

Submission No. 977
(Inq into better support for carers)

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Inquiry into Better Support for Carers

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

Dear Secretary

I am 39 and care for my younger sister Evelyn who is 37 and has Downs Syndrome. Evelyn lives with me, my husband and our two children aged 5 and 11. Her level of need is high and she has no ability to verbally communicate and nor is she literate. There is no treatment for Evelyn's condition and apart from strict repetitious routine to maintain a few skills; Evelyn's intellectual ability is not going to improve. She does little for herself without verbal prompting and or physical assistance. Her personal hygiene, domestic, lifestyle and administrative tasks are completed by me – this includes full toileting, changing sanitary pads during menstruation, undressing, showering, drying, hair styling, brushing teeth, application of body creams and deodorants, dressing, organizing and serving medication then breakfast, washing of urinated bed linen and or pillows and blankets, remaking her bed and cleaning any areas where she has urinated, toileting repeatedly throughout the day, organizing appropriate activities each day, ensuring medical appointments are attended, prescriptions filled, incontinence products ordered, instigating and participating with her in exercise and healthy eating strategies, preparing meals, shopping for all necessary clothing, shoe wear, personal hygiene and grocery items, modifying off the rack to clothes to suit her shape, sewing clothes to suit her shape and mending them when she rips off the buttons because she cannot actually undo them, laundering of clothes and towels with special attention to any items containing blood, feces or urine, ironing clothes, arranging personal appointments (haircuts, pathology etc), driving Evelyn to those appointments, waiting with her at appointments, acting as interpreter for her to obtain the necessary service/item at each appointment, building rapport with people whom she comes in contact with, arranging payment for services and products, keeping an accurate account of her funds for the Guardianship Tribunal, attending to her mail from Centrelink and other organizations, completing forms and returning correspondence, maintaining administrators files, making phone calls, arranging airfare bookings and payment to enable another family member to travel 1000km to us to provide respite, settling Evelyn into bed at night, getting her up in the night to toilet to minimise the time it takes to clean up a wet bed the following morning AND THIS IS ALL IN ADDITION TO THE NECESSARY TASKS WHICH ONE WOULD EXPECT TO PERFORM AS A MOTHER, WIFE AND SELF EMPLOYED PERSON.

I have never known a time in my life where I did not have the responsibility of caring for Evelyn, either hands-on or from a distance as an administrator for her affairs. Until my 23 year old niece commented to me she was annoyed at being asked to look after Evelyn for a couple of hours and that she shouldn't have been put in a situation where she had to wipe Evelyn's bum – I hadn't realized the extent to which others were free of such responsibility and how much it takes for an individual to give of themselves and get past some rather unpleasant issues to be a Carer. The professionals in hospitals and nursing establishments who perform such tasks are trained, provided with safety and health protection equipment, remunerated, have back up staff available, work limited shift hours per week and no doubt have access to stress leave when needed. I BELIEVE THAT LEGISLATORS DO NOT REALISE THE EXTENT TO WHICH CARERS SACRIFICE THEIR FREEDOM AND THE CONTRIBUTION THEY MAKE TO BETTER THE LIVES OF OTHERS. THE HARD WORK OF CARERS REDUCES THE DEMAND ON THE SERVICES OF PROFESSIONAL CARING ORGANISATIONS YET THE POSITION IS NOT FINANCIALLY REWARDING AND HOLDS SIMILAR STATUS TO BEING A "DOLE BLUDGER." CARERS WHO RECEIVE A PENSION ARE PENALISED WHEN THEIR WORKING SPOUSE RECEIVES A PAY RISE, NOT THAT THE CARER'S CONDITIONS HAVE IMPROVED OR THEIR BURDEN LESSENED IN ANY WAY – WHAT AN ABSOLUTE INSULT. IRRESPECTIVE OF FINANCIAL STANDING, CARERS SHOULD BE RENUMERATED APPROPRIATELY NOT UTILISED AS CHEAP AND CONVENIENT LABOUR.

