

CONSUMER EMPOWERMENT INITIATIVE

Exploring service provision from a consumer perspective

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Report Prepared by:

**Lisa Gilbert
Angela Coker
Joyleen Thomas**

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In conjunction with

Southern Services Reform Group: Consumer Reference Group

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Consumer Empowerment Initiative

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Project Manager

Joyleen Thomas

Project Consultants

Lisa Gilbert and Angela Coker

Introduction

This project is an initiative of the Home and Community Care services (HACC) funded Better Practice Project (BBP), auspiced by Aged and community Services, in conjunction with the Southern Services Reform Group Consumer Reference Group (SSRG /CRG). They have worked together to develop a project, engaging the assistance of a team of project consultants and interviewers, to research the levels of empowerment and influence that consumers in the south of Adelaide experience within the services that they receive.

This exploratory research involved narrative approach interviews that encouraged people to share their stories, both positive and negative, attempting to capture the essence of their experiences while receiving a service of some sort. A total of 50 people were interviewed that had accessed 68 actual services, from daily personal care to occasional home help assistance. These stories were then interpreted by means of various theoretical frameworks and consumer empowerment and participation concepts.

The result is an invaluable insight into the very personal and heart felt experiences of people who need to rely on services to help them within their day-to-day lives, and just how empowered or disempowered these people feel within influencing the services that they receive. Barriers to consumers influencing the services they receive are explored, with some themes and descriptions of what approaches work well and those that are not as successful being identified. The information gathered may prove useful for service providers to consider as a resource, for finding ways to involve consumers in service planning and delivery in more effective and meaningful ways.

The project team is indebted to those consumers and services who were willing to engage in this challenging process, and although it is acknowledged that this is only the beginning piece of work that needs to be done around empowering consumers, the stories explored are a positive step towards changing the culture of consumerism and service provision.

Background

The Better Practice Project has identified that while many people are no longer being supported in institutions, there is still a risk of people not being empowered to influence services, either at an individual service level or at an agency or systems level. For many people there is still a reluctance to question the way in which services are provided in their lives and while services frequently attempt to consult with consumers when planning the delivery of their services, many services relate that they are struggling to involve consumers in meaningful and influential ways.

As a result of discussions and concerns expressed through the meetings with the SSRG Consumer Reference Group, the BPP felt well placed to explore issues around the inadequate influence and power people have in the systems and services they use. It was thought that a narrative form of interviewing people might be most appropriate to encourage those consumers who might not usually speak up in any other context, to share their stories.

Therefore, it was decided to work together to develop a project to explore how empowered consumers felt within influencing services that they receive, to expose any barriers or challenges that make it difficult for consumers to feel empowered and to discover ways in which service providers can involve consumers in meaningful and influential ways. Given that it involved a southern consumer reference group, it was agreed to confine the scope of this project to services in the South of Adelaide, predominantly in the City of Onkaparinga local government area.

Before approaching consumers, an opportunity arose through the BPP and SSRG Consumer Reference Group to explore with more than 100 service providers in the South ways in which consumers can be involved in service planning. Dr Michael Kendrick facilitated the interactive workshop distinguishing between “Realistic, empowering processes vs. tokenistic gestures” sometimes made under the guise of “Consumer participation”. The service providers were interviewed and told us that they:

- “Wanted to learn how to better provide client created services”
- “Wanted to focus on working ‘with’ the person, rather than ‘doing’ for them”

- “Wanted a bottom-up and more consumer driven approach”

In order to assist service providers to develop strategies and safeguards necessary to ensure that interactions are effective and empowering for all involved, it was necessary to hear from consumers to get their perspective.

Project Overview

The HACC funded, Better Practice Project (BPP), is a resource to agencies across South Australia. Assistance from the BPP will be, as services want it to be. The Consumer Empowerment Project is a short-term developmental piece of work, qualitative in nature and influenced by the work of various empowerment and consumer participation theoretical frameworks (Kendrick 2004, Kivnick 1997, Wolfensberger 2002, National Resource Centre for Consumer Participation in Health 2005).

Other influences that informed the design of this project including conversations and meetings with the SSRG Consumer Reference Group and Acute/Community Interface Group, Southern Adelaide Health Service consumer project officer and the Northern Collaborative Project. A narrative approach to consumer interviews was used, providing the Project team with a variety of rich stories and extraordinarily forthright information about the experience of consumers within services.

Project Objectives

- To provide opportunities for consumers to share their own experiences which will illustrate and inform the development of services
- To determine how empowered consumers in the southern area of Adelaide feel within influencing the services that they receive
- To expose any barriers or challenges that make it difficult for consumers to feel empowered within the service they receive
- To discover ways in which service providers can involve consumers in more meaningful and influential ways
- To link the Better Practice Project to an informed consumer base

Project Team

The BPP has provided the resources to undertake this initiative. The CRG has provided input and advice to the project as well as identifying and engaging consumers who wished to share their experiences in a variety of ways. The project team consisted of Joyleen Thomas, Manager Better Practice Project, and Project Consultants, Lisa Gilbert and Angela Coker. Cheryl Keller and Marilyn Nuske provided interview support, on behalf of the BPP.

Demographics

Consumers interviewed were from various local Government Areas, including: City of Onkaparinga, City of Marion, City of Unley and City of Mitcham. The majority of consumers interviewed reside in the City of Onkaparinga. As of the 2001 census there were over 140,000 people living in this area with more than 14,000 people over the age of 65, representing around 11% of the total population of City of Onkaparinga. Of the total population, just over 70% were Australian born, while of those born in other countries, 13% were from the United Kingdom. (City of Onkaparinga Community Profile and Atlas 2005).

