



SOUTHERN SERVICES REFORM GROUP

Consumer Empowerment Survey Report 2011/2012

The Southern Services Reform Group has established a new Consumer Workgroup to facilitate community services reform and system improvement through consumer centred solutions. A consumer survey was created based on the research done in 2005 entitled the 'Consumer Empowerment Initiative Report' (Better Practice Project, SSRG Consumer Reference Group). The consumers targeted were from the HACC target group and included older frail people, younger people with a disability and their carers. Consumers either filled in the survey independently or were interviewed by the SSRG Project Officer. Their thoughts and experiences are described below and will be correlated using the following empowerment principles –

Empowerment Principle 1: 'Ask not tell'

Empowerment Principle 2: 'Individuals will have influence over all aspects of the services they receive.'

Empowerment Principle 3: 'Information about the service will be provided.'

Empowerment Principle 4: 'People's relationships and roles will be nurtured and supported by the way in which services are provided.'

Empowerment Principle 5: 'Each person will be considered as a unique individual.'

Empowerment principle 6: 'People will be confident that there will be no consequences as a result of change.'

Conclusions will be drawn while also being mindful that the numbers surveyed are small and the results can really only be seen as a 'snapshot' in time. Other views and comments were also sought from consumers attached to two support groups delivered by Alzheimer's Australia, SA. This was to ensure a broader range of feedback and give this report greater validity.

Consumers' names are not disclosed nor the names of any community organisation that they receive services from or have contact with. Each consumer is identified as a number – Consumer one, Consumer two etc. and groups are identified as group one, group two. The following is a summary of what consumers said and their experiences of the system – both positive and negative.

Consumer One

Consumer one began the discussion with – ‘How the hell does the average person start? It’s like a secret society. You simply have to hope you ‘hit’ the right person. It takes a long time and the whole process is confusing and frustrating.’ Consumer one ‘finally’ received a service after being denied by one organisation and referred on to another during a time when she desperately needed assistance. Following an assessment she was offered cleaning services for one hour per month, which did not adequately meet her needs at the time, nor did it take into account her personal standards of cleanliness. They also gave her a walking frame that she didn’t ask for and never used!

Consumer one also raised concerns about the standard of cleaning – ‘there are so many tasks that workers are not allowed to do.’ She then went on to describe the care worker as a ‘lovely girl but doesn’t clean very well.’ Consumer one was equally concerned about the lack of identification of workers – they regularly arrive at consumer one’s home without an ID badge which is not such an issue if the worker is a regular visitor but not appropriate when it is someone new. In general, consumer one felt strongly that there is a lack of services, lengthy waiting lists and there are not enough skilled workers to adequately address the needs of the sector.

Transport was another identified gap – the hospital that consumer one needed to attend was outside of the council perimeter; therefore she could not access community transport options. When asked if she felt confident to discuss aspects of her service with the service provider she said she was but also added that many of her acquaintances will say things like ‘Ooooh, don’t say anything dear.’ or ‘You’re wasting your time.’ or ‘You want to be careful.’ She said that some consumers are fearful that a criticism of a service will have a negative impact and potentially affect services received.

Consumer one concluded by raising concerns about the standard of training of care workers and the ability of service providers to offer flexible services to meet consumer needs.

Consumer Two

Consumer two had a good experience when first accessing services, however she was in crisis mode by the time she decided that she required assistance. She believes that the first coordinator she dealt with was efficient, knowledgeable and got results. This person made the experience a positive one. She has a different coordinator now and does experience things being forgotten and workers turning up that she doesn't know about, but she is extremely forgiving and believes these glitches are understandable.

Initially consumer two's response to services was 'grateful' but she now feels more in control. She has significant input regarding who comes to her home however it does 'fall down' sometimes when the program assistant organises a replacement worker and the coordinator is not consulted about their suitability. The biggest issue identified was the lack of training of workers in regards to understanding dementia. Consumer two feels strongly that the training is not systematic and is not thorough enough. Some workers that have come to her home have been unsure and behaved in a defensive manner. They have continually defended their actions rather than taking 'on board' her suggestions. 'I know what works for me and my mum. I know the workers are learning but they need to find a way to respect my mum and the disease.' She also felt strongly that care workers, in general, do not receive the respect they deserve and are not valued as highly as they should be in our society.

