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Productivity Commission - Disability Care and Support Public Inquiry

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Thank you for inviting public submissions to the crucial task of framing a more equitable set of economic choices for people with disabilities in Australia. There are clearly substantial economic costs to exclusion. As a society, if Australia could increase people's active participation, it would create ever-widening benefits of inclusion.

I am writing with a personal background as the wife of Richard Llewellyn AM, a disability pioneer in this country. Richard, my husband of 32 years, was 95% paralysed from polio in 1957. He had involvement in setting policy throughout the 1980s at national and state levels. Richard died in 2004, but his thoughts are still very relevant. I have continued our work of creating a more accessible built environment as an access consultant.

Others will address their sectoral interests in this Inquiry, but I would like to comment from the inside as someone who has both watched and helped create 30 years of progress in disability. From this life experience, I wish to contribute some philosophical, linguistic and economic models to the mix of the Commission's Inquiry.

Two Thinkers on One Issue – The Centrality of Self-Interest

One of the most profound thinkers in Australia today who understands the problems of the welfare trap and poor service delivery models is Noel Pearson. His insights far transcend aboriginal perspectives. There are many parallels between Noel Pearson's recent thoughts (*The Australian* 24th July 2010[1]) and those of Richard Llewellyn. From 1972, he advocated the very same philosophical ideas about motivation to lift disadvantaged Australians from poverty that Noel Pearson writes about 38 years later.

The first premise of both Pearson and Llewellyn's philosophy is a belief in the **primacy of the individual**, their thoughts, actions and ability to act in often hopeless situations. What could be more hopeless than being in a remote dysfunctional community, with grief, poverty, isolation, dysfunction and disability all around? People with disabilities experience much of the same, and like aboriginal people, it remains unacknowledged. However, many people experience hidden disabilities so they become even more invisible. Or in the case of the double disadvantage experienced by aboriginal people with disabilities, life becomes even harder.

In the *Australian* article, Pearson writes of three planks based on Adam Smith's pivotal economic philosophy, which are completely relevant to the Productivity Commission into the National Disability Insurance Scheme. 'Self interest is the engine of development...The problem is that self-interest is the last thing that come to mind when Australian leaders, policy makers

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[1] Based on a speech delivered to the Centre for Independent Studies Consilium 2010 by Noel Pearson

and citizens come to consider indigenous policy. But not only is self-interest relevant to any serious intention to close the gap on disadvantage, it is absolutely central.'

For Richard Llewellyn, self-interest was the primary driver for moving forward people with disability which he spoke about over and over. In his own situation, after a year in an iron lung and a year in a geriatric ward, aged 21, he was rejected by the Commonwealth Rehabilitation Service because he couldn't hold his fingers up on an old-fashioned typewriter. The only expectation in 1959 for handicapped people was apparently clerical. They refused to give him £500, the equivalent funding of the cost of his rehabilitation, which he asked for to start his own business. He got no pay-out for his disability was caused by illness, not an accident. But, with his parent's help, he started Adelaide's first self-help mixed business, a combination of deli, library, dry-cleaning business. He went on to run several successful businesses in SA, including directing two contemporary art galleries.

Richard had a 20 year career in the SA Public Service, finishing with 7 years as the Adviser to the Premier on Disability to SA Premier John Bannon. He then began a disability access consultancy with me which he ran for another 7 years.

Richard also fathered 4 children, travelled interstate and overseas, invented key disability equipment and challenged conventional welfare blocks in Adelaide, then nationally, to listen to the voices of people with disabilities. He believed in self-interest but also in creating a society without barriers so that people could make choices to participate as they wished. He was an advocate for raised expectations of people with disabilities but with structural and systemic supports to enable this citizenship to flourish.

He began his wider role of encouraging more people to be advocates by mobilizing people in the late 1970s in a Club for Physically Handicapped. It met alternately at the Home for Incurables or Regency Park Centre for Crippled Children. People came together to learn how to be more active, participate and run committees. In the process, this Club started a movement that created many national leaders from SA in this field. Individuals count and it is in all of our interests that people with disabilities, not those of us who work with, live with and love them, push the agendas forward. Disability led initiatives, which tap the principle of self-interest, are the most efficient market mechanism to ensure progress happens. People who are living this experience have the passion, commitment, black humour and crap-detecting instincts to give over and above the normal because they are stakeholders in a larger vision of progress.