Project Population

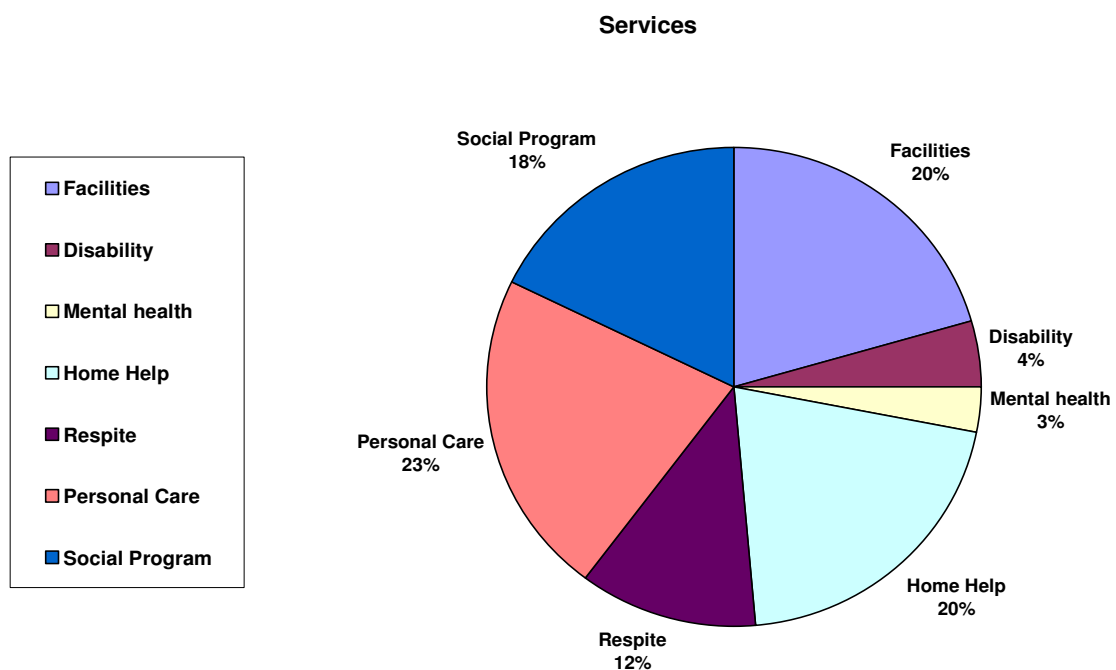
A total of 50 people were interviewed, including individuals, married couples and carers. The people were all consumers of services and had a diverse range of needs. Whilst there were people who had immigrated to Australia, including some from culturally and linguistically diverse backgrounds, there were no indigenous Australians in the sample population. The majority of the people interviewed were over the age of 60 years (78%), with 42% being over the age of 80. While 58% of consumers were female and 42% of consumers were male.

Gender	Number	Percent	Age	Number	Percent
Male	21	42	20-29	1	2
Female	29	58	30-39	1	2
			40-49	3	6
			50-59	6	12
			60-69	9	18
			70-79	9	18
			80-89	19	38
			90+	2	4
total	50	100	total	50	100

Services

There were actually 68 different services being accessed by the 50 people interviewed, which are outlined in the following list and percentage graph.

- Personal care: aged care package, palliative care, rehabilitation
- Home Help: domestic assistance, aged care package, private services
- Respite: residential, in home and centre-based
- Social Program: clubs, social support within facilities, lifestyle services
- Facilities: supported residential care, residential aged care, hospital
- Disability services
- Mental Health Services



Limitations

This narrative enquiry of consumers, concerning their feelings and understanding of influence and empowerment within services that they receive, is solely focussed on the individual experience. No attempt has been made to compare these experiences with those of the service providers, which is helpful to take into account when considering the findings.

Methodology

Recruitment

Initially members of the SSRG Consumer Reference Group were interviewed, to inform the interview method and to involve their knowledge of the consumer participation process. Service providers were asked to identify and engage consumers who wished to share their experiences in a variety of ways, and this method of recruitment represented most of the project population. Other opportunities for consumers to be involved in the project were via advertising at community centres and within community groups.

Interview Process

The review of various literature (Better Practice Project Report 2000, Degenholtz & Kivnick 1997, Kendrick 2004, Kivnick 1998, Kivnick & Murray 1997, National Resource Centre for Consumer Participation in Health 2005, Wolfensberger 2002, and Wolfensberger & Thomas 1994) led to the development of six statements which identify some of the most effective ways to encourage consumer empowerment and involvement in service planning and delivery. For each of these statements, a number of empowerment best practice principles were identified, and questions based on these principles were then developed as a guide for the interviewers.

Interviews were mostly conducted one-one in the person's own home, however a few were completed in informal settings such as parks and a few formal settings such as facilities and acute settings. One focus group was conducted at a local community centre. Throughout the interviews people were encouraged to speak openly about their experiences of services, and interviewers introduced questions informally during the discussion to help gather information as to what extent the empowerment principles were included in service delivery.

During the compilation of the stories, people's experiences were interpreted utilising theoretical frameworks such as Dr Michael Kendrick's work, 'Discerning Actual levels of Substantive Empowerment' (2004) and the National Resource Centre for Consumer participation in Health's "Ladder of Consumer Participation" (2005). The findings of this interpretation of stories are presented in a narrative form to encourage association with the person's individual experience. The results presented are based on the 68 individual experiences of services, as described by the 50 people interviewed. All names have been changed to protect confidentiality as agreed with the consumers.

FINDINGS

Empowerment Principle 1

“Ask not tell”

- *The service will work with the person to establish their needs and plan the right response*
- *The service will acknowledge the strength and skills of the person*
- *Individuals will have a say over who provides the service and how it was provided*

People’s stories revealed that in relation to these empowerment principles that most services attempted to, meet their needs by offering a pre-determined package of care. Although consumers might be able to influence certain days and times, they rarely had any say over who was providing their service, or to access support other than what was a standard program. Over half (57% n=39) of the people’s experiences suggested that services kept them informed about the support they received and attempted to plan services to meet their needs, however they did not believe that they had any actual decision making power in this process or had their own individual strengths and skills acknowledged. 16% (n=11) of service experiences indicated that people did feel that they were involved in determining what the service they received was by discussions with service providers, while 26% (n=18) indicated that people could directly influence how their service was delivered and could ask for a change of carer if necessary.

