Submission to Inquiry into Disability Care and Support

Foreword

I am 66 years old and have sole care of my thirty-two year old intellectually and physically disabled son, who also has one of the worst recorded cases, world wide, of sleep apnoea.

I have had sole care of him since his father left when he was eighteen months old –he being unable to deal with the idea of having a son who was obviously not going to follow in his footsteps in any way, and wanting a life without the grief and the responsibility.

I have been a member of self help groups, worked to get in home care from Councils to the level it is now, was on the original committee of "Interchange" for the Southern Region – just some of the hats I have worn over the years.

However - I have **no discernible future and nor has my son.**

My son attends a Day Placement facility which does not totally cater for his needs – although it fills in his day and gives him a sense of belonging. He is on the urgent waiting list for a residential home and has been for some twelve years without any sign of a placement being offered. He and I live together and I care for him 24 hours a day, seven days a week – except for the 35 hours he is at his Day placement and the 18 hours a week of ‘in home’ respite I receive.

Holidays he is condemned to spend alone with me – with a few hours of in home respite giving him some sort of variation – as there are no holiday programs for high needs intellectually disabled. Unlike other young men, he is unable to go to the movies or football or have any other kind of recreation with his peers during these holiday times.

I have always wanted to care for my son. Most of what he has learned, I have taught him – very little being taught by the schools he has attended. I love him dearly and learn from him daily. I have no real wish for him to go to residential care as I know he will not thrive as he has with me, but my age is beginning to show and I know that I will reach a point physically when I can no longer care for him. However, after being on lists of one kind of another for over 20 years – no offer for housing has ever been made to us and I have no reason to believe an offer will be made in the foreseeable future.

I am past retirement age with no thought of retirement – no planning for trips overseas – or even to the Peninsula! I have nothing…. No superannuation …no real friends…nothing in front of me other than anxiety and grief about the future for my son. I have to maintain our home as best I can on the pension …I have no other children to offer assistance….I have to attend medical appointments as a public patient and get in the queue behind those who can afford to insure themselves, and even aged pensioners – who have only to attain a certain age and have less than a certain amount of money to obtain the same benefits that I do without having to put any effort into anything – other than the hobbies etc. they choose to do.

I gave up my career as a successful actress in order to care for my son and there has been no opportunity to indulge in anything but basic living since then. Any money I accumulate goes on equipment/car maintenance/and other necessities essential to my son's well being and enjoyment of life. There is no superannuation to look forward to spending – no great trip to plan for. The only thing I can plan for is to get through each day, as I am needed, and there is no end plan. There is no time limit. There is no date ahead where my life will be given back to me for what it is worth at my age; no date where my son will begin what is to be the beginning of his final chapter. There is no pathway to follow to help my son adjust to his future….because he has no idea what that entails!

The concept of moving to a residential unit and living with others is not in his consciousness. He has no desire to leave home…no desire to be independent….because for him it is not independence… It is moving from a home where he is loved and understood, encouraged and reassured to a place where he will be following 'rules of the house'., and living with people he does not know or necessarily, care to be with. Individualised attention will not be the norm – although it may sometimes come if he is lucky. He will have to conform in a way no 'normal' person is made to conform – and he will have no way to complain or change things because he can't. If he is lucky there may be a staff member he can relate to and feel affection for – providing they happen to be on duty!!

There is no pathway to lead him gradually to acceptance of his future. One day there will be a phone call, a visit to a strange house, and a date on which I will have to pack his bags and deliver him to the place that will be his home, with people he has never met. I don't know how I will do that……

The truth is that I, and others, are constantly weighing up whether our children would be better served if we went as far as we can and then take both of us out.   This solution has been agreed as being a possibly better option for our children by many, many professionals in the field.

What I do know is that things have to change radically in the care of the disabled in this country = we have too much as a nation to allow the situation to continue as it has.

My son and his peers are citizens too – and they have the right to be treated with respect for their individuality – and for what each and everyone of them can teach us all.

