

Issues raised by Carers and Consumers were forwarded to participants, Members of Parliament (Both State and Federal) in the region and Ageing, Disability and Home, Human Services Department, NSW – to follow up Australian Government Department of Health and Ageing and SSWAHS

Information, Training and Education

Issue/Gap Identified	Strategies to Address	By whom	By when
Training for carers in role, effect of disability of client, complex needs Proper training for carers now to take care of the person they care for Better informed about how the different symptoms of different injuries effect patients	Map availability of this type of training Advocate to run training in SWS	Carers Interagency/ Carers & Consumers Working Party	
Lack of information and lack of knowledge of who to ask for - Centrelink as central point for information about services Isolated people: how to access information and services	Education about Services continues Get to Know the Aged Care System run with Carers Access Points Demonstration Project rolling out to SWS in the future Liaise with Centrelink Social Workers so that they have comprehensive knowledge about services available and up-to-date resources	Carers Interagency/ Carers & Consumers Working Party	
Forward Planning for Carers/Power of Attorney	Advocate to run training on forward planning for Carers Run training on Power of Attorney		
How to find out about existing Carer Support Groups	As part of the Met South Carers Project this is being done Will distribute this Carer Support Groups List widely		
Promote counseling for Carers Counselling for Carer Support Groups	Carers NSW, Alzheimers NSW offers counseling, promote the availability of counseling for carers		
Information distribution through carer networks	Development Workers in SWS to ensure that information relevant for Carers is distributed through Carer Networks	All development workers, workers who support Carers	Ongoing
A specific worker for Carers of People with Acquired Brain Injury	Ensure that this need is raised with the Funding Bodies		
Community Care – Carers educate other Carers	Mentor Carer Support Group Leaders on the Community Care		

Issue/Gap Identified	Strategies to Address	By whom	By when
	System Provide resources AFFORDs Carers Training Package		
Lack of knowledge about services	Ensure that Services provide a LGA specific directory for their clients when they do an assessment Look into running some training for Carer & Consumers on using the support services website to find services	Community Care Services/ HACC Development Officer support services training	
Find out about what's available through others, not services, not good enough	Services note the need to inform clients about the services available, basic education to direct care workers and volunteers as well as Coordinator and Management levels	Community Care Services	
Information available in multi mediums eg printed and audio, SBS, newspaper	Continue to create accessible information in a variety of mediums MAP worker has developed audio format on HACC services for Khmer clients, working on another language, SWCT audio and written information, BCT has DVD on the service currently in Arabic and Vietnamese		
Do HACC Services assist people with Mental Illness	Services are clear about who they can provide services to – HACC DO Sutherland has developed a fact sheet for Service Providers, will distribute when approved Clear and consistent information needs to be given to consumers	HACC DOs re the fact sheet & then distribute to services for 2 nd strategy to be implemented	

Support to Carers to Continue to Care

Issue/Gap Identified	Strategies to Address	By whom	By when
Breaks for Carers: Somewhere for ShortBreaks Holiday outings with information sessions, weekends away Evening Group Activities – cinema, theatre, etc Socialising Activities	Map what's available in the area in relation to breaks for Carers Apply for Clubs Funding and other opportunities to meet these needs	Carers Interagency/ Carers & Consumers Working Party	

Issue/Gap Identified	Strategies to Address	By whom	By when
Support Groups for Carers and Transport to attend Support Groups	Map existing Groups and identify gaps Advocate for transport component to be a part of Carer Support Groups as well as Respite		
Access to therapy when the Carer is unwell – physio, OT	Find out the availability of such therapy services for Carers to assist them to continue to care		
Services providing service to Carers	HACC program has Carers as one of its target group Include this issue for planning		
Who takes care of Carers if they are sick	Promotion of Emergency Respite options for Carers Training for Carers on Emergency Plans		