Consumer Three

Consumer three has been accessing services for a long period of time and feels confident about telling service providers what her needs are and feels she is a partner in service delivery. She is confident about discussing any issues of concern with the provider and feels she is treated as a unique individual. Reaching this level of service confidence has taken a long time (many years) however consumer three does state that her initial experience was a very difficult and frustrating time.

Consumer Four

Consumer four described the initial process of trying to access services as a 'well-kept secret'. What has helped her situation is being part of a support group where the members are all in similar situations – the members run the group themselves and are not connected to or relying on community services. She is connected with respite services but has concerns about how these services are delivered because of lack of continuity of worker and a fear that care worker training is not sufficient. She went on to say how disappointed she is that caring is not valued, that it is seen as 'women's work' and in our capitalist driven environment caring doesn't have a dollar value and this impacts on the way it is managed. 'If caring came under the 3 P's – power, property and prestige there would be high standards of training and care workers would be appropriately paid.'

Consumer four feels the community care system is a maze and somehow one is expected to navigate it. She viewed the process as being full of 'faceless organisations' and 'bureaucratic processes.....out there somewhere, unconnected.' She also said that it is difficult to obtain satisfactory services that meet her needs because she doesn't want to 'make waves.'

Consumer Five

Consumer five has also been connected to a support group but differs from Consumer four as it is organised and delivered by a community services organisation. The support group also offered carer education which she participated in. The carer education was developed using self management principles and solution focused processes - it was delivered over an eight week period. Some of the topics explored included health and wellbeing, communication, feelings, managing stress and relationships.

Consumer five began accessing respite services after her initial contact with the support group and was able to use the same organisation to support a 'seamless' transition through the system. She was able to use the same coordinators that ran the carer education and support group to discuss and organise respite for her husband in a day respite program. She describes her experience with services as very positive and it has made a difference to her ability to manage the caring role. A big part of her assessment of services is how it affects her husband. He has

responded in a positive manner and consumer five states – ‘He is much happier.’

Consumer Six

Consumer six has a health related background which helped him to understand the system and access services with ease. He felt that doctors, social workers and councils play an integral role in the process. He believed that he had been adequately consulted during the planning of his in home services and it was his responsibility to ‘show them’ (the service provider) his needs and requirements.

Consumer six indicated that he had influence over the service he received and he was able to adapt the service to his needs. He also highlighted the importance of a trusting relationship with staff that allowed him to freely discuss his requirements.

Consumer Seven

Conversely, consumer seven’s experience in trying to access services was very difficult. She described the service provider as being too busy to help and was given no advice or direction as to where to go next. She described the initial contact as being time consuming, frustrating and being given the ‘run around’. When consumer seven did access help she was not given the opportunity to be involved in the planning of the service. She was told what she needed without the service provider even knowing the details of her situation. She was told when and where the service was to be held and was not asked at any point whether it would suit her needs.

Consumer seven does not feel she has any say in how the service is delivered, has no input regards to decision making and there is no flexibility when needed. The care workers constantly change and there is little evidence that client information is being passed on. This makes it difficult for trusting relationships to develop.

This consumer feels strongly that she is not treated respectfully, in fact quite the opposite. ‘The providers think they know what is best without any partnership with me.’ The service makes assumptions about her needs, she feels they are incapable of looking ‘outside the box’ and are inflexible.

Consumer seven does not feel confident in requesting changes to the services she receives. She experienced a negative response when she did make a complaint and changes were made to her service without any discussion with her.

Summary of Consumer Workgroup responses

A range of views have been expressed by the consumers who took part in this survey. It is difficult to make finite conclusions but the experiences do possibly suggest that specific organisations may play a role in the consumer experience. (A range of organisations are being accessed by this consumer group.)

Broadly however, four consumers are experiencing a generally positive interaction with community services but three consumers are not. For two of those consumers the depth of their dissatisfaction is considerable, demonstrated by their reluctance to even use services. That in itself is a devastating situation.

