

Interchange Respite Care (NSW) Inc.

Leading, Supporting and Enhancing Respite and Social Support Service Provision across NSW



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The National Respite & Social Support Conference

Two weeks.

July 31 - August 2, 2007.

Plenary Session 4. Carers Perspective Panel.

Carers: Felicity Maddison, Elizabeth Martin, June Waites,
and Pam Alexander.

Facilitator: Kevin Marron

This panel comprised 4 female carers who were primary carers for teenage & adult children with a profound disability and autism, and an ageing spouse with dementia.

The session commenced with an introduction from each of the panel members as to their current caring circumstances and a brief history on their lives.

The session then comprised 5 questions put forward by the Facilitator to which each carer provided a response based on their own experiences and personal opinion.

Question 1: Our first Plenary session on Tuesday was on Assessment Tools and the development of the new Carers Eligibility and Needs Assessment tool. What are your recollections of being assessed and your experiences of the processes. Is it a necessary evil, an opportunity to be heard, to shallow or too detailed.

- need a single point of entry to the service system;
- this can be demoralising – having to give very personal information;
- Respite should be an entitlement, so assessments should only be for the support needs of the carer;
- This process can be difficult when assessors are judgemental;
- It can be frustrating at spending hours re-telling the same information over & over, - information should be shared across agencies;
- There needs to be respect for the care recipient when they are present at assessment interviews, particularly when their needs are being discussed in front of them;
- An Australia Card, - it would be good to have a way of storing information that could be easily accessed,
- A good assessment, based on support needs, is required and necessary to provide appropriate care.

Question 2: Now many carers and families may experience a variety of providers in their lifetime whilst others only have 1. How have you found relationships with providers you have used, and how accommodating have they been in meeting your needs. What is the quality of support workers in our industry.

- the service I use and their workers are great;
- many Day Services still operate on 'kindergarten' hours (9am till 3pm) which can make it difficult for working carers;
- it can be difficult obtaining a diagnosis;
- schools can be a nightmare in receiving appropriate support & service
- initially, many years ago, when I entered the service system, advice from some providers was to place my child in an institution;
- assessments are repeated over & over;
- some services offered are not necessarily those that I needed;
- services should share information;
- services speaking about the care recipient should be sensitive to their needs & individuality;
- services I have used and been very flexible;
- I have observed an increased level of training and skills amongst support workers over the years;
- On-going training for workers is essential;
- Understanding of the essentials of disability are necessary;
- In my experience, support staff who came into my home often undermined the family authority and the response strategies I had in place;
- Asking for help can be very difficult;
- Flexibility of hours has been a very good part of the service I have received.

Question 3: What is, or has been, the value to you of the service you have received.

Respondent 1.

- flexibility of respite. Can combine allotted hours to have a full week-end;
- true respite has enabled the carer to have the freedom to have quality time "you can be who you are";
- respite support has since been withdrawn and phone calls to the state department have been frustrating. Feels that respite hours offered often does not address the carers true needs.

Respondent 2.

- respite means being able to plan ahead;
- to have quality time as a couple;
- time without the children;
- having a respite service that plans 6 months ahead

Respondent 3.

- enables them to be a couple;
- time to talk;
- quiet time;
- regular respite time once a month is very important.

Respondent 4.

- time on my own;
- time to think and be yourself;
- peace of mind knowing that my spouse is being cared for;
- carers who will accept my spouse's pet dog as being included in the care time;

- less anxiety for me.

Question 4: What is, or has been, the value to your care recipient of the service they have received.

- has taught them to interact with their peers;
- the quality of respite for the carer depends on the quality of care and choices in social activities for the care recipient, and the quality of support staff;
- genuine respite is when the carer and the couple can go away for a holiday;
- for me, priority and value was in finding staff who would let my spouse have his dog in their car;
- having fun & enjoyment in the activities they get involved in;
- a service based on his needs – not what the provider perceives to be his needs;
- as parents we are happy that the respite program is meeting our son's needs;
- individualised program,
- flexible service;
- not everything should be categorised as respite.

Question 5: Tomorrow we will be talking about the Australian Taxation system and is it really efficiently structured to collect what we need to meet community care costs. But we are always told now that there is not enough money in the system and that consumers /clients need to pay their fair share of the service cost and make a contribution. This we call fees. How do you feel about paying fees and are they valid. Is this fair, and is it affordable for you.

- how do we survive on a Carer's Pension;
- on the Disability pension – it is too great an impost to extract fees from this. There is not enough in this support to survive on without having to lose more in fees;
- Respite should be an entitlement – free and accessible;
- Families are forced to supplement the cost of service fees;
- The Government should recognise that carers have saved the community millions of dollars by providing care;
- Uniformity is needed – different organisations have different charges;
- We have not asked to be in this position – we should be better supported.