For my income I have to work 24 hours a day. I sit up at night watching my son sleep in case he stops breathing. I toilet him, bathe him, walk for miles with him in his wheelchair – which I haul in and out of the car. I maintain his physical fitness, educate him and above all…fight for him - because I love him, and have endless admiration for him and the physical and mental fight he has to do the simple things - and I believe he is a heroic human being who deserves the same rights as every other person born.

It is for these reasons I wish to offer a submission to this inquiry – to help those following on. Unfortunately ill health and a badly injured shoulder – incurred in caring for my son - has not left me as much time as I would have liked, nor the ability to type for long periods, but I will do what I can to make clear the changes that need to be made - and made quickly. The entire scope of this enquiry is beyond me – given my time restrains – but I have suggestions that may be valuable.

I hear calls constantly from bodies demanding services from Governments – and while I strongly agree we need them – I do realise that governments have a great many calls on their resources and not everything can be free to those receiving services.

I also speak mainly on behalf of those disabled who have been disabled since birth and have an intellectual disability – often combined with physical disabilities.

The range of disability is vast – even among my son and his peers – but too often ‘disability’ is used as an all encompassing word to cover many types. Even in the working of the most recent Disability Act - written by the disabled, for the disabled - we parents who attended meetings etc. began not attending as the needs of our children were swept aside by the more capable disabled. I have had cause in several meetings to refuse to allow the physically disabled to eliminate wordings that precluded parents of the intellectually disabled speaking for their sons and daughters. With all due respect, the only person who can speak for my son is me! He has no speech..and he cannot express himself to others. He cannot make complaints, ask for what he wants etc. The only person that can do that with any reliability and understanding is myself….and the other parents of my sons peers. Because a person is disabled does not mean they are somehow totally aware of any other disabled person’s needs.

HOW DO WE CHANGE THINGS AND WHAT IS NEEDED?

1.

National Permanent All Party Committee for Disabled be established

Disability is here to stay. Despite all the advances in medicines/therapies etc. there will always be a need for care for the disabled ….so let there be a permanent, on going body who are properly informed and responsible for policies and guidelines – regardless of which party is currently in power. The wastage in changes with new policies etc. with successive changes in governments – if eliminated – could finance a lot of things.

Disabled/Parents/ Professionals/Government representatives to be part of the Advisory Body. All members of the committee to have first hand experience and knowledge of disability in at least one of its forms.

Policies be Nationwide so that transfers from State to State can be effected easily/

Committee responsible for: Funding arrangements, policies, creation and Implementation of registers etc.

2

Creation of Disability Information Centres - in all capital cities and major country centres

Centres to have information on all aspects of disability from pension entitlements, Crisis management, how to obtain a Case Manager, referrals to medical practitioners and specialists etc. to care options, housing options, respite options, alternative therapies.

Most of the information parents receive is by word of mouth from other parents – or from various groups they may happen to be members of.

However the majority of parents simply are uninformed and have very little idea of what is available or where to go to for assistance – other than contacting the Department and begging for a Case manager. Very few realise that there are alternatives to government funded Residential units. Even fewer are aware of alternative therapy options.

Information and guidance is essential and must be freely available.

We need urgently a central information centre where parents can obtain advice, look at what is available and weigh up options.

Recognition that parents/carers are equally as important as the disabled person.

They are responsible for meeting the daily needs of the child, for investigation into options for help, for physical and other therapies – and they need as much care and support as the disabled child. Without the parent/parents the child will struggle to achieve it’s potential – as evidenced by those who are placed in care at an early age.

Caring is a job – and should be respected as such.

3.

SEPARATION OF DISABILITIES - to more efficiently assess needs

The range of disabilities is enormous but can be broken down to some extent by the type of disability and amount of care required by each child/adult.

a. **Those present at/or shortly after birth – Intellectual/physical/both**

High Priority must be given to assisting in the early diagnosis and management of those in this category. Early diagnosis and education of parents can lead to greatly increased outcomes for the child – and currently so much time is lost in trying to access assistance etc.

