Submission to the Productivity Commission Review on Disability Care and Support Inquiry

My former next door neighbour of 16 years has a daughter with an intellectual disability. I had never given a lot of thought to their situation until I retired in 2001. I quickly found out that there were many people in my own neighbourhood in this situation and many of them were looking after adult children in the 30–45 year range and were unable to determine a secure future for them other than a retirement home.

Subsequently I have been involved on a daily basis for 7 years with adult children (in Sunshine Movement Inc.), parent/carers, service providers, school age children (as a volunteer librarian in a Special School), as well as a term on the Ministerial Regional Community Forum for the State Government with the Succession Planning issue as a major.

Parents and carers have attempted to make comprehensive plans but have been drowning in a morass of legalese, form-filling, bureaucratic musical chairs, wall-to-wall agencies designed to help with everything their child needs ***except*** the thing that they most need as aging parent/carers of sons/daughters with severe disabilities – life term supported accommodation options that will provide a situation where their disabled son or daughter feels valued, and can live in an environment that is viable and sustainable. Naturally parents with children still at school may need this back-up earlier rather than later, there is no way of knowing – this extra stress is not needed.

- The system therefore must be made user friendly
- The system must be community based, with reinforcing circles of support, with the aim of improving the individual's level of independence and thus their quality of life and where they can help by using and exercising the abilities they do have and learn new skills.
- It is very important that families are empowered to direct the succession planning process with professional assistance as may be required.

It is well known that under the existing government policies the unmet need will never be met.
In simple terms the severely disabled cannot live without government support, and under the current system there will never be enough public funding to meet that need.
So to deal effectively with this whole problem will require a huge change in government policy particularly at State level.
The current situation where crisis intervention is the “norm” is not at all appropriate.
It is too expensive and we must move to a situation where:

- There are effective partnerships established with all stakeholders including the families, service providers, developers, financial institutions, and government.

- Government agencies stop micro managing the whole system and delegate much greater powers to act to the competent major service providers,
- Governments role should be to set policies, impose standards, allocate public funding and monitor performance.
- The system must be proactive and not just reactive.

This would greatly reduce the level of staff and facilities required in the public service and in turn free up significant funding that could be applied to meeting the need. It would also improve the efficiency of the service agencies that currently need to devote a large amount of time and energy in dealing with unnecessary bureaucracy. The present situation where the government deals on a case by case basis at a very detailed and personal level is grossly inefficient. The aim should be to measure the success of the program outputs and impact and not on the micro-managing of the inputs.

There needs to be more flexibility in how Government funding for disability services are allocated. Most service organisations are organised on the basis of the funding they receive (which is tagged), and this limits their ability to introduce innovations and develop more effective ways of delivering the much needed support services. The more progressive service organisations see the issues but do not want to bite the hand that feeds them because of the possible threat of losing funding.

The truth of the matter lays in the fact that parent/carers and the organisations that provide direct services are the best placed to know what is needed and are also more able to respond to changing circumstances.

An example is the importance of a planned transition to independent supported living for adult sons and daughters with severe disabilities. Yet there are currently no funded programs that specifically address the transitional aspects. Succession planning is very important in developing the most appropriate options and a key part of this should be a staged transition to supported independent living. This period of transition allows for the testing of the mix and matching process for co-tenants, the evaluation of how much support is really needed, and the assessment of specific skills training that can be undertaken. This transition process is aimed at ensuring the best possible arrangements for viability and long term stability.

To be able to address the unmet need in respect to providing adequate services and life term supported independent living for sons and daughters of aging parents, will not only require changes to current government policies, but also ways in which additional resources can be applied.

The proposed National Disability Scheme could be very effective in addressing the funding shortfall, so long as this in its self does not impose another layer of bureaucracy.

The Key Questions

My comments on the key questions raised in your document are below but before I continue it is necessary to say that when planning for the future, there is no ‘one size fits all’ solution for people with disabilities and those who care for them.

This has been a major hurdle to establishing an acceptable solution to the problem as government policy, by necessity as well as inclination, has still taken the one solution suits all approach that, in effect, has satisfied very few.