The reasons behind this reluctance are by no means small or insignificant. On the contrary, the reasons are connected to standard of training and confidence in care workers skill set. It reveals a lack of confidence in the system, in particular education and training standards. The survey also revealed that for at least two people their experience was far from empowering – they reported no control or influence into how services were managed. One consumer openly shares that she was told exactly what she needed, not asked, not consulted. Surely, basic consumer rights have been ignored. This raises the issue around right relationship as defined by Michael Kendrick (The Better Practice Project, 2009) “An ethical condition that exists between services and those they serve when the people served are seen and treated with appropriate respect, integrity and value and where they are enabled to be decisively influential in how they are to be assisted.”

Interestingly, another issue that really stands out in this ‘snapshot of consumer experience’ is the concern regarding society’s reaction towards care workers. At least two consumers were concerned about their low status in the community and their low pay. What we value in our community doesn’t always make sense – consumer four’s comments certainly present a logical argument. ‘If caring came under the 3 P’s –

power, property and prestige there would be high standards of training and care workers would be appropriately paid.'

Alzheimer's Australia SA Consumer Group One

Group one was a small group of consumers consisting of six women who care for their husbands. All men have a diagnosis of dementia and are under the age of 65 years – they all have younger onset dementia. Some are still in their forties and fifties – arguably still in the prime of their life. Their stories and experiences were shared; the conversation was both moving and distressing.

When the group was asked about their experiences finding and accessing services their answers included the words 'brick wall' and 'restricted'. They felt that most of the leg work had to be done by the individual – only sometimes were referrals made by a service provider. They described situations where options were restricted – a package of care not being offered because the care recipient was too young, not yet 65 years. One carer who was deemed eligible to receive an extended age care at home package for her husband has been waiting 18 months for its implementation! The women spoke very highly of belonging to a support group and they emphasised the important role the group plays in sharing valuable information about services, options and strategies. There was also agreement that having a good coordinator was beneficial.

Over all the carers did not feel they had much influence over services or service flexibility. The feeling was that they had to 'fit in' with the service provider's schedule and expectations. Phrases like 'you are allowed to have' are being used by providers. One carer was only able to access 8 hours of care which was not enough to adequately support her because her husband's needs were considerable and she was also responsible for caring for her young children. Consequently she was forced to place her husband in a residential care facility which was devastating and distressing for both carer and care recipient.

There was a strong feeling amongst the group participants that change of care worker caused considerable anxiety for their partners – they would ideally prefer the same care worker ongoing. However, this was not always possible, especially if they became eligible for a package

through a different provider which meant a new coordinator and new care workers. One carer shared a story about a new worker who came to help her husband with personal care and 'was so nasty' that she caused her to 'end up in tears'. She felt unable to make a complaint in fear of what the consequences might have been.

There was also discussion about the timing of services. One carer was denied the service time she requested and felt the pressure daily, having to be ready and dressed each morning much earlier than would have occurred in her 'normal' routine. She felt that she was never allowed to sleep in and relax and this had become detrimental to her own health and wellbeing.

Use of respite was discussed and the women felt that what was on offer wasn't long enough and difficult to access because of too few places available. They felt that additional respite was required to assist them in managing the caring role. Their words were 'we need lots more respite'.

A difference in service provision between the different councils was also highlighted. What one person could access in council A, another couldn't access in council B even though the circumstances and outcome was very similar. This situation caused dissatisfaction and confusion among the consumers – it didn't make any sense.

This group is different from the 'norm'. The age of the care recipient dictates a disability funding stream, however the condition is an illness most commonly seen in elderly people. It could be argued that age care services are best equipped to provide the care required as they are the experts regarding dementia. One carer wanted to know what happens when her husband turns 65 – do the service arrangements suddenly change from disability to aged care? Another carer felt that they should not be part of aged care or disability but be recognised as a separate group titled Neurological Degenerative Diseases. The carers unanimously agreed that 'one size doesn't fit all'. Each individual has different needs, different abilities, different support networks and different skills. Service delivery needs to be flexible.

Alzheimer's Australia SA Consumer Group Two

The second consumer group was much larger but equally as vocal and passionate about achieving positive outcomes from the sector. They were also a younger onset dementia group – twenty individuals, both consumers and carers. When asked about finding and accessing services the comments included the following – ‘it took years’, ‘lots of phone calls’, ‘on a wait list’, ‘have to pay for services’, ‘refused because under 65 years’ and ‘didn’t receive any help to find services’. Other comments indicated that the system was difficult to work through, that it was like a ‘bowl of noodles’, that they were given little help to piece it all together and how useful it would have been to have a case manager to help navigate the maze.