- New born/early infancy

For those presenting difficulties in the first weeks/months after birth there is a very real need, that is largely unmet, for support not only for the child, but more especially for the parents. Very little support is gained from family or friends as they feel inadequate and cannot cope with what is happening. Parents often are very emotionally isolated as others don't want to have to cope with the child who does not behave as they are used to and the grief of the parents. Grief is all encompassing for some months – and even years – as one comes to terms with losing the dreams you had for your child and your family and for yourself.

Those early weeks/months/years are a nightmare for parents – especially for the mothers – as gradually you notice small signs that things are not as they are with other babies. Kindly friends, families and even professionals, reassure you that all is well, 'all babies are different', and other such platitudes - resulting in many cases in a reluctance of the parents to talk to anyone about their concerns….and they do not pursue the problems until things are at a stage where the difficulties are obvious. This can delay treatment and development of the baby – as the early a problem is diagnosed and treatment/therapy can commence the better the possible outcome. In many other cases, the uncertainty and very real feelings of failure by the mother and the unwillingness of the father to acknowledge they have a problem results in relationship break ups, or in many many cases a divided family when one parent or the other has the care of the disabled child almost exclusively.

In my own case, the denial by medical people surrounding my husband and I that there were any unusual signs – which they later confessed they had recognised but didn't want to say – led directly to conflict and eventual break up of our marriage.
My insistence on consulting a paediatrician was a waste of money according to his father, but the results from that consultation were far more wide reaching. The doctor concerned = without examining my son – declared the

only thing wrong was me = I was told I resented him “because I had to give up my career - go home and be a mother!:

I had no backup or assistance from his father who accused me of being insane….he refused to attend paediatric appointments..stating the only person that had anything wrong was me! My son’s failure to thrive I felt directly responsible for, given that all around me reassured me there were no problems. I broke down and entered a Clinic when he was three months old. The time I spent there actually reaffirmed that I was not wrong and when I returned home I spent hours phoning self-help groups, clinics etc. until I was given the name of a paediatrician. On seeing my son – aged 8 months – his first words were “he has a problem”. I was elated – now we could do something!

I have seen many, many situations such as these. Situations where mothers have been told to place their baby in an institution and forget it – and often the mothers visit clandestinely. Others who have constantly taken their children to doctors, emergency wards to be told they are overanxious etc – leading one mother to block the main lift doors of the hospital until someone saw her child. While the police were in the process of forcibly removing her, a specialist intervened and took the mother and child to his office. He took charge and within a short space of time confirmed what the mother suspected. She had a seriously ill child with heart problems and brain damage.

RECOMMENDATION:

1. All babies be seen by paediatricians at regular intervals dewing the first eighteen months.

2. Provision of services in home to train parents in the care of their child – in behaviour management/physiotherapy.

3. Counselling be provided: Parents need both grief counselling and relationship counselling early. They need to be able to speak frankly of their concerns etc. and of troubles in the relationships

4. Domestic/transport/miscellaneous assistance be provided as required according to family circumstances.

5. Care available for other children in the family.

FUNDING

I suggest a compulsory Insurance Policy be taken out when pregnancy is confirmed. This would need to be a minimal amount, but would defray costs that must be borne by the Government once disability is diagnosed. Families dealing with disability and diagnosis are forced to have at least one parent cease work and take on full time care. If governments can fund maternity leave, they are obligated to fund the care of the disabled child by compensating for the lack of income by at least one parent. In the case of single parents government would have to cover all costs.

b. Those occurring childhood due to illness/accident

While acknowledging that all disability is regrettable and a hardship, there are far less difficulties – though certainly no less grief and despair – in gaining assistance from friends and families for children who have had a normal childhood and developed their personalities, speech etc.
The same emotional supports are needed at the time of the accident/illness but in most cases physical and moral support are obtained from friends or family who gather to assist.

Continue the compulsory insurance policy through childhood to obtain funds to cover costs.

In the case of a family where at least one parent can continue work, fees to be on a sliding scale of affordability for the necessary services. Fees to be minimal.

e. Those occurring due to accident/illness involving prior knowledge of danger e.g. acquired brain injury due to traffic accidents/ extreme sports/ ignoring danger warnings etc.