Aged Services

Issue/Gap Identified	Strategies to Address	By whom	By when
Not enough packages (Community Aged Care Packages or Extended Aged Care at Home/ Extended Aged Care at Home – Dementia packages) available – flexibility within packages and services – needs to fit client needs not what services are wanting to offer	Forward this issue to Department of Health and Ageing for a response	HACC Development Officer will draft up a letter with feedback from Carers & Consumers Forum	
Expense of residential respite and you must have 2 weeks	Forward this issue to Department of Health and Ageing for a response	Forward this issue to Department of Health and Ageing for a response	
Want to stay at home rather than go to Nursing Home	Forward this issue to Department of Health and Ageing for a response	Forward this issue to Department of Health and Ageing for a response	

Disability Services

Issue/Gap Identified	Strategies to Address	By whom	By when
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Issue/Gap Identified	Strategies to Address	By whom	By when
Supported Employment: No social outings or support, low pay No service helping parents to go around to businesses to seek employment for their son or daughter with a disability	Seek response from Supported Employment Providers		
Respite: Respite and communication, request respite – 4 months earlier (school terms) no replies 3 or 4 months Need for more respite too much uncertainty Flexible respite should in fact be truly flexible To receive respite providers require that a doctor fill out more than 30 pages of forms in relation to the client Short Term Emergency respite for foster carers from Commonwealth Carer Respite	Seek response from Respite providers		
Social Support: Not enough social outings cut to only once per month	Seek response from Social Support providers		
Supported Accommodation: Forward planning for Ageing Carers – eg 2 sons with disability, what will happen if the Carer passes away, won't take referral now	Seek response from ADHC		

HACC Services

Issue/Gap Identified	Strategies to Address	By whom	By when
Case Management: Waits for Case workers causing hardship Carers are not trained case managers for complex needs	Issue to be identified for Planning		

Issue/Gap Identified	Strategies to Address	By whom	By when
<p>Centre Based Day Care:</p> <p>Cannot get husband a place at Day Care, wait list too long</p> <p>Day Care Centre – unable to transport client, no answer from coordinator, will not allow because he missed twice</p> <p>Day Care, long waiting list, cut back in number of days available, more outings for the elderly during the week</p> <p>Concern about continuing services with increasing needs</p> <p>Day Care, socialising, outing to break the isolation (Khmer Carers)</p> <p>Outing activity more of that and longer – 1-2 days</p>	<p>Refer on to Day Care Coordination Meetings for response</p>		
<p>Community Nurse required especially to give medication to clients</p>	<p>Seek a response from Community Nurses</p>		
<p>Domestic Assistance:</p> <ul style="list-style-type: none"> Someone to defrost freezer *Quality of domestic help, won't/can't move anything or clean properly ie dust around things or under things or cobwebs on the ceiling Services needed for Carer, had to cancel as couldn't afford to pay for son in supported employment and her own fees *Domestic Assistance provider changes workers, continuity, no times the same, not doing what has been agreed - this is causing stress as Carer has to stay at home to ensure that the showering of her son happens *Worker not always on time No services are available now 	<p>Seek a response from Domestic Assistance providers</p> <p>New funding received in SWS for Domestic Assistance providers, vacancies @ April 2010 available</p>		

Issue/Gap Identified	Strategies to Address	By whom	By when
Food Services: Inflexible service time	Seek response from the Food Services in the region		
Home Modifications and Maintenance: <ul style="list-style-type: none"> • Waits for home modifications • How & Where to access Home Modifications and Maintenance services • Lack of home modifications/maintenance services such as: Plumbing, gardening maintenance; leaking toilets (more so for frail aged carers), expensive to do it privately • The waiting list for the Occupational Therapist is too long 18 months wait 	Seek response from the Home Mods Services in the region		
Lawn Mowing and Garden Maintenance: <ul style="list-style-type: none"> • Tree cutting/lopping • *Lawn mowing - would like to get a service • No-one to do weeding, etc • Garden or Lawn Mowing Services, Liverpool & Fairfield areas, long waiting lists or not taking referrals • Lawnmowing is a gap in service 	Additional funding received for Lawn Mowing Seek response from Lawn Mowing Services Need to pursue about Garden Maintenance service – possible opportunities through new funding received for Garden Maintenance employment initiatives		
Neighbour Aid/Social Support How/where to access social support/companionship on a regular basis	Promotion of the service – refer to Neighbour Aid Services		
Personal Care: Workers not trained in hair washing	Refer to services, implement training for workers		
Occupational Therapy: Waiting for their assessment for things to	Planning to note waiting times Need to address the issue of recruiting and retaining OTs to these		

