

Stop to Listen: Findings from the ACT Young Carers Research Project





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Research Project

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The project was managed by Tim Moore who also compiled this report. It was conducted with the Young Carers Research Team which included peer researchers Jamie Gray, Rebecca Johnstone, Morgan Pettit, Madeleine Nield and Jess Butler with support, training and guidance from Elizabeth Morgan of Morgan Disney and Associates and Helen McPherson from the Youth Coalition.

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Drowning Inside

We look fine on the Outside
We love and care and flirt
But on the inside we're drowning
Under all the pain and hurt

We try to swim to the surface
Using good times as our power
But the bad times all catch up with us
And we're deep under within the hour

We're wading and wading and wading
Through the pain and hurtful times
People think we're doing quite all right
But read between the lines

They don't know the pain we feel
I wish they could understand
Instead I have to keep on walking
And bury it under the sand

I hate it when they stare at them
They didn't do anything wrong
And yet because they're disabled
It seems they don't even belong

They just keep pushing and pulling
And pushing me more and more
And sometimes I can't take it
And I fall right down to the floor

I don't know how I keep on going
And I don't how we all do
We survive another stressful day
And awake the next all new

It's getting harder everyday
The weights grow more and more
And slowly I sink down deeper
To the bottom of the ocean floor

Options pop up in my life
Of suicidal release
Its seems like a good idea
To let myself rest in peace

I want to let it all go
And drop the weights of pain
I just want it all to stop
Like the end of stormy rain

But then I look at my family
How would they do without me
They'd be stuck with the pain
And I would be free

And so I realise the facts
I can't go and die
I've so much to live for
So I get up and try

Try to keep it together
Try to swim to the top
Try to make it feel all right
Try to make the pain stop

But the pain will never stop
The pain doesn't go away
The pain will always be there
The pain will always stay

We shout out in pain and tears
A Voice that cries for support
A voice that's never heard out
A voice that chocks and distorts

One person may hear this poem
While a million wont even bother
But at least one more person will understand
What it is to be a young carer

1 SUMMARY

1.1 Executive Summary

This research project, funded by the ACT Department of Disability, Housing and Community Services through the Carers Recognition Grants Program, sought to discover more about the lived experiences, needs and goals of young carers in the ACT in an attempt to identify more responsive and accessible service delivery.

For the purposes of this research report, young carers were defined as:

children and young people under the age of 18 who care for a family member with an illness or disability, or a drug or alcohol or mental health issue.

It has been shown that caring can be a positive experience for children and young people when they receive adequate levels of support but that when unsupported, young carers can experience significant physical, emotional, social, educational, and financial hardship.

It is discomfoting, therefore, to find that most research has shown that for a range of political and practical reasons, many young carers and their families are sustained in positions of significant disadvantage and suffer on without the supports and services that they both need and deserve.

While there has been considerable discussion about the service needs and experiences of carers, generally, there has been little research focusing on the specific needs of young carers and their access to appropriate, responsive and quality services.

This has been for a number of reasons. Firstly, viewed primarily as incapable, children and young people's roles as social citizens are discredited, which leads to a situation where communities either disbelieve or problematise their care responsibilities and fail to afford them the support they need. Secondly, afraid of stigma, inappropriate intervention or shame, many families have felt compelled to hide young caring from the eyes of the community. Thirdly, young caring raises a moral and economic tension – do we condone young caring (including its negative impacts) and save the community significant expense or do we prohibit it and further problematise those who assume such roles?

This study attempted to navigate its way through this potential minefield by acknowledging that young caring is a natural, potentially life-affirming and skill-developing experience and by seeking out children and young people's own reflections on their roles and how they, themselves, see caring impacting on their lives.

1.2 Methodology

This study was undertaken using a multi-method qualitative research approach. It included in-depth face-to-face interviews, focus groups and workshops with both young carers and other key informants. In total, 50 young carers including 27 males and 23 females were interviewed. The young people interviewed were selected using both purposeful and convenience samples, with attention to recruiting a cross section of children and young people with respect to age, gender and cultural background.

The research strategy also included interviews and focus groups with a range of professionals including youth workers, teachers, mental health workers, advocates, funding bodies and parents. A Literature Review preceded the data collection and was used to develop the scope of the inquiry.

The study was conducted using an emancipatory peer-based model with a group of young carers aged 17 to 21 trained as social researchers. This Young Carers Research Team helped design research tools, conducted interviews, workshopped major themes and provided feedback and analysis.