In general conversation, one group member recounted a story about their 90 year old relative who was receiving some services to assist with cleaning. She explained that the services were lacking in continuity, making it difficult for the elderly gentleman to manage. On one occasion the worker decided to change and wash his sheets and quilt when it was not needed as they were already clean. The worker insisted and he relented, leaving him feeling bullied and in no way in control. Another carer shared a story about an incident that happened to his wife. She was accessing transport provided by Council but unfortunately had an episode where she was incontinent while using the transport. The outcome was that she was not subsequently picked up and was left waiting for three hours because the service simply stopped without proper consultation with the family.

When enquiring if group members have been asked about the kind of services they require rather than told what they can have, one gentleman was very vocal in sharing a recent experience where he was asking about a possible package of care and the coordinator became very forthright and told him exactly what would be provided. The conversation did not go well and he asked the coordinator to call him back...at the time of this meeting the call had not yet been received.

There was a feeling that individuals did not have a great deal of influence over all aspects of services received and the following comment highlighted a lack of flexibility – ‘If the time of a service needs to be changed you are at risk of missing out altogether.’

Unfortunately not more information could be gathered at this meeting. The group were keen to have some supper and talk between themselves. Once again the significance of support groups cannot be overlooked. At a glance it was evident that this was a close knit group and the support that they received at this gathering was significant. Overall, the feeling towards services was not particularly positive and perhaps highlights the 'extra' difficulties involved for those suffering from younger onset dementia.

Analysis of the Survey: Consumer Empowerment Principles and HACC Service Principles

It would appear from the consumer conversations that were carried out in this 'snapshot' review that the sector is struggling to meet all the requirements of the Empowerment Principles developed in the Consumer Empowerment Initiative Report (2005).

While there was evidence to support that some consumers are being consulted regarding their needs, not all feel they are given that opportunity. In some cases consumers felt they were 'at the mercy' of the coordinator and there were numerous people that voiced concerns about being somehow penalised for 'making waves' or asking for changes to more adequately address their needs.

It was evident that trusting and meaningful relationships with coordinators and care workers occurs throughout the sector. However it must be noted that some consumers reported the change of care workers as being a traumatic experience, coupled with concern that new workers may not have the knowledge and skills for the task required.

Generally consumers have indicated that the empowerment principles are not being adequately addressed by all service providers. Interestingly these principles were developed in 2005 and fit in well with the 'thinking' of the recently launched HACC Service Principles. Empowerment principle one links with the first service principle – it acknowledges the strengths and skills of the person while the service principle suggests promoting each consumer's opportunity to '...maximise his or her capacity and quality of life.' Empowerment principle two includes the assumption that individuals should have the opportunity to make decisions about the service they receive which links closely with service principle three that states choice and control should

be optimised. In empowerment principle three the words 'depthful discussion' and 'trusting and open relationships' are used. This links with 'comprehensive, holistic assessment' (service principle one) and 'take time to listen and understand' (service principle two).

Empowerment principle four includes valuing family, friends and informal networks which correlates with supporting community and civic participation in service principle five. Considering each individual as unique (empowerment principle five) relates to person centred goals and individualised plans in service principle one. Empowerment principle six states that individuals should be confident that there will be no adverse consequences if they ask for changes in services which indirectly relates to service providers building rapport and working respectfully with consumers (service principle two). Admittedly there are gaps when embarking on this exercise; however the similarities between the documents far outweigh the differences.

What does this mean for the sector? It possibly is indicating that rhetoric is finally going to turn into action with the formal introduction of the HACC service principles and this will surely encourage all service providers to manage services in a much more client centred, client directed manner which will promote greater innovation, flexibility and most importantly consumer satisfaction. There is also evidence that support groups and support networks are vital for carer wellbeing and should be part of a best practice model. Finally, this 'snapshot of consumer experience' indicates there is still work to be done but knowing that and being on the 'right track' will surely have a positive impact.

References

Better Practice Project, 2006 The Better Practice Project Handbook

A Better Practice project Initiative in conjunction with Southern Services Reform Group: Consumer Reference Group, 2005 Consumer Empowerment Initiative Report

Government of South Australia, 2010 South Australian Home and Community Care (HACC) Service Principles