



IMPROVING THE FOCUS ON CARER NEEDS IN INITIAL CONTACT AND INITIAL NEEDS IDENTIFICATION

FINAL REPORT

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ACRONYMS

ACAS	-	Aged Care Assessment Service
BATS	-	Better Access to Services
CACP	-	Community Aged Care Package
CALD	-	Culturally and Linguistically Diverse
CAV	-	Carers Association Victoria
CP	-	Care Planning
DHS	-	Department of Human Services
HACC	-	Home and Community Care
IC	-	Initial Contact
IM	-	Information Management
INI	-	Initial Needs Identification
PCP	-	Primary Care Partnership
PPPS	-	Practices, Processes, Protocols and Systems
WMR	-	Western Metropolitan Region

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1. EXECUTIVE SUMMARY

In October, 2001, the three Primary Care Partnerships (PCP) in the Western Metropolitan Region (WMR) – Moonee Valley Melbourne, Westbay and Brimbank-Melton - were advised by the Department of Human Services (DHS) that their Regional PCP's Cross Alliance Submission for Service Coordination had been successful. Improving the Focus on Carer Needs in Initial Contact (IC), Initial Needs Identification (INI) and Care Planning (CP) was one of the nine projects funded.

The Cross Alliance Better Access to Services (BATS) Mapping Report (Feb,2001), prepared by Deb Warren, identified that improving the focus on carer needs was a key issue for future BATS/IM developments and articulated two suggestions for promoting carer perspective in assessment:

- The Carers Association of Victoria (CAV) resource document "*Putting Carers in the Picture – Improving the focus on carer needs in aged care assessment*" be used for the development of an agreed Protocol across the WMR for working with carers;
- An ongoing training program be developed for Assessment Officers and Case Managers around the CAV's resource manual including the trialing of the Assessment Tools provided in the manual.

This project therefore aimed to promote a carer perspective by trialing the IC and INI Service Coordination Tool Templates with the carer population.

At the outset, however, and with the agreement of the Project Reference Group and DHS it was decided to build on the PCP Service Coordination Implementation already underway in the WMR. Carers Victoria, in a submission to DHS as part of the 2001 trial of the Service Coordination Tool Templates, had identified that templates failed to include a clear framework to encourage an holistic focus on the needs of the 'care giving unit,' at both the practice and planning levels. Extensive work both in Victoria and nationally has also identified the need for greater carer focus and this view was supported by PCP Agencies in the WMR.

Consequently, the focus of the project was changed to include:

- the development of protocols to assist in the process of INI for carers
- the development of triggers to initiate an assessment for carers
- the development of a Carer Profile.

The major focus of this project has been the development of a Carer Profile with supporting Guidelines. The process used to develop the Carer Profile included a comprehensive review of Australian literature and available assessment tools, consideration of information from the 2001 trial of the Service Coordination Tool Templates and Profiles, the development of a draft Carer Profile in consultation with

carers which was trialed with the six WMR Local Government HACC Services and five other PCP agencies, the evaluation of the trial and subsequently, the further development of the Carer Profile.

The purpose of the Carer Profile is to focus on the caring role, as the carer understands his/her role during the processes of Initial Contact (IC) and Initial Needs Identification (INI). The intention is that use of the Profile will assist the carer in conjunction with the practitioner to determine initial needs and to decide on further actions.

Overall 69% of agencies and 79% of Local Government HACC Services felt that the Profile improved the focus on carer needs and assisted carers to better identify their needs. Carers who were involved in the trial were invited to provide feedback on the Carer Profile and expressed enthusiasm for the Carer Profile and the focus it provides on the carer role.

The Recommendations which follow provide the opportunity for the further development of the Carer Profile and incorporation into the Service Coordination Tool Templates and Profiles. This will ensure that the role of carers and discussions of their needs become an integrated part of IC and INI through a formal process and will enhance care outcomes for both consumers and carers.

2. RECOMMENDATIONS

1. **That DHS include the Carer Profile with the Service Coordination Tool Templates and there is a statewide trial of the Carer Profile with a cross section of agencies and carers.**

The outcomes of this project have clearly supported the need for a greater focus on carer needs and have demonstrated that the Carer Profile provides that focus during IC and INI. A DHS statewide trial will provide the opportunity to test the Profile with a greater number and more comprehensive cross section of agencies and in a diversity of caring situations. This will determine whether changes to the Carer Profile are required for inclusion with the Service Coordination Tool Templates.

2. **That the Carer Profile be trialed for a period of eight weeks and that the trial include:**

- **initial training and workforce development using the CAV document “Putting Carers in the Picture” as a resource;**
- **agency support during the eight week testing period;**
- **a process for evaluation and subsequent adjustments to the Carer Profile**
- **introduction across the service system.**

An eight week trial is recommended as the Project pilot of two to four weeks was insufficient time to evaluate the Profile fully. An eight week period was found to be the minimum time for effective evaluation of the Service Coordination Tool Templates. Apart from the eight week trial period, it will be important to allow time for setting up the trial, working with agencies during the eight week testing period, evaluation and further developmental work as determined by the evaluation. In this way the addition of the Carer Profile to the Service Coordination Tool Templates will be managed in a manner which supports the purpose and intent of the Profile.

Agencies involved in the trial will include those that are mandated as well as a range of other primary care agencies including the Victorian Carer Support Services. It will also be important to include Aged Care Assessment Services (ACAS) as these services are often the entry point to the service system for many people.

Training and workforce development will be a key activity of the trial with those agencies involved. Support needs to be provided to those agencies to assist in the introduction of the Carer Profile during the trial period. Those involved will need to have a consistent understanding of the purpose and intent of the Carer Profile in order to evaluate.

The trial will need to consider the development of the Carer Profile in electronic form, consistent with current software development.

3. That the Carer Profile and Guidelines are launched in the WMR as a means of promoting the outcome of this project.

The development of the Carer Profile and Guidelines is a significant outcome which potentially has positive implications for best practice across the whole service system. A launch provides the opportunity to focus on this development.

3. PROJECT BACKGROUND

In October, 2001, the three Primary Care Partnerships in the Western Metropolitan Region – Moonee Valley Melbourne, Westbay and Brimbank-Melton - were advised by the Department of Human Services that the Regional Cross Alliance Submission for Service Coordination had been successful. Nine projects were funded as Stage 1 and Stage 2 projects. Improving the Focus on Carer Needs in Initial Contact, Initial Needs Identification and Care Planning was one of three Stage 2 projects which commenced in July, 2002. The Cross Alliance Better Access to Services Mapping Report (Feb, 2001) prepared by Deb Warren, identified that improving the focus on carer needs was a key issue for future BATS/IM Information Management developments. Carers Association Victoria also submitted comments concerning the piloting of the Service Coordination Tool Templates which included the need for an holistic focus on the care giving unit, the need for carer identification and recognition and consent and capacity.

The Moonee Valley Melbourne PCP (MVM PCP) was designated as the Project Auspice on behalf of the WMR Cross Alliance Management Group. As Project Auspice the MVM PCP undertook project management through the MVM PCP Manager and a Project Reference Group. With the appointment of Architalk Consultants, Thelma Castles and Stuart Absalom, project completion was scheduled for December, 2002.

Scope of Project

The scope of the Project, as stated in the Project Brief, was to improve the focus on carers' needs in IC, INI and CP and enhance care outcomes for both clients and carers.

At the outset of the Project the scope was redefined to focus on the processes of IC and INI only.

Project Objective

The overall objectives of the project, as stated, were:

- To better focus service provision on carer needs.
- To inform the development of statewide processes and practice around carer needs.
- To field test the IC and INI tools across the whole region and determine the need for specific tool component and/or additional information requirements addressing carer needs.
- To inform the development of agreed WMR Protocols for IC and INI in relation to working with carers by researching current practice, field testing tools and drawing on current project work.
- To field test the Interagency Referral Protocols and electronic Service Directory to the extent they were developed with service providers.