1.3 Key Findings

Regarding the types of children and young people caring and their levels of responsibility:

- Young carers are often caring for more than one relative at a time, and for relatives with more than one condition;
- Young carers often care for significant periods of time (an average of 6.4 hours per day) for a substantial duration (average of 6 years);
- Young carers caring for a relative with an episodic condition (primarily mental health) do not identify times when they have no care responsibilities;
- Most young carers live in families experiencing financial hardship;
- No young carers in the sample received either a Centrelink Carers Allowance or a Carers Payment; and
- Young carers who are incarcerated often continue their care responsibilities from detention. They may have been sentenced for committing a crime associated with their family's poverty or what they see as their care responsibilities.

Regarding the types of caring tasks they assume:

- A large number of young carers are responsible for tasks around the home (78%), for caring for other relatives (including ensuring their safety) (78%), providing emotional support (74%), helping financially (50%) and protecting the family (68%);
- These caring responsibilities are more intense than their non-caring peers and are most often provided without supervision or support; and
- Young carers often assume similar levels of caring responsibility to adults.

Regarding the impacts of caring on their lives, their health and wellbeing and their participation:

- Young carers may experience positive impacts of caring including feelings of pride and worth, a sense of accomplishment, greater levels of fitness, greater resilience, stronger family relationships, better outcomes in education, more skills and a positive outlook on life;
- Young carers may experience negative impacts of caring including fatigue, injury, greater levels of stress, anxiety and feelings of hopelessness, family conflict and breakdown, financial insecurity, limited social and recreational opportunities and poor outcomes in education; and
- Young carers caring for a relative with an alcohol or other drug issue are likely to experience similar impacts of care to other young carers, though they may experience greater social isolation, be exposed to less safe situations and be less likely to receive support.

Regarding the support that young carers and their families receive:

- A large number of the young carers in the sample did not receive informal support from their extended family but often were co-carers with siblings and / or parents;
- Only five young carers could identify a service for their family that they could access more than once a month and 7 a support that was on-going;
- Supports that young carers and their families received included respite, domiciliary care, in-home support, emergency relief, and family support; and
- Supports that young carers received focusing on them included personal support, counselling and holiday camps.

Regarding the types of support they would like to receive:

- Young carers called for more support for their relatives and families including more personal support, respite, in-home care, assistance with employment, family-based rehabilitation, family counselling and mediation, advocacy and financial support; and
- Young carers called for more support for themselves including help with education, community awareness, recognition and respect, training of professionals, information on their relative's condition, information on available services, respite and personal support.

Regarding the perceived and real barriers to their access to services:

- Service issues: many young carers would not access services because they weren't considered to be of an adequate standard, because they had had bad experiences in the past and because they could not adequately cater for their family's and cared-for relative's needs;
- Access issues: many young carers felt they could not access services because they were too expensive, did not provide transport or were too far away;
- Promotion issues: many young carers did not access services because they did not know what was available or how to access support or because they felt that they were not eligible;

- Family-based issues: some young carers did not access services because they felt that their families could cope alone, for issues of pride, for fear of scrutiny and blame and because family members preferred to get help internally;
- Co-ordination issues: some young carers did not receive support because it was too difficult to assess the needs of the whole family and to provide services that responded flexibly and holistically; and
- Sociological issues: some young carers did not receive the support they needed because people did not believe that children and young people should or could take on significant care responsibilities, because families felt that they needed to hide their caring for fear of child removal, increased supervision or victim-blaming or because services felt that they were not equipped to respond to the needs of children and young people.

In *Reading Between the Lines* the Young Carers Research Team proposed that the following definition be used to promote, support and target services to children and young people with care responsibilities:

Young carers are children and young people who care for or help care within a family affected by the illness, disability, drug or alcohol and / or mental health issue of one or more of its members or friends.

Proposed Strategies and Recommendations arising from the research

Barrier identified through the research	Strategies proposed to address the issue:
Families often do not access services because they are not available	<ol style="list-style-type: none"> 1) that the ACT Government increase the level of resourcing made available to community members with an illness, disability, AOD or mental health issue to meet real need; 2) that the ACT Department of Disability, Housing and Community Services and ACT Health develop and fund a flexible brokerage model to be made available to young carers and their families to purchase additional in-home and respite support so that young carers can take time out of their caring, reconnect to mainstream opportunities (such as education and employment) and to life-enhancing activities;
Families often do not access services because they do not respond to the needs of the whole family	<ol style="list-style-type: none"> 3) that guidelines are developed and services resourced so that the needs of the whole family are taken into consideration when assessing the need of clients within disability, health, AOD, and mental health services; 4) that brokerage is made available to address the needs of all family members, and the family as a unit, associated with caring (rather than just those of the cared-for relative). These may include access to respite, family mediation, counselling, social and emotional support;
Families often do not access services because they do not believe that they are of a high enough quality	<ol style="list-style-type: none"> 5) that standards of care in disability and health services be investigated to ensure consumer and carer confidence 6) that carer complaints mechanisms are developed within government funded programs to ensure that quality improvement can be assured 7) that mechanisms for young carers to be involved in quality assurance processes be identified and developed