Disability is a drain on resources and somewhere there needs to be a "consequences of your own actions" ……….

Continue the compulsory insurance scheme to assist with funding.

Obviously urgent medical attention is required but once in rehabilitation, fees be introduced according to ability to pay.

In reality, these people often receive a lot more services and priorities than those who were born with disabilities and have never had a choice. Why should someone decide to dive into a pool in spite of a warning sign, and then sue for compensation and line up for services – which are often given ahead of others?

Access to services on a user pays basis - Fees – sliding scale.

d. Self inflicted: Alcoholism, obesity, "chronic fatigue"

These should not be entitled to a full disability pension without contributing in some way to society. I get extremely angry when my son is forced to wait outside a disabled toilet and then find the occupier is an alcoholic, or obese and not entitled to use these facilities but do so claiming they are disabled.

Services to be user pays; or an equivalent amount of community service hours be compulsory to obtain their pension.

e. Mental illness;

A high needs category but with compulsory family counselling to be undertaken. So often problems have begun in childhood and remain unresolved while the families deny they have any part in the problems.

In **separating categories** it would be possible to more accurately assess needs.

SUMMARY

Priority One: New- borns and their parents during the diagnosis period.
Specialist treatment/diagnosis be available regardless of ability to pay.
Other fees: according to ability to pay.

TWO: Single parents – regardless of age of disabled if disabled is living at home.
Support for single mothers to include assistance with home maintenance

THREE: assess priorities according to need - financially
Informal supports available.
Age and health of primary carer – and the disabled person.

Size of family

Establishment of community help groups

Informal/Unpaid support from the community:

Caring for a sick/disabled baby is time consuming and anxiety ridden.
Parents – especially mothers = need friends, assistance with household
I was fortunate to travel to Perth when I was in a Television show for their annual 'Appealathon" – which is in aid of disabled children. I was totally unprepared for what I saw. The involvement of the community in not only raising funds, but in assisting with disabled people was stunning.

In all suburbs there are 'community helpers' who are in contact as soon as they are aware that there is a need – and provide everything from a shoulder to cry on, to cooking a meal and driving /accompanying parents on hospital visits. This is done for nothing and from a great community spirit.

How do we get 'Community Spirit?"

People, in general, do not communicate well with the disabled – especially those with intellectual disabilities. They very often move away - while sympathetically glancing at the carers/parents. This is born from ignorance of the disabled and often a horror of what they see. This is not easy to overcome, no matter what policy may be in place with reference to acceptance - therefore we must look to the future generations to change this.

A. Place all educational facilities on the same sites – from kindergarten and early intervention centres to primary and high schools.

Let the disabled be part of the community from the start.

Very young children, while noticing differences and showing curiosity about them, do not necessarily condemn those who are not like themselves. By combining all children in early childhood settings – where applicable – young healthy children will become accustomed to what they see, and will also have the opportunity to see what their disabled friends ARE able to do. Although the disabled children would need their own facility, playgrounds and free times could be mixed. Classes, where applicable, could include the disabled, and a “big brother” big sister’ program be utilised in the playground on a rotation basis.

Not only would this take the mystery and fear out of dealing with the disabled, it would also result in less capital expenditure on facilities who can share recreational and other areas.

B. Parent to Parent meetings centred around Early Development centres. Most centres roster parents on to do ‘fruit duty’ and other things where parents of the non – disabled can also assist with the disabled – and could be rostered to do just that.   Encourage and create mutual sharing times between parents so that they can learn that disability is just someone being ‘different’ rather than ‘inhuman’

C Creation of volunteer community assistance in local areas

Assistance can range from transport/ housework/childminding – anything that may assist.   Encourage the community to be aware of the need for assistance.

3. CREATION OF A FORMAL STUDY PATH FOR THOSE WISHING TO WORK IN THE AREA OF DISABILITY AS PROFESSIONAL CARE WORKERS. \\

(See attached: My Choice….

