

PARLIAMENTARY INQUIRY

BETTER SUPPORT FOR CARERS

Prompt Notes

Introduction

- Thanks for the opportunity to be heard
- My views are at variance from most – a voice in the wilderness
- Acknowledged that there's not enough to go around
- But it's not all doom and gloom
- Data from ABS survey *Disability, ageing & Carers (2003)*. Data for Australia, and Primary Carers unless otherwise stated.
(Note:- "S" = Summary publication; "p" = page number; "T" = table number; "Txx" = Supplementary table number)

Key Points

- **Kith and Kin are the backbone of the system**
 - 94% pwd live in community; 6% in cared accommodation (Sp4)
 - 79% pwd helped by Kith and Kin; 53% by Agencies (Sp7)
 - 68% help provided by Kith & Kin; 27% Agencies; 5% no one (ST15)
- Kith & Kin are passionate, tough and resilient
 - 36% Primary Carers 40+ hours per week; 55% 20+ hours (T21)
- They don't ask for much, but when they ask they really mean it. They are at the end of their tether and need help now
 - 44% Primary Carers do not need support; 32% get enough; (76% fine); 24% need more help (T16)
 - 76% don't use or need respite; 7% don't need more; 17% need more (T14)
- **It's the frail helping the feeble**
 - Many Primary Carers are themselves aged or disabled. 24% are 65+; 40% have a disability (note:- double counting applies) (Sp3)
- **It's not a bottomless pit**
 - 39% pwd no help needed; 37% needs fully met; 22% partly met; 3% not met (Sp6)
- **Those *with* greatest needs are *in* greatest need**
 - 50% profound have unmet needs; 41% severe; 26% moderate; 16% mild (Sp7)
- **But it's not all doom and gloom**
 - Most Primary Carers "preferred" to do so (Do it better 39%; Family responsibility 58%; Emotional obligation 34%) than seemed "trapped" (No one else available 23%; Willing 15%; Cost 17%; No other

arrangements available 12%; No choice 18%). Note:- Double counting applies)(ST33)

- Effects on relationships of Primary Carers are not all negative (T9)
 - With recipient twice as many were brought closer together than strained the relationship (34% vs 17%)
 - With partners and other family 8% were strained while 5% were drawn closer together.

- **It's not just what they say, it's what they mean**
 - Example from Minister's Office (in public domain)
 - 90 year old mother caring for 60 year old daughter wanted residential care. However, did not really want it there and then, but wanted peace of mind that there was somewhere for the daughter to go when mum could no longer cope. This requires confidence and trust, that when the time comes, help will be at hand.

- **Penny pinching is false economy**
 - Example from Minister's Office (in public domain)
 - Shortfall of \$20k for Christmas holiday respite program resulted in no respite for single mother with two handicapped children. She hit one child over the head with a hammer. Both children were immediately placed in to residential care (cost \$50k pa each = \$100k), and mum was charged with attempted murder and later acquitted. (Police and Court costs c\$100k). Thus, for a shortfall of \$20k, \$200k of expenditure was incurred, let alone the human costs. This erodes confidence and trust and is a blight on the system.

- **The problem will get worse before it gets better**
 - Demographic factors will see the number of people with disabilities increase, while the pool of Carers who can help out decrease.
 - The number of people with disabilities will increase due to the ageing of the population and increasing longevity; while the advances in medical technology will cut both ways – by cures and ameliorating the impact on one hand, offset by increasing survival for previously terminal conditions.
 - The pool of potential carers will decrease due to smaller family size (fewer people to share in the caring role), high family breakdown (fewer people with a strong personal commitment to help out), greater workforce participation rates (fewer people with the time to help out) greater workforce mobility (fewer extended family members to help out)

Where do we go from here?

Support Services

There's not enough to go around. The obvious first and easy step is to provide more services and more support. For the cost of one weekend newspaper per household in Australia each week, would provide around\$1.3b, (or about \$130m in WA) (\$2.50 x 52 weeks x 10,000,000 households = \$1,300,000,000). Given the broad community

support when the Carer Bonus seemed under threat, it seems that an allocation of this magnitude would garner community support rather than political backlash.