4. METHODOLOGY

The broad approach to achieve the outcomes was to:

- Establish a Project Reference Group.
- Detail a dynamic Project Plan.
- Build rapport and encourage acceptance of the Consultants.
- Gain agreement and commitment to the Project Plan from managers and practitioners who had been identified as stakeholders.
- Identify the differing needs and beliefs of those involved including individuals, groups and agencies.
- Ensure all parties gained an accurate view of the Project Plan and any emerging issues.
- Review current documentation relating to the Project.
- Review progress of the WMR PCP Cross Alliance Service Coordination projects and ensure a coordinated approach with these interrelated projects.
- Meet regularly throughout the Project with the Project Reference Group and identified personnel and provide progress reports at agreed times.
- Liaise with key agencies/service providers, particularly those who were involved in the DHS trial of the INI and CP tools.
- Identify and consult with Stage II key project participants in relation to field testing the IC, INI and CP tools.
- Identify and consult with relevant client/client groups, carers/carers groups and the Cross Regional Consumer and Carers Participation working group.
- Develop an operational framework for consultations which may include forums, focus groups, workshops, interviews and field testing of tools (IC, INI), Interagency Referral Protocol and eService Directory.
- Undertake consultations according to the operational framework.
- Identify changes in work practice and strategies to address required changes which ensured a sustainable approach to addressing carers' needs.
- Review outcomes of consultations and field testing and develop recommendations/adjustments as necessary.
- Build on current best practice.
- Present a final report which summarised the outcomes of the Project.

The Stages of the Project were:

Stage 1	Clarification
Stage 2	Familiarisation and Planning
Stage 3	Consultations
Stage 4	Data Analysis and Development of Recommendations
Stage 5	Preparation and Presentation of Final Report

At the outset of the project it was decided to build on the PCP Service Coordination Implementation already underway in the WMR and the extensive work both in Victoria

and nationally that has occurred in regard to carers. Consequently, the Reference Group agreed to change the focus of the project to include:

- the development of protocols to assist in the process of INI for carers
- the development of triggers to initiate an assessment for carers
- the development of a Carer Profile.

An operational framework was developed with the Project Reference Group and built on existing knowledge in relation to the experience of carers and their inclusion in assessment processes. The major focus was the development of the Carer Profile which was trialed in a range of care situations and with a range of agencies through an action research approach. The feedback from agencies and carers led to the refinement of the profile and the subsequent development of Guidelines on how to use the profile.

Throughout the Project, the consultants worked closely with the Reference Group, met regularly with the MVM PCP Executive Officer and other Stage 2 Project staff and the Regional Project Coordinator. Monthly Reports were made to the Cross Alliance Management Group and a presentation was made at the September Regional Forum for PCP agencies at which a number of agencies indicated their interest in participating in the trial. Various discussions occurred with DHS, both at the regional and central level, to promote the adoption of project outcomes. Carers Week in October, 2002, provided an opportunity to publicise the project within the WMR through an article in the Leader group on newspapers (see Appendix 1, page 17).

The Project Reference Group was as follows:

Jo McMillan	RDNS and Chair of the Reference Group until September, 2002
Hazel Ingram	City of Moonee Valley, Chair from October, 2002 and Vice Chair of WMR Service Coordination Working Group
Anne Muldowney	Carers Victoria
Jeanette Wallish	ISIS
Fay Brassington	Carer
Priscilla Mayne	City of Wyndham
Di Couch	MVM PCP Executive Officer
Kerryn Lockett	MVM Service Coordination Project Worker
Janet Shaw	Carer Links West
Vern Hughes	Carer (joined the Reference Group in September, 2002)

Robyn Close from Care Connect, while unable to attend meetings, agreed to read and have input into project outcomes.

5. DEVELOPMENT OF THE CARER PROFILE

Process

The process used to develop the Carer Profile included a comprehensive review of Australian literature and available assessment tools, consideration of information from the initial trial of the Service Coordination Tool Templates and commitment to the aim of this Project – to focus on carer needs in Initial Contact and Initial Needs Identification.

The Australian literature reviewed included:

- Pierce, G and Nankervis, J: *Putting Carers in the Picture: Improving the focus on carer needs in aged care assessment*, (Carers Association Victoria), 1998
- Maddock, A, Kilner, D, Isam, C: *Carer Needs Assessment Trial*, (Royal District Nursing Service of South Australia and Carers Association of South Australia), 1998
- Warning – Caring is a Health Hazard, National Survey of Carer Health and Wellbeing, (Carers Association of Australia), 1999

The Carer Profile was then developed to be compatible with the current profiles in the Service Coordination Tool Templates and Profiles and was trialed with agencies and carers.

Purpose

The purpose of the Carer Profile is to focus on the caring role, as the carer understands his/her role during the processes of Initial Contact and Initial Needs Identification. While the experience of caring varies, there are a number of factors which may signal the need for additional assistance. These factors form the basis of this profile (see Appendix 2, Carer Profile, Guidelines and Flowchart, page 18). The intention is that use of the profile will assist the carer in conjunction with the practitioner to determine initial needs and to decide on further actions.

The Profile has been designed in two sections.

Section 1

Collects carer details that relate to HACC MDS and the Commonwealth Respite Program MDS and addresses privacy and confidentiality. The Carer Information segment begins to explore the caregiving role using well established indicators of carer stress – length of caring and the hours taken up with caring each week; whether the care recipient can be left alone and whether there are aspects of health or behaviour which are hard to deal with. This area has been scored as a means of determining whether further assistance is required.

Section 2

Allows further exploration of the caregiving role using well researched questions that relate to caring. Each segment of Section 2 is inter-related to each other in order to build a picture of the overall situation. By this means it is likely that outcomes will be enhanced for the care recipient as well as the caregiver.

Development Process.

The development process included action research with a small sample of carers and PCP agencies across the WMR. In order to confirm the feedback from the initial pilot in 2001 by DHS of the Service Coordination Tool Templates and Profiles in relation to carers, a selected sample of carers accessing HACC services from the Cities of Wyndham and Moonee Valley participated in a review of the existing Tool Templates and Profiles.

Feedback from Carers and Agency Staff

The feedback from this review indicated the following:

- difficulty in deciding who is the consumer – the child/older person or the carer
- inappropriateness of questions for younger person with a disability
- current practice of noting information about the carer and then inputting the data in the screen marked - Notes Section
- no specific section of the INI that is relevant to the needs of the carer
- determining who is the recipient of respite
- CACPs is funded to provide services to the consumer only
- skill level of the staff undertaking the assessment and their ability to determine when the carer needs to be registered as a separate consumer
- the need for triggers and tools that support the assessment of carers
- implications for workforce training.

This feedback was consistent with the submission made by Carers Victoria in response to the 2001 DHS pilot.

Flow Chart Development

Following the review the first draft of the Carer Profile with an accompanying flow chart was completed in preparation for the trial with a range of WMR PCP agencies.

6. CARER PROFILE TRIAL

PCP agencies were informed about the Project at a Regional Workshop held in September, 2002. Specifically, this provided the opportunity to inform agencies about the development of the Carer Profile and to enlist support for the trial.

The following agencies agreed to be involved:

- RDNS
- ISIS
- Shire of Melton
- Essendon Day Centre
- Carer Links West
- Shire of Wyndham
- Melbourne City Council
- Doutta Galla Community Health Service
- Brimbank City Council
- NW ACAS
- Moonee Valley City Council
- Maribyrnong City Council
- Hobsons Bay City Council

The process for the trial involved meeting with agencies to discuss the Carer Profile, clarify its purpose and determine the carer cohort group. Evaluation Questions about the Carer Profile were also distributed (see Appendix 3, page 25). The process was as follows:

Meeting Dates and Timelines

The trial was conducted over a four week period with an initial meeting to outline the trial and a meeting to evaluate the documentation at the end of the four weeks. Agencies that were unable to attend the scheduled meetings were followed up individually.

The cohort group

It was anticipated that each agency would have no more than 3 assessments/reviews to complete for the trial. Agencies were asked to consider the cohort group and determine whether the cohort matched their current data base. The following carer cohort group was confirmed:

- Carer of a younger person with a disability – birth to 18
- Carer of a person from 19 – 64
- Carer of an older person 65 – 79
- Carer of an older person 80+
- Carer who is under 25 years of age
- Frail aged carer who is caring for an adult with a disability

- Aged carer caring for a frail aged person
- Multigenerational carer i.e. caring for child with disability and elderly relative
- Carer of workforce age
- CALD carer
- Caring for a CALD person where there is a conflict in the caring culture
- Carer who has had a long term caring responsibility
- Male carer
- Carer at risk because caring for a person with:
 - challenging behaviour
 - a mental illness
 - multiple and complex care needs.