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proceed OT (Vet Affairs) 8 weeks of visiting still has not developed plan			
Podiatry: Lack of podiatry services	Planning to note lack of services, acute care focus		
Respite: <ul style="list-style-type: none"> *Expansion of funds for more service provision especially respite Respite no services being received, long waiting lists Limited to 63 days of respite per year – why? Respite not sufficient – time slots don't fit needs of carers (dementia carer) In home respite and overnight respite for more than one night, when carer is not available because they are sick in hospital 	Feed into planning process Expand on NRCP mapping initiative of their respite to include all respite options, Ageing and Disability Carers		
Transport: Community Transport some of the services not affordable	Refer to Community Transport for a Response		

The Community Care Service System

Issue/Gap Identified	Strategies to Address	By whom	By when
Equipment, aids and technology <ul style="list-style-type: none"> Emergency Response System too expensive Vital Call, very good service Wheelchairs or assistive technologies – increased funding Long waiting list to provide incontinence pads 6 month wait for special shoes 	Review developments for PADP, make sure that information is distributed to services to distribute to clients	Follow up by Tara Prince HACC DO	

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Financial Concerns <ul style="list-style-type: none"> • *Cost of Services • Services at home – financial juggling, guilty if you can't pay, self esteem • Need clarification about fees for the services 	<p>Ongoing issue about fees, developments in a National Fee Policy, advocate on behalf of our clients, Cumberland/Prospect Development Officer and services have developed a paper around this issue</p>	<p>Follow up by Tara Prince HACC DO</p>	
Referral and Assessment Concerns <ul style="list-style-type: none"> • No follow up when contacted by consumers • Feedback from services when referral gets put in • Phone assessment is inadequate • Gaps with eligibility criteria • Too much information – not enough support eventuates because of lack of funding ie information provided okay but support services can be full with waiting lists (disability consumer) • *Independent way of assessing people's needs so there is a level playing field for all <p>Assessment should be simplified, clear and be able to be appealed</p>	<p>Distribute this information to services to respond</p> <p>Demonstration Project may resolve some of these issues</p> <p>Do services have a right of appeal for referrals that are not successful is it promoted to consumers?</p>		
Smaller organisations not getting fair share of funding allocations	Noted in Planning – seek response from ADHC		
Big Difference between Department of Veteran Affairs and other consumers' service entitlements	Response from Department of Health & Ageing?		
Boundaries within services ie either disabilities or intellectual disabilities mean	Included in Planning for Disability Services		

Issue/Gap Identified	Strategies to Address	By whom	By when
services not available to everyone – not a level playing field in that intellectual can receive more than physical disabilities			
Being told by the service what you need and want *Personalised services needed ie to fit needs of clients/carers not what services are willing to offer	Services note this feedback as well as ADHC through Planning, continuing issues of flexibility and accountability		
Ethnic workers needed rather than interpreters Language needs: forms in their language, information, people that they can speak to Advocacy, support for Elderly from culturally and linguistically diverse backgrounds without carers especially for emergency need	Noted in Planning Continually identified as an issue by culturally and linguistically diverse clients and the communities Promotion of the CALD Advocacy Support Counselling and follow up of additional funding never allocated		
Social Inclusion as a community service	Noted by services		
How to feedback and complain about services provided quality	Services' clients know how to complain about the service they receive and that there is no retribution, a way to improve the service being received		
Waiting Lists	Noted in Planning		
Reduce isolation less stress	Noted in Planning, Ben Soc project in Bankstown looking at Isolation		

The Wellness Approach – Impact Services

Issue/Gap Identified	Strategies to Address	By whom	By when
<ul style="list-style-type: none"> Daughter insists in inclusion in discussions about her so wellness could work No two people with disability are exactly the same, so impact services - wellness approach could assist Maintain your own independence – fear of unknown 	As this new approach rolls out consider the feedback received at the Forum		

