A Consumer Perspective on the need for reform of community care

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"There is no news only olds"

Russell Baker, US Newspaper columnist 1980s

The issues we are considering today are not new. We are re-visiting some endemic issues in the community and the service system. Hopefully we can draw on previous learning, in aged care, disability services and consumer participation to inform new initiatives in a changing environment.

In this brief address today I want to talk with you about three things, which have system wide implications including implications for the Commonwealth which is the focus of our session.

Blind Spots in the Vision (Myer 2002)
Partnership with Consumers
A learning system

BLIND SPOTS IN THE VISION

The Vision (Myer 2002) proposes significant industry reform by 2020 so that by then older Australians can be confident they can access the care and support they need.

The solutions advanced (pertinent to this conference) are focussed on coordination, planning, community care and housing.

Coordination

Community care

- well resourced
- flexible
- robust
- integrated network
- meets changing needs of individuals

Reforms Needed

- community care
- housing
- administration funding
- industry planning

All of these elements are necessary and significant reforms, but I suggest they are not sufficient.

Missing from this vision is a focus on the consumers whose interests the reforms are designed to serve. ‘Consumer’ (a poor term which focusses on the customer element of relationships which have many more aspects to them), includes users/recipients of services, their advocates, self-help groups or associations and representative organisations.

As a woman who will be 79 years old in 2020 I want to see many positive changes before then for myself and my currently 89 year old mother and all our peers. More radical change with all elements of health and aged care are needed today (not just by 2020) – one which empowers consumer to become key players in every part of the system as designers, planners and evaluators.

A new vision requires the capacity to imagine what might be and to devise ways to construct something different to what we have now.

The capacity to vision and to imagine requires the capacity to stand reality aside for a

moment - not to yearn for some utopia where disease and disability have been eradicated - but to make opportunities to recognise and eliminate our own blind spots.

Problem solving, creation of innovation frequently requires questioning of all assumptions - many may be reinforced in this process, but others may be exposed as "blind spots," misleading our efforts. Neither can visioning be a one off event - re-visioning needs to be a continuous process as our realisation of where may be possible shifts as our perspectives change.

How can we recognise and challenge ageism in our thinking about policy, practice and possible achievements?

For example: Do low expectations in general of older people's capacities to learn, grow and live with a disability/chronic disease influence our judgements of what may be possible in various situations?

What influence does research on the social determinants of health have on policies and practice? For example: Social isolation and loneliness, commonly thought of as inevitable in older age, are usually regarded as the results of illness and disability. What if they are amongst the causes of ill health as well as amongst the outcomes? Our practice would then shift to building social connectedness rather than merely compensating for symptoms of mental and physical illness.

The Vision largely takes people and their needs as given – yes there are references to different patterns of disability and health status but the Vision does not accord rehabilitation, health promotion and disease prevention a central place in the vision or the service system.

PARTNERSHIPS WITH CONSUMERS

The extensive literature and practice of consumer participation could support a full conference of its own. Today I want to suggest a change of perspective about one facet of consumer partnerships and person centred care which could drive innovation, learning and new visions for community care as a whole.

COTA National Seniors advocates strong partnerships with consumers at all levels of the community care system – direct service, learning initiatives, evaluation, and policy and planning.

The central concept of the Vision is one of "enabling older people to live safely in their own homes as long as possible". What would be the impact of changing that idea to one of enabling older people to enjoy quality of life and maximum participation in the society*?*

Once the basic necessities are assured, maintaining independence or autonomy in important matters is a major component for most people's quality of life. Independence is highly prized by most people in our community – older people are no different. But what are the key elements/defining characteristics of "independence".

In the aged care debate independence is frequently interpreted simplistically to mean remaining at home, rather than entering residential care. However, remaining at home, outside the routines and organisation of an aged care facility, keeps open the possibility if independence but does not guarantee it.

For most people independence is concerned with maintenance and growth of self-identity, together with a capacity to make personal and economic decisions on matters of importance. The Disability movement has done a lot of work in the last 25 years identifying and taking action on physical, psychological and spiritual aspects of independence whilst. Aged care has tended to focus on physical aspects only.

Community care service system (the care itself, funding and accountability procedures) commonly ignores, but worse yet if we are not alert to the risk, may undermine rather than build independence. Building strong partnerships with consumers, which draw on the strengths and capacities of all involved, must be a fundamental component in strategies for improvement.

A Paradigm Shift from Deficit to Assets

In this context "assets" refers to personal characteristics and community assets as well as to individual material assets. I will focus on the former two for today s address.

Let’s take a fresh look at the people used as illustrations of issues in the Myer Vision from a different perspective. Instead of looking at their deficits and how to compensate for them let’s look at the assets that there may be in the situation.

