

**Submission to House of Representatives  
Family and Community Committee**

**Opportunities around Care Directions  
A Personal Perspective**

Becky – June 2008

I am responding to the call by the House of Representatives Family and Community Committee and Federal Community Services Minister Jenny Macklin for people to share their personal experience of caring and suggest ideas for better government strategies. My own experience of caring spans most of my adult life and is both personal and political. I have been a carer for love and have endured many highs and lows of this rich experience. The following is a personal perspective from this rather unique experience.

**MY PERSONAL EXPERIENCE**

In 1972, I fell in love and began a 32 year relationship with my future husband, Richard [REDACTED]. He was a very dynamic intelligent man, who became a quadriplegic as a result of poliomyelitis he had in 1957. Polio, unlike spinal injury, leaves a person with intact sensation, but paralyses muscles. My husband Richard was 95 per cent paralysed and could only move his fingers and rotate his neck but luckily was still able to carry on an active sex life. He used a tray on the front of his wheelchair to perform 'trick movements', lifting his right arm with his left hand to feed himself.

When I met him, he was running his own business, an art gallery which he had built at the back of his own home. He had married his first wife in 1960 and had two children while running several different types of self-employment ventures, with good success.

In 1972, very few Australians with physical disabilities were out in the world – the environment was hostile, with steps at every kerb, into most shops, schools, workplaces. There was one unisex toilet in our city of a million people – at the State Library of SA. There were no support services if you lived in the community, no transport options except being lifted into a normal taxi, no special vehicles and electric wheelchairs were in their infancy. My husband had invented one of the first lifting machines in 1958 and we still used that simple pump-up hydraulic machine until the year 2000, when we got an electric hoist.

Everywhere we went, people stared. They didn't know what to make of a 'cripple' who wanted to be out in life assisted by a crazy woman who wanted to be with him and push him everywhere. Our life together gradually became one of advocacy and activism after a trip to the US in 1977, where my husband took a course at a university and saw how culturally determined many of these Australian attitudes were.

Even in the 1970s US, people even more severely disabled than Richard were EXPECTED to study and to work. Universities were made accessible, vehicles were adapted, employers

were given assistance to modify premises and practices. The US knew that people with disabilities (still called 'handicapped') were a valuable economic resource if liberated from barriers to work and a drain on the economy and society if not.

We returned to Australia in 1978 and began to campaign for the federal Government to be part of the UN International Year of Disabled Persons, IYDP 1981. Richard was on national planning committee where he was a strong advocate for people to speak with their own voice. As his only support person, I traveled with him to meetings in Canberra and Sydney, lifted into planes on a pallet stuck in a forklift and no sides. He argued with Senator Margaret Guilfoyle to reframe the committee from doctors and managers of sheltered workshops for IYDP, asking how she would have liked a committee for the International Year of Women with only one woman representative on it.

Senator Guilfoyle then re-constituted the committee to make it the first representative national committee of disabled people themselves from most sectors, although intellectual disability was still largely from charity organizations and mental health was not really represented. Carers were represented by one woman from NSW who worked in the field.

The UN Year, IYDP 1981 has been widely considered the most successful UN year in Australia. One of the keys was the new synergies created by leaders with disabilities getting to know and understand the issues and concerns for each other, as the group traveled widely and listened to people across the country to set the agenda for change. It ushered in change and participation at a rate that has seen this field grow and blossom over the past 27 years. Every aspect of disability has 'come out' since then, including carers as a huge sector at every level.

Our family grew over the years. I step-parented Richard's two older children. We also had two children, a son in 1979 and daughter in 1982. His parents were dead and mine were in the US, so we had virtually no family physical help. I got Richard up every morning, toileted, dressed, fed him, transferred him into our car, put the children in the back and drove him to work, then did this all again in the late afternoon.

I had been a special education teacher prior to the birth of our children but the care responsibilities and the fact that Richard was already doing interstate committee work, meant that I became a full-time family support. He felt proud to be the breadwinner for our family, as even with his severe physical disabilities, he was a very capable employee. Eventually, he rose in the public service to become Advisor to the Premier of SA.

