

Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family,
Community, Housing and Youth
PO Box 6021
Parliament House
CANBERRA ACT 2600

Dec 29 17/08

Dear Secretary

I wish to make a submission to the House of Representatives Standing Committee on Family, Community, Housing and Youth's Inquiry into Better Support for Carers.

I am submitting to the Inquiry because:

1. The following summary may contribute to further understandings of the caring role and its impact on individuals and families, particularly in relation to ageing carers and significant transition periods in the lives of people with disabilities.
2. This summary also seeks to highlight the **reality** rather than the **rhetoric** of caring - and subsequent tensions between disability service providers (government and non-government) and their impact on the daily life and work of carers, their families and individuals with a disability.
3. It is hoped that the Inquiry, by offering a voice to carers such as myself, will follow through with policies and practices which are:
 - Non Idealistic,
 - Practical,
 - Local and Particular,
 - Critically and Rigorously Evaluated,
 - Partial and Effective in focus and not attempting the grandiose and impossible.

1. The role and contribution of carers in society

As a carer I feel that my role is neither fully understood nor appreciated by the general population or by disability service providers in particular.

I am grateful to organizations such as VALID, RIAC, FOCDGS and Carer's Victoria which attempt to provide information, support and advice to carers.

Although I am appreciative of being able to submit to this Enquiry, it would be far less time consuming and effective if it was expected that carers, as key stakeholders, were regularly offered:

1.1 Opportunities to review and contribute to a range of disability initiatives across the three tiers of Government, including Disability Service providers.

1.2 Reliable follow-up, feed-back and actions arising from transparent findings and recommendations derived from critical and rigorous analysis.

1.3 Clear procedures and willing assistance at all levels for accessing legitimate funds and resources for carers and the people they care for. (So often, it is a battle, one feels guilty for even enquiring when in reality the programs/resources are an entitlement, no formal evidence is given that fundings/programs have been applied for, no reasons are provided for failed applications.)

2. The barriers to social and economic and participation for carers

As a carer, I face the following problems which impact on my social and economic participation:

Our Caring Role Goes Beyond Usual Parenting Responsibilities: We are in our early sixties.

Our 23 year old daughter has a dual diagnosis: Intellectual Disability and a Psychiatric Condition.

While the role of parenting is ongoing and changing for most people, the degree that we have to parent doesn't necessarily decrease as our daughter matures. In many ways, there are new intensities and complexities.

The degree of caring, monitoring, management is not much different to having a very young child yet becomes more complex as the disabled person matures. Just some examples which show the time and responsibility allocation required of the caring role, hence the impact on our social and economic participation:

2.1 Living Situation for our daughter-

2.1.1 Full-time at home with parents: While this is currently the desired option for all concerned it remains our sole responsibility with the accompanying challenges and impacts it creates.

2.1.2 Respite is offered approximately every 5 to 6 weeks for a weekend. This is NOT enjoyed by our daughter as the organization running the respite is unable to plan and coordinate for other attendees who have similar abilities/interests to her own.

2.1.3 This situation reflects the ethos of many disability service providers in our area – The rhetoric and positive public recognition is apparent while crucial matters effecting individuals, families and carers are rarely recognised or addressed. For example the staff do their best but the management appears to offer no avenue for review and/or monitoring that is transparent to carers.

2.1.4 Because of the above the respite service is sometimes cancelled by us, or extended to 8 weekly intervals due to the mismatching of our daughter's needs. We are currently considering cancelling the service. (Without wanting to appear over critical, the organization appears to have enough funding for elite vehicles for staff.)

2.1.5 Our City Council offers 3 hours respite per fortnight.

2.1.6 There are costs involved for all respite services.

2.2 Education & Supported Employment for our daughter – Given the choices available, we attempt to support our daughter's attendance for 4 days per week in two settings- one educational, the other, supported disability employment. Her attendance is often partial, depending on our daughter's health and the suitability of the programs provided.

2.2.1 It is frustrating however, at the local level to experience resistance, refusal and judgmental challenges when requesting transparency of funding for State Government Futures for Young Adults allocation for our daughter. We have recently found that her small allocation has not been used to its full capacity since inception. A more tailored weekly program may have been negotiated if the funding had been offered more transparently and flexibly.

2.2.2 The attempts by Federal Governments to have disability employment organizations follow "open employment" models may release government funding to such organizations but appears to us, as carers, to have little relevance to the diverse needs of employees exemplified by our daughter. We have watched the incredible growth of such organizations in our regional city while very little commensurate support has resulted for us as carers. Auditors have not sought our comment when these organizations undergo review.