An example of services planning the right response in partnership with the individuals involved was a married couple, Bill and Mary, who were receiving respite from a variety of services. Bill and Mary have been married for 46 years, previously living in rural communities where Bill worked as a Butcher. They were shocked when in her late 50’s Mary began to demonstrate signs of early onset dementia. Bill retired early at the age of 60, determined to provide all the care that Mary may need. It wasn’t until he finally became depressed and quite unwell, exhausted from trying to meet Mary’s needs independently, that he finally turned to services.

Bill explained that it was very difficult to navigate through the maze of aged care services, but once they finally began to receive a package of care, which involved in home and centre based respite, it was a successful experience. Bill described feeling like he was ‘pulled out of a deep dark hole’, with the carers providing the support and time to do things without having to worry about Mary. This gave him the time and energy to be able to continue to care for Mary, supporting her at home for as long as possible. Bill’s experience of the service was such that he felt well supported with carers that became ‘like family’ and were able to provide the type of care and support that they needed without taking over their privacy.

The only unsatisfactory experience of the services that Bill and Mary accessed was the fact that there were 4 different services involved in making up the package of care that they needed, which led to confusion at times with carers not arriving when they were expected or conversely arriving unexpectedly. This was mentioned by several other people that were interviewed, including Mr and Mrs Davis, who explained that they felt insecure with the home services they were receiving given that a carer had given a months notice and yet they had still not been told who would be coming to the next weeks scheduled visit. Certainly there was no evidence of the individual having an influence about who provided their service.

An example of a poor response by service providers not only not meeting a person’s needs, but also actually causing harm, was experienced during an episode of residential respite by Mrs Andrew’s 82-year-old mother, Nell. When Mrs Andrews arranged for her mother to enter into residential respite so that she could address her own healthcare issues, her mother’s medications were changed without any consultation with Mrs Andrews or her mother’s doctor, Nell being unable to have the insight into managing her own medication. The result of this change to Nell’s medication was so severe that she stopped eating and drinking, became constipated and became less mobile.

As Mrs Andrews was too unwell to visit her mother during this time, as she was in hospital herself, she phoned the facility regularly to ensure her mothers well being, being reassured that all was well, which was clearly far from the truth. This deterioration which Mrs Andrews believed was due to medication changes, led to Nell having to be admitted to hospital, and upon her return home was unable to function as

well as she had before, requiring a much higher level of care. Mrs Andrews wishes she had never placed her mother into residential respite.

Pam and Michael also had poor experiences with respite services working with people to acknowledge their strengths and skills in order to plan the best service. They are a couple in their 70's who live in their own home in the outer southern suburbs of Adelaide. Michael had a stroke some years previously that has left him with communication difficulties, although he continues to manage his daily living needs with assistance from his wife Pam. He loves to keep active, particularly looking after his greenhouse in the backyard, and attending social gatherings.

When Pam and Michael accessed in home respite so that Pam could confidently go out shopping and to appointments with worrying about how Michael was managing, it did not work because the carer they were assigned wouldn't let Michael go out into the backyard to his greenhouse, trying to encourage him to sit down so that they knew he was safe and under their supervision. Rather than complaining, or trying a different carer, they chose to make do without respite unless it was an emergency situation. However, when an emergency came in the form of Pam needing to go into hospital for unexpected surgery, they were unable to access any respite. Even after ringing their local member of parliament for assistance they were unable to get any help, and eventually Michael was admitted to hospital as well, to ensure his safety.

Planned residential respite was also a poor experience for Michael, who as a result of his need for narcotic analgesia for chronic neuralgic pain caused by his stroke, always has to go into high level care where there is a registered nurse available to administer the medication. Michael explained that residing in high-level care residential respite left him feeling bored and frustrated. Both Nell and Michael's stories suggest that even the most empowered people, who have the knowledge and resources to advocate for their own or their loved one's needs, can become very disempowered by service providers responding to people's needs inappropriately, and that carers can also become disempowered by default.

Empowerment Principle 2

“Individuals will have influence over all aspects of the services they receive”

- *Individuals are aware of how they can have an influence*
- *The person consistently has a say in the way the service is provided*
- *Individuals will expect flexibility and responsiveness at all times*
- *Individuals will have the opportunity to have a decision-making role in the service*

Very few people’s experiences (9% n=6) actually described situations where they had a direct influence and true decision making capacity within all or most the services that they received, with 12%(n=9) having a direct influence over some services. Often services consulted with them (15% n=10) to try to meet their needs in a way that the person needed or desired, however this usually did not result in a direct change to the way the service was delivered. Most experiences (63% n=43) suggested that people were just grateful to receive any assistance at all, and were not aware or did not think that it was possible, to consistently have an influence over all aspects of the service that they received.

One of the people who felt that they had significant influence and a decision making role within the service he received was George, a 70-year-old man who lives in a unit with his beloved dog Patch. He is clearly a highly empowered individual who has had work experience in management, which has provided him with the skills to be able to advocate for himself very well. However, he explains that even with this ability, without a service that takes the time to get to know an individual and their specific needs, the amount of influence he is able to have within the service he receives is limited.

Fortunately the community aged care package providers that deliver George’s service, have taken the time to consult with him over exactly what it is that he needs, and have encouraged him to feedback on the type of service and who it is that delivers it. Consequently George feels that he has true decision making ability within the services, only gets help in the specific areas he nominates and has carers who he feels safe and

comfortable with. He is confident that if his care needs increase he will be able to access more assistance, as this is what he has been told by the package coordinators. Regrettably, this is not the case with all aged care providers. Phyllis and Alice are elderly sisters who have lived together for many years and are very involved in their church community. They are very happy with the service they receive within their community aged care package, including personal care, cleaning, shopping, transport to appointments etc, however while they say how grateful they are, they mention things incidentally that are concerning. Instances such as carers being rushed, trying to 'fit them in' between other jobs, not having time to talk and get to know each other even though they are engaging in very personal activities together such as showering, visits being cancelled and rescheduled to meet another's clients needs, care workers arriving late without phoning to reassure the Phyllis and Alice that there is no need to be worried.

Several people who were receiving personal care described situations such as this, including one care worker who wanted to leave before the client was even dressed. People talked about feeling patronised, disrespected and explained that the attitude of the individual care worker could make such a difference to their experience of the service, and indeed their experience as a person. Despite this, many people were reluctant to complain to the service about their experience because of their tendency to want to be grateful for whatever assistance they received, even if it did not suit their actual needs or was not delivered when or where they needed it.