He was denied access to the government superannuation fund because of his disability in 1975 when he first became employed as a public servant and was only permitted to join for the last 5 years of his public servant life. This has been a major structural disadvantage to our family because of overt discrimination in the system which, because of his paralysis and possible 'risk' to the fund, did not let him participate in the benefits accorded his working peers. Obviously, there are flow-on effects for our family.

In 1999, when I broke my shoulder skiing with my grandson, support workers began to come into our home to get Richard up Monday to Friday. Used flexibly as we did, these people gave us a wonderful boost and provided assistance that freed our energy in many ways. Apart from that help, I have acted as his sole carer because I felt that was part of being his wife. I loved him and he had certain physical support requirements and I tried to meet them as just one of many of the dimensions in our overall marriage.

In 1998, Richard left the public service and we began our own business consulting on disability access. This began a new level in our relationship, an intellectual partnership that harnessed our joint skills into one service that provided our income while it made our city more accessible and trained countless people in disability awareness. My husband died of cancer in 2004 and I have gone into a new era of life after a period of mourning, well-trained by my life in caring to cope with adversity and transition.

What I have learned is that disability, a blind spot in our society that none of us want to acknowledge: our physical and mental limits as human beings. Disability and the care responsibilities it impose offers an abundance of ideas, resources, comedy, pathos and joy that are immensely satisfying if we are not afraid to confront it. As our society is now entering a huge aging momentum with the known demographic of disability, it is timely to bring new ideas to the table and re-orient assumptions and attitudes that discount such richness.

#### CONSEQUENCES IN HOW WE THINK AND TALK ABOUT 'CARERS'

The history of disability in Australia is tied up in many stereotypes, myths and prejudices. Institutional and charitable mind-sets were imported from the British empire, as well as convicts. These models have operated during most of the 20<sup>th</sup> century and ran parallel with the disability rights movement that emerged in 1981. Words such as 'in-valid' used as the adjective for the Commonwealth disability pension meant that each fortnight people were reinforced in how useless they were.

The term 'carer' has been used since the late 1980s to give value (unpaid) to a large number of people in our society. The label itself is intended to boost carers' image and role. 'Being a carer' is something many people feel in awe of and often say "I couldn't do that!". This type of mini-adulation from outsiders in a world short on heroes and heroines is one of the realities of being a carer in Australia. The fact that many people would not be able to do caring, even if they had to, is also part of that picture. Carers are sort of canonised and set apart as a particular set of wonderful people. Which carers tend to be.

But is this type of heroic language enough to compensate people for lost opportunities in terms of employment, time to develop their own lives and relationships? Is this role identity enough to carry people through grueling time of unending demands? In a workplace, people would be paid for that sort of commitment and responsibility. We hope that our positive valuing of the label 'carer' somehow sustains people to do the often superhuman without the usual set of rewards.

One of the achievements of IYDP 1981 was the national campaign for more neutral words to be used around disability. In 1981, the word 'handicapped' (cap in hand) was seen as too demeaning with its associations with begging for charity and the word 'disabled' came to be used widely. Within a few years, this term mutated to the more neutral term 'disability' which does not suggest the common meaning of 'disabled' as 'broken down.'

A further important development has been the wide acceptance within the Australian community of the use of 'people first' language styles, such as 'person with a disability', 'Mary who has an intellectual disability', 'the passengers who use wheelchairs'. The person's name or role is listed first and the disability characteristic is secondary. The carer lobby has been against using 'people first' terminology for their field, insisting that the short-hand 'carer' is better. It is shorter, but is it better?

'Carer' as a term changes a person with a name and many other roles into someone who is defined by an external reality – the shifting medical and health status of someone with whom they are in relationship. I cared for Richard before the word 'carer' was invented by the start-up advocacy groups for this purpose in the late 1980s. At that time, we both campaigned against the term. We insisted we had a mutual, if interdependent relationship, **both caring equally about the other**. What does 'carer' instantly imply about the 'caree'? This dimension is conveniently overlooked by the care advocacy lobby.