The Documentation

The following documentation was emailed to agencies prior to the first meeting.

- The draft Carer Profile
- An outline of the trial (see Appendix 4, page 29)
- Evaluation questions for the participants to complete.

Focus Groups with Carers

Three carer focus groups were planned across the WMR. It was decided to link in with existing carers groups but this proved difficult as many of them meet on an informal basis and attendance by carers varies depending on their individual situations. Subsequently, it was agreed that carers who participated in the trial be followed up to provide feedback.

7. RESULTS OF CARER PROFILE TRIAL

Results from the trial were based on the Evaluation Questions (see Appendix 3, page 25) completed by staff from participating agencies and are summarised below. All six WMR Local Government HACC services and the five other agencies involved indicated the value of the Carer Profile.

Overview of the findings

There were 29 evaluations completed as follows: Local Government (14), Royal District Nursing Service (2), Western Aged Care Assessment Service (3), ISIS Primary Care Linkages/CACPs (5), Carer Links West (2) and Doutta Galla Community Health Service (3). The Local Government areas included all those in the WMR - Melbourne City Council, Moonee Valley City Council, Hobsons Bay City Council, Wyndham City Council, Maribyrnong City Council and the Shire of Melton.

All subsections of the cohort group were covered except for - Carer who is under 25 years of age and Caring for a CALD person where there is a conflict in the caring culture.

Agencies completed the Profile with the aim of further assisting the development of the Carer Profile and its subsequent inclusion in the current Service Coordination Tool Templates.

Agency Feedback

Feedback on Focus on Carer Needs

Overall 69% of agencies and 79% of Local Government HACC Services felt that the profile improved the focus on carer needs and assisted carers to better identify their needs (see to Appendix 5, page 34 – Analysis of Evaluation Questions).

Comments about the Carer Profile included:

“Gives a clearer picture of the situation and particular questions prompt further discussion”

“Gave me a bigger picture of the impact of caring”

“The Profile was most beneficial in assisting me work out what the carer/client respite needs were”

“Assists in identifying specific ways in which support can be provided”

“Excellent tool for indicating stressors for home and family dynamics”

Feedback on Carer Profile in relation to Service Coordination Tool Templates

There was general agreement (76% overall, 86% LG) that the Carer Profile is a useful addition to the existing Service Coordination Tool Templates and Profiles as “the INI does not have much detail about carers.” Some agencies indicated that they have a

carer assessment tool and hence it will be important to be clear about the purpose of the Carer Profile. 76% indicated that the Carer Profile was easy to follow.

Feedback on changes or additions to the profile

The evaluation sought feedback from agencies about changes or additions to the particular segments of the Carer Profile and respondents indicated no additions or changes as follows:

- Carer Details (83%)
- Carer Information (90%)
- Carer's Overall Health (93%)
- Impact of Caring (57%)
- Information (76%)
- Priority Needs (80%)
- Role as carer (69%)

Impact of Caring received suggested changes as follows:

- Ensure that questions are not intrusive or negative
- Replace words such as inconvenient and confining
- Questions need to be rephrased for CALD carers
- Should be worded as a question not a statement
- Insufficient space for detailed complex answers
- Use prompts to access information
- Some of the statements are hard to understand

Feedback on the Profile Scoring System

The scoring system raised comments which related to its accurate reflection of the caring situation. While 71% of Local Government responses supported the system, only 48% overall felt that the system was a useful indicator. One possible reason for this difference is that Local Government and those agencies using the Service Coordination Tool Templates and Profiles are familiar with the Tools and the scoring systems used in the Profiles.

We consider that support for the Carer Profile from agencies was very high considering that:

- the Carer Profile was a draft and there was limited training associated with its use;
- the trial required agencies to collect extra data above their already considerable involvement in PCP work;
- the development of the profile was still occurring at the time of the trial - for example, discussions were being held with DHS;

- the trial sample was small.

Carer Feedback

A small number of carers who were involved in the trial provided feedback on the Carer Profile. Each carer interviewed expressed enthusiasm for the Carer Profile and the focus it provides on the carer role. Valuable input and comments were also contributed by the carers on the Project Reference Group. The following quotes from carers were noted:

"It is important that carers are considered as a separate entity"

"Support for the carer is a critical part of support for the person being cared for "

"Carer respite means that we can have a normal life"

Further development of the Carer Profile

The evaluation process clearly indicated where additional work was required on the Carer Profile and highlighted the need for specific guidelines to support the use of the Carer Profile. Further development occurred as follows:

- **How To Complete the Carer Profile Guidelines** were developed in a similar format to the existing Service Coordination Tool Templates and Profile Guidelines in order to support the inclusion of the Carer Profile in the future. The guidelines explain the purpose, benefits and components of the Carer Profile.
- **The consent section of the Profile** was changed to cover carer consent, consent in regard to how the profile is stored, whether the Consumer Consent Form has been completed and whether the care-recipient is aware that details are being collected.
- **The scoring system** was changed to allow the score to be recorded.
- **The statements in Impact of Caring** were re-ordered.
- **The role of carer section** was changed to a summary section to allow the carer, in conjunction with the practitioner, the opportunity to summarise how he/she feels about the caring role.

The positive results of this project indicate the value of the Carer Profile. However, its adoption as part of the Service Coordination Tool Templates will require further testing across a wide range of agencies with a diversity of carers. Testing the profile widely will enable greater evaluation of its applicability across the range of PCP agencies, as the sample size was small in this Project.

Training and workforce development will be important to ensure that the intent and purpose of the Carer Profile is consistently understood. While it is well recognized that many agencies do focus on carer needs, this focus is not formalised and may be dependent on the skill and experience of practitioners.

Consultations with DHS

Consultations with DHS Central Office also formed part of the evaluation process. Following the carer profile trial, an evaluation meeting was held with DHS Central Office. This meeting proved positive in regard to the outcomes of the Project and highlighted areas where further consideration was required, specifically in regard to privacy and confidentiality.

A further meeting considered the guidelines and the changes suggested at the first meeting and supported the proposed recommendations for a statewide trial of the Carer Profile.

Limitations of the Trial

In considering the valuable outcomes of this Project, it is important to acknowledge that it has been limited in scope. In particular, the limitations include:

- The small number of cares involved.
- Limited time availability by those agencies involved.
- Limited training opportunities to prepare assessment workers.
- No guidelines to support the Carer Profile at the time of the trial.

Significantly, the trial coincided with the involvement of agencies in other competing PCP activities, which had particular impact on the capacity of agencies to participate.

8. OUTCOMES AND CONCLUSION

The major outcome of this project has been the development of the Carer Profile with supporting Guidelines and Flow Chart which has been developed in consultation with carers and service providers. The Carer Profile, supporting guidelines and flowchart are now part of the WMR Service Coordination Best Practice and Continuous Improvement Manual. The process undertaken, while limited to the Western Metropolitan Region, clearly indicates the value of a more formalised approach to the role of carers. In addition, the documentation is in a form which enables easy adoption for a more extensive trial and evaluation across the state.

The implementation of this project raised the awareness of carer needs in those WMR PCP agencies that participated in the trial. Those WMR PCP agencies now have access to a process which improves the focus on carers through the processes of IC, INI and CP.

The Project also provided some valuable opportunities for promoting and publicising work in which other PCPs have expressed interest. Media releases appeared in the Leader Group of newspapers during Carers' Week, 2002 (see Appendix1, page 17). A presentation about the project was made at the Statewide Consumer/Carer Group meeting in December, 2002. Presentations to the Municipal Association of Victoria (MAV) and LPro (Local Government Professionals) are planned for early in 2003.

An expression of interest to present at the statewide PCP Best Practice Conference in February, 2003, was also successful.

Time to focus on caring for the carers

By Julie Griffiths

A NEW project focusing on the needs of people who care for loved ones with an illness or disability will be provided during National Carers Week this month.