1. Who should be the key focus

I assume the target group are as described in the terms of reference- “disability from birth, or acquired through an accident or health condition but not due to the natural process of ageing”.

Within the target group it is imperative that early intervention be identified as a means by which other important aspects for a satisfactory solution to each individual’s problems can be discovered and achieved.
Therefore the key group are those who are born with an intellectual disability as other forms of disability do not inhibit or affect the intellectual powers and as such do not require the same “womb to tomb” care nor are they as extensively restricted in the process of achieving a full and independent life.

I believe that the earlier a child can be diagnosed, the better in terms of their life time care. One aspect that was mooted many years ago was the setting up of a register, starting from birth and children who had a difficult, traumatic birth and were at risk of brain damage from lack of oxygen etc would be recorded and then when development was delayed they would be targeted right from the onset not three or four years down the track as is usually the case. I am not sure who would hold this register but this could form the initial basis of a record for these children.

2. How they may be practically and reliably identified

This is a difficult issue and is more readily understood and identified by ongoing assessment prior to reaching school age.
The process would be more reliable if a standard definition, with degrees, of intellectual disability was accepted at the earliest convenience by the various government agencies currently involved in order to facilitate the move to a national system. This definition would also have to be acceptable to medical professionals to avoid confusion.

It must be remembered that these are individuals no different from a “normal” baby or child.
All parents find they cannot treat all of their children in the same manner and individual characteristics need to be observed and incorporated into the child’s upbringing and eventually these observations allows the parent to guide their child in the early decisions that will form their future life of independence and the choices/decisions they make in that life.

Therefore it is clear that the parent forms an irreplaceable part of an acceptable assessment program.
They actually do not need a “Dr. Who” to tell them their child is disabled but they do need the said doctor to establish the type and name of the disability to allow the experiences and daily observations associated with this disorder to be brought into the child’s early development.
Decisions cannot be made by the medical professional alone nor can his/her decision be regarded as absolute as many dedicated parent carers have shown by their extensive and continuous therapy in spite of their doctor’s negative approach. Hope is also a positive aspect and should never be eliminated from the mix.

From personal experiences related to me it would appear that many GPs are not in a position to be helpful when assessing a child with a disability and you get the usual glib responses – eg Einstein did not talk till he was four, they are just lazy, you are neurotic, etc. As in the previous comment I believe an "at risk" register should be set up as many intellectual disabilities result from birth trauma and if this was the case, then maybe doctors would look a little more carefully when a parents brings a child to them for assistance noting that this child is "different". There should be someone responsible for assessment of these children using a standard assessment, modified for different disabilities.

By the time the child is ready for pre-school or grade 1 it will be much easier to assess their particular type and level of disability and therefore the level and nature of the support they need.

Following the commencement of their formal education the teacher will become a significant part of the ongoing assessment. It is here assumed that State Special Schools have the ability right now and will only need detail of the new systems requirements as well as the range of the minor and major assessment protocols.

It is also desirable for the parent carer to be involved with a service provider as early as possible in their child's development and the service provider will also be part of the continuous assessment process

We are not sure that schools are the best places to be responsible for progressive assessment or holding of records. This was the case many years ago I understand when children were assessed by Qld Sub-normal Childrens Association (now Endeavour) and then ultimately went to an Endeavour School. They kept records for these children and when the time came for them to leave school they had built up a good portfolio recording disability, accomplishments, skills and identified where future training would be required once the child left school. This would be much more difficult to achieve in the Education Department system as not all children with a disability attend a Special School. The latest figures I have available are that one in three children with a disability do this while the rest are supported in mainstream schools or special education units in normal schools.

3. Which groups are most in need of additional support and help

The groups that the ongoing pre-school assessments reveal in most need of additional support. This assessment cannot be made on the child alone but must include the family environment in which they find themselves as these influences must be part of any successful strategy.

4. The kinds of services that need to be increased or created

A housing and/or accommodation scheme that allows not only individual freedom and "own space" but also the opportunity to socialise with like people of their choice in a suburban social setting.

This is where options are particularly valuable.