I still believe that this word, used as a tool of government policy, is a source of inbuilt resentment by one person for the other. It differentiates one as the 'goodie', the other the 'baddie'. One the 'giver', the other the 'taker', one the 'active', the other the 'passive,' harking back to the medical model of people with impairments as 'patient', passively suffering. 'Carer' reinforces one person's actions against the other's, the person who has been linguistically categorised in a deficit model of 'need'. International definitions of disability such as those of the WHO focus on a medical impairment as 'loss of function or bodily part'. But that is the disability itself, not the person. The current language of care mixes these up, I believe purposely, for an industrial imperative.

Using 'carer' as a role commodifies an emotional response based on love to substitute for pay. It builds huge resentments on people who perform the same tasks, often equally lovingly, but get paid for it as 'work'. Real love can never be commodified. The transaction happening in what we currently term 'care' is actually the enactment of responsibility based on the disability of a person they have a relationship with, whether that be family, kinship or friendship. The person who has a disability requires that action to live and it is the relationship of responsibility to the obligations of the person's impairment, not so much to that individual person.

This is why 'people first' language is so important when thinking about policy in this field. Bob who has cerebral palsy needs to have someone help him communicate. He may not need someone to 'care' about or for him – he needs speech assistant. Sally who has a hearing impairment may need someone to sign Auslan for her at church or University. She does not need a carer. She needs an interpreter. Yet in both these and countless other examples, the

person who performs these roles is lumped under the banner 'carer', often without the dignity of their name being used. We could talk more clearly about both the impairment and requirements of a situation by being more specific; Lloyd who helps his frail mother by taking her shopping and to medical appointments, rather than calling him her carer. He loves his mother and he helps her, just as she did him.

My husband couldn't walk, or dress, or toilet himself. I felt I had responsibilities to him to assist and compensate for what he couldn't do, so that he could save his energy for what really mattered to him. I saw myself as his wife, not his carer, because a spouse does things for the person they love. This is especially true of children who are in a family where there is a major disability present. Whether they are siblings of a child with disabilities, children or parents of a person with disability, their lives are altered and stigmatised for being different. And often, they are different, for much of the energy and budget of the whole household goes into compensating for and managing the consequences of disability.

What would be more useful is to retain the common word used for a relationship, 'wife', 'husband', 'daughter', 'son', 'neighbour', 'friend' and add the phrase, "with disability responsibilities" or "who supports that person". What we now loosely call 'child carers' would be brought into focus as 'children with disability responsibilities' or 'children who support their parent'. Both 'support' and 'responsibility' have a more neutral and accurate description of the real task and are not loaded with an emotional term. They value and describe the behaviour of a person and their response to their obligation in a family.

Current policy does not look at the family where disability is present as a whole dynamic, because our language has limited us to the dualistic 'carer'/ 'caree' model. This undervalues both the person with a disability and the more complex situation when people live in the same dwelling with a person with disabilities. Living with disability in a family, imposes responsibilities on all who are part of that family system. But that has nothing necessarily to do with 'caring', not so much an external behaviour as an emotional state or internal decision.

Framing policy around families where disability is present and the consequent responsibilities that are shared by the members of that constellation, would better recognise the contribution of each person in that family constellation, including the person with disabilities. New policy language could shift the focus away from implied but unspoken assumptions about care or love, to much more healthy focus on positive values of each individual in that family and their contributions of citizenship, self-discipline, empathy and sharing. People could break out of the programming which binds them into a whole set of emotional assumptions which may or may not need to be there for support of the disability to take place.

At once, you break the unnatural power relationship of 'carer' and 'caree' and free these people to be people who live with disability and manage the responsibilities imposed by the impairment without stigmatising the person with the disability as well as those in their family constellation.

Our models of disability coming from historical roots miss out on so much of the positive side of a lived disability experience. They miss the adaptability, the humor, the strength to persist and overcome from people who share this experience as a family. We all know the power of people who live these stories to inspire our nation. So many 'Australian Stories' on ABC TV deal with people living with, overcoming and accepting their health and disability status. How can we harness this power, the positive power of disability and how it changes people, with a renewed focus on whole families and their social and economic potential in the public policy of this new Government?

### CARE LOBBY INDUSTRY

The voice **of** people with disabilities has, like that of aboriginal Australians, been muffled in favour of the voice **for**. The disability citizen and consumer model, during the 12 years of the Coalition Government, has been cleverly downgraded to a more soothing, charitable model based on pity and a conditioned victimhood, the carers' lobby. It is not in their interests to promote, display or market the positive view which has a more neutral values orientation than 'poor me' carer model.

