



Housing and Support Needs of Ageing Carers of Adult Children with Mental Illness: A Snapshot Carer Housing and Supports Survey, July 2009

Families with adult children with a mental illness have a range of complex needs for housing and support for their adult child. Often the adult child only lives independently with a great deal of support from parents and family. Over time Carers SA has been receiving consistent messages about the lack of housing and support options.

A group of Carers who were struggling to find housing and service support solutions for their adult children with mental illnesses established the Mental Health Carers Housing Group, supported by Carers SA, to raise the issues across the community and government sectors, in particular in mental health, housing and social inclusion.

The initiative for the Housing and Support Survey came from Carers. The survey was prepared in order to capture the views of a broad range of Carers so as to offer an indicative picture, a snapshot as it were, of the needs that have been expressed to Carers SA.

The survey was forwarded to members of Carers SA's Mental Health Carers Task Group and Mental Health Carers Housing Group and associated networks in July 2009.

The importance of the issues to the respondents was indicated by most responses returning to Carers SA within a fortnight even though no return date was given.

31 replies were received. 3 were excluded from further analysis because the respondent was not caring for an adult child with a mental illness. Not everyone responded to every question.

Responses were received from across the state, 63% from rural South Australia and 37% from the Adelaide metropolitan area.

Survey Highlights

- The average age of the Carers was 64, ranging from 48 to 81, with that of the care recipients 38, ranging from 21 to 50.
- 82% of the care recipients were in the public sector, however only 54% had a Key Worker.
- 86% of the care recipients would require supported accommodation when the Carer was no longer able to undertake the caring role: but that accommodation had not been arranged in 92% of cases.
- 93% of the care recipients were either living "at home" with the Carer or independently but with a great deal of support from the Carer/family.
- 58% of the respondents were seeking better accommodation options, including supports, for the care recipient.
- An average of only 28% of services, across a range of living, health and social services required by, and provided to, the care recipients were provided by someone other than the Carer.
 - One fifth of housekeeping support was provided by someone other than the Carer.
 - Less than half of the medication support was provided by someone other than the Carer.
 - Approximately two thirds of social services, physical health and rehabilitation services were provided by someone other than the Carer.

Conclusion

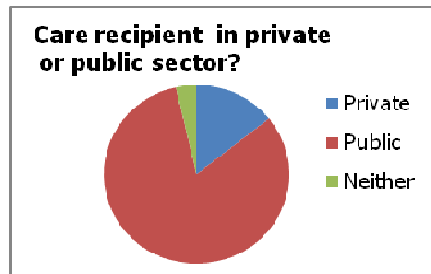
- People with mental illness face a bleak future in the absence of the support provided by family Carers.
- People with mental illness and their Carers face inadequate accommodation choices.
- Without the ongoing support of their Carers many people with mental illness would be homeless.

Carers SA calls on the Government to recognise and include the reduced capacity of ageing Carers to continue to provide housing and associated living, social and health supports to their adult children in the assessment and provision of social housing and social supports to people with mental illness and establish a priority pathway to social housing and service supports within mental health programs for them.

Survey Details By Question

Is the person you care for in the Private or Public mental health system?

28 respondents: 4 (14%) private; 23 (82%) public; 1 (4%) neither.



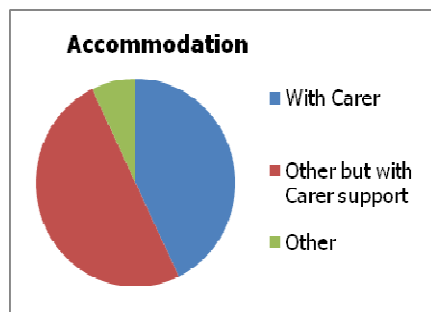
Where does the adult child you care for live: at home with me; in other accommodation but mainly with Carer/or family support; or in other accommodation.

28 respondents: 12 (43%) "at home"; 14 (50%) in other accommodation but mainly with Carer/or family support; 2 (7%) elsewhere.

Other accommodation, including with Carer/family support was listed as:

- Housing SA (4).
- House owned by family (2).
- Rental accommodation (3).
- Community housing (ROOFS) (1).
- Own Home (1).
- Boarding house (1).
- Homeless ("couch hopping") (1).
- Not specified if rental or owner occupied (2).
- Russell House (1).
- Rehabilitation ward (1).
- Same town three streets away (1).
- Lives with wife, who also has a mental health disability (1).

Two respondents indicated that the care recipient shared accommodation between the Carer's home and a Trust home in one case and Russell House in the other.