Dependent upon the assessments and the individual requirements and requests of the person being accommodated then there is a need for

- Individual apartments but part of a larger complex in a suburban setting.
- Individual apartments within one house but with a common area. This type would be suitable for the mix and match option also in a suburban setting.
- A gated community incorporating the previous two types of accommodation but also having accommodation for 'normal' individuals that will form part of the greater community aspect but will double as "friends to help and safeguard as needed". In other words a person who is interested in the disabled and is willing to be part of this community. These will be unpaid and most probably retired individuals. They could serve many functions. I know people of this type now that are willing to take on this type of activity.

- Organizations such as the Brisbane Housing Company have demonstrated they are well able to build and rent/sell suitable accommodation in a community setting. They have been financially backed by the state and have been encourage to duplicate their operation on the Gold Coast. They are considering a similar operation in Logan at this time.

I agree that long term accommodation is a major issue but ageing is also another area that needs to be looked at. In ten years time, a third of all people in sheltered workshops and ATSS centres will be over 45 years of age – where to for them. These facilities will no longer be able to offer them what they need. Research and planning needs to be done now to address this very important issue and not wait until this is a fait accompli.

5. Ways of achieving early intervention

If pre-schools serve a useful function for normal children then it is not unreasonable to assume that intellectual children would benefit from Special pre-schools for 12 months prior to regular Special School.

This option is already available to parents but many lack the support to embark on this step. Maybe some form of counselling should also form part of the assessment process.

6. How to encourage full participation by people with disability and their carers in the community and work

Experience has shown that disabled children easily form social relationships with normal as well as disabled children and adults.
They also have their special friends, favourite people, and people they dislike both in the normal and the disabled community.
In other words they are as normal as you and I in that regard.

The question should rather be how do we encourage the community and work to fully participate in the lives of the disabled and their carers.

The answer to this question is more elusive but is currently being positively targeted by exposing the general public to the abilities of the disabled not their disabilities. After all we "normal" folk do not want our lack of ability or inability in any area to be emphasised and we certainly do not benefit from exposure of that nature.

Even with all the talk of integration the Community at large are not prepared to accept people with an intellectual disability. To enable people with a disability to integrate more fully into the community, an education process needs to take place with the "so called normal" people in the community. This is difficult as even though many of these people do not have a disability they are struggling to cope in the day to day bustle of life.

7. How to give people with disabilities or their carers more power to make their own decisions

State Government initiatives, such as has been part of DSQ's approach for a number of years, have targeted the parent carers as they have often over-protected their child and often show no signs of changing their approach.
In fact it is clear that many parents are more dependent upon their children than they are willing to admit.
When the parent carer seeks to actually allow the child to make decisions then they learn and become more independent – some to the extent of going out locally on their own, mastering the mobile phone, cooking, etc.

This approach is an absolute necessary part of early intervention if some of the problems due to the parents isolation technique are to be avoided as the day will surely come when the parents will be either incapable of continuing in their role or have departed this life.

The above is not exactly true as with many of our children their development is much slower than with normal children and as in one case early intervention, which did occur, would not have equipped the child with the above skills. Things have to be learned along the way in small steps and therefore I believe it is never too late to teach them new skills.

Education and training is a life long issue for people with a disability and just because a person with a disability no longer attends school, doors should not be shut to them. Some adult children attend a special TAFE programme but places are limited and maybe more training facilities should be established teaching lifestyle skills.

8. How to enable people with disabilities or their carers to appeal against decisions by others that they think are wrong

It will probably need a specialist disability ombudsman as well as legislative changes covering aspects of the law that are not clear at present concerning the ability of a disabled person to make decisions concerning their own well being and future.
Here again the assessment results over time will be of great use to help establish the extent to which the desires of the disabled person and/or their parent carer compliment or conflict with each other and the ramifications of that choice. Implicit in this assessment is the need to conform to any legal requirements.
To a large extent the level of input of the disabled person and/or the parent carer allowed in the appeal should reflect the level of responsibility that this would place on all concerned and whether the associated risks are adequately comprehended and understood.
As in all these processes for the population at large the final outcome can and often is not exactly what was wanted. This is a situation all have to accept if we are to avoid the pitfall of removing and taking over the rights of the individual.
The day will come when the parent carer is no longer able to contribute to the decision making process so the changes to the system whether legislative or not must consider whether a non-parent should have exactly the same rights as a parent carer.