Moonbee Valley Primary Care Partnership is managing the project, which is looking for ways to ensure the needs of carers are considered when they first come in contact with support services.

A survey, "Self" and will be conducted in 1999 showing

that the physical, mental and emotional health of carers is being affected by the demands of caring for someone with a chronic illness.

The project aims to develop systems to support carers' needs and enhance care outcomes for them and the people they care for.

As part of the project, a wider outcome, a specialist need information service detailing all support services available to carers will be set up to ensure service providers can give carers a complete list of services available.

to them from counsellors, Primary Care Partnerships and community health services.

Support services available for carers include general home care, personal care and respite services.

■ Moonbee Valley Council is holding a training tea to recognise carers in the municipality of the Moonbee Valley Civic Centre, 9 Kellaway Ave, Moonbee, on Thursday, October 27, at 10.30am. The evening opens new carers interested in accessing support services will later.



Fay Brassington and council worker Hazel Ingram.

Accepting support

Fay Brassington is always happy to help anyone who needs it, but she says it is often difficult for people to accept the support that is offered.

Mrs Brassington, 70, cares for her husband, Len, 73, who suffers from a condition known as Pick's Disease.

She has been a full-time carer for 10 years and admits she would not have coped as well without the support services provided through outlets such as Moonbee Valley Council and Moonbee Valley Primary Care Partnership.

Mrs Brassington still expects to receive

were particularly helpful for her because they provided the opportunity to meet people and socialise.

"It's been good because I've met people who do offer me help not known to me."

The council's respite program has also provided the husband couple with opportunities to take holidays together, along with other carers and their partners, and support staff.

Mrs Brassington urged carers who had not used support services to take advantage of support such as home care, personal care and respite services.

THE KITCHEN APPLIANCE PACKAGES SALE



The Kiltwear Galleries

APPENDIX 2

Profile: Carer

The form is provided as a guide only and does not constitute a contract.

Record Agency Assigned Consumer Identifier (initial contact agency)

or affix label here

SECTION 1: Carer details:

Family Name:	Title (click one) <input type="checkbox"/> Mr <input type="checkbox"/> Mrs <input type="checkbox"/> Ms <input type="checkbox"/> Other
Given Names:	Preferred Name/s:
Date of birth: (dd/mm/yyyy)	Sex (click one) <input type="checkbox"/> Male <input type="checkbox"/> Female
Country of Birth: Australia <input type="checkbox"/> Other <input type="checkbox"/>	Indigenous Status
If other, specify:	Please specify:
Interpreter Required: Yes <input type="checkbox"/> No <input type="checkbox"/>	Preferred Language
	Please specify:

Cares for:

Consent:

Name:	Carer Consent to complete profile: <input type="checkbox"/> Yes <input type="checkbox"/> No
Contact details: (number) (street)	Consent to include profile with care recipient record: <input type="checkbox"/> Yes <input type="checkbox"/> No
Phone:	If no, separate carer record commenced: <input type="checkbox"/>
Relationship to carer:	Consumer Consent Form completed for referral: <input type="checkbox"/> Yes <input type="checkbox"/> No
Co-resident carer: <input type="checkbox"/> Yes <input type="checkbox"/> No	Care-recipient aware that their details are being collected: <input type="checkbox"/> Yes <input type="checkbox"/> No

Carer Information: (Indicators for particular focus on carer and the care situation)

Item	Question	Score	Score
1.	Over what period has caring been provided by you?	Under 1 year	0
		Between 1 year and 5 years	1
		Over 5 years	0
2.	How many hours per week are taken up with caring?	Less than 20 hours	2
		Between 20 and 30 hours	1
		More than 30 hours	0
3.	Can the person you care for be left alone?	Yes	2
		No	0
4.	Does the person you care for have health or behaviour problems that you find hard to deal with?	Yes	0
		No	2
		Total	

Scores – If the carer scores over 6 ensure the carer has appropriate information. If the score is 6 or less, complete following sections which will assist you in deciding, with the carer, whether the carer becomes a consumer and the INI is complete initial needs identification is to be undertaken.

SECTION 2:

Carer's Overall Health
In general, would you say your health is:
Excellent Very Good Good Fair Poor

Please indicate any current health problems which affect your capacity to care:

Office Use Only: CP Page 1 of 2

Name: _____ Designation/Agency: _____

Sign: _____ Date: _____ Contact Number: _____

If information becomes superseded, indicate below and record updated information on a new form

The information of this form has been superseded

Date: _____ Name: _____ Sign: _____

APPENDIX 2

Profile: Carer			
Impact of Caring			
The following is a list of things which some carers have found difficult in helping to look after someone. Please indicate which, if any, apply to you and give examples from your experience as a carer.			
	Yes	No	
There have been changes in personal plans such as _____	<input type="checkbox"/>	<input type="checkbox"/>	
There have been family adjustments because _____	<input type="checkbox"/>	<input type="checkbox"/>	
There have been other demands on my time from _____	<input type="checkbox"/>	<input type="checkbox"/>	
There have been emotional adjustments because _____	<input type="checkbox"/>	<input type="checkbox"/>	
There have been work adjustments because _____	<input type="checkbox"/>	<input type="checkbox"/>	
My sleep is disturbed because _____	<input type="checkbox"/>	<input type="checkbox"/>	
It is problematic because _____	<input type="checkbox"/>	<input type="checkbox"/>	
It is a physical strain because _____	<input type="checkbox"/>	<input type="checkbox"/>	
It is confining because _____	<input type="checkbox"/>	<input type="checkbox"/>	
Some behaviour is upsetting such as _____	<input type="checkbox"/>	<input type="checkbox"/>	
Some health aspects are difficult because _____	<input type="checkbox"/>	<input type="checkbox"/>	
It is upsetting to find the person in my care has changed so much from his/her former self	<input type="checkbox"/>	<input type="checkbox"/>	
It is a financial strain _____	<input type="checkbox"/>	<input type="checkbox"/>	
Feeling completely overwhelmed because _____	<input type="checkbox"/>	<input type="checkbox"/>	
Information			
How much do you understand about:	<i>Sufficient</i>	<i>Need more information</i>	<i>N/A</i>
The health problem of the person you are caring for _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
The likely progression of the health problem _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Medications used by the person in your care _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community supports available _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Caring safely in the home _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How to access services and assistance _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strategies for coping with the demands of care _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Care coordination services _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specific aspects of care _____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Priority Needs What do you see as your most important needs (in order of priority to you)?			
1. _____			
2. _____			
3. _____			
Summary <i>(tick the most appropriate)</i>		Comments	
Able to continue	<input type="checkbox"/>		
Able to continue with some assistance	<input type="checkbox"/>		
Need a lot of assistance to continue	<input type="checkbox"/>		
Unable to continue	<input type="checkbox"/>		
Completion of these sections, will assist you in deciding, with the carer, whether the carer becomes a consumer and initial need identification will be undertaken with the carer.			
Office Use Only:			CP Page 2 of 2
Name: _____	Designation/Agency: _____		
Sign: _____	Date: _____	Contact number: _____	
If information becomes superseded, indicate below and record updated information on a new form			
The information of this form has been superseded			
Date: _____	Name: _____	Sign: _____	

HOW TO COMPLETE THE CARER PROFILE

The Carer Profile is designed to provide focus on the caring role, as the carer understands his/her role during the processes of Initial Contact (IC) and Initial Needs Identification (INI). While the experience of caring varies, there are a number of factors which may signal the need for additional assistance; these factors form the basis of this profile. This profile relates specifically to carers, and normal procedures that relate to IC and INI are to be followed for care-recipients.

Use of the profile will assist the carer in conjunction with the practitioner to determine initial needs and to decide on further actions. The profile uses widely adopted indicators for determining potential carer stress and is based on the carer's perceptions of the situation. The profile supports the carer in their caring role, by initiating a process which can identify an agreed service response. It is likely that the outcome for the care-recipient will be enhanced through a more structured carer focus. Seek permission and consent from the carer and ascertain whether the carer wishes to undertake this contact with or without the care-recipient.

The accompanying flowchart details the process.

The data items are shown in the following table.

