

Submission No. 1017

(Inq into better support for carers)

AOC 28/7/08

July 1 2008

Committee Secretary  
Standing Committee on Family, Community, Housing and Youth  
PO Box 6021  
House of Representatives  
Parliament House  
CANBERRA ACT 2600

Dear Secretary,

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

My husband and I are both full time carers for two teenage girls with severe disability and high support needs. These girls are not our own children. We care for them via a program that used to be called the 'Family Options Program', providing children that were without a family able to support them, with a new family and home-based care. Having heard only recently of your enquiry, I believe our experience is probably a little different to most, and therefore of value for your consideration.

I have a personal life long history of experience with disability, as my sister had severe disability as these girls do. I am a trained teacher with additional qualifications in special teaching, and for the 12 years prior to caring for these girls, I worked in counselling and welfare, including supporting families with disabled children. I am well qualified and committed to the care of these young people, and we have done respite care for twenty five years as our own family was growing up. My husband is also a caring and committed individual and we are a formidable team in what we have chosen to do.

We have cared for our first foster child with Rett Syndrome (a degenerative disability) for 1 year as respite carers and a further 4 1/2 years as full time carers. She was 10 years old when she came to us and is now almost 15 – a young adult. She is epileptic, has severe scoliosis, and her mobility and motor skills are deteriorating now, mainly due to her Rett's condition. She is *totally* dependent on our constant care and we are not able to leave her alone. She attends a special school during the week, but is often unwell and spends many days at home or attending medical appointments. Our second child came to us after a series of failed placements elsewhere. She is now 12 and we have cared for her for 2 1/2 years. She has a severe intellectual disability, no language, and came to us with extreme behavioural issues. I gave up my work to take this second child on and we provide her with the stability and behavioural program she needs. She has been a success story in terms of her development, but continues to remain a daily challenge and also requires constant care and supervision. It is no longer possible to consider looking after both girls alone, due to their supervision and different support needs. We see this as our work, each child requiring one on one support. I will add, that last year, we were awarded the NDS Distinguished Service Award for 'outstanding contribution in a voluntary capacity' to people with disability.

Our role is to care for these two young people full time. This in itself is an enormous task. We are not paid to do this 24 hour work. As well as our day to day care we have to consult with our case workers and agency, attend numerous meetings and medical consultations, provide all that is required for their health and well being – such as daily medications, changing nappies, changing beds, exercising, providing community access and leisure opportunities, feeding, dressing, bathing. One child has a father who is custodian and the other has custody with the DHS, so these are other relationships requiring sensitivity and negotiation all the time. We are not able to work currently although we still talk about doing some part time work if possible, in the future, for our own well being. Friends laugh that we could possibly consider more work alongside what we do now. The reality is that we are becoming more tied to this care role and less likely to be able to pursue paid work. It is extremely isolating for two previously adventurous people.

Financially, we manage on the reimbursement of costs that are provided for the girls. We have applied numerous times for a carer's pension, but are knocked back on the grounds that we have a small farm worth more than the assets limit. By changing our mortgage from our home to this farm and putting it on the market, we have managed to be given \$100 each per week. I find this situation appalling. Our farm is our only asset, and our personal pleasure and focus. It belongs to us and our children and I believe when we are working so hard for these foster children – who's care is the responsibility of the Australian government – we should be automatically receiving a pension for that 'work'. I believe the government uses volunteers, like as ourselves, to save themselves the cost of caring for these children. We have committed to care for these kids until they reach adulthood and hopefully have another option of care such as a community-based house. This will be about 10 years of service to the community. We have forfeited these 10 years of work and the 'super' savings that our peers are accruing. We are entirely unsure what we will live on once 60, but are pretty sure the government won't be rewarding us for our commitment. Surely this is one area that can be addressed by your inquiry: that if you believe these children should be in home based care, you need to provide a salary with fair working benefits to the carers of these, other people's, children. We provide for these kids the same as is provided in

community based facilities, where the workers are rostered on, have days off, regular leave entitlements and are paid for what they do, in addition to having the funds to provide for their clients. We work ongoing 24 hour shifts, voluntarily.