A group of people interviewed lived in supported residential facilities, and although these people varied in ages from their 20's to their 80's, and were experiencing challenges such as mental health issues, poverty and homelessness, intellectual disabilities, and drug and alcohol related problems, their needs in the rest home were all met in the same way. Their stories included situations of not being able to enter the kitchen to make a cup of tea and, having no influence about what type of meals were served and when. This group of people appeared quite socially disadvantaged, many of them becoming so disempowered by repeated experiences of vulnerability and institutionalisation that they were certainly not familiar with expecting to having an active decision making role within the service that they received.

Another example of a person having absolutely no influence or decision-making capacity within their service was 59-year-old Trevor. He developed Multiple Sclerosis at the age of 55, which forced him to retire early, and to become wheel chair bound. Sandra his wife became his carer, and together they manage his personal care and mobility needs. Trevor is fiercely independent and tries to remain as independent as he possibly can, keeping as much muscle tone as possible by being as active as he can. This couple's experience of services was via the disability sector, and was alarmingly unresponsive to Trevor's needs.

Trevor and Sandra explained that he was supplied with a sling lifter, once transferring from bed to chair etc. became very difficult for them both. Trevor requested a stand lifter instead so that he could keep exercising what muscle tone he had left. Despite many phone calls, assessments by occupation therapists and letters from his doctor, Trevor was told that given his prognosis he may as well keep the sling lifter, and was refused a stand lifter. Trevor and Sandra have refused to use the sling lifter until absolutely necessary, and so they are transferring without a lifter, placing them both in a potentially dangerous situation.

Trevor's story is one of trying to advocate for his needs initially personally, then via doctors and eventually by lobbying politically. This was to no avail, because until Trevor became eligible for aged care services, he did not feel that his needs were met. Now that he has personal care, household assistance and respite services via the aged care sector, he feels that some of the pressure and stress has been reduced on the caring role for Sandra and increased his own ability to cope with his illness. Trevor's story suggests that although he feels empowered in other aspects of his life, his attempts to apply the same principles when receiving a service are ineffective, leaving him feeling worthless and powerless.

As one lady explained, someone who is a very empowered consumer representative, and manages her own disabilities as well as supporting children with disabilities;

“The services have all the power, and can use their discretion about who gets what”.

Empowerment Principle 3

“Information about the service will be provided”

- *Regular contact between staff and service recipients*
- *Time created for depthful discussion with service recipients to establish trusting and open relationships*
- *Information will be provided in a variety of meaningful ways e.g. brochures, manuals, interviews*
- *Information is readily available*

While some (19% n=13) people described situations where services made regular contact with them, and provided adequate information, there were many (57% n=39) circumstances where people felt that this occurred on a superficial level, and that while seeking feedback and consultation occurred, there were no clear outcomes. The experiences 24% (n=16) in which people who had received regular contact with depthful discussions, felt as if the service really got to know them as an individual. They explained that it led to open and trusting relationships, which in turn resulted in their needs being met most appropriately and feeling as if they were involved in the decision making process, certainly feeling empowered as consumers

A 59-year-old lady, Susan, who was receiving personal care and home help from an aged care service, explained that the coordinators frequently made contact, provided necessary information and regularly sent out questionnaires and client satisfaction surveys, and yet they seemed like superficial relationships and tokenistic gestures with no real effects. This was because she still had important unmet needs, and found the service to be inflexible. No amount of feed back changed Susan’s circumstances, and simple things like the care workers having the time to take her shopping, rather than do the shopping for her from a list, meant the loss of roles and independence.

Several people who were receiving disability services explained that their coordinators changed so often that they frequently only spoke over the phone, never having the opportunity to meet face to face. Simon, a 38 year old man who had developed motor neurone disease that left him requiring a wheel chair and full daily living assistance,

actually moved to Adelaide from the Riverland on the advice from service providers, in order to be able to have more access to services, which did not happen. The disability service was not able to meet his needs, which meant that his elderly mother and father had to travel each week to Adelaide just to ensure that his basic needs were met. In this situation the little amount of information that was forthcoming, was actually incorrect, and placed Simon in difficult circumstances.

A disturbing situation around providing clear, culturally appropriate information, involved a home help program and an elderly man from a non-English speaking background. Mr Dimitri migrated to Australia as a young man, working in the markets, as he raised several children with his beloved wife. Once his wife died, Mr Dimitri decided to move to a retirement village in the south of Adelaide, relying on a gopher to be able to independently mobilise around his community. The only assistance Mr Dimitri really needed was with his house cleaning.

A home help service commenced, with which Mr Dimitri was delighted, pleased with the standard of the work done, as well as getting along with the worker performing the cleaning. Unexpectedly, the worker explained one day that the cleaning must stop, and that this was to be the final visit. Mr Dimitri was very confused, upset and distressed, because having a clean house was very important to him. Out of desperation he negotiated to get his neighbours cleaner to come in, a private service, which cost more than Mr Dimitri could really afford. Once an advocate explored what had happened on Mr Dimitri's behalf, it was discovered that the cleaning had been stopped because he had not returned a required document sent out by the home care service. Once this was corrected the previous cleaner was reinstated, much to Mr Dimitri's relief.

Bill and Mary, whose story was referred to previously (see page 11), were one of the few people to experience meaningful consumer participation through various forums. Bill was asked to feedback about the service both via written evaluations and verbal interviews. He was also invited to attend some focus groups where he believes he had the ability to voice his opinions, to really be listened to and to participate with initiating change within the service. Bill explained that the staff made regular contact and always treated Mary respectfully and with warm empathy, adapting to her changing moods.

