From the Inside-Out - A Carers View
Why Don't unpaid family Carers of people with disabilities have Rights?

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As a full time unpaid family carer and Honorary President of the Gippsland Carers Association Inc., I am often asked to comment on and give assistance to Carers regarding Government Legislation like Guardianship, Administration, State Trustees and the Rules applying to the delivery of support services such as day programs, and respite. Mostly this assistance is about the absence of any Rights and about unreal expectations and pressures applied to unpaid family members involved, particularly as these matters relate to the family member with primary care for an adult with dependent disabilities.

It may be helpful to at first give you an overview of my own situation as I find that significant others are better able to appreciate and understand our issues if they appreciate and understand our role and place in the lives of persons with dependent disabilities.

I am the sole-parent (Primary) Carer for my 34 year old daughter who is profoundly disabled as a result of the effects of the Rubella Virus. She is profoundly deaf, legally blind, apraxic and incontinent at night. The insidious affects of Rubella do not stop there. My daughter has a congenital cardiac condition complicated by a condition of Tachycardia (rapid beating of the heart) for which she has daily maintenance medication. By far the most challenging aspect of her condition is that she is apraxic. Apraxia was once described as having a computer that all the information can be programmed into; but, which defies all logic when asked to give that information back out again. This disability means she is unable to initiate activity without prompting and would very quickly lose all her hard won skills if left to her own devises. Although able to move about her own environment unaided she is never the less totally dependent on others for all her needs of daily living.

The Absence of Rights:
My first encounter with the Guardianship and Administration Board (GAB, now known as VCAT) and it's Legislation was when my daughter required a surgical procedure that came within the jurisdiction of the Legislation for Consent. Thus began my education and the realisation that I, as my daughter's Primary unpaid Carer actually have 'No Rights' at all.

In order that this discussion may be of benefit to the reader it is necessary to briefly outline the circumstances I find myself in as a result of my involvement with the 'system' an involvement I might add which is now virtually compulsory as a result of the first encounter with GAB. I should make it plain here that the GAB did agree that the surgical procedure was warranted and I was made Temporary Legal Guardian in order that consent be given to the medical profession to proceed. It is when the follow up review was held that the problems began; let me explain!

Since the Order giving me temporary Guardianship of my daughter meant reading about the Legislation I read this: "That Guardianship conferred upon the Guardian the same rights over the disabled person as if they were their own child." That made perfectly logical sense to me at the time as I was caring for someone who was my "own child" in every sense of the word. I had to accept all the same responsibilities for my chronologically adult daughter, but forever "mentally dependent child" as I had for her welfare, when she was a "minor child"

Since my daughter was declared to be a "Represented Person" (the terminology used by the Legislation) there was no doubt in my mind that I should continue to be Guardian for my daughter, but, the GAB had other ideas. At review, my request for Plenary (ongoing) Guardianship was denied and I was asked instead to become "Formal Administrator" of my daughters income which is a Disability Pension and related allowances.

It was explained to me that formal administrators have control over the financial affairs of the represented person and therefore this was all that was required for my daughter's welfare! Asking for that to be explained I was told that the GAB was only interested in ensuring the wellbeing of the person with a disability and that I actually had "no-rights" as her unpaid primary carer save those conferred by the Board.

I expressed my concern that Administration would place an additional burden upon my shoulders. To keep books of accounts and to complete annual statements I felt were unnecessary, and my objections had everything to do with the fact that I care for my daughter on duty, 24/24 hours/ 365 days a year for a mere $42 per week Carer Allowance.
I was further shocked to learn that my daughter was expected to pay 'them' for the privilege of checking such returns, even though her only income is a pension!

At this first encounter with a Review, I was asked if I would accept the role of Administrator if the need to keep Books of Accounts and the payment of fees were waived and I reluctantly agreed. 20/20 future vision would have been a good thing because it seems that rules can be changed without notice and that is exactly what happened next.

In 2002, I received a notice informing me that the Guardianship and Administration Board had been amalgamated with others to become The Civil and Administrative Tribunal (VCAT) and that those previous decisions to waive fees were revoked. This letter included a request for the payment of fees for the preceding year, and I was incensed. How could this bunch of bureaucrats change the rules without consultation; that was easy, they have all the rights and we have none. I requested a Review Hearing to consider that my Administration Order be rescinded, and I reinstated my request for Plenary Guardianship.

To cut a long story short, the Review again denied my application for Plenary Guardianship on the grounds that they accepted that my daughter was very well cared for and she did not therefore need a Guardian.