ITEM	Data Type
Section 1	
Carer Details	Box & tick
Cares for	Box & tick
Consent	Tick
Carer Information	Score
Section 2	
Carer's Overall Health	Tick & comment
Impact of Caring Information	Tick
Priority Needs	Comment
Role as carer	Tick
Comments	Summary

Section 1

Carer Details

Collecting carer details will ensure that all relevant information is together in the one form and as such allows the profile to be used as a stand alone document. Although this duplicates information collected in the Consumer Information Tool Template, it also provides additional information specific to the carer – date of birth, country of birth, whether an interpreter is required and preferred language and indigenous status. This information is important for referral to services, for example a respite program.

Evidence/source – HACC MDS & Commonwealth Respite Program MDS.

Cares for

As with the previous information this duplicates the Consumer Information Tool Template. Similarly, it collects information together as well as whether the carer is co-resident. Once completed there is flexibility to use the profile as a stand alone document.

Evidence/source – HACCC MDS & Commonwealth Respite Program MDS

Consent

Consent is required for the collection of information and this consent includes the use and disclosure of information. Discuss with the carer the options for the storage of their information – there maybe information that the carer does not wish the care-recipient to know, in which case a separate record will be required. Complete this segment as follows:

- Indicate whether consent has been obtained from the carer to complete the profile.
- Indicate whether the care-recipient is aware that his/her details may be collected for the purpose of supporting the carer.
- Indicate whether the carer has given consent for their information to be stored with the care-recipient's record and is aware of the reasons for this consent. If no, indicate that a separate record is to be commenced
- Complete the Consumer Consent Tool Template if the outcome is a referral to another service/agency.

Carer Information

Find out some key aspects of the caring role – length of caring – there will be specific adjustments in the first year of caring and over five years indicates that considerable adjustment has been made and that the situation is long term; hours that are involved in caring each week; whether the care-recipient can be left alone; health and behaviour which may be hard to deal with. These questions are important and are well established indicators of carer stress. The scoring system is designed to assist in deciding whether further information is required. Note that a score between 0 – 6 suggests that Section 2 of the profile be completed.

No further action is required if the score is over 6. However, ask the carer questions such as, “Would you like further information that may assist you - about services, support groups, the care-recipient's health?” Ensure that the profile information in Section 1 is included in the care-recipient's record – if consent has been given by the carer - and that the carer information is reviewed regularly, for example, at the next care-recipient review or when the care situation changes. It may also be suggested that the carer make contact if the situation changes.

A score between 0 – 6 provides the opportunity to explore the caring role more specifically, with the carer and possibly the care-recipient, by completing Section 2 of the profile.

Evidence/source – Pierce, G & Nankervis, J - Putting Carers In the Picture, 1998

Section 2

Completing Section 2 will allow the carer to explore the care giving role and their perception of how that role is undertaken in conjunction with the practitioner. Each segment of Section 2 is interconnected and will provide a picture of the overall situation. While the focus is on the carer, it is likely that outcomes for the care-recipient will be enhanced. The approach, if possible, should be on self reporting by the carer.

Carer's Overall Health

This question is selected from the SF-36 (Ware, J E, Kosinski, M. & Kellar, S D – Health Summary Scales, The Health Institute, New England Medical Center, 1993) and is used in the Carer Needs Assessment Form (South Australia, 1998). It is consistent with the self reporting approach used with the range of Service Coordination profiles.

In asking the carer about their health, inquire about how they are going and whether they have experienced any recent changes in their health. Tick the box that best matches their description of their overall health and make relevant comments including whether their medical practitioner has or has not been told.

Evidence/source – SF-36 & Carer Assessment Form (South Australia, 1998)

Impact of Caring

These statements have been selected from the Caregiver Strain Index (Butler, Fricke and Humphries, 1993) currently in use by RDNS. This index has proven ability as a valid screening instrument in assessing the impact of caring in a multidimensional manner using commonly identified stressors.

A positive response to seven or more items on the index would indicate a greater level of stress (Butler et al 1993:48).

The format provides carers with the opportunity to respond freely to the statements and to give examples if desired. The index can also be used as a prompt by practitioners and the statements explained, if necessary. This flexibility means that the index can be used in a manner which is appropriate to the situation. Where possible, however, it is important to obtain the carer's perception.

Evidence/source – Carer Strain Index & Maddock et al Carer Needs Assessment Trial, 1998

Information & Priority Needs In your role as carer

This provides the carer with an opportunity to indicate gaps in information and explores the carer's understanding in a range of identified areas. It is important to consider these areas in conjunction with Priority Needs and the carer's perception of their ability to undertake the role of carer.

In the Information segment tick the most appropriate response and assist the carer to detail the three most important Priority Needs based on the responses to the previous parts of Section 2. These are priorities perceived to be important by the carer at the time of this engagement and will likely change over time.

Evidence/source – Carer Needs Assessment Form (South Australia, 1998)

Summary

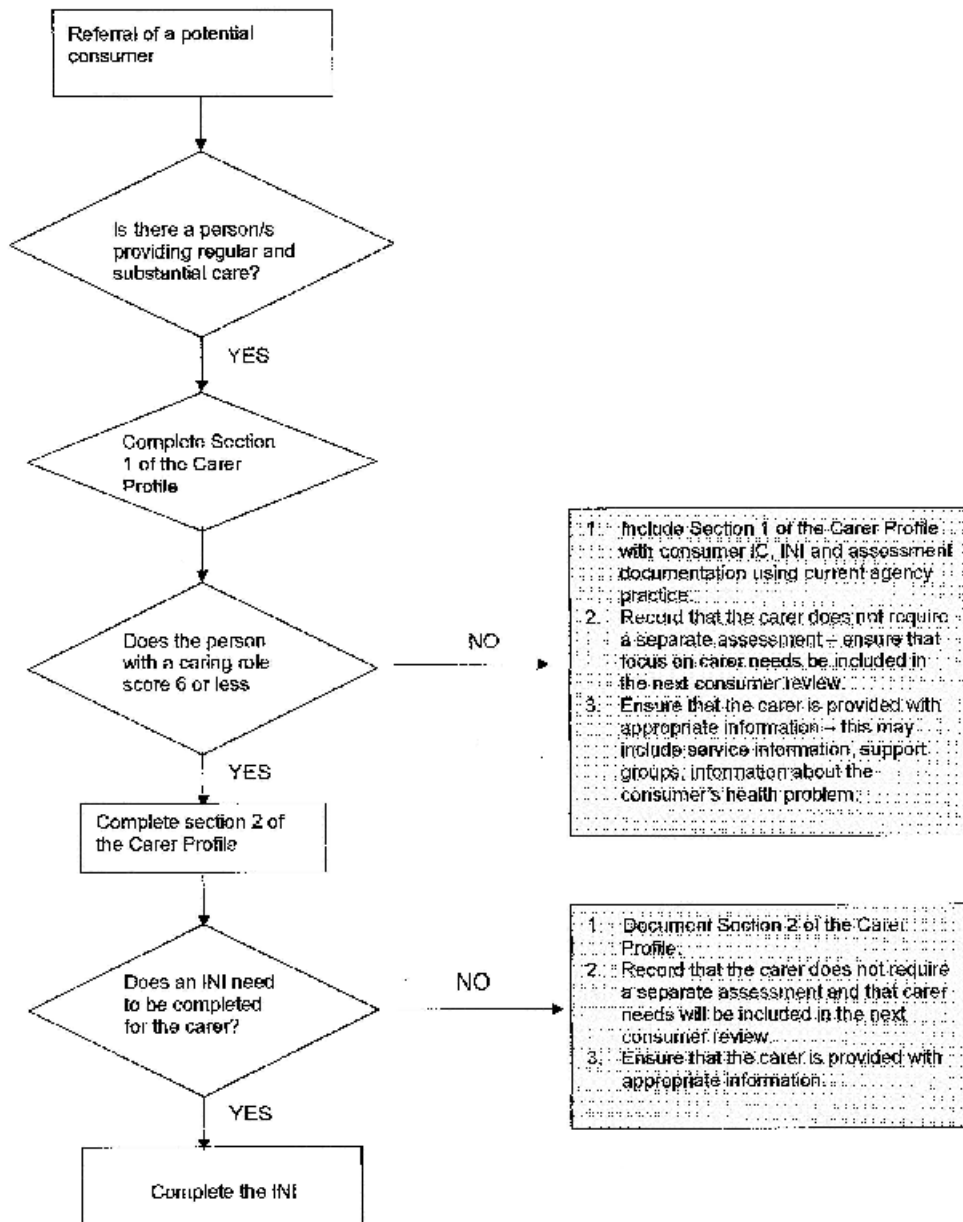
This provides the carer, in conjunction with the practitioner, the opportunity to summarise how he/she feels about the caring role. Complete this segment based on the information gained in the previous segments and confirm with the carer the most appropriate response.