Families often do not access services because they cannot afford them	<p>8) that the ACT Government urgently review the nature of fee-for-service provision in the ACT</p> <p>9) that brokerage funds be made available to young carers and their families to secure additional supports and services for their cared-for relatives</p> <p>10) that mainstream services promote and advocate for young carers to receive the Centrelink Carers Payment and Allowance when appropriate</p> <p>11) that a system of discounts be investigated to reduce the costs of health care treatment, medical supplies and medications be investigated</p>
Families often do not access services because transport is not available	<p>12) that transport models that are responsive to the needs of cared-for relatives and their families are explored and developed</p> <p>13) that brokerage be made available to young carers and their families to ensure their access to services through appropriate transport options</p>
Families often do not access services because they do not know what services are available or how to access them	<p>14) that accessible information resources focusing on available supports, services and user rights (like that developed by the Mental Health Foundation) be developed and broadly distributed;</p> <p>15) that the CIRSACT database of services be maintained and promoted to the broad community; and</p> <p>16) that the Making Contact website be maintained and extended to include information about services available to young carers and their families.</p>
Families often do not access services because they are fearful of external scrutiny, blame and fear of child removal	<p>17) that the Commissioner for Children and Young People be resourced to research and design appropriate and responsive supports for families affected by illness, disability, mental health and alcohol and other drug issues that resources and maintains families;</p> <p>18) that the community sector be resourced to develop appropriate protocols and guidelines and training on how to enact them;</p>
Families often do not access services because they feel guilty in asking for them	<p>19) that families are provided with information and support that legitimises help-seeking;</p> <p>20) that services working with families support appropriate referrals and ensure family dignity through the project; and</p> <p>21) that caring be promoted as the responsibility of the whole community so that families do not feel pressured into working alone.</p>

Responding to Barriers, Enabling Supports for Young Carers

Barrier identified through the research	Strategies proposed to address the issue:
Young carers don't identify as being young carers	<p>22) that widespread awareness-raising activities be funded including advertising on the television, radio, in the newspaper, and through youth publications (including BMA, and lip mag) and the development of information resources be funded to promote young caring as a natural, positive experience and that it is legitimate and appropriate for young carers to ask for support when needed;</p>

Young carers don't access services for fear of unwarranted interventions	See recommendations 17 and 18
Young carers don't identify as being a young carer for fear of bullying or harassment	23) that a community focused strategy be developed to target the myths, phobias and harassment of people with an illness, disability, mental health or alcohol or other drug issue and their families; 24) that training (similar to those focusing on homophobia) be developed for schools, including students, teachers, welfare staff, counsellors and youth workers, to combat harassment and bullying and to support 'hidden' young carers to identify and access appropriate support
Services do not recognise or know how to best support young carers	25) that children and young people in families affected by illness, disability, AOD and mental health issues be identified as a priority target within children and youth services and that this be written into service contracts and reported against; 26) that practice guidelines for working with young carers and their families (similar to those developed in the UK and those for children of parents with a mental illness) be developed and distributed with training on how to enact them; 27) that, in conjunction with TAE, training sessions be developed with carers (including young carers) and service providers and be provided to the major tertiary and training organisations as core units in their pre-entry and post-entry study for welfare courses and associated university qualifications; and 28) that training sessions be developed and possibly facilitated by young carers for teachers, youth workers, social workers, counsellors and others coming into contact with children and young people; (from the community, youth, AOD, disability, health and mental health sectors), schools and youth services
Services do not have a good understanding of the family issues of clients (including young caring)	29) that good practice for working with families be explored and promoted to children and young services in the ACT; 30) that links between family-focused services and supports such as ReConnect be resourced to enhance understanding of family issues and how they impact on children and young people; 31) that family-focussed training be provided to workers within the youth and community sectors to inform practice;
Young carers aren't recognised in 'at risk' or priority targets	32) that young carers and other children and young people in families affected by illness, disability, AOD and mental health issues be identified as a priority target within children and youth services and education;
Services aren't flexible enough for young carers to access	33) that the Office for Children, Youth and Family Support review the provision of out-of-hour services to young people in the ACT and to resource key services to provide extra supports during key periods (including weekends)