Empowerment Principle 4

“People’s relationships and roles will be nurtured and supported by the way in which services are provided”

- *Services will recognise the value of the contribution of family, friends and informal networks and do not take over roles of family and friends and give them the message that they do it better*
- *Services will not damage the existing roles that people have and will support the development of new roles where appropriate*
- *The individual is secure in the relationship with the service*

About a quarter (26% n=18) of people’s experiences of services, both of the person receiving the care as well as their families and friends, suggested that by getting help with personal care, household duties and respite, they were able to maintain their roles of wife, mother friend etc. so that their roles were supported and their relationships acknowledged, encouraging them to feel secure. This was particularly important for those people trying to cope with challenges created by health and age related illnesses, they needed to have their significant others there as support, not feeling overstressed and uncomfortable.

However, around half of the stories (56% n=38) explained that this support involved resources just to survive, rarely or not all supporting roles and relationships and 18% (n=12) described circumstance where this occasionally occurred. Such as one lady who was so grateful to have the time to “*get some sleep*” because her husband had dementia and was frequently up at night, and provided very little opportunity to engage in any life enhancement opportunities or to strengthen and develop roles and relationships, leaving them feeling insecure and powerless.

An 80-year-old lady, Thelma, explained how she had lost a lot of friends following the death of her husband. Thelma and her husband migrated to Australia from England and had no children, so the friendships they made when they first arrived in Australia were very important. They loved to travel around Australia, and went back to England a few times to visits family and friends. This all stopped when Thelma’s husband had a stroke. She cared for him at home with the support of services, and was devoted to him until he eventually passed away.

Thelma was devastated when her husband died because she had depended so heavily upon him as her partner, friend and also with practical supports such as driving etc. Before long Thelma realised that she was becoming increasingly socially isolated, having lost contact with most of her previous friends and began to feel lost and depressed. When Thelma became involved with a social support service, she was given an opportunity to turn her life around by meeting new people and developing new relationships. From a very withdrawn, self conscious woman lacking the confidence to even communicate with new people, she grew into a socially out going, open, friendly person who was willing to try new things.

Another elderly woman, Joan, who had nursed her husband at home as he was dying of cancer, explained how palliative care services were so supportive that they took the time to sit down and really talk with her husband each time they came. She explained that she was pleased with how the services respected her role as wife and carer, and only provided the care that she was unable to do. In this way Joan felt well supported in her role as a wife, provided what care she could, and yet was still able to have time to herself when she needed it. She also felt that the service supported the whole family when her husband became terminal, providing support and accommodation at the facility where he eventually went for his final days. The importance of this type of support was highlighted by the way Joan proudly told how one of the nurses even came to the funeral, validating the relationship that she felt the family had with the service.

An elderly couple in their 80's Bob and Pearl, who received support from an aged care service, also highlighted the importance of the relationship with the service provider. They were so fiercely independent that they were very reluctant to accept help, even though it may prevent them placing themselves in dangerous situations. Therefore, it was very important that the worker, who initially made contact, took the time to get to know the couple and to develop a trusting relationship. It was also important for the worker to value the role that Bob and Pearl's daughter played in their life, taking care not to take over any of her responsibilities because the couple received a great deal of pleasure and support from having her involved in their lives. It was fortunate that the worker was aware of this situation and was able to find ways to support Bob and Pearl

in a safe way, as well as removing some of the pressure placed upon the daughter, without taking over any of the daughter's roles.

A group of people that lived in a supported residential facility explained how their relationship with the residential service was far from secure. There were instances of residents actually losing their homes, with no prior warning. Phillip is middle-aged man who has lived in supported homes for most of his life due to his inability to manage on his own because of mental health issues. Recently he was required to enter into a mental health hospital for a period of time, to receive treatment for an acute problem. When Phillip was to return home he was told that his room had been given to someone else so he would have to relocate to another facility. He was very upset because he had made friends and strong relationships with the residents at the previous home, and had felt safe and secure in that environment.

Not only did Phillip have to begin to make new relationships with residents and workers at the new facility, he also lost something dear to him, his fishing rod. He explained that this had gone missing from the facility storeroom, and while he was saving up for a new one, was no longer able to engage in one of his favourite pastimes, fishing. Phillip's story highlights the effect on someone who, while trying to recover from an acute illness, loses his home, his most treasured possession, his friends and his whole sense of security. He had neither the knowledge nor resources to make any complaint, or to influence those decisions made concerning his life. Phillip is still quietly hoping that somehow he might be able return to his home one day, back with his friends.

Empowerment Principle 5

“Each person will be considered as a unique individual”

- *Celebrate diversity*
- *Service will know the person and what is important to them*
- *Service will not make assumptions about the individual*
- *Staff will have a high standard of behaviour*
- *Trusting and open relationships exist between service provider and service recipient*

The majority of people's stories 78% (n=53) explained that while services provided invaluable assistance, it was assumed that all people had much the same needs that could be met in similar ways, with few examples of celebrating individual diversity and attempting to meet more than the basic needs. The experiences (21% n=15) where people did feel as if their uniqueness was valued, were nearly all receiving services that were able to include social and lifestyle needs in their programs, and were supported by their organisations with the time and resources to develop trusting and open relationships, which in turn allowed them to feel quite empowered.

A service that proved to be successful at celebrating people's diversity were social support programs working with residents from rest homes. Although very few people that lived in these supported residential facilities and were involved with social support programs agreed to be interviewed, those that did told stories of having their individual needs truly considered and their diversity celebrated. Several of the people interviewed had been assisted by a social support program to find employment at a workshop, or to attend various learning groups including, numeracy, art/craft and dressmaking and designing.

The people that had begun working explained that they had a new role in society. They were able to catch a bus each week and travel to work, meeting other people and earning their own money. One lady explained that she now had money to spend on her passion, knitting, and all of the people who commenced working said that they felt more productive and better about themselves, and were more optimistic about the future.

While the social support programs did endeavor to celebrate the diversity of this very disempowered group of people, and they certainly had developed trusting relationships, the achievements made by these people did not really produce long lasting social capital. The friendships and commitments formed, were mostly with people from the same facilities and work places, and required ongoing support. It may be beneficial to the residents if the programs could progress to another level and support these people to develop more natural, informal, independently sustainable, social and employment relationships.