Are you seeking better accommodation with supports for them?

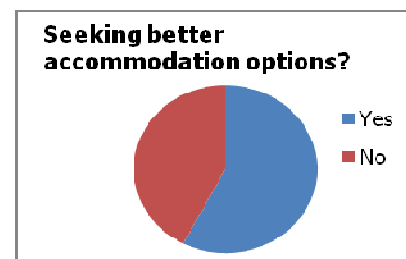
26 respondents: 15 (58%) yes; 11 (42%) no.

Accommodation being sought included:

- Supported housing (4).
- House or unit (4) ("with some help available").
- Housing SA (1).
- Community housing (ROOFS: "On waiting list") (1).
- "Within our community before I'm too old and burned out."
- "I have been told that there is nothing suitable for my son."

Comments from the "Nos" included:

- Accommodation is "OK" but support, eg household tasks, needed (2).
- Not yet (2).



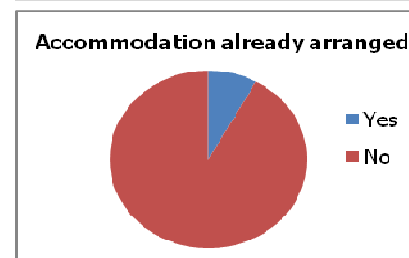
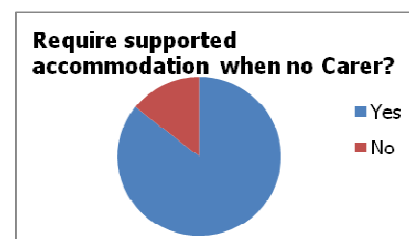
When you are no longer able to care for the person for whom you are currently caring, will that person require supported accommodation?

28 respondents: 24 (86%) yes; 4 (14%) no.

If Yes, has that accommodation already been arranged?

25 respondents: 2 (8%) yes; 23 (92%) no.

Comments included one "Yes" stating that it was "in process" and one "No" respondent that there was "none available".

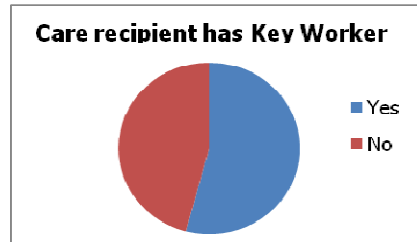


Does the person you care for have a Key Worker?

24 respondents: 13 (54%) yes; 11 (46%) no.

Comments included:

- Only for four more weeks.
- I think so: should have.
- Connected to Marion Mental Health, very little contact.
- Managed by GP.
- Not yet: being discussed between treating team and family.



Is the person you care for provided with the following supports by anyone other than yourself? If so, who provides this support?

Housekeeping

25 respondents: 5 (20%) yes; 20 (80%) no.

Housekeeping provided by:

- Other family member.
- Care recipient’s wife.
- Ward staff.
- Boarding house.

Medication

25 respondents: 11 (44%) yes; 14 (56%) no.

Medication provided by:

- Beaufort Clinic.
- Key Worker.
- Partner.
- Other family member
- Mental health nurse care, hospital.
- Psychiatrist.
- Russell House.
- GP.
- Clinical/ward staff.
- Western Mobile Assertive Care.

Clothing Care

25 respondents: 1 (4%) yes; 24 (96%) no.

Clothing care provided by another family member.

Social Services

25 respondents: 9 (36%) yes; 16 (64%) no.

Social services provided by:

- Easter Mental Health Services.
- Life Without Barriers.
- Mental health psychologist and psychiatrist.
- Mental Health.
- Government Disability Pension.
- Russell House.

- On the ward.
- NEAMI.

Physical Health

25 respondents: 8 (32%) yes; 17 (68%) no.

Physical health assistance provided by:

- GP.
- RDNS for diabetes.
- Local hospital.
- Doctor (“we see that he keeps appointments”).
- Ward (“still needs my input”).

Rehabilitation Services

23 respondents: 7 (30%) yes; 16 (70%) no.

Rehabilitation services provided by:

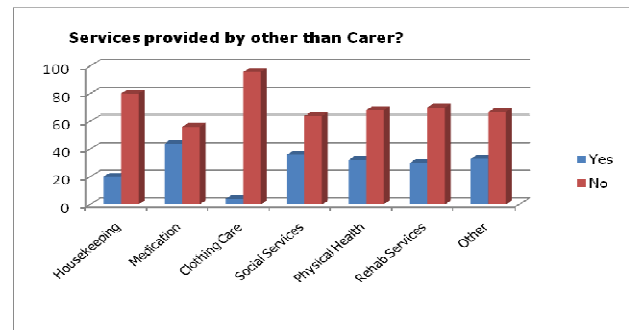
- NEAMI.
- MIND.
- Baptist Community Services.
- Life Without Barriers.
- Glenside Hospital.
- “We see that he keeps appointments.”