Services aren't affordable to young carers experiencing poverty	34) that brokerage funds be made available to young carers to access supports (such as counselling) and to enable them to reconnect to mainstream life opportunities including social and recreational activities, 'time out' and respite, education and employment
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<p>There is a lack of services that meet specific needs</p>	<p>35) that the needs of children under the age of 10 be urgently identified with appropriate interventions and supports developed; 36) that the needs of carers aged between 18 and 25 be identified and supported in their transitions to adult carer services; 37) that the linkages between parental alcohol or other drug use and homelessness be researched with appropriate responses developed; 38) that the linkages between the illness, disability or AOD issue in the family and criminality be identified; and 39) that the scope of existing young carer, youth and children’s services and their capacity to better</p>
<p>Young carers do not know what services are available</p>	<p>40) that accessible information resources focusing on available supports, services and user rights (like that developed by the Mental Health Foundation) be developed and broadly distributed; 41) that the CIRSACT database of services be maintained and promoted to the broad community; and 42) that the Making Contact website be maintained and extended to include information about services available to young carers and their families.</p>

Responding to gaps in service

<p>Young carers are not provided with age-appropriate information or education about their cared-for relative's condition</p>	<p>43) that specialised disability, health, mental health and AOD services be funded to develop age-appropriate information that is accessible to children and young people and outlines the main effects, symptomology and treatments of the major illnesses, disabilities, AOD and mental health conditions, that these resources be available on-line and that existing generic age-appropriate information (such as that developed by SANE, the Cancer Council, and ARAFMI) be purchased and distributed to schools and youth services and be made available for general access by children and young people</p> <p>44) that health professionals be brokered to provide age-appropriate advice and information (similar to those available through CIT Skills for Carers for adult carers) to young carers either individually, with their families or in group settings;</p> <p>45) that health professionals working with, and with the permission of cared-for relatives engage family members (including young carers), and provide them with information about their relative's condition and treatment plan</p>
<p>Young carers often do not achieve satisfactory outcomes in education because of a lack of flexibility, a lack of time available and lateness to class</p>	<p>46) that training, information and educational resources (similar to those focusing on homophobia) be developed in partnership between carer, disability, mental health, AOD and youth services and be provided in schools to teachers, students, counsellors, youth support workers and welfare staff to combat harassment and bullying and to support 'hidden' young carers to identify and access appropriate support;</p> <p>47) that the ACT Department of Education and Training fund a flexible brokerage model to be provided through regional community services and made available to young carers to cover the costs of education including school fees, uniforms, excursions and extra-curricular activities;</p> <p>48) that ACT DET develops protocols with DDHCS and ACTH to ensure adequate levels of support to young carers' families during key periods in their education to ensure access;</p> <p>49) that schools with support from DET develop flexible guidelines for working with young carers;</p> <p>50) that DET investigate flexible learning models including recognition of prior learning and off-line programs that can complement their involvement in mainstream education and their caring responsibilities;</p> <p>51) that telephones are made available to young carers so that they can be in contact with their relatives throughout the day;</p>
<p>Young carers do not access respite to alleviate the negative impacts of caring and give them an opportunity to relax, rejuvenate and re-engage with community opportunities and resources such as education, employment, and social activities</p>	<p>52) that a host family respite program similar to that currently existing at Barnardos (which focuses on children of parents with a mental illness) be developed to respond to the needs of all young carers;</p> <p>53) that the viability of a 'teen house' for young carers needing temporary respite be investigated;</p> <p>54) that social, peer-based recreational activities (such as St Nicholas Young Carers Program) be extended so that they can provide more frequent respite and social support to young</p>

	carers;
Respite is not usually provided to the whole family making it inaccessible or unresponsive to the family's needs	<p>55) that brokerage be made available to families to go on holidays together and be supported by accompanying workers when needed;</p> <p>56) that family-based camp programs be explored where carers and cared-for relatives can meet other families in similar situations and be supported by workers who are available when needed;</p>
Respite is not usually available for people with a mental health and / or an alcohol or other drug issue	<p>57) that appropriate and responsive respite models for people affected by a mental health and / or an alcohol or other drug issue be investigated and considered for funding;</p> <p>58) that the model used at Warren I'Anson house be replicated and be made available to sole parents with a mental illness and their children;</p> <p>59) that the model used at Karralika be replicated and be made available to mothers and fathers with an AOD issue and their family;</p>