Issue/Gap Identified	Strategies to Address	By whom	By when
<ul style="list-style-type: none"> • Personal touch • Centring on me • Independence • Frustrating – I feel bad when I can't do • Learned uselessness – I need motivation to keep doing things and to show my kids I can do things • Reduce Depression • Negotiation • Focus on what I can do, not what I can't do • Fear – ask for help- not sure what they are assessing for me – can't care for self – into a nursing home • How to include Carers in this approach? • Will they reduce services once they ask what you need? • Use of assistive technology to encourage people to help themselves is a positive approach • Depends on type of disability person has as to how well this approach will work • *Personal Approach, client sets the priorities of what is needed, what the person wants not what the service wants • It does not apply to carers for younger people with a disability • For participants from non-English speaking background, communication was seen as a major issue, participants 			

Issue/Gap Identified	Strategies to Address	By whom	By when
expressed the wish for more English conversation classes and more interpreters			

Other Issues

Issue/Gap Identified	Strategies to Address	By whom	By when
Advocacy and Support Someone to help out with community service applications (fill out the form/follow up the application)			
Centrelink Centrelink's limit pension recipient's travel within 13 weeks, otherwise, pension will cease			
Costs of living Costs for medications and treatments ie injections			
If husband goes into hospital – medication changed – then sent home not knowing how the medication affects the person as they have only monitored them for a short time			
Exercise, good nutrition and information on how to maintain good health were the key More information and educational sessions on health			
Lack of information on services for example			

Issue/Gap Identified	Strategies to Address	By whom	By when
upon leaving hospital, GP			
Mental Health <ul style="list-style-type: none"> • Appropriate services for young mental health consumers, for example, employment • Appropriate accommodation for mental health consumers • Living skills programs for mental health consumers • Long waiting list to access current mental health services 	Refer on to Mental Health Services and seek a response		
Related to General Practitioners and Specialists <ul style="list-style-type: none"> • Medicare item no. for doctors for forms, etc • Bulk billing GPs, Specialists, - gap expensive • Medicare and specialist charge – gap, for example 5 specialists – gap half (\$70-\$80) how do you pay? • Waiting times at Doctor's terrible • *Communication between doctors • GP – Community Care Plan • *Education for GPs • Medicare item number for GPs – filling out forms, community care plan, shared carer support for carers <p>Lack of knowledge of GPs about what is available</p>	Refer on to our GP Divisions		

Issue/Gap Identified	Strategies to Address	By whom	By when
Housing <ul style="list-style-type: none"> Lower level needs, long waiting lists Concerns about future accommodation needs 	Refer on to Housing, advocate at Stakeholder Forums, etc		
Legal <ul style="list-style-type: none"> Legal aid for people who speak other languages Power of Attorney Wills 	More education for our Carers and Consumers, regularly send out information about available services		
Planning for the Future <ul style="list-style-type: none"> Will Service & Funeral Services Insurance for Older Carers Bilingual Financial Advisors re the future of carers' assets to assure the financial future of the consumer 	<p>Can the Council workers follow up bullet points 1 & 2?</p> <p>Insurance for Older Carers, seek advice from Carers NSW on this</p>		
Political Environment Need to get politicians to understand the services to people with disability	<p>The best people to do this are the carers and consumers themselves, services to encourage their carers and consumers to visit their local members of parliament, Local Councillors</p> <p>Promote any educational opportunities for carers and consumers to participate in self advocacy education/workshops</p>		
Public Transport <ul style="list-style-type: none"> Changes in the bus timetables and routes <i>The Pensioner All Day Ticket is great</i> Missing Doctor/Specialist appointments when transport/ambulance is late – attitudes of health staff and transport staff ie taxi drivers Doctors Appointment, sometimes bus service not early enough Taxi Drivers who won't help disabled 	<p>Community Transport Organisations to advocate on behalf of these issues when they can, as well as Development workers</p> <p>South West Community Transport implementing a policy of not using taxi drivers who have not had training on the needs of people with a disability</p>		