My request to have the Administration Order rescinded because I felt it grossly unjust that Fees had to be paid was also denied on the grounds that my daughter was a represented person and a Formal Administrator must be appointed. The suggested ultimatum was that in the absence of a willing unpaid Administrator the State Trustees would "have to" be appointed! This now is the beginning of a battle for justice and 'Rights' for unpaid family Carers and those for whom they care.

Over 2.3 million families are currently providing more than 90% of the accommodation, personal care and support needs of Australians with dependent disabilities. The value of this contribution is conservatively estimated to be in excess of $27 Billion a year to the national economy. An ageing population, the dramatic drop in birth rates and the ever increasing numbers o f women entering/remaining in the 'paid' workforce together with Government Policy to keep people out of facility-based care are factors dramatically impacting upon the availability of unpaid care. None of these factors, however impact as strongly as the felt effects of Legislation and Policy which command Responsibility but deny Rights.

We believe that the following issues need to be addressed as a matter of urgency if unpaid family caring is to be available to future generations of Victorians/Australians with dependent disabilities:

- Unpaid family members as Primary Carers of the disabled are being treated as unpaid (slave) labour.
- No Legislation exists to protect unpaid family Carers from exploitation by Governments in spite of the fact they (Carers) deliver over 90% of the accommodation, personal care and support needs of all persons with dependent disabilities.
- Legislation that confers on Government Agencies and their paid servants Guardianship Rights over represented persons but denies those rights to unpaid primary family Carers is by its very nature, discriminatory.
- Legislation that has the power to appoint State Trustees to manage my daughter's finances whilst she is living under my roof and receiving a free total care service 365 days per year (save for rare respite) whilst denying me any legal options or 'rights' that mirror my responsibilities is grossly discriminatory.
- Legislation that requires trust on the one hand i.e. "you are obviously caring for your daughter very well so she does not need a Guardian" but on the other hand says we don't trust you to manage her Pension are quite plainly discriminatory.
- Legislation that requires a person with a disability (a represented person) to account for how their pension/benefit is spent when no other welfare recipient has to do the same is surely discriminatory?
- Legislation that seeks to enforce formal Administration upon those unfortunate enough to fall into the hands of VCAT whilst allowing the vast majority of persons in informal arrangement with their families to continue unfettered is also seen as discriminatory.

[According to the ABS population stats on persons with severe and profound disabilities, there are some 166,200 persons aged 0-64 in Victoria who have a severe/profound disability. So isn't it odd that the senior management of my daughter's Financial Institution didn't know how to set up a Formal Administration Account without first checking with head office?]

We have so many concerns about the absence of rights for unpaid family Carers that I took my concerns and the concerns of our Association to the Victorian Equal Opportunity Commission on a number of critical issues. Since they are only able to handle individual cases, we went further and asked the Public Law Clearing House to look at our claims about discrimination against unpaid family Carers.

A peculiar word "Comparator" has crept into the jargon being used to say sorry "we can't help you." It seems that someone else needs to have won a discrimination or equal opportunity claim in order for the long suffering unpaid family Carer to even get past base-one on Human Rights and Equal Opportunity in this country! I cannot even find the particular word 'Comparator' in any of my dictionaries.

Does it need a "Comparator" to say unpaid slave labour is unacceptable in Australian society?

Does it need a Comparator, to say that over half a million full-time 'primary' unpaid Carers have a right to expect meaningful compensation for contributing over $25 Billion every year to Australia's economy? [Based upon the average cost of a facility-based 'cared' accommodation bed of $50,000 per year.]

Does it need a Comparator, to say we have a right to expect days off, annual leave, retirement planning.
Does it need a comparator to say we have a right to expect Legislation governing the 'Rights' of disabled persons will also confer 'Rights' upon those who accept the enormous Responsibility for every-day care of those same persons?

Are we so far into 'economic rationalism' that don't think those in our community who give up their own right to paid work, the right to live a free and unfettered life, who give up all entitlements enjoyed by the masses of paid care workers, have any rights at all; because they accept the moral responsibility to care?

I have 3 other adult children. Two of my sons were born with Phenylketonuria. I have one son who escaped the disability afflicting his peers, he left home when he was 17 because he could not handle his "dummy brothers and sister" or all the attention they needed. I have spent a life-time (over 40 Years) caring for each of them with all my strength and all the skill I could muster. I have given over 33 years of my life to caring for my daughter and will continue to do so in the face of the burgeoning 2000 strong, waiting list for government funded shared supported accommodation in Victoria. [A list which freely admits that Critical category clients wait an average of 116 weeks for a service.]