Comments

Completion of Section 2 will assist in determining where to from here. Information gained in each segment of this Section provides a picture of the caring role and how that role is being performed. Consider all aspects – overall health, impact of caring, information, priority needs and summarise the required action.

| If the carer's needs are not being met undertake a separate initial needs identification process with the carer and make appropriate referrals to a carer support agency or information service.

Flowchart - improving the focus on carer needs



If yes, Please specify

Impact of Caring

Yes ? No ?

If yes, Please specify

Information

Yes ? No ?

If yes, Please specify

Priority Needs

Yes ? No ?

If yes, Please specify

Your role as a carer

Yes ? No ?

If yes, Please specify

3. Is the Carer Profile a useful addition to assessment profiles?

Yes ? No ?

If no, Please specify

4. Does the scoring system in Section 1 give an accurate reflection of the caring situation?

Yes ? No ?

If no, Please specify

5. Does Section 2 assist in you in deciding, with the carer, whether the carer becomes a consumer and the INI (or relevant agency tools) is completed?

Yes ? No ?

If no, Please specify

Does the Carer Profile fit with your current documentation system?

Yes ? No ?

If no, Please indicate what changes may be required

6. Does the flow chart accurately reflect the process?

Yes ? No ?

If no, Please specify

7. Does the Carer Profile further assist you to improve the focus on carer needs?

Yes ? No ?

If yes, Please specify

If no, Please specify

8. Does the Carer Profile assist carers to identify their needs better?

Yes ? No ?

If no, Please comment

9. How long did it take you to complete the Carer Profile?

Section 1.....minutes Section 2.....minutes

10. Any Further comments

Thank you for your participation.

Please complete and fax to Stuart Absalom, 9397 0030, by Friday, 8th November, 2002

APPENDIX 4

IMPROVING THE FOCUS ON CARER NEEDS IN INITIAL CONTACT, INITIAL NEEDS IDENTIFICATION AND CARE PLANNING

Trial Guidelines

1. Meeting Dates and Timelines

The trial of the documentation to focus on carer needs will be conducted between Tuesday, 15th October and Friday, 8th November. The initial meeting to outline the trial will be held on Monday, 14th October 9.30am -11.00am at 7 Matthews Ave Niddrie in the former Preschool Building. The meeting to evaluate the documentation will be held on Tuesday, 12th November 9.30am -11.00am at 7 Matthews Ave Niddrie. If the dates for the initial meeting or evaluation meeting do not suit, please contact Stuart (9397 5959) or Thelma (9682 2090) directly to discuss alternatives.

2. Agencies involved in the trial

- RDNS
- ISIS
- Shire of Melton
- Essendon Day Centre
- Carerlinks West
- Shire of Wyndham
- Melbourne City Council
- Doutta Galla Community Health Service
- Brimbank City Council
- NW ACAS
- Moonee Valley City Council
- Maribyrnong City Council
- Hobsons Bay City Council

3. The cohort group

It is anticipated that each agency would have no more than 3 assessments/reviews to complete for the trial. Could you please consider the cohort group and determine whether these match your data base or fit with new referrals. If so, could you please advise either Stuart or Thelma prior to the meeting on the 14th October. At this meeting cohort groups will be allocated to each agency.

- Carer of a younger person with a disability – birth to 18
- Carer of a person form 19 – 64
- Carer of an older person 65 – 79
- Carer of an older person 80+
- Carer who is under 25 years of age

- Frail aged carer who is caring for an adult with a disability
- Aged carer caring for a frail aged person
- Multigenerational carer i.e. caring for child with disability and elderly relative
- Carer of workforce age
- CALD carer
- Caring for a CALD where there is a conflict in the caring culture
- Carer who has had a long term caring responsibility
- Male carer
- Carer at risk because caring for a person with:
 - challenging behaviour
 - a mental illness
 - multiple and complex care needs

4. The Documentation

The following documentation will be emailed to you prior to the meeting on the 14th October.

- The Carer Profile (including triggers)
- Expectation of the participants
- Evaluation questions for the participants to complete

5. Focus Groups with Carers

We will be conducting 3 Carer focus groups across the WMR.

IMPROVING THE FOCUS ON CARER NEEDS IN INITIAL CONTACT, INITIAL NEEDS IDENTIFICATION AND CARE PLANNING

Outline of the Session with Agencies

1. Introduction

Stuart and I were appointed to this Project in late July 2002 with an ambitious completion date of the middle of December. The Reference Group consists of representatives from RDNS, Carers Victoria, ISIS, City of Wyndham, City of Moonee Valley, Carerlinks West as well as two carers to assist us with the project.

2. Aim

The aim of the Carers project is to improve the focus on carers needs in Initial Contact, Initial Needs Identification and Care Planning.

3. Overview of the Project

The following is a summary of outcomes up to 14th October 2002

- Comprehensive literature research within Australia and overseas
- Conducted an initial pretest of the INI with Moonee Valley and Wyndham to confirm earlier findings of the inappropriateness of the INI for carers
- Changed the focus of the project to the development of a Carer Profile
- Development of protocols, triggers and carer profile based on literature search
- Development of an operational framework for the trial which details key stakeholders, sample of carers, the methodology and the timing
- Development of evaluation criteria and processes that will assist in formulating recommendations about adjustments to the IC, INI, and CP tools and requirements for workforce development
- Publicised the project
- Met with DHS

4. Explanation of the Documentation

Profile: Carer

- Outline the process which resulted in the development of the Carer Profile
- The Carer Profile is not an assessment tool
- Agreement by the reference Group
- Profile has been completed with a carer
- Go through the carer details (MSD compatibility)
- Triggers & scoring system - the triggers are included within the Carer Profile and the scoring system follows that of the INI suite of tools. Completion of the triggers and if the score is 6 or under then completion of the Carer Profile.
- Completion of the Carer Profile will assist assessment staff in deciding with the carer whether the carer becomes a consumer and the INI is completed.
- The Carer Profile is assessing burden of caring & does not provide info eg support groups

Protocols and Supporting Flow Chart

Evaluation Questions

What would the trial involve for agencies?

- An initial meeting on Monday, 14th October to explain the trial, the documents, and the evaluation questions
- 3 contacts with clients/carers either new or clients who may require a review
- An evaluation meeting to be held in on Tuesday, 12th November
- a timeframe of October and early November

Matching the Carer Profile to Agencies

- Carer of a younger person with a disability – birth to 18
- Carer of a person form 19 – 64
- Carer of an older person 65 – 79
- Carer of an older person 80+
- Carer who is under 25 years of age
- Frail aged carer who is caring for an adult with a disability
- Aged carer caring for a frail aged person
- Multigenerational carer i.e. caring for child with disability and elderly relative
- Carer of workforce age
- CALD carer
- Caring for a CALD where there is a conflict in the caring culture
- Carer who has had a long term caring responsibility
- Male carer
- Carer at risk because caring for a person with:
 - challenging behaviour
 - a mental illness
 - multiple and complex care needs

Following the trial

Draft recommendations which will include:

- information from previous work in regard to carers as identified in the literature review;
- analysis of data and information collected as part of the Consultation Stage;
- results of the field testing of the protocols;
- identification of workforce development issues.

The recommendations will take into account:

- the development of carer responsive Practices, Processes, Protocols and Systems (PPPS) including referral triggers;
- the identification of comprehensive carer needs;
- workforce development opportunities including PPPS, training and support of agencies/personnel;

- consistency of approach through practice processes and the development of strong interagency relationships;
- development of practice principles/guidelines for PCP agencies.

The draft recommendations will be distributed to all stakeholders for comment, review and refinement in the middle of November.