In 1979, Richard was appointed to the National Advisory Council for the Handicapped (note the paternalist language – 'for' the 'handicapped'). NACH had carriage to plan the United Nations International Year of Disabled People 1981 (IYDP). Richard went to the first meeting in Canberra as the *only* individual with a disability. The rest were doctors, bureaucrats and sheltered workshop bosses. He told them this wasn't good enough in planning a year about disabled people and arranged to see the Minister for Social Security who appointed the committee, Senator Margaret Guilfoyle.

Richard asked Sen. Guilfoyle a simple self-interest question: "If this were the International Year of Women, would you accept a representative committee with one women and all the rest men?" Sen. Guilfoyle swept away the old committee and replaced it with what was considered in its time a ground-breaking committee: people representing their own disabilities as well as key umbrella organisations of the non-government sector.

This disparate group travelled throughout the country in 1981, challenging airlines, hotels, transport services and local people with disabilities to wake up to the possibilities of a more open society. The Year's slogan "Break Down the Barriers" was devised by Phillip Adams in conjunction with people with disabilities and featured people who have contributed significantly throughout history and culture *with*, *not in spite of*, their disabilities. This Australian Non-Government Organisations Committee for IYDP helped steer Australia's progress in what was internationally considered the most effective national response to the 1981 United Nations Year.

1981 was the birth of the disability rights movement in Australia, much wider community awareness of living with a disability and a watershed year in language. The fruit of this accent on individual achievement with collective power was realised in the 1992 Disability Discrimination Act (DDA). The key finding of the IYDP Committee from all its national consultations was that people needed 'income security', that is, they needed what the National Disability Insurance Scheme may offer. As part of an Australian Rehabilitation Council on Disability program with the IYDP Committee, I wrote a discussion paper on this topic for national circulation[2]. The idea of trying to rationalise and improve economic treatment of

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[2] Income security policies for mentally and physically disabled people in Australia : final draft for discussion, February 1981, second printing, April 1981, prepared by Becky Llewellyn for the Australian Council for Rehabilitation of Disabled and the IYDP National Committee of Non-Government Organisations (Australia), Canberra, A.C.T. : Thompson, Government Printer, 1981.

disability is not new: this is what people were calling for in their United Nations year of focus, almost 3 decades ago. Self-interest dictated a way out of the poverty trap as a top priority.

One of Richard's primary policy thrusts in policy was to be crystal clear about limiting eligibility to those who had genuine disabilities through very clear guidelines based on the international definitions of disability. In 2008, Australia ratified the United Nations (UN) Convention on the Rights of Persons with a Disability which could provide a strong foundation, along with the definitions in the DDA. The Convention emphasises that environmental and attitudinal barriers are just as important in defining disability as an individual's physical or intellectual impairment. Richard was afraid that, as we have seen with the rorts and tendency for scams that have come in the pink batts government scheme, there would be many who would want the easy option of disability benefits.

The fact that in every economic downturn the disability pension numbers fly upwards points to this trend, where people who are marginally effected seem to be able to claim disability. Doctors are easily manipulated to provide car permits, unaware that their actions put so much pressure on existing facilities meant for a more limited supply. The key challenge of any new scheme is to target criteria very clearly to intended recipients.

Pearson says that the second article of liberal philosophy after self-interest if we are serious about decreasing disadvantage is choice. As he says, 'The power of choice is the concomitant to self interest. Both take the individual as the principal actor in development.' He acknowledges that choice is power and if there is only one model, or one that is in the hands of other people, it will not self-propel people into making progress.