2.3 Leisure for our daughter – remains responsibility of parents with limited options provided by disability leisure providers:

2.3.1 Good experiences stop when funding ceases, other options require person to meet the program rather than the reverse.

2.3.2 One very successful model, funds now greatly reduced, is the Interchange Social group. Young adults with similar abilities and interests plan together with support workers to have monthly outings in the community. (approximately 4 hours duration)
Another successful program is the modified netball program.

2.3.3 Impact Leisure Organisation has been successfully utilized by our daughter. This has meant we have outlaid considerable money for our daughter to access such holidays. (\$000's)

2.4 Health of our daughter - Dual disability and complex needs can combine to severely challenge routine day to day activities.

2.4.1 After 23 years, such activities considered normal and expected in the majority of families remain challenges for us - personal hygiene, clothing, diet, personal safety, leisure, reasonable mood etc.

2.4.2 Despite professional support, mental health symptoms can cause disruption, stress and potential for self-harm if not managed carefully and sensitively.

2.4.3 As is the case for many people with disabilities, additional associated expenses and management is necessary: ear operations, travel to Specialist treatments, podiatry visits, optometry, frequent GP visits etc.

2.5 Challenges to Employment/Study - We *carefully and thriftily* manage our self managed "retirement" although it is not retirement in the usually understood sense.

2.5.1 Neither of us can work due to the shared caring role, I can only do intermittent consultancy work.

2.5.2 We don't qualify for the Carer Payment.

2.5.3 Due to the stresses of the carer role I had to cease doing a PhD some four years ago.

2.5.4 Meeting the financial needs of caring far exceeds our daughter's DSP allowance. Just two examples:

- Our legal, will making costs for instance are far more complex than most. We sought out specifically experienced professional advice regarding provision for disabled family member.
- Living 21 kilometers outside a regional city, with no public transport available, we need to own and run **two reliable** cars in case one carer cannot pick up our daughter if unwell at supported employment or education activities.

2.6 Experience of family - Extended family holidays have not been taken for more than seventeen years. As one carer is required at home in the role, separate "breaks" are now the norm although infrequently taken. The needs of other siblings require careful balancing and despite considerable effort usually come second.

2.7 Particular difficulties/Changing needs - The transition stage from school student to young adult has been particularly challenging.

2.7.1 The rhetoric of "Disability Service Providers" at all levels is neither convincing nor backed by evidence.

2.7.2 The growth in this area of employment is significant, yet for us the effect as key stakeholders is minimal at best.

2.7.3 Competition might be healthy in this area of service provision yet our needs would be better met if a real, reliable and professional choice was available.

2.7.4 Our circumstances have generally remained the same while programs/personnel come and go, are not particularly well planned, co-ordinated, targeted or diverse enough to meet our particular needs. For example we constantly battle to seek appropriate case management for our daughter while the Department of Human Services have for over four years, attempted to close our case. This is not a supportive situation!

2.7.5 Services need very careful scrutiny as to who really benefits and how initiatives are evaluated: local, partial, critical and rigorously evaluated measures are needed.

2.7.6 One organization that has really helped is E.W. Tipping who have recognised a need in our case and have offered a professional service at no cost.

3. The practical measures required to better support carers

As a carer I need help with:

3.1 Getting reliable, appropriate information.

3.2 Having timely professional support and co-ordination as in an effective Case Manager who, in consultation with us, attempts to meet some of the needs of our daughter and ourselves.

3.3 Opportunities to contribute to program and policy implementation, review and recommendation.

3.3 Future planning for our daughter which gives us all certainty and confidence.

3.4 Sharing the responsibility in a genuine and effective manner.

3.5 Interpreting the rhetoric and making real the reality.

3.6 Some recognition and recompense for self funded retirees who are full time carers in their sixties and are unable to meet the assets test for Carer Payment.

3.7 Some recognition and remuneration for our geographical position (in addition to our daughter's mobility allowance) which requires us to maintain and run two reliable vehicles for her transportation needs.

4. Strategies to assist carers to access opportunities and choices

4.1 Action planning which encompasses the views of key stakeholders at all times; during the planning, during the action, during the evaluation and during the reflection and recommendation. (See also 3.1 – 3.7 above)

Thank you for taking my views into consideration as part of the Committee's Inquiry. I look forward to reviewing any recommendations you make to improve life for carers in Australia.