the community anticipate that people with severe and profound disability, including children and young people will have personal, life-long support through their personal funding plans and improved links to the community.

Participants in the ACT NDIS trial will be phased in over the next two years, with:

- children 2-4 years to transition by the end of 2014
- young people with high and complex needs who left school between 2008 and 2013 to transition by the end 2014
- all school leavers with disability to transition by the end 2014
- primary and high school-age children with disability to transition in 2015.

The recent ACT NDIS Early Intervention Forum, on Monday 2 June, highlighted the concern of many parents and service providers present about whether there would be sufficient transitioning time, support and service providers to meet the demand of children eligible for the NDIS, and what services would be available for children who weren't eligible.⁴⁶

⁴¹ The Better Start initiative is being transferred into the NDIS and Carers ACT funding for this program ceases 1 July 2015.

⁴² ACT Government (2014) *Human Services Blueprint*. Accessible at http://www.communityservices.act.gov.au/home/current_news/human-services-blueprint

⁴³ The provision of appropriate, flexible and responsive support for carers of children and young people with disability is essential to minimise the health, social and financial impact of caring of parents and families. Further discussion about the impact of caring is discussed in the Australian Bureau of Statistic's *Caring in the Community, Australia, 2012*. See footnote 14.

⁴⁴ Carers ACT (2012a), *ibid*

⁴⁵ Around one-third (32%) of primary carers felt weary or lacked energy because of their caring role, and 30% frequently felt worried or depressed. Carers who spent an average of 40 hours or more a week providing care were more likely to report these adverse effects than those who spent less than 20 hours per week according to Australian Institute of Health's *Australia's Welfare 2013*.

⁴⁶ Observation from author of this Carers ACT response, who attended the forum.

Similar to the discussion about the NDIS and young carers in 2. *Children and young people with a caring role in their family* above, Carers ACT is also concerned about the consequences for children and young people (and their families) who are ineligible for the NDIS. While the government has stated that nobody will be worse off with the NDIS there is uncertainty about the availability of adequate block funded services from the ACT and Australian Governments for this population group. Insufficient services for non NDIS eligible children and young people with disability will mean that parents or siblings (young carers) will need to provide unmet formal services.^{47,48}

Recommendation 2

Carers ACT recommends that the ACT Government regularly monitor its key human services and children and young people's plans for their responsiveness in supporting families of children and young people with a disability or mental illness in the ACT through a family-centred and whole-of-government strategy.⁴⁹ This strategy should address:

- How we raise awareness of children and young people with disability to provide responsive early intervention through the Our Human Services and children and young people's plans.
- What training and assistance we provide for staff and service providers to identify families with children and young people with disability that have not been identified for referral to the ACT NDIS trial and its assessment process and to support their appropriate referral and assessment.
- What timely information and referral pathways we provide to improve support to children and young people with disability and their families, including unmet needs for home help, respite, transport and culturally-appropriate services.
- How to identify the specific support needs of children and young people with disability and their families whose circumstances and concerns may not be appropriately addressed, including young people of Indigenous and Culturally and Linguistically Diverse backgrounds, with the launch of the ACT NDIS trial on 1 July 2014.

⁴⁷ Currently, almost two thirds of primary carers (61.6%) whose main recipients aged less than 15 years reported spending 40 hours or more per week caring (see footnote 20). Any unmet need is likely to increase this level of care, and increase the economic, social, health and financial family disadvantages.

⁴⁸ A media release issued by ACT Minister for Disability Joy Burch on 30 June 2014 indicated that early childhood education and care, special needs transport, assessment services for children who may have autism or developmental delays will continue to be provided by the ACT Government during and beyond the NDIS trial to prevent disruption in schools.

⁴⁹ The Director General ACT Community Services Directorate indicated in the directorate's 2012-2013 Annual Report that single agencies or agencies trying to help in family-centred models often only scratch the surface, but that for deep and complex problems new ways of addressing these problems, and bringing together different types of assistance is required. Accessible at http://www.communityservices.act.gov.au/home/publications/annual_reports/2012-2013/annual-report-volume-one/a-performance-and-management-reporting/a1-director-general-overview