However, if this is the only strategy it will just raise the tip of the iceberg. It doesn't matter much where you draw the line; those that just miss out will feel hard done by. An additional strategy would be to also better manage expectations.

The two most fundamental concerns driving Carers are:-

- How can I get through today? Which is about services and support; and
- Who will Care when I'm gone? Which is about expectations.

Below are some suggestions which could be considered to better manage expectations.

Confidence & Trust

There is a marked lack of confidence and trust by Kith and Kin in what government agencies say and do. This has been brought about by false promises and weasel words which have poisoned the well of good-will and partnership.

- When the Government announced an "efficiency dividend" for funded agencies, the impression was created that agencies would get a bonus for the good work they had done for many years. Instead, it meant that the funding levels were cut, the "dividend" going to Government, not agencies.
- When Post-School Options is said to be "full-time funding", the expectation is that day activities will be provided for an equivalent of full-time schooling, 9:00 to 3:00, 5 days per week, 40 weeks per year. When it actually means the maximum level of funding available, Carers feel betrayed and misled
- When people in obvious critical need are left on the wait-list time and time again, others lose confidence that their needs will be met when they hit the wall. This results in a scramble to get on the wait-list.
- When disabled children leave school, and are left on the scrap heap at home under mum's feet 24 hours a day, 7 days a week, 52 weeks of the year, this is a great disruption to the family. After a few years, the family seeks full-time residential care so that they can get their life back on a reasonable basis. Full-time residential care costs around \$75k pa, while Post-School Options cost around \$15k pa. Thus, for every person kept out of residential care, 5 people can have their needs met within the family. Short-changing families by offering part-time day activities is false economy, as it hastens the rate at which full-time residential care is required.

Service Model

The introduction of a "business model", based on contracts and deliverables, as distinct from a "service model based on helping out as best one can, has had a subtle but profound impact on the mind-set of agencies. Now if the contract specifies \$1m

for 100 clients, when client 101 turns up, they can not be accommodated, as they aren't part of the contract. Under the "service model" agencies would do the best they could to accommodate as many as possible.

Further, as cost pressures increase, high-cost clients are replaced with lower-cost clients as vacancies become available, resulting in a gravitational pull towards clients at the cheaper / easier end of the disability spectrum. This systemic creep further disadvantages those in greatest need, and whose Carers are most in need of support. If there's not enough to go around, it's natural to give preference to the cheap and easy ones, rather than the expensive difficult ones.

The "service model" was a partnership between government, agencies, people with disabilities, and their Carers, where each did the best they could in a spirit of cooperation and good will to meet the changing circumstances as they emerged. It was "people first", not "what does the contract specify".

Empowerment

Currently funding allocations are made by bureaucrats, and regardless of what those decisions are, those who miss out are sorely aggrieved and critical of the process.

An alternative approach would be to devolve the decision-making (or at least recommendation-making) to those who are affected by the decision. In WA there are Regional Advisory Councils which could be assigned this task. By localising the decision (or recommendation) making, it brings in greater sensitivity and responsiveness to local circumstances, as well as empowering those most affected by the decision.

Needs Based

The system is needs based – those with the greatest needs are helped first.

However, this gives incentives to race to the bottom, and rewards those who can provide the most heart-wrenching stories.

An alternative model would be based on a Social Contract. This could be done on a "matching" basis, where if the family provides the primary care for the first half (say 30 years) of a congenitally handicapped person's life, the community would guarantee to do the rest when it is called on. For late-onset disabilities, there could be a matching of inputs – either time or dollars. This would reintroduce some rights and responsibilities to the system, and stop the "race to the bottom". A needs-based safety-net would still be required for exceptional circumstances.

Summary

- Kith and Kin are the backbone of the system
- They don't ask for much, but when they do ask they really mean it
- There's not enough to go around, but it is not a bottomless pit

- Get more bang for your buck by helping families continue their caring role rather than picking up the pieces when it has collapsed – Help Carers Care
- Rebuild the partnership of confidence and trust
- Manage expectations

I trust these comments are taken in the spirit in which they are intended – to help make it better

Thank you for the opportunity to comment

Charlie
Carer and
Chairman of Intework

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