Paid carer workers are vitally necessary to the well being of a large number of the disabled, and yet there is no formal educational degree that must be undertaken. We have people coming to care for our children who range from students with no training, some with minor mental illnesses wanting to help, a few trained and experienced workers. Training courses – which are supposed to be undertaken vary to a ridiculous degree and most do not teach even the basics of care…..such as personal care, behavioural management etc.

A Division 4 Certificate can be undertaken over 2 years with lectures etc; and the same Certificate can be done on line in the course of 6 weeks.

Professional care workers need to be just that……'professional'. They need to have a career with a future for themselves and to be paid a wage commensurate with what many are called upon to do. Seniority and experience is not rewarded and they are paid less than a professional wage. Little wonder that they use caring often as a fill in job en route to something else. For those who care for the disabled in their homes, with no other professional backup, and the total responsibility for someone who may have no speech, be inclined to seizures, be incontinent etc. they need a wage that is at least on a par with nurses.

A university or TAFE course that a student at high school can consider as a real option for a career, should be available and aptitude and interest should be measured to be accepted to undertake the course. Training must include bathing, toileting, behaviour management and practical on the job experience. Some may choose to graduate at the basic level – whatever that is decided to be – while others may continue to gain more expertise in both specialist fields and management. Some may decide to specialise in in-home care, others may find residential care better suits them. Create a career for these people and pay them commensurate with the standard they have chosen for themselves, with the option to continue (or return to) their course at a later date. Acknowledge their experience and seniority in their pay packet. Regardless – pay them what they worth – not the pittance they are paid now.

If this were undertaken there would be a higher number of carers, dedicated to their chosen career path. Clients would in all likelihood achieve higher standards if they have people who are interested in more than just filling in their hours, and are educated about the people with whom they are dealing.

Currently people enrol with agencies while they are studying something else; many enrol as they want some part time work and think it might be more interesting than cleaning!! Most join agencies as they have heard of the job through word of mouth or an advertisement….but few

We are offered 'trained staff' to give us some respite hours.   I have had over 300 different carers through my home over the years – 70 percent of whom required at least three weeks or me of me working alongside them and training them before I could contemplate leaving my son in their sole care. (Note: the carer is getting paid, the support agency is getting paid and their staff are getting paid while I train the staff for no money on the time that I am paying them to give me some respite!!!!)

Let there be no doubt that while governments fund many programs, the clients and their carers see little of that money.   Service providers and their staff – and often the coloured magazines telling us how wonderful they are – have first pick, next come the staff and lastly the clients. Despite what clients request Service providers modify to their own specifications those requests and then we can have what they offer.

PRIORITIES

These must be rated on a needs basis:

1. Early diagnosis and support – parents are the most important therapist a child can have. Parents are motivated and struggle to help their child in any way they can. Early support to head off trauma, and deal with the very real grief that the dreams you had for your child will not eventuate, will have the effect of not only supporting parents emotionally and physically, but go a long way to assist parents to become not only advocates for their children, but therapists as well. The earlier the input the more hopeful the outcome – and many who have not had early input may well, in the future, be able to lead productive lives and contribute to the work force.

2 Single parent families who have few informal supports and little income.

3Carers and the disabled clients are a package. One does not go without the other. In order for the client to achieve their potential, remain healthy and learn as much as they can – it is the carer who has the responsibility. Carers must be supported to avoid burn out and isolation that then leads to depression and lack of incentive.

4 Housing must be provided as a matter of urgency – the list is currently 6,000 plus and constantly growing. Parents/carers are aging and can not be expected to cope into their eighties.

PAEDIATRIC REFERRALS

SUPPORT FOR PARENTS DURING DIAGNOSTIC STAGE

1. Following the birth of any child there can be periods of anxiety, depression in new mothers – especially those having their first child and those who have little or no emotional or physical support - eg. Single mothers.