A couple that receives a community aged care package feel as though their service meets their needs in a unique and valued way, encouraging them to feel acknowledged as individuals and consequently empowered. Christine cares for her husband John, who experienced a stroke several years earlier, leaving him with disabilities that require assistance with personal care. The aged care services that they receive are able to support them very well, and they both feel that the service providers know them as unique people and have high standards of behavior that have led to an open, trusting relationship. The way that the service meets their needs individually, and in a flexible and accommodating way, makes them feel valued as individuals. Christine explained that when she had to go into hospital for surgery, the service helped them to access respite for John, and then actually brought him in from the residential facility he was staying at to visit her in hospital. They felt that this type of consideration by the staff, and responsiveness from the service, met their needs in a valued and respectful way.

This was a very different experience from that of Mr and Mrs Williams, who have been married for almost 65 years, he is 93 and she is 87. They met over 70 years ago when Mr Williams met the girl of his dreams, Mrs Williams, who was only 14 at the time. They have 3 children, several grandchildren and many great grandchildren, living in the country where Mr Williams used to love building things with his hands. They moved to their current location several years ago to be closer to family, living in a unit their family had especially built to accommodate them, at the back of their daughter's home.

Mr and Mrs Williams like to be as independent as possible, however their health issues have meant that they need help with house duties. Although their family is very supportive, they all work during the week and are busy with their own commitments.

Consequently they looked for assistance from a home help service. Their initial experience of the service was one of assumptions, judgements and of patronising attitudes from the staff. The person that came in to plan their service commented, “*Is this all there is?*” and then decided that they would only need one hour of assistance because the area was so small.

Mr and Mrs Williams feel that they have been penalised because they live close to family. They explained that they understand that there are many people much worse off than they are, but that they are battling to remain independent. Mrs Williams, who is the carer for her husband, feels she could cope better if they had just a little more assistance at least on a fortnightly basis as they want to remain as independent from their family as they can. They have been very disappointed in the lack of thoughtfulness by the service they receive, and certainly do not feel valued as unique individuals by the service, or as empowered consumers.

Elsie is an 82-year-old lady receiving personal care assistance in her home in a retirement village. She tells a story of services making assumptions that she will adapt to services that are provided in the same way that they are provided to everyone else. Elsie described the service she received in glowing terms, and although she didn't know who the coordinator of the service was, she could recite every carers name individually as well as their interests and family situations, all 6 of them! She was very pleased with the opportunity to have daily showering assistance, and explained that it had taken her quite a while to get used to ‘stripping off’ in front of complete strangers, but now that she has had to do it in front of so many different people that she has given up trying to maintain any sense of privacy or dignity. Elsie accepted this as one of the unavoidable disadvantages of receiving personal care assistance.

Empowerment Principle 6

“People are confident that there will be no consequences as a result of requesting change”

- *No fear of losing what you have got*
- *Individuals and significant others will not feel like they are being judged by the service*

While 32% (n=22) of experiences described people feeling secure within their service and feeling that they had a direct influence around most or all, and 12 % (n=8) around some, of the significant decisions made around change and did not feel judged by the services, many stories (56% n=38) suggested that people felt as though they had no effective decision making power around changing their service, and some were even afraid to say anything for fear of the consequences upon themselves or their loved ones. It was clear that where the empowerment principles were not included within services, people were left feeling quite powerless and vulnerable.

Institutional care was one of the most difficult environments for people to request change and to feel secure in their service given that so much of the decision making power rests with the carers providing 24 hour care. Stella is a lady whose her mother, Gwen, is in a residential facility with quite high care needs, and is unable to communicate anymore. Stella explains that while the residential care facility staff provide lots of information, have regular meetings around care plans, invite her to attend focus groups etc, she is too afraid to ask that Gwen be given more to eat, or to comment on her care, because she is fearful of what the consequences may be for Gwen. This is a significant barrier to consumer participation given that the organisation has attempted to consult and seek feedback from residents and their families, and yet the current culture of consumerism of not complaining prevents them from doing so truthfully.

This barrier was also evident in community programs as people refused to complain about their service because they were afraid that they might be judged as ‘ungrateful’ and could actually run the risk of losing the service. Dot and her husband Jim look after their mother Daphne who is in her 80’s, and came to live with them because she was

unable to manage at home due to dementia. Daphne suffered a heart attack shortly after moving in with Dot and Jim, and now needs quite a lot of assistance with all aspects of her daily living. Jim still works, so it is up to Dot to provide a lot of Daphne's care. They were very pleased when they began to receive services to assist Daphne with showering and to provide some respite for Dot.

The service informed them of how many hours they would be able to have, what type of assistance they could receive, and they also had no influence over who provided their service. The first carer that provided showering assistance was someone they all felt uncomfortable with and did not trust, and eventually left before a replacement carer could be found, leaving the family to feel quite insecure about their service. Now that the carer they have gets along so well with Daphne, and both Dot and Jim feel that they have an excellent rapport with her, they are so frightened of losing her that they have threatened to leave the service if the carer is taken away from them. Certainly there appears to be little evidence of the family feeling secure and empowered within the service.

Beryl was made to feel quite vulnerable by the changes to the service she was receiving. This 78-year-old lady cares for her husband, Ross, who has dementia. Beryl recently experienced a fall that left her with lots of pain, complicated by the chronic arthritis that also challenges her. Consequently upon discharge from hospital, help within the home, as well as equipment to help her mobilise was organised. The problem came when this short-term service decided to pick up their equipment before an ongoing, long-term service had been able to organise equipment and carers to meet her needs. Beryl was left feeling frightened, at risk of falling again, and with increasing pain, so she had to urgently organise to hire a walker from another service. Her experience with the workers who provide household assistance was also very poor, with late minute cancellations and presenting as very unreliable.

Beryl feels manipulated by this worker, fearing that the coordinator in the organisation is unaware that the carers are behaving in such a way. Once again there was a reluctance to complain and to cause problems for the worker, not wishing to be judged by the service as a 'trouble maker'.

Another lady, Josie, who had moved to Australia from England after her husband died, to be closer to her family, explained that the home cleaning and shopping service she received met her needs well and she got along very well with the workers. However, given encouragement she reluctantly admitted that the gardening assistance she received was far from helpful, it was actually something that bothered her and yet she was reluctant to feed this back to the coordinator.