'Caring' and the emotive political advocacy lobby that has been built up over two decades appears to me to be actually code for demarcation disputes between paid and unpaid assistance. Even as whole industries of paid support workers, attendants, personal support assistants have sprung up, 'carer' has become cemented as a way of differentiating the person who assists someone because of love, friendship, blood relationship, etc. who is usually 'unpaid'.

The person with the disability gets little attention in this whole model, except as 'the problem' who creates 'the need' or 'the unmet need'. In other words, their impairments actually generate the economic imperative for all these support industries, and yet, their worth and value in doing this is not reinforced.

Rather, disability, the lever for an incredible growth industry, is denigrated by the carer lobby itself with its not too covert message that it is alright for carers to blame the person with disabilities for their 'lot in life'. I have worked as a facilitator for carers' meetings and have seen the strength and depth of people who are carers leached away by the implicit negative modeling of carer organizations which **MUST** have people unhappy and dissatisfied, so they can act as lobbyists and advocates.

Researchers for the carer lobby have witnessed and listen to countless carers around tables with each other, reinforcing the image fostered and conditioned by their 'industrial advocates' – the carer lobby. Typical of this type of carer self-help group language about the very person they care for is: 'the trap I'm in', 'the source of all my problems', 'the dark cloud in my life', 'the drain of my energy, hope, enthusiasm'. A toxic addiction to resentment of their 'caree' is reinforced in carer group sessions which does little for catharsis or emphasis of the value of a lived experience of disability.

Fostered and abetted by the carer associations, this approach does not emphasise a win-win approach to living with disability. It is not helpful when people have to go home from these groups after their tea and biscuit to be responsible for someone and be full of these negative, martyrish concepts. The carer goes home with a new chip on their shoulder, and woe be to a person with disabilities who is not appreciative, or not grateful of the 'sacrifices' their carer is making **for them**.

People who come into the carer network as newcomers soon learn it is OK to say and think in this way, which is why the carer bodies do not welcome participation by people with disabilities in their groups. They know it is unfair, biased and non-team oriented, but this is how they have built a constituency with a voracious need for government aid – the 'poor us' victims of disability.

Carers have had strong lobbies now for 20 years, and in the meantime, people with disabilities have marginalised their own lobbies through in-fighting and the vastly increasing numbers and types of conditions being brought into wider definitions of disability. The last Coalition Government downgraded the Commissioner for Disability Discrimination role, refusing to re-appoint Commissioner Elizabeth Hastings, who had a major disability, and then letting the role limp along with acting commissioners for years. Structurally, people with disabilities have lost the strong voice they had in the 1980s and the new voice is from organisations employing almost exclusively able-bodied people to lobby for able-bodied carers.

Like any life experience, there are always two sides to caring. Rarely do we see the positive accentuated because how can you feel sorry for carers if what is really happening has positive consequences you don't want to display? It is not in the political interests of carer associations interests to say or do anything positive about the person cared for. They do not accent the positive growth and developmental aspects of caring, the incredible spiritual and empathetic skills developed through being in touch with suffering and being a witness and aid to perseverance, adaptability, courage and acceptance. Our world, with its rapidly depleting resource base and possible need to adapt to rapid and destructive climate change, needs the insights of people who have done this type of adapting around disability. Carers and the people they assist understand about interdependence – a quality our world will need to learn somehow. What better source of inspiration than people living this already in our midst?

Sadly, I believe that the self-interest of the care lobby tends to distort and reinforce only the negative aspects of any care experience for its own advantage. The vast array of programs and services they offer in terms of counseling and self-help groups continue to reinforce only one side of the disability experience. Is this because underlying it all, is the long-term political objective for family carers to be fully paid, like the workers with more dignified job descriptions and titles? What would it take to pacify this voracious lobby?

Hopefully, this inquiry will begin to unpick many of the unspoken agendas between the paid and unpaid caring sectors and create a new model that clarifies and de-stigmatises the role that people with disabilities play in their family and society as that of a positive force that

needs support for compensating activities and equipment to deal respectfully with the limitations imposed by disabilities.