APPENDIX 5

IMPROVING THE FOCUS ON CARER NEEDS IN INITIAL CONTACT, INITIAL NEEDS IDENTIFICATION AND CARE PLANNING

ANALYSIS OF QUESTIONS – NOVEMBER, 2002

Number of responses - 29

Responses from the following organizations

- Local Government - 14
 - Melbourne City Council - 1
 - Moonee Valley City Council - 3
 - Hobsons Bay City Council - 3
 - Wyndham City Council - 2
 - Maribyrnong City Council – 2
 - Shire of Melton – 3
- Royal District Nursing Service – 2
- Western Aged Care Assessment Service – 3
- ISIS Primary Care Linkages/CACPs – 5
- Carer Links West – 2
- Doutta Galla Community Health Service – 3

Carer Cohort Group

- Carer of a younger person with a disability – birth to 18 - **4**
- Carer of a person form 19 – 64 - **2**
- Carer of an older person 65 – 79 - **3**
- Carer of an older person 80+
- Carer who is under 25 years of age
- Frail aged carer who is caring for an adult with a disability - **1**
- Aged carer caring for a frail aged person - **1**
- Multigenerational carer i.e. caring for child with disability and elderly relative
- Carer of workforce age - **1**
- CALD carer - **3**
- Caring for a CALD where there is a conflict in the caring culture
- Carer who has had a long term caring responsibility - **1**
- Male carer - **3**
- Carer at risk because caring for a person with:
 - challenging behaviour - **2**
 - a mental illness - **1**
 - multiple and complex care needs – **1**

LOCAL GOVERNMENT

11. Is the format of the Carer Profile easy to follow?

Yes	12	No	1
-----	----	----	---

If no, Please specify

12. Are there any additions or changes to the following:

Carer Details

Yes	2	No	11
-----	---	----	----

If yes, Please specify

Marital status, type of income

Some carers are not comfortable with the amount of detail eg DOB

Indicators

Yes	1	No	12
-----	---	----	----

If yes, Please specify

Carers Overall Health

Yes	0	No	13
-----	---	----	----

If yes, Please specify

Sometimes difficult for carers to articulate

Impact of Caring

Yes	6	No	8
-----	---	----	---

If yes, Please specify

Should be conducted away from the consumer - 2

Difficult for a parent to answer who feels it is her duty to carer for her child

Questions are too intrusive and too negative

What does personal plans mean, too broad

Inconvenient is inappropriate especially if caring for loved one – 2

Overlap between difficulties due to caring and other family issues

Information

Yes	2	No	12
-----	---	----	----

If yes, Please specify

Not appropriate for HACC assessment - 2

Priority Needs

Yes	1	No	13
-----	---	----	----

If yes, Please specify

Difficult for parent to answer as family is main priority

Your role as a carer

Yes	4	No	10
------------	---	-----------	----

If yes, Please specify

Parent felt uncomfortable in answering as feared child could be taken away

Needs to take account of fluctuating feelings

13. Is the Carer Profile a useful addition to assessment profiles?

Yes	12	No	2
------------	----	-----------	---

If no, Please specify

Not in this format

Definitely, as INI does not currently have much detail re carers

14. Does the scoring system in Section 1 give an accurate reflection of the caring situation?

Yes	10	No	3
------------	----	-----------	---

If no, Please specify

Aim of scoring system is not clear, if above 6 then give them information about what?

15. Does Section 2 assist in you in deciding, with the carer, whether the carer becomes a consumer and the INI (or relevant agency tools) is completed?

Yes	12	No	2
------------	----	-----------	---

If no, Please specify

Yes, but only if it helps deciding who should be the client, the child or the parent

Most of the criteria during intake is gained to assess whether client is eligible for service

Does the Carer Profile fit with your current documentation system?

Yes	10	No	2
------------	----	-----------	---

Depends on the electronic system to support the Profile

The information could be entered under general text of Sharikat

It gathers very similar information to respite application that must be completed for carers

Sharikat needs to be modified - 2

16. Does the flow chart accurately reflect the process?

Yes	13	No	0
------------	----	-----------	---

If no, Please specify

17. Does the Carer Profile further assist you to improve the focus on carer needs?

Yes	11	No	3
------------	----	-----------	---

If yes, Please specify

Yes, but it makes the carer feel like I was looking for reasons for her not coping
Good to assist I referral process to appropriate services
Gives a clearer picture of the situation and particular questions prompt further discussion
Many respite funding applications require this level of specific information which isn't necessarily gathered
You have a bigger picture of the impact of caring
Gives more detail for service requirements for carer

If no, Please specify

It is good to be able to state the carer's needs but I find the whole form a bit overwhelming
Carer is prompted at assessment regarding their needs
We have always focused on the needs of the child and the family

18. Does the Carer Profile assist carers to identify their needs better?

Yes	11	No	3
------------	----	-----------	---

If no, Please comment

It made the parent feel she was painting a negative picture of her child, she felt uncomfortable & embarrassed

Already very aware of personal/family needs

Carers may not be aware that they have needs that can be addressed

19. How long did it take you to complete the Carer Profile?

Section 1: 3, 5, 10, 15 minutes

Section 2: 5, 8, 10, 15, 20 minutes

20. Any Further comments

Concern re entering data and how this fits with the INI *confusion re the purpose of the form I think(MCC)*

Conduct assessment with carer in a separate session - 2

Section 1: may be relevant for statistical reasons and Section 2 needs to be relevant & sensitive to carer and client

Needs to be more reflective of families who care for a younger person with a disability – 1

Profile needs to include care of siblings for carers of younger person with a disability – 1

The Profile could be part of the INI as an option, if the carer is a client then there will be an expectation for services

Asking these specific questions helps acknowledge carers in their role – often assessments are more than gathering information

I envisage that the Carer Profile would be filed with both the consumer and carer if they both become a client

The Profile is very beneficial in assisting me work out what the client/carers respite needs were

The use of the Profile in regard to privacy and confidentiality is not clear

Needs a section for clients who are receiving a carers pension and if not how they can access information

21. Difference in the Services Offered

Assisted in making appropriate referrals

22. How was Information Collected

Entered in progress notes and used to establish a Care Plan

ROYAL DISTRICT NURSING SERVICE

1. Is the format of the Carer Profile easy to follow?
Yes 2 No 0

If no, Please specify

2. Are there any additions or changes to the following:

Carer Details
Yes 0 No 2

If yes, Please specify

Indicators
Yes 0 No 2

If yes, Please specify

Carers Overall Health
Yes 0 No 2

If yes, Please specify

Impact of Caring
Yes 0 No 2

If yes, Please specify

Information
Yes 0 No 0

If yes, Please specify

Priority Needs
Yes 0 No 0

If yes, Please specify

Your role as a carer
Yes 0 No 0

If yes, Please specify

3. Is the Carer Profile a useful addition to assessment profiles?
Yes 2 No 0

If no, Please specify

4. Does the scoring system in Section 1 give an accurate reflection of the caring situation?

Yes 0 No 2

If no, Please specify

5. Does Section 2 assist in you in deciding, with the carer, whether the carer becomes a consumer and the INI (or relevant agency tools) is completed?

Yes 0 No 2

If no, Please specify

The carer doesn't see that he has any needs at this stage that haven't been addressed - 2

Does the Carer Profile fit with your current documentation system?