The other greatest issue I have is that of respite. The issue of respite for families has been ongoing for years and years, and yet is so poorly addressed. From my experience as a carer, the ONE SAVING GRACE that would make ALL the difference to the tough commitment of caring for a family member with high support needs, is respite. We need more respite centres and a certainty for families that they can get a break. Without regular respite, we would not have been able to emotionally survive this commitment. We are lucky in a sense that the Department needs to support us with respite or the placement will break down. We are not allowed to use other adults in our own family network to support us, as other families may be able to. Any person who cares for these children needs to go through the rigorous assessment process which is preventing carers coming forward (tho I understand it's necessity). Our problem has, to date, been that the respite centres available will only provide care for 2 or 3 nights at a time, meaning we cannot have 'leave' unless the agency can recruit another family to offer us this break. Can you see that the system is tripping itself up by not providing the optimum of services for people such as us, who are providing for the children who have already experienced a traumatic family breakdown, risking a further family breakdown due to sheer exhaustion? Other than an obvious need to get a break from our 24 hour daily commitment, we struggle with our relationships with our own children as we have no time to provide for them. They are young adults (just). They need our support too, and currently fail to get a lot of time and certainly no financial support from us. We have a strong marital relationship that has been truly tested by the stresses and physically and emotionally challenging work we do.

I feel I have rambled on but I do hope you get a picture of our experience. We considered this work we do carefully at both points of accepting a child into our care. I need to say that each of these children waited 18 months to find a long term family and I know that the situation is dire in terms of finding families that will take this responsibility on. And it IS a huge responsibility to care for another's child, certainly one with huge support needs. We were really coerced into taking the second child, and of course become more committed to her as the time passes and we see what she have achieved, primarily that she now knows she is worthy and loved. However our physical and emotional health will be the test. We are wise enough that we will hand back these children when we can no longer manage our lives and relationships. We are lucky. We can hand them back when everything becomes too hard (and it IS becoming harder by the day). Where will they go? If you knew them, you would understand that they have very few other options.

I believe there is no option now for young people under 18 years, to be placed in facility-based community care. They are required to be placed in home care. Having experienced and observed the situation for others, as well as these two, I question whether this is best practice for some older, higher needs young people with disability. We are at a point of seeing little evidence that we can offer better care for 'K' in our home, than what she would experience in a facility. She is as happy as long as her care needs are met. In a facility, staffing, care of staff, and adequate provision for clients would be mandatory. The roles would be shared and not required to be

organised by a single or couple of voluntary carers. Can you see that there needs to be some flexibility in our system and more real consideration of options?

Please put more resources in to the care of these children. The family based model itself is a wonderful, and often successful, option, I still believe. However, you have to consider that, those few families putting up their hand to care for children or adults with extremely high support needs, ought to be seriously acknowledged for what they do, and what they forfeit. You cannot just accept we are forever 'giving volunteers'. We are people that deserve acknowledgement for our skills and commitment, and we need real support in financial terms as well as respite. We are doing an important job. You also have to consider that sometimes the job is beyond our ability, and that other options HAVE to be available. Always, in the back of my mind, is that if we have to give this full time care away, we will be far better off working in a CRU or respite facility, being paid, having holidays, saving super for our future financial survival, and being free to have a life outside our work – some space for us.

I hope you get the feel of my story and it is useful for your inquiry. This is a story of a second chance for these kids, but I'm not sure that the government really puts in place enough to ensure that a second chance is a successful one. The success, for these two, is due to personal commitments of the people involved, certainly not to a government's support of them. We are currently awaiting scoliosis surgery for 'K'. She has been on a waiting list for 2 years at the RCH, Melbourne. We also require a car modification so that we can transport her in her wheel chair. There are no funds provided to her for the costs of this - \$30,000. We cannot, and should we? pay for this. We built the extra bedroom we needed, and we have one spare room for our own family to use when they come home. I remember 10 years ago there was an establishment fund of about \$40,000 to assist setting up a placement. No longer.

If you need further details of our experience please feel free to make contact, or take the opportunity to come and see what we are doing. I must add that the agency supporting our placement, particularly our case worker for the children, do whatever they can to support us. They too are dependent on the good will and provision of government to provide what is necessary to maintain a placement. They too know it is not enough, and that volunteer carers are becoming harder and harder to find. Providing a salary and the benefits of employment, above the cost reimbursement, could only enhance their opportunities to recruit more carers.

Good luck with the inquiry and I look forward to hearing of some exciting recommendations for children with disabilities, young and old, and their families, birth or new.

Yours Sincerely,

Robin