Josie explained that while the gardener was very nice, he had his own ideas about what should be attended to in the garden and how. He did not listen to her requests, just doing things as he felt they should be done. Although this clearly irritated Josie, she did not wish to feed this back to the service in case it affected the rest of her service that she was very happy with, and she certainly did not wish to appear ungrateful. The fear of being judged by the service as ungrateful resulted in Josie feeling quite powerless, having to accept someone changing her garden to please themselves, rather than to meet her needs.

Discussion

It is evident from these precious stories that people have shared, that the most positive experiences of services, within which the people felt most empowered and influential, did indeed include the empowerment principles identified. The stories that described situations that left people feeling unimportant, receiving a service that might meet their basic needs but which did not regard them as individuals, and that did not allow them to have an input into the planning and delivery of the service, did not include the empowerment principles.

The key elements that were identified during the interviews that contributed to a consumer feeling empowered included:

- The service took the time to get to know the person as an individual
- There was an open and trusting relationship created that also acknowledged the significant others in the persons life
- The service involved the person in the planning of the service, responding to specific needs rather than offering a standard package of care
- The service included life enhancement opportunities, taking a holistic approach to the persons needs, such as social supports etc.
- Feed back and was actively sought, in a variety of ways, from the coordination level to the actual worker who delivered the hands on care, this feed back was then responded to with evidence presented back to the person so that they had confidence in the quality process
- The people receiving the service felt secure, not being afraid of losing their service if they complained, and could ask for increased services if their care needs changed

Barriers and challenges:

There were some barriers and challenges to consumers feeling empowered and having an influence within the services they received, identified in these people's experiences, that not only involved ways in which services behaved, but also because of long standing attitudes held by consumers that created a culture resistant to consumer participation. As well as not including the determined empowerment principles, there were some particular areas that were repeatedly highlighted throughout the stories.

- ***People are reluctant to complain because they feel 'grateful'***

Many people were of the mind set that they must be 'grateful' for the help that they received, and that if it was not exactly what they wanted or needed then at least they were getting something. There were comments like "there are others that need help more than me" and "it is better than nothing". Often these people were consulted by services, however their response was based on being courteous and polite, not wishing to be judged by the service as being 'unappreciative' or 'complaining'.

- ***There needs to be evidence of change resulting from feedback and no negative consequences***

A few people mentioned that there was no point complaining or feeding back to services because "nothing was ever changed anyway". They felt that they needed to have evidence that what they said had been listened to and acted upon, otherwise they were wasting their time providing feedback. Others explained that they were afraid that there would be consequences of responding to evaluations honestly.

- ***Consumer groups need to have a clear purpose and achieve outcomes***

Several people mentioned that while they enjoyed attending consumer participation groups, and often learnt a lot of new information, they did not feel that they were worthwhile unless there was some form of activity with a clear purpose and achievable outcomes. Otherwise it became a different type of group i.e.: educational, social, support group, and there might be other places they already go to attend such groups.

- *There needs to be opportunities to engage consumers individually in an environment of their choosing*

Some of the people interviewed indicated that they would not wish to attend a group environment to talk truthfully about their experience of services. This was because of reasons such as fear of judgement by other consumers, privacy about which services they actually received, fear of speaking in public and reluctance to complain in front of others.

Themes:

During the interpretation of these remarkable stories, several themes emerged that were peripheral to how empowered and influential people felt within the service that they received, but still related to the subject and appeared to be valuable considerations when exploring the empowerment of consumers. While the majority of the people interviewed were living in their own homes, some were still living in institutionalised care, or had had experiences of such care, and wished for these experiences to be included.

1. *‘The level of personal empowerment that someone has is not directly related to the level of empowerment they feel when receiving a service’*

This means that even if a person feels quite empowered in their life, a service can make them feel very disempowered, and conversely, a disempowered person can feel quite empowered by the way a service interacts with them. This was evidenced by stories of people who had held highly valued roles within their communities and workplaces, and yet found that they had very little to no influence around the services they received. It was clear also that the carer of someone receiving services can also become disempowered by default, so if the service allowed the person to become disempowered, even the most empowered carer became disempowered also.

2. *‘The most socially disadvantaged group that had led a lifetime of disempowerment, appeared to be a group that could achieve the greatest outcomes if service providers were able to overcome the significant barriers to empower these consumers and encourage their participation and influence potential’*

This group of people included some of those living in supported residential facilities, rest homes and public housing, many of whom were attempting to overcome barriers created by mental health issues, disabilities, drug and alcohol related problems and/or poverty. Consequently, this group of people have become disempowered by repeated experiences of vulnerability and institutionalisation. The overriding theme from this group was that these people have incredible strength to have survived these experiences in life and that if a service was able to overcome the significant barriers to truly engage with this client group, great outcomes could be achieved.

3. *'The people who appeared the most independent highlighted the crucial need for services to adopt an empowering approach when initially coming into contact with people who are accessing services for the first time'*

Some people prided themselves on being independent to such an extent that examples of incredible resourcefulness and ingenuity were revealed, but so were situations of people placing themselves at risk unnecessarily because they were reluctant to seek help.

Further exploration discovered that often these people had already experienced significant loss in their lives e.g.; immigration, retirement, death of spouses, medical illness/disability that their refusal to seek help was actually a defence against further loss of control within their lives. Therefore, if their initial experience with receiving a service was not respectful and encouraged their influence, they may refuse to accept further assistance and possibly place themselves at continued risk.

4. *'Institutional care, such as residential facilities and hospitals were by far the most disempowered group'*

It was overwhelmingly obvious that this group had the least influence on the service they received, just by the fact that they were in an institutional environment that was outside of their control. This made this group particularly vulnerable, and there were situations where people were actually harmed by services while in their care. People's experiences of care were dependent upon things such as staff attitude, and whether or not family were encouraged to visit, which could change an individual's experience from wonderful to disastrous. These circumstances were the ones in which people were most reluctant to feed back openly and honestly, because they were receiving 24 hour care and were frequently so dependent upon those services delivering their care, that they were fearful of potential negative consequences.