From 1913, Australia was a leader in supporting people with disabilities, albeit with different language to describe people. It pioneered the Invalid Pension which provided a standard stipend across the country. Many other western countries did not provide this through government until much later. Beyond this low subsistence, now the re-named Disability Benefit and allowances, charity, with all of its drawbacks for both the giver and receiver, forces many people into a passive 'grateful' role just to have basics. This is dependency and conformity, not choice.

The third of Pearson's economic motivators, absent from both the indigenous and disability policy arenas is private property. Parliamentary Secretary for Disabilities and Children's Services, Bill Shorten, speaks eloquently on the fact that most people with disabilities and their families find themselves in a cycle of poverty. It is the poverty, rather than the disability, which causes most disadvantage, or certainly adds several layers of barriers to overcome.

Richard Llewellyn came out of two years in an infectious diseases hospital determined to make money. For him, money equalled choice. He knew with money he had choices to buy what he needed, although in 1959 there were no services, equipment, access taxis, adapted houses, etc but he managed. He set out with full intention to work with what mental powers he had to make money.

He did that well, but not without many barriers being put in his way. When he succeeded in cornering the market for flat rental in Adelaide, his competitors lobbied government for a law that providers needed to pass a course only provided in an upstairs venue. He had to leave that business. On joining the SA Government where he served for over 20 years, he was denied access to the-then generous superannuation scheme because of his pre-existing disability, hence seriously disadvantaging him against what was available to his peers. He was finally considered eligible for a reduced Government super scheme in the final 6 years of his work.

So, Richard worked hard to create an original asset, then build assets from that. It was something he was particularly good at and I supported this. What drove him was the spectre of not having choice and being forced to live in the 'Home for Incurables', later renamed Julia Farr Centre in Adelaide. Fear and loathing, self-interest and choice propelled him to secure our future with private property assets. It gave him confidence, pride and identity. Imagine what economic potential would be unleashed if a much larger pool of currently disadvantaged Australians could access these powerful pay-offs.

Getting Clear on Language to Change Action

Disability is a blind spot in our society because it poses a threatening idea that none of us want to acknowledge: our physical and mental limits as human beings. On the contrary, my experience is that disability and the care responsibilities it impose offer an abundance of ideas, resources, comedy, pathos and joy that are immensely satisfying if we are not afraid to confront them. As our society is now entering a huge ageing momentum with the known demographic of disability, it is timely to get very clear where our thinking has come from about disability, its effects and how that shapes our actions.

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, along with convicts. These models have operated during most of the 20th 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 gruelling 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.

Richard Llewellyn believed that getting the language right determines the action. I still believe that this word, ‘carer’ 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, 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. It uses the word ‘need’ to justify action, not the more neutral ‘requirement’ or ‘assist’, which are dignified, not loaded.

Using ‘carer’ as a role commodifies an emotional response based on love to substitute for pay. It builds huge resentments towards 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. 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 may need to have someone assist him communicate. He may not need someone to ‘care’ about or for him – he requires a speech assistant. Sally who has a hearing impairment may want someone to sign Auslan for her at church or University. She does not need a carer. She requires 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, is her son, not her carer. He loves his mother and he helps her, just as she did him in earlier days.

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. He reciprocated in supporting our family, financially and emotionally. Where there is a major disability present, siblings of a child with disabilities, children or parents of a person with disability have 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.

Framing policy around families where disability is present and the consequent responsibilities that are shared by the members of that constellation, would recognise the contribution of each person in that family, kinship or friendship 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 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.

Practical Strategies to Release Economic Potential of People with Disabilities

Unfortunately, the terms of reference of the Productivity Commission have an implicit bias to 'service delivery'. In terms of Pearson's concepts using Adam Smith's influential liberal philosophy based on self-interest, choice and private property, why not look at models of economic development other than service delivery that are used in other parts of the world to assist people living in poverty? For instance, what about micro credit for small business? The welfare model in itself is limiting and has a magic pudding effect on bureaucracy. Who gets the benefit – those who are being served or those administering the schemes?

Service delivery implies a lack of trust in the recipients which is embedded in disability concepts of the past. Secular service delivery in remote Australia has been a dismal failure on all counts except providing economic benefits to the industry of fly-in, fly-out consultants and advisers. Please look at the parallels between these two arenas before setting up a new 'service delivery' model. One size does not fit all, and not taking into account basic drivers of economic development will lead to a poor outcome.