I think that part of the problem here is that there is no one Central Authority responsible for collating and keeping information on the disabled sons/daughters and parent/carers have lost count of the many times they have been through this process. At this point most appeals are completely unsatisfactory and maybe a little understanding of family situations would be beneficial to people sitting in judgement and making decisions. No one case is the same and this needs to be kept in mind at all times. We can have guidelines, but these must be flexible and leeway given to the disabled people and their parent/carers to input as they often know more clearly what is required.

9. How to improve service delivery – including coordination, costs, timeliness and innovation

To improve any aspect of service delivery necessitates partnerships in a real sense.
Partnerships between government, service provider, the disabled, school, parent carer and other interested parties.

The four issues mentioned – coordination, costs, timeliness and innovation have a common solution – partnerships.

- Coordination and consolidation of the numerous service providers doing, to a large extent the same or similar activity is a top priority item. As federal and state money is used to fund these agencies considerable cost savings are possible while at the same time making staff available to improve the service. I believe from personal experiences that the government departments currently monitoring these providers are well aware that some fall short of the standard that parents want or are willing to accept.

- The consolidation of government departments and service providers should produce cost savings by economies of scale and avoiding duplications. Furthermore some costs can be carried by the parents themselves as I know of parents who have made financial provision for their child and are very willing to invest that in secure accommodation for the life of their child and then are willing that the property then is willed to the NDIS as long as it is used for the very same purpose for which it had been established.
- Timeliness must be related to need as in any health, welfare or safety situation. This will also save funds being wasted via the same cure/medicine suits all.
- Innovation will be the natural result of a more open and cooperative approach by all concerned. There will hardly be a need to invite it as it will happen as situations develop that have not been considered and accounted for previously. Currently government procedures are not flexible, options, should they exist, are again fixed in concrete and therefore stifle any innovation before it can be born. Experience has shown that innovative suggestions and concepts are immediately rejected if they do not conform to current policy.

See comment above under point 1 re register held somewhere. Many parents of children with a disability now do not select the option of special school and for every child in a special school, I think there are two out in main stream schools being supported. It is very difficult to include them in any process yet they are really an integral part of any new concepts as there will come a time when they require support and often have not used any service provider etc.

10. The factors that affect how much support people get and who decides this

Again this depends upon the continuing assessment and will reflect changing circumstance with age, condition, etc. The situation and condition of a disabled child is liable to change rapidly – the system must be able to respond in a timely manner.
The service provider who, as time goes by, would have replaced parent carer and school teacher as the source of the most up to date knowledge of the disabled person should, with a medical professional if required, be the main decision maker in the partnership.

Many factors determine how much support people should get and these are not always decided by the people “in the know” so people who require more support often miss out. With so many service providers I am not sure how this can be done better. Most of the bureaucrats in Government have a very limited knowledge of the needs of these people they make decisions for. Hence, we keep harping back to a central database/register where all information is stored and is accessible by departments, GPS, etc.

11. How to ensure any good aspects of current approaches are preserved

We believe that a partnership between all parties will quickly establish those areas that are highly beneficial and have shown over time their efficacy.
These need to be identified as early as possible in order to fit them into the proposed model as well as planning how to maintain them in the interim as they may be co-dependent upon other current practises that will be abandoned.
Until we know what aspects are regarded as good aspects we cannot effectively plan.

12. What to do in rural and remote areas where it is harder to get services

This is a difficult issue but must be an integral part of any plan. Possibly a rail based version of the flying doctor would be the most efficient.

A group of all relevant parties in the partnership visit an area via the rail network. The train can be a regular scheduled train other than one or more carriages attached that have been adapted to service all aspects of need for the disabled in the area. These folk will be known under the current system. This should be a regular event for each area in order for the continuous assessment to be made.
It is extremely important that these folk are accommodated in their home area.
In the absence of any local service provider or Special School it would be useful to locate, if possible, a willing local with the interest and ability to act in a NDIS support role. This would be an honorary position.

At present people living in rural areas generally are disadvantaged as services and specialist support are not always readily available so I think the idea above is good and sends the correct message to the people in these disadvantaged circumstances. One very positive aspect of living in a rural community is the fact that there is often much more support and acceptance of people with a disability into their community.