Some disabilities are evident at birth or manifest within a very short period of time following – but the majority begin to manifest when a baby fails to achieve milestones, behaves oddly, doesn't sleep, feed etc. In many cases these seem to be of no concern and parents are told that all will be well- time will let them catch up etc. Unexplained bouts of crying, failure to thrive, to feed are often dismissed by medical people as being 'part of the individual make up ' of the child. In my son's case there was little specific trouble except a failure to feed properly….which was diagnosed by the midwives at the hospital as being 'because he is a Scorpio' My concerns were put aside by our doctor and the nurse at the health centre. At six weeks, he would not wake properly and I was about to take him to the Children's hospital, a midwife arrived to visit. This nurse had had experience with physically disabled newborns and immediately suspected difficulties with his sucking reflex. **I had** t0 express milk and she put numerous holes in a teat, held his cheeks together and he had a proper feed for the first time. When – months later – I found a paediatrician who would listen – it was discovered he had an extremely high palate and could not form the suction necessary without the assistance of having his cheeks held firmly while feeding.

This was followed by a tendency to throw himself backwards, failure to sleep and to thrive generally. My concerns were negated by friends who gave me every reason possible for his various small behaviours. His father supported their views and negated my feelings

When he was three months old I requested a visit to a paediatrician – who informed me prior to examining him, that I had resented giving up my career and to go home and be a mother!! His answer to his failure (still) to feed properly was that perhaps he did not like milk = and to try giving him steak to suck on.

By this time I was frantic and feeling a complete failure as a mother. I became nervous around him, and I had no support from my husband. My mother assisted where she could, but the general atmosphere was that my son was OK and I was just being ridiculous.

This resulted in a breakdown and hospitalisation for me. My son was in a Baby home and I felt that I had destroyed him single-handedly. When I finally returned home and looked at the situation that had developed with my husband's lack of co-operation and my ever increasing knowledge that something was indeed amiss….I chased everything I could find and searched the phone book for people to speak to. I was finally recommended to another paediatrician when my son was eight months old. His first words were …'you have a problem'….and they were a gift to me. All I wanted was to know whether there were problems so that we could work on them, or to know that there was nothing so that I could work on me.

Many months of tests followed, periods of waiting for developmental stages etc. Eventually there was physiotherapy and other treatments recommended.

My husband, his father, refused to attend paediatric visits, did not believe what he was being told and did not want to be part of all this. He left when my son was eighteen months old.

During this time, my only real support was my mother – who was also inclined to deny the obvious. I had no-one to talk to/ to ask for help/ to give me any kind of support.

This is the highest priority there is. Any child will develop to the best of their potential if the world around them is loving, stimulating and filled with stimulation. For the child who has inherent difficulties to begin with, a disturbed atmosphere with parents who are emotionally worn out and torn apart, they are struggling to achieve at the smallest level.

I would want every baby to be supervised by a paediatrician for the first year of their lives, so that is problems do appear to present they can be picked up quickly and parents are supported and encouraged. So many of us have had to literally fight to get our children diagnosed and assisted.

Birth to Death plan
For Intellectually Disabled

Each child to have a ‘birth to death’ plan from early childhood, which would include educational options available, possibility of work opportunities where applicable, choice of future housing. This can be altered along the way and depending on the individual’s development, but it would allow for future planning and give more certainty to families/carers

Pathways to Residential care:

It is rare that a disabled child would have no need to go into residential care at some stage in their lives – even if that entry is later in life.

It is time for a real choice to be given – for individuals and their families to decide the style of living they would like and which would best suit. In the same way that other citizens are entitled to live where they choose – even if they choose to live in dangerous places (prone to bush fires/floods etc.) – and the community bears the cost if those choices lead to disasters – so should the disabled have a right to choose the life style that best suits their needs and likes.

Currently there are few choices – and most, whether government or privately funded – involve living in a single house – or block of units somewhere. This model results in the isolation of the client with those others sharing the home and little else.

We need a range of choices – from village style housing, to farms, to neighbourhood houses…and anything else that 'normal' people have choices of.

Respite: Choices to be given that are real choices:
Eg. In home   Respite houses   Holiday programs

Carers must be given respite that reflects **their** needs – rather than the current funding that is assigned to the disabled: to give them activities etc and the carers have respite by default. Carers are as important as those they care for.