## **FIVE PRACTICAL GOVERNMENT STRATEGIES FROM MY PERSONAL EXPERIENCE OF LIVING WITH DISABILITY**

### **1. TAX INCENTIVES TO COUNTER EXTRA COSTS OF DISABILITY**

- *There should be tax incentives for people with disabilities to work as they have to pay so much more for equipment and travel costs to participate in employment.*

With my husband's equipment needs so high, our single income family was forever penalised by his disability by having to buy our own electric wheelchairs, other essential equipment and later a disability lift-equipped van, let alone the loss of my earning potential foregone. Based on our lived experience of the consequences of disability and our concerns about the lack of policy consideration for its costs, we pioneered the phrase, "the extra costs of disability", researched and wrote national discussion papers on how to compensate people for these costs in the early 1980s.

The sad fact is that in all this time, little focused strategy has gone into how to break the nexus of disability and poverty. As part of trying to make the government aware of how discriminatory its tax policies were, Richard once ran a campaign through *The Australian* newspaper with a large photo of a businessman in front of his Mazarati sports car next to Richard, dressed in a suit, in his electric wheelchair.

The Government allowed one item, his luxury car, as a business tax deduction. The other item, the essential electric wheelchair, not a luxury mobility aid, was not tax deductible. Why would someone leave a pension to go into open employment with this type of disincentive?

There were no and still are no tax incentives for people with disabilities to work when they have to pay so much more for equipment and travel costs although medical costs are capped and acknowledged past a limit. The Commonwealth Mobility Allowance was Prime Minister Malcolm Fraser's personal response to this campaign and it has been an important part of a package of recognition, but is not enough to make a structural difference when there are so many barriers to employment.

### **2. ENCOURAGE SELF-EMPLOYMENT INITIATIVES**

- *Give access to low-interest business start-up loans, marketing and training assistance people ask for so people with a shared lived experience of disability could use their skills of resilience and adaptation to great advantage for themselves, their families, their society and economy to break the cycle of poverty.*

Carers who have to give up employment altogether, as I did, or who can work part-time, now get either Carer's Allowance or Carer's Benefit. In our inflating economy, these government provisions keep people in a holding pattern that grinds away at life. Choices and opportunities seem like a distant dream for other people, people who are 'free'.



The current benefit structure tends to reinforce the locked in, caged feeling of people dependent and interdependent.

Employment is very difficult for people who care for someone with chronic illness, disability or frailty. A person never knows when they might be called home to assist someone for medical or mental health reasons. Carers fear being labeled 'unreliable' because of forces that are out of their control – the health of the person they care for, depending on their condition. This lack of control because of love for someone you care for can tend to be a breeding ground for discontent and dissatisfaction that erode the bonds of love.

My experience with people who are on the margins of society is that, for many reasons, self-employment is a better option. You can do what you can do, from where you can do it, with the time you can find and as you decide. You can do as little or as much as you can or want to do. You can work from home and still care. You can work together, as we did and actually build your relationship into a family business, with profit opening up choices and happiness.

Currently, the model that builds on this internationally is the trend to microfinance. It started in India, with small loans to women to create their own businesses, but has mushroomed for people who are not going to be able to work in the mainstream. Small-business opportunities that can be started with low-interest loans as per the microfinance model to make poor borrowers better off. Australia still is a land of opportunities and there are many niches unfilled. People with disabilities, who have time, with some support and training, could move to fill these gaps with innovative businesses for themselves and their carers, possibly augmenting their government support or perhaps creating enough profit to get off benefits.

Resources put into training in business skills, encouraging entrepreneurship, business mentors for carers and people with disabilities and workshops to share and work together would be innovative ways to help carers and those they care for break the cycle of poverty. Miniaturisation and electronic communication have brought the possibility of home businesses into the realm of the doable so people could make work from home with computer and business skills.

No one wants to be dependent on government. But our society has not given tools to people to help them lift their own expectation and imagine a way forward that includes their participation.