Other

18 respondents: 6 (33%) yes; 12 (67%) no.

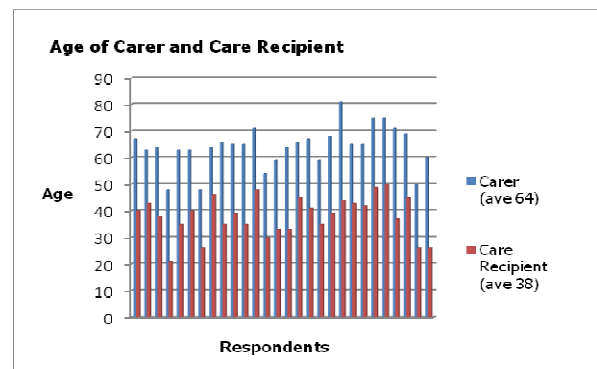
Other services provided by:

- Private psychiatrist.
- Friend who is psychiatric nurse (occasional counselling).
- MIFSA.
- Psychotherapist and GROW self help group.



What is your age? What is the age of the person you care for?

28 respondents: Carers’ average age of 64; care recipients’ average age 38.



Any Further Comments?

Support

They need support in a crisis situation and running a house.

He needs support in normal day to day operating his household and in handling crisis situations with his illness.

We support and let her work out her life the best way she can. We put out medication it's up to her to take it.

Will they be able to have supervision? Some need constant contact, some need to know someone cares and encouragement.

More Services

I would like her to have more help and supervision in social services, physical health and rehab services.

Accommodation With Support

My adult son who suffers from Schizophrenia was living in rental accommodation for 8 years. We approached the landlord for reasonable 'upgrades' but he only undertook the most 'low level' repairs but with consistent rent increases.

I made application to Roofs Housing for accommodation where he would be able to live without the threat of eviction if he (as he often did) became unwell. After 6 years 'in the system' and much lobbying we were successful in obtaining a comfortable unit. This was not an easy task.

However it became obvious to us our son was unable to look after himself: cleanliness, health and vulnerability issues made it clear that supported accommodation would be more appropriate, but is almost impossible to obtain. With this in mind I began to 'pressure' the mental health system, the Minister and others to recognize the need for us to re house our son. We have been assured he will fit the criteria for entry into the Glenside. Redevelopment I am sceptical.

Suitable accommodation available for mentally ill people is at a critical level and is not being addressed. He cannot be housed where I live as there are no services to support the needs of the mentally ill. He has stayed with us with for holidays with disastrous results.

I am not sure the outcomes of this approach will meet the needs of our son but the options available despite enormous amounts of money been spent on mental health have not 'hit the spot' for the majority of mentally ill people.

The Accommodation Needed Is Not Available

The type of accommodation that my son needs – and I'm told 10% of people with a mental illness like him require – is just not available. This is why he is homeless, bunking down with drug addicts and moving amongst friends who will allow him to stay a night or two on their couch.

Very early after my son's diagnosis I was advised by a mental health service that it would be in mine and my other children's best interests not to allow my son back home after another stint in hospital. I was assured that they would find suitable accommodation for him. The outcome was that my son spent many months couch hopping and living in hovels.

I was informed that for my son to acquire accommodation he would have to go into the service provider and ask for housing. How could he do this if he was unwell most of the time?

We would find him extremely unwell, doing drugs, committing crimes and being taken advantage of.

He has been part of the forensic mental health system for the last six and half years. He has lost the ability to cope with the normal day to day living that we take for granted, such as cooking, cleaning, budgeting and meeting his other obligations.

I'm told that he requires a very high level of intense support in accommodation that is not available to people like him, so unfortunately they just fall through the cracks. There is no system in place (long term accommodation) for forensic patients who have lived in a high level support system moving back into the community.

The prognosis – death or a longer stint in jail (which I was told may be the best place for him).

Acknowledgement

Thanks to the Carers who responded and to the Mental Health Carers Task Group and the Mental Health Carers Housing Group for their input.



Supporting Family Carers

PO Box 410 Unley SA 5061:
Telephone 8291 5600: Fax 8271 6388:
Email info@carers-sa.asn.au:
Website: www.carers-sa.asn.au