13. Reducing unfairness, so that people with similar levels of need get similar support

The current system generates unfairness.
Unfairness will be reduced or eliminated if the system starts to treat individuals as individuals rather than the one size fits all approach.

14. Getting rid of wasteful paper burdens, overlapping assessments [the run around] and reducing duplication in the system

- Some wasteful paper burdens should disappear as soon as the government departments are consolidate into a National unit. More wasteful paper burdens should disappear as soon as the government departments involved understand that the responsibility and risks associated with the new system have to be managed by all concerned and that the result of increased flexibility and independence of the disabled has by necessity reduced all parties' legal exposure while the responsibility of the disabled person increases. There is no simple way to avoid this and minimise paper work while maximising freedom. This happens with normal kids even before they reach their majority. The risks to the disabled person would, under a risk management protocol, be commensurate with the freedom achieved through the continuous assessment program and in that sense will be no different to a normal child whom has been instructed adequately.
- Overlapping assessments should disappear with the new assessment protocol and the reduction of agencies. This also reduces paperwork as well as parental frustration.
- Similarly duplication is reduced as stated in earlier comments

15. How to finance a new scheme so that there is enough money to deliver the services that are needed and provide greater certainty about adequate care in the future

- Primarily this scheme should be funded by a levy as with Medicare or Superannuation.
- It is expected that an overall reduction in costs associated with the consolidation and reduction in the range of agencies and governments departments will allow a more efficient use of current budget allocations.
- As mentioned earlier parents are willing to provide for the future of their child.
- For those who are unable to provide independently then their child can still receive rent support and the equivalent of a state house.
- Many service providers have financial arrangements with developers already to build suitable accommodation in a normal subdivision. These houses can accommodate 2, 3 or 4 people who

have already been mixed and matched. I am well aware of a group of those who wish to do this and with whom they would like to live. I know this because the children (all young adults in the 30 to 40 year old range) have told the parents. As ageing parents it has become a priority issue to prepare their children for life without them to look after them. They have relished the freedom that this has given them and so far no significant problems have occurred. Parents and Service Providers are delighted.

- As mentioned in point 4 above the Brisbane Housing Co. (a non-profit organization) is particularly cost effective and efficient entity.

16. The practical aspects of a scheme that will work, such as how existing arrangements would fit into a new scheme, how to manage risks and costs, and ideas for attracting people to work in disability services

- Staff issues can be resolved to some extent at least by paying a wage that is more commensurate with the requirements of the expectations than that currently. This comment is based on personal experiences from state sponsored conferences where comments such as “my 16 year old son working at McDonalds gets a higher hourly rate than I do.” It is expected by any parent that the care extended to their child involves staff who, assuming realistic expectations, are well placed in the salary structure. It may be that more adequate qualifications and training are required. This will lift the image and status of these essential people. The very essence of the system is the lifelong well being of the disabled person and this cannot be achieved by employing people who are clearly underpaid and therefore, by implication, undervalued.
- Opportunities for advancement will also attract those who are willing to grow into the world of disability services. It may be possible to insist that this be part of their degree namely a year’s internship as a carer.
- A fully integrated National Disability Scheme may even involve the nursing degree and certificate courses. The role of carer after the parent is gone cannot be left in the hands of an inadequately qualified and/or underpaid amateur.

17. How long would be needed to start a new scheme, and what would happen in the interim

This is very difficult to judge as the rate defining stage will inevitably be the government’s reorganization. Parent carers I have consulted have no firm time line as the mechanisms involved are largely unknown to them but suspect that 4 or 5 years would be needed.

As far as everyone else is concerned a much shorter time is feasible, and greatly needed, as many service providers are as innovative as possible even with the restrictions imposed upon then by the funding agency and already do many of the things that parents want but most cannot because of the department’s restrictions and unwillingness to innovate. It is to be noted that, in Queensland, this situation is changing and DSQ is enthusiastic about this new approach.

This is something that can not be achieved overnight and requires much forethought, careful planning and input from all parties. It is also dependant on what funds will be available to start the planning process for change.

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