As the Productivity Commission, you will be concerned that this is an economic winner for Australia. Releasing people's motivation, skills, and drive should over the long term move people up. The US has long expected more of people with disabilities in terms of educational, workforce and democratic participation. We take a paternalistic, coddling service delivery attitude, based on UK-exported Commonwealth culture, at our peril.

The key to progress is to expect a disability led set of components to create the NDIS and insist that people with disabilities themselves shape, monitor, administer and guide its path forward, following in Senator Guilfoyle's path of 1980. That is the way to create accountability and good use of tax-payer dollars.

Finally, I would like to add five suggestions to the mix of policy considerations, from my lived experience over thirty years with Richard.

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 Richard'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 promoted the phrase, "the extra costs of disability".

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 the businessman one item, his luxury car, as a business tax deduction. The other item, the essential electric wheelchair which we had to buy, 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 the IYDP campaign and it has been an important part of a package of recognition, but is only a first step towards making a structural difference when there are so many barriers to employment and further education.

2. ENCOURAGE SELF-EMPLOYMENT INITIATIVES: *Give access to low-interest business start-up loans, marketing and training assistance 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 have disabilities and those 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.

Miniaturisation, broadband and electronic communication have brought the possibility of home businesses into the realm of the do-able so people could make work from home with computer and business skills. 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 people with disabilities break the cycle of poverty.

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 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 so that they are not penalised for initiative. Linking Health Care Card entitlements to the Disability Pension also acts against enterprise. It should be available to people who meet disability criteria regardless to increase fluidity into the world of work.

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. Models and mentors who are successful could frame a new sense of opportunity.

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, to 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 solely being 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 solving real-life disability challenges 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 welfare and individual employment models.

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 compared to a manual chair. Equipment is a key compensation for many impairments instead of human help. 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 travelling 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.

In almost every situation involving physical and sensory disability, there could be a question – could this disability requirement be met by the right piece of independent living equipment? Sourcing the equipment for independence could yield an amazing efficiency dividend, compared to hours of human support assistance. As well, new niche industries will spring up in response to varied disabilities and the quest for more active participation.

5. FUND 'FAMILIES WITH DISABILITY RESPONSIBILITIES': *Conceptualise new self-managed funding 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.

Policy setters are not using the words and concepts which reflect the reality of the situation, so solutions do not target accurately enough. Although people with disabilities have lobbied for self-managed funding of care hours in Australia for thirty years, it is only now being implemented on a trial basis. The bureaucracy is loathe to trust and yet people with disabilities will on the whole use resources extremely efficiently and maximise opportunity. These are people used to encountering and solving problems every day and are grounded in what works and doesn't work for them.

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. 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. Conceptualising these responsibilities as 'requirements', rather than ‘needs’ also gives the scheme a quantitative neutrality based on respect, dignity and limits, assisting evaluation and equitable spread of resources.

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 counselling would begin to see themselves stepping into society feeling understood and supported. Those with high physical support requirements would be able to choose the model that gives them the degree of control and choice they want in their support arrangements, not the current lock-step regime often decided by others.

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. Saying this, it is of key importance that the person with disabilities feels comfortable with this scenario, as some people do not want their family involved with decisions regarding their life. Others do not have families at all. 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 situation 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 family, including a child with disabilities, could negotiate for regular time to go play or take their other children on an outing while someone cared for their 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, travel and enjoy life as others do.

In my experience and many other families with disability that I know, policy initiatives that try to make our families the same is futile. Disability’s uniqueness imposes 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 unique requirements. This would spur active participation in all of our society, giving positive reinforcement from the wider community to families that have disability responsibilities.

It is time to move Australia past antiquated social, legal and service models that do not reflect our contemporary understanding of disability and its consequences for those who live with it. Best wishes with your deliberations in creating levers based in proven successful economic philosophy to lift people out of the poverty and inequality they find themselves in.