### 3. EXPLORE TEAM BUSINESS OPPORTUNITIES

- *Support the establishment of completely new types of organisations that act as business opportunity brokers to teams of people with disabilities and their family members.*

The basic truth is when you are a 'carer', you are not free to do things as an individual, hence the traditional huge emphasis on 'respite': getting away from 'the problem'. This dualistic model – problem – escape – is not helpful or healthy. It prioritises the negative rather than accents the positive, to paraphrase a well-worn maxim.

Our society and especially our economy lose out when we divide carers from the person they care for, as if they were enemies. This huge undervalued, but skilled set of people are not being seen as economic resources, but rather as objects of pity to help the 'care industry' ramp up yet more government dependency, as it pits the cared for against the carers.

A new model, valuing the family team that has to be together, would provide a realistic base from which to explore opportunities. It makes perfect sense that in a market based economy, we might emphasise the benefits of people who are together and have found ways to capitalise on that synergy to form small home-based profit-making units, rather than welfare recipients.

The reality is that if people could break the need for **employing a sole individual**, and instead, harness the new **potential of a small business team** who are together, rather than running away from that reality, much new thinking could evolve. We could do this by conceptualising the opportunities and synergies of team work and setting up entrepreneurial strategies to capitalise on the energy of families and couples, children and parents, who have found ways to communicate and live so closely.

Examples of new team business opportunities may be placing teams of people who have lived experience of disability inside organisations and businesses to model and train in co-operative strategies, how to work interdependently, how to listen or how to share. Weekend workshops for executives doing disability simulations could be just as exciting and challenging as abseiling and military type exercises. Community offenders could find out about real risk by spending time helping out and being mentored by families with disability responsibilities. Families with disabilities could work with other families experiencing difficulties, inspiring them with their realism, empathy and adaption strategies.

The problem-solving abilities of people who live with major disabilities of all types are major assets in our society and we have failed to see them as levers for growing business and profit because we have been fixated on the individual employment model.

#### 4. INVEST IN BACKLOG OF EQUIPMENT NEEDS

- *Invest in the equipment needs of the person with a disability. The correct gear takes a lot of weight and time off the person who care. This would be one of the fastest ways to improve life for both carer and cared for – to meet unfulfilled equipment needs.*

The past three decades have seen incredible development of disability technology, including electric wheelchairs, which gave unbelievable freedom for both of us. Equipment is a key compensation for many impairments. In fact, some standard pieces of equipment in homes today first started as disability equipment, most notably, the computer mouse.

Richard liked inventing and helped pioneer the stretch taxi design, the now standard kerb ramp design, the portable ramps used in taxis and trains, a personal traveling lifting machine and sling for airplane transfers. He believed it was important to use equipment to safeguard my back. In all these years I have kept quite safe through this wise use of lifting and other equipment.

## 5. FUND 'FAMILIES WITH DISABILITY RESPONSIBILITIES'

- *As with the Rudd Government emphasis on 'working families', conceptualise new policy measures and strategies to capitalise on the positive team power of 'families with disability responsibilities' for funding beyond minimal personal care needs. Care hours to be a matter for whole family discussion and use.*

The statistics of family break-up, break-down and stress for people living around disability are startling. Marriages break up at a much higher rate, siblings of young people with disability have more problems, and health outcomes of people with caring responsibilities are significantly worse than their peers. Even with increased support dollars going into in-home care and out-of-home day options, our government policy has not really come to terms with the actual conditions which create these problems. We are not using the words and concepts which reflect the reality of the situation, so of course, our solutions do not target accurately enough. It looks as if the government is failing to keep up with needs because we have not looked at the **family constellation** as the base that needs flexible support and acknowledgement by our policies.

As mentioned in the introduction, any home that has a person with a disability, has a whole family-wide set of responsibilities, which sets them apart from other families. If we could break the current narrow focus on one person as 'carer' and one as 'caree', a whole new service paradigm could flow from changing the language to that of 'families with disability responsibilities' with families as the basis, not individuals.

Support services could provide a much wider array of choice, based on the initiative and negotiation with all members of families with disability responsibilities. Families with increased positive disability training, mentoring and grief counseling would begin to see themselves stepping into society feeling understood and supported. Those with high physical support needs would be able to choose a model that gave them the degree of control and choice they want in their support arrangements, not the current lock-step regime often decided by others. Support services within homes could be utilised much more flexibly if children, parents and spouses were seen as people who could negotiate for a paid or volunteer support worker to do one of their tasks, so they could spend more active time with the person they love and care for as a matter of course.