I believe that Legislation in this state means I don't even have the right to decide that all my years of service and devoted contribution to my daughter means I can give my estate to my sons when I die. Since I have given her everything in life; is it not therefore fair that my other 3 children deserve; at the end game, to at least benefit from my death? I believe that State Trustees have the power to over-ride such a decision! No justice or equality for me or for my other children here, would you say?

This leads me to ask:

- Is it not time for Human Rights and Equal Opportunity to be afforded to unpaid family Carers?
- Is it not time for those in positions of power to legislate for Human Rights and Equal Opportunity for us?
- Who will stand up for us if the Human Rights and Equal Opportunity Commission won't/can't ?
- Why cannot we be the generation of unpaid family Carers who say "make us the precedent and make us the comparator" for others to follow?
- Is there no legal or human rights avenue for the voiceless to be heard?
- Does not the Federal Government "Mutual Obligation Policy" apply as a two-way street? Carers give $27.2 Billion annually to the national economy and what do you give us in return? NO RIGHTS and for most Carers, NO PAY either!
- Is it not a responsibility of Federal, State and Territory Governments to Legislate to support unpaid Carers in their vital and irreplaceable role? including changing damaging legislation that harms and hinders?

It is a sad further indictment of Governments and the senior bureaucrats that advise them, that the 67% cohort of unpaid Carers of persons with dependent disabilities aged between 18 and 65 years do not even have a 'funded' family advocacy service targeted for them, even though the other two age groups, children and the elderly are well served with Government funded advocacy. The only people who can advocate for so many of us then it would seem; are ourselves.

It is surely discriminatory that choices in accommodation services are available to persons with dependent disabilities aged over 65 years i.e. Nursing Homes, Hostels, village living and cluster apartments, but all these living options are denied to persons with dependent disabilities aged less than 65 years under the guise of these services being institutional and therefore unacceptable.

The Victorian Department of Human Services is currently conducting a review of the IDPS Act 1986 and Disability Services Act 1991. It is clearly evident that the Department wishes to amalgamate these two Acts and we believe aims to 'water down' the governments responsibility to provide accommodation and support services placing more and more emphasis on encouraging unpaid family care to the greatest extent possible.

There is a clear and present evidence of this policy in the fact that there are currently more than 3180 persons on the Victorian supported accommodation waiting list with 1068 rated as Urgent and 685 as High Need. The average waiting time for an Urgent placement is currently 112 weeks.

There are in addition to this waiting list some 1122 persons on the waiting list for Home First living support services. Most if not all of these persons are living with frail, elderly parents, or have moved to urgent because parents have died.

It is the view of the families represented by our regional Carers Association that Disability Legislation must contain:

1. A clear 'entitlement' to funded accommodation and support services that cannot be changed at the whim of the government of the day. Such entitlement must mirror Federal Legislation such as the 'entitlement to a Disability Support Pension for all qualifying persons'.

2. There must be an end to discrimination in the choice of accommodation and support services based on the age of the person with a dependent disability.

3. There must be Legislation which appoints a 'Disability Complaints Commissioner' as an Independent avenue for persons with disabilities and their caring families to seek 'enforceable remedy' of complaints.

Where families accept the responsibility to provide ongoing accommodation and support services to persons with dependent disabilities, those families must also have an 'entitlement' to freedom from discrimination:

1. Disability Discrimination Legislation must extend specifically to Primary Carers of persons with dependent disability.
2. Primary unpaid family Carers must be given an 'entitlement to support services' which assist them in their vital role.
3. Primary Family Carers of adult persons with dependent disabilities must be afforded the 'Rights' that go with the 'Responsibilities' and be entitled to be appointed as Legal Guardian to Represented Persons.

It is clearly discriminatory practice for Governments to (TRUST) allow Primary Carer families to accept full-time care responsibility 365 days per year for a person with dependent disability, but demonstrate NO TRUST in the family to manage that person's annual Pension entitlement. This is the most discriminatory practice of all and will ultimately result in Families 'opting out' of the unpaid accommodation care role.

I read in a number of submissions that very few Disability Discrimination Claims had been made to HREOC. With some 90% of accommodation and care needs being provided by unpaid family Carers who clearly have NO RIGHTS AT ALL, why is this a surprised.

Yours sincerely,

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