Respite houses to be attached to Day program centres – so that the clients using the respite are familiar with the others with whom they are forced to live while there – and not having to cope with people they have never seen before and staff that come and go.

I ask you to consider the consequences of taking a 'normal' adult to a strange house and informing them they have to stay there until called for - be that in a day, week or a month. Try telling a normal child/young adult that they will have a lovely time and then try leaving them with no-one the know, and not necessarily a single person they may relate to. Then try staffing that house with people who did not speak English - a similar predicament to those who have no speech. Should that young person run off they will be picked up by the Police and returned. Could I suggest that someone try that, and then tell those of us with disabled people that 'respite houses' are great!!!!!!!

Why are the disabled lesser people?

Cluster housing for the more able. Independent units for those who require only minimal supervision with a unit offered free of charge to people who would act as emergency help/general advisors (These could be retired people, University students etc.)

Village housing allows the individual to reside in a setting where they can have the companionship of a number of their peers. If elderly people and others are encouraged to move into retirement villages, where facilities can be shared, and they have social contact with their peers – why can't the disabled enjoy the same? Disability villages could be built alongside Retirement villages allowing older parents to live in the same vicinity and share in the care of their adult child, while having a life of their own.

Rural/farm villages may be preferred by certain people and could operate in the same. Residents may be able to work on the farm and become self sustainable.

Residences transforming to residentials

There are many older parents who still have children at home and who are still waiting for accommodation to be offered (I am one of those). I would prefer my son to remain in his own home, rather than go through the trauma of moving elsewhere with people he doesn't know and doesn't want to know.

Under this plan, providing the house is appropriate, those requiring housing come into the family home with the parent and he original resident. The family member would be part of the care team and be present at night – thus eliminating the need for overnight staff. – and present during the day if a resident is ill and unable to attend a day centre. The 'House Parent/Parents" would continue to receive a pension, but not a salary. Rates , Maintenance etc. would be paid by the Government – and either the Government would buy the house or pay for rental of those coming in to live. House parent/parents to have funded holidays each year of two weeks. This would provide almost instant housing for those on the waiting list, greatly reduce staff costs and allow the co-tenants time in a family atmosphere to adjust to each other. If, in time, the house is deemed to be inadequate and other housing is found they would move as a unit.

When the parent/parents are no longer able to care for those in the home – government could provide them with a small unit – rented if necessary and the home becomes a fully residential care facility.

There are an endless number of models of care that choices could be made from. The essential part of a plan is that whatever model is deemed by the client and family to contain the elements necessary for a happy life…the client could be introduced to the facility gradually over a number of years until it became a very familiar place – making final transition much more successful and less traumatic.

Transition from home to residential/community care must be planned and executed over a number of years to avoid trauma to the individual.

I have known, personally, three disabled young people who have died a short while after being moved into care. Eliminate the unknown process and give the disabled the same choices as the rest of the population.

The trauma of leaving home would be eased as they could be familiarised over a period of years. **Bear in mind: The majority of the <u>intellectually disabled do not want to leave home.</u> The majority do not conceive of 'independent living' and are <u>not</u> looking forward to a home of their own.** Therefore the move to permanent residential care can be totally traumatic for them and an experience that a 'normal' child would not be expected to undergo. The population would rise as one with calls of 'outrage' and 'inhumanity' if all young people were simply told they had to live in a certain house, with certain people and no correspondence would be entered into. Why should the disabled have to undergo that trauma?

With the current situation, with no beds available and a waiting list of thousands, there is little choice given….an offer is made, and if rejected, you are back on the bottom again. There is no opportunity to familiarise the child with the place they will have to spend the rest of their lives. Staff work on rosters, with substitute = and often unknown – staff coming in when a regular is sick. I personally know of several who have become further disabled when this change has occurred – and some have died.

We are talking about individuals who have as much right to have a choice as anyone else – and lumping together because they are on a list is inhumane and an indictment on our society.

Create the various types of housing; Let the disabled/and or their parents decide the model that would best suit their needs in the future and place therm on a needs list for that particular housing model. From that time onwards, the child is slowly familiarised with the model – visits for morning tea, recreational outings etc. that can go on occurring until there is a place available.