Outcomes

To return to the initial objectives outlined at the commencement of this project, it appears that the key objectives have been met, as well as some clear indications identified for the need for further work to be done in this area.

1. To provide opportunities for consumers to share their own experiences which will illustrate and inform the development of services

The project has clearly provided an opportunity for consumers to share many precious stories, both positive and negative, that are available as valuable resources for service providers who wish to have a glimpse into authentic and candid experiences of services. The stories gathered provide an insight into how empowered consumers feel and to what extent they actually participate within the influencing of the service they receive.

2. To determine how empowered consumers in the southern area of Adelaide feel within influencing the services that they receive

Of the 50 people that have been interviewed, in both one to one interviews in their own homes, as well a focus group in a community centre, approximately 60% of the stories gathered suggested that people felt quite disempowered within the services that they received and felt that although they were informed about the service, they did not make any significant decisions about the actual service they received. 15 % of experiences explained that people were consulted by the service providers, and asked to give their thoughts about the service they received, but still had no direct influence upon the direct service delivery. Those stories describing people having a direct influence on some to all, of the significant decisions made about the service made up 25% of the total number of people's experiences.

3. To expose any barriers or challenges that make it difficult for consumers to feel empowered within the service they receive

The barriers and challenges exposed included services not delivering their services in an empowering way as outlined by the empowerment principles, but also to seek feedback

from consumers in lots of different ways to ensure that even the frailest and vulnerable people have a voice. If consumer participation groups are formed as a way of obtaining this feed back they would be more effective if they have a clear purpose and achievable outcomes, and any feed back needs to be actioned with the consequences reported back to the consumers in order to encourage trust and confidence in these quality processes.

A major barrier to consumers becoming empowered is the culture of 'being grateful'. In some case services attempted to empower consumers unsuccessfully because the people themselves refused to complain or to feed back openly and honestly for fear of appearing unappreciative or other negative consequences.

4. To discover ways in which service providers can involve consumers in meaningful and influential ways

Services can empower people and involve them in meaningful and influential ways by delivering a service based on the empowerment principles outlined. These qualities need to be embedded into service provider's practice at every level, from management to coordinator to care worker, so that the person receiving the service can feel secure and empowered within the service that they receive.

Services may also have a role to play in helping to initiate a change in the culture of consumer participation. Services may wish to be involved in the education and encouragement of consumers to acknowledge that it is their right, as well as their responsibility, to engage in feed back in order to initiate a change within services that is able to meet their needs in the most appropriate way. This would also require education and support for services to accept honest feedback as a quality improvement process, rather than a blaming exercise, which would result in services more suited to what people actually need and want.

5. To link the Better Practice Project to an informed consumer base

The BPP now has access to these valuable stories that are available as a resource to services and consumers alike, to inform quality processes, staff training and system development and improvement.

Recommendations

The information and knowledge gained by the generosity of those people brave enough to share their remarkable stories can be utilized to further the exploration and development of strategies to help empower people within influencing the services that they receive. It is apparent from the outcomes of this particular project that there are some clear directions for the future that include:

- Developing a range of individual service and system level strategies that complement and go beyond our current quality systems, towards empowering consumers, as well as developing tools to review and evaluate those approaches
- Identify strategies to build confidence and empower consumers
- Build underpinning principles for a strong consumer voice
- To guide and change service provision, including expanding, strengthening and influencing staff training for the future.

Conclusion

Therefore, after exploring service provision from a consumer's perspective, it is clear that there is a lot of work left to be done around ensuring that consumers influence and participate within service planning and delivery, in effective and meaningful ways.

With approximately 60% of the stories gathered from people being interviewed describing experiences that indicated they were quite disempowered within the services that they receive, it is clear that services have significant challenges to overcome in order to achieve the goal of effective consumer participation. The identified themes and barriers also highlight the need for a change in consumer culture, for without the confidence to have a voice, no amount of consulting via focus groups, surveys etc will achieve honest, open feedback and consequent consumer empowerment.

It is acknowledged that this initiative is only a small step towards the path of true consumer empowerment; however its strength lies in that it is from the consumer perspective. Adopting a consumer's perspective has allowed a glimpse into some very successful models of service delivery, that encourage consumers to participate and to consequently feel empowered, as well as descriptions of poor practice that not only leave people feeling disempowered but sometimes even do more damage by placing people at risk.

The hope is then, that both consumers and service providers may work together towards achieving the goal of effective and meaningful consumer influence and participation, and that the stories and experience gathered within this initiative will assist in this process.

Reference List

- Better Practice Project Report (2000) *A Unique Life to Live*, Community Options South, Aged Care and Housing Group Inc, SA
- City of Onkaparinga Community Profile and Atlas, (2005)
<http://www.id.com.au/onkaparinga/>
- Degenholtz, H. Kane, R. A, & Kivnick, H. Q. (1997). *Care-related preferences and values of elderly community-based LTC consumers: Can case managers learn what's important to clients?* *The Gerontologist*, 17 (6), 767-776.
- Kendrick, M. (2004) *Levels of Empowerment*, Planet Advocacy, 7 March 6-7
- Kendrick, M. (2004) *The Next Generation In Human Services And The Emerging Challenges For Case Management*, *Australian Journal of Case Management*, 6 (1)
- Kivnick, H. Q. (1998). *Through the life cycle: Psychosocial thoughts on old age*. In G. H. Pollock & S. I. Greenspan (Eds.). *The course of life* (7) 119-134. Madison, CT: International Universities Press.
- Kivnick, H. Q., & Murray. S. V. (1997). *Vital involvement: An overlooked source of identity in frail elders*. *Journal of Aging and Identity*, 2 (3), 205-223.
- National Resource Centre for Consumer Participation in Health (2005) *Information Series, Methods and Models of Consumer Participation*,
<http://www.participateinhealth.org.au>
- Wolfensberger, W. (2002). *Social Role Valorisation and, or Versus, "Empowerment"*, *Mental Retardation*, 40 (3), 252-258
- Wolfensberger, W., & Thomas, S., (1994) *An Analysis of the Client Role from a Social Role Valorisation Perspective*. Syracuse University, USA, p 4-5