My suggestion is to widen the current budget emphasis on 'carers' towards the actual source of the care requirement through a new program of family negotiation on how care hours are distributed and used. That does not mean widening the definition of disability or of who is eligible, nor even of widening the budget in the first place. The key questions may be about severity of disability and its impact on the household. I believe we would see much greater social, emotional and economic outcomes if a family roundtable made consensus decisions with all members involved of what assistance was most beneficial for their unique situation and then allocated resources for the package of their choice. Family breakdown is much less likely if all members have had a role in speaking up for their needs and working to create a package that meets their family needs that are exacerbated by care of the disability responsibilities. For all of those in such families, there could be enhanced relationships, self-

image, self-confidence, self-worth with increased control of their finances, time, care and life choices.

Part of the emphasis is on bringing more enjoyment into the lives of those who experience disability and not just supporting personal care. A parent with a child with disabilities could negotiate for regular time to go play or take other children on an outing while someone cared for the child with disabilities. The wife with disabilities could use some of her care hours to have a night out with her husband while she had a support worker clean the house. Or they could negotiate a piece of equipment for home or family recreation that all could play and enjoy together.

People with disabilities could re-establish a more respectful and balanced role in their relationship with their families, moving the dynamic to a healthier team effort based on normal family possibilities rather than a lopsided balance focusing completely on personal care only. These families need the Government to support a wider definition of families who are supported to have fun, to study, work, volunteer and enjoy life as others do.

In my experience and that of hundreds of families with disability that I know, policy initiatives that try to make our families the same is futile because disability imposes a limitations on sameness. There would be positive spin-offs to families with disability responsibilities if the balance of power and government funding were tipped closer to the source of the real requirements to spur active participation in all of our society while it gave positive reinforcement to families that have disability responsibilities. They may come up with new strategies, new directions, opportunities and choices which do not represent 'the same range of opportunities and choices' which is one of the terms of reference of this inquiry.

Let us step out of **fearing the difference of disability** and find new ways for our society to celebrate and learn from it. With the baby boomers entering their sixties, it is clear that this group, if none before it, will push the envelope on what they want and how they want it. Does the Government want to be at the forefront of this change? Can we develop new alternatives based on fresh thinking and language or will we cling to century-old outdated models?

### SUMMARY

Any investigation into the opportunities for care directions needs to seriously examine its fundamental expectations, language and assumptions of what the care relationship implies. First principles of dignity, respect and equality for people with disabilities, found in the Disability Discrimination Act, will assist decisions that will lead to new directions. Bending to the loudest and best resourced voice, that of carer industry advocates and lobbyists, will entrench current directions.

The very pivotal foundation is redefining and focusing new initiatives on 'families with disability responsibilities', much as the current Government did when it focused on 'working families'. Hopefully, these initiatives will convert the former into the latter, with all the consequent benefits for our society and the health and well-being of family members.

Caring is one of the most wonderful life experiences a person can have. As one who lived this for 32 years, I believe the most fruitful perspective for the inquiry would be to examine how the government can build models of support and enablement that appreciate and enhance the positive life-building skills and experiences focusing around the person with disabilities and their family members with disability responsibilities.

I suggest the following as opportunities around care directions:

1. Tax incentives to counter extra costs of disability
2. Encourage self-employment initiatives
3. Explore team business opportunities
4. Invest in backlog of equipment needs
5. Fund 'families with disability responsibilities'

The new Commonwealth Labor Government is in a position to move away from medical and charitable models reinforced by the previous administration, towards business and entrepreneurial models of disability citizenship and valuing families with disability responsibilities.

Implicit in that change of direction is support for the employment of and participatory leadership opportunities for people with disabilities and their families, as the best suited people with passion and experience to shape directions. This new dynamic could provide a new team voice with shared outcomes, much as the original IYDP Committee of people with lived experience of disability did, setting vital directions for this growing community reality.

Becky

June 11<sup>th</sup> 2008