Staff: Permanent staff to be appointed as usual, but relief staff to be obtained from interested parties in the community where possible. To avoid having strangers suddenly appear who are unfamiliar with the residents and their needs, create a 'relief staff list' of people who could/would step in where necessary due to staff illness – so that there is a consistency of care from people known to the clients. These people could be drawn from those wanting only casual or occasion work and prepared to be 'on call'.

The Disabled and their Carers- THIS IS A PACKAGE – not an individual plan for the disabled only .

So many inquiries, plans, schemes are presented that purport to represent the needs of the disabled – but preclude the family and close supports without whom the person would not survive. It is essential that the whole package be examined as very often the parent/parents are the best therapists/carers for the individual but their needs are not examined other than in terms of a pension and some miniscule support hours.

Currently a child is diagnosed as 'having a problem' – more accurate diagnosis often taking many months or years to finalise. It is the family that provides the care, support and undertakes the medical procession that is entailed. Many hours are spent in researching, finding specialists, often 'flying blind' with your child in providing care – all, often, without formal supports of any kind. My husband left when my son was 18 months old and took no part in any of the diagnostic process and provided no physical or emotional support.

This is a gruelling time as formal supports cannot be sought until diagnosis has been made – especially if one does not have the friends or family who are willing to assist – or to provide relief. Many parents simply go with the first diagnosis suggested and many seek permanent care for their children at an early age simply because it is a physical, mental and emotional marathon.

However, it is always the child who is focused on – never the parent/parents/family who are called upon to deal with all the issues encountered.

FORWARD PLANNING

Some years ago, I went to Perth to assist with their annual 'Appealathon" – which is run to assist the disabled of W.A. I was stunned to find how far ahead they were in the assistance to families in the early stages of going through the maze.

I am unsure if it still operates, but they instituted a 'Slow Leaning Children's' corporation. All babies there were, then, monitored by paediatricians in their first year so that problems were picked up at an early stage – and unlike those of us in the Eastern States – parents did not have to fight to find a doctor/specialist who would answer any queries they have.

The Slow Leaning Children's Incorporate acted as a nerve centre for parents and had lists of volunteers from all neighbourhoods who would go and support that family with everything from housework to support on medical appointments, to just being someone to talk to.

I was part of a self-help group in the early '80's who devised a questionnaire for paediatrician as to why many, many parents had to go through hell before anyone would tell them they had a problem. In my own case the first paediatrician I consult because I had concerns simply informed me that I had resented giving up my career; that his failure to feed or thrive was because he possibly would rather have steak; and I should' go home and be a mother'. This advice led me shortly after to a clinical breakdown but also to believe in myself and fight to find answers. At age 8 months my son was finally acknowledged to have problems and something could begin. What a waste of time!!

INTRODUCTION INTO AUSTRALIA OF ALTERNATIVE THERAPIES WHICH HAVE PROVEN SUCCESS OVERSEAS.

Parents have the right to find the best treatment they can for their child – to give them the best chance of a productive life possible.

There are some very, proven, effective therapies available overseas that are out of the reach of Australian children and families. The costs involved in fares to travel, long term accommodation, and the loss of employment during the time required in therapy/treatments makes them unattainable for most.

Invite centres to open in this country so that Australian's can avail themselves of all that is on offer.

Families could then remain intact, employment be continued, and children and adults given every chance.

Payment would be "user pays", unless the Government could find some way to assist. Even if they are not funded, allow parents to have the choice to use their expertise.

I took my son to the Option Institute and Fellowship in America – where they have found a ‘cure’ for Autism. I got funding through Actor’s Equity, mortgaged my house, and sold my car to do this. My son started speaking and made many rapid advances in the short time I could afford to stay.

Unfortunately I received no support on our return home – ‘professionals’ being afraid of something new and of losing their jobs etc. and as a single person I was unable to continue the program to the intensive degree required to be fully effective. However, despite his problems, my son is very different to many of his peers – and is happy!

Option is just one of many. We need them. Allow us to have them!