> *Mr Adams is cared for by his wife after suffering a series of strokes. Mrs Adams is helped with day care, nursing visits, occasional respite care and housekeeping. But they had to wait a long time to get this care and Mr Adams was assessed at least five times by different teams and visited by more people than Mrs Adams can remember. (Myer 2002)*

Mr Adams retains his passion for pigeon breeding and racing but cannot manage his birds now. The community officer worked with Mr Adams, local breeders and the nearby racing club. Club members now take Mr Adams to meetings and race days. He enjoys the company and is a great source of advice to new breeders. He is no longer bored and boring but interested to share his experiences with his wife and hear about what she has been doing in his absence. Mrs Adams has reduced anxiety, enjoys the time he is out to pursue some of her own interests and needs less support with house keeping.

> *Until the age of 83, Mr Banh has lived alone in his family home with 10 steps at both entrances. After fracturing his hip, even with hospital-based rehabilitation, he can no longer get in and out of his home and his family is concerned about his safety. Mr Banh and his family must decide if he can move back home or if he needs to move to a low care residential facility when he is discharged from hospital. (Myer 2002)*

Mr Banh received intensive rehabilitation in his home. A local handyman installed a temporary ramp. The community officer facilitated a family conference to address their

fears, Mr Banh's views about the risks he wished to take, his options and possibilities. Mr Banh decided to sell his home and buy a unit that is located a few doors from his granddaughter. She and her family enjoy the crops of fresh vegetables that he now produces in their formerly neglected garden and he feels happier about being able to call on them if necessary. He is learning the computer and using the Internet to communicate with overseas family and friends.

> *Mrs Costos is a very frail 79 year old who suffers moderate dementia. Her husband, who has heart problems and osteoarthritis, cares for her at home. Mrs Costos was admitted to hospital after a fall. Now back home, she needs more assistance than she did previously. Mr Costos learnt he would have to wait for six months before receiving additional community services to help him care for his wife. The staff at the hospital have advised him to arrange residential care for her. (Myer 2002)*

Mrs Costas is a talented oil painter. Her GP referred her to a strength training program where she gained muscle mass and strength and improved her balance. Falls were avoided or intensive rehabilitation focussed on getting her back to painting and into a painting group for people with mixed abilities where she is comfortable.. She spends hours at her easel. Members of her extended family are interested in her new art work and she is able to show some of the youngsters different techniques even though she cannot describe them very articulately. Mr Costos is benefiting from pain management and exercise.

> *Mrs Donaldson managed to live alone with constant support from her daughter. As she became more frail, her daughter worried about her nutrition and safety. After a fall, Mrs Donaldson became incontinent. As a pensioner, she has no assets apart from her home. She is not able to afford any more help and with her daughter, decided to apply for residential care. (Myer 2002)*

Mrs Donaldson undertook a strength training program. As well as the direct physical benefits she felt so much more alive in the company of others in the group and in her new confidence in doing a range of activities at home and in the community. Her appetite improved remarkably and she really enjoyed her turn to organise a lunch for the three new friends she made at the gym. She has joined the local "walking train" providing safe, healthy transport to school for local youngsters. The continence problem remains but she realises that she can manage with the support of a self-help group. She now values herself more highly, rather than seeing herself as a burden to her daughter and has decided realise some of her home equity for a holiday, a personal trainer and home renovations to make life easier.

Of course the people are much more complex than these brief paragraphs suggest but skilled community workers can use a variety of innovative techniques to enable people to focus on what is most important to them and the most valuable form of assistance to help them achieve it. The consumer would then drive the resulting service mix, some of the activities may look the same (home care, attendant care, personal care) but the meaning attached to them would be very different.

A LEARNING SYSTEM

There are multiple implications for the Commonwealth of the Vision and my additions - in relationships with the state and territories, in funding, quality and accountability provisions, program design and connections between the ageing and the disability sectors. The Myer Foundation paper (Myer 2002) and other speakers today articulate these clearly.

In this brief address I want to draw attention to a potential innovative change strategy for the Commonwealth that has the potential to drive reform in ways we cannot yet even imagine. The Commonwealth should provide leadership and support for the creation and maintenance of a learning system. The notion of a community care system, which is actually driven by the people for whom it is established, is not something that can be completely specified and regulated from our current state of knowledge. We need to foster participatory learning in and across all parts of the system. This is not the same as the necessary education and training of people working in the community care. A learning system involves people working together to identify and explore key issues, a commitment to resourcing such learning, and mechanisms to ensure that the outcomes of learning influence practice and policy. The recipients of services and service delivery staff would be as important to the organised learning activities as mangers or policy makers. Understanding what makes the most positive contributions to their lives and work and finding the most effective ways of supporting those elements should be the central focus of the learning across all parts of the system.

Reference

The Myer Foundation (2002) *2020 A Vision for Aged Care in Australia*, Melbourne, Myer Foundation, 2002

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