I can remember social workers visiting our home when I was a child to check on our windowed mother - to me they were the social police, from a child's view they offered little help but made sure that we passed muster for gaining the privilege of not being taken away from our mum. Looking at my own children today, it seems unimaginable that a child can know a feeling of such indignance at being surveyed by a complete stranger as to your worth. Apart from our mother's care Evelyn has lived in a residential some 1000km away from the town we grew up in and has also been in the care of two of our older sisters at different times over the past 18 years. In the years prior to the time of our mother's death 10 years ago we were advised of the changes occurring at that time to multi bed residentials and that the Department of Families was gearing up for people with disabilities to live independently and that multi bed residentials were being phased out. Those residentials which did not comply with the Department's requirements would not be assisted by government funds to maintain their operation. As part of this process I, my mother and Evelyn were all interviewed by an assigned psychologist to provide a profile for the department. (An interesting interview considering Evelyn does not speak.) It seems this process went nowhere and achieved nothing but to falsely raise expectations. It greatly distressed my mother in her final years knowing that Evelyn needed 24 hour supervision and faced an uncertain future in a residential. Our mother suspected the lip service to a better housing structure would not see fruition. For a relatively uneducated woman, my mother was a very wise lady. THE INDEPENDENT LIVING IDEA HAS NOT DELIVERED MUCH OF WHAT WAS PROMISED, MULTI BED FACILITIES HAVE DECLINED IN NUMBER BECAUSE PROVIDERS BELIEVED THEY WERE NO LONGER A DESIRABLE OPTION AND WOULD NOT BE ABLE TO RUN UNAIDED BY THE GOVERNMENT AND THUS FAMILY MEMBERS HAVE BORE THE BRUNT OF THE WORK LOAD. NO ONE WANTS TO SEE A RETURN OF MASSIVE INSTITUTIONS TO HOUSE PEOPLE WITH DISABILITIES, CLEARLY THE ANSWER INTO BETTER SUPPORT FOR CARERS COMES IN THE PROVISION OF ACCESS TO SUITABLE HOUSING WITH TRUSTWORTHY AND RELIABLE STAFF TO ENABLE CARERS TO HAVE REASONABLE BREAKS AND ALSO PROVIDE A LONGTERM SOLUTION WHERE CARERS ARE NEARING THE END OF THEIR CARING YEARS.

When Evelyn came to live with my own young family two years ago and I began the complex task of juggling caring, parenting, family life, household responsibilities and work – it was apparent that there was little available in terms of support options. With the exception of a local respite centre every organisation I contacted queried whether Evelyn received "funding" to determine if she was eligible to access their service - she does not receive this funding. An application made by my elder sister in 2004 has never been actioned and upon contacting the office who received the application the person advised me that Evelyn's name was unknown to her and that her situation must not have been a priority. We have muddled through using the respite service, a sister who we fly from 1000km away to assist us, the odd stay at a respite residential and a few hours of in home care via Community Care. Upon experiencing a family and health crisis at the beginning of this year I had reason to seek the assistance of Community Care for some ongoing assistance. A representative came to my home to meet us all and we discussed the application form to be completed to enable Evelyn to receive funding. I was then confronted with the same undignified process of proving my worth but now I have to do it in writing to be considered and discussed by a complete panel of strangers who have the benefit of remaining anonymous and removed. This application process is the same whether funding is being sort for a few hours a week in home care on a recurring basis or permanent fulltime care. I could complete and submit the application form with the knowledge that in the past year only two support packages for funding were awarded in our cities region, funding wasn't being allocated for some months and it was uncertain we were of any real priority – what help is this?. Our remaining options to source ongoing assistance were to pay a Care Organisation at a rate of \$28 per hour plus mileage for a private Carer or the other alternative to ensure immediate ongoing care is to sign a document which effectively abandons Evelyn. What a sole destroying decision it must be to reach the point of considering abandonment. Worse still abandonment does not mean the person requiring care will receive quality services or be in an appropriate environment. Our situation has been remedied at our expense to financially support another family member to travel to us and to cope with the whole situation I have been prescribed Anti depressant medication. **NOT MUCH HAS CHANGED IN 30 YEARS. THIS FUNDING APPLICATION IS NOT SO MUCH ABOUT THE PERSON WITH THE DISABILITY AS IT IS ABOUT THE CARER. QUESTIONS ARE WORDED IN SUCH A WAY THAT THE CARERS SELF WORTH, ABILITY AND COMMITMENT TO THE PERSON FOR WHOM THEY CARE FOR IS CONFRONTED. UNLESS A CARER HAS REACHED BREAKING POINT THERE IS NO LONG TERM SOLUTION AND THIS IS JUST A MEANS OF CRISIS MISMANAGEMENT.**

Thank you for the opportunity to forward my views. I look forward to an improvement in the situation surrounding the concerns of all Carers.

Yours faithfully

Karoline