Yes 0 No 2

Could be more incorporated with carer stress tool - 2

6. Does the flow chart accurately reflect the process?

Yes 2 No 0

If no, Please specify

7. Does the Carer Profile further assist you to improve the focus on carer needs?

Yes 2 No 0

If yes, Please specify

As it is an assessment it is more detailed

If no, Please specify

8. Does the Carer Profile assist carers to identify their needs better?

Yes 1 No 1

If no, Please comment

Carers may not be aware that they have needs that can be addressed

9. How long did it take you to complete the Carer Profile?

Section 1: 15, 30 minutes Section 2: 20 minutes

10. Any Further comments

More multichoice with N/A

Ask the person being cared for if they think there are any concerns about the carer

ISIS

- 1. Is the format of the Carer Profile easy to follow?**
Yes 3 No 2

If no, Please specify

Guidelines required for use of the Profile

- 2. Are there any additions or changes to the following:**

Carer Details

Yes 0 No 5

If yes, Please specify

Indicators

Yes 0 No 4

If yes, Please specify

Carers Overall Health

Yes 0 No 5

If yes, Please specify

Impact of Caring

Yes 1 No 4

If yes, Please specify

Should be worded as a question not a statement
Words such as inconvenient and confining are not words carers like to use
Questions need to be rephrased for CALD carers
Needed prompts to get the information

Information

Yes 0 No 5

If yes, Please specify

Useful as prompted ideas for service provision

Priority Needs

Yes 0 No 4

If yes, Please specify

Not clear whether this relates to met or unmet needs
Useful to identify what service would be the most useful

Your role as a carer

Yes 1 No 4

If yes, Please specify

- 3. Is the Carer Profile a useful addition to assessment profiles?**
Yes 4 No 1

If no, Please specify

Suggest that "without assistance" is added to Able to continue

4. Does the scoring system in Section 1 give an accurate reflection of the caring situation?

Yes 2 **No** 3

If no, Please specify

Basis of scoring not clear
Carers underestimate the time spent caring
Scoring does not necessarily indicate the extent and stress of caring

5. Does Section 2 assist in you in deciding, with the carer, whether the carer becomes a consumer and the INI (or relevant agency tools) is completed?

Yes 2 **No** 2

If no, Please specify

Does the Carer Profile fit with your current documentation system?

Yes 3 **No** 1

Need an electronic version of the Profile
Existing software does not allow a file for the carer – however carer information is considered when developing care plans

6. Does the flow chart accurately reflect the process?

Yes 4 **No** 0

If no, Please specify

7. Does the Carer Profile further assist you to improve the focus on carer needs?

Yes 4 **No** 1

If yes, Please specify

Assists in identifying specifically ways in which support can be provided
Good opportunity to discuss role with carer

If no, Please specify

8. Does the Carer Profile assist carers to identify their needs better?

Yes 2 **No** 1

If no, Please comment

9. How long did it take you to complete the Carer Profile?

Section 1: 2/5/15/10/4 **Section 2:** 15/5/30/20/4

10. Any Further comments

Written information for the carer about the Profile and its use

WACAS

1. Is the format of the Carer Profile easy to follow?
Yes 3 No 0

If no, Please specify

2. Are there any additions or changes to the following:

Carer Details

Yes 1 No 2

If yes, Please specify

Indicators

Yes 0 No 3

If yes, Please specify

Carers Overall Health

Yes 0 No 3

If yes, Please specify

Impact of Caring

Yes 2 No 1

If yes, Please specify

Too lengthy for ACAS purposes
Carer not comfortable trying to think of examples

Information

Yes 1 No 1

If yes, Please specify

Tendency for carer to say yes to all questions
Too lengthy for ACAS purposes

Priority Needs

Yes 0 No 2

If yes, Please specify

Helpful

Your role as a carer

Yes 1 No 1

If yes, Please specify

3. Is the Carer Profile a useful addition to assessment profiles?

Yes 0 No 1

If no, Please specify

Would not be able to offer this level of career assessment.

Difficult to assess carer's insight into the needs of the client and whether their judgement about their capacity to care is realistic

CARER LINKS WEST

- 1. Is the format of the Carer Profile easy to follow?**
 Yes 1 No 1

If no, Please specify

Language not easy to follow for carers
 Expanded to include carers who are not co-residents eg travel arrangements

- 2. Are there any additions or changes to the following:**

Carer Details

- Yes 1 No 1

If yes, Please specify

Carers are often caring for other family members eg siblings, spouse of person requiring care

Indicators

- Yes 0 No 2

If yes, Please specify

Scoring is easily followed and adequate

Carers Overall Health

- Yes 1 No 1

If yes, Please specify

Expand to allow for carers who have several comments

Impact of Caring

- Yes 1 No 1

If yes, Please specify

Excellent tool for indicating stressors for home and family dynamics
 Insufficient space for detailed complex answers

Information

- Yes 0 No 2

If yes, Please specify

Priority Needs

- Yes 1 No 1

If yes, Please specify

Good – more writing space would be helpful

Your role as a carer

- Yes 0 No 2

If yes, Please specify

- 3. Is the Carer Profile a useful addition to assessment profiles?**
 Yes 1 No 0 Somewhat 1

If no, Please specify

Time consuming and got no more information than with normal assessment bit if it helps to feedback to DHS then worthwhile

4. Does the scoring system in Section 1 give an accurate reflection of the caring situation?

Yes 2 **No** 0

If no, Please specify

5. Does Section 2 assist in you in deciding, with the carer, whether the carer becomes a consumer and the INI (or relevant agency tools) is completed?

Yes 2 **No** 0

If no, Please specify

The carer doesn't see that he has any needs at this stage that haven't been addressed - 2

Does the Carer Profile fit with your current documentation system?

Yes 1 **No** 1

Could be more incorporated with carer stress tool - 2

6. Does the flow chart accurately reflect the process?

Yes 1 **No** 0

If no, Please specify

7. Does the Carer Profile further assist you to improve the focus on carer needs?

Yes 1 **No** 0 **Somewhat** 1

If yes, Please specify

Very useful in determining need and potential resource/linkages
Provides a way of organizing and collecting information

If no, Please specify

8. Does the Carer Profile assist carers to identify their needs better?

Yes 2 **No** 0

If no, Please comment

9. How long did it take you to complete the Carer Profile?

Section 1: 13/25 minutes **Section 2: 20/20 minutes**

10. Any Further comments

One carer was from CALD background – completing section 2 was difficult for her. Section 2 took a while to complete as it was necessary to refer to Section 1 – with familiarity the process will be much quicker
Carer reported that it was difficult to summarise responses in “Impact of Caring” section – huge open ended questions that are good for discussion but difficult to report in current format

DOUTTA GALLA COMMUNITY HEALTH SERVICE

1. Is the format of the Carer Profile easy to follow?
Yes 1 **No** 2

If no, Please specify

Provide statements that carers could choose from
 Some questions not clear eg Priority Needs
 A bit lengthy and some questions are very leading

2. Are there any additions or changes to the following:

Carer Details
Yes 0 **No** 3

If yes, Please specify

Indicators
Yes 0 **No** 3

If yes, Please specify

Carers Overall Health
Yes 0 **No** 3

If yes, Please specify

Impact of Caring
Yes 2 **No** 1

If yes, Please specify

Wording of some examples hard to understand

Information
Yes 1 **No** 2

If yes, Please specify

Points/questions would be more effective if in simpler language particularly for CALD communities

Priority Needs
Yes 1 **No** 2

If yes, Please specify

Need as question to understand what this question is about

Your role as a carer
Yes 0 **No** 3

If yes, Please specify

3. Is the Carer Profile a useful addition to assessment profiles?

Yes 3 **No** 0

If no, Please specify

If it could be revised to fit on one page

4. Does the scoring system in Section 1 give an accurate reflection of the caring situation?

Yes 1 **No** 2

If no, Please specify

with Caring, although for long hours, may not be constantly demanding for the carer who lives
those being cared for
Need more testing with a variety of carers
The way carers cope can be quite subjective depending on the carer's personality

5. Does Section 2 assist in you in deciding, with the carer, whether the carer becomes a consumer and the INI (or relevant agency tools) is completed?

Yes 2 **No** 1

If no, Please specify

In completing OT assessment and INI had already become aware of carer's issues

Does the Carer Profile fit with your current documentation system?

Yes 2 **No** 1

6. Does the flow chart accurately reflect the process?

Yes 2 **No** 0

If no, Please specify

7. Does the Carer Profile further assist you to improve the focus on carer needs?

Yes 2 **No** 0 **Somewhat** 1

If yes, Please specify

Would be more effective with the changes mentioned above

If no, Please specify

8. Does the Carer Profile assist carers to identify their needs better?

Yes 2 **No** 1

If no, Please comment

Experience has been that carers often know their needs quite well

9. How long did it take you to complete the Carer Profile?

Section 1: 5, 10, 35 minutes

Section 2: 15 minutes

10. Any Further comments

Important to provide